

VICTORIA UNIVERSITY

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**REASONS FOR USE AND DISCLOSURE OF
COMPLEMENTARY MEDICINE BY PEOPLE WITH
HAEMOGLOBINOPATHY**

By

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STUDENT DECLARATION

I, Helen Georgiou, declare that the PhD thesis entitled, Reasons for Use and Disclosure of Complementary Medicine by People with Haemoglobinopathy, is no more than 100,000 words in length, exclusive of tables, figures, appendices, references and footnotes. This thesis contains no material that has been submitted previously, in whole or in part, for the award of any other academic degree or diploma. Except where otherwise indicated, in this thesis is my own work.

Signature...



.....Date...12 December 2006...

DEDICATION

This thesis is dedicated to my mother, Lucy Georgiou for encouraging me with good humour, and for teaching me the importance of resilience.

And to

My cousin Peter Anastasi I extend my love and gratitude for supporting me financially and emotionally through the years of study. Without you Peter there would not have been a thesis.

ABSTRACT

An increasing number of people with chronic illness use complementary and alternative medicine (CAM) (Metz, 2000) and rarely disclose such use to treating biomedical physicians [B/M] (Adler & Fosket, 1999). Although the incidence of CAM use amongst people with chronic illness has been investigated (Nader et al., 2000; Sharon & Mark, 2006; Yang et al., 2002) research specifically examining that section of people who require ongoing biomedical treatment from a very early age until death has never before been conducted. This thesis examined the patterns of self-prescribed and CAM practitioner prescribed CAM use, reasons for CAM use and disclosure of CAM use to treating physicians, among people with a lifelong medical condition, thalassaemia major (TM).

To examine the reasons for use and disclosure of CAM in this population, 21 people (eight males, 13 females) aged between 24 and 43 years volunteered for the three-phase study, which forms the thesis. The participants were English speakers whose physical and cognitive capacities did not prevent participation in the study. Interviews were conducted in the participants' homes and followed standard consent procedures. All phases were conducted face-to-face.

In Phase 1, using an in-depth unstructured questionnaire and two structured questions, participants were asked about their medical history, CAM use and whether they disclosed such use to their biomedical physician/s. In addition, the participants were asked to nominate any CAM practices they had heard of, that people might use. A written list was devised as the participants mentioned CAM therapies/treatments. The participants were then asked which of these CAM therapies/treatments they had used.

In Phase 1, all of the participants reported having multiple co-morbidities and at least one major surgical procedure. Twelve of the participants reported using CAM

when asked a dichotomous choice question. All participants were found to be CAM users when CAM was estimated according to the substances and therapies that participants reported using. Phase 1 showed that CAM estimates varied according to which CAM definition was applied to analyse the data. In Phase 1 there was only one participant out of 21 (4.76%) who reported CAM disclosure and disclosure was ongoing in that case.

The reasons for CAM use and disclosure were elicited using in-depth conversational interviews, which constituted Phases 2 and 3 respectively. The operational definition of CAM devised for this thesis was based on the intent of CAM use and not prescribed by a biomedical physician. Based on the operational definition of CAM proposed for thesis there were 21 CAM users. Examination of the reasons the participants gave for CAM use confirmed there were 21 CAM users. Phase 2 showed the participants wanted safe and effective treatment to manage and cure the primary illness and co-morbidities. Phase 2 also indicated that CAM was used, at times in lieu of biomedicine, to prevent illnesses and to enhance quality of life (QoL) and to increase life expectancy. Phase 2 showed biomedical failure and adverse outcomes from biomedicine motivated CAM use. These reasons shaped perceptions of dissatisfaction with biomedical treatment and the prescribers of such treatment.

Phase 3, addressed CAM disclosure, showed most of the participants considered they had disclosed their CAM use when they asked their treating biomedical physician about CAM. Phase 3 demonstrated most participants attempted to disclose CAM use and whilst they felt it was important for the treating physician to know about such use, they abandoned disclosure because of dissatisfaction with biomedical practitioners' responses to their attempts to disclose. Other reasons for non-disclosure or aborted disclosure included a desire to maintain privacy and a belief that CAM was harmless. Phases 2 and 3 showed core reasons for CAM use and CAM

non-disclosure were dissatisfaction and a loss of confidence in biomedicine. The one person who did disclose CAM use stated disclosure symbolised their dissatisfaction with biomedicine.

This thesis showed people with a serious life-long illness used CAM because biomedicine was often ineffective, frequently palliative and sometimes considered deleterious to health. These aspects of biomedical care instigated dissatisfaction and a loss of confidence in biomedicine treatment and practitioners. The negative perceptions held by the participants of biomedical treatment and biomedical physicians were the primary motivators for CAM use and disclosure. All participants were found to be CAM users and this might have serious implications for their on-going biomedical treatment because some CAM products have a pharmacological effect that might interact with prescribed biomedicine medication.

The findings suggest CAM was beneficial in an environment in which biomedicine could only offer palliative care, but this finding requires further research. This thesis showed that CAM use and disclosure are complex issues, deserving in-depth examination in people with a range of medical conditions, as well as in the general population.

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CHAPTER 1: INTRODUCTION

Predominantly complementary and alternative medicine (CAM) is considered to be health-care practices different from those of biomedicine (Caspi, Koithan & Criddle, 2004). In Australia CAM use has been estimated to be as low as 48.5% (MacLennan, Wilson & Taylor, 1998) to as high as 75% (Benoussan, 1999). Worldwide estimates for the adult general population for CAM use vary from as low as 32% (Verhoef, Russel & Love, 1994) to as high as 80% (Bodeker & Kronenberg, 2002).

To explain the difference in CAM estimates some researchers suggested CAM surveys have inadequate response rates and are not population based, as claimed (Bodeker & Kronenberg, 2002; Ernst, 2000a). Such methodological issues partially explain disparity of CAM findings; however, the literature showed there are others, such as the definition of CAM. For example, rarely have CAM therapies been differentiated as health behaviours used as a form of treatment from those used as part of lifestyle. Whilst many researchers (Adams et al. 2003; Rao et al. 1999; Patterson et al., 2002) did not consider self-prescribed treatments CAM, others have consistently failed to differentiate CAM that was self-prescribed from that which might be prescribed by a CAM practitioner, even when repeating studies such as McLennan et al. (1996, 2003). Thus, CAM surveys have consistently alarmed the public by including all self-prescribed and practitioner use into one statistic. Despite these methodological problems there is agreement across the literature that CAM is used by all sections of the population, including the chronically ill.

CAM use has been found in people with difficult to treat or chronic illnesses such as arthritis (Rao et al., 1999), life threatening illnesses such as cancer (Boon et al., 2000), the critically ill (Richards, Nagel, Markie, Elwell & Barone, 2003) and acquired immuno-deficiency syndromes (AIDS) (Furler et al., 2002). In people with cancer CAM use has been estimated to be as low as 16% (Downer et al. 1994) to as high as 70.2% (Patterson et al., 2002). Whilst variance in CAM estimates has been attributed to a lack of differentiation of

illnesses (Sparber & Wootton, 2002), even with illness differentiation CAM estimates vary. For example, CAM use in people with prostate cancer has been estimated to be as low as 30% (Boon et al., 2003; Lee et al., 2002) to as high as 58.8% (Patterson et al., 2002).

Differences in CAM estimates have been attributed to time and or place (Wang, Patten & Russell, 2001) but CAM estimates for apparently similar populations taken around the same time vary substantially. For example, estimated CAM use for American children with cancer ranged from 8.7% (Faw, Ballentine, Ballentine & Eys, 1997) to 65% (Friedman et al., 1997). Therefore some variables do not explain the different CAM estimates. However, whilst such variables are plausible because all variables influence estimates (Harris, 1999) the reasons people with a serious and or chronic illness use CAM in an environment of highly sophisticated biomedicine, has proven equally difficult to determine.

In an effort to explain the growing enthusiasm for CAM some researchers have pointed to individual differences such as, philosophical beliefs, seeking of control over health and socio-demographic characteristics of people, as predictive of CAM use (Astin, 1998; Verheij et al., 1999; Williams, 2001). Empirical evidence disputes such theoretical predictors for CAM use (Zollman & Vickers, 2000). Therefore, the profile of the CAM user remains discreet.

Although surveys on CAM use are valuable in exploring commonalities amongst population groups their applicability to the issues that lead to CAM use and the decision to disclose such use to treating physicians is limited. Result variations found in quantitative surveys suggest that the measurement of causal relationship between variables is not the most appropriate method to examine the individual's processes and meanings associated with CAM use (Sparber & Wootton, 2002). Thus, other research methods are needed to explore the reasons for CAM use from the individual's perspective to increase understanding of why people use CAM.

Eventhough some CAM treatments can reduce morbidity, mortality and the adverse effects of biomedical treatment (Alexander et al., 1994; Nader, 2000) there are particular concerns about the concurrent use of CAM and prescribed medicines (Furgh-Berman 2000; Miller, 1998). For example, an increasing number reports suggested some CAM therapies such as, herbs and vitamins, can mask or distort the effects of biomedical treatments (Richardson, Sanders, Palmer, Greisinger & Singletary, 2000). For this reason, the possible effects of combining biomedical treatment with some CAM might be harmful not only because of interactivity but also because they might lead to inaccurate biochemical assay results, causing treating physicians to increase drug dosages to dangerous levels or reduce them to levels at which they are ineffective (Braun, 2001; Niggemann & Grüber, 2003). Such concerns are plausible because people with chronic illnesses have been found to often use CAM therapies concurrently with biomedicine (Cassileth et al., 2001; Metz et al., 2001). Consequently, understanding the behaviour of people who use CAM and biomedicine concurrently is particularly pertinent because non-disclosure of CAM therapies to treating physicians is noted to be as high as 66% to 70% (Elikins, Marcus, Rajab & Durgam, 2005; Lazar & O'Connor, 1997). As a result non-disclosure of CAM use to biomedical practitioners can be dangerous. Accordingly it is important to study reasons for CAM use and disclosure in people who use pharmaceuticals daily.

There are people with genetic disorders such as those with β -thalassaemia major (TM) who are chronically ill from birth and for whom biomedicine is essential for survival. Whilst, most research available on people with TM is limited to biomedical issues (Atkin & Ahmad 2001) such people might also use CAM. A comprehensive search of the literature yielded only one article specifically related to CAM and TM. This article detailed a biomedical clinical trial of a naturally occurring substance from which a potential biomedical drug could be manufactured for the treatment of TM (Mihara, Maruyama & Sumi, 1992). Moreover, a study of the reasons for CAM use and its disclosure to treating physicians has never been

undertaken with people who depend on biomedical medical treatment from cradle to grave. Thus, exploration of the reasons for CAM use and disclosure amongst people with lifelong conditions like TM is of particular concern, and appropriate. Therefore the purpose of this thesis was to examine the reasons for use and disclosure to treating physicians of CAM by people with TM.

As noted, surveys are limited in exploring the reasons people give for using CAM. Therefore a method that furthers the understanding of the social and psychological phenomena under investigation is required (Chenitz & Swanson, 1986). To add to our understanding of people with lifelong illnesses who use CAM the research was conducted in three-phases using qualitative research to inductively generate an explanation for CAM use and disclosure. Phase 1 determined the socio-demographics, self-reported medical history and types, and patterns of CAM used by people with TM. Phase 1 also examined the incidence of disclosure to treating physicians of CAM treatments by people with TM. Phase 2 examined the reasons why people with TM decided to use CAM. The third and final phase examined factors that influenced disclosure of CAM treatments to treating physicians.

CHAPTER 2: LITERATURE REVIEW

This review of the literature deals with the use and disclosure of CAM and provides a description of some treatments considered CAM. The Literature Review presents and discusses definitions and terms used to describe CAM. Frequency of CAM use and CAM disclosure and the issues that relate to these phenomena are examined and discussed with particular emphasis on the concurrent use of CAM and biomedicine. In this review reasons for CAM use and CAM disclosure are explored in detail. The haemoglobinopathies are discussed with specific emphasis on β -thalassaemia major (TM). An overview of the pathology, treatment, some of the clinical trials undertaken and quality of life of people with TM is provided. Finally, the review examined evidence of CAM use and disclosure by those with a chronic illness. In the final section of the Literature Review the purpose of the thesis is stated.

Complementary and Alternative Medicine

Complementary and alternative medicines (CAM) originated from a wide array of sources, such as folklore (kitchen remedies), Eastern philosophy (Chinese Medicine), traditional knowledge (Ayurvedic Medicine), techno-science (laser acupuncture) and consumer culture (evening primrose oil for menopausal women) (National Center for Complementary and Alternative Medicine (NCCAM), 2002). Some health-related practices considered CAM, are complementary to biomedicine and others provide an alternative to such treatment (NCCAM, 2002). CAM has been used to describe disparate therapies/substances, behaviors and activities that might be used singly or in combination for wellbeing, health maintenance, preventive purposes and/or treatment (NCCAM, 2002). Therefore CAM is considered anything that falls beyond the scope of biomedicine that person undertakes for health purposes (Bica et al., 2003; Krauss et al., 1998; Sleath et al., 2001). The rationale applied to differentiate therapies, treatments and substances considered outside of the rubric of biomedicine informs this section of the literature review.

Rationale used to Differentiate CAM from Biomedicine

CAM, defined as treatments that lack scientific evidence of efficacy (Beyerstein; 1997; Ferry, Johnson & Wallace, 2002) imply only quantifiable scientifically proven medicine exists (Fontanarosa & Lundberg, 1998; Leibovici & Hayes, 1999). Scientific proof as a differentiator of CAM and biomedicine does not work because the biomedical community has always used and implemented new technologies and treatments that have not been rigorously evaluated (Fontarosa & Lundberg, 1998; Morreim, 2003).

CAM definitions that proposed CAM therapies/products were not used in hospitals and not prescribed and not practiced by biomedical doctors (Bica et al., 2003; Buchbinder et al., 2002; Cassileth, 1999; Eisenberg et al., 1999; Ferry Johnson & Wallace, 2002) are not accurate because biomedical practitioners commonly use such treatments (Eastwood, 2000; Kotsirilos 1995; NCCAM, 2002). Moreover at “least half of alternative practitioners are biomedical practitioners” (Cassileth, 1991, p. 299). Hence, there is evidence to show CAM “therapies have always existed side-by-side with standard medical treatments” (Martin, 2001, S-14). For example, acupuncture was recommended and used by biomedical physicians as early as 1892 (Lytle, 1993). Thus some CAM treatments such as hypnosis, vitamin therapy, homoeopathy, relaxation therapies, nutritional medicine and herbal treatments have and are still included as part of biomedical practice (Eastwood, 2000; Easthope, Tranter & Gill, 2001; Willis, 1994). Peculiarly such products/treatments are not considered CAM when administered or prescribed by biomedical physicians (Buchbinder et al., 2002; Ferry Johnson & Wallace, 2002; Pachter et al., 1998), which suggests in countries such as Israel and France where CAM practices are restricted to administration by biomedical practitioners (Dorozynski, 1996, Grinstein, Elhayany, Goldberg & Shvarts, 2002; Hufford, 2003; London et al., 2003) no-one uses CAM or estimates claiming to be of CAM use are of biomedicine use.

In contrast there is the view that therapies such as special diets, massage, acupuncture and exercise are CAM, even when prescribed by a biomedical practitioner (Eisenberg, 2002). Hence attempts to define CAM as treatment that lacks scientific evidence or not used by a biomedicine practitioner have failed to provide a lasting definition of CAM.

In the next section of the review an overview of some treatments/therapies often considered CAM is provided. In addition, some of the scientific research literature on CAM is provided for contextual reference.

Over-the-Counter Medicines

OTC products fall into other classifications of CAM, such as ingestible and tactile therapy. As a group, substances such as cod-liver oil, analgesics, topical lotions such as, arnica cream and aromatherapy oils (Featherstone et al., 2003), herbal supplements (Read, Klomp, Mather & Todd, 2002), and vitamins and minerals (Madsen et al., 2003) are referred to as over-the-counter-medicines (OTC). OTC might be self-prescribed or recommended by a CAM or biomedical practitioner. OTC products are considered CAM (Nilsson, Trehn & Asplund, 2001; Reid, 2004) when not prescribed by a biomedical physician (Buchbinder et al., 2002; Furler et al., 2003).

Complete Systems of Medicine

Complete systems of medicine operate from their own unique theoretical and philosophical basis and are considered alternative medicine (NCCAM, 2002).

Chinese (CM) and Ayurvedic medicine (AM). CM and AM are complete and complex systems of medicine with their own unique diagnostic and treatment principles (Moody, Eaden, Bhakta, Sher & Mayberry, 1998; Xu, 2001). To treat and prevent disease CM and AM incorporate patho-physiology and a range of therapies that includes an extensive and effectual range of medicines and techniques (O'Brien, 2002; Sharma & Clark, 1998; Tataryn, 2002). CM incorporates practices such as herbalism, Tui Na, acupuncture, cupping, moxibustion (the heating of an acupuncture point or needle with a smoldering herb), Qi Gong, diet therapy and

Tai chi (O'Brien, 2002; Tataryn, 2002; Xu, 2001; Zhang, 1998). AM incorporates practices such as herbs, Yoga, meditation, diet therapy and aromatherapy (Thomas, 2002; Rees & Weil, 2001). In addition, CM and AM consider behavioural adjustment fundamental to the therapeutic process (Rees & Weil, 2001; Zhang, 1998).

Naturopathic medicine. The philosophical foundation of naturopathy is based on the healing power of nature, which means the body has its own healing energy within. Therefore, naturopathy holds the fundamental belief that with the help of naturopathic treatment the body, if it is in a healthy and helpful environment, can repair its-self and recover from illness (Strasen, 1999). Naturopathy practice aims to prevent, diagnose and treat conditions of the human mind and body by integrating biomedical health sciences with a range of natural therapies and traditional medicines, such as CM (Steyer, 2001; Strasen, 1999; Zollman & Vickers, 1999). Some of the strategies employed to bring about a therapeutic response include herbs, nutrition, hydrotherapy, homoeopathy, massage, exercise, megavitamins, colour, essences and fasting (Steyer, 2001; Zollman & Vickers, 1999). Like other complete systems of medicine naturopaths aim to educate, empower and motivate the client to assume more personal responsibility for their health by adopting a healthy attitude, lifestyle and diet (Steyer, 2001; Strasen, 1999).

Research into the benefits of naturopathy is best viewed from individual therapies, such as herbal medicine (Steyer, 2001).

Tactile Therapies

Tactile therapies cover a wide range of CAM treatments such as, acupuncture and various forms of massage and body manipulation. In this discussion acupuncture, an invasive treatment (Sierpina & Frenkel, 2005) is not included here because some people consider it an energy therapy. Thus, acupuncture is discussed under energy therapies.

Massage therapy. Therapeutic massage evolved from many ancient forms of healing such as Tui Na (Cohen & Doner, 1996; Zollman & Vickers, 2000). Swedish massage one of

the better-known forms of massage was systemised and developed in the 18th century (Zollman & Vickers, 2000). Many massage treatments involve the manipulation of soft tissues of the body by various manual movements such as rubbing, pressing, kneading, rolling, slapping and tapping (Beck, 1994a; Tappan, 1988). An emollient such as oil, talc, soap or water might be used to facilitate movement of the hands over the body (Zollman & Vickers, 2000).

Tui Na. Tui Na is a manual therapy that employs various techniques including massage, cupping and scraping along the meridians to release the Xie Qi/evil pathogen (obstruction) (Deng et al., 1990).

Research has shown massage therapy has many positive effects, such as reduction of anxiety, improved mood states and pain relief (Corley, Ferriter, Zeh & Gifford, 1995; Fraser & Kerr, 1993; Ironson et al., 1996). A decrease in blood pressure, heart and respiratory rates are physiological effects produced by massage therapy (Fakouri & Jones, 1987; Longworth, 1982).

Reflexology. Reflexology is based on the system of Chinese Medicine and was introduced to the West in 1913 (Siev-Ner, Gamus, Lerner-Geva & Achiron, 2003). As a therapy, reflexology utilises pressure point massage of the extremities of the body such as the foot, ear or hand to bring about therapeutic benefit (Siev-Ner, Gamus, Lerner-Geva & Achiron, 2003). Theoretically, within each of these extremities are corresponding trigger points for the organs of the body such as the spleen and large intestine (Siev-Ner et al., 2003).

Reflexology has been shown to be more effective than non-specific massage for the treatment of pre-menstrual symptoms (Oleson & Flocco, 1993) and therapeutically beneficial for people with multiple sclerosis (Siev-Ner et al., 2003; Richardson, 1997). The therapeutic effect of reflexology might be due to the release of endomorphic opiates (Siev-Ner et al., 2003), which are important for pain regulation and immune function (Andersson & Lunderberg, 1995; Khansari, Murgu & Faith, 1990).

Osteopathy and chiropractic. The root of osteopathy and chiropractic therapies can be traced back to 2,700 B.C. (Steyer, 2001) to traditions such as bone setting in Chinese Medicine (Zollman & Vickers, 2000). In the late 19th century osteopathy and chiropractic were standardised in the United States (Steyer, 2001; Zollman & Vickers, 2000). Originally both schools operated as complete systems of medicine with the belief that all illnesses including those of an infectious nature could be treated using body manipulation as the treatment (Zollman & Vickers, 2000). Today, however, the emphasis is on musculoskeletal disorders (Kaptchuk & Eisenberg, 1998). There are differences between the two treatments, informed by their theoretical foundations.

Osteopathy uses biomedical diagnosis and therapy including biomedical medicines, surgery and radiation (Anderson, Anderson & Glanze, 1998). In contrast to biomedicine, osteopathy places greater emphasis on the influence of the relationship between the organs and the muscular skeletal system (Anderson et al., 1998). Chiropractic therapy is based on the theory that the state of a person's health is determined in general by the condition of the nervous system (Anderson, 1998; Steyer, 2001). In most cases chiropractic treatment involves mechanical manipulation of the spinal column (Anderson, 1998; Steyer, 2001). Some practitioners employ radiology for diagnosis and use physiotherapy and diet in addition to spinal manipulation (Anderson, 1998). Chiropractic therapy does not employ biomedical drugs or surgery (*Ibid*, p. 319).

Esoteric Exercise Systems

Tai Chi, Yoga and Qi Gong. *Tai Chi, Yoga and Qi Gong* are cognitively based, low-exertion exercise programs that combine meditative mindfulness with slower movement or even static muscular exercise (La Forge, 1995; Taylor-Piliae & Froelicher, 2004). Such activities stimulate both the mind and body by combining breathing, relaxation and slow gentle structured movements (Cheng, 1999; Lidor, 1999; Taylor-Piliae & Froelicher, 2004). In China Tai chi has been practiced for many hundreds of years as a preventive measure and a

remedy for almost every ailment (Cheng, 1999; Taylor-Piliae & Froelicher, 2004). The aim of Tai chi, yoga and Qi Gong is to increase flexibility, level of fitness and strength within the limits of the person (Roberts, 2003).

Many randomised studies found Tai chi and Yoga therapeutically beneficial. For example, in a study of 98 people after nine days of Yoga the ratio of total cholesterol to high-density lipoprotein (HDL) cholesterol, and total triglycerides were significantly lower, and HDL cholesterol significantly higher (Bijlani et al., 2005). Other studies found Yoga improved cardiopulmonary status (Telles, Reddy & Nagendra 2000), reduced resting heart rate and left ventricular end diastolic volume (Konar, Latha & Bhuvaneshwaran, 2000), positively reduced blood pressure and was as effective in controlling hypertension as drug therapy or biofeedback (Chaudhury, Bhatnagar, Bhatnagar, & Chaudhury, 1988; Murugesan, Govindarajulu & Bera, 2000), and benefitted many illnesses including asthma, chronic bronchitis, diabetes mellitus and chronic post-stroke hemiparesis (Bastille & Gill-Body, 2004; Behera, 1998; Bijlani et al., 2005; Nagendra & Narathna, 1986). Similarly, many studies have found Tai chi had far-reaching therapeutic benefits including a lowering of blood pressure and blood lipids (Tsai et al., 2003), a reduction in the effects of sensorimotor aging (Shan, Daniels & Gu, 2004), improved visually impaired participants' sense of independence, balance of single leg-stances and total knee flexion, and power (Miszko, Ramsey & Blasch, 2004) and improved aerobic capacity (Taylor-Piliae & Froelicher, 2004).

Scientific evidence shows many manipulative therapies are efficacious and beneficial (Grinstein et al., 2002; Horstman, 2004). Whilst, from these techniques modern biomedical techniques such as physiotherapy evolved (Raub, 2002) and some, such as Yoga and Tai chi are recommended to people with arthritis in preference to other forms of exercise, which can worsen symptoms (Horstman, 2004), they are still considered CAM (Raub, 2003) when used outside of the biomedical setting.

Mind-body Therapies

Prayer and meditation, commonly referred to as traditional folk medicine, are healing practices associated with religious practices and beliefs, such as Hinduism, Buddhism and Christianity (Shoenberger, Matheis, Shiflett & Cotter, 2003). Meditation, spirituality, prayer and mindfulness all utilise the mind to focus intentionally on internal or external experiences (Tacón, 2003; Wolpe, 1994). Hence, because these terms are possibly describing the same type of therapy they will be discussed here as one entity.

Considerable evidence exists that mind-body interventions positively influence many illnesses and that psychosocial factors and spirituality play an important role in health by modulating the effect of illness (Astin et al., 2003; Aviles, Whelan & Hernke, 2001; Highfield, 2000). For example, in people with cancer, meditation reduced irritability and depression (Specia, Carlson, Goodey & Angen, 2000), in adults decreased blood pressure and coronary arteriosclerosis (Castillo-Richmond et al., 2000) and seizure frequency in people with epilepsy (Deepak, Manchanda & Maheshwari, 1997) and benefited ischaemic heart disease (Yogendra et al., 2004).

Research shows many mind-body techniques, such as meditation, have been incorporated into biomedical care (Hawks & Moyad, 2003; Kabat-Zinn, 1996) as a form of cognitive therapy and coping strategy (Cooper-Effa, Blount, Kaslow, Rothenberg & Eckman, 2001; Tacón, 2003). This suggests, by generally adopting mind-body therapies, biomedicine has accepted the empirical evidence demonstrating the benefits of such interventions. Therefore the reasons mind-body therapies are considered CAM must lie beyond biomedical practices and scientific evidence.

Energy Therapies

CAM therapies such as biofield therapies, homoeopathy, Qi gong, Reiki, acupuncture, magnet therapy, bio-electromagnetic therapy, electro-dermal therapy, therapeutic (healing) touch and phototherapy are collectively known as energy medicine (Rubik, 2002). Such

therapies involve the use of energy fields that purportedly enter the body to engender therapeutic effect (Coughlin & Micozzi, 2002; Gerber, 2001; Hawks & Moyad, 2003). Some energy therapies such as phototherapy are modern and others, such as Qi Gong and acupuncture, are ancient conceptions (Coughlin & Micozzi, 2002; Johnson, Stewart, & Howell, 2000; Rubik, 2002). For example, acupuncture as a form of treatment is over 3,000 years old and whilst it originated in China it is commonly practiced as a routine biomedical treatment not only in Asia but also since the late 1970's it has gained popularity in the Western world (Ernst, 2001).

Acupuncture, involves the insertion of very thin solid needles at particular points along the meridians/channels (Deng et al., 1990; Steyer, 2001), acts physiologically and has been shown to be therapeutically beneficial for pain relief and chemotherapy induced nausea and vomiting (Collins & Thomas, 2004; Hui et al., 2000; Streitberger, Diefenbacher & Bauer, 2004).

In a study of 66 people with muscular skeletal problems healing touch reduced severe intractable pain and provided marked physical and psychological functioning (Weze, Leathard & Stevens, 2004). Similarly, in people with cancer therapeutic touch was beneficial in reducing pain and anxiety (Ferrel-Torry & Glick, 1993).

Energy medicine has been shown to have positive therapeutic effects (Coughlin & Micozzi, 2002; Johnson, Stewart, & Howell, 2000) but is considered CAM possibly because for most of these treatments the mechanism by which the therapeutic effect is exerted is not well understood (Rubik, 2002; Weiner et al., 2003).

Ingested Medicinal Therapies

Ingested CAM therapies such as OTC medicines, herbs, kitchen remedies, and food are considered CAM (Drew et al., 2001; Factor-Litvak et al., 2001; Kaufman et al., 2002).

Aromatherapy. Whilst aromatherapy is often defined as a tactile therapy (NCCAM, 2002), as a medicinal therapy it has been used for 6, 000 years as a tool for relaxation, food

enhancer and for pleasure (Flemming, 2000; Shauer, 1998; Thomas, 2002). Aromatherapy is based on the use of the essences/volatile oils of plants (Thomas, 2002), such as rosemary (*rosemary officinalis*) (Grieve, 1998).

Aromatherapy has been shown to exert a physiological effect on the body (Meyer, 1996; Stevenson, 1994) through its anti-inflammatory, antiseptic, appetite-stimulating, carminative, circulation-stimulating, deodorising, expectorant, granulation-simulating, hyperaemic, anti-microbial, antiviral and sedative properties (Grieve, 1998; Scrace, 2003).

In clinical trials aromatherapy was found to reduce anxiety (Flemming, 2000), menopausal symptoms (Murakami, Shiota, Hayashi, & Ishizuka, 2005) and mild insomnia (Lewith, Godfrey & Prescott, 2005).

Herbal Medicine. Herbal medicine, also known as phytomedicine and botanical medicine, has been used for thousands of years by every culture for healing, food, art, perfumery, and for spiritual practices (Lust, 1974). For example, the discovery of medicinal plants in a Neanderthal tomb suggested that herbs might have been used therapeutically 60,000 years ago (Solecki & Shanidar, 1975). Five thousand years ago, the Sumerians described medicinal uses for plants (Lust, 1974) and the first known Chinese Materia Medica dates back to 2,700 BC (Bensky, Clavey, & Stöger, 2004). Many of the herbs noted in the early Materia Medica form the backbone of Chinese Medicine, as it is practiced today (Bensky, et al., 2004). The ancient Greek and Roman herbal practices preserved in the writings of Hippocrates and Galen form the root of modern medicine (Lust, 1974). Accordingly, the use of herbal medicine informs systems of medicine considered CAM, as well as biomedicine.

Although many drugs are now synthetically derived, plants and other organic material remain the precursor to new drugs (Tansey, 2003). About 25% of all prescription medicines such as morphine, digoxin, emetine, aspirin and digitalis are directly or indirectly derived from plants and other organic material (Dahl, 2001; Goldman, 2001; Martin, 2001). For

example, many new drugs such as TNP-470, perillyl alcohol, homoharringtonine, flavopiridol and paclitaxel used to treat cancer are derived from either plant or fungi (Neveu, 2004; Tansey, 2003).

The use of organic materials is not limited to the manufacture of biomedicines. Biomedical physicians often resort to natural products such as morphine and marijuana when pharmaceutical drugs fail to provide relief to suffering patients (Neveu, 2004; Martin, 2001; Schulman & Oliff, 2003).

Some herbal medicine could also be considered diet therapy because common cooking ingredients are used medicinally by some systems of medicine (Xu, 2001). Therefore common flavouring ingredients used for cooking such as fenugreek and aniseed, used to treat weakness and oedema of the legs, indigestion and to stimulate lactation (Basch, Ulbricht, Kuo, Szapary & Smith, 2003; Bensky et al., 2004), blur the boundary between food and medicinal herbs.

Diet Therapy. Diet therapy is also known as nutritional therapy, medical foods, nutritional foods and nutraceuticals (Xu, 2001). Such therapy can include the use of herbal medicines, megavitamins, vitamins and minerals and fortified foods. These therapies are often used in combination or singularly by complete systems of medicine (Basch, Ulbricht, Kuo, Szapary & Smith, 2003; Xu, 2001) and biomedicine.

Food serves many purposes including sustenance and pleasure, as part of social interaction and as therapy. For example, according to CM, food and medicine come from the same source and an excess of food or lack of food cause sickness (Xu, 2001; Zhang, 1990). Therefore because food is important for the prevention and treatment of disease (Xu, 2001; Zhang, 1990) it is used as part of the therapeutic process (Murray & Pizzorno, 1999; Xu, 2001).

There are many different philosophical approaches to diet therapy. Some diets are based on elimination of certain foods such as wheat and dairy products, others are more radical such

as the vegan diet that excludes all animal products (Zolman & Vickers, 2000). Another approach to diet therapy is to incorporate supplements such as vitamins, minerals and/or herbs, into the therapy (Hawks & Moyad, 2003). Some diets are illness specific. For example, the Gerson diet a mostly raw vegetarian, low salt, low fat, high potassium diet that incorporates other elements, such as coffee enemas, vitamins and mineral supplements, used to treat cancer and counteract liver damage (Cassileth, 1998a; Zolman & Vickers, 2000).

Central to Hippocratic medicine is that for the preservation of health or healing, the correct diet is pivotal (Sigerist, 1977). The use of diet therapy, however, within the biomedical setting is limited to people with particular disorders such as cardiovascular disease and rare metabolic disorders (Zollman & Vickers, 2000).

Homoeopathy. Homoeopathy, one of the most widely used forms of treatment is a 200-year-old system of internal medicine that originated in Germany, is practiced in most countries (McCarthy, 2005; Poitevin, 1999). Biomedical physicians once extensively used homoeopathy and some continue to use it clinical practice (Eastwood, 2000). Homoeopathy is a remedy based on treating like with like, *similia similibus curentur*, using micro dilutions of alcohol extractions of substances (Jonas & Jacobs, 1996; Lansky, 2003).

As often no active constituent can be detected in homeopathic potions they are assumed to have no interacting properties with pharmaceuticals, therefore the therapeutic effect is considered placebo (Furnham, 2000b; Shang et al., 2005; Jonas, Kaptchuk & Linde, 2003). The reporting of adverse effects (Jacobs et al., 1998) and findings that homoeopathy exerts specific physical effects contradicts the theory of placebo explanation (Ullman, 2003). Therefore, the notion that the micro dilution of homoeopathy is impotent has not been validated by research (Jonas, Kaptchuk & Linde, 2003).

Section Summary

This section of the literature review provided an overview of some types of therapies and substances often referred to as CAM. An overview of some research studies evaluating some of these therapies and substances was also provided.

Complete systems of medicine have their own theoretical foundations and some like CM and AM are thousands of years old. Some like naturopathy and homoeopathy were developed in the West and have a shorter history. All complete systems of medicine treat the manifestation of a disease (symptoms), its effects (signs) and its causes (pathogenesis). Common to all complete systems of medicine is the prevention of disease through lifestyle education that aims to support health and well-being.

This review showed some CAM treatments such as cognitive based therapies have been incorporated into biomedical practice. Some non-invasive methods such as massage and meditation are precursors to physiotherapy and psychology. Technology and science has brought about therapies that use electromagnetic fields, magnetic fields and electrical impulses for healing purposes.

The classification of ingestible therapies covers a wide range of products including food, aromatherapy and vitamins and minerals and homoeopathy. This review showed many CAM substances are the precursors to biomedical drugs and some like vitamins and minerals are used by biomedicine. Thus, why many treatments and substances are considered CAM is not clear. Perhaps the differentiating factor is positioned in the praxis of biomedicine and CAM.

Differentiating Biomedicine from CAM

This section of the literature reviews terms used to describe CAM and biomedicine to provide some understanding of the rationale researchers applied to differentiating CAM from biomedicine.

Differentiating medicine on the basis of praxis. Many CAM practices can be discriminated from biomedicine by the way they deal with illness. For example, Chinese (CM) and Ayurvedic medicine (AM) consider chronic illness to be an expression of infirmity in the whole person, or a pattern of disharmony (Covington, 2001; Sharma & Clark, 1998; Xu, 2001). CM and AM tailor treatment to address all aspects of the person with results measured in terms of individualised clinical outcomes (Covington, 2001; Lao, 1999). In contrast, biomedicine seeks to attribute cause or specific organ dysfunction (Covington, 2001). Biomedical treatment "attempts to produce, through drugs or surgery, a condition opposite or antagonistic to that affecting the ill person" (Rothenberg & Chapman, 1989, p. 19). The main thrust of biomedical treatment is to specifically target disease and measure results based on common clinical outcomes (Bell et al., 2003). Therefore, biomedicine is assumed to be "more deductive" and CAM "more intuitive" (Barrett et al., 2005, p. 937).

Yet, how CAM is differentiated from biomedicine is complex and controversial (Kaptchuk & Eisenberg, 2001). For instance, the praxis of most CAM practices, such as Chinese medicine is based on wholistic care (Lee & Bishop, 2001; Steyer, 2001). Whilst some biomedical health professionals consider they practice wholistic medicine (Cassidy, 1998) and some recognise the "participation of the whole person (biopsychosociology) is needed to increase the patient's optimal health course" (Tacón, 2003, p. 64), there is a difference between wholistic CAM and biomedical practice.

The difference between wholistic CAM care and wholistic biomedical care is that CAM practitioners treat all aspects of the person including how the experience of the illness affects the individual (Eshkevari, 2003; Lee & Bishop, 2001). Conversely, biomedical practitioners have difficulty in attending to a persons' illness experience because biomedical physicians are trained to see illness as a set of signs and symptoms that define a disease state (McWhinney, 1997). Thus, biomedical physicians compartmentalise disease and refer a client on to other biomedical professionals, such as psychiatrists/psychologists and dieticians,

for treatment that falls outside of the expertise and/or practice of the biomedical physician (McWhinney, 1997). In contrast, CAM practitioners when treating a person address all aspects of the individual including the mind, body and lifestyle of the person (Steyer, 2001).

Terminology and practice. The literature shows terms used to describe biomedicine, such as Western, traditional, standard or conventional, are culturally derived and inappropriate for global use because they are equally applicable to other forms of medicine, such as Auyvedic medicine (AM) when practiced in countries, such as India (Cassidy, 2003; Hufford 2003). Hence, practices like AM and CM are neither complementary nor alternative in many non-western countries and as only 20% of the world's populations use biomedicine, most people might consider biomedicine as complementary or alternative medicine because it departs from their traditional medicine (Bielory, 2002; Ernst & Fugh-Berman, 2002). Thus, terms such as non-traditional, alternative or unconventional can be misleading (Dahl, 2001; Farnsworth et al., 1985) because they are can be applied universally.

For research purposes discrete and accurate terminology is essential when describing CAM and biomedicine (Cassidy, 2004) because it is used to convey the variables/measures in an organised and familiar manner to facilitate common understanding of what is being studied, the findings and the interpretation of the findings (Minichiello, Sullivan & Axford, 1999). Hence, the findings of studies that use terms that have common meanings can be interpreted differently to the intent of the researchers.

Although there is a need to differentiate CAM from biomedicine for reliability and validity of research findings (Cassileth, 1999) this might not be possible because therapies and treatments considered CAM are rapidly subsumed into biomedical care (Manheimer, Anderson & Stein, 2003). CAM therapies subsumed into biomedical practice are often renamed and this adds to the difficulty of differentiating CAM from biomedicine (Eastwood, 2000). For example, using terms such as muscular-skeletal therapy in lieu of massage, adding the word medical to acupuncture, nutritional and environmental therapy in place of diet

therapy and referring to orthopaedics in place of bone-setting medicine (Eastwood, 2000; Featherstone, 1991) disallow any logical differentiation between biomedicine and CAM.

Use of the term CAM. The term CAM is a synthesis of common research and political language the purpose of which is to describe a public phenomenon in a recognisable manner (Hufford, 2003). However, review of the literature on CAM raised several issues relating to the definition of CAM, including how the term CAM evolved and is used, the arbitrary definitions of CAM, the way in which health behaviours and therapies are differentiated as CAM and the variable definitions of the constituent parts of the acronym CAM. These issues are discussed in this section of the review.

Purportedly the term CAM evolved over time from various phraseologies such as fringe medicine, alternative, unconventional and complementary medicine (Turner, 1998). Conversely, it has been suggested that the term complementary is commonly used in Europe, whereas in the United States the term alternative is used to describe the same therapies (Cassileth, 1998; Ernst & Fugh-Berman, 2002). As a consequence the terms used to describe treatments considered not to be part of biomedicine evolved historically or are specific to geographical placement of where the treatment is used and/or spoken about, depending on the writer's viewpoint. This suggests the terms complementary and alternative medicine refer to the same type of medicine, however, there is very little support for this. For instance, complementary medicine, also known as integrated medicine, has been defined as treatment used in conjunction with biomedicine (NCCAM, 2002; Strasen, 1999; Standish et al., 2001). Alternative medicine, also known as unconventional medicine, has been defined as treatment used in lieu of biomedicine (Cassileth, 1999; NCCAM, 2002). Therefore, because complementary and alternative medicines are not the same and each has a distinct meaning it is important to differentiate these terms (Cassileth et al., 2001a; Yoon-Hang, Lichtenstein & Waalen, 2002; Zappa & Cassileth, 2003) to understand the phenomenon under investigation.

CAM Definitions

This section of the review discusses how researchers defined CAM. Articles were sourced using keywords such as *CAM*, *complementary and alternative medicine* and, *integrative, unconventional* and *definition*, from numerous databases such as EMBASE, MEDLINE, Academic Search Elite, CINHALL, PSYCHLIT, CANLIT and Blackwell Science were used to inform this section of the review. The retrieved lists culled articles not written in English. Whilst the selected 111 CAM research studies and CAM discussion papers, written from 1993 to 2006, is a small representation of the 30,000 plus CAM articles they were chosen for the purpose of defining CAM. Whilst I reviewed over 1000 papers those chosen to be included in the review represent the most common CAM definitions used by researchers.

The papers chosen for this section of the review show that CAM lacks a universal definition and serve to illustrate that the definition of CAM has not evolved much since the biomedical profession saw it as a threat and began reporting on the CAM phenomena negatively in 1986 and then in a more positive light in 1993 (Owen, Lewith & Stephens, 2001). Previous to 1993 most articles related to CAM appeared under singular headings such as *life-sustaining treatments* (Everhart & Pearlman, 1990), individual herbs/vegetables such as *allium vegetables* (You et al., 1989), *medicinal plants in therapy* (Farnsworth, et al., 1985), *unproven remedies* (Kestin, Miller, Littlejohn & Walqvist, 1985) and *alternative medicine* (Moore, Phipps, Marcer & Lewith, 1985), a term still employed by MEDLINE.

Depicted in Table 2.1a are definitions used by the Cochrane Collaboration (1997), the landmark survey by Eisenberg et al. (1993), NCCAM (2002), and the unconventional medicine categories as differentiated by the National Institute of Health of Alternative Medicine's (NIH) (1992).

Most definitions, depicted in full in Appendix 1, share a common denominator that differentiates CAM from biomedicine on the basis of prescriber. This means any product or therapy used and not prescribed by a biomedical physician, was considered CAM. In contrast,

the Cochrane Collaboration definition differentiated CAM from biomedicine on the basis of what was accepted by “the politically dominant health system of a particular society or culture in a given historical period” (1997, p. 50). Therefore the Cochrane definition allowed for flexibility and recognised that the “boundaries within CAM and between the CAM domain and the domain of the dominant system are not always sharp or fixed” (1997, p.50).

Table 2.1a: *Definitions of CAM by Organisation*

Author & date	CAM definition
Cochrane Collaboration, 1997	CAM is a broad domain of healing resources that encompasses all health systems, modalities, and practices and their accompanying theories and beliefs, other than those intrinsic to the politically dominant health system of a particular society or culture in a given historical period. CAM includes all such practices and ideas self defined by the users as preventing or treating illness or promoting health and wellbeing. Boundaries within CAM and between the CAM domain and the domain of the dominant system are not always sharp or fixed (p.50).
Eisenberg et al. (1993)	Medical interventions, not taught at US medical schools or generally available at US hospitals (Eisenberg et al., 1993).
NCCAM, 2002	Terms for complementary and alternative medicine include unconventional, non-conventional, unproven, and irregular medicine or health care. Some uses of dietary supplements have been incorporated into conventional medicine...The list of what is considered to be CAM changes continually, as those therapies that are proven to be safe and effective become adopted into conventional health care and as new approaches to health care emerge.) Complementary medicine is used together with conventional medicine. An example of a complementary therapy is using aromatherapy to help lessen a patient's discomfort following surgery. Alternative medicine is used in place of conventional medicine. An example of an alternative therapy is using a special diet to treat cancer instead of undergoing surgery, radiation, or chemotherapy that has been recommended by a conventional doctor. Integrative medicine, as defined by NCCAM, combines mainstream medical therapies and CAM therapies for which there is some high-quality scientific evidence of safety and effectiveness (Appendix 1)
NIH, 1992	The NIH unconventional medicine categories: diet & nutrition, mind-body techniques, bio-electromagnetics, alternative systems of medical practice (traditional & folk remedies). Pharmacologic and biologic treatments. Manual healing methods. Herbal medicine (p. 202-270).

The year, author and type of type of CAM article and CAM definition used by authors are illustrated in Tables 2.1b and 2.1c. Table 2.1b shows most authors used the Eisenberg et al. (1993) definition, few used the NCCAM (2002) definition of CAM and some used a synthesised version of one of more of the CAM definitions depicted in Table 2.1a.

As shown in Table 2.1b the Eisenberg et al. (1993) CAM definition from which the NIH (1995) definition evolved (Hufford, 2003), was often quoted and used for research purposes.

The Eisenberg et al. (1993) CAM definition was based on therapies not covered by insurance, not taught in medical schools and not funded for research purposes. CAM could be used to describe many innovative biomedical techniques, such as bone marrow transplantation, because they are not covered by insurance (Corless et al., 2000), if the Eisenberg et al. (1993) definition is applied literally. In addition, transplant surgeons should be considered CAM practitioners and many courses such as those taught in schools of nursing and social work are not taught in medical schools, so they too could also be considered CAM (Corless et al., 2000). Further, research funding is available for studies of CAM and insurance is available for CAM (Coreless et al., 2000; Sharma, Haas & Stano, 2003), and CAM has been taught in biomedical colleges and universities (Owen, Lewith, Stephens, 2001) since at least the mid 1990's (Carston, Stuart & Jonas, 1997). For these reasons, the Eisenberg et al. (1993) definition of CAM, which has persisted for more than a decade, is not an appropriate definition of treatments considered different to biomedicine because none of the criteria proposed by Eisenberg and colleagues functions as intended.

Self-prescribed treatments, as illustrated in Table 2.1b, were not considered CAM by many researchers (e.g. Adams et al. 2003; Rao et al. 1999; Patterson et al., 2002). This again suggests the definition of CAM, is dependent upon the prescriber. For example, many researchers (e.g. Anderson et al., 2000; Boon & Brown, 1999; Sleath et al., 2001) as shown in Table 2.1b included self-prescribed over-the-counter medicine (OTC) such as, paracetamol and some vitamins and minerals, as CAM (Biddle, Simpson & Wilkinson, 2003) and many others did not consider them CAM (e.g. Chhay, Rynes, Kajimura-Beck & Broekmeier, 2002; Clifford et al 2003; Madsen et al. 2003; Zochling et al., 2004). Some OTC treatments were not considered CAM if they were 'safe' (Taylor et al. 2004) or "generally accepted by mainstream medicine" (Patterson et al., 2002, p. 480). There is no evidence to suggest that all

CAM products/treatments are not safe but there is evidence that shows all products including prescribed medicines and OTC medicines are dangerous (Sørensen, 2002). Thus, safety is not an appropriate differentiator of CAM and biomedicine.

Table 2.1b: *Researcher Definitions of CAM*

Year of study	Author & type of publication	CAM definition
2005	Ang et al. Survey CAM use	CAM modalities...selected to represent the five categories of CAM, based on... NCCAM: alternative medical systems (homeopathy); mind-body interventions (hypnosis, prayer, healing ritual, meditation, and yoga); biologically based therapies (aromatherapy, home remedies, herbal remedies...vitamins...minerals and antioxidants; manipulation...body-based methods (chiropractic, mass therapy)...energy therapies (acupuncture, therapeutic touch...qi qong) (p.870).
2004	Caspi, Koithan & Criddle Qual. study	CAM is not a homogenous field and CAM is a categorical term that covers a broad range of more than 100 healing philosophies, approaches, and therapeutic modalities that allopathic medicine does not commonly study, understand, accept, use, or, make available...may be used instead of conventional therapies (...alternative) or in conjunction with them (...complementary) (p.2).
	Tan et al. Survey CAM use	CAM...“diagnosis, treatment, and/or prevention...complements mainstream medicine by contribution to...common whole, by satisfying a demand not met by orthodoxy...diversifying the conceptual frame works of medicine (Ernst et al., 1995) (p. 861).
	Taylor et al. Survey CAM use	Any product...herbal remedies, vitamin, mineral...natural products...purchased without...prescription at...health food store, supermarket or from alternative medicine magazines...catalogues for...purpose of self treatment’...as vitamin and mineral supplements are also used in ‘traditional’ medical practice...considered free of significant adverse effects, data relating to their use were not analysed (p. 401). Some OTC treatments were not considered CAM if considered safe.
	Zochling et al. Survey CAM use	For...purposes of...study, complementary and alternative medicines’ (CAM)... defined...medicinal preparations...purchased over the counter without medical prescription, do not have general medical acceptance for...use...do not include... paracetamol, aspirin, or ibuprofen (p. 549).
2003	Adams et al. Survey CAM use	Did not include...use of self-prescribed CAM medications (p. 299)...defined CAM use as consultation with alternative health practitioner...did not include the use of self-prescribed CAM medications, although this is considerably more extensive than the use of alternative health practitioners (p. 300).
	Chan et al. 2003. Survey	NCCAM definition

Table 2.1b: *Researcher Definitions of CAM (continued...)*

Year of study	Author & type of publication	CAM definition
2003	Chang et al. Survey CAM use	Alternative therapy...defined as therapy not generally provided by most conventional clinics and hospitals (Guggan, 2001; Eisenberg et al.,1998)... described as unorthodox, non-Western, or non-allopathic medical practice.... alternative therapy and omplementary therapy...used interchangeably, the term “complementary therapy”...used to describe alternative therapies in the pursuit of good health (Gordon et al., 1998) (p. 696).
	Clifford et al. Survey CAM use	CMs...defined...any nonprescription medicine...included nutritional supplements or herbal preparations either purchased from a supermarket, health food shop, pharmacy, naturopath, homeopath or herbalist, by mail order or over the Internet, or grown at home. CMs...classified as nutritional supplements (e.g vitamins, minerals, shark cartilage, amino acids), botanical supplements (e.g Saw palmetto, St John’s Wort), and homeopathic medicine. Over the counter analgesics (e.g paracetamol) and non-herbal laxatives (e.g. dioccytl sodium succinate) were excluded (p. 261).
	Featherstone et al. Survey CAM use	Complementary and alternative medicines are: Any treatments, self help techniques...not normally provided by doctors and other healthcare professionals in the [National Health Service] (p.1081).
	Foote-Ardah. Survey CAM use	CAM...diverse therapeutic practices...not presently...a part of medical training or practice in countries, such as...United States, Canada...Great Britain, where allopathic medicine forms...basis of...national health care system (WHO, 2002).
	Furler et al. Survey CAM use	CAM was defined...treatment not commonly provided by physicians or medical practitioner, and used in conjunction with (i.e. complementary) or in place of (i.e. alternative) standard medical treatments (p. 157).
	Hawks & Moyad. Review	Complementary and alternative therapies...not the same... NCCAM (2003). Complementary medicine is used together with conventional medicine. Alternative medicine is used in place of conventional medicine (NCCAM, 2003) (p.221).
	Keegan. Review	An alternative therapy...used instead of a conventional or mainstream therapy... acupuncture is an alternative therapy...complementary therapy may be an alternative therapy, but becomes complementary when used in conjunction with conventional therapy...help to potentiate effect of the conventional therapy... massage...can stand alone as an alternative therapy...also be used in conjunction ...conventional regimes for a variety of problems (p. 56).
	Koh et al. Survey CAM use	Complementary and alternative medicine (CAM” is defined as “interventions not widely taught in medical schools or available at hospitals (Eisenberg et al., 1993) (p. 51).

Table 2.1b: *Researcher Definitions of CAM (continued...)*

Year of study	Author & type of publication	CAM definition
	Leong, Pong & Chan. Survey CAM use	Alternative medicine is usually defined as medical interventions not taught widely at US medical schools or generally available at US hospitals...the meaning of the term must change across cultures...over time...defining characteristic of alternative medicine...operates on a different set of concepts from conventional medicine...we equated TCM to alternative medicine in this study (p. 660).
2003	Williamson et al. Survey CAM use	Eskinazi (1998) proposed a definition of CAM based on societal beliefs, defining CAM as: A broad set of health care practices...not readily integrated into... dominant health care model...pose challenges to diverse societal beliefs and practices...Eskinazi's description offers a solid definition for the present study and allows for revisions based on changing societal beliefs and practices (¶ 6 & 7).
2002	Egede et al. Survey CAM use	The MEP defined CAM as “approaches to health care that are different from those typically practiced by medical doctors in the U.S.” (¶ 9).
	Gaylord & Crotty. Article	Interventions not used nor taught in ‘mainstream’ American hospitals or other western hospitals” (p. 63).
	Norred, 2002 Survey	In this study CAM includes herbs, dietary supplements, vitamins, and homeopathic medicines that typically are not prescribed by conventional Western physicians (NCCAM) (p. 1013).
	Patterson et al. Survey CAM use	Alternative providers; mental/other therapies...meditation, prayer, group support; dietary supplements. Alternative medicine...defined as use...above therapies...term alternative medicine...all “unconventional” treatments, regardless..whether..patient was using a particular therapy instead of conventional medicine (i.e. alternative) or in addition to conventional medicine (i.e. complementary) (p. 479). Because standard one-a-day multivitamins appear to be generally accepted b mainstream medicine, we did not classify these preparations as alternative supplements to avoid overestimations of alternative medicine use (p.480).
	Peter et al. Survey CAM use	Medical interventions not taught widely at US medical schools or generally available at US hospitals (p. 396).
	Rosenbaum & Stewart. Article	Alternative therapies...defined as...treatments whose aim is to prevent, diagnose...improve disease or disability...not been approved by health authorities. Complementary therapies...group of therapies...diagnostic disciplines...exist...outside the institutions where conventional health care is taught and provided (p. 50-51).
	Shumay et al. Survey CAM use	Used NCCAM's CAM domains and CAM therapies as named by participants.

Table 2.1b: *Researcher Definitions of CAM (continued...)*

Year of study	Author & type of publication	CAM definition
2002	Weigner et al. Retrospective review	Interventions not generally available in hospital-based oncology practices in the United States, with the understanding that some of these are gaining acceptance in the conventional realm and may fail to meet our current definition (p. 889)
2001	Duggan et al. Survey CAM use	(CAM) therapy...defined as “therapy not generally provided by most clinics and hospitals...”complementary and alternative medicine...defined through a process...practices that do not form part of the dominant system for managing health and disease (p. 159).
	Eisenberg et al. Survey CAM use	(CAM) therapies (also known as integrative or unconventional therapies have been defined as “... interventions neither taught widely at US medical schools nor generally available in US hospitals (p. 344).
	Jain & Astin, Survey CAM use	Use of CAM was defined as use of...acupuncture, biofeedback, chiropractic, guided imagery, herbal medicine, homeopathy, lifestyle diets, massage, meditation, and megavitamin therapy (p. 690-691).
	Grueigen et al. Survey CAM use	Alternative medicines have been defined as practices neither widely taught in US medical schools nor generally available in US hospitals (p. 206).
	Lewis et al. Survey CAM use	Neither taught widely in U.S medical schools nor generally available in U.S. hospitals (p. 681).
	Nilsson, Ttrehn & Asplund. Longitudinal CAM use survey	In this study CAM products are defined as minerals, vitamins and other substances not prescribed by a physician (p. 226). We have defined CAM remedies as drugs or natural products that are not prescribed by Swedish physicians and for which there is no consensus in the medical community that there is a medical indication. This means that also vitamin and mineral supplements not prescribed by doctors are included (p. 231).
	Novak & Chapman. Survey CAM use	Complementary and alternative therapies (CAT)...defined as health interventions and practices that are rarely taught or practiced within the dominant medical system (p. 141).
	Silverstein & Spiegel. Survey CAM use	Alternative medical therapies comprise those interventions, which are neither taught widely in medical schools nor are generally available in US hospitals (p. 159-160).

Table 2.1b: *Researcher Definitions of CAM (continued...)*

Year of study	Author & type of publication	CAM definition
2001	Sleath et al. Survey	Alternative therapies were defined as those therapies included in the National Institutes of Health's Office of Alternative Medicine's classification system..(1) alternative systems of medical practice (2) bioelectromagnetic applications (3) diet, nutrition lifestyle changes (4) herbal therapies (5) manual healing (6) mind-body control (7) pharmacologic and biologic treatments (p. 310).
	Wilkinson & Simpson. Survey CAM use	Complementary therapies are generally defined as those therapies not taught as part of mainstream medical care (p.166).
2000	Barrett et al. Survey CAM use	Our operational definition of CAM...consistent with that definition [Eisenberg definition]. Inclusion criteria...focused on issues of reimbursement...herbal medicine, homeopathy...mind-body medicine...not generally reimbursable...most therapies not prescribed by physicians...covered by third-party payers...considered osteopathy ...chiropractic as conventional medicine...acupuncture in the alternative category...we let patients and providers describe to us their definitions and understandings of "complementary" and "alternative" (pp. 234-235).
	Gruner. Article	CM is more commonly known as "alternative medicine" and again would take many pages to properly define, but for simplicity I will as that which falls out of the rubric of EBM (p. 13).
	Knippels & Weiss. Survey CAM use	Alternative medicine as a broad set of health care practices...available to the public...not readily integrated into the dominant health care model, because they pose challenges to diverse societal beliefs and practices (cultural, economic, scientific, medical and educational) (Eskinazi, 1998). In line with previous studies of alternative medicine use (Ernst, 1997)...included food supplements (p. 436).
	Oldendick et al. Survey CAM use	Adopted a version of the operational definition used by Eisenberg et al. ...National Centre for Complementary and Alternative Medicine of the National Institutes of Health... definition permits the inclusion of a wide range of therapies...given our initial focus on the use of "alternative" therapies among the public, enables us to identify those treatments that the general population considers to be outside the traditional mainstream (p. 375).
1999	Adler & Fosket, Survey CAM use	Complementary and alternative medicine (CAM)...defined as all health care resources to which people have recourse other than those intrinsic to biomedicine and its specific theoretical and practice models (p.453)
	Boon & Brown. Perceptions of CAM	CAM...use of natural care products (including herbs, homeopathy...nutritional supplements)...seeking health advice (i.e. regarding treatment, prevention of disease, as well as health maintenance) from individuals...generally considered conventional health care professionals...important to recognize that this definition is necessarily time and culture dependant (p. 639).

Table 2.1b: *Researcher Definitions of CAM (continued...)*

Year of study	Author & type of publication	CAM definition
1999	Ness & Sherman. Review	In general, CAM is defined as a spectrum of clinical practices that: do not conform to the standards of mainstream medical community receive relatively little attention in U.S. medical schools and are not commonly reimbursed by health insurance plans (p. 33).
	Rao et al. Survey CAM use	Intervention not usually prescribed by physicians. Relaxation techniques, exercise programs, or over the counter salves...not included because...prescribed for pain management...interested in interventions costs attached ...did not consider prayer a type of CAM (p. 410).
	Strasen. Article	Complementary medicine includes...practices and practitioners...are external to traditional or allopathic medicine. Originally...called “alternative medicine”...recently advocates of a combination of allopathic medicine for acute diseases and complementary medicine for maintaining health and wellness have coined the term integrative medicine (p. 246).
	Wynia et al. Survey CAM use	Complementary and alternative medical therapies have been defined as therapies “not routinely taught at US medical schools and not routinely available at US hospitals” (Eisenberg et al., 1993) (p. 448).
1998	Astin. Survey CAM use	Neither taught widely in U.S. medical schools nor generally available in U.S. hospitals...” (p. 1548). Deemed not to be alternative or unconventional if... treatments... to treat particular health related problems: exercise for lung problems, high blood pressure, heart problems; obesity, muscle strains, or back problems...Psychotherapy for depression or anxiety... self help group for depression or anxiety.... “alternative medicine”...thus delimited to exclude... practices already part of standard treatment eg exercise to treat hypertension, psychotherapy to treat depression (p. 1459).
	Cassileth. Article	The terms alternative in the United States and complementary in Europe and elsewhere both encompass a wide array of treatments and products (p. 243).
	Eisenberg et al. Survey CAM use	Alternative...therapies...interventions neither taught...medical schools nor generally available...US hospitals (p. 1569).

Overall, the CAM definitions depicted in Table 2.1b show CAM was defined heterogeneously, which suggests comparison of CAM research might be difficult and/or illogical.

As depicted in Table 2.1c many authors developed their own CAM definition. Also shown in Table 2.1c is that many authors (Colebunders et al., 2003; Dolder et al., 2003; Haddad, 2003; Hall, Bissonette, Boyd & Theodorescu, 2003; London et al. 2003) did not use a CAM definition but did include a range of CAM treatments/therapies as tick-box choices in structured questionnaires (Cherniack et al., 2001; Madsen et al., 2003; Wolsko et al. 2000). Whilst some researchers acknowledged that defining CAM was difficult (Davis & Dardin, 2003; Salmenperä, 2002) the methods used to differentiate therapies and/treatment as CAM was not made clear in studies that did not provide a CAM definition. Thus, because there was no CAM definition it was not possible to generalise the criteria used for choosing the therapies and/treatments used to measure CAM use.

For the purpose of comparing CAM estimates in studies where participants asked for a CAM definition when no CAM definition was operationalised (Oneschuk, Hanson & Bruera, 2000) was problematic for two reasons. Firstly, because in such studies there is the assumption that all participants, except those who asked for a CAM definition had the same understanding as the researcher, which might not have been the case (Cassileth, 1999; Manheimer et al., 2003). Secondly, because the phenomenon, CAM use, being measured and/or the criterion used to describe the phenomenon was not made clear (Minichiello, Sullivan & Axford, 1999) the use of CAM cannot logically be compared with other studies.

Differentiating Complementary from Alternative Medicine

Complementary therapy is considered as part of a spectrum of wholistic care in support of biomedicine (Cassileth, 1999; NCCAM, 2002). In this context, complementary therapy operates to manage symptoms and to enhance the quality of life for participants and important others, with aims not unlike those of palliative care (Zappa & Cassileth, 2003). In contrast, many researchers considered alternative medicine, expensive, invasive, possibly unsafe practice that aimed to cure (Eisenberg, 2002; Cassileth, Schraub, Robinson & Vickers, 2001; Zappa & Cassileth, 2003). Such definitions disallow differentiation between CAM and

Table 2.1c: *Individualised Definitions of CAM*

Year of study	Author & type of publication	CAM definition
2005	Elkins et al. Survey CAM use	None cited
	Colebunders et al. Survey CAM use	
2003	Davis & Darden. Survey CAM use	The definition of complementary and alternative medicine (CAM) is not well established. It is generally accepted to be the integration of nonallopathic methods into preventive or acute health care (p.393).
	Haddad. Article, CAM ethics	None cited
	Hall et al. Survey CAM use	
	Kimby et al. 2003. Survey CAM use	The term “unconventional treatment “ is chosen to emphasize that both alternative therapists as well as medical doctors practice unconventional treatments (p. 550).
	London et al. Survey CAM use	None cited
	Nayak et al. Survey CAM use	Unconventional treatments we refer to here as complementary and alternative medicine (CAM) (p. 182).
	Madsen et al. Survey CAM use	CAM was divided into...1) authorised herbal medicine (HM), 2) alternative therapy and 3) chiropractic. HM was divided into 1) herbal drugs, 2) vitamin/mineral preparations, 3) dietary supplements, including herbal extracts and others which are not classified as herbal drugs, and 4) preparations which could not be classified...iron-supplement, D- or K- vitamins for children aged below 1 year plus ordinary vitamin tablets were not registered as CAM (p. 235).
	Rickhi et al. Survey CAM use	None cited

Table 2.1c: *Individualised Definitions of CAM (continued)*...

Year of study	Author & type of publication	CAM definition
2003	Vallerand et al. Survey CAM use	None cited
	Wetzel et al. Article	
2002	Berman et al. Survey of CAM referrals by B/M physicians	
	Buchbinder et al. Survey CAM use	Treatment that was initiated by the patient, excluding treatment that had been prescribed by their doctor (p. 209).
	Cassileth et al. Article	Integrative cancer treatment refers to conventional treatment provided in tandem with complementary and sometimes alternative therapies (p. 47).
	Rynes, Kajimura-Beck & Broekmeier. Survey CAM use	None cited. Vitamins and calcium not considered alternative medicine.
	Chi-Keong et al. Survey CAM use	None cited
	Day. Survey CAM use	None cited. There is a wide range of complementary or alternative (CAM) medicine therapies available. Such therapies include naturopathy, homeopathy, herbal remedies and physical therapies (eg. massage, chiropractic treatments (p. 343).
	Ferry et al. Survey CAM use	Alternative therapy...defined as a treatment...based on belief rather than scientific proof of efficacy...alternative therapy...referred to as complementary therapy as patients were still using the conventional therapy in parallel to the alternative. Alternative therapy in the UK...mainly used to help relieve injury...mode of relaxation...general well being, or as alternative to conventional medicine (p. 612). Complementary therapy...therapy had to be initiated on the patients' own initiative as opposed to being suggested by their doctor or healthcare professional (p. 613).

Table 2.1c: *Individualised Definitions of CAM (continued)*...

Year of study	Author & type of publication	CAM definition
2002	Fong & Fong. Survey CAM use	None cited
	Grinstein et al. Survey of literature	We have used the words “complementary medicine” to mean a combination of approaches to curing disease, including treatments not used in conservative medicine (p. 437).
	Huber et al. Survey CAM use	None cited
	Lee et al. Survey CAM use	
	Lewith et al. Survey CAM use	
	Ong et al. Survey CAM use	
	Rafferty et al. Survey	
	Salmenperä, Survey	CT’s are defined as comprising all treatments and therapies not covered by official medicine (p.44)
	Shane-Mcwhorter & Geil. Case studies	None cited
	Shenfield et al. 2002. Survey CAM use	
Schäfer et al. 2002. Survey CAM use	AM [alternative medicine]....defined as distinct therapeutic procedures not including herbs, food supplements, home remedies or minor adjuvant measures...also obtained data on homeopathy and acupuncture, which to some extent became part of the conventional therapeutic concept and are no longer commonly viewed as alternative medicine (p. 695).	

Table 2.1c: *Individualised Definitions of CAM (continued)*...

Year of study	Author & type of publication	CAM definition
2002	Yang et al. Survey CAM use	None cited
2001	Blanc et al. Survey CAM use	To assess the prevalence of such practices... also referred to as “complementary” or “unorthodox” therapies (p. 1421). List of ‘alternative therapies’ included in questionnaire.
	Cherniack et al. Survey	None cited. List of CAM including vitamins & minerals, herbal medicines, supplements, alternative care systems, self-help or lifestyle methods (p. 278).
	Dong et al. Survey CAM use	Acupuncture is regarded as alternative medicine (p. 651).
	Furnham & Lovet. Survey CAM use	None cited
	Kemper & Wornham.	
	Kessler et al. (a). Survey CAM use	No mention was made of complementary and alternative therapies in characterizing the study (p. 290).
	Richardson et al. Survey CAM use	None cited
	Standish et al. Survey CAM use	It is not approved by the Food & Drug Administration (FDA)...Not routinely taught in conventional medicine schools...Taken in a dosage differing from the FDA’s approval...Is used for a condition differing from the FDA’s approval or...Is not covered by most insurance policies (p. 197-198).
2000	Anderson et al. Survey CAM use	Any product, including herbal remedies, vitamins, minerals, and natural products, that may be purchased at a health food store, pharmacy, supermarket, or alternative store/magazine for the purpose of self-treatment (p. 958).
	Conroy et al. 2000. Survey CAM use	Unconventional medical services...all the major complementary therapies, vitamins and mineral supplements, other complementary remedies, exercise and relaxation techniques (¶ 30).

Table 2.1c: *Individualised Definitions of CAM (continued)*...

Year of study	Author & type of publication	CAM definition
2000	Furnham, (a). Survey CAM use	Alternative practices can be roughly divided into future-ologies that are mainly concerned with personality assessment & future prediction, (eg astrology..) & those concerned with different forms of complementary medicine (eg acupuncture, osteopathy) (p. 72).
	Furnham, (b) Survey CAM use	None cited.
	Palinkas & Kabongo. Survey CAM use	
	Sparber et al. (a). Survey	None cited. Acknowledged literature variations of CAM definitions
	Unützer et al. Survey-reanalysis	To assess the use of complementary and alternative medicine ...did you use any alternative or folk medicine...included the following statement to give examples of alternative medicine therapies “Alternative medicine includes therapies like homeopathic medicine, acupuncture, massage therapy, herbal medicine and spiritual healing”...has become harder to make clear distinctions between conventional alternative medicine...Participants were asked to use their “own judgement whether the services they reported were “alternative” (p.183).
	Wolsko et al. Survey CAM use	None cited. “Five types of alternative medicine practitioners (acupuncture, chiropracty, herbal, medicine/dietary or vitamin supplements, medication/relaxation and massage” (p. 322).
1999	Bullock. Survey CAM use	None cited
	Druss & Rosenheck. Survey	The terms alternative and complementary medicine suggest two contradictory possibilities. Whether individuals use conventional therapies as a substitute for or as an “add on” to conventional medical treatments is uncertain (p. 651).
	Söllner et al. Survey CAM use	Alternative therapies...used specifically to influence the course of cancer...not used as standard medical treatment because of their non medical character or the lack of proven efficacy; complementary therapies...treatments aimed at symptom control or enhancing the quality of patients’ lives...relaxation, psychotherapy or participation in self help group...explicitly used to reduce distress & to improve the patient’s subjective well-being...not considered...CAM (p. 317).

Table 2.1c: *Individualised Definitions of CAM (continued)*...

Year of study	Author & type of publication	CAM definition
1998	Berg & Arnetz. Survey CAM use	None cited. Ten types of alternative medical remedies were listed (p. 278).
	Krauss et al. Survey CAM use	None cited
	Moody et al. Survey CAM use	
	Pachter et al. Survey CAM use	Not usually defined as alternative/complementary medicine, folk medicine or ethnomedicine describes various alternative practices and therapies...used by members of a cultural minority group...ethnomedicine can be...a subset of alternative/complementary medicine (p. 1083).
1996	Fleischer et al. Survey CAM use	None cited

experimental biomedicine, which can also be described as unsafe, invasive, expensive and a final effort to cure (Lamarine, 2001). For example, Phelybutrate and Hydroxea Urea, an anti-neoplastic drug used experimentally to increase foetal haemoglobin (Hbf) had limited efficacy and severe adverse affects such as myelotoxicity, teratogenecity and oncogeneticity (Castro & Oswaldo, 1999; Stamatopoulos & Neinhuis, 1992).

Alternative medicine has also been defined as CAM treatment used to treat conditions that fail to respond to biomedical care (Yoon-Hang, Lichtenstein & Waalen, 2002). However, when CAM treatment was used to treat adverse effects resulting from biomedical care it was considered complementary medicine (NCCAM, 2002; Zappa & Cassileth, 2003), which suggests complementary medicine was practised alongside and often in biomedicine settings and that alternative treatments were practised in settings other than biomedicine hospitals

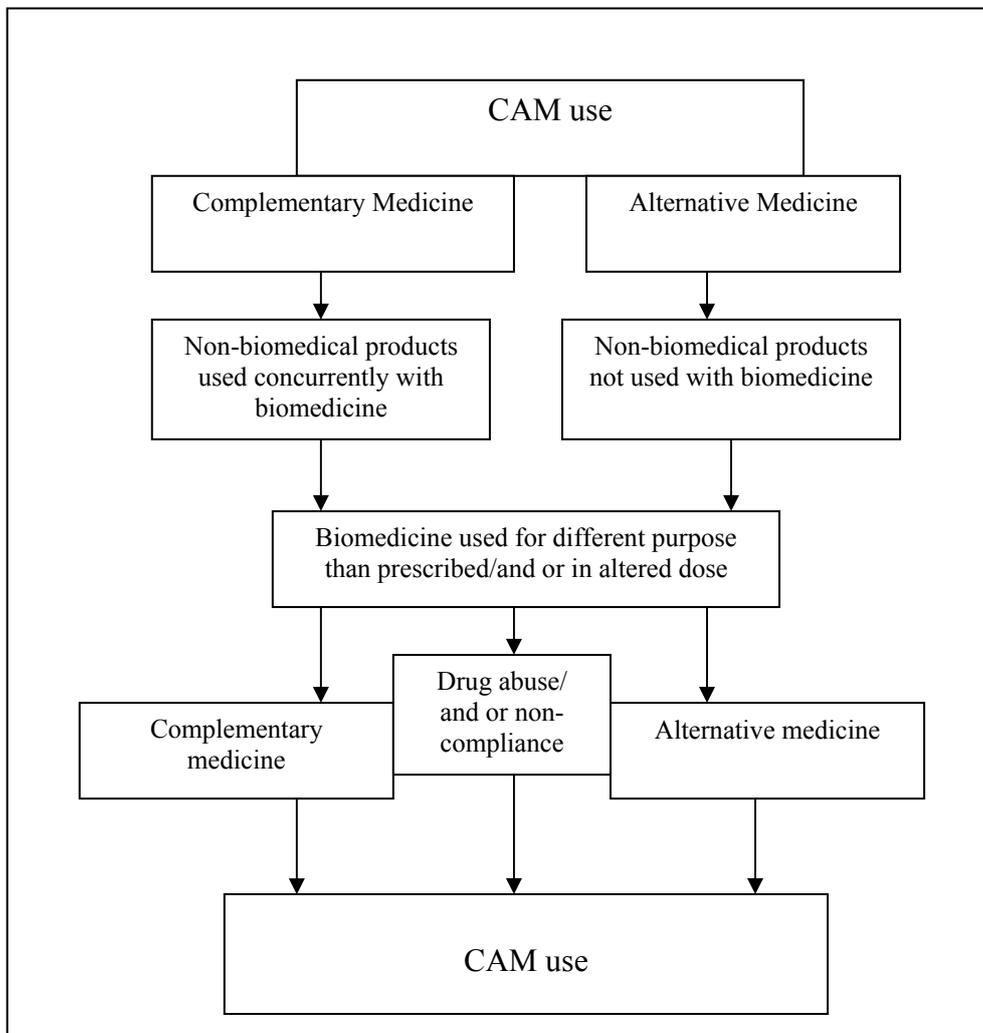


Figure 2.1: *Differentiating Complementary and Alternative Medicine*

(Cassileth, Schraub, Robinson & Vickers, 2001). The use of such criteria for differentiating complementary from alternative medicine is problematic because new or experimental biomedicine, such as gene therapy and stem cell technology (Wheelwright, 2001) undertaken in biomedicine hospitals can also be referred to as CAM (Corless et al., 2000; Factor-Litvak et al., 2001; Johnston et al., 2001). Therefore, the term alternative CAM treatment is problematic (Wootton & Sparber, 2001) and provides a plausible explanation for different CAM estimates such as, those for HIV that ranged from 22% (Kassler, Blanc & Greenblatt, 1991) to 100% (Nokes, Kendrew & Longo, 1995) for apparently equivalent research.

The acronym CAM represents the terms complementary and alternative medicine (NCCAM, 2002). Despite complementary medicine (CM) and alternative medicine (AM)

being different (NCCAM, 2002) some researchers considered “CM is [was] more commonly known as “alternative medicine” (Gruner, 2003, p. 13), accordingly inferring that complementary and alternative medicine were the same. Thus, many CAM definitions were contrary to how NCCAM defined CAM because they did not acknowledge that complementary medicine is different to alternative medicine (NCCAM, 2002). In addition some CAM definitions were ambiguous because they failed to acknowledge that CAM is an acronym, as the following example shows:

Complementary and alternative medicine (CAM) is defined as methods used in the diagnosis, treatment or prevention of disease that complement mainstream medicine, as opposed to alternative therapies, which are used as direct substitute for mainstream medicine. (Lengacher et al., 2002, p. 1445).

CAM definitions that classified CAM therapies from “most alternative to least alternative” (Owens, Taylor & DeGood, 1999, p. 531-532) were not accurate representations of the NCCAM (2002) definition of CAM and did not as claimed “represent all the categories of alternative therapies as defined by the NCCAM” (Owens et al., 1999, p. 531-532) accurately describe CAM therapies as described by NCCAM, illustrated in Table 2.1a. In addition, some CAM definitions lacked clarity because they inferred practices such as, prayer and music are efficacious, proven and not CAM, as shown in this example.

Music and prayer are clearly more complementary...Other modalities for which there is little solid evidence of efficacy such as using static magnets for pain or shark cartilage for cancer are more clearly categorized as CAM. (Owens et al., 1999, p. 531)

Thus, many operationalised CAM definitions used for research purposes made it difficult to know whether estimated use of non-medical treatments/substances was for alternative and/or complementary medicine.

Health Behaviour and the Definition of CAM

This section of the review presents the rationale used by researchers to define a wide range of activities and behaviours such as, non-compliance to biomedical treatment regimens, drug abuse, eating, prayer and exercise, as CAM. As shown in Figure 2.1, CAM is the acronym of complementary and alternative medicine, complementary medicine can be any

product/therapy not considered biomedical that is used with biomedicine and alternative medicine could be any product/therapy not considered biomedical in nature that is used in lieu of biomedicine. Also depicted in Figure 2.1 is how behaviours such as, drug abuse and non-compliance to biomedical regimens, can be defined as complementary or alternative medicine, or drug abuse, non-compliance or CAM. Consequently, the manner by which the acronym CAM and the terms of complementary and alternative medicine have been used and defined by researchers provides little understanding of CAM.

Depicted in Table 2.2 is the author and rationale used to differentiate activities/and or substances as CAM. As noted in Table 2.2 many products and/or activities undertaken by people (Drew, 2001; Balfour, 2000; Buchbinder et al. 2002; Fairfield et al. 1998) such as, the acquisition of educational material (Balfour, 2000, p. 313) were measured as CAM. Without elaboration from the researcher it was difficult to know if such behaviour would be considered biomedicine if the person had acquired such material through their biomedical physician's clinic, or was recommended to access such material by their treating biomedical physician. Whilst not all researchers agreed and excluded substances such as marijuana (Furler et al., 2003), measuring such products/substances as CAM suggests they were a medical intervention. Furthermore, there is a misconception about how some therapies/and or substances are administered. For example, acupuncture cannot be a "homed-based" (Pachter et al. 1998, p. 1085) treatment because in some countries, such as Australia (Chinese Medical Registration Board, 2005) and Canada (Johnson, 1999), acupuncture requires trained practitioners for its delivery. Moreover, it is highly unlikely that a person without training in acupuncture would needle himself or herself.

CAM defined as prescribed medicines taken in a manner not recommended by a biomedical physician (Buchbinder et al., 2002; Fairfield et al., 1998; Ferry, Johnson & Wallace, 2002) is problematic because such behaviour describes the degree to which a person

acts in accordance with a prescribed biomedical regimen (Erlen, 1997; Sieber & Kaplan, 2000).

Table 2.2: *Activities and CAM*

Author & date	Activity, Substance	CAM	NOT CAM	Rationale used to include or exclude as CAM
Astin, 1998; Suarez & Reese, 2000	Psychotherapy and exercise		√	When used to treat specific disorders, such as depression and cardiovascular disease
Balfour, 2000	Accessing books, videos and newsletters	√		To gain knowledge about FMS (p. 313).
Bica et al. 2003	Folic acid, multivitamins and iron supplements		√	Because they “are often prescribed or recommended by allopathic physicians” (p. 74)
Drew, 2001	Any non-medically prescribed substance containing active substances with a complementary or traditional use	√		Because people use them in the belief that they have therapeutic benefit
Nilsson et al. 2001; Reid, 2004	OTC		√	When not prescribed by B/M physicians
Nicholas et al. 2002	Acupuncture, massage, medications (prescription, OTC, vitamins, topical), exercise rest, elevation, (substance use alcohol & marijuana).	√		Self care strategies
Pachter et al. 1998	Herbal tea or other non-biomedical treatment, such as homeopathy, acupuncture, humidifier		√	When recommended by a biomedical practitioner
Rao, 1999	Diet, exercise, OTC	√		Because people use them in the belief that they have therapeutic benefit
	Prayer		√	No cost attached

In addition, prescribed medicine taken for purposes other than as prescribed or in alternative dosages is classified as substance abuse (Poulin, 2001). This suggests behaviours considered by biomedical practitioners, sociologists and psychologists as non-adherence to a drug regimen or drug abuse were defined as CAM.

If OTC and all non-prescribed drugs including alcohol and caffeine are measured as CAM, CAM use has been grossly underestimated. For example, in Australia, 95% of 12 year-old and 98% of 15 year-old school children self-prescribed and took analgesic medications (NDSUCDHAC, 2001). Similarly, in America a survey of OTC drug use in the elderly found that 90% of the participants took OTC pain medications (Amoako, Richardson-Campbell, & Kennedy-Malone, 2003).

As shown in Table 2.1c CAM was defined as a substance “taken in a dosage differing from the FDA’s approval...used for a condition differing from the FDA’s approval” (Standish et al., 2001, pp. 197-198). This definition, as noted earlier, can be described as drug abuse and it can also be described as experimental biomedicine because some biomedicines are used experimentally for diseases other than that for which they were originally conceived. For example, thalidomide originally prescribed as a sedative and for prima gravis nausea, has been used as a cancer (Kerst et al., 2005; Sleijfer, Kruit & Gerrit, 2004) and lupus treatment (Karim, Ruiz-Irastorza, Khamashta & Hughes, 2001). Thus differentiating CAM from biomedicines on the basis of standards that American Federal Drug Authority (FDA) places on the use of medicines is illogical.

Diet therapy. CAM was defined as “any non-medically prescribed substance containing active substances with a complementary or traditional use that a person uses with the belief that it will improve their health or well being” (Drew et al., 2001, p. 39). Therefore the common cold remedy, honey and lemon was considered CAM (Factor-Litvak et al., 2001) possibly because honey contains antimicrobial and antiviral compounds (Tichy & Novak, 2000), lemon juice contains Vitamin C, and/or because anecdotally honey and lemon has been

known and used by many cultures, as a treatment for colds and or because it was not prescribed by a biomedical physician.

Another reason for considering diet therapy as CAM might be because “in most countries complementary medicines are regulated as ‘foods’ ” (Cumming, 2000, p. 57) or because “there is no sharp borderline between food and drug” (Sigerist, 1977, p. 147). This later point suggests that common foods do not fall beyond the purview of biomedicine and that food/diet therapy does not differentiate biomedicine from CAM adequately.

There is an explicit assumption that biomedical physicians have a major role in promoting dietary change (Department of Health, 1994, 1998, 1999) but even in the face of mounting empirical evidence that shows dietary habits are precursors to disease and higher rates of mortality and morbidity (Bonilla-Fernandez, Lopez-Cervantes, Torres-Sánchez, Tortolero-Luna & Lopez-Carrillo, 2003; Hooper et al., 2003) biomedical physicians have been found to be reticent about advising their patients about diet believing that advice such as ‘eat healthy’ was sufficient (Novak & Chapman, 2001; Sørensen, 2002; Weiger, 2002). For example, even when advised to, biomedical physicians were reticent to discourage women with breast cancers from using macrobiotic diets because of their high phytoestrogen content (Weiger et al., 2002). Thus, the rationale for considering diet as a CAM because it falls beyond the purview of biomedicine is not supported by the literature.

Although diet is the most frequently used regimen (Curth, 2003) and research shows it is imperative biomedical practitioners consider patients’ dietary practices to avoid possible adverse effects and to potentiate treatment regimens (Sørensen, 2002) the literature shows food is differentiated as CAM or biomedicine on the basis of the researcher’s point of view, rather than the context in which it is used.

Preventive care and lifestyle practices. Preventive care and lifestyle practices and health regimens are concepts aimed at preventing disease (Longrigg, 1998) by various means such as, exercise, diet (Curth, 2003) and “lifestyle drugs” (Gilbert, Walley & New, 2000, p. 1341)

such as, lipid-lowering biomedicines (*ibid*, p. 1342). Thus, preventive care whether practised as a lifestyle in the form of exercise or as the taking of prophylactic biomedicines, is of the biomedical domain because such practices are used to prevent illness (Márk, Nagy, Konacs & Deli, 1998).

Not all agree that lifestyle is part of the biomedical domain because such practices move away from the fundamentals of biomedicine that emphasise biochemical and treatment explanations for diseases (Cassileth, 1999; Hufford, 2003). In contrast, lifestyle practices such as home remedies, diet and maintaining sound social relationships are considered part of culture (Leininger, 1991) and not a form of medicine even though such routines have substantial bearing on the prevention of illness (Papadopoulos, 1999).

Although the Guidelines for Adolescent Preventative Services (GAP) encouraged biomedical practitioners to provide preventive guidance and risk factor screening for lifestyle issues such as exercise, nutrition and obesity, biomedical physicians were disinclined to implement preventive care but likely to screen for risk (Zink, Levin & Rosenthal, 2003). An explanation for this phenomenon might lie in the relationship between the biomedical physician and the patient, whereby the process of consultation includes assessment, diagnosis and treatment (Lupton, 1994; Morgan, 1998). Whilst such practice is indicative of the emphasis that biomedicine places on disease and cure (Kaptchuk & Eisenberg, 2001) with pharmaceutical intervention the core of care (Siahpush, 1998) some researchers considered that the difference between lifestyle and healthcare is positioned in “the perception of what is illness and what is within the sphere of personal responsibility rather than health care might depend on whether one is a potential patient or a potential payer” (Gilbert et al., 2000, p. 1341). Whilst opinions and practices amongst biomedical practitioners differ and there is little evidence to suggest that preventive medicine does not fall beyond the scope of biomedicine (Curth, 2003) or other systems of medicine (Xu, 2002) differentiating healthcare from

lifestyle on the basis of pay is possibly a reflection of the historically bitter feud over turf (Eisenberg, 2002), rather than logical differentiation.

Integrative medicine. Integrative medicine is a term that is often used to refer to CAM (Tiran, 2006). CAM practices such as, hypnosis, chiropractic, meditation and acupuncture incorporated into biomedical practice has been referred to as “mainstream” (Cohen, Pwenham, Pirota & Da Costa, 2005, pp. 995-996) or integrated medicine (Verhoef, Mulkins & Boon, 2005). Whilst CAM therapies integrated into biomedicine are those with empirical evidence supporting their efficacy, the philosophical underpinnings of such therapies are not considered (Caspi & Bell, 2004). Therefore integrative medicine is not the practice of CAM within the biomedical domain; rather it is appropriation of other modalities.

Often CAM therapies subsumed into biomedical practice are re-named and this adds to the difficulty of separating CAM from biomedicine (Eastwood, 2000). For example, using terms, such as muscular-skeletal therapy in lieu of massage; adding the word medical to acupuncture; nutritional and environmental therapy in place of diet therapy and referring to orthopaedic surgery in place of bone-setting medicine legitimises the practices into biomedical care (Eastwood, 2000). Therefore, integrative medicine can be referred to as *medicalisation*, used to describe; “socially created boundaries between lifestyle wishes and health needs” (Gilbert et al., 2000, p. 1341) and the appropriation by biomedicine of common human phenomenon such as birthing, human behaviours and afflictions such as alcoholism, common human activities such as exercise, spirituality and prayer, massage, rest and the taking of chicken soup (Golden, 1999; Hufford, 2003; Williams; 2001). Thus medicalisation is indicative of the successful inclusion of common practices into the biomedical domain (Hufford, 2003; Williams, 2001) that disallows any sensible differentiation between CAM, biomedicine and common practices, which might or might not be for health purposes.

Whilst there is a need to differentiate between therapies aimed at curing and practices that might enhance and/or harm health it should be done in context. For example, in a study of

people with sickle beta-thalassaemia physical stress induced by exercise could elicit painful crises that could induce myocardial ischemia even when participants had normal coronary arteries (Aessopos, 2001). Much of the available literature, however, does not support the view that biomedical practitioners actively configure lifestyle advice/practices into their treatment regimen because such advice was considered inappropriate (Novak & Chapman 2001). Although there is ample empirical evidence that shows instructions about lifestyle practices are essential to health and accordingly to any practice of medicine, whether lifestyle is CAM or biomedicine remains controversial

Spirituality. Activities considered CAM such as spirituality, religion and prayer informs this section of the literature review.

In the USA prayer is the most frequently used CAM (Chang, Servellen & Lombardi, 2004; Eisenberg et al., 1998; Lengacher et al., 2002; Yeh et al., 2002). The introduction of spirituality into medical schools suggests that biomedicine is appropriating a CAM therapy or considers spirituality a legitimate health-care practice (Barnes et al., 2000). That spirituality should be considered part of the biomedical domain is at odds with the notion that CAM therapies are CAM because they lack clinical efficacy and biological plausibility (Hoffer, 2003).

Some studies showed despite endorsement of prayer as a legitimate health care practice by some people practising in the area of biomedicine, there was a disinclination to use it as part of biomedical therapeutic practice, except in life-threatening situations (Barnes et al., 2000; Schoenberger, Matheis, Shiflett, & Cotter, 2002). Biomedical carers were also found to be unwilling to refer people for religious consultations even though referral to other professionals is intrinsic to the physician's role (Schoenberger et al., 2002). Therefore the literature shows there is a lack of consistency between opinions and behaviour that is possibly driven by the association between prayer and religion, ethical concerns, or that biomedical physicians lack the expertise to recommend religious practice (Schoenberger et al., 2002;

Sloan et al., 2000). In addition, biomedical physicians might be reticent to refer people to therapies that biomedicine discouraged because such referrals might have negative financial and peer repercussions on their practices (Kemper & Barnes, 2003; Schoenberger et al., 2002). This suggests the medical and political divide between CAM and biomedicine (Angell & Kassier, 1998; Matheis, Shiflett & Cotter, 2002) is the reason spirituality is classified as CAM and not because it does meet scientific criteria.

Section Summary

This review showed researchers did not use consistent criteria to define CAM and operationalise CAM. This review identified differentiating therapies into sharp and fixed categories such as, integrative, CAM, complementary and/or alternative medicine, does not work because there was a perpetual shift, overlap and redefining of what was considered CAM and congruent interplay between CAM and biomedicine (Peter, 2002). Therefore, suggesting very different values result for what appears to be the same variable.

This section pointed out that even though the definition of CAM varied enormously and what it was that deemed a therapy to be CAM was unclear because terms used to describe CAM were used interchangeably (Eisenberg et al., 1998; Unützer, 2000; Zollman & Vickers, 2000), the term “CAM is a chaotic conception without taxonomic closure” (Doel & Segrott, 2003, p. 131), which makes studying CAM difficult (Patterson et al., 2002) and confusing because of the lack of specificity. Thus, the definition of CAM must influence the interpretation of CAM survey results and the interpretation of conclusions drawn from the research.

Frequency of CAM Use

The following section reviews the reported frequency of CAM use by the general community and people with chronic illnesses. The present section particularly emphasised self-prescribed and CAM provider CAM use amongst people who required ongoing biomedical treatment. In addition, CAM user profiles, accuracy and interpretation of research

results are compared and discussed. For the purposes of this review CAM estimates were referred to as ‘CAM’ because many researchers (e.g. Fong & Fong, 2002; Sanders et al., 2003; Spiegelblatt et al., 1994) failed to distinguish between CAM, complementary and alternative treatment and or failed to define any of the terms.

Estimated CAM use for the general population. In this section of the review the emphasis is on estimated CAM use for each country. Thus, the first column in Table 2.3 is ‘country’. Table 2.3 shows the country in which the study took place, the author, and estimated frequency of CAM use for general populations.

As illustrated in Table 2.3 for adults in developing countries the use of CAM ranged from 40% (Bodeker & Kronenberg, 2002; Chi, 1994) to 80% (Bodeker & Kronenberg, 2002) and for the developed world from 33% (Zollman & Vickers, 1999) to 81% (Kaufman et al., 2002). These CAM estimates suggest CAM is a worldwide phenomenon and at least half the population of the world uses CAM.

As shown in Table 2.3 CAM estimates for the general population range from 15% (Adams, Sibbritt, Easthope & Young 2003) to 80% because to date there have been no population-based studies (Bodeker & Kronenberg, 2002.). Whilst it is “difficult or impossible” (Schofield & Jamieson, 1999, p. 149) to survey an entire population, a population-based study can be a “subset” of a population defined geographically, by time or other characteristics (*Ibid*, p. 149). Hence, as most CAM studies had defined characteristics for the focus of the research such claims cannot be supported.

Other researchers (Cassileth, 1984; Metz et al., 2001; Sparber & Wootton, 2002) suggested variables such as participant eligibility, socio-demographics, chronic illness, time of CAM use and setting were responsible for variations in CAM estimates. The next subsections of the review compared studies according to these variables.

Participant eligibility. CAM research shows selection criteria often excluded an estimated 10% (Cassileth et al., 1984) to 62.33% of participants (Oneschuk et al., 2000).

Table 2.3: *CAM Estimates for the General Population by Country*

Country	Author/Year Qualitative (QL), Quantitative (QN)	CAM Estimate %
Africa	Bodeker & Kronenberg, 2002. Discussion paper	80
America	Astin et al. 2000. Medicare recipients. Elderly. QN	30
	Astin, 1998. 1035. Individuals. National population Randomised written survey. Elderly QN	40
	Barnes et al. 2004. Advance Data from vital and health statics. Survey conducted in 2002 by the National Center for Health Statistics, the Centers for Diseases Control and Prevention. QN	62
	Cherniack, Senzel & Pan, 2001. 421 older participants. Cross sectional survey. Interviews. QN.	58
	Eisenberg et al. 2001. 831 adults seeing a biomedical doctor and using CAM. 48 contiguous states National telephone survey. QN	33.24
	Eisenberg et al. 1998. National telephone survey. QN	42.1
	Eisenberg et al. 1993. National telephone survey. QN	33
	Kessler et al. 2001b. 2055 respondents. Retrospective nationally representative telephone survey. QN	67.6
	Kaufman et al. 2002. 2,590 participants the Slone Survey (1998-1999) randomised telephone survey, conducted in 48 contiguous states and the District of Columbia USA. QN	81
	Odendick et al. 2000. 1,584 (RR66%). Adults from South Carolina Population based-cross sectional study. African Americans, rural & low income.	44
	Rafferty, McGee, Miller & Reyes, 2002. 3,764 Michigan adults. Population-based telephone survey of adults conducted by state health department in cooperation with the Centers for Disease Control and Prevention. QN	49.7
Verhoef, Russel & Love, 1994 Alberta (USA)-rural population. QN	32	

Table 2.3: *CAM Estimates for the General Population by Country (continued...)*

Country	Author/Year Qualitative (QL), Quantitative (QN)	CAM Estimate %
Australia	Adams, Sibbritt, Easthope & Young 2003. Cross-sectional postal questionnaire, baseline survey of the Australian Longitudinal Study on Women's Health. QN (n=12939) 70-75 years of age (n=14099) 45-50years of age (n= 14779) 18-23 years of age	15 28 19
	Astin, 1998. 1035 (RR69%) randomly selected people. Written survey participants. QN	50
	Benoussan, 1999. (Figures taken from government census). QN	57
	MacLennan et al. 1998 South Australia. QN	48.5
	MacLennan et al. 2002. 3027 people South Australia. Personal interview QN	52.1
	Wilkinson & Simpson, 2001 Rural community NSW. Postal quest., 300 returned (RR 31.4%). QN	52
Canada	Bodeker & Kronenberg, 2002. Discussion paper	70
Chile		80
China		40
	Chi, 1994. QN	60
Columbia	Bodeker & Kronenberg, 2002. Discussion paper	40
Germany	Ernst, 2000a. Systematic review	64
	Schäfer et al., 2002. QN	64
U.K	Thomas, Coleman & Nicholl, 2001. QN	50
	Zollman & Vickers, 1999. Discussion paper	33

Participant exclusion can arise because of physical or psychological impairment (Oneschuk et al., 2000). In addition, participants who opted out of biomedical care after a positive diagnosis for cancer or because they might be not easily traceable might also be excluded for ethical and privacy issues (Cassileth et al., 1984). Other reasons for excluding people include selection criteria might only call for participants from treatment centres (Ang et al., 2005; Leong et al., 2003; Manheimer et al., 2003; Yang et al., 2002) or from treatment registries (Furler et al., 2003; Lee et al., 2002a; Shumay et al., 2002). Whilst such selection methods might exclude some people, because they are systematic, they afford a high degree representativeness of the target population (Schofield & Jamieson, 1999). Some selection methods, however, such as convenience sampling might not be representative of the target population and purposive sampling carries a high risk of conscious sample bias (*Ibid*, p.151). As a consequence, participant selection methods could account for some of the disparity in estimated CAM use.

Estimated CAM and socio-demographics for the general population. Table 2.4 shows author/s, date, and place of study and socio-demographics of CAM users. As depicted in Table 2.4 CAM use in industrialised countries such as, America, England, Australia and Taiwan, was predominantly associated with being female, higher income and increased education, not shown is that many researchers found no such association (Astin, 1998; Astin, Pelletier, Ariane & Haskell, 2000; Elder, Gillcrest & Minz, 1989) or minimal difference between the socio-demographic profiles of CAM users (Wolsko et al., 2000; VanDeCreek, Rogers & Lester, 1999). Similarly, in a study of 421 older American participants although being female was associated with CAM use, race, age by decade and income were not associated with such use (Cherniack, Senzel & Pan, 2001). Also shown in Table 2.4 is that converse correlates were found in developing countries such as, India, where men and people with lower education and socio-economic status were more likely to use CAM. In contrast, in Singapore those with higher education were no more likely than their less well-educated

counterparts to choose their indigenous medicine in preference to biomedicine (Lee & Bishop, 2003). Whilst, cultural differences were not often associated with CAM use and in general, socio-demographics were poor predictors of CAM use, the empirical data suggests socio-demographic profiles of CAM users can be generalised relative to developed or undeveloped country.

Estimated CAM and socio-demographics for people with a chronic and/or serious illness. Table 2.4 shows the socio-demographic profile, female, higher education and income, of CAM users with serious and/or chronic illness were like those for the general population (Gotay et al., 1999; Yang et al., 2002). Although, these results are somewhat similar to those found in people with HIV (Greenblatt, Hollander, McMaster & Henke, 1991; Ostrow et al., 1997) findings amongst such people are not consistent. For example, whereas marital status was not, income of \$US15, 000 or more per year was an effective predictor of CAM use (Duggan, Peteronn, Schultz, Khuder & Charkraborty, 2001) and whilst HIV CAM users were more likely to have better social support than non-users, socio-demographic profiles were found not to differ (Anderson, O'Connor, MacGregor, & Schwatz, 1993; Knippels & Weiss, 2000).

Conversely whilst some studies of people with cancer found income was not associated with CAM use, being female and higher levels of education (Patterson et al., 2002; Shumay et al., 2002) and being Caucasian were associated with heavier CAM use (Shumay et al., 2002). CAM use in men with prostate cancer was associated with being less than 40 years of age, higher education level, influenced by friends and relatives with prostate cancer, and participation in social or religious group (Lee et al., 2002a). In men with prostate cancer aged between 40 to 89 years, ethnicity correlated with CAM use only when members of each ethnic group was examined separately (Lee et al., 2002a). Converse associations for CAM use were found in undeveloped countries amongst those with serious illnesses such as epilepsy (Tandon, Prabhakar & Pandhi, 2002) and leukaemia (Gupta, Shafiq, Kuman & Panhi, 2002).

Table 2.4: *Socio-demographics of CAM users*

Place of study	Author & date	Gender		Education		Economic Status		Age (years)		Ethnicity
		Female	Male	< than secondary school	Secondary school or >	Low	High	Up to 40	> 40	
America	Astin, 1998				√					
	Blair et al. 2002				√					Caucasian
	Duggan et al. 2001		√				√	√		
	Downer et al. 2000	√			√					
	Bair et al. 2002									Caucasian
	Cherniack et al. 2001.	√								
	Cherrington et al. 2003			√					√	
	Conboy et al. 2005	√				√				Caucasian

Table 2.4: Socio-demographics of CAM users (continued...)

Place of study	Author & date	Gender		Education		Economic Status		Age (years)		Ethnicity
		Female	Male	< than secondary school	Secondary school or >	Low	High	Up to 40	> 40	
America	Cuellar et al. 2003			√					√	African Americans
	Furler et al. 2003	√								
	Gotay et al. 1999.	√								
	Lee et al. 2002								√	Asian
						√			√	
	Patterson et al. 2002	√						√		
	Read et al. 2002.	√				√				
	Shumay et al. 2002	√				√				Caucasian

Table 2.4: *Socio-demographics of CAM users (continued...)*

Place of study	Author & date	Gender		Education		Economic Status		Age (years)		Ethnicity
		Female	Male	< than secondary school	Secondary school or >	Low	High	Up to 40	> 40	
Australia	Adams et al. 2003								√	
	DeVisser & Grierson 2002	√			√					
	MacLennan et al. 1996, 2002	√								
	Williamson et al. 2003	√		√						
Canada	Ruedy et al. 1999	√								
India	Gupta et al. 2002		√	√		√				
	Silverstein & Spiegel, 2001		√	√		√				

Table 2.4: *Socio-demographics of CAM users (continued...)*

Place of study	Author & date	Gender		Education		Economic Status		Age (years)		Ethnicity
		Female	Male	< than secondary school	Secondary school or >	Low	High	Up to 40	> 40	
India	Tandon et al. 2002		√	√		√				
Switzerland	Quattropani et al. 2003	√						√		
Taiwan	Yang et al. 2002	√			√		√	√		
Turkey	Tan, Uzun, Akçay, 2004	√								
U.K	Thomas et al. 1991	√			√					

Whilst empirical evidence shows female gender was consistently associated with CAM use, it is important to note “women in general are the primary consumers of health care” (Cherniak, Senzel & Pan, 2001, p. 227).

In addition, although, some researchers (Eisenberg et al., 2001; Wolsko et al., 2000) found socio-demographics were inconclusive predictors of CAM use the association between socio-demographics and CAM use should be viewed in context. For example, in the U.S. A. (Chicago) amongst people with HIV, whilst CAM use was found predominantly in men, 88% of respondents were men, 70% were homosexual and 80% were single (Duggan et al., 2001). Thus, the use of socio-demographics for comparison of CAM estimates should be viewed prudently.

Comparison of CAM estimates for chronic and acute illness. Although, estimates of CAM use have consistently been found to be higher amongst people with a chronic than amongst those with an acute illness (Boon & Brown, 1999; Bullock et al., 1999; Eisenberg et al., 1993) there have been exceptions. For instance, a postal questionnaire sent to 14,000 adults (RR 64%) in four English counties showed 60% of CAM users had a chronic illness or disability, but CAM use was not higher amongst the chronically ill when compared with those for the general population (Chi-Keong, Petersen, Bodeker & Stewart-Brown 2002). It has been proposed that such findings are generalisations in instances where illness differentiation has not taken place (Sparber & Wootten, 2002).

Even with illness differentiation some studies show CAM estimates amongst some chronic illnesses such as diabetes are comparable with those of the American general population (Egede et al., 2002; Yeh et al., 2002). In addition, CAM estimates vary for the same illness. For example, amongst people with diabetes CAM estimates ranged from 25% (Schoenberg et al., 2004) to 57% (Yeh et al., 2002). Similarly, in people with cancer CAM estimates range from as low as 24.2% (Rees et al., 2000) to as high as 84% (Morris, Johnson, Homer & Walts, 2000). Moreover, CAM estimates vary depending on how participants and researchers differentiated illness. For example, in people with psychological

illnesses Kessler et al. (2001) reported that 65.9% of respondents with self-defined anxiety attacks and 66.7% of respondents with self-defined “severe depression” used alternative and complementary medicine therapies. In contrast, using structured diagnostic screening interviews to establish diagnosis of various types of mental disorder, 21.3% of participants who used CAM had a diagnosed mental disorder (Unützer et al., 2000). Whilst, self-rated levels of health were found to influence CAM estimates in both chronic and general population findings (Astin, 1998; Eisenberg, 1998), CAM estimates for the chronically ill were not always found to be higher, as illustrated in Table 2.5.

Illustrated in Table 2.5 are the methods, settings and sample used for estimating CAM use amongst specific groups of people with a chronic or serious illness. The emphasis in this section is the sample from which CAM estimates were taken. Thus, the first column illustrates the type of illness.

Although findings were inconsistent, frequency of CAM use amongst the chronically ill appeared to be associated with the degree of enduring illness. For example, in people with multiple sclerosis, chronicity, increased disability and earlier age of onset of disability was associated with increased CAM use (Marrie, Haddjimihael & Vollmer, 2003; Nayak et al., 2003). Similarly, people with diabetes were twice more likely than the general population to use CAM if co-morbidities were present (Egede et al., 2002) and in people with Parkinson’s disease (Ferry et al., 2002), and in those with major depression (Wang, Patten & Russell, 2001). Whilst CAM use was associated with the number of co-existing illnesses, with the exception of the study by Ferry et al. (2002), most studies did not show whether CAM use was for the co-morbidity, the main illness or both or whether increased CAM use was because of the co-morbidity. CAM use, though, was significantly higher among people with malignant cancers than among people with acute or chronic non-malignant diseases (Kauppauf et al., 2000). Correspondingly, amongst Dutch HIV positive gay men CAM use correlated with being symptomatic (Knippels & Weiss, 2000). Such results suggest people

used CAM because biomedicine was failing to address their health needs and that severity of disease and CAM use are associated.

Table 2.5: CAM Estimates for Specific Population

Specific population	Illness category	Author/Year, Study methods, (QL=Qualitative, QN=Quantitative)	Country	Estimate CAM %
Allergies	Autoimmune	Schäfer et al. 2002. QN.	Germany	26.5
Arthritis		Rao et al. 1999. QN	America	63
Asthma or rhinosinusitis		Blanc et al. 2001. QL.		42
Lupus		Leong, Pong & Chan, 2003 QN		38
Lupus erythematosus		Ramos-Remus, 1997. QN	Mexico	65
Aggregate for prostate, breast & ovarian	Cancer	Patterson et al. 2002. QN	America	70.2
Advanced cancer		Oneschuk et al., 2000. QN		28
Breast cancer		Adler & Fosket, 1999. QL		72
		Boon et al. 2000. QL	Canada	83.33
		Boon & Brown, 1999. QL		69.44
		Burstein et al. 1999.	America	51.2
		Lengacher et al. 2002. QN		77-78
Morris et al. 2000.		84		
Patterson et al. 2002. QN		86.5		
Colon cancer				63.7

Table 2.5: CAM Estimates for Specific Population (continued...)

Specific population	Illness category	Author/Year, Study methods, (QL=Qualitative, QN=Quantitative)	Country	Estimate CAM %
Gynaecological cancer		Gruenigen et al. 2001. QN	America	56
Haematological cancer not differentiated	Cancer	Kappauf et al. 2000. QN		43-65
Leukaemia		Gupta et al. 2002. QN	India	56.6
Melanoma		Söllner et al., 1997. QN.	Austria	14 (current use)
Ovarian cancer		Powell et al. 2002. QN	America	51
Prostate		Hall et al. 2003. QN		37
Cancer not differentiated		Lee et al. 2002a. QN		30
		Patterson et al., 2002. QN		58.8
		Downer et al. 1994. QN		16
		Maskarinec et al. 2000. QN		24.7
		Shumay et al, 2002. QN		40.54
	Sparber et al 2000. QN	91 sometime 84 post-diagnosis 64 pre-diagnosis		
Menopause	Cessation of menses	Blair et al. 2002. QN.	48.5	
Chronic illness not specified	Chronic illness	Chi-Keong et al., 2002. QN	U.K	60

Table 2.5: CAM Estimates for Specific Population (continued...)

Specific population	Illness category	Author/Year, Study methods, (QL=Qualitative, QN=Quantitative)	Country	CAM Estimate %
Dermatological	Psoriasis	Clark et al. 1998. QN	U. K.	69
	Atopic dermatitis	Jensen, 1990. QN	Norway	51
	Psoriasis			43
Drug abuse	I.V. drug users	Manheimer et al., 2003.. QN	America	45
GIT diseases	Inflammatory bowel disease	Moody et al. 1998. European (E) with ulcerative colitis & Crohn's disease with coeliac diseases, Asians (A) with irritable bowel disease. QN	England	E18 8 A23
			Switzerland	47
	Chronic liver	Yang et al. 2002. QN	Taiwan	37.9
				Chronic GIT diseases
HIV	Immunodeficiency syndrome	Bica et al. 2003. QN	America	72
		Chang et al. 2003. QN.		87.91
		Colebunders et al 2003. QN. 1996-1997 1998-1999	Europe	63
				87
		De Visser & Grierson, 2002. QN.	Australia	55
		Duggan et al. 2001. QN	America	40-67
		Furler et al. 2003. QN		77-89

Table 2.5: CAM Estimates for Specific Population (continued...)

Specific population	Illness category	Author/Year, Study methods, (QL=Qualitative, QN=Quantitative)	Country	CAM Estimate %
HIV	Immunodeficiency syndrome	Knippels & Weiss, 2000 QN	America	71.4
Dermatological	Various dermatological	Berg & Arnetz, 1998. QN	Sweden	35 lifetime use
HIV	Immunodeficiency syndrome	Nokes, Kendrew & Long, 1995. QN	America	100
		Sparber et al. 2000(a). QN		84
Diabetes	Metabolic	Egede et al. 2002. QN		
		Clifford et al. 2003. QN.	Australia	23.6
		Schoenberg et al 2004. QL	America	25
		Yeh et al., 2002. QN.		57
Neurological	Neurological	Freeman et al., 1997. QN		30
Neuropathy in HIV		Nicholas et al., 2002. QN & QL		44
Epilepsy		Tandon et al. 2002. QN	India	32
Headache syndromes		Peter et al. 2002. QN	America	84
Parkinson's		Ferry et al. 2002. QN	UK	54
		Rajendran et al. 2001. QN	America	40
People attending primary care	Primary Care	Conroy et al., 2000.QN	Ireland	60
		Featherstone, 2003. QN	Scotland	71

Table 2.5: CAM Estimates for Specific Population (continued...)

Specific population	Illness category	Author/Year, Study method, (QL=Qualitative, QN=Quantitative)	Country	CAM Estimate %
People attending primary care	Primary Care	Palinkas & Kabongo, 2000. QN	America	21
Psychiatrgic disorders not differentiated	Psychiatric	Druss & Rosenbeck, 1999	America	8
		Druss et al 2000. QN		9.8
Psychiatric disorders (anxiety, schizophrenia, depressive disorders)	Psychiatric	Elkins et al. 2005. QN		64
Anxiety		Knaudt et al. 1999. QN		16.5
Depression		Kessler et al. 2001a. QN		65.9
Dysthymia				66.7
Panic disorder		Unützer et al. 2000. QN Met criteria for disorder		16.4
Generalised Anxiety Disorder				Did not meet criteria for disorder
		Major depression		Met criteria for disorder
Did not meet criteria for disorder				20.5
Major depression		Met criteria for disorder	14.2	
			Did not meet criteria for disorder	13.7
	Wang et al. 2001. QN. 1994-1995 1996-1997	22.4		
		Did not meet criteria for disorder	13.7	
			7.8	
			12.9	

Table 2.5: *CAM Estimates for Specific Population (continued...)*

Specific population	Illness category	Author/Year, Study methods, (QL=Qualitative, QN=Quantitative)	Country	Estimate CAM %
Subjective symptom	Pain	Buck et al. 2005 QN	America	55.2
2 weeks before surgery	Surgery	Vallerand, 2003. QN		76
Surgical patients		Norred, 2002. QN		67

Although research findings suggest frequency of CAM use increases in the presence of co-morbidities and severity of disease, none of the reviewed studies defined chronicity and severity of disease status. Therefore, meaningful comparison of CAM estimates based on many CAM estimates was difficult. Despite the lack of differentiation of disease status the methods used to conduct the studies might account for the disparate CAM estimates. Hence, the next section of the review compares CAM estimates with the methods used to conduct the studies.

Comparison of CAM estimates for quantitative and qualitative studies. As shown in Table 2.5 quantitative studies estimating CAM use amongst people with HIV estimated CAM use ranged from 40% (Duggan et al., 2001) to 100% (Nokes, Kendrew & Long, 1995). Similarly, qualitative studies showed CAM use in women with breast cancer ranged from 67% to 83.33% (Boon & Brown, 1999, 2000). Hence, both methods show different CAM estimates for apparently similar samples. Quantitative methods show the largest range from 8% (Druss & Rosenbeck, 1999; Moody et al., 1998) to 100% (Johnson, 1999; Nokes, Kendrew & Long, 1995), a difference of 92%. Such differences might be attributed to temporality and geographical differences (Ernst & White, 2000; Grenfell et al., 1998; Shenfield, Atkin & Kristoffersen, 1997; Wang, Patten & Russell, 2001) or how disorders were differentiated. For example, the studies illustrated in Table 2.5 show estimated CAM use

for people with self-reported psychiatric disorders ranged from 8% (Druss & Rosenbeck, 1999) to 66.7% (Kessler et al. 2001a). In contrast, CAM use for people who were assessed through a diagnostic interview and met the diagnostic criteria for psychiatric illness ranged from 7.8% (Wang, Patten & Russell, 2001) to 32% (Unützer et al., 2000). This suggests generalisations about a population defined by some sampling frames, such as self-reporting of health status, were not reliable.

Amongst children the estimated range of CAM use was significantly more variable than those shown for adults. Thus, in the next section CAM estimates for children are reviewed for the purpose of finding some explanation for the disparate CAM estimates.

CAM estimates for children. The author, type of study, sample and estimated CAM use amongst children are depicted in Table 2.6. As illustrated in Table 2.6 estimated CAM use for children in the general population ranged from 2% to 84% (Davis & Darden, 2003; Spiegelblatt et al., 1994), for children needing biomedical care from 7% to 64% (Tsang et al., 2001; Sanders et al., 2003) and for hospital-based children from 29% to 46% (Arminshaw & Grant, 1999; Fong & Fong, 2002). Comparison of the reviewed literature showed the highest CAM estimate amongst children attending outpatients was 53% (Madsen, Andersen, Nielsen, Dolmer & Damkeir, 2003), 59% for children requiring intensive biomedical treatment (Moenkhoff et al., 1999) and 64% for children with a serious disorder such as, congenital heart disease (Sanders et al., 2003).

Overall, as illustrated in Table 2.6, estimates of CAM use amongst children are as variable as for adults. Many researchers (e.g. Bodeker & Kronenberg, 2002; Cassileth et al, 1984; Shenfield, Lim & Allan, 2002) suggested settings such as those affiliated with the biomedical care of people influenced CAM estimates because they might not be conducive to openness. There is support for this view because studies that used self-administered questionnaires (Chan et al., 2003; Moenkhoff et al., 1999; Spiegelblatt et al., 1994) for children had the highest CAM estimates. This suggests face-to-face interviews might be perceived not to protect anonymity.

Table 2.6: *CAM Estimates for Children*

Sample	Author/Year Study methods (QL=Qualitative QN=Quantitative)	Country	CAM estimate %
General population	Davis & Darden, 2003. QN	Australia.	2
	Menniti-Ippolito et al. 2002. QN	Italy	9.2
General population	Trapani et al. 2002. Italy. QN	Italy	46.1
	Spiegelblatt et al. 1994. QN	French Canadian	84
Paediatric outpatients	Ang et al. 2005. QN	America	38 Healthy
			25 Asthma
Paediatric outpatients	Ang et al. 2005. QN	America	22 HIV
	Day, 2002. QN	Australia	35.9
	Madsen et al. 2003. QN	Denmark	53
	Simpson et al. 1998. QN	U.K	21
	Spiegelblatt et al., 1994. QN	French Canadian	11
Hospital emergency department	Tsang et al., 2001. QN	America	7
Tertiary care children's hospital	Lanski et al., 2003. QN		45
Children with cancer	Spix et al. 2004. QN	Germany	34
Children with special needs	Sanders et al. 2003. QN	America	64
Children in intensive care	Moenkhoff et al. 1999. QN		59

Table 2.6: *CAM Estimates for Children (continued...)*

Sample	Author/Year Study methods (QL=Qualitative QN=Quantitative)	Country	CAM estimate %
Acutely ill hospitalised children	Arminshaw & Grant, 1999. QN	New Zealand	29
Children with atopic dermatitis in secondary care	Johnston et al. 2003 QN	U. K	46

Time of CAM use. The time when a study takes place has been suggested as an explanation for different CAM estimates (Wang et al., 2001). Whilst, it has also been suggested that the use of CAM use is rising (Eisenberg et al., 1998; MacLennan et al., 2002; Caspi, Koithan & Criddle, 2004) Table 2.6 shows recently published studies have relatively low CAM estimates for seriously ill and healthy children (Ang et al., 2005; Spix et al., 2004) when compared with some earlier studies (Moenkhoff, Baenziger, Fischer & Fanconi, 1999; Spiegelblatt et al., 1994). Thus, time of when a study was conducted does not explain the disparate CAM estimates. In addition, comparison of CAM estimates suggests that the use of CAM might not be increasing, as claimed (Ang et al., 2005; MacLennan et al., 2002). Time of use, when a person uses CAM is a variable that is likely to influence CAM estimates and is reviewed in the next section.

Table 2.7 shows the illness/sub population, author, date and time of CAM use measured. Whilst, the studies depicted in Table 2.7 illustrate the variability of time frames used to measure CAM they do not support as claimed that people who lived for longer periods after receiving a cancer diagnosis were more likely to use CAM (Metz, 2001; Sparber et al., 2000b). These studies also show that time of CAM use consistently affected CAM estimates. Not shown in Table 2.7 are findings that demonstrated CAM frequency in women with breast cancer increased post diagnosis when variables such as prayer, spiritual healing, yoga and

therapeutic touch were excluded (Lengacher et al., 2002). This suggests CAM estimates were influenced, as noted throughout the literature review, by how CAM was defined and how individual substances/therapies were classified, and whether they were included in the study. Moreover terms such as ‘lifetime’ in some studies were defined as CAM use undertaken in consultation with a CAM practitioner, or previous or present use of alternative therapy (Marrie et al., 2003) and as “at some time during their lifetime” (Featherstone et al., 2003, p. 1080). Whilst randomly differentiating the term ‘lifetime’ informs that CAM has been used, it cannot illustrate that some people might have used CAM on one single occasion (Madsen et al., 2003), daily or intermittently. In addition, although the studies in Table 2.7

Table 2.7: *Estimated CAM by Illness/sub Population and Time of Use*

Illness/sub population	Author & date of study	Time of use	Estimated CAM use % or number (N) as provided by author
Breast cancer	Burstein et al. 1999	At some point in time	51.2%
		Used CAM, if only the last three months considered	34.8%
		Women most recently diagnosed	75%
		Survivors two to five year post diagnosis	25%
	Crocetti et al. 1998	Pre-diagnosis	9%
		Post- diagnosis	16%
Cancer	Risberg et al. 1998	Four months post initial CAM survey	26%
		12 months post initial CAM survey	24%
		24 months post initial CAM survey	18%

Table 2.7: *Estimated CAM by Illness/sub population and Time of Use (continued...)*

Illness/sub population	Author & date of study	Time of use	Estimated CAM use % or number (N) as provided by author
Cancer	Risberg et al. 1998	60 months post diagnosis post initial CAM survey	27%
Cancer and clinical trials	Sparber et al. 2000b	Sometime	91N
		Post-diagnosis	84N
		Pre-diagnosis	64N
Cardiac and oncology	Chhay et al. 2002	Current users	40%
		Any use earlier that 14 days before interview	16
Dermatology	Berg & Arnetz, 1998	Lifetime	35%
General population	Downer et al. 2000	Used during lifetime	51.7%
		In the past twelve months	43.7%
	Rafferty et al., 2002	At least 1 CAM therapy in the previous 12 months	49.7%
HIV	Duggan et al. 2001	Used CAM at some time	67%
		Current users of CAM	40%
Multiple sclerosis	Marrie et al. 2003	Lifetime use of CAM	54%
		Current use	30%
Rheumatologic condition	Rao et al. 1999	Currently	83N
		Had used in the past	64N
		Tried at least one type of CAM	63%

Table 2.7: *Estimated CAM by Illness/sub population and Time of Use (continued...)*

Illness/sub population	Author & date of study	Time of use	Estimated CAM use % or number (N) as provided by author
Stanford Alumni	Jain & Astin, 2001	Previous year	49
		At least once in past 5 years	57

suggest time of use influenced CAM estimates; logical comparison of the studies was difficult because allocated time frames were arbitrarily defined as immediate past year (Eisenberg et al., 1993; 2001; Harnack, Rydell & Stang, 2001), past 6 months (Cronan et al., 1989; Moore et al., 2000), lifetime (Featherstone, 2003; Marrie et al., 2003) and as current use and 14 days prior to interview (Chhay, Rynes, Kajimura-Beck & Broekmeier, 2002).

Estimates of CAM Therapies

Provided in Table 2.8 is an overview of CAM estimates for therapies and substances. The emphasis in this section is the sample from which CAM estimates were taken. Thus, the first column indicated the type of specific illness for each group, or other identifying feature, such as outpatient/inpatient. Also illustrated in Table 2.8 is the estimated use for each therapy and or substance and the total CAM estimate for all therapies for each of the studies reviewed.

Estimates of CAM therapies for the general population. In America a study of 2590 ambulatory adults' recent patterns of medication use found 14% had taken one herbal/ supplement in the preceding week, 40% had taken vitamins/minerals and 17-23% took OTC analgesics (Kaufman et al., 2002). These estimates differ to those of an annual study of risk factors and behaviours, which found of 3,764 participants 20.5%, used herbal supplements and 8.2% large dose vitamins or minerals (Rafferty et al., 2002). In comparison an earlier American national CAM survey showed 12% of the sample used an herbal preparation in a one-year period (Eisenberg et al., 1998), which contrasts with a later study that showed herbal

use amongst women with menopausal symptoms was 24.9 % (Dailey et al. 2003). As illustrated in Table 2.8 CAM estimates in American studies showed herbal use was lower than the estimated 26% found to be used by Australians (MacLennan et al., 2002). In comparison, 4.9% of CAM users used menopausal products (MacLennan et al., 2002) that were not differentiated.

Table 2.8: *Estimates of CAM Therapies by Illness/sub Population*

Sample	Author	Most frequently used				Any CAM %
		Tactile therapy	%	Ingestible therapy	%	
General population Adults	Astin, 1998 Adults	Chiropractic Exercise & Movement Relaxation	15.7 7.2 6.9	Lifestyle diet	8.0	42
	Eisenberg et al. 1998	-		Herbs	12	42.1
	Downer et al. 2000 Mostly African Americans	Relaxation techniques, massage, imagery or visualisation Chiropractics Healing (including healers, spiritual, Native American healers or energy healing)	- - -	Home remedies Herbal medicine Homeopathy vitamins Commercial weight loss Lifestyle diets	- - - - -	44 last 12 months 51.7 during lifetime
	MacLennan et al. 2002	Aromatherapy oils	15.3	Chinese medicines Evening primrose oil Ginseng Herbal Homeopathy Menopausal products Mineral supplements (excl. iron & calcium) Vitamins	3.2 8.0 5.0 13.4 4.3 4.9 10.6 36.4	52.1

Table 2.8: *Estimates of CAM Therapies by Illness/sub Population*

Sample	Author	Most frequently used				Any CAM %
		Tactile therapy	%	Ingestible therapy	%	
General population Adults	MacLennan et al. 1993	Aromatherapy oils	3.5	Chinese medicines Evening primrose oil Ginseng Herbal Homeopathy Menopausal products Mineral supplements (excl. iron & calcium) Vitamins	1.8 7.8 3.0 9.9 4.4 1.4 9.2 37.6	48.5
	Wilkinson & Simpson, 2001	Chiropractic Massage	26.1 25.1	Vitamin C Multi-vitamins B group vitamins Vitamin/mineral	46.4 45.6 30.1 68.7	70.3
General population children	Menniti-Ippolito et al. 2002	Manual treatments acupuncture	1.0 0.4	Homeopathy Herbal medicine	7.6 2.4	9.2
	Spigelblatt et al. 1994	Naturopathy, chiropractics, acupuncture	-	Homeopathy	-	84
	Trapani et al. 2002	Manipulative treatments Acupuncture	6 5	Homeopathy Herbal medicine	72 17	46.1
Children in ICU	Moenkhoﬀ et al. 1990	Acupressure Sweet oil Turpentine Pine needles Cow chips	10 25 - - -	Homeopathy Bach flower remedies	55 27	59
Paediatric emergency dept.	Lanski et al. 2003	-	-	Aloe plant/juice Echinacea Ephedra Albuterol	44 33 - -	45
Children with special needs	Sanders et al. 2003	Spiritual healing/ blessing/ prayer massage	40 33	Ingested herbs special diets	19 16.5	64

Table 2.8: *Estimates of CAM Therapies by Illness/sub Population (Continued...)*

Sample	Author	Most frequently used			%	Any CAM %
		Tactile therapy	%	Ingestible therapy		
Children	Sibinga et al. 2004	Biomechanical bio-energetic lifestyle/mind-body	22.2 15.2 15.2	Biochemical	72.22	21
Arthritis	Rao et al. 1999 Estimates for current users	Chiropractics Copper/ magnetics Electrical stimulation	45 42 37	Mega-vitamins Diet Supplements Herbs	24 32 41	63
Asthma or rhino-sinusitis	Blanc et al. 2001	Acupuncture Reflexology, massage (includes aromatherapy)	5 15	Any herbal Ephedra products Homeopathy Chinese herbs Any caffeine Black tea or coffee Other caffeine product	24 10 10 10 18 14 8	42
Breast cancer	Boon et al. 2000	Body work (eg reiki, massage, therapeutic touch) Meditation Faith healing	14 10 3	Vitamins & minerals Herbal remedies Green tea Essiac Special foods Shark cartilage Homeopathy	50 25 17 15 15 5 4	67
	Lengacher et al. 2002	Prayer and spiritual practices Support group Humour/ laughter Massage	59 51 43 27	Vitamins and minerals Antioxidants Herbs Health foods	64 39 20 15	77 Ingestible 78 Tactile
Breast cancer	Patterson et al. 2002	Mental or other therapies	30.2	Dietary supplements	79.4	86.5
Colorectal Cancer		Mental or other therapies	16.4	Dietary supplements	56.9	63.7
Ovarian cancer	Powell et al. 2002	-	-	Herbs	51	51

Table 2.8: *Estimates of CAM Therapies by Illness/sub Population (Continued...)*

Sample	Author	Most frequently used			%	Any CAM %
		Tactile therapy	%	Ingestible therapy		
Prostate Cancer	Boon et al. 2003	-	-	Vitamin E, Saw palmetto and selenium CAM therapies mostly dietary changes	26.5 17	29.8
	Lee et al. 2002	Physical Massage/body work Acupuncture/acupressure Chiropractic Movement Mental health Counselling/support group Relaxation Spiritual/faith healing	3.1 0.6 0.9 0.4 1.5 14.7 9.8 3.0 4.1	Herbal remedies Dietary Macrobiotic Megavitamin Other Homeopathy	16.4 9.2 1.1 3.7 6.5 0.4	30
	Patterson et al. 2002	Mental or other therapies	9.7	Dietary supplements	56.1	58.8
Cancer not differentiated	Downer et al. 1994	Healing Relaxation Visualisation Acupuncture Aromatherapy	64.61 35.38 33.84 13.85 7.69	Diet (all types) Homeopathy Vitamins Herbals	26.1 24.6 20 20	16
Cancer not differentiated	Shumay et al. 2002. Caucasian, Asian & Pacific Islander ethnicities	Religion/spiritual Meditation Massage or body work Guided imagery Support group Relaxation Acupuncture Healing touch Yoga Reiki Chiropractor Native Hawaiian healing	38.7 22.4 20.2 19.1 14.0 14.0 13.4 13.4 10.6 6.67 6.17	Herbs or supplements Vitamins or minerals Special diet Naturopath Homeopathy Chelation Vitamin C injections I.V. drip	46.6 40.4 38.2 8.4 6.1 1.6 1.1 0.5	40.54

Table 2.8: *Estimates of CAM Therapies by Illness/sub Population (Continued...)*

Sample	Author	Most frequently used			%	Any CAM %
		Tactile therapy	%	Ingestible therapy		
Diabetes type 2 Plantar warts	Parry et al. 1996 African-Americans	Folk remedies Salt Aloe vera	- - -	Herbal teas Juices Garlic and water	- - -	90
Diabetes	Schoenberg et al. 2004	Spiritual intervention	5	Dietary remedies Herbal remedies	9 15	25
	Yeh et al. 2002	Solitary prayer/ spiritual practices	28	Herbal remedies Commercial diets	7 6	25
Cardiology, GIT, Oncology Psycho-somatic inpatients	Huber, 2004	Physical training Massage Acupuncture	21 19 10	Diet Vitamins/ trace elements Herbal treatment Homeopathy	19 19 13 7	54
Endocrine & liver disorders Rheumatologic	Downer et al. 2000	Exercise Prayer Relaxation Massage Self-help group Imagery	- - - - - -	-	-	57
Chronic liver (CL)/ GIT disease	Yang et al. 2002	Acupuncture Chiropractic Gua Sha (scratching) Qigong Cupping Incense ash	18 13 10 8 7 2	Chinese herbal medicine Nutritional supplements	95 13	37.9 CL 39.2 GIT

Table 2.8: *Estimates of CAM Therapies by Illness/sub Population (Continued...)*

Sample	Author	Most frequently used			%	Any CAM %
		Tactile therapy	%	Ingestible therapy		
Headache Syndromes	Peter al. 2002	Massage	42	Herbs Vitamins/ nutritional supplements	5	84
		Exercise Acupuncture biofeedback & chiropractic	30 19 15		14	
HIV	Duggan et al. 2001	Counselling	27	Herbal Megavitamin Dietary supplements	43	In the past 67 Current use 40
	Exercise Lifestyle- changes Prayer therapy	43 38 24	24 37			
HIV	Furler et al. 2003	CAM Mind body	61.5	CAM or CAMVIT Vitamins Multivitamin Herbals CAM-micronutrient	57.7	76.9 (CAM) 89.4% (CAM micro- nutrient)
		CAM activities Spiritual practices/ prayer Meditation Aromathera py Imagery/ visualisation	64.4 47.1 26.0 15.4 14.4		48.1 30.8 88.5	
HIV	Knippels & Weiss, 2000.	Massage Psycho- spiritual eg yoga, meditation & imagery Acupuncture	21.4 15.7 5.7	Food supplements herbal products Homeopathy	62.9 17.1 21.4	71.4
	Nicholas et al. 2002	Acupuncture massage, exercise, rest/ elevation Topical medications	8		Prescription OTC, vitamins and substances such as alcohol and marijuana	
Primary care menopause symptoms	Dailey et al. 2003	-	-	Herbs	24.9	24.9

Table 2.8: *Estimates of CAM Therapies by Illness/sub Population (Continued)...*

Sample	Author	Most frequently used			%	Any CAM %
		Tactile therapy	%	Ingestible therapy		
Pain	Vallerand et al. 2003	-	-	Any herbal product	28	76
Parkinson's	Ferry et al. 2002	Aromatherapy Massage Spiritualism, reflexology, acupuncture & conductive education	14 15.8 7.0	Simple analgesics Cod liver oil Multi-vitamins Aperients Garlic tablets	14.6 10.4 8.3 6.3	54
People who had a transplant	Matthees et al. 2001	Relaxation Prayer	-	-	-	88
Physical disabilities	Krauss et al. 1998	Exercise Relaxation Massage Prayer Self help group Imagery	-	-	-	57
Out-patients	Wainapel et al. 1998	Massage Chiropractic Acupuncture	-	Vitamins Supplements	-	29

Classifications such as, 'menopausal products' do not inform the reader what these products are. Menopausal products can be herbs, vitamins and minerals, diet supplements rich in soy or a combination of all these substances. Thus, in terms of comparing CAM substances/products estimates for broadly defined 'CAM' such as menopausal products are meaningless. In Australia, as illustrated in Table 2.8, the use of vitamins and minerals ranged from 47% (MacLennan et al., 2002) to 68.7% (Wilkinson & Simpson, 2001). These results show a difference of over 20% in vitamin and mineral use that could be also attributed to the way CAM substances were defined. For example, CAM substances measured

individually as herbal, ginseng and Chinese medicines (MacLennan et al., 2002) in the same study is illogical because they can all be broadly defined as herbs, and as shown Table 2.8 most studies measured herbs as a group. As a result any rational appraisal and comparison of CAM studies was problematical for many reasons but mostly because the way CAM therapies were classified.

Estimates of CAM therapies for the chronically ill. Amongst people with life-threatening illnesses such as, cancer (Duggan et al., 2001) and HIV/AIDS (Shumay et al., 2002), or with illness requiring hospitalisation (Tan, Uzun & Akçay, 2004) were more likely to use ingestible rather than tactile CAM products. In women with cancer estimated use of herbs ranged from 20% (Lengacher et al. 2002) to 51% (Powell et al., 2002). Similarly the use of vitamins ranged between 50% (Boon et al., 2000) and 64% (Lengacher et al. 2002). The most popular CAM therapies used by 50% of people with HIV were counselling and herbal therapy (Duggan et al., 2001) and 62.9% used food supplements (Knippels & Weiss, 2000). Similarly, people with Parkinson's disease predominantly used ingestible CAM products to treat Parkinson's disease (Rajendran, Thomson & Reich, 2001). In contrast, Ferry, Johnson and Wallis (2002) found most participants with Parkinson's disease used CAM tactile therapies solely for the treatment of Parkinson's disease and ingestible CAM for co-morbidities. This suggests for meaningful comparison of frequency of CAM use, reasons for use of CAM need to be considered, not only reported use.

As shown in Table 2.8 the classification used to differentiate CAM was mostly illogical. For example, in some studies prayer, spirituality, and meditation were measured separately, and in others such practices were measured as a group. Some tactile therapies were not measured individually they were measured as a group, as 'manual therapies'. As shown in Table 2.8 therapies, such as aromatherapy and substances such as aloe vera, garlic and salt were classified as tactile therapies (Lanski et al., 2003; MacLennan et al., 2002; Parry et al. 1996). Such products can be used as inhalants, taken orally or applied topically yet no study was found that had differentiated these CAM according to use. In addition, the basis

for defining chiropractics, a tactile therapy, as invasive therapy (Wolsko et al., 2000) was not explained by the author.

Shown in Table 2.8 are examples of biomedical prescription drugs such as, Albuterol, which is an adrenergic β -2 antagonist, used for the prevention of exercise-induced asthma (Skidmore-Roth, 2000, p. 83) and substances such as alcohol and marijuana (Lanski et al., 2003; Nicholas et al., 2002) that were measured as a CAM. Treatments such as intravenous (I.V) drip, usually associated with biomedicine, were measured as a CAM (Shumay et al., 2002) but without knowing which substance was infused it is not easy to say if it was a CAM. Hence, comparison of CAM estimates based on individual CAM substances/products was complicated because of the dissimilar way CAM therapies and substances were described and because such products were arbitrarily defined as CAM. Hence, without universal descriptors of CAM products and clear principles of classification for differentiation between CAM and biomedical substances comparisons of study findings are meaningless.

The arbitrary methods used to gather data also made comparisons difficult because for some studies participants were given a list of CAM therapies/and or substances to choose from (Peter et al., 2002) and others relied on the memory of participants by allowing them to list the therapies they had used in the past year (Wilkinson & Simpson, 2000). Similarly, most of the studies showed an idiosyncratic choice of substances and therapies used as measures and this affected CAM estimates. For example, excluding prayer (Rao et al., 1999) substantially decreased the estimated frequency of CAM use by 20% (Yeh et al., 2002). Thus, any meaningful comparison of CAM therapies and substances was difficult.

Section Summary and Discussion

The reviewed literature showed in developed countries up to 70% and in developing countries up to 80% of the population used some form of CAM (Benoussan, 1999; Bodeker & Kronenberg, 2002). This review showed CAM was used by all sections of the community including children, the elderly, the generally well, people with a chronic illness and/or serious illness and by people enrolled in biomedical clinical trials (Boon et al., 2000;

Colebunders et al., 2003; Conboy et al., 2005; Davis & Darden, 2003; Metz, 2000; Niggemann & Gruber, 2003; Simpson & Roman, 2001; Sparber et al., 2000a, 2000b; Read, Klomp, Mather & Todd, 2002; Shenfield, Lim & Allen, 2002). As suggested by many researchers (Bodeker & Kronenberg, 2002; Cassileth, 1999; Sparber & Wootton, 2002) and identified by this review CAM estimates might be inaccurate or are at least inconsistent because of the methods employed to conduct research. For example, alternative medicine defined as “an adjunct to conventional therapy” (Marrie et al., 2003, p. 464) was one of the problems identified. Studies that purported 26.5% of participants used “alternative medicine” (AM) (Schäfer et al., 2002, p. 694) and “overall, 39.1% reported that they used AM and conventional therapies concurrently” (*Ibid*, p. 964) were reporting the use of complementary medicine and not the use of alternative medicine, as claimed.

Studies that measured CAM as treatments/substances not prescribed or recommended by a biomedical physician (Buchbinder et al. 2002; Bica et al., 2003; Ferry, Johnson & Wallace, 2002; Pachter et al., 1998) and reported physicians recommended CAM and did not omit such responses from the CAM estimate (Kappauf et al., 2000; Rafferty et al., 2002) were possibly over-reporting the frequency of CAM use. Similarly those studies that did not ask who prescribed the CAM therapy might have inaccurately estimated CAM. Studies which purportedly estimated CAM use in countries such as Israel (Kitai et al., 1998) where CAM practice is restricted to biomedical practitioners (Grinstein et al., 2002; Hufford, 2003; London et al., 2003) suggests such estimates were for biomedical use, if the definition is taken literally. Hence, estimates for CAM use obtained in countries such as Israel are illogical when CAM was defined as a therapy/substance not prescribed by a biomedical practitioner (Kitai et al., 1998).

Moreover, there was very little evidence to suggest that estimates of self-prescribed CAM use were differentiated from CAM practitioner prescribed CAM use. Such a distinction is important because very different usage rates apply to each of these and range between 8% of the population for practitioner based CAM (Druss & Rosenheck 1999) to 70.3%

of the population for all types of CAM, including OTC and self-help in developed countries (Wilkinson & Simpson, 2001). Hence, operationalised CAM definitions and the terminology used to describe CAM were problematic because it distorted research results across studies (Cassileth, 1999). Accordingly, frequencies of CAM use might not be a true reflection of CAM use.

Whilst all variables have some affect on CAM estimates (Harris, 1999) there was insufficient evidence that time and place and socio-demographics (Metz, 2000; Metz et al., 2001) were reliable predictors of CAM use (Eisenberg et al., 2001; Ernst & White, 2000; Wolsko et al., 2000). For example, it cannot be assumed that people who use Chinese medicine are Asians or live in Asia.

This review identified face-to-face interviews in biomedical settings might have inhibited responses CAM because CAM estimates taken by such means were lower those estimated from data collected by self-administered questionnaires, in similar settings. Thus whilst settings affiliated with the biomedical care of people influenced CAM estimates because they were not conducive to openness (Bodeker & Kronenberg, 2002; Cassileth et al., 1984; Shenfield et al., 2002), the empirical evidence points to the method of data collection as the inhibitor of responses.

Despite many researchers considering prayer a CAM therapy (Eisenberg et al., 1988; VandeCreek et al., 1999; Yeh et al., 2002) in some studies it was omitted as a measure (Rao et al., 1999; Wolsko et al., 2002) because it had no cost attached to it and therefore not considered “a type of CAM” (Rao et al., 1999, p. 410). Excluding therapies/practices from measurement in CAM surveys (Rao et al., 1999) or differentiating therapies/products considered CAM from biomedicine on the basis of payment (Gilbert et al., 2000) ignore that CAM is differentiated from biomedicine because it is a form of therapy that is not offered by biomedicine (Cassileth, 1999). Hence, CAM estimates based on type of substance or therapy were not easily comparable because differentiation of and inclusion of variables was dependent on the researcher’s point of view.

Comparison of CAM definitions used by researchers, as shown in Table 2.1, with the disparate terminology used to describe therapies and substances as illustrated in Table 2.8 suggested there was an association between CAM definitions and how individual substances and therapies were classified. This review suggests this association affected CAM estimates. For example, treatments of western derivation such as naturopathy, massage and homoeopathy and therapeutic touch were defined and measured as a group as “traditional or ethnic medicine” (Lengacher et al., 2002, p. 1449), or as individual tactile or ingestible therapies (Lee et al., 2002; Shumay et al., 2002). Other researchers allocated some therapies to more than one domain, which meant Chinese herbs and Chinese herbalist were allocated to “both alternative systems and biologically based treatments” (Shumay et al., 2000, p. 669). Such definitions reflect concerns regarding operationalised CAM definitions (Cassileth, 1999; Eisenberg et al., 2002; Shumay et al., 2000) because they appear to be the variable which most affects CAM estimates.

This review identified many problems with the methods used to estimate CAM. The definition of CAM used to guide the studies was identified as being inconsistent, absent in some cases, ambiguous and arbitrary. Consequently, meaningful and logical comparisons of CAM estimates were impractical because researchers defined variables heterogeneously.

Reasons for the Use of CAM

This section of the literature reviews study findings on the reasons for CAM use. Comparison of qualitative and quantitative studies were made to determine if the methods employed for the studies showed any significant differences in the reasons for CAM use. Reasons for CAM use were explored amongst different samples such as, the general population and the chronically ill. In this review particular emphasis was placed on the reasons for CAM use provided by people with a chronic and/or serious illness who required ongoing biomedical treatment. This section begins with an overview of the empirical theoretical predictors for CAM use.

Empirical Theoretical Predictors of CAM Use

Reportedly health status, philosophical and cultural and personal beliefs, financial concerns and push pull factors predicted CAM use (Astin, Shapiro, Lee & Shapiro, 1999; Furnham & Smith, 1998; Kemper & Barnes, 2003; Lazar & O'Connor, 1997; Skidmore-Roth, 2001). There is contrasting evidence that suggests they are not predictive of CAM use (Wolsko et al., 2000; Zollman & Vickers, 2000).

Health status and dissatisfaction with biomedicine. People attending a biomedical practitioner perceived themselves as having diminished health (Conroy, Smyth, Siriwardena & Fernandes, 2000; Furnham & Smith, 1988) and the use of a biomedical practitioner was the “strongest predictor” (Marrie et al., 2003, p. 464) of CAM use. Therefore, the finding that a perception of lower health status was predictive of CAM use (Astin, 1998; Boone, Brown, Gavin & Westlake, 2003; Druss & Rosenheck, 1999; Wolsko et al., 2000) is not surprising in view of the evidence showing biomedicine does not satisfy the health needs of people and shifting attitudes toward biomedicine mean people no longer rely solely on biomedicine (Milden & Stokols, 2004). In addition, many people use CAM in the belief that it will provide a higher level of physical and psychological health (Sutherland & Verhoef, 1994; Swartzman et al., 2002; Tandon et al., 2002). Viewed as whole these findings suggest perceived lower health status and dissatisfaction with biomedicine were associated.

Cultural and personal beliefs. Whilst, an overview of the literature on public attitudes towards CAM characterised CAM users as people who held alternative meanings or ideologies toward society (Astin et al. 1999; Kaptchuk & Eisenberg, 2001), there is no evidence that shows CAM users who rejected biomedicine (Wolsko et al., 2000; Zollman & Vickers, 2000) because they had a faith in natural remedies, subscribed to a wholistic view of health that included individual responsibility (Caspi, Koithan & Criddle, 2004; Siahpush, 1999) are associated.

Research findings on CAM and the rise of belief in the mysterious, and the occult had ambiguous findings. For example, whilst some studies found no correlation

between CAM use and beliefs in the paranormal (Furnham 2000a; Newport & Strausberg, 2001) others found a strong association between paranormal healing and religion (Verheij, de Bakker & Groenewegen, 1999; Rice, 2003). Often such predictors for CAM use were based on associative factors rather than the actual responses of people. For example, in Astin et al. (1999) survey questions focused on belief in the power of religion and conventional medicine and satisfaction levels with biomedicine, and not on reasons for CAM use.

Another view supports that world views might be predictive of CAM use (Buck, Baldwin & Schwatz, 2005). There are four world views and the cognitive processes that they represent; formism (events can be explained through categorical or either or thinking, mechanistic (events are attributed to cause and effect), contextualism (cause and effect occur within differing contexts), and organicism (continual unfolding of phenomenon from the source of the integrated whole) (Berry, 1984). Whilst Buck et al. (2005) found people with formistic views were more likely to use biomedicine there was not a significant association between CAM use and the four world views. There are competing explanations regarding the use of CAM that indicate that such use is problem-oriented rather than a reflection of a comprehensive ideology. This means that CAM use is driven by need unfilled by biomedicine (Gupta, 2002; Mitzdorf et al., 1999; Oldendick et al., 2000; Rao et al., 1999). Therefore, the evidence suggests CAM use is driven by pragmatism not ideology.

In addition, CAM use predicted on the basis of cultural heritage might be misplaced when measured without regard to country of practice. For example, in Korea Ayurvedic medicine and chiropractics are considered CAM, Oriental Medicine is not considered CAM (Lee et al., 2002b), in India Ayurvedic medicine is not considered CAM (Tandon et al., 2002) whereas in the western world all are considered CAM (Blanc et al. 2001; Downer et al. 2000; MacLennan et al., 2002). More importantly research shows CAM use cannot be predicted on the basis of culture because belief models are a complex cognitive process (Lee & Bishop, 2003). For example, in a study exploring the Singaporean Chinese beliefs about psychological problems, participants did not reject Western medicine and neither “necessarily

receptive to their indigenous therapies” (Lee & Bishop, 2003, p. 235). There is research evidence, however, that showed CAM use was driven by the need for effective treatment rather than cultural/personal beliefs (Coulehan, 1999; Lee & Bishop, 2003), which suggests that predictions of CAM use based on cultural differences are generalisations.

Financial concerns. Research findings suggested people with higher incomes and those with higher levels of education were more likely to use CAM (Astin, 1998; Eisenberg et al., 1993, 1998; MacLennan et al., 2002). Whilst a study of people with psychiatric disorders found CAM users had similar demographics only 12% were uninsured (Druss & Rosenheck, 1999). Therefore, although there is evidence to suggest out-of pocket costs of CAM might inhibit CAM use, CAM use amongst people with diabetes was higher amongst those who were uninsured (Egede et al., 2002) that suggests a lack of insurance did not influence CAM use. Similarly results from countries, such as Taiwan, where CAM is relatively inexpensive because the National Health Insurance covers most of the cost, of the 458 people surveyed with liver or gastrointestinal disease 75% used CAM in conjunction with biomedicine (Yang et al., 2002) suggests insurance motivated CAM use. In contrast, an American study showed people with public or private health insurance were more likely to use biomedicine and if they were self-payers they would use CAM (Sharma, Haas & Stano, 2003).

The evidence on health insurance and use CAM should be viewed in context. For example, it has been suggested a lack of insurance motivated CAM use amongst some people such as immigrants in America, because they could not avail themselves to health insurance (Eisenberg, 2002, p. 225). Women have less private health insurance than men (Pamuk, Makuc, Reuben & Lochner, 1998) and this might in part explain why more women use CAM Conboy et al., 2005). Similarly, in Russia people might be motivated to use CAM because biomedical products are expensive and difficult to procure (Ingram, 1996). Consequently, CAM use might not be a matter of choice but rather one of the penalties of the high cost of biomedical care (Eisenberg, 2002).

Table 2.9 shows the author, date and whether CAM use was influenced by insurance or cost of CAM or biomedicine. Most of the studies from developed countries found a lack of insurance did not impede CAM use (Burg et al. 1998; DeVisser & Grierson, 2002; Egede et al., 2002) despite evidence to suggest in some cases such as, people with AIDS, many respondents live below the poverty line (DeVisser & Grierson, 2002). In contrast, in developing countries such as India, CAM users were in part motivated by the high cost of biomedicine (Tandon et al., 2002) where both CAM and biomedicine were expensive (Gupta et al., 2002). Such findings suggest cost, as a predictor of CAM use, was influenced by geographical placement of the study. Table 2.9 also illustrates CAM use was not influenced a lack of insurance (Burg et al., 1998; De Visser et al., 2002; Egede et al., 2002) and that cost of biomedicine motivated CAM use (Bodeker & Kronenberg 2002; Gupta et al., 2002).

Table 2.9: *Insurance and Cost as Reasons to Use CAM*

Author & date	CAM use influenced by lack of insurance		Cost of CAM as a barrier to CAM use		Cost of biomedicine reason to use CAM	
	Yes	No	Yes	No	Yes	No
Burg et al. 1998		√				
Boon & Brown, 1999			√			
Bodeker & Kronenberg 2002					√	
DeVisser & Grierson, 2002		√		√		
Egede et al. 2002		√				
Gupta et al. 2002					√	
Ingram, 1996					√	
Sharma, Haas & Stano, 2003					√	
Tandon et al. 2002					√	

Despite the limited information on cost and CAM use, empirical evidence suggests cost does not inhibit CAM use. Conversely, cost does inhibit biomedical use and does in some instances provide people with the impetus to use CAM.

In this next section research studies examining the reasons people gave for using CAM are compared with the conclusions drawn and the methods used for the studies. Table 2.10 and 2.11 summarise the reasons for CAM use as reported by participants, according to quantitative and qualitative studies respectively. Tables 2.10 and 2.11 are in date order followed by the author in alphabetical order.

These tables illustrate that the literature revealed additional reasons for CAM use over a period of 11 years. For example, Moore et al. (1985) found only two reasons for CAM use, specific ailment and failure of biomedicine. Whereas later authors, most notably Mitzdorf et al. (1999), Oldendick et al. (2000), Rao et al. (1999), Gupta (2002), Furler et al. (2003) and Mennit-Ippolit et al. (2002) found additional reasons for the use of CAM. These included CAM had greater efficacy, health status, health maintenance, treatment of last resort, desire to avoid biomedicine, side effects of biomedicine, health care satisfaction, treat psychological symptoms, symptom pain relief, well-being, overall health, cost of biomedicine, failure of biomedicine and cure.

Quantitative studies, illustrated in Table 2.10, show the most frequently cited reasons for CAM use were; to treat a specific disorder; biomedicine failed and or had adverse effects. Similarly, Table 2.11 summarises the reasons for CAM use found in qualitative studies and shows the most frequently cited reasons for CAM use were to treat a specific disorder; biomedicine failed and or had adverse effects, dissatisfaction with biomedicine, and treatment of last resort.

Quantitative Studies

In this section of the review reasons for CAM use, as reported by quantitative studies for the general population and the chronically ill, are discussed.

Reasons for CAM use amongst the general population. Although some evidence suggests CAM was used as part of the person's lifestyle and not as a form of medical treatment (Eisenberg et al., 1998; Kessler et al., 2001b; Oldendick et al., 2000), most studies show participants reported using CAM for relief of musculoskeletal problems and distressing and painful conditions (Astin, 1998; Eisenberg et al., 1998; Menniti-Ippolito et al., 2002), which suggests CAM use was a form of treatment, not a lifestyle practice. In children CAM was used because it was "the only available treatment" (Menniti-Ippolito et al., p. 690), had less side effects/toxicity and offered better patient/practitioner relationships. Similarly, amongst adults there is research to suggest that people use CAM because they believe it is safe (Biddle, Simpson & Wilkinson, 2003). Thus, for the general population the reviewed literature suggests CAM use was associated with dissatisfaction in biomedicine, driven by biomedical inadequacy, side effects and poor doctor/patient relationships.

Reasons for CAM use amongst people with chronic/serious illnesses. CAM users have consistently been found to have poorer health and more medical problems that are usually chronic in nature (Blais et al., 1997; Eisenberg et al., 1998; Vincent & Furnham, 1996). Therefore, the majority of people who seek relief through CAM therapies are those with distressing and painful conditions (Bullock et al., 1977; 1999; Cronan, Kaplan & Kozin, 1993; Paramore, 1997). For example, poorer physical health associated with chronic illnesses accounted for 60% of CAM use, and 35% of such use was for pain (Chi-Keong et al., 2002). rheumatologic condition (Rao et al., 1999) and in people with HIV/AIDS CAM was used to attenuate the symptoms that might be associated with the primary illness (Fairfield et al., 1998). Similarly, in a study of 80 people with Parkinson's disease 38.7% reported the use of at least one form of complementary solely for the treatment of Parkinson's disease (Ferry et al., 2002).

Table 2.10: *Reasons for CAM Use Reported in Quantitative Studies*

Author	Self care minor ailment	Dissatisfaction with Dr	Could help	Overall health	Fear of reoccurrence	Well-being	Health care satisfaction	Wholistic care	Cure	Reduce biomedicine	Boost immune system	Negative exp with BM	Symptom/Pain relief	Improve QoL	Psychological sx	Cultural/personal beliefs	Side affects of BM	Desire to avoid BM	Failure of BM	T/ment of last resort	Specific ailment	Health maintenance	Prevention	CAM preferred/pre-dx	Cost of biomedicine	CAM < adverse effects	CAM more natural/safer	Health status	Greater efficacy	
Moore et al. 1985																			✓		✓									
Cronan et al. 1993													✓																	
Furnham & Bhagrath 1993						✓										✓														
Astin, 1998															✓	✓						✓					✓			
Bullock et al. 1999													✓									✓								
Mitzdorf et al. 1999												✓		✓			✓	✓			✓						✓			
Moenkhoff et al. 1999																	✓													
Rao et al. 1999													✓						✓		✓					✓				
Oldendick et al. 2000														✓							✓	✓				✓				

Table 2.10: *Reasons for CAM use reported in Quantitative Studies (continued)...*

Author	Greater efficacy	Health status	CAM more natural/safer	CAM < adverse effects	Cost of biomedicine	CAM preferred/pre-dx	Prevention	Health maintenance	Specific ailment	T/ment of last resort	Failure of BM	Desire to avoid BM	Side affects of BM	Cultural/personal beliefs	Psychological sx	Improve QoL	Symptom/Pain relief	Negative exp with BM	Boost immune system	Reduce biomedicine	Cure	Wholistic care	Health care satisfaction	Well-being	Fear of reoccurrence	Overall health	Could help	Dissatisfaction with Dr	Self care minor ailment
Bode et al. 2001			✓								✓		✓		✓														
Duggan et al. 2001									✓			✓	✓																
Kessler et al., 2001b							✓	✓		✓																			
Standish et al. 2001								✓						✓			✓												
Gupta et al., 2002				✓	✓				✓	✓	✓		✓								✓	✓							
Kaufman et al. 2002									✓																✓				
Lengacher et al. 2002																												✓	
Menniti-Ippolit et al. 2002	✓	✓							✓	✓			✓	✓		✓	✓					✓							
Peter et al., 2002									✓	✓							✓	✓											

Table 2.10: Reasons for CAM use reported in Quantitative Studies (continued)...

Author	Self care minor	Dissatisfaction with	Could help	Overall health	Fear of reoccurrence	Well-being	Health care	Wholistic care	Cure	Reduce biomedicine	Boost immune	Negative exp with	Symptom/Pain relief	Improve QoL	Psychological sx	Cultural/personal	Side affects of BM	Desire to avoid BM	Failure of BM	Treatment of last	Specific ailment	Health maintenance	Prevention	CAM preferred/pre-	Cost of biomedicine	CAM < adverse	CAM more	Health status	Greater efficacy	
Raferty et al 2002							✓					✓	✓																	
Yang et al. 2002																	✓	✓								✓	✓			
Furler et al. 2003					✓							✓			✓	✓						✓								
Johnston et al. 2003																	✓													
Quattropani et al. 2003																										✓	✓			
Rickhi et al. 2003															✓						✓	✓								
Vallerand et al. 2003														✓																
Junker et al. 2004																			✓					✓						

Thus, the literature suggested people used CAM to treat the primary illness and or its associated symptoms. Similarly, a bleak prognosis or when the expertises of biomedicine could do no more for people was found to influence the decision to use CAM (Hall et al., 2003; Rosenbaum & Stewart, 2002). These finding suggest CAM use was influenced by illnesses for which little, palliative (Chhay et al., 2002) or only ineffective treatment was available from biomedicine.

Most quantitative studies (Chhay, Rynes, Kajimura-Beck & Broekmeier, 2002; Furler et al., 2003; Furnham & Forey, 1994; Quattropiani et al., 2003; Rao et al., 1999; Smart, Maryberry & Atkinson, 1986; Standish et al., 2002) found the adverse effects of biomedicine and a perceived lack of biomedical efficacy motivated people to use CAM. For example, in a study of 191 HIV infected people using a structured questionnaire 67% reported they had used CAM at some at time to control HIV and 56% abandoned biomedicine because of adverse effects (Duggan et al., 2001). Conversely, less adverse effects from biomedicine were reported when CAM was used (Duggan et al., 2001). Similarly, in a U.K. study of 100 children attending outpatient clinics for atopic dermatitis, using structured face-to-face structured questionnaires CAM was used because biomedicine had not worked and because of the associated adverse effects of such treatment (Johnston et al., 2003). In India 34% of 533 participants with leukaemia used CAM because of adverse drug reactions (Gupta et al., 2002) and in a study of 1,000 people with epilepsy the lack of efficacy and adverse effects of biomedicine (Tandon et al., 2002).

Similarly, in an American hospital-based study of 128 people being treated for severe blood illnesses and cancer, whilst participants were not directly asked about what it was that motivated CAM use, the researchers suggested the use of CAM might be related to a person's perception of an unfavourable diagnosis, and efficacy of treatment rather than to its medically expected outcome (Kappauf et al., 2000). In contrast, even though CAM users reported being

2.11: Reasons for CAM use reported in Qualitative Studies

Author	Control	Try anything	Self care minor ailment	Dissatisfaction with Dr	Could help	Overall health	Fear of reoccurrence	Well-being	Health care satisfaction	Wholistic care	Cure	Reduce biomedicine	Boost immune system	Negative exp with BM	Symptom/Pain relief	Improve QoL	Psychological sx	Cultural/personal beliefs	Side affects of BM	Desire to avoid BM	Failure of BM	T/ment of last resort	Specific ailment	Health maintenance	Prevention	CAM preferred/pre-dx	Cost of biomedicine	CAM < adverse effects	CAM more natural/safer	Health status	Greater efficacy			
Adler & Fosket, 1999	✓														✓												✓							
Bode, Müller & Storck, 2001																												✓						
Boon & Brown, 1999																												✓						
Boon et al. 2000																					✓	✓	✓	✓			✓							
Sleath et al. 2001																✓						✓												
Read et al. 2002																								✓			✓	✓		✓				
Shumay et al. 2002										✓										✓										✓				
Canales & Geller, 2003																✓								✓										
Parker et al 2006																												✓						
Read et al., 2002																											✓	✓						

critical about the efficacy biomedicine this was not the reason for using CAM (Furnham & Smith, 1988). Rather dissatisfaction with biomedicine was found to be associated with “disenchantment and bad experience of conventional medical practitioners” (Furnham & Smith, 1988, p. 459; Read et al., 2002; Rickhie et al., 2003; Shumay, Maskarinec, Gotay, Heiby & Kakai, 2003). Thus, dissatisfaction with biomedicine motivated CAM use because biomedical practitioners did not show empathy (Oldendick et al. 2000; Spiegel, Stroud & Fyfe, 1998; Standish et al., 2001) and because biomedicine was ineffective and/or had adverse effects (Duggan et al., 2001; Johnston et al., 2003). Hence, there is empirical evidence to show CAM use was associated with dissatisfaction with two aspects of biomedical care, the treatment effect and the biomedical consult.

Qualitative Studies

Reasons for CAM use amongst the general population. In a study of people over 50 years of age the issue of safety was the rationale for taking herbal supplements in preference to OTC or prescribed medicines (Read et al., 2002). In addition, participants were found to prefer herbal products to “drugs” (Read et al., 2002, p. 65) because they were safer, non-addictive, had no adverse effects and healed whereas prescription drugs covered up the symptoms, and became ineffective over time because the body developed a “tolerance” (*Ibid et al.*, p. 65) to the medicine.

Reasons for CAM use amongst people with serious/chronic illness. Whilst most of the extant literature on reasons for CAM use comes from quantitative studies, qualitative studies mostly show the same reasons as those found in quantitative studies. For example, in a focus-group study of 66 breast cancer survivors found CAM was used to relieve physical and psychological symptoms (Canales & Geller, 2003) and in women living with gynaecological cancers CAM was used to prevent further illness, improve chances of survival, biomedical treatment failed and/or had adverse effects, improve quality of life, reduce adverse effects of biomedicine and to gain some control over the disease (Adler & Fosket, 1999; Boon & Brown,

1999; Canales & Geller, 2003; Parker, Adams, Gaynor, Pond & Smith, 2006). In a study involving 14 cancer survivors' reasons given for CAM use included to avoid bodily harm, a belief that biomedicine would not make a difference to the disease outcome and that CAM was effective and the less harmful option (Shumay et al., 2002). A belief that CAM was natural and harmless (Bode, Müller & Storck, 2001) was commonly cited as a reason for CAM use and added impetus to last resort attempts to cure an illness (Boon & Brown, 1999). The literature also shows participants given a bleak prognosis were prepared "to try anything" (Boon & Brown, 1999, p. 641) because they "had nothing to lose" (p. 641). Overwhelmingly the literature showed a lack of biomedical efficacy, adverse effects and dissatisfaction with biomedical physicians and treatment motivated CAM use (Boon & Brown, 1999, 2000; Boon et al., 2003a; Mitzdorf et al., 1999; Paltiel et al., 2001).

In contrast Barrett et al. (2003) found CAM use was driven by value-laden, sociocultural and belief centred reasons. Such belief centred reasons might often be driven by the notion that biomedicine is depersonalised, focused on the individual body rather socio-environmental factors (Donahue & McGuire, 1994) and neglects the individual by not providing knowledge (Salmon, 1984) and because it objectifies disease (Good, 1994). This suggests that a prime motivator for CAM use is dissatisfaction with the delivery of biomedicine, which entails patient-physician interaction. These results are consistent with results and interpretations found in numerous CAM quantitative studies and studies about patient decision-making (Baugniel, Boon & Østbye, 2000; Dickinson, 1996; Ernst et al., 1995; Furnham, 1996; Jonas, 1998; Kelner & Wellman, 1997; Mansell, Poses, Kazi, & Duefield, 2000; Street et al., 2003) that suggest that patient-physician communication is problematic.

Section Summary

In this section of the literature review the theoretical predictors were compared with the reasons people gave for CAM use. The review also compared the reasons given for CAM use

by the general population and chronically ill. The literature review compared the reasons for CAM use as found in qualitative and quantitative studies.

This review, while limited to studies dating from 1993-2006, suggests people use CAM as a form of treatment with curative intent and for the relief of many disorders and to attenuate the side effects of treatment (Adler & Fosket, 1999; Boon & Brown, 1999; Canales & Geller, 2003; Duggan et al., 2001; Johnston et al., 2003; Quattropani et al., 2003; Read et al., 2002).

The theoretical predictors of CAM were in most cases different to the reasons people gave for CAM use. For example, none of the studies reviewed showed that people gave culture as a reason for CAM use.

Despite some evidence showing that dissatisfaction with biomedicine did not motivate CAM use (Astin, 1998; Kappauf, 2000), most of the extant literature showed otherwise. Furthermore, dissatisfaction with biomedicine was the only predictor that matched participants' reasons for CAM use (Boon & Brown, 1999; Junker et al., 2004; Mizdorf et al., 1999; Read et al., 2002; Rickhi et al., 2003).

There were noted methodological faults with some studies. For example, there was an error with one of the independent variables that measured general satisfaction and satisfaction with biomedical practitioners which might account for the way findings were interpreted. For instance, a Likert scale was used for the response set for each question, two of the items used a four-point scale, and one used a five-point scale (Astin, 1998). Likert scales conventionally use the five-point scale, which offer a neutral anchor point from which the respondent can select. The use of a four-point scale infers the absence of such a neutral point and is often referred to as a forced-response Likert scale (Minichiello et al., 1999). Questions with different response sets should not be combined into a single scale (Minichiello et al., 1999). Hence, any statistical analyses such as factor analysis and logistic regression done on questions with different scaling methods would not be valid.

Disclosure of CAM Use to Treating Medical Practitioners

This section of the Literature Review discusses the estimates of CAM disclosure to treating biomedical physicians. The reasons given by participants for CAM disclosure were also examined.

To make sense of the estimated rates of CAM disclosure it is necessary to provide, where possible, the CAM estimate taken from the same study. Shown in Table 2.12 are the author, year, and method of the study, country and sample characteristic, estimated CAM use and CAM disclosure.

CAM disclosure, as shown in Table 2.12, in most instances, was very low in comparison to estimated CAM use. In some instances, for example in children (Menniti-Ippolito, 2002) and in adults seeking primary care (Palinkas & Kabongo, 2000) where estimated CAM use was low the rate of disclosure was comparatively very high. Table 2.12 illustrates that CAM use was well above 60% and CAM disclosure was predominantly below 50% in people with HIV and arthritis (Furler et al., 2003; Rao et al., 1999) and as low as 4% in people with leukaemia (Gupta et al., 2002). As depicted in Table 2.12 qualitative and quantitative studies show similar rates of CAM disclosure in the general population, children and amongst people with a serious/chronic illness. For example, in a 5-year prospective cohort study consisting of four interview cycles Adler and Fosket (1999) found only 54% of 84 women with recently diagnosed breast cancer divulged their CAM use to their biomedical physician. In contrast, Adler and Fosket (1999) found 94% of the women discussed their biomedical history with their CAM practitioner, which again suggests biomedical environments inhibit CAM disclosure because they are not conducive to openness.

Table 2.12: *Estimated CAM Use and CAM Disclosure*

Author, year, method country Quantitative (QN), Qualitative (QL)	Characteristic of sample	CAM use %	CAM disclosure %
Ader, 1999. QN	Breast cancer	55	33
Adler & Fosket, 1999. America QL		72	54
Chang et al. 2003. QN.	HIV	87.91	51
Balneaves et al. QN	Breast cancer	67	47
Chen, Bernard, & Cottrell, 1999. QN	Family physician's and patient's knowledge and attitudes regarding traditional Chinese medicine	66	90 (clinic 1) 67 (clinic 2)
Chhay, Rynes, Kajimura-Beck & Broemeier, 2002. QN	Inpatients	56	59
Del Mundo, 2002. QN	CAM use by rural primary care patients	47	60
Duggan et al. 2001. QN	HIV	67	43
Downer et al. 1994. England QN	Undifferentiated Cancer	16	56
Eisenberg et al. 2000. America. QN	Consulting with a biomedical doctor and using CAM	33.24	63-72
Elder, 1997. QN	Family practice patients	50	62
Furler et al. 2003. America QN	HIV	77-89	<50
Gupta et al. 2002. India QN	Leukaemia	56.6	3.8
Hilsden, 1998. QN	Inflammatory bowel disease	51	62
Johnson, 1999. QN	Older rural women	100	23

Table 2.12: *Estimated CAM Use and CAM Disclosure (Continued)...*

Author, year, method country Quantitative (QN), Qualitative (QL)	Characteristic of sample	CAM use %	CAM disclosure %
Kappauf et al. 2000 America QN	Haematological cancer undifferentiated	43	< 50
	Undifferentiated Malignant Haematological cancer	65	
Menniti-Ippolito, 2002. Italy QN	Children	9.1	65.1
Nam, 1999. QN	Prostate cancer clinic support group	27 41	88
Palinkas & Kabongo, 2000. America. QN	People visiting primary care	21	60
Powell et al. 2002. America QN	Ovarian cancer	51	48
Quattropani et al. 2003. QN	Inflammatory bowel disease	47	69
Rafferty et al. 2002 America. QN	Adults	49.7	45.9
Rao et al. 1999. America QN	America, people with arthritis	63	47
Spix et al. 2004. Germany. QN	Children	34	9
Swenson et al. (2004) QL	Adults attending urgent care or general internal medicine clinics	55	50
Tan, Uzun & Akçay, 2004. QN	Turkey, general population	70	15.2
Tasaki et al. 2002. America. QL	Cancer	34	66
Verhoef, Scott & Hilsden (1998) QN	Inflammatory bowel disease	-	71

Table 2.12: *Estimated CAM Use and CAM Disclosure (Continued)...*

Author, year, method country Quantitative (QN), Qualitative (QL)	Characteristic of sample	CAM use %	CAM disclosure %
Yeh et al., 2002. America QN.	Diabetes	57	57

CAM Disclosure and Associated Variables

There is very little information about the variables associated with CAM disclosure possibly because the main focus of CAM research has been on CAM use. What little information is known about CAM disclosure has come from studies on CAM use, which suggested the patient-physician encounter, and socio-demographics were associated with CAM disclosure. Both of these variables will be discussed in this next section of the review.

Patient-Physician Communication

The rate of CAM disclosure was influenced by “physician-patient communication about CAM” (Rao et al., 1999, p. 413). For example, in study of communication between older patients and physicians, 10% of participants discussed alternative therapies with their treating doctor and 83% did not disclose their use of such therapies because in only 3.4% of patient-physician encounters the biomedical physician had initiated discussions about CAM (Sleath et al., 2001). Similarly, in more than 90% of cases where the prescribing physician was unaware of CAM use the participants reported the physician had not inquired about such use (Furler et al., 2003). A study of patient/physician communication showed the rate of disclosure was commensurate with discussions about CAM use with participants, possibly because only 20 of the physicians (37%) routinely discussed CAM with participants (Wynia et al., 1999).

Rates of CAM disclosure do not appear to be influenced by whether the biomedical physician recommended CAM treatment. For example, in a cross sectional interview of 128 people in biomedical oncology and haematology outpatient and inpatient departments only half the users informed their hospital physician of their adjunctive use of CAM, even though 41%

frequently identified biomedical physicians as the source of treatment recommendation (Kappauf et al., 2000). Similarly, in a general population survey whilst the majority of participants, 61.3%, had CAM recommended by their treating biomedical physician only 45.9% disclosed such use (Rafferty et al., 2002). In contrast, many studies (e.g. Busse et al., 2005; Oldendick et al., 2000; Wynia et al., 1999) found the rate of CAM disclosure fell dramatically in cases where the treating physician did not recommend healing therapies. Moreover, the biomedical physician's views that CAM was helpful was found to have increased communication about CAM, whilst biomedical physicians who perceived CAM was dangerous did not increase discussion and were less likely to ask about such use (Wynia et al., 1999). As depicted in Table 2.12, in countries, such as Switzerland, where biomedical practitioners frequently discuss CAM with patients, two-thirds of CAM users disclosed such use (Quattropani et al., 2003). This finding is diametrically opposite to most studies (e.g. Furler et al., 2003; Rafferty et al., 2002; Rao et al., 1999) that show less than half or two-thirds of CAM users do not disclose their CAM use to their treating physician.

Socio-demographic and Health Status

CAM disclosure was found to be associated with “female sex, ethnicity, education, learned helplessness, rheumatologic diagnosis and regular use of CAM and use of several types of CAM” (Rao et al., 1999, p. 413). Similarly, people who rated their health as poor were more predisposed to discussing CAM with their treating physicians and in turn were more likely to have been provided with more information regarding these therapies than their counterparts who rated their health better (Sleath et al., 2001). Contrasting evidence showed sociodemographic variables, such as ethnicity, did not influence the rate of disclosure to treating physicians (Sleath et al., 2001). For people who rated their health as poor, open communication about alternative therapies was driven by biomedical failure (Sleath et al., 2001).

In the next section of the review the reasons people within the general population gave for CAM disclosure are followed by the reasons people with a chronic/serious illness gave for CAM disclosure.

Reasons for CAM Disclosure amongst the General Population

In a U.S National representative household sample the reasons for non-disclosure of CAM included the doctor did not ask, the doctor would not understand, none of the doctor's business, the doctor might disapprove, doctor would discourage CAM use, it was not important for the doctor to know and fear of doctor refusing treatment (Eisenberg et al., 2001). Some of these reasons for non-disclosure of CAM suggest there is concern with the perceived prejudices of medical practitioners, regarding other forms of therapy. Most reasons for non-disclosure suggest interactions between treating physicians and patients who are unevenly matched in knowledge and or expertise (Becker, 1970) presents a disproportion of power that reinforces the doctor's position of expert because the treating physician is the holder of the knowledge (Heszen-Klemens, 1987; West, 1979). Thus, the reasons for withholding information regarding CAM use to treating biomedical physicians suggest the biomedical consult is either not inherently geared to solicit such information and or people inhabit an unequal space in the consult because they are intimidated by the consultation process.

Reasons for CAM disclosure Amongst the Chronically/seriously Ill

Several quantitative studies reported that barriers for non-disclosure include personal embarrassment and a sense of biomedical professional disinterest (Shenfield et al., 2002). It has been suggested that anticipation of practitioner disinterest is often a result of the doctor not asking about CAM (Powell et al., 2003; Shenfield, Lim & Allen, 2002). Although, over 90% of women with ovarian cancer reported initiating conversations about CAM use with their treating physician, the reasons they gave for not disclosing their CAM use included the doctor did not ask, the doctor did not have time and they had not seen the doctor since commencement of the herbs (Powell et al., 2003). A high percentage, 44%, of the women with

ovarian cancer also reported the doctor would not want to know and they felt/knew that the doctor would not be supportive, contributed to their decision not to disclose their CAM use (Powell et al., 2002). These participants also reported feeling disappointed that the treating doctor was not supportive or neutral when they sought information about herbs and possible interactions with chemotherapy (Powell et al., 2002). Thus, for people with a chronic and/or serious disorder anticipation of a negative response, a belief that the biomedical physician was unable or unwilling to contribute useful information, a perception that disclosure of CAM use was not relevant and an unwillingness or inability of the conventional practitioner to contribute useful information (Adler & Fosket, 1999; Balneaves et al., 1999; Powell et al., 2003; Shenfield, Lim & Allen, 2002) were reasons for non-disclosure of CAM.

These reasons for non-disclosure of CAM as found in a qualitative study of 93 people with cancer (Tasaki, Maskarinec, Shumay, Tatsumura, & Kakai, 2002) and other studies, centred on three barriers to successful communication. These barriers were identified as physicians' indifference or opposition toward CAM use, physicians' emphasis on scientific evidence, and patients' anticipation of a negative response (Boon et al., 2000; Tan, Uzun & Akçay, 2004; Tasaki et al., 2002). Thus, empirical evidence suggests the exchange of knowledge and the communication experience between the health practitioner and patient affect health behaviours such as compliance (Heisler, Bournight, Hayward, Smith & Kerr, 2002), CAM use (Boon & Brown, 1999) and CAM disclosure.

Summary and Discussion

The review of the existing literature on CAM disclosure suggested CAM disclosure estimates were disproportionate with estimates for CAM use. There was little support that socio-demographics and health status influenced the rate of disclosure.

The most common reasons for not disclosing CAM use to treating physicians was because they did not ask and because participants did not have the opportunity to discuss CAM use (Corbin-Winslow & Shapiro, 2002; Furler et al., 2003; Palinkas & Kabongo, 2000).

Although, people welcomed open discussion with their biomedical physicians about CAM use

such discussions were “cautiously modulated” (Adler & Fosket, 1999, p. 453) because of anticipation that the biomedical physician would disapprove of such use (*Ibid*, 1999). Hence, reasons for non-disclosure include the often-cited issue of communication barriers between patient and practitioner (Drivdal & Miser, 1998; Eisenberg et al., 1993, 1998). This suggests to date, most studies have minimally addressed the communication experiences that underlie such reasoning and therefore do not substantially explain the processes by which participants select to disclose CAM treatment.

To better understand these factors it is necessary to consider the influences that shape and drive healthcare decisions. For instance, the relationship that develops between a patient and treating physician, the psycho-social impact of treatment and support by significant others (Playle & Keeley, 1998; Stanhope, 2002) are influences which to date have not been explored as reasons for non-disclosure of CAM use.

Implications of Non-disclosure

To effectively manage first line treatment it is important for treating physicians to know, which participants are using CAM treatment (Oldendick et al., 2000) because herbs or vitamins can mask or distort the effects of biomedical treatments (Shane-McWhorter & Geil, 2002; Richardson et al., 2000). In those who undergo intensive biomedical intervention the need for full disclosure of CAM use to conventional practitioners is paramount. Those with chronic illnesses, such β -thalassaemia major (TM), in addition to having intensive biomedical treatment, could also be using CAM treatments.

Whilst biomedical research into illnesses like thalassaemia major (TM) is extensive and ongoing there is no knowledge pertaining to concurrent CAM and biomedical use amongst this population. Hence, in light of the issues regarding CAM, it is important to determine the frequency of use and the reasons why people with TM would use CAM, despite their lifetime use and need for biomedical treatment. Further, the explanations and patterns of non-disclosure of CAM use which such people give need investigating.

Theoretical Perspectives on Health Decision-making

What it is that influences personal health behaviour choices has been explored by many researchers who believe grasping an understanding of health behaviours will lead to a premise from which health carers can influence appropriate health practices (Gochman, 1997).

Psychological theories such as the health belief model, the theory of reasoned action, and locus of control, and self-efficacy theory are used to explain decision-making in the health context.

The health belief model focuses on evaluation of perceived end results of alternative behaviours based on the likelihood of the consequences occurring from a perceived threat, such as susceptibility to or severity of disease (Kaplan et al., 1993). The theory of reasoned action relies on the premise that 'rational' people base decision making upon internal states expressed and evaluated as positive or negative influences, based on perceived consequences shaped by attitudes, subjective norms and significant others (Kaplan et al., 1993).

Underpinning the theories such as the health belief model and health promotion model is the construct of motivation, which differentiates the behaviour as defensive, supportive, or precautionary (Palank, 1991). In contrast, identical behaviours executed by people could be for different reasons such as prevention, promotion or maintenance of health (Laffrey, 1990). Although these theories provide some insight into factors that influence decision-making, they are prescriptive models of how people should make decisions. Individuals with chronic illnesses face many challenges including constant changes in the focus of their lives (Charmatz, 1983), which are often driven by increased physical symptoms, diminished coping resources and decreased emotional strength (Kuehn & Winters, 1994). Consequently, situations that arise out of chronic illness are exceedingly complex.

The enduring nature of chronic illnesses, such as TM, places many demands on people who have such illnesses. These demands include the need for them to follow invasive treatment regimes, which can accentuate health problems. In addition, in people with TM physical symptoms and complications increase with age (Chan et al., 1999; Piga et al., 2001; Pippard & Weatherall, 2000). This requires people with TM to be adaptable at times when

they have diminished personal and or physical capabilities, which suggests the ongoing nature of TM is a constant strain on the resources of people with TM.

To better understand a person's perspective when faced with making treatment choices during the course of chronic illness and because the role of personal characteristics in adaptation in such situations is unclear, this thesis examined how certain health decisions are made from the perspective of the participants, rather than set out to test a specific and limited theory. Following analysis of the reasons people give for their use and disclosure of CAM, in the thesis Discussion section, the efficacy of existing theories for explaining CAM use and disclosure will be considered, alongside the possible development of an original model.

Haemoglobinopathies

In this section of the review the definition of chronic and serious illness and 'life-long' will be defined, as it will be used this thesis. The definition of thalassaemia major (TM) is followed by the worldwide prevalence of TM. This section of the review defines and provides an overview of thalassaemia major and provides an overview of the treatment, and prognosis of TM.

Definitions of Life-long and Chronic Illness

Lifelong illness operationalised for this thesis was defined as an illness diagnosed in the first few months after birth requiring biomedical treatment shortly after birth and persisted until death. Chronic illness has been defined as "one that lasts for a substantial period of time or that has sequelae that are debilitating for a long period of time" (Perrin, 1985, p. 2; Watt, 2000) and as a physical or psychological illness that interferes in daily life for longer than three months in a year or requires hospitalisation for more than one month in a year (Pless & Pinkerton, 1975). TM requires biomedical treatment from infancy until death and is the most severe form of congenital haemolytic anaemia (Kanj et al., 2000). Hence, TM can be categorised as a severe and chronic disease, requiring life-long treatment.

Definition and Prevalence of Haemoglobinopathies

Worldwide, over 7% of the population carry a significant globin¹ gene mutation (Liu, Weatherall, & Clegg, 2001). Worldwide, the most prevalent monogenic² disorders are the haemoglobinopathies (Liu, Weatherall, & Clegg, 2001), which are a diverse group of genetically determined disorders affecting adult haemoglobin production (Nathan, 1995; Neinhuis et al., 1979). The World Health Organisation (WHO) listed the haemoglobinopathies as one of the most urgent health problems that it has to deal with (Lammi & Webster, 1994). Of the haemoglobinopathies, TM is one of the most commonly inherited disorders that have worldwide impact on health and longevity (Clouston & Jane 1998; Pippard & Weatherall, 2000). In addition to the high cost of treatment for TM, its increasing prevalence, high morbidity and mortality rates within the first few years of life in people left untreated (Mentzer & Kan, 2001) contributed to concerns expressed by WHO (Lammi & Webster, 1994).

Definition of Thalassaemia Major

Thalassaemia major (TM) is an inherited disorder of haemoglobin production (Monastero et al., 2000). TM is an autosomal recessive disorder characterised by the defective ability to synthesise the β -chain of adult haemoglobin (Vardaxis, 1999). TM is recognised by severe anaemia, fever, failure to thrive, splenomegaly and increased deposition of iron in the tissues (Anderson, Anderson & Glanze, 1998; Weatherall, 2001).

Treatment of Thalassaemia Major

People with TM are actively biomedically treated for the duration of their life (Paula et al., 2003; Olivieri & Brittenham, 1997). Therefore, people with TM require ongoing and extensive biochemical and other assays to monitor disease status and prescribed drug levels (Capellini et al., 2000; Singer & Vichinsky, 1999). Treatment for people with TM includes regular blood transfusions (two-four weekly intervals) to maintain oxygen-carrying capacity of the blood (Weatherall & Provan, 2000); daily injections (administered over ten hours) for iron

¹ globin, a group of four globulin protein molecules that become bound by the iron in haem molecules to form haemoglobin or myoglobin

² monogenic (monofactorial inheritance), condition resulting from the transmission of a single specific gene

removal (Modell, Maren & Matthew, 2001) medications such as vitamins and mineral supplements, hormone replacement therapy, and the administration of medicines/surgery when necessary for acute conditions, and/or complications such as infections, as they arise (Cappellini, Cohen, Eleptheriou, Piga, & Porter, 2000). Whilst, many of these medicines are beneficial, there are associated risks, such as cancer from oestrogen replacement (Singer & Vichinsky, 1999), cardiomyopathy¹ from iron overload (Athanasios, 2002; Hahalis, 2002) and toxic effects from iron chelation treatment (Li Volti, Maccarone, LiVolti & Romeo, 2001; Taher et al., 2001).

Sequelae of Treatment and Pathogenesis

Frequent blood transfusions and the rapid destruction of red blood cells frees large amounts of iron, which is deposited in all the vital organs such as the heart and liver causing them to become fibrotic and dysfunctional (Monastero et al., 2000). Whilst, cardiomyopathy is the primary cause of death in people with TM (Mariotti et al., 1993, 1998; Zurlo et al., 1998) and the exact pathogenesis for cardiac disease in people with TM is yet to be determined, it has been postulated that frequent blood transfusions lead to iron overload, which lead to hypertrophy (enlargement) of the heart muscle and chronic anaemia leads to cardiac dysfunction (Jessup & Manno, 1998). Renal dysfunction is attributed to chronic anaemia, medicine toxicity and iron overload (Koliakos, 2003). Thus, iron overload is the cause of other co-morbidities such as hepatic fibrosis and cirrhosis, pulmonary dysfunction, multiple endocrinopathies (diabetes mellitus, hypogonadism, and hypoparathyroidism), growth failure, sexual immaturity and bone changes (Dabrowska et al., 2000; Koliakos, 2003; Monastero et al., 2000). Hepatic disease is a common cause of death after the age of 15 years in people with TM (Zurlo et al., 1998). Iron overload promotes the growth of hepatitis C virus and bacteria such as *Yersinia enterocolitica*, promotes the formation of intracellular free radicals causing oxidative damage and effects the adaptive and innate immune systems (Cunningham-Rundles,

¹ Cardiomyopathy is any disease that affects the function or structure of the heart (Anderson, Anderson & Glanze, 1998).
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2000; Pallister & Rotstein, 2001). Oxidative stress is also involved in the pathogenesis of increased destruction of thalassaemia red blood cells (Kattamis & Kattamis, 2000), which contributes to iron-overloading. The secondary cause of death in people with TM is infection such as HIV, hepatitis B and C (Weiner, 2003) and bacterial infections such as *Yersinia enterocolitica* and pneumococcal septicaemia (Li, Shing, Chik, Lee & Yuen, 2001).

People with TM are at major risk of infections (Cimaz et al., 2001; Waghorn, 2001; Weiner, 2003) and the risk of bacterial infections increases with the severity of anaemia, splenectomy, acquired viruses such as HIV, hepatitis B and C, iron overload and defective adaptive/innate immune response (Li et al., 2001; Monastero et al., 2000; Piga, Donato & Monasterolo, 2001; Weiner, 2003). Thus, in general people with TM are predisposed to infection for numerous reasons and biomedical treatment is both prophylactic and therapeutic. For instance, biomedical physicians use chemoprophylaxis and immuno-prophylaxis (Cappellini et al., 2000; Cimaz et al., 2001) to prevent infections such as pneumonia (Cappellini et al., 2000) and immediate hospitalisation, intravenous antibiotics and surgery if sepsis reaches the vital organs for any infection (Alebouyeh & Massoavi, 2003; Castagnola & Fioredda, 2003; Davidson & Wall, 2001).

In people with thalassaemia major (TM), splenomegaly is a common complication caused mainly by massive erythropoieses (Cappellini et al., 2000). When the spleen continues to enlarge, hypersplenism results and corrective measures such as splenectomy¹, is required (Fosberg & Nathan, 1990). People who have undergone a splenectomy are prone to bacterial infections (Anderson, Anderson & Glanze, 1998) and are prescribed antibiotics drugs, such as penicillin, on a daily basis (Cappellini et al., 2000; Rebullà & Modell, 1991). Such prophylactic treatment is needed because biomedical treatment, splenectomy, used to correct erythropoieses results in a compromised immune system that maximises the risk of infections in people with TM. In comparison with the normal population the risk of postsplenectomy

¹ Splenectomy, surgical removal of the spleen. Undertaken when abnormal enlargement of the spleen occurs, as a result of haemolysis.
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sepsis is increased for people with TM (Deodhar, Marshall & Barnes, 1993; Sumaraju, Leon & Smith, 2001).

For people with TM several factors cause excessive bone resorption which reduces bone mass (Aydinok et al., 2002; Salehi, Koski & Ondra, 2004; Voskaridou & Terpos, 2004). Whilst, bone disease in people with TM is a poorly understood process (Voskaridou et al., 2001) several factors have been found to be associated with bone pathologies including nutritional deficiencies, endocrine failure, desferrioxamine (DFO) toxicity, persistent bone-marrow expansion, blood transfusions, hypogonadism, iron-induced injury, Vitamin D deficiency and chronic hypoxia (Akpek, Canatan, Araç & Ilgit, 2001; Monastero et al., 2000; Voskaridou et al., 2001). Thus, bone disease in people with TM is associated with biomedical treatment and the disease process.

Biomedical treatment for TM and the chronic nature of TM cause many complications that affect every organ of the body and psychological wellness (Piga et al., 2001; Sadowski, 2002). Hence, the biomedical treatment for TM and the pathological processes associated with TM pose many challenges for treating physicians, and for people with TM.

Prognosis of Thalassaemia Major

Although intensive blood transfusion regimens and iron chelating medicines lead to a significant prolongation of life expectancy, new complications such as hepatocellular carcinoma (Borgna-Pignatti et al., 2004; El-Sayed et al., 2003) alongside those commonly attributed to TM, as noted earlier, contribute to morbidity and mortality. There are other complications such as neurological pathologies and psychological adjustment difficulties and cognitive deficits (Aydinok, et al., 2002; Monastero et al., 2000; Piga et al., 2001; Sadowski, 2002) that are not well understood (Atkin & Ahmad, 2000, 2001) that complicate the prognosis of TM. Amplified responses to numerous patho-physiological conditions such as inflammation, optic/aural neuropathy, and metabolism of medications (Monastero et al., 2000; Piga et al., 2001), also complicate the prognosis of TM. For example, in the vascular system,

endothelial cell damage and proliferation caused by inflammation has been associated with pulmonary artery occlusion (Butthep et al., 2002).

Clinical Trials for Thalassaemia Major

In an attempt to cure TM and/or treat associated secondary pathologies many synthetic agents have been used in clinical trials, none of which to date have been universally adopted for first line therapy because of associated adverse effects (Castro & Oswaldo, 1999; Olivieri & Brittenham, 1997; Pippard & Weatherall, 2000; Stamatopoulos & Neinhuis, 1992). For example, abandonment of a clinical trial of deferiprone, an oral chelator, was necessary because of serious adverse effect such as liver fibrosis, neutropenia, and death from agranulocytosis (Olivieri, 1996; Olivieri & Brittenham, 1997). Thus, efforts to replace the current sub-cutaneous nightly infusion treatment with an oral chelator have not been successful (Weatherall, 2000). In an effort to cure TM, bone marrow transplantation, an aggressive and complex procedure has been increasingly adopted but its use is limited because it is associated with a high morbidity and mortality rate often caused by complications such as infection, cardiac tamponade, and graft-versus host disease (Angelucci & Mariotti, 1992; Kelly, Ross, Gray & Smith, 2000; Lawson et al., 2003).

More radical emerging treatments such as gene might potentially affect a cure for TM and whilst it is possible to introduce intact beta-globin genes into murine hematopoietic stem cells using retroviral vectors, the efficiency of transfer is low, expression of the transgene is suboptimal and long-term stability is limited by gene silencing, and position effects (Persons & Neinhuis, 2000). In addition the use of vector carriers such as human immuno-deficiency virus (HIV) or other adenoviruses/retroviruses, required for insertion of the transgene carry enormous risk to the recipient, future offspring and the general community (Baum, 2000; Seppa, 2001; Wheelwright, 2001) and total bone marrow ablation pre-transplantation of modified DNA makes it inherently dangerous for the recipient (Sadelain, 2002).

Some CAM substances have been found in clinical trials to be of benefit to people with TM. For instance, the common earthworm (*Pheretima aspergillum*), a thrombolytic agent,

decreased haemolysis in people with TM (Mihara, Maruyama & Sumi, 1992) and antioxidants such as tea polyphenols, Vitamin P (rutin) and curcemin (a flavanoid) were found to protect red blood cells from oxidative haemolysis (Kattamis & Kattamis, 2001; Ma et al., 2000). A double-blind, cross-over placebo-controlled study of the effect of Vitamin E on platelet functions was performed on 25 people with TM (Unchern et al., 2003). The findings suggested that Vitamin E might delay hypoxaemia and pulmonary occlusion in splenectomised people with TM because it reduced platelet reactivity (Unchern et al., 2003). Whilst, these treatments appear to offer substantial benefits to be people with TM and appear to be safe, to date none of these therapies have been adopted as mainstream therapy.

Potential Implications of Concurrent CAM and Biomedical Use

People with thalassaemia major (TM) are prescribed numerous medicines some of which are taken on a daily basis, and others administered during hospital visits (Mentzer & Kan, 2001). Whilst some CAM therapies might be beneficial the use of some CAM therapies potentially might magnify the disease status of people with TM because some medicines and CAM components interact (Shane-McWhorter & Geil, 2002; Myers, 2002). Currently, whilst there is no research of CAM use amongst people with TM, it is possible that some might self prescribe vitamins, and minerals such as Vitamin C, and iron which can lead to cardiac pathologies (Cappellini et al., 2000). Vitamin C is readily available in food, and often prescribed to improve the iron chelating¹ action of desferrioxamine² (DFO) can cause increased tissue iron toxicity, when taken in excess amounts, which can lead to lethal iron deposits in the heart (Cappellini et al., 2000). People with TM who take digoxin for cardiac arrhythmias (Cappellini et al., 2000) are at risk of elevating digoxin to dangerous levels if they take Chinese silk vine, a common commercial substitute for Siberian ginseng known to contain cardiac glycosides (Niggemann & Grüber, 2003; Shane-Whorter & Geil, 2003). Commonly used in the treatment of people with TM, anticoagulants such as warfarin and

¹ Chelation: method to combine metal in complexes in which the metal is part of the ring

² Desferrioxamine: (chemical name) a naturally occurring siderophore – currently the only drug widely available for iron chelation

aspirin taken with ginseng (*Panax ginseng*), garlic (*Allium sativum*) or ginkgo (*Ginkgo biloba*) increase the anticoagulation potency of such drugs (Furgh-Berman, 2000; Miller, 1998) and might result in death when blood coagulation indices are altered beyond the therapeutically desired level (Miller, 1998).

Despite potentially fatal implications of concurrent CAM use in people with TM, an extensive search of the literature failed to find any information pertaining to CAM use amongst such individuals.

Section Summary

Thalassaemia major (TM) is a serious blood disorder that requires biomedical treatment intervention from a very age until the death of a person. For the sake of survival, palliative care is the only option for people with TM. Whilst, such palliative care provides a modicum of optimal health and increases longevity, it has long-term outcomes that eventually lead to death.

People with TM are prescribed many pharmaceutical medicines, most of which have inherent long-term adverse and life-threatening affects. To lessen mishap from over or insufficient dosages of such medicines careful monitoring is required. The research literature shows that some CAM therapies, such as herbs or vitamins can mask or distort the effects of conventional treatments and the concurrent use of antioxidants may enhance or reduce the effects pharmaceutical medicines, yet the possible use of CAM amongst people with TM has not been explored. Knowledge of CAM use by people with TM is imperative to biomedical practitioners responsible for monitoring and administering safe and effective care. People with TM are often at the forefront of clinical trials and knowledge of the use of CAM by biomedical practitioners is also important, for accurate reflection and validity of clinical trial data.

Importance of this Current Research

Often complementary and alternative medicine (CAM) and biomedicine are used concurrently (Adler & Fosket, 1999; Balneaves et al., 1999; Boon et al., 2000; Richardson et al., 2000). As noted by many researchers (e.g. Cassileth et al., 1984; Downer et al., 1994;

Zollman & Vickers, 1999a) the phenomenon of the concurrent use of CAM and biomedical is increasing and disclosure of such practice remains low. Much of the suggested reasons for CAM use and for disclosure of such use have not been based on the actual responses of CAM users, but on correlative factors. Thus, the motivation for CAM use and the specific purpose for which people seek to use such treatments is not clear. The use of CAM is particularly puzzling in light of the huge advances that biomedical technology has made and the impact it has on many people, particularly on those whose everyday existence depends upon it. This thesis is based on a three-phase study, which explored the reasons people with a severe lifelong chronic illness gave for CAM use and its disclosure to treating physicians.

As the demand for CAM continues to rise, research relating to these therapies and their concurrent use with biomedicine becomes more urgent. Pertaining to CAM use the literature review showed a good deal of information has been amassed through surveys. Such information, whilst informative was simultaneously difficult to analyse because of the problems identified with the methods, and operational definition of CAM, used to conduct the studies. Although statistically meaningful generalisations provided some insight, they have no applicability or at best are incomplete evidence when applied to individual cases (Guba & Lincoln, 2004).

Deductive studies limit responses to fixed categories and set behaviour patterns for both the researcher and interviewer, which limit responses because they disallow the establishment, a balanced and empathetic relationship (Denzin & Lincoln, 2000). In addition, study settings such as those undertaken in medical clinics or hospital environments tend to limit response rates and are subject to under reporting biases (Peter et al., 2002; Rao et al., 1999). The use of medical personnel for the recruitment of participants and administration of studies disallows the establishment of a balanced and empathetic relationship (Chao-Hsing et al., 1999; Denzin & Lincoln, 2000). The concerns about the relative power of practitioners and participants in the biomedical setting, as well as the perceived prejudices of medical practitioners regarding CAM have also been found to influence responses (Shenfield, Lim &

Allen, 2002). For these reasons a researcher not affiliated with the biomedical treatment of participants was important for rapport building (Minichiello et al., 1999) because good rapport tends to increase responsiveness (Denzin & Lincoln, 2000). These reasons suggested the need for an in-depth study, which could access a larger and more comprehensive amount of data (Denzin & Lincoln, 2000).

To overcome limitations that disallow exploration of responses of some survey methods, as outlined earlier, qualitative methods were chosen for this thesis. This thesis subscribed to inductive methods even though all human endeavours are subject to error it predominantly befitted exploration of individual perspectives (Guba & Lincoln, 2004).

Relevance of This Thesis

It is important to study people with TM, within the context of meanings and rationale that they attach to their health-behaviour (Guba & Lincoln, 2004), because they are intensively biomedically treated for the duration of their life, which means those who use CAM might be jeopardising their health. Thus, this research is relevant to the biomedical treatment of people with TM and to the knowledge surrounding the health behaviours of those with a chronic illness, in the context of CAM use and CAM disclosure.

Contribution to Knowledge

This thesis is the first to explore issues relating to the use and disclosure of CAM in people with TM by adding to the limited psychosocial knowledge base pertaining to this group of people (Atkin & Ahmad, 2001). The thesis will also provide an opportunity to critically examine the rationale that shapes CAM use, and disclosure amongst people such as those with TM who require ongoing biomedical treatment, which impacts every aspect of their life, psychological and physical wellbeing (Caro et al., 2002).

In addition, this thesis will add a valuable dimension in the understanding of CAM use and disclosure by the chronically ill by exploring the discrepancy between the noteworthy rise in CAM use and its limited disclosure to biomedicine practitioners. Identification of factors surrounding the disclosure of CAM use by people living with TM represents a significant step

towards supporting biomedical practitioners, patient educators, information services, and support group. This thesis might assist policy makers, and program planners, by providing greater understanding of the issues surrounding use CAM, and its disclosure.

Knowledge of CAM use amongst people with TM would also enhance appropriate coordination between disparate healing strategies, the need for which is highlighted by the fact that the use of CAM is not included as an exclusion criterion for therapeutic trials, and as such may significantly affect the validity of trial results (Sparber et al., 2000). Understanding these issues is critical to the provision of optimal medical and psychosocial support to people facing situations in which they must evaluate treatment options, and act in ways that will optimise their physical and psychological wellbeing. The thesis will therefore, add a hitherto unexplored dimension to the well documented physiological and treatment aspects of TM.

CHAPTER 3: METHODS

In this research I examined the reasons people with thalassaemia major (TM) gave for using complementary and alternative medicine and for disclosing such use to their biomedical physicians/s. Qualitative methods were used to explore these issues because we do not understand the experience of people with conditions like TM that might lead them to use and disclose their CAM use. Qualitative research is a ‘discovery-orientated’ approach, which should be used to explore areas that have been relatively neglected by research or for topics that the researcher believes there is need for in-depth exploration to extend understanding, or when the researcher suspects that present knowledge or theories might be biased or incorrect (Morse & Field, 1995; Morse & Chung, 2003). Therefore, qualitative data collection provided the scope for understanding the behaviour of people with TM, a group never before studied in relation in CAM use and CAM disclosure.

Method

The purpose of grounded theory, developed by Glaser and Strauss (1967) is to inductively generate an explanation that furthers the understanding of the social and psychological phenomena under investigation (Chenitz & Swanson, 1986). For this thesis I did not seek to verify or falsify a preconceived hypothesis, so the issues of interest for this research required open exploration using grounded theory (Glaser & Strauss, 1967). This research used a key concept of grounded theory, whereby the incoming information from the participants was analysed immediately post-interview (Webb & Kevern, 2000) to sharpen the guiding research questions, shown in Appendix 2. Such methods allowed for examination of complex and contingent situations, behaviours and interactions that influenced CAM use and CAM disclosure.

Purpose

The purpose of the thesis was to examine the reasons people with thalassaemia major (TM) use CAM and disclose such use to treating biomedical physicians. To do this it was first

necessary to determine the incidence of CAM use and CAM disclosure and the types of CAM people with TM used.

Aims

The main aims of this thesis were to examine the patterns of CAM use amongst people with TM and to explore the reasons that people give for CAM use/non-use and disclosure/non-disclosure of CAM to conventional practitioners.

In particular, the thesis in Phase 1:

- (a) Surveyed the socio-demographics and self-reported medical history of people with TM
- (b) Determined the incidence of disclosure of CAM use by people with TM
- (c) Determined the occurrence, types, and frequency of use of CAM medicine by people with TM.
- (d) Explored the participants meaning of CAM.

In Phase 2:

- (a) Determined the reasons why people with TM choose to undertake CAM treatment
- (b) Examined the factors that influenced CAM use

In Phase 3:

- (a) Determined the reasons why people with TM choose to disclose their use of CAM, to treating biomedical physicians.
- (b) Examined factors influencing disclosure of CAM use to biomedical physicians
- (c) Examined how people with TM chose to disclose their CAM use.

Following the use of a brief survey administered by interview in Phase 1, this thesis adopted a grounded theory approach for Phases 2 and 3. In Phase 1, identification of use, disclosure, and types of CAM was surveyed and whether or not such use was undertaken under the supervision of a CAM practitioner.

Figure 3.1 illustrates how it was proposed that the phases of the research should be conducted. In Phase 2, those who reported using CAM were to be interviewed further to identify reasons for such use. Those reporting not using CAM were to be interviewed for

reasons why they had not used CAM. Similarly, for Phase 3, individuals identified as disclosers of CAM use to conventional medical practitioners were to be interviewed further to examine their reasons for disclosure. CAM users who did not disclose such use to biomedical practitioners were to be interviewed to identify reasons for nondisclosure. Using in-depth, unstructured conversation- style interviews, participants were encouraged to openly discuss CAM use and disclosure.

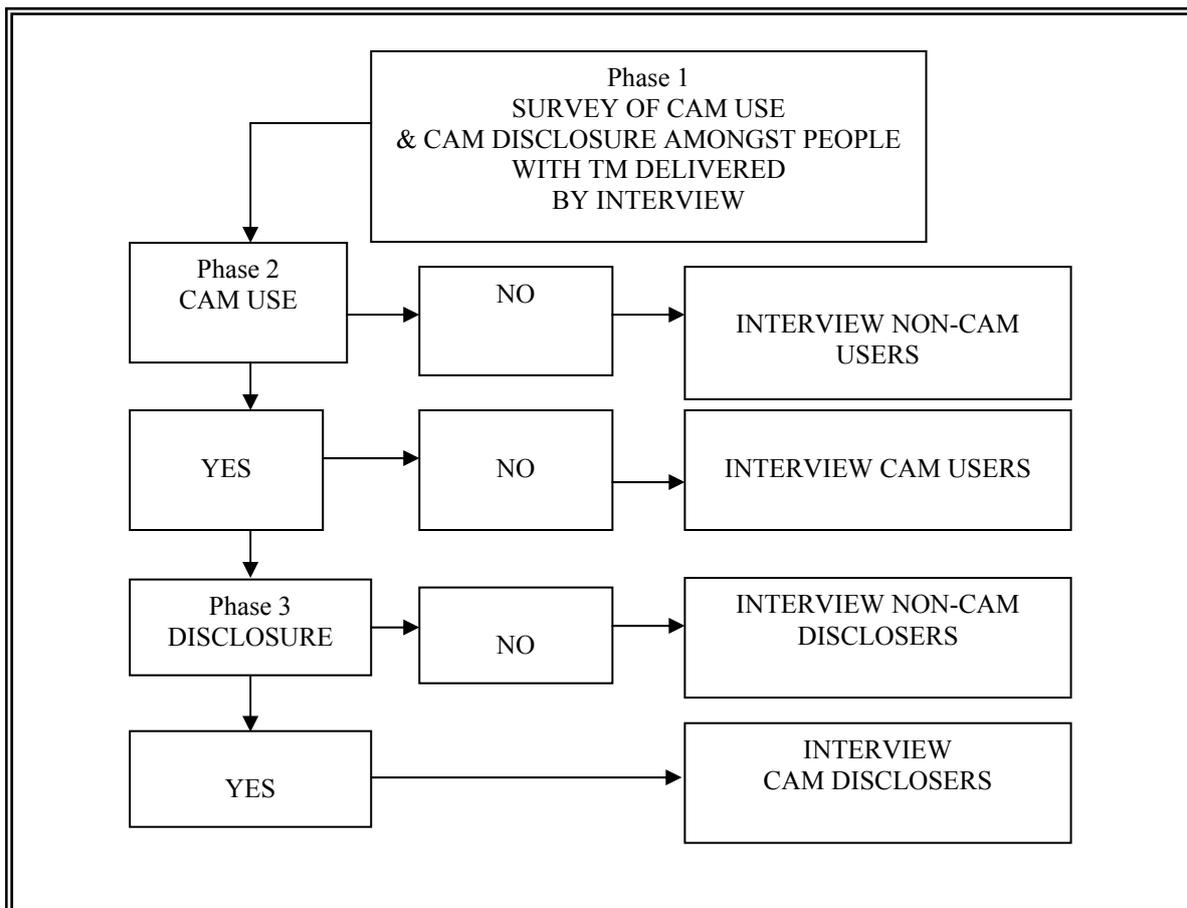


Figure 3.1: *Schematic of Phases of Thesis*

Subject to the comfort and willingness of participants, Phases 2 and 3 flowed on immediately after the initial, brief, exploratory interview (Phase 1).

Research Rigour

Developing and creating an environment in which participants developed good rapport and built a sound relationship with the researcher was important to encourage participants to make honest and truthful responses (Denzin & Lincoln, 2000).

Strategies, such as reframing questions and asking participants what they understood a particular question referred to, were also undertaken to avoid misunderstandings, and for misconceptions and misunderstanding of information to be corrected. These strategies gave context to the participants' responses, essential for understanding the meanings that the participants made of their experiences that lead to CAM use and disclosure.

The process of adding new issues raised in the participants' responses to the interview guide, for the interviews that followed, ensured that the reasons for CAM use and CAM disclosure were accurately identified and delineated, and directed the inquiry process. These strategies were adopted to enhance credibility of the information collected (Minichiello, Aroni, Timewell, & Alexander, 1995).

Credibility was enhanced by several means (Holloway & Wheeler, 2002), including interviews that were long enough, 60 to 120 minutes, to allow participants to voice their experiences and meanings, open-ended questions with probes to achieve thick data rich in CAM experiences. In addition, coding was performed in consultation with a colleague. Consensus resolved any differing interpretations. Periodic debriefing to ask thoughtful questions about the emerging results was performed by the colleague who was experienced in qualitative research, but had no direct involvement in the research.

To achieve confirmability the researcher kept an audit trail in the form of memos during the research, which provided the analytical process with transparency (Rodgers & Cowles, 1993). Personal thoughts and feelings as they influenced the project (Beck, 1994b) were discussed and recorded prior to and during the research with a colleague. By using the actual words of the participants to enable "vivid and faithful description of the phenomenon" (Beck, 1994b, p. 264) credibility was enhanced. Accurately identifying and describing, from the perspective of the participants, what they meant by particular terms, such as: "alternative medicine", medicine, "be well" and "doctor", further enhanced credibility.

Participants

Homogeneous sampling was used to select participants who exhibited similar characteristics because the aim of this research was to examine, in-depth, the common experience (Llewellyn, Sullivan & Minichiello, 1999, p. 188) that motivated CAM use and CAM disclosure amongst people with a serious disorder that required on-going biomedical attention. Thus, eligibility was limited to people with TM, aged 18 years and over.

Participants were English speakers in whom cognitive or physical impairment did not prevent completion of the interviews. Recruitment of participants was through patient support groups. Relevant support groups, such as the Thalassaemia Society of Victoria (TSV) agreed to disseminate notices asking for participants through their respective newsletters. As shown in Appendix 2, these notices provided a brief explanation of the project, selection criteria, proposed commencement date, and contact phone numbers for those wishing to participate.

Comments on Sample Size

The sample sizes for Phase 2 and Phase 3 of the research were based on theoretical saturation. From a grounded theory perspective, saturation refers to a situation in which no additional data is found in further interviews that would add to the themes being developed and examined (Morse et al., 2002). Because the range of CAM modalities is wide, I considered it likely that reasons for CAM use would be more varied than reasons for CAM disclosure. Thus, although it was not possible to predict sample sizes, I estimated that saturation might be around 12-15 participants for CAM use and seven to 10 participants for CAM non-users, CAM disclosers and CAM non-disclosers. Participants were recruited until theoretical saturation of data was achieved. Saturation was met with 21 participants.

Design

This qualitative research used methods based on those of grounded theory, as described by Glaser & Strauss (1967). In this approach, although the researcher was inductively driven, the researcher shifted between cycles of inductive data collection and analysis to deductive cycles of testing and verification with the ultimate goal of developing theory. Important

themes or questions were identified inductively from the data. Then verification of the data was deductively evaluated to confirm or qualify the exploratory findings in subsequent data. This led to decisions as to which data to collect next and as the new data was analysed the cycles of induction and deduction began again. This more or less simultaneous data collection and processing enabled the data collection efforts to be directed more specifically at fleshing out themes and patterns, filling in gaps, clearing up anomalies or conflicts, and extending the range of information that could be accommodated. Gradually themes and the relationship between them were constructed and became more definite (Denzin & Lincoln, 2000), thus, enabling the development of theory, one firmly grounded in the data and uninfluenced by other prevailing theory (Strauss & Corbin, 1994). The data collection process reached ‘saturation’ which by definition meant there was no new information arising from the data collected. Thus, there was no point in adding any further exemplars.

Research methods of administration, recruitment and settings were likely to influence responses, because people with TM are over-investigated in the biomedical context. So they tend to “ferociously guard their privacy, and are wary of new staff members” (personal conversation with Ms Libby Reid, Nurse Manager, 3 August 2001). The concerns about the relative power of practitioners and participants in the biomedical setting, as well as the perceived prejudices of medical practitioners, regarding other forms of therapy, as noted in the literature review, were also likely to influence responses. This suggested that an “outsider” researcher, distant from the biases that over-familiarity bears, was important in building rapport, as was personal communication with participants (Minichiello, Madison, Hays, Courtney & St John, 1999). Whilst, the researcher of this thesis is a practitioner of Chinese medicine, the researcher was not affiliated with the health care of the participants.

CAM Definition Applied to the Thesis

For the purpose of this thesis the operational definition of CAM had to fulfil the following three criteria:

- a) The treatment or practice was self-prescribed or prescribed by a CAM practitioner.

- b) The treatment or practice was not prescribed by a biomedical physician.
- c) The treatment or practice was used with intent to treat or prevent an illness or sign/symptom of an illness.

In addition a treatment used to replace a prescribed biomedicine was considered alternative medicine and a prescribed biomedicine taken at an altered dosage on the advice of a CAM practitioner was considered complementary medicine.

Measures

Information about participants' socio-demographics, CAM use and disclosure was sought by semi-structured questions, as shown in Appendix 2, delivered in conversational interviews (Phase 1). Phase 1 surveyed self-reported medical history and prescribed biomedicines, health behaviours, the patterns of CAM use and CAM disclosure, identified known/heard and used CAM therapies. In Phase 1 the participants were also asked to categorise the CAM products/therapies they had mentioned, as biomedicine, CAM, CAM and biomedicine, lifestyle or all.

In Phase 2, participants were asked about their understanding of CAM, complementary and alternative medicine and the reasons why they chose to use CAM. Similarly, in Phase 3 participants' reasons for CAM disclosure and reasons for non-CAM disclosure were explored. It was proposed, as Figure 3.1 illustrates, that in Phase 2 participants who said they were non-CAM users would be interviewed about their reasons for non-use, and if they had ever thought of using CAM.

As all participants were considered to be CAM users, according to the operational definition of CAM that was applied to this research, no interviews about reasons for not using CAM were conducted. Discussions relating to CAM that participants had with their treating physician; other discussions; reactions of the person with whom they were discussing CAM; how they made the choice to disclose, and whether they thought it was important to disclose CAM use to biomedical practitioners were explored. All three phases used in-depth,

unstructured, conversation-style interviews to solicit information and flowed consecutively on from one another.

Survey of CAM Use and Disclosure

The brief interview in Phase 1 was based on a survey, which sought socio-demographic data from each participant. Oral responses were recorded in writing as part of the memo notes and they were also tape-recorded. A conversational interview approach was chosen for the conduct of this survey because of concern that participants might not be forthcoming if asked to write survey responses. Development of rapport during Phase 1 was considered to be essential to the effort to obtain reliable information at this stage and in Phases 2 and 3. The survey included semi-structured and guiding questions, as shown in Appendix 2 to discover the types of CAM used, frequency of use, whether a CAM practitioner prescribed the CAM, and whether or not disclosure of such use to biomedical practitioners occurred. With prior permission from the participants, tape recording was employed to record and check information recorded in the filed notes, and to help familiarise the participants with the presence of a tape recorder for Phases 2 and 3.

In-depth Interviews about the Use and Disclosure of CAM

Unstructured, in-depth interviews were employed in Phases 2 and 3, to allow for exploration of responses to the issues surrounding the use and disclosure of CAM (Minichiello et al., 1995). The in-depth, unstructured interviews allowed for probing of subjective perceptions, meanings, understanding, values, reasons for use, and definitions that the participants held on CAM. The interview approach also facilitated the development of rapport, which was important to gain trust and, thus, obtain honest answers about CAM use and disclosure (Minichiello et al., 1999).

An interactive interviewing style described by Spradley (1979) and Silverman (2000) was utilised for all three phases. The interview guides illustrated in appendix 2 were further developed throughout the research process and were increasingly used to direct the

conversation towards emerging themes that were conceptually rich and to clarify areas of confusion.

In Phase 2, participants' reasons for deciding to seek CAM consultation and take up of CAM treatment were examined. In Phase 3, the in-depth, unstructured, conversation-style interviews were directed toward discovering the factors that influenced CAM disclosure to biomedical practitioners. With prior permission of participants the in-depth unstructured interviews were tape-recorded. This allowed capture of the full scope of the interaction in the interviews and facilitated familiarity with the data by permitting the recorded data to be repeatedly reviewed. During and after the interviews in Phases 2 and 3, memo notes were taken.

Procedure

People who expressed an interest in the project were asked to designate whether they wanted the interviews to take place in their homes or at the office of the Thalassaemia Society of Victoria (TSV). Prior permission was sought and granted from TSV for the use of their premises. All of the participants were met at their homes as they requested. Participants were then informed about what participation involved, that measures, such as coding of their names, would be undertaken to maximise confidentiality, that participation in the study was voluntary, and that they were free to ask questions or raise concerns at any time. The participants were given the plain language statement (PLS), shown in Appendix 4, and given time to read it. The participants were then asked if they understood the PLS and whether they had any questions. Consent to participate was acknowledged by the signing of a consent form, shown in Appendix 5. To establish rapport, upon meeting and greeting participants, I thanked them for agreeing to take part in the study and informed them that what they had to say was considered to be very important (Minichiello et al., 1999).

At the commencement of Phase 1, the survey interview, participants were invited to talk about themselves and their illness to help them feel comfortable and to encourage them to describe their true feelings and thoughts. The interview flowed in a natural, conversational

manner to keep participants at ease and continue to develop and maintain rapport. These procedures encouraged honest responses to the items concerning CAM use and disclosure, which occurred toward the end of this brief interview phase. As the participants spoke about the CAM therapies they knew/heard of they were recorded by pen on paper, as a list. From this list the participants were asked to identify the CAM therapies they had used.

Phases 2 and 3 followed on directly from Phase 1, with the proviso that participants were able and willing to continue. All of the participants were able to continue and all three phases were conducted sequentially on the same day. Whilst alternative arrangements to accommodate people who did not feel able to continue at this time were offered, they were not needed. All participants were interviewed for CAM use. Participants for Phase 3 were identified on the basis of their Phase 1 responses. All participants were interviewed about their reasons for disclosure or non-disclosure. Interviews continued until each category, disclosers and non-disclosers, was saturated.

Analysis

Analysis Phase 1. Socio-demographics and biomedical history, including number of comorbidities and types of biomedical medicines prescribed, as reported by participants, were recorded. Individuals were classified as CAM users/non-users, as well as CAM disclosers/non-disclosers. Percentages of CAM use and disclosure were calculated. Frequency of use and type of CAM were categorised and tabulated. Similarly, patterns of use and disclosure were categorised and tabulated.

Analysis Phase 2 and 3. The in-depth interviews from Phases 2 and 3 were transcribed verbatim to provide raw data for analysis. The constant comparison method was used to analyse each interview after it happened and prior to the next interview to avoid 'preconceived standardized codes' (Denzin & Lincoln, 2000). Memo notes were considered along with the interview transcript to provide the most thorough examination possible of the material. Two of the principles for grounded theory are that analysis takes place before, during and post-data collection, using the constant comparison and saturation method (Browne & Sullivan, 1999;

Charmaz, 1983, 1995; Guba & Lincoln, 2004). The steps for data analysis were performed cyclically and by continuously processing the data to reduce, organise and interpret, and restructure the guiding interview questions.

All transcripts were read to get a sense of the whole. Each interview was coded to identify essential meaning. The meaning units were discriminated on the basis of relevance to the study and were defined for consistent application throughout. Similarly, coded data were examined and probed to make the disciplinary value of each unit more explicit (Giorgi, 1997). Themes were derived as patterns emerged, and their essential properties were defined. The essential patterns were synthesized into themes to provide a broad, comprehensive, and wholistic narrative structure of the phenomenon. Throughout the analytical process, memos and tables were constructed. The visual representations of the patterns permitted an overview of the emerging results.

There was a systematic effort to check and refine evolving patterns of data to determine the need for further review of the literature (Charmaz, 1983) related to CAM, TM, and chronic illness, as well as for further hypothesis development and guiding interview questions. Further, to reflect and interpret the data accurately, flexibility in developing, expanding, modifying and eliminating categories was undertaken (Minichiello et al., 1999). In Phase 2, raw data statements were coded, and then drawn into repeated patterns from which themes of reasons for CAM use and non-use are identified. In Phase 3, similarly, raw data statements were coded and then drawn into repeated patterns from which themes of reasons for disclosure and non-disclosure were identified. The themes were developed in a hierarchical manner and emerged as first, second and third-order themes. From the third-order themes emerged the general dimensions.

CHAPTER 4: PHASE 1 RESULTS OF CAM USE and DISCLOSURE in PEOPLE with an HAEMOGLOBINOPATHY

In this chapter I present the survey results. Phase 1 determined the participants' incidence of CAM use and CAM disclosure to biomedical practitioners. Examined the occurrence, types, and frequency of use of complementary and alternative medicine by people with TM, and surveyed a range of demographics, medical history and health behaviours. Participants were asked to name the CAM therapies they had heard of and used. In Phase 1 participants' responses to therapies mentioned, used and who prescribed the CAM were collated for the purposes of comparison of reported CAM use, with actual CAM use.

Participants were asked to nominate the complementary and/or alternative therapies that they had heard of. Whilst participants spoke a list was devised of the nominated CAM therapies. Participants were then asked to classify the therapies they mentioned as CAM, biomedicine, 'CAM and 'biomedicine', 'lifestyle' or 'other'. The participants were then asked to nominate the therapies they had used and who prescribed them. To refresh the participants' memories I asked after every therapy mentioned. To every participant's list of therapies I added psychologist, psychiatrist and social worker, for two reasons. Firstly, such practitioners are an integral part of the biomedical "team" approach (Personal conversation with Ms Libby Reid, Nurse Manager, MMTU, 3rd August, 2001) at MMTU, the treatment centre, which many of the participants attended. Secondly, because behavioural modification used by psychiatrists and psychologists are considered complementary/integrative medicine (NCCAM, 2002). To the participants' list kitchen remedies were added because they were considered CAM (Factor-Litvak et al., 2001).

Findings

Demographics. The sample consisted of 21 people with β -thalassaemia major (TM). Table 4.1 illustrates the participants' age, gender, ethnicity, and place of birth, marital status, educational level, and income levels. As a group the levels of income and education of the

participants were relatively high. Table 4.1 shows most of the participants were relatively young, Caucasian of Greek descent and in a permanent relationship.

Table 4.1: *Demographics*

Variable	Number of participants
Diagnosis	
β -thalassaemia major	21
Age (years)	
21-30	7
31-40	12
41-50	2
Gender	
Female	13
Male	8
Marital status	
Single	6
Permanent relationship	13
Separated	2
Progeny	9
Birth place	
Australia	18
Other	3
Ethnicity	
European	17
Middle Eastern	3
Asian	1
Education	
Secondary school	7
TAFE	6
Higher education	8

Table 4.1: *Demographics (continued...)*

Variable	Number of participants
Household income	
<\$20-39,000	6
\$40-80,000	12
>\$81,0000	3

Self-reported medical history. The self-reported medical history of the participants is shown in Table 4.2. The findings show most of the participants were diagnosed with TM before their second birthday and most commenced blood transfusion treatment shortly after diagnosis. Most of the participants commenced iron-chelation therapy before their tenth birthday. All of the participants reported at least one surgical procedure. The surgical procedures reported included splenectomy, cholecystectomy, appendectomy, thyroidectomy, tonsillectomy, laparoscopy, and insertion of cardiac pace maker and defibrillator, and removal of tumorous growths. Seven of the nine participants who were parents required biomedical assistance for conception such as invitro-fertilisation.

Table 4.2: *Self-Reported Medical History*

Variable	Number of participants
Age of diagnosis	
3-36 months	15
37- >48 months	6
Age first transfused (months)	
< 12-36 months	15
37- >49 months	6
Age comm. chelating (years)	
2-5 years	3
6-10 years	14
11-15 years	4

Table 4.2: *Self-Reported Medical History (continued)*...

Variable	Number of participants
Pre-transfusion haemoglobin level (g/dl) ¹	
8-10	6
>10-11	11
>11	4
Frequency of transfusion (wk)	
2-3 weeks	10
3-4 week	11
Major Surgical Procedures	
Splenectomy	17
Other	9

Detailed in Table 4.3 are the co-morbidities reported by the participants. All of the participants reported multiple co-morbidities many of which are serious in terms of chronicity, life expectancy and quality of life. Table 4.3 shows six of the participants reported having cardiomyopathy, which in terms of life expectancy is the most serious co-morbidity. Eleven of the participants reported blood transfusion acquired Hepatitis C, also a life-limiting disorder. Two of the participants reported having hypothyroidism, which was described as:

I've got an under active thyroid...I'm on medication for that...I think thyroxine [name of biomedical medication] and I can't remember...I had gained a lot of weight and I was always tired (P4).

Low T3 or T4 or something like that, so I have a tablet a day....I kept on putting on weight and I used to get really cold and tired that sort of thing (P15).

Fifteen of the participants, nine females and six males, reported delayed or arrested puberty.

¹ Normal haemoglobin levels: Male: 13.5-18g/dl; female: 12-16g/dl

Table 4.3: *Reported Known Co-morbidities*

Co-morbidity Number of participants	
Participants reporting co-morbidities	21
Audio-visual	5
Cardiomyopathy (inc cardiac arrhythmias)	6
Depression	5
Diabetes	4
Infertility	13
Iron overload	20
Hepatitis B	1
Hepatitis C	11
Hypothyroidism	2
Liver cirrhosis	1
Osteoporosis (& borderline ie osteopenia/ic)	18

The following comments illustrate how the participants described their abnormal sexual development and early sexual decline:

I was put on the pill when my periods stopped...my period stopped about a year after they started...I think I was 17 when I had my first period and by 18 or so it was all over (P1).

I didn't develop any breasts and I never had a period until I went on the pill. About 18 years old when I first went on the pill (P9).

I never had a period until I was put on the pill...I must have been about 18 years old (P17).

My mum noticed that when I was at the age of about 15 she saw my brother, you know he's younger than me, was growing much faster than I ...from the age of basically 15 I went on hormone replacement...because I was very short, I was one of the shortest kids...I can't produce (ah) sperm (so um) (P5)

I was normal but as we age it affects our sperm, and now I have no libido and a very low sperm count. The sperm is no good and that's why my wife can't get pregnant (P6).

All participants who were parents reported requiring biomedical assistance to conceive. Treatments included spermatogenesis, ovulation induction, and invitro-fertilisation and donor sperm.

Table 4.4: *Use of Prescribed Medications*

Medication	Prescribed
Antibiotics	17
Anticoagulants	3
Antidepressants	3
Diuretics (daily)	5
(during blood transfusion)	21
Heart Medications	4
Hormone Replacement	19
Iron chelator (DFO)	21
Vitamins & Minerals	21
Other	5

Eighteen participants reported having osteoporosis. Three of these participants reported having had bone fractures, and one participant reported multiple past bone fractures. The biomedical drugs prescribed for the participants are shown in Table 4.4. All participants reported taking multiple prescribed medications. All seventeen asplenic participants were prescribed prophylactic antibiotics. Only three of the seventeen participants prescribed prophylactic antibiotics reported being compliant with the biomedical treatment regimen. All participants in the study reported being compliant with Desferal (DFO) in terms of frequency of use (six nights/week), but some adjusted the dose. Fifteen of the participants reported being prescribed Vitamin C for concurrent administration with DFO. Most of the participants prescribed Vitamin C increased the dose. Four of the twenty-one participants who had been

prescribed vitamins and minerals reported altering the dosages. These findings indicated many participants were non-adherers to some biomedical regimens. All of the participants with cardiomyopathy and or osteoporosis reported taking prescribed medicines for the conditions. Three of the four participants with diabetes reported the diabetes was being controlled by diet; the other was taking prescribed insulin injections. Five of the participants with hepatitis C reported being involved in a clinical trial testing Interferon antiviral therapy. Of the five of the participants diagnosed with depression only one participant reported taking anti-depressants at the time of the interview. Seven of the participants took vitamins and minerals not biomedically prescribed.

Nineteen participants reported not being fully compliant with prescribed medicines. None of the participants reported biomedicine prescription non-compliance to their treating physician.

Reported health behaviour. When the participants were asked to explain what activities/therapies, apart from biomedicine, they used to maintain their health they responded by making short brief comments, listed in Table 4.5.

Table 4.5: *Health Behaviours*

Reported behaviour	Number of participants
Good diet	18
Don't eat foods with iron in them	16
Try and exercise	5
Don't smoke	21
Drink only socially	6
Take care of myself	13
Do things, like take extra vitamins and stuff	16

Most of the participants reported they ‘take care of myself’ by ‘do[ing] things like taking extra vitamins and things’. Therefore, the participants’ responses indicated there were 16 CAM users when data was analysed using the CAM definition used by many researchers (e.g. Huber, 2004; Furler et al., 2003; Lengacher et al., 2002; Peter al., 2002). There were 18 CAM users when the participants responses were analysed using the CAM definition that considered ‘good food’ and iron-reduced diets as CAM because they were used for health purposes (Drew, 2001; Rao, 1999).

CAM Use and CAM Disclosure

Reported CAM Use and CAM disclosure. From the dichotomous Yes/No response format to the posed question, “Have you ever used or do you use CAM, also referred to as complementary and or alternative medicine?” Many of the participants asked for clarification of the question because they were not familiar with the terms CAM and complementary/alternative medicine. For those participants who asked for clarification the question was put to them as:

CAM is an acronym of three words, complementary and alternative medicine. CAM or complementary and alternative medicine is anything you do for your health, which is not prescribed or recommended by your doctor.

Eight females and four of male participants reported CAM use. The participants who reported CAM use were then asked whether or not they had informed their doctor that they used CAM. Only one person, a male, reported disclosing CAM to the treating physician.

Illustrated in Table 4.6 are the CAM treatments/products the participants reported knowing about and how they categorised them. Some participants differentiated Chinese Medicine (CM) herbs from other herbs. CM was considered “medicine” and CAM. Ayurvedic medicine was also considered “medicine”. Most participants considered kitchen remedies, such as “things like lemon and honey” and “alcohol and pepper” compresses used for “colds”, were “just what you do to get better”, or “make you better”. These responses suggested kitchen remedies were used as a form of treatment.

Table 4.6: *Reported Known Therapies*

Therapy	Participants No:	Participant Classification of Therapy				
		CAM	Biomedicine	CAM & biomedicine	Lifestyle	Other
Acupuncture	12	8	2	2	-	-
Aromatherapy	2	-	-	-	2	-
Ayurvedic	1	-	-	-	-	1
Bach Flower remedies	6	6	-	-	-	-
Chiropractic	4	-	3	-	1	-
Diet (total)	18	3	6	7		-
Fortified drink/food	10	-	8	2	-	-
Iron-reduced diet	16	-	4	12	-	-
Liver cleansing	3	2	1	-	-	-
Probiotics	6	4	1	-	1	-
Weight loss	10	3	5	1	1	-
Exercise (total)	19	5	5	4	5	-
Gym	5	-	-	4	1	-
Tai chi	2	2	-	-	-	-
Yoga	6	4	-	2	-	-
Walking	7	-	-	4	3	-
Herbal (total)	19	15	2	2	-	-

Table 4.6: *Reported Known Therapies(continued)...*

Therapy	Participants No:	Participant Classification of Therapy				
		CAM	Biomedicine	CAM & biomedicine	Lifestyle	Other
Chinese Herbal Med	10	6	-	-	-	4
Garlic/ horseradish	4	4	-	-	-	-
Spirulina	2	2	-	-	-	-
St John's Wort	6	1	3	2	-	-
St Mary's Thistle	6	4	1	1	-	-
Wheatgrass	9	2	3	4	-	-
Homoeopathy	6	3	2	1	-	-
Hypnosis	1	-	1	-	-	-
Iridology	2	2	-	-	-	-
Kitchen remedies	20	1	-	2	4	13
Kinseology	1	1	-	-	-	-
Massage	16	7	2	5	1	1
MORA	1	1	-	-	-	-
Meditation	1	-	-	-	-	1
Naturopathy	8	8	-	-	-	-
Osteopathy	2	2	-	-	-	-
OTC (total)	21	-	21	-	-	-

Table 4.6: *Reported Known Therapies (continued...)*

Therapy	Participants No:	Participant Classification of Therapy				
		CAM	Biomedicine	CAM & biomedicine	Lifestyle	Other
Topical OTC	16	-	16	-	-	-
Cold/cough OTC	17	-	15	2	-	-
Pain relievers OTC	21	-	21	-	-	-
Psychiatrist	21	18	3	-	-	-
Psychologist	21	20	1	-	-	-
Prayer	3	-	-	1	1	1
Reflexology	2	2	-	-	-	-
Social worker	21	21	-	-	-	-
Vitamins & mineral (total)	21	15	-	15	6	-
Calcium	20	-	19	1	-	-
Executive B	6	-	-	-	6	-
Folic acid	21	-	21	-	-	-
Vitamin B12	8	7	-	1	-	-
Vitamin C	21	21	-	-	-	-
Vitamin E	6	6	-	-	-	-

Of the two participants who mentioned colloidal chelation one considered it biomedicine because iron chelation was part of their biomedical regimen. Interestingly, Table 4.6 shows fortified food/drink was considered by many of the participants as biomedicine because biomedical physicians use “things like that for some diseases”. Similarly, few participants considered some herbal products such as, St John’s Wort biomedicine because psychologists often recommended them. Most participants considered wheat grass a CAM and biomedicine because biomedical practitioners prescribed it.

None of the participants considered over-the-counter (OTC) medicines, CAM. Most participants considered vitamins, such as folic acid and vitamins C, and minerals, such as calcium, biomedicine because they were part of their biomedical regimen.

Illustrated in Table 4.7, *Therapies Known and Used and Who Prescribed the CAM*, are the substances the participants reported using and the who prescriber was. As shown in Table 4.7 two participants reported using hydrotherapy prescribed by a biomedical physician as illustrated in Table 4.6 participants considered such treatment biomedicine. Similarly, nine participants reported using wheat grass at the time of the interview and reported they were part of a trial, conducted by a biomedical physician, to test whether wheat grass could switch on foetal haemoglobin. Four wheat grass users originally had the product prescribed by a CAM practitioner. As shown in Table 4.6 wheat grass was mostly considered both CAM and biomedicine.

Estimating CAM use from the participants’ responses to the therapies and substances they reported using was difficult because in many instances a CAM practitioner and a biomedical physician concurrently and or at some point in time had prescribed some CAM therapies and substances, such as vitamins and minerals. Similarly, even though, OTC, hot water/pack, hydrotherapy and acupuncture were considered CAM by many researchers (e.g. Anderson et al., 2000; Bica et al., 2003; Dolan & Lewith, 1998; Featherstone et al., 2003) the participants reported some biomedical practitioners recommended and/or administered some of these therapies.

Table 4.7: *Therapies Known and Used, and Who Prescribed the CAM*

Therapy	Used	Prescriber (multiple choice permitted)		
		Biomedical practitioner	CAM Practitioner	Self
Acupuncture	7	3	7	-
Aromatherapy	2	-	-	2
Ayurvedic	1	-	1	-
Bach Flower remedies	6	-	4	2
Chiropractic	4	2	-	2
Diet (total)	17	3	8	6
Fortified drink/food	10	-	2	8
Iron-reduced food	16	5	9	3
Liver cleansing	2	-	1	1
Probiotics	6	-	6	-
Weight loss	6	4	-	2
Exercise (total)	7	-	5	2
Gym	1	-	-	1
Yoga	4	-	2	4
Walking	7	-	5	2
Herbal (total)	14	-	6	3
Chinese Herbal Med.	10	-	8	2
Garlic/horseradish	4	-	2	2

Table 4.7: *Therapies Known and Used, and Who Prescribed the CAM (Continued...)*

Therapy	Used	Prescriber (multiple choice permitted)		
		Biomedical practitioner	CAM Practitioner	Self
Spirulina	2	-	1	2
St John's Wort	4	-	4	1
St Mary's Thistle	5	-	5	2
Wheat grass	9	7	2	2
Homoeopathy	4	-	4	-
Hydrotherapy	2	2	-	-
Hypnosis	2	1	1	-
Kinseology	1	-	1	-
Kitchen remedies	12	3	1	11
Massage	6	-	6	2
Naturopathy	8	1	7	-
Osteopathy	2	-	2	-
OTC (total)	21	21	-	21
Cold Sore Med	18	5	-	13
Cold/cough	19	-	2	17
Pain relievers	21	21	-	21
Psychiatrist	4	4	-	-
Psychologist	8	4	-	-
Prayer	2	1	-	1

Table 4.7: *Therapies Known and Used, and Who Prescribed the CAM (Continued...)*

Therapy	Used	Prescriber (multiple choice permitted)		
		Biomedical practitioner	CAM Practitioner	Self
Reflexology	2	-	2	-
Social Worker	21	21	-	-
Vitamins & Minerals (total)	21	21	4	6
Calcium	14	14	4	4
Executive B	6	-	1	6
Folic acid	17	17	6	1
Vitamin B12	8	1	3	4
Vitamin C	18	15	1	4
Vitamin E	6	-	6	1

There were numerous CAM estimates, each dependant on which CAM definition was applied to analyse the data. For example, when the NCCAM (2002) definition of CAM was applied for the purpose of analysis it was estimated that all participants were CAM users (100%). In contrast, when vitamins and minerals and kitchen remedies, such as steam inhalation and lemon and honey tea were removed on the basis that they had been prescribed by a biomedical practitioner, estimated CAM use fell significantly to 8 users, 38%. Based on the operational CAM definition used for this research, all of the participants were considered CAM users because all of the participants reported using at least one CAM substance/treatment not prescribed/recommended by a medical practitioner and the participants' responses suggested they used the therapies as a CAM as a treatment.

Summary

Phase 1 showed all of the participants in this study met the categorisation of severe and chronic illness outlined in Chapter 2. Phase 1 showed all of the participants have much co-morbidity, and all participants had at least one surgical procedure. All participants used CAM and biomedicine concurrently. This means CAM was used with all classes of biomedical drugs.

Phase 1 showed, based on the dichotomous formatted questions “did you or have you used CAM/disclosed CAM use?”, that there were twelve CAM users and one CAM discloser. From the data in Table 4.6 estimated CAM use was estimated to be as high as 100% and as low as 38% depending on which CAM definition was used to analyse the data.. In addition, based on the therapies/substances the participants reported they had used, actual CAM use was higher than reported. Phase 1 showed all of the participants received biomedical care and used CAM concurrently. Phase 1 showed there was only one CAM discloser.

Phase 1 indicated the definition of CAM used by most researchers (e.g. Day, 2002; Furler et al., 2003; Keegan, 2003) was different to the participants’ understanding of CAM.

Discussion

This discussion section makes comparisons with other CAM studies. Comparisons of the demographics, self-reported medical and prescribed medicines, and health behaviours are made in the context of reported CAM use and CAM disclosure. Comparisons of reported CAM use and CAM disclosure are made with various CAM definitions as applied by other studies. Conclusions drawn from Phase 1 are presented along with implications for practice and suggestions for future research that result directly from Phase 1.

Conclusions and Relationship of Findings to Research

Demographics. Although the small sample in this study does limit comparisons the results showed that reported CAM use was; more common in women than in men, CAM use for females was 66%, and the highest percentage of CAM users, 42.85%, were aged between 31 and 40 year old age. The nature of TM as a cradle to grave illness might explain why CAM

users in the present study were younger. Whilst most CAM studies amongst people with a serious illness showed CAM users were predominantly women (Furler et al., 2003; Patterson et al., 2002; Shumay et al., 2002; Zochling et al. 2004) the rate by which women reported CAM use in Phase 1 was markedly higher. Most CAM users had tertiary qualifications. The participants' level of education was found to be higher when compared with general population CAM studies (Astin, 1998; Eisenberg et al., 1998) and considerably less than estimated in some breast cancer surveys (Lengacher et al., 2002). The difference in education levels might be due psychological abnormalities (Logothetis et al., 1971; Sadowski et al., 2001) and/or cognitive defects (Monastero et al., 2000) or the enduring nature of TM, which affects schooling because of time lost through treatment and episodes of acute illness (Ratip et al., 1995). The findings of this research suggest that the later reason is the most plausible to explain the difference between the education levels of people breast cancer, whose illness is not endured during their formative years as in the case of people with TM.

There is the potential for volunteer bias in that TM people who were better educated were more likely to see the benefit of this present study than people with less education. The higher level of education of the study group might also reflect the relatively high annual household salary. Hence, inferences in regard to salary and income are limited because people who are more educated are also more likely to hold better jobs, whereas those without these things might have lacked the confidence or did not see/or appreciate the value of volunteering for the present study.

The majority of CAM users were in a permanent relationship. Marital status has not been previously associated with CAM use (Shumay et al., 2002) but the present study showed that as a variable it is worth including in future studies. Previous research into CAM use has not used the association of parenting as a predictor for CAM use. Although, limited inferences can be drawn from the results of Phase 1 because of the small sample size, parenting might be worth considering as a variable in future studies because more than a third of the participants were parents.

Self-reported medical history. All participants had multiple pathologies. The participants reported an average of five co-morbidities per person; this is higher than previously reported in CAM surveys (De Visser & Grierson, 2002; Egede et al., 2002). By comparison Phase 1 showed significantly higher incidences of CAM use and hepatitis C than a study amongst people with HIV/AIDS (DeVisser & Grieson, 2002).

Self-reported medication. Polypharmacy was the norm amongst the participants. Overall, the findings of Phase 1 appeared to be consistent with those from other studies that showed concurrent use of CAM and biomedicine was common (Featherstone et al., 2003; Ong et al., 2002; Standish et al., 2002). The inference that concurrent use of biomedicine and CAM is common amongst people with TM needs to be tempered with the knowledge that all people with TM must have biomedicine to survive, and consequently all will be taking prescribed medicines. This study found that biomedical adherence amongst the participants was variable.

Health-behaviours. Phase 1 showed all of the participants reported they were non-smokers and most of the participants reported other health behaviours, such as eating well and exercising, these could be considered positive health behaviours. Similarly, Bair et al. (2002) found CAM users reported more positive health behaviours than non-users.

Estimated CAM Use and Disclosure

In Phase 1, twelve participants reported CAM use and only one person reported disclosing such use to biomedical physicians. All participants were considered CAM users because of the therapies and substances the participants reported using. The results of Phase 1 suggest variable CAM definitions provide an explanation for this phenomenon. Phase 1 showed and confirmed as Furler et al. (2003) found that estimated CAM was associated with which CAM definition was applied.

Phase 1 illustrated the participants' mostly differentiated CAM from biomedicine, on the basis of prescriber and whether the product had some resonance with their biomedical treatment. For example, colloidal chelation was considered biomedicine because the term 'chelation' was associated with the participants' biomedical iron-chelating regimen.

Participants described some *CAM*, such as hydrotherapy as biomedicine because a biomedical physician had recommended it. Whilst, it appears that the participants differentiated *CAM* from biomedicine on the basis of the prescriber or because they knew/thought biomedical practitioners prescribed such products, such as fortified food, this was not always the case. For example, most participants defined psychiatrists, social workers and psychologists as *CAM*, despite participants having been referred to these practitioners by their biomedical practitioner. The findings from Phase 1 suggest the participants don't differentiate products/substances into biomedicine and *CAM* unless challenged to do so. When challenged to differentiate *CAM* from biomedicine the findings suggest the participants, as most researchers, are just as unclear about what *CAM* means.

Accuracy of estimated CAM use and disclosure. Reported *CAM* use for this study has been underestimated if prescription medicines taken in a manner other than prescribed and/or treatments that were initiated by the participant are considered to be a *CAM* therapy or treatment, as many researchers suggested (Buchbinder et al., 2002; Ferry et al., 2002; Zochling et al. 2004). Recalculation of *CAM* use for the present study, using such a definition would significantly alter the results because all participants, 100%, would be classified as *CAM* users.

Using the same *CAM* definition noted earlier, recalculation to include participants who did not report altering prescribed medicine schedules creates another dimension to non-disclosure. None of the participants reported disclosing non-participatory behaviour in complying with prescribed medicines, yet one person disclosed their use of *CAM*. Even though there are many competing definitions, this type of health behaviour is considered non-adherence (Murphy & Canales, 2001; Playle & Keeley, 1998) and drug abuse (Poulin, 2001). Self-adjustment of doses of prescribed medicines was reported to be common practice by the participants in the present study. For example, some participants reported only taking the prescribed antibiotic when they had a cold, others didn't take the medicine at all and some increased the dose of their prescribed vitamins. Participants were asked if they had informed

their treating doctor that they had altered the dose or ceased taking medicine. All participants reported being non-adherent at times and not disclosing such practices to their treating physician. Hence, all participants of the study would be considered CAM users and non-disclosers of CAM, if biomedical non-adherence was accepted as CAM use. Thus, estimated disclosure of CAM in this context becomes a grey area because none of the participants reported disclosing non-compliance to their treating biomedical physician, yet one person disclosed CAM use. Hence, estimated CAM disclosure rates cannot accurately be estimated without further exploration of participant behaviour and tighter definitions of CAM. In addition, there appears to be no supporting evidence that CAM use is synonymous with biomedical non-adherence. Hence, in this context reported CAM use and CAM disclosure for Phase 1 would appear to be accurate.

When non-compliance was not considered CAM, but the taking of non-prescribed substances, such as vitamins and minerals was considered CAM, the estimated CAM use for this survey was significantly different from that reported. Six participants reported taking non-prescribed Vitamin E, yet only two of these participants reported using CAM. Hence, recalculation of CAM use would give an estimate of 16 participants (76.19%) using CAM, for Phase 1. This would increase the estimate of CAM use by 19.05%. By comparison when vitamins and minerals were included as CAM Furler et al. (2003) found the estimated use of CAM increased by 23%. Comparison of such recalculated CAM use for the present study and the study by Furler is difficult. In the Furler study, vitamins and minerals were not differentiated into prescribed and non-prescribed medicines, as they were for Phase 1.

The reported manner by which the participants of the study take prescribed medicine does not appear to fit the NCCAM (2002) definition of complementary or alternative medicine. All of the therapies/substances the participants used are considered CAM (Gruner, 2000; Sleath et al 2001; Standish et al., 2001). However, hydrotherapy and hot water bottle/heat pack application are not considered CAM when prescribed by a biomedical health practitioner (Buchbinder et al., 2002). Hence, as these therapies were reported as being

recommended by biomedical physicians they are not CAM (Buchbinder et al., 2002). To other researchers (Novak & Chapman, 2001; Strasen, 1999) these therapies would be considered CAM. Therefore, using such definitions in calculating CAM use, made very little sense. Most of the participants reported some type of dietary intervention and all used non-prescribed OTC substances. Hence, according to some CAM definitions (e. g. Day, 2002; Wolsko et al., 2000) all the people in this Phase 1 would be considered CAM users. The findings indicate the application of specific CAM definitions significantly alter estimated CAM use. Phase 1 has illustrated that most applied CAM definitions are of little practical use because they do not accurately distinguish between CAM users and non-users in a meaningful way.

Comparison of Estimated CAM Use and Disclosure with Other Research

Phase 1 indicated all participants used CAM and disclosure of such use to treating physicians was extremely low, with only one participant reporting disclosure. Estimated CAM use, 100%, in Phase 1 was noticeably higher in comparison to CAM studies of people with haematological illnesses (Gupta et al., 2002; Kappauf et al., 2000; Welch, 2001). Estimated disclosure, 4.76%, for this present survey is much lower than for studies conducted in developed countries amongst people taking prescribed medications, such as the United States (Kappauf et al., 2000; Welch, 2001) and Australia (MacLennan, Wilson & Taylor, 2002; Shenfield et al., 2002). Thus, estimated CAM use in the present research was higher than for people with particular symptoms, such as pain (Buck, Baldwin & Schwatz, 2005; Vallerand, 2003), for serious illnesses, such as HIV/AIDS (Furler et al., 2003), cardiac disease and bone marrow transplant (Huber, Klein, Ber, Lüdtkke & Werner, 2004), diabetes (Yeh et al., 2002) and osteoarthritis (Zochling et al., 200). In Phase 1 estimated CAM disclosure was significantly lower than for studies amongst the chronically ill (Chang, Servellen & Lombardi, 2003; Vallerand et al., 2003).

Comparing CAM use and disclosure estimates for this present survey with those of other CAM surveys was very difficult for numerous reasons. The sample size for the present study was very small in comparison to most other surveys. As there were no previous

estimates for CAM use amongst people with a lifetime serious illness, it was difficult to compare the survey results with other studies. Comparisons of CAM studies amongst the chronically ill were also very difficult because of the diverse range of illnesses. For example, distinctions were rarely made between a chronic, but relatively stable disease like asthma and a chronic but unstable disease that is progressively degenerative, such as TM. Also distinctions were rarely made between life-long illnesses that threaten life in the short and long-term, such as TM, and immediately life-threatening illness such as some cancers and HIV/AIDS.

This present survey is the first to estimate CAM use and CAM disclosure amongst people who for their entire lifetime must adhere biomedical regimens to survive. The present survey is also the first to address CAM use and disclosure amongst people with TM and one of the very few to specifically identify the haematological illness. The present research was not aligned with the biomedical care of the participants and was conducted in their homes, unlike the two aforementioned haematological surveys, which were conducted in hospital settings and took place in different geographic areas, namely India (Gupta et al., 2002) and the United States (Kappauf et al., 2000; Welch, 2001). Thus, comparison between this research and other research could only be made in general terms because the studies had different values.

Phase 1 showed the participants used mostly ingestible CAM products. All participants reported using vitamins and minerals and most reported using exercise and diet. Other studies have found that dietary supplements, vitamins and mineral and herbs were commonly used amongst people with a serious/chronic illness (Bica et al., 2003; Patterson et al., 2002; Rajendran, Thomson & Reich, 2001). Reported herb use in Phase 1 of this present study was significantly higher, 66.66%, than previously found for people with a chronic/serious illness in countries, such as America (Furler et al., 2003; Huber, 2004; Patterson et al., 2002; Powell et al., 2001; Schoenberg et al., 2004; Yeh et al. 2002) and for the Australian general population 3.2% (MacLennan et al., 2002). Conversely, herbal use in this research was 30% less than the 95% estimated for people with serious gastrointestinal and liver disease, in Taiwan (Yang et al. 2002). Thus, only illogical comparisons can be made when comparing CAM estimates for

countries where therapies, such as Chinese Medicine, are part of the health system (Yang et al. 2002) with CAM estimates for countries, such as Australia, where the dominant health system is biomedicine.

Phase 1 showed many participants used multiple CAM therapies/substances simultaneously. Whilst, in people with Parkinson disease used only one complementary therapy, the most common being massage and aromatherapy (Ferry et al., 2002), most studies show CAM users used more than CAM treatment but did not evaluate whether such regimens were simultaneously used. In Phase 1 there was an inverse relationship between tactile and ingestible CAM because all participants were found to use some form of ingestible CAM and seven participants reported using tactile therapies, such as exercise. All participants reported having used the services of a social worker, which to date has not been classified but could be considered complementary/integrative medicine (NCCAM, 2002) because such supportive services were used in the biomedical setting, as reported by the participants.

Implications of the Findings

Considering the amount and type of medications prescribed and used by the participants and estimated CAM use, 100%, raises the possibility of drug and CAM interactions. The types of OTC reportedly used by the participants suggest interactions between the prescribed medicine and non-prescribed substances were likely. For example, more food-drug reactions have been reported for warfarin than for any other prescribed medicine (Heck, Dewitt & Lukes, 2000). Thus, the findings illustrate for those participants taking fortified foods, OTC, vitamins and/or minerals there was an increased risk of taking Vitamin C to dangerous levels. Whilst the participants were prescribed Vitamin C, when taken incorrectly or in higher doses Vitamin C can increase the toxicity of iron (Cappellini et al., 2000). In addition, participants reported using herbal medicines. Herbal formulae might contain herbs such as dan shen (*Salvia miltiorrhiza*) and dang gui (*Angelica sinensis*), which can potentiate anticoagulant therapy and might alter bleeding times and should therefore not be used concomitantly with warfarin (Williamson, 2003), a biomedical drug prescribed for some of the participants.

Future Research

Phase 1 showed people with TM use multiple CAM products/substances concomitantly with their prescribed biomedicines. This finding shows there is a need for research evaluating prescribed medicines and CAM substances, including dietary products in people with TM.

Conclusions

The findings indicate all participants were concurrent CAM and biomedical users and disclosure of CAM was minimal. Phase 1 indicated CAM use amongst people with TM was difficult to estimate because biomedical physicians prescribed many substances and some products considered CAM. The results of this survey indicated participants considered some CAM products biomedical because of their association with either their biomedical treatment or biomedical physician. The findings suggest participants had little or no understanding of the term CAM. Phase 1 illustrated most CAM definitions did not provide accurate CAM estimates.

CHAPTER 5: PHASE 2 REASONS for CAM USE by PEOPLE with THALASSAEMIA MAJOR

In this chapter, I present the second part of the analysis and interpretation of data gathered in this thesis, addressing the central issue of reasons for CAM use.

As described in chapter 3, the absence of new reasons for CAM use in the participants' responses indicated theoretical saturation (Denzin & Lincoln, 2000) and contributed to the decision to cease data collection. The qualitative data were analysed using the constant comparative method, whereby a continual and systematic process was applied, incorporating data collection and concurrent analysis. While collecting data, each word and line was examined to label the participants' meaning. Mostly the actual words used by the participants were assigned to categories in developing the themes. This helped to maintain the participants' own, rather than the researcher's meanings for the use of CAM. Where it was not possible to use the participants' actual words, I assigned a label for the theme.

Descriptive themes evolved further as analysis progressed and were clustered into first and second-order themes, which then formed the third-order themes that emerged from the data. The third-order themes were then classified into general dimensions. The general dimensions conceptualise how the third and lower-order themes relate to each other. The third-order themes reveal the underlying patterns within the lower order themes. Appendix 6 illustrates the 382 raw data statements used for hierarchic development of the themes and shows how the themes evolved. Illustrated in Table 5.1 is the hierarchic development of the themes, for reasons for CAM use. Table 5.1 also presents the general dimensions and themes. There were 42 first-order themes that were classified into 17 second-order themes, which were further classified into five third-order themes. Finally, the third-order themes were grouped under four general dimensions. The four general dimensions were seeking treatment, negative view of biomedicine, self-determination, and attributes of CAM.

Table 5.1: *Hierarchical Development of Themes for Reasons for CAM Use*

First-Order Themes	Second-Order Themes	Third-Order Themes	General Dimensions	
Seeks treatment for co-morbidity associated with TM treatment	Seeks treatment for co-morbidity associated with TM	Seeks treatment for co-morbidity	Seeks treatment	
Seeks treatment for co-morbidity associated with main pathology of TM				
Seeks treatment for psychological symptoms	Seeks treatment for symptoms			
Seeks treatment for physical symptoms				
Seeks treatment to keep haemoglobin high	Seeks treatment for blood abnormalities	Seeks treatment for TM		
Seeks treatment to cure TM				
Seeks treatment without adverse effects	Seeks treatment without adverse effects	Seeks particular type of treatment		
Seeks treatment that works	Seeks effective treatment			
Seeks treatment for recurring illness				
Seeks to prevent co-morbidities	Seeks preventive treatment			
Seeks preventive treatment for sign/symptom of TM				
Seeks safer alternative to biomedicine	Seeks alternative to biomedicine			
Seeks natural treatment as an alternative to biomedicine				
Loss of confidence because preventive biomedicine failed	Loss of confidence in biomedical treatment			Loss of confidence in biomedicine

Table 5.1: *Hierarchical Development of Themes for Reasons for CAM Use*

First-Order Themes	Second-Order Themes	Third-Order Themes	General Dimensions
Loss of confidence because biomedicine failed to prevent illness from recurring	Loss of confidence in biomedical treatment	Loss of confidence in biomedicine	Negative view of biomedicine
Loss of confidence because biomedicine does not do what it is supposed to do			
Loss of confidence because biomedicine is a band-aide			
Loss of confidence because biomedical failed to cure			
Loss of confidence because of the limitations of biomedicine			
Loss of confidence in a particular treatment			
Loss of confidence in TM treatment	Loss of confidence treating physicians(s)	Loss of confidence in biomedicine	Negative view of biomedicine
Loss of confidence treating physicians(s) ability and/or knowledge			
Loss of confidence in treating physicians(s) advice	Loss of confidence because of adverse effects of biomedicine	Loss of confidence in biomedicine	Negative view of biomedicine
Loss of confidence because adverse effects cause co-morbidities			
Loss of confidence because prescribed medicines have unpleasant adverse effects			
Loss of confidence in biomedicine because adverse effects/events caused irreparable damage			
Loss of confidence in biomedicine because adverse effect/event caused by biomedicine required treatment			

Table 5.1: *Hierarchical Development of Themes for Reasons for CAM Use (continued)...*

First-Order Themes	Second-Order Themes	Third-Order Themes	General Dimensions
Avoiding biomedical treatment	Avoiding biomedicine	Loss of confidence in biomedicine	Negative view of biomedicine
Avoiding biomedical practitioners			
Rejection of biomedical treatment	Rejection of biomedical methods		
Rejection of biomedical guidance			
Doing what is best	Actively engaging	Taking control	Self-determination
Doing something			
Taking control to sustain wellness	Taking control to attain quality of life (QoL)		
Taking control to maintain and improve health			
Taking control to increase longevity			
CAM Beneficial	CAM harmless	CAM treatment attributes	CAM attributes
CAM safe			
CAM natural			
CAM practitioners are caring and empathetic	CAM practitioner desirable qualities	CAM practitioner attributes	
CAM practitioners have better skills			

To increase trust-worthiness of the analysis, the participants were constantly asked for their meanings of the terms they used. In addition, the raw data statements and the first-order themes that were developed from the raw data statements were shown to the participants to verify that the themes were an accurate description of what they had reported. As well, raw data statements, themes and general dimensions were independently peer reviewed by a colleague with substantial experience of inductive content analysis. The colleague and I discussed where there was lack of agreement and arrived at consensus about raw data classification. These processes were used to enhance rigour of the data analysis.

To reflect on the multiple realities that create the reasons for CAM use the analysis and interpretation of the data are reported in narrative style that draws on direct quotations from the participants' transcripts. Each general dimension is addressed in turn. The description of the general dimension includes identification of third-order themes, within which lower-order themes are discussed. Participant responses are identified with the letter 'P', signifying participant, and the code number assigned to each.

General Dimension 1: Seeking Treatment

The general dimension seeking treatment refers to the reasons the participants gave for using complementary and/or alternative medicine (CAM) to treat aspects of thalassaemia major (TM), co-morbidities of TM and/or any symptoms of illness. It is a wide-ranging category, reflecting the reasons the participants looked to CAM for care and management of illnesses and associated symptoms. Seeking treatment is about using CAM to combat, ameliorate and/or prevent disease and disorders. This general dimension is about the use of CAM treatment for comfort and relief from existing medical conditions and their symptoms, some of which were related to the disease process of TM and others possibly not. This general dimension is also about the use of CAM to overcome or prevent the damaging consequences of TM treatment, which often resulted in co-morbidities. This general dimension is also about using CAM because the participants wanted something that could provide relief from the signs and symptoms of TM and its pathological complications. Seeking treatment has three third-

order themes, seeks treatment for co-morbidity, seeks treatment for thalassaemia major, and seeks particular type of treatment.

Third-Order Theme: Seeks Treatment for Co-Morbidity

As discussed in the literature review people with TM have many health problems, such as osteoporosis and endocrine dysfunction (Aydinok et al., 2002; Salehi, Koski, Ondra, 2004; Voskaridou & Terpos, 2004). Thus, this theme is about using CAM to treat secondary illnesses. This theme is about using CAM to improve or cure acute and chronic illnesses, to find succour from acute and chronic symptoms, and to prevent illnesses. Most of the participants reported using CAM to treat and/or prevent serious and non-life threatening illnesses. Most of the illnesses for which the participants reported using CAM were associated with TM and/or treatment for TM, as shown by these responses:

I just did it [used CAM] to stop keep getting ...for cold and things. Urinary tract infections and I've used hypnosis to get over my fear of driving (P2).

I did have my spleen out...once it's [the spleen] out you're on penicillin for life...so I used it [CAM] to build my immunity [immune system] and for colds and other things (P7).

I used it [CAM] to reduce my AST [liver enzyme]. It [AST level] was getting up pretty high because of the hep [Hepatitis C] (P12).

This third-order theme had two second-order themes. The second-order themes are *seeks treatment for specific co-morbidity associated with TM* and *seeks treatment for symptoms*.

Second-Order Theme: Seeks Treatment for Co-Morbidities Associated with TM

The second-order theme, seeks treatment for co-morbidity associated with TM treatment, is about using CAM to ameliorate complications that arose because of treatment used for TM and the sequelae of TM. Many participants reported looking to CAM to provide relief from serious co-morbidities because the symptoms frightened them, as this comment shows:

I used to get really scared when my heart skipped beats or pounded really hard, and sometimes I used to faint. They [biomedical physicians] reckon I've got cardiomyopathy that's why I was getting those things [symptoms]. I just wanted them

[symptoms] to stop because I knew they were bad. That's basically why I went the first time to the naturopath (P11).

Most participants reported they used CAM to treat the cause of symptoms and not merely the manifesting symptoms because they considered this was the only way to have permanent relief, as this comment typifies:

I didn't just want the palpitations to go away I wanted I wanted my heart to get better and to stop the damage (P17).

All of the participants who had undergone a splenectomy reported using CAM to treat and/or prevent infections:

I just did it [used CAM] to stop keep getting infections and sick all time. As soon as the course of [biomedical] drugs stopped I would get sick again. That doesn't happen now (P20).

All participants who did not have a splenectomy also reported using CAM treatments to overcome infections, as these responses show:

I have used, yes I have...I think I've used Echinacea. I've used garlic and horseradish to help with my sinus problems (P12).

I use it [CAM] for the flu and chest colds things like that and I find I get over colds and the flu faster than when I take antibiotics (P16).

Most of the participants reported using CAM to treat the effects of endocrine deficiencies such as osteoporosis, and infertility. These illnesses can be described as secondary co-morbidities and as typified in the following statement many of the participants were using CAM to treat multiple co-morbidities:

Probiotics for the irritable bowel...I take capsules for my bones. I had acupuncture. Muscle pain and sinus and I have had herbs and I had that naturopath stuff when I was trying to get pregnant (P3).

Most of the participants expressed a deep awareness of their health and the implications it had on their life. Their self-awareness seemed to centre on understanding and fulfilling their personal emotional and physical needs, and vulnerabilities, which they reportedly used CAM to overcome. For instance, many of the participants reported they were motivated to use CAM because of concern for their family. Many participants reported they

used CAM because some illnesses were unbearably debilitating and/or shortened their life-expectancy. These reasons for CAM are shown in these statements:

It's upsetting after all we go through and then to get hep C through no fault of mine. I worry about my boys. I worry about leaving them without a mother. More than anything that's probably why I use other [treatments] things (P3).

I used to be OK you know before the hep C. It made me very sick... I kept getting worse, I lost my job, I couldn't study, and I'd sleep most of the day...I could not go on like that. It was bad enough having to do everything I had to do for the thal, without having to put up with this [hepatitis C] (P7).

The first-order themes of which there are two detail the health issues for which the participants sought CAM treatment. The first-order themes were *seeks treatment for specific co-morbidity associated with TM treatment* and *seeks treatment for co-morbidity associated with main pathology of TM*.

First-order theme: Seeks treatment for co-morbidity associated with thalassaemia major treatment. This first-order theme is about using CAM to deal with co-morbidities caused by the interminable treatment for TM. Many of the participants reported that they used CAM to improve or moderate the effects of iron overload because it caused other co-morbidities, as shown in these statements.

The iron, gotta get rid of that because its deadly, it causes most of our problems...my practitioner [CAM] doesn't exactly give me things to get rid of the iron but more to stop the damage and detoxifying...that helps bring the iron down...and the diet she told me to have. It all helps (P9).

I wanted help for the iron because it was because of that I got diabetes...to treat the diabetes because if that gets worse it causes other diseases (P12).

A few of the participants commented that CAM was used as a method to improve hepatic [liver] function, which had become impaired because of the hepatitis C virus, as shown by this statement:

I wanted something for the hep C because it damages the liver...it [CAM] improve[d] my liver function (P3).

First-order theme: Seeks treatment for co-morbidity associated with main pathology of thalassaemia major. The first-order theme is about the use of CAM to treat or manage the illnesses/complications that occurred because of the natural progress of TM. Many of the

participants reported using CAM to treat infertility and as indicated by the following response because they were concerned about their health and the prognosis of TM:

We want a baby and so we will try anything...yeah they [biomedical physicians] give me injections [HRT] but they don't seem to be working so we are seeing some one [CAM practitioner] else as well. Yes, our boy was naturally conceived but this time around it just isn't working because of the thal...but they [biomedical practitioners] never tell you that. We're desperate because things [health] aren't getting any better. It's now or never [to have a baby] (P2).

Most of the participants reported using CAM for osteopenia or osteoporosis because they were concerned at about its prognosis, as illustrated in these comments:

I mean my bone density is um osteopenosis [osteopenia], which is borderline. I've used it [CAM] to stop it from getting worse, to strengthen my bones so I don't get osteoporosis (P1).

Gosh I am not even thirty and I've osteoporosis. What am I going to be like when I'm forty...if I live to that age?...of course alternative medicines are the best for that sort of thing because the [biomedical] doctors can't do much...I mean I was on calcium and things and my bones were getting worse (P13).

Second-Order Theme: Seeks Treatment for Symptoms

This second-order theme is about the reasons the participants used CAM to treat symptoms associated with co-morbidities. This theme is about using CAM to treat objective and subjective symptoms. This theme is about using CAM to relieve verifiable signs such as, injection site wounds and subjective symptoms such as anger, depression and pain. Most of the participants reported that they used CAM to treat the emotional and physical symptoms associated with complying with treatment, as illustrated in this comment:

I couldn't function...it [the pain] upset me because I couldn't look after my baby. I couldn't get out of bed the pain was bad...I was sick that's why [used CAM] (P4).

The two first-order themes, *seeks treatment for psychological symptoms* and *seeks treatment for physical symptoms*, differentiate CAM use for physical symptoms from those of a psychological nature.

First-order theme: Treating psychological symptoms of co-morbidities. This theme is about the reasons the participants gave for seeking to treat psychological symptoms, with CAM. This theme is about using CAM for stress management and to overcome negative

feelings of self. Few participants reported that they were being biomedically treated for psychological disorders and at the same time used CAM to curb symptoms, as this comment shows:

I wanted something for depression because the [bio-] medicine [antidepressant] I'm on makes me lose weight and stops me eating. Well we [participant and spouse] are having counselling...but I wanted to try something [CAM], which would help me more (P2).

Some participants who were not receiving psychological support also reported using CAM to moderate psychological symptoms, as shown this response:

I used to scream at everyone when I got low, especially before a transfusion. I find the yoga and stuff I take [CAM] help me. I am not so panicky (P12).

Some of the participants' statements show CAM treatment was sought to improve the signs of co-morbidities which affected their sense of self, as shown by this comment:

I try and keep fit. I go to the gym but nothings help this thal body...big belly, no tits, no bum I feel so ugly...I have a boy's body. It's because of the damage to our glands...I'm hoping one day with the herbs I take I won't need to take the pill...be like other girls (P21).

Some participants reported they used CAM because their treatment made them feel dependent and vulnerable, as shown in this comment:

We have to have it [biomedical treatment] because we can't live without it. I suppose I use [CAM] it because I want to live like a normal person...don't want to be sick and have treatment all the time (P10).

Many of the participants believed they had limited life expectancy because of TM and co-morbidities such as hepatitis C. Expectation of premature death was worsened by the distress and un-wellness caused by biomedicine. As shown in these statements these reasons motivated CAM use:

I was scared that I was going to get liver cancer [from hep C] and die...I became a recluse, I couldn't work I was a mess...they [biomedical practitioners] kept saying was I was depressed and that I should see a psychologist. I was already on anti-depressants, which a psychiatrist prescribed...I was [on antidepressive medication] until I started seeing my Chinese practitioner. I wanted them [biomedical practitioners] to do something about the hep C, because they [biomedical practitioners] said if I didn't have the treatment [Interferon] I would get cancer, but when I had the treatment it made me sick...you can't win you know...they wouldn't do anything, all they would say is "see a psychologist" and that I was on the waiting list...I was desperate I needed help. I wasn't

mad. I might have been depressed but that's because they [biomedical personnel weren't listening...that's why I started using this alternative stuff (P18).

We are always in pain from the needles but if we don't do them we are dead, but we are dead anyway. I had to find other [CAM] things to help because I don't want to die young (P19).

All participants with hepatitis C reported using CAM to help them cope the illness.

Thus, CAM was used as a form of psychological support as shown in typified in these responses:

They [biomedical practitioners] scared me witless and caused my family to worry a lot. I had to do something to get help... something to help me cope (P3).

I was desperate I needed help. I wasn't mad. I might have been depressed but that's because they [biomedical physicians] weren't listening...my [CAM] practitioner listened and changed my life, probably saved my life in more than one-way. Because I was suicidal, I mean I couldn't go on like that (P18).

First-order theme: Seeks treatment for physical symptoms. This theme refers to treating physical symptoms that were associated with co-morbidities. Many participants aimed to alleviate some of the negative subjective experiences related to these co-morbidities. Some participants reported using CAM treatment that would assuage, control or relieve symptoms associated with bone disorders. Participants reported they used CAM to treat symptoms because biomedicine was not providing relief, as these statements show:

I found a herbalist...my back used to get really sore and I didn't want things to get worse which they were becoming even though I was doing everything [complying with biomedical treatment]...my bones weren't getting any better...they were becoming thinner (P9).

When my blood used to get really low I used to get this horrible tingling but painful sensation in the fingertips, it's really hard to explain how hideous it was...and I couldn't sleep...the back pain when the blood was low was horrible it used to drive me crazy and keep me awake at night. Basically I went to get that sorted because they [biomedical practitioners] couldn't help (P20).

All participants who reported having cardiomyopathy used CAM to treat the signs and symptoms of the illness. A few of the participants reported they wanted something to decrease cardiac hypertrophy (enlargement of the heart) by making it "normal". These reasons for CAM use are typified in the following comment:

To make my heart better...the heart muscles weren't working properly [cardiomyopathy]...I was getting palpitations. I've been on this stuff [herbs] now for about six months because I want my heart to go back to normal (P17).

Many participants reported seeking comfort and relief from CAM for symptoms caused by nightly injections used to chelate excess iron from the body, as illustrated by these statements:

Like I told you before the [injection] sites ulcerate, get infected...always have bumps and lumps, bruises that sort of thing. Alternative medicine helps that too (P6).

I use it [CAM] because I find it helps with the pain and bruising...from the needles (P19).

Cardiac hypoxia and pulmonary hypertension and other co-morbidities can cause respiratory difficulties in people with TM, even in those optimally transfused (Zakynthinos et al., 2001). All participants in this study reported that they were transfused every three to four weeks, which is optimal blood transfusion therapy (Cappellini et al., 2000). Many participants reported they used CAM to treat respiratory difficulties and fatigue. These reasons for using CAM are illustrated in these comments:

I was just sick of being tired and short of breathe even after a transfusion I still felt tired especially after eating I just wanted to go to sleep. It's probably because of my spleen which is too big or too much blood. Yes, I feel better. Don't know if it will save my spleen though (P6).

Sometimes it was hard to breathe...I just wanted to be able to go up and down stairs...just to be able to go for a walk without having to stop for a breath every five or ten minutes...I've been taking this stuff...my [CAM] practitioner says will help (P16).

Third-Order Theme: Seeks Treatment for TM

The third-order theme seeks treatment for TM, is about using CAM to improve, attenuate and/or ameliorate the signs and the symptoms of TM. Thus, this theme indicates CAM was used to treat the blood aspect of TM. This, theme also refers to CAM treatment used to alleviate the main pathology, TM. Thus this theme refers to using CAM to cure TM. Most of the participants reported using CAM to treat TM by treating the blood, as shown in these comments:

I take it [CAM] because it's good for the blood. I mean the stuff [CAM prescription] I get makes it [blood] stronger (P15).

I've used them [CAM]...to help my immunity...help improve the blood (P17).

This third-order theme had one second-order theme, *seeks treatment for blood abnormalities*

Second-Order Theme: Seeks Treatment for Blood Abnormalities

This theme is about using CAM to treat the underlying blood pathology causing the symptoms and so is about using CAM to treat the effects of abnormal blood cell levels. Most of the participants treated blood abnormalities with CAM because the effects of the signs and symptoms made them uncomfortable, as shown in these statements:

One of the first reasons I went [to CAM practitioner] was because my haemoglobins levels were falling too low and because of that I was always tired and had back pain (P3).

I just wanted to stop bruising all over the place. A small tap and I would bruise. I didn't feel sick or anything I just hated the sight of them and they hurt because they were really big (P9).

This theme refers to CAM use to treat the symptoms caused by anaemia, a major sign of TM. This theme is about using CAM to increase time intervals between blood transfusions. Thus this theme is about decreasing the need for biomedical treatment and about negating the need for TM treatment. Most participants reported using CAM to attenuate the debilitating symptoms of a low haemoglobin, as these responses show:

When my blood was low I found I couldn't do what I wanted...because I was always running out of breath. It was like my life was on hold until the next transfusion (P17).

I was just so tired all the time. I had palpitations, sore back and legs... I felt really yuk...I just wanted to feel the same from one transfusion to the next (P20).

Most of the participants reported using CAM to attenuate the effects of abnormal blood cell levels, decrease the amount of blood needed and to increase the time interval between transfusions, as these statements show:

I got sick of going in every week for trannies...I mean it was bad, they [biomedical nurses] were taking blood for a cross-match on the day I was having my blood...I mean it was like I was always there [hospital]...I wanted not to have to go every week and that's what happened...every two to three weeks now [with CAM treatment] (P5).

I wanted to stop my blood from clotting because it's dangerous. It means I could have a heart attack because the blood gets thick (P9).

I mean I was going in every two weeks for blood...I'm hoping that I only need blood once a month or at least need less blood [meaning less blood at each transfusion] (P15).

When my white cells went crazy from the [biomedical] drug I couldn't breath properly and he [CAM] practitioner treated me for that, while they [biomedical practitioners] just said, "we'll wait and see what happens" (P16).

This second-order theme had two first-order themes; *seeks treatment to keep haemoglobin high* and *seeks treatment to cure TM*.

First-order theme: Seeks treatment to keep haemoglobin high. This theme is about CAM use to improve the haemoglobin level and/or to prevent it from falling. Most of the participants reported using CAM to increase haemoglobin levels to feel better. Many of the participants used CAM to slow the haemolytic process, as a result conserving their haemoglobin, so less blood would be required at each transfusion. These reasons for using CAM are shown in these comments:

Basically I want my blood levels higher. Because you feel better, I can't describe it, but unless you have experienced it you can't possibly know what it is like. It is just awful it makes you feel terrible. You can't think you can't work its horrible (P15).

To have higher haemoglobin when I go in for my tranny [transfusion] so I wouldn't have to have so much blood...stop the blood from breaking down...detox that sort of thing (P19).

First-order theme: Seeks treatment to cure thalassaemia major. This theme is about using CAM as a means of finding a cure for TM. This refers to healing TM, which predominantly means using CAM to overcome the body's inability to synthesise haemoglobin. Most participants stated that they used CAM "to be well" or "better" to "improve haemoglobin levels" and to stop "the blood from falling" which meant in some contexts they wanted a cure for TM. Thus, whilst most participants did not overtly express seeking CAM treatment as a means of curing TM their comments suggested a cure was expected or hoped for, as typified by these statements:

I use Chinese medicine for the thalassaemia...for the blood to stay up and our problems...if the blood stays up, then you don't need to have blood [transfusions]. That's the main thing I suppose (P6).

I don't like being sick; you know I'd like to be well. I suppose it means...it would be great to never have any more treatment...That is probably impossible, but if my blood improves and I need less treatment [blood] and I don't get many infections, and things then I suppose that's the best we can have (P8).

I will do anything if it makes me well, not to be sick. I suppose we all get sick from time to time, but having blood and the injections is a pain. I'm really hoping the herbs will stop the blood from going down, because that will mean I will be well (P11).

Some of the participants' comments directly expressed that they used CAM to cure

TM, as shown in these comments:

We are going to give it [wheat grass] a go because he [CAM practitioner] says it works by making the body make blood (P5).

I suppose that means I want to better period, like forever, so I can be normal. Isn't that why you go to the doctor, so you can get better? It's the same thing whether you see a naturopath or herbalist or whatever (P18).

Third-Order Theme: Seeks Particular Type of Treatment

Seeks particular type of treatment reflects the use of CAM because such treatment was considered to have no adverse effects, was effective in healing and could prevent illness. This theme also refers to using CAM as an alternative method of treatment to biomedicine. Many participants reported they used CAM because they wanted treatment to be safe and effective. In seeking such treatment many participants reported they wanted an alternative to biomedicine. These reasons for using CAM are exemplified in the following statement:

I just wanted something to help me...it had to work and it had to be safe because the stuff I was getting [biomedicine] wasn't really safe and I didn't think it was working because I had to keep taking it...I just got sick of taking it [biomedicine] and found something different (P3).

The theme seeks particular type of treatment had four second-order themes; *seeks treatment without adverse effects*, *seeks effective treatment*, *seeks preventive treatment* and *seeks alternative treatment*.

Second-Order Theme: Seeks Treatment without Adverse Effects

This second-order theme is about seeking out CAM because the participants wanted treatment that did not have unfavourable outcomes. This theme is about using CAM because it could alleviate a health problem and would not cause unwanted, annoying and unpleasant

consequences. Thus, this theme is about using CAM because participants wanted benign treatment. Most of the participants reported they wanted to use CAM because they wanted treatment that healed or prevented illnesses without making them ill, as shown by these statements.

Look what's the point of having a drug or whatever that in the process of supposedly making you well makes you sick? That, I don't really feel is good medicine...if you can get something that doesn't make you sick then you should use it (P3).

I want treatment that has no side effects because sometimes how you feel after the drugs can be worse than what they were meant to fix. I once heard from a doctor that all medicines have side effects because that means they're working. I reckon that's a load of crock-shit because I haven't experienced that with my alternative medicines. They just make me better (P14).

I wanted something that helped when I got a cold...but didn't make me sick...I've used garlic and horseradish instead of antibiotics (P17).

There was only one first-order theme and it was the same as the second-order theme.

Thus, further exemplars are provided to illustrate the use of CAM because participants wanted treatment without adverse effects. Many participants suggested the search for effective treatment that had no side-effects was one of the primary reasons for seeking CAM in the first instance, as shown in these responses:

I just knew in my heart that I had to find something else rather than rely on medicines that made me sick (P16).

I couldn't cope with being sick from the medicines so I just said to myself "no more" and looked into things [CAM] that could do the job but not make me sick...if you don't then eventually you will need more drugs and that is not an option for me (P20).

Second-Order Theme: Seeks Effective Treatment

This theme is about using CAM to avoid the need for repeat treatment. Many of the participants used CAM because they believed illnesses should be treated once to avoid them becoming chronic, as this statement shows:

I use it [CAM] to fix the other things [not TM] that go wrong...they shouldn't be allowed to become another big problem, because that just means more drugs and things, and that's too horrible, because in the end it's all the problems that kill us (P16).

For this second-order theme there was two first-order themes, *seeks treatment that works* and *seeks treatment for recurring illness*.

First-order theme: Seeks treatment that works. This theme refers to using CAM to secure treatment that achieved the therapeutic benefit for which it was prescribed. Many participants' reported that treatment "that works", was treatment that met its therapeutic objectives and treatment that provided a lasting effect. These ideals of effective treatment motivated CAM use, as typified in these responses:

What I did was see a herbalist because the [biomedical] treatment I got didn't work. After a course of herbs it [helicobacter pylori] was gone and that was four years ago, and it's not come back. Do you understand what I am trying to say? It worked and that's important, it has to work or forget it (P3).

I wanted something that worked properly because what we go through is like a merry-go-round because you need this for that and that for that and then something else it just goes on and on. I want things [illnesses] to be fixed for good (P12).

First-order theme: Seeks treatment for recurring illness. This first-order theme is about using CAM to alleviate illnesses that persisted despite biomedical treatment. This theme was also about chronic illnesses that required ongoing biomedical treatment, which was not acceptable to some participants. Many of the participants' responses showed that CAM treatment was for recurring illness, such as infections that would not yield to biomedical treatment, as shown in these responses:

I needed to treat the infections that kept coming back. I had antibiotics after antibiotics and they didn't work...well they worked while I was on them and then they [infections] would come back when I stopped the antibiotics (P9).

I went to the practitioner [CAM] for...urinary tract infections, which used to come back all the time. That drove me nuts...I couldn't keep having drugs that only worked when I was on them... soon as I would stop taking the medicine [the antibiotics] the urinary tract infection would come back (P11).

Some participants' reported they used CAM because they wanted permanent solutions to illnesses, not manageability of symptoms:

As I said I was desperate about my migraines I was told I would have to take it [biomedical drug] forever. I didn't want that. I wanted something that got rid of them [migraines] for good (P3).

Second-Order Theme: Seeks Preventive Treatment

This theme is about using CAM as a form of prophylactic treatment to prevent co-morbidities and to prevent the signs and symptoms of illnesses. These responses highlight the illnesses, signs and symptoms, which CAM treatment was used to prevent:

I wanted something that would fight infections and something that would boost my immunity [immune] system (P1).

I am hoping that I can prevent other illnesses; I've already got diabetes and heart problems (P9).

In this theme there were two first-order themes, *seeks preventive treatment for co-morbidities* and *seeks preventive treatment for specific signs of TM*.

First-order theme: Seeks preventive treatment for co-morbidities. This theme is about using CAM to prevent illness. This theme refers to CAM use for the prevention of co-morbidities that might arise because of TM treatment or because of the natural course of TM. Many participants reported using CAM to prevent infections by using CAM to improve their immune status. Some of the participants reported they used diet therapy to decrease the amount of iron they would ingest, to decrease iron-overload. The following statements illustrate these reasons for CAM use:

I take Echinacea and things like that to stop getting cold and flu, and I don't eat too much meat...I avoid foods with too much iron (P1).

I have used it [CAM] so I don't get hay fever and things. Stuff like the flu, normal stuff that people get (P12).

First-order theme: Seeks preventive treatment for specific signs of thalassaemia major.

This theme is about using CAM to prevent the signs and symptoms of the main pathology, thalassaemia major. Many of the participants reported using CAM to prevent the haemoglobin from falling. Many of the participants reported using CAM to alleviate the symptoms and/or signs of anaemia, consequences of low haemoglobin. These reasons for using CAM are exemplified in these statements:

When we have blood it's to get your haemoglobin up but it's better to stop it from falling and that's why I have the herbs, to stop it [haemoglobin] from falling (P6).

I was sick of being tired and short of breath and cold basically that's why I started [using CAM] (P20).

Second-Order Theme: Seeks Alternative to Biomedical Treatment

This theme is about using CAM because it was not biomedically based. This theme is about seeking to treat illnesses with products participants considered not pharmaceutically derived. This theme is about the participants' perceptions that CAM was safe because it was natural. Some participants used the term "natural" to describe a treatment/product, which they considered not to be a biomedical medicine. Natural meant a substance without chemical additives, this meant a product that had not been made artificially or refined. These participants' statements highlight the distinctions they made between CAM and biomedical treatment:

Natural things, rather than man made medication (P3).

It's [CAM] natural. You are putting something natural into our body (P4).

There is [are] no chemicals added to them [CAM] like drugs [pharmaceuticals] (P10).

Western medicine or whatever you want to call it is dangerous because it is made in a laboratory with chemicals (P11).

This second order theme had two first-order themes, *seeks safer alternative to biomedical treatment* and *seeks natural treatment as an alternative to biomedicine*.

First-order theme: Seeks safer alternative to biomedicine. This theme is about using CAM in lieu of biomedicine because it was considered the safer option, as shown by these comments:

I wanted to try something else different. I wanted something that wasn't going to hurt me, like the stuff they wanted to give me for my migraines (P3).

I started using when I realised that the treatments we were getting weren't that safe. I just thought it was better to use medicines [CAM] that could make you better, made you stronger not weaker that sort of thing (P7).

First-order theme: Seeks natural treatment as an alternative to biomedicine. This theme refers to using CAM as an alternative to some biomedicines because it was natural.

Many of the participants reported they wanted to use CAM because CAM products/substances were “natural”, as the following responses show:

I wanted something more natural. You know what I mean not drugs and things, like we get from the hospital (P3).

I'd like to treat it [depression] without using the medicines because they're not natural (P6).

Summary of General Dimension 1

The general dimension of seeking treatment explored the reasons the participants gave for using CAM to alleviate, mollify, attenuate and combat all types of illnesses and symptoms. Seeking treatment shows CAM was used to treat co-existing disorders and the signs and symptoms of such illnesses. In this general dimension CAM was used to treat the cause of illnesses, which suggests CAM was used with curative intent.

This general dimension shows the participants used CAM treatment to treat the symptoms and signs of TM because they wanted relief, alleviation and or improvement in disease status. The participants used CAM to treat the signs and symptoms of TM, so they would feel better and because they wanted to decrease their dependency on biomedicine. By using CAM to treat TM, many of the participants' comments suggest CAM was used with curative intent.

This general dimension illustrates some of the decisive factors for seeking CAM treatment were to manage recurring illnesses and for the prevention of illnesses and symptoms of co-morbidities. The CAM treatments chosen by the participants had to be efficacious and safe, as far as they could determine. The findings in this general dimension show that CAM was used as an alternative to biomedicine and as complementary to biomedicine.

General Dimension 2: Negative View of Biomedicine

The general dimension negative view of biomedicine refers to the reasons, provided by the participants of this study, which reflected that CAM use was motivated by disenchantment with biomedicine. In negative view of biomedicine, there were two discrete characteristics that motivated CAM use, the biomedical treatment effect and the interaction between the biomedical physician and the participant. Thus, this general dimension is about CAM use

motivated by a loss of confidence in biomedicine, prompted by biomedical treatment that failed to meet its therapeutic goals, was limited, had unwanted effects that became problematic and poor patient/physician interaction.

This general dimension is also about CAM use motivated by a rejection of biomedicine. Rejection of biomedicine expressed the loss of confidence the participants felt toward biomedical treatment and/or biomedical practitioners. Thus, CAM was used to either avoid biomedical and/or biomedical physicians, and/or used in lieu of biomedicine. These negative views of biomedicine are represented by the two third-order themes, *loss of confidence in biomedicine* and *rejection of biomedicine*.

Third-Order Theme: Loss of Confidence in Biomedicine

This theme is about the use of CAM treatments because the participants considered biomedical drugs and/or therapeutic methods employed failed to provide succour and relief. Thus, this third-order theme is about CAM use because of a loss of confidence in biomedicine. This theme is about biomedical failure, disenchantment with biomedical practitioners and the adverse effects of biomedicine. These are the issues that triggered a loss of confidence in biomedicine, which motivated CAM use. Thus, this theme is about CAM use because of inefficacy of biomedicine, unfavourable patient/doctor relationships and unfavourable effects of biomedicine. This third-order theme exemplifies that a loss of confidence in biomedicine motivated CAM use because of two inextricably linked reasons. The first reason relates to the treatment experience and the second to the encounter with health professionals, predominantly the treating physician. According to the participants, when the credibility of a treatment/medicine was in question they lost confidence in biomedicine and biomedical physicians and turned to CAM treatments.

The participants suggested placement of their trust in a treatment was founded on the treating biomedical physicians' knowledge/advice and the manner by which information was delivered, as well as the treatment outcome. When participants considered there was a breach of trust, they lost confidence and used CAM treatments, as illustrated in these statements:

Western medicine thinks it can make everything well again, but there are lots of illnesses they don't even come close in fixing. You only have to look at us, they try and keep us alive but at the same time what they [biomedicine practitioners] do is our undoing (P9).

Using CAM saved me I really believe that...sometimes it [biomedicine] is completely useless..my bones were getting worse even when I was on the pill and calcium to stop them becoming worse. When I told my [biomedical] doctor he just said talk to the endocrinologist and when I did that he [endocrinologist] said "well what do you expect you've got that", so they don't even care. When it comes to our bones they [biomedical physicians] know nothing and care even less. Now I don't take the pill, so I don't get the bloating. For my bones I take calcium but not that crap they [biomedical physicians] prescribe. They give us the cheapest form of calcium...tough that you don't absorb it....I exercise and other things that my [CAM practitioner] says will help (P20).

I use other medicines [CAM] because I just don't think that [biomedicine] medicine has all the answers. Because [biomedicine] it can't make us better ...the drugs they give us to prevent us getting sick can't even stop us from getting sick and the worst of it is they [biomedical] physicians don't believe us and make out like they know what we should and should not be feeling (P21).

This third-order theme had three second-order themes; *loss of confidence in biomedical treatment*, *loss of confidence treating physicians* and *loss of confidence in biomedicine because of adverse effects*.

Second-Order Theme: Loss of Confidence in Biomedical Treatment

The second-order theme is about using CAM because prescribed biomedical therapy did not prevent, alleviate, relieve, attenuate or cure an illness and/or its accompanying signs and symptom. Thus, this theme is also about using CAM because biomedicine failed. This theme is about using CAM because biomedicine failed to prevent and successfully treat recurring illnesses. Thus, this theme refers to the use of CAM because biomedicine was ineffective, which means it did not meet its therapeutic goals. This theme is about using CAM because biomedicine was palliative treatment, rather than curative. This theme is about CAM use because biomedicine was limited and some biomedicines failed to restore health to the level participants claimed they enjoyed before some biomedical treatments. Thus, this theme relates to CAM use because of a loss of confidence in particular biomedicines and in treatment for TM. Most of the participants came to use CAM because biomedical failures consistently reminded them of their incurable health status and vulnerability. Many of the participants

claimed that when biomedicine failed, its sequelae left them in worse health than before treatment. This statement articulates these reasons for CAM use:

They couldn't treat it [irritable bowel syndrome] even though they tried and failed six times they [biomedical physicians] still wanted me to have more treatment even when the treatments they were using were making me even sicker. I can't tell you how many drugs I was on...and I still didn't get better...there is no cure for that but when they [biomedical physicians] couldn't cure irritable bowel I couldn't handle it so I went to her [CAM practitioner]. Cured? No [not of TM] but I haven't got irritable bowel anymore (P3).

This second-order theme had eight first-order themes; *loss of confidence because preventive biomedicine failed, loss of confidence because biomedicine failed to prevent illness from recurring, loss of confidence because biomedicine does not do what it is supposed to do, loss of confidence because biomedicine is a band-aid, loss of confidence because biomedicine failed to cure, loss of confidence because of the limitations of biomedicine, loss of confidence in a particular treatment and loss of confidence in TM treatment.*

First-order theme: Loss of confidence because preventive biomedicine failed. This theme is about using CAM because prescribed prophylactic medicines failed to prevent infections. This theme refers to the use of CAM because biomedical treatment that failed to prevent illnesses was considered not to be worth taking. Most of the participants who had been prescribed biomedical treatment as a preventive measure against infections reported using CAM because the medicine was ineffective, as typified in this statement:

Antibiotics don't work...I still got sick. They give them to you to stop infections but they [antibiotics] don't do that. Well they didn't work for me they only made me sick...I stopped them...now use other things [herbs] to help my immune system (P10).

Many of the participants reported using CAM because prescribed preventive biomedicine that failed was considered "dangerous" and useless, as these statements show:

Anyway it's dangerous taking antibiotics all the time. I stopped them because I couldn't see the point in taking something that wasn't working. I mean it never stopped the flu or a cold or anything from happening (P8).

Supposed to take penicillin but there is no point in taking it, it doesn't work, I don't take it (P15).

First-order theme: Loss of confidence because biomedicine failed to prevent illness from recurring. This theme is about using CAM because biomedical treatment prescribed to alleviate an illness failed to prevent further recurrence of the illness. Many of the participants reported they used CAM because biomedical failures and biomedical treatment in general were a never-ending cycle of illness and treatment, as shown in this statement:

Treatment [biomedicine] didn't work for me, because if it did then I wouldn't have needed more treatment. I was tired of treatments that didn't work. I had to have something that stopped treatment after treatment after treatment...I had to have antibiotics to stop infections but that obviously doing its job because I still got sick. I had a course of antibiotics for my sinus problem, it cleared for a while then it came back again and again, and I had to have more antibiotics. I didn't want to put up with that shit anymore that's why [used CAM] (P15).

Most of the participants reported that they used CAM because biomedicine repeatedly failed to relieve 'simple' illnesses. As reported by some participants they became even more disenchanted with biomedicine, when simple illnesses were successfully treated by CAM, as this example comment shows:

The medicines don't always work because it [UTI] kept coming back again and again...how many times can you have medicines for something as simple as a urinary tract infection or thrush? How come he [CAM practitioner] got rid of it [UTI] and they [biomedical practitioners] couldn't? (P13).

First-order theme: Loss of confidence because biomedicine does not do what it is supposed to do. This theme was about the use of CAM when biomedicine failed to provide some improvement in the disease or symptom for which the treatment had been prescribed. This theme is about using CAM because unsuccessful biomedical healing methods lead to further treatment interventions. Some of the participants reported they used CAM because biomedical failures meant they had to have more biomedical drugs. Some of the participants reported they felt aggrieved by biomedical practitioners who shifted blame for pharmaceutical failures onto the participants and this triggered CAM use. These reasons for CAM use are exemplified in this statement:

When drugs don't work it's a poor excuse to blame that, [TM] and not the drug...they [biomedical physicians] say, "we can't understand why this is happening"...it's a way of saying "it's your fault"...what is worse is that most of the drugs that are meant to make you better actually make you sick, so you need another drug to fix that problem

up. That's sinful, isn't it? I don't think we should put up with that, that's why I use it [CAM] (P17).

Many participants reported they used CAM because continued biomedical failure caused them to become upset. Many of the participants reported they used CAM when biomedicine failed because if they did not seek other help they considered they were acquiescing to inadequate biomedical treatment. These reasons for using CAM are illustrated in the following statements:

They couldn't treat it [IBS] and I got really frustrated and upset...I let them [biomedical practitioners] do what they thought was best, but they tried and failed six times. I used herbs and things and they worked (P3).

What are you supposed to do when, when things they [biomedical practitioners] do don't work properly? You have to look elsewhere, because if you don't the only option is to keep taking drugs that don't help you, in the hope they will eventually. I don't think that is good; I'd rather do something rather than putting up with things that don't work, because that's just like saying it's OK to give me things that don't work (P12).

First-order theme: Loss of confidence because biomedicine is a band-aide. This theme is about using CAM because biomedical treatment was palliative. Many of the participants reported they used CAM because they recognised that biomedical treatment for TM and other illnesses was not curative but "band-aide" treatment, as typified in these statements:

I still need blood and stuff for my bones because it only [biomedicine] works for a little time. Yes I know the herbs don't cure that but I feel better and I know when I go there [CAM practitioner] for other things I will be fixed up and I don't have to suffer and get pissed off (P12).

A lot of the drugs don't cure you they just patch things up, it's like band-aides, it just covers things up. Like our blood transfusions. Like the stuff they give us because our hormones are low. I mean if they weren't only cover up drugs and they really worked I wouldn't need the hormones anymore, would I? (P13).

Some participants reported using CAM when biomedical treatments prescribed on a long-term basis were considered to be masking symptoms. Prescribing biomedicines to mask symptoms lead to a loss of confidence and CAM use, as this statement shows:

I couldn't see why I should take something that was only going to cover things up. Yeah, it [pharmaceutical] was getting rid of the pain, but how stupid is that, if you think about it logically? I mean, what about where the pain was coming from? Nothing was being done about that and that just made me think this is not on, I can't keep going like this. I thought about it and thought it and in the end I just thought this is silly and

gave up on them [pain killers] because I was just so angry that they [pharmaceuticals] weren't being given to me to really fix the problem (P11).

First-order theme: Loss of confidence because biomedicine failed to cure. This theme is about using CAM for illnesses for which there was no known biomedical cure. This theme is about using CAM because of the discontent participants felt with the absence of a cure for iatrogenic illnesses. Many participants with serious illnesses for which there was no known biomedical cure turned to CAM. All of the participants who had acquired illnesses from TM treatment expressed discontent with biomedicine and turned to CAM. Most participants with hepatitis C projected their anger toward the failure of biomedicine to cure this illness by commenting that biomedicine in general was useless because it could not cure “anything” and “anything” included TM. These reasons for using CAM are shown in these comments:

I got the hepatitis C from the blood like I told you and it's not curable, they [biomedical practitioners] can't do anything except monitor and wait for the liver cancer or something like that to happen, and then they can't cure that anyway. So what are you meant to do, sit around and wait and be sick, because it makes you quite unwell? I won't do that I have to try and find something that will help me (P3).

They [biomedicine] can't cure anything, not thalassaemia not hepatitis that's how good they are. I know the herbs won't cure me of thalassaemia or hepatitis C but they sure make me feel better....maybe I won't get liver cancer if I keep going [using herbal medicine] (P18).

First-order theme: Loss of confidence because of the limitations of biomedicine. In this theme the reasons for CAM use revolve around inadequacies of biomedical treatment, as experienced and understood by the participants. This theme is about CAM use because biomedicine was considered pointless when it was no longer capable of producing therapeutic benefits. Some participants reported that it was better to use CAM than to rely on biomedicine when it could do no more, as shown by this statement:

The reality is if a disease is terminal they [biomedical practitioners] can't do anything about it so why bother with it? Well you can't push it is what I mean, there's no point, because they [biomedical practitioners] haven't got any more drugs and things to throw at you...if you've got the energy...it's best to look outside the hospital...because the only thing they can do...is make you comfortable until you die. That's basically what happens to us (P12).

When biomedicine reached its therapeutic limit, many of the participants used CAM because they became disillusioned, angry and distrustful, as this response shows:

I was told that there was nothing else that could be done about my heart condition I was so angry and f...d off, because I couldn't believe that's all they could do, I mean you tend to think they can everything, because they [biomedical practitioners] make you believe that. That was one big lesson for me. That's when I started seeing my [CAM] practitioner because I didn't want to die...I still get upset when I think about how useless both the drugs and doctors are when you really need them (P17).

Some participants reported using CAM to provide comfort and relief because biomedicine could do no more and because whilst biomedical physicians acknowledged there was nothing else they could do, they persisted with giving advice, as typified in this statement:

They told me I wasn't gonna make it. I had to do something... treating physicians] told me to say good-bye to my family and they were still forbidding me to eat what I wanted and I wanted something cool and juicy. I was gonna die and they were they telling me what to do, I can't make sense of that can you?...I just had to do something for the fluid where your skin is just about to rip because of the fluid retention (P5).

First-order theme: Loss of confidence in a particular treatment. This theme is about using CAM because the participants' considered specific biomedicines were no longer therapeutically beneficial. The participants considered such biomedicines "worthless". According to some participants, continuing with biomedical treatment they considered worthless was a futile exercise because it meant further disappointment, as shown in this example:

I was always having something [biomedical medication] for something and nothing was really working...I had a gastric ulcer and then that seemed better, but then I got irritable bowel and I had to have antibiotics for that which weren't working and then the gastric ulcer came back and it was like I was going around in circles, you know drugs and more drugs. In the end I just gave up because it [biomedical treatment] was worthless, it made me really angry...how can they [drugs] not work? They [biomedical practitioners] said the irritable bowel would go away when I relaxed more because they said it [irritable bowel] was caused by stress. More like it the drugs weren't working. So I just gave up [biomedical practitioners'] smart arse comments and excuses for things [drugs] not working and got some real help. You know there is only so much you will put up with. Like we don't put up with enough as it is, we have to put up with excuses...I wasn't going to just take those things [drugs] anymore because I couldn't see the sense in it (P1).

Most of the participants developed a loss of confidence in particular treatments and turned to CAM when they developed co-morbidities despite their reported strict adherence to a biomedical regimen, as shown in this statement:

I used to take penicillin all the time, even when it made me feel sick. But then I got a really bad infection and I had to have more antibiotics, and I thought why take it [penicillin] it isn't doing anything. It just made me sick. I stopped taking it and then I went to see the naturopath (P17).

First-order theme: Loss of confidence in TM treatment. This theme is about the use of CAM because there was a loss of trust in the ability of biomedicine to treat TM. Although CAM use was motivated by a loss of confidence in TM treatment, biomedicine was never completely abandoned because as shown by the participants' comments they recognised that biomedicine was keeping them alive. Some of the participants suggested that such treatment was not enough because the biomedical process contributed to their demise. Some of the participants suggested biomedicine was not a panacea to ease suffering, rather a cause of it. The following examples illustrate these reasons for CAM use:

I mean if you think about it [biomedical treatment]...it's not really good...it's a life of suffering. You have all these things done to you...it never comes to an end, that is until you die. Well the herbs and things make it [biomedicine] bearable because I need less [biomedical] drugs and things (P1).

It [biomedical treatment] can damage you for good, well it does damage us...but that is a hard thing to admit, because it does keep us alive until it kills us, does that make sense? So you have to find things [CAM] that can help you because you lose your faith especially when things aren't looking good and no [biomedical] treatment is going to be any good (P14).

Second-Order Theme: Loss of Confidence in Treating Physicians

This second-order theme is about turning to CAM because medical encounters were considered unhelpful, demoralising or a "waste of time". This theme is about CAM use because medical encounters reportedly were fraught with experiences that left "a bad taste in your mouth". Thus, this theme is also about CAM use triggered by a loss of confidence in biomedical physicians' ability to deliver information in a manner conducive to harmonious relationship. Such encounters lead to a loss of confidence in the person responsible for

delivery of biomedical treatment. The following comments reflect these reasons for using

CAM:

When my [biomedical physician] treated me like a bimbo it left a bad taste in my mouth. He treated me like I was dumb...because he never explained anything he just said I had to take this [biomedicine]. I never said anything then, but I can tell you inside I was fuming...I just ignore them and do what I want to. Like I don't take everything I'm told to, I only take things that I think are right. That means taking herbs and vitamins or whatever I need at the time. They [biomedical practitioners] don't scare me anymore, even though they try. Well, they say things like if you don't do this or that you will get this or that, but I don't care what they say (P8).

I have given up on totally trusting them [biomedical practitioners]...they make mistakes, but they never admit them, which is really bad man. After they stuffed me about, I couldn't even face them [biomedical practitioners]... and a few other things that happened, I thought no never again...found myself someone [CAM practitioner] who could look after things...I can tell you now no one treats you with as much disrespect as a [biomedical] doctor or nurse does when they get things wrong (P14).

Some participants reported turning to CAM when they considered biomedical physicians lacked compassion or were perceived to be threatening, as shown in these statements:

I'm very annoyed that I wasn't told I had hep C until they wanted to recruit me for a trial. It was bad enough to be told about the hep C but then they [biomedical practitioners] threatened me. Because when they told me I had hep C...they said I would get liver cancer if I didn't go on the trial...that was the only hope. That is a threat. It's a threat because they [biomedical practitioners] are saying if you don't have this treatment you are going to die, but the treatment isn't real because it didn't work (P3).

They [practitioners] don't know how hard it is for us with hep C. Are they stupid or do they just act stupid?...I'd like to see them have thal and hepatitis C and see how they feel. You know they don't care because they keep expecting us to keep working, they did nothing to help us get some compensation for this death sentence, like the haemophiliacs got...they just don't care...they don't help you get [Government] benefits nothing. They do the opposite...I'm pissed off with them (P17).

Some participants considered practitioners belittled them and showed a lack of respect when they did not answer questions in a direct fashion. As shown in this response, CAM use ensued when participants felt insulted by the manner in which the treating physician communicated with them:

They [biomedical practitioners] do my head in, because they think they [biomedical practitioners] are really clever when they avoid answering questions...that infuriates me...nothing makes me madder (P8).

There were two first-order themes for loss of confidence in treating physicians that explain the reasons for CAM use generated by a sense of disillusionment with biomedical practitioners; *loss of confidence in physicians' knowledge and/or ability* and *loss of confidence in physicians' advice*.

First-order theme: Loss of confidence in treating physicians' knowledge and/or ability.

This theme is about CAM use when the participants considered the information given by the biomedical physician could not be substantiated. This theme is about CAM use because of a loss of confidence in confidence physicians' knowledge and/or ability to deal with the participants' health concerns. Some of the participants reported they used CAM because they considered the biomedical physician lacked knowledge and/or did not have the ability to communicate information appropriately, as shown in the following comments:

I asked him [treating physician] about the type of foods and about the sorts of things that would generally help me. He just laughed and said I was doing really well. I mean I was always tired so how well is that? When he laughed I felt like an idiot, like I was wasting his time or something (P1).

He [treating physician] didn't know anything about the stuff I wanted to take instead of the warfarin. What he said was "we can't control the dose and I don't know what it is". I mean how can you not control the dose if you don't know what it is? It didn't make sense. I just went off and saw a naturopath because he [biomedical practitioner] totally lost me (P3).

Many of the participants reported they turned to CAM when they distrusted the physician's knowledge to accurately diagnose and treat:

I kept telling them [biomedical physicians] I was unwell and they wouldn't believe me so I had to get help...I was feeling unwell for quite a while and they gave me some antibiotics because they said I had the flu. I didn't have the flu, I had a kidney infection and ended up in hospital, and when I complained about the back pain they [biomedical physicians] told me it was muscle strain, I kept saying it wasn't muscle strain... I gave up, got out of hospital and went and saw my [CAM] practitioner (P9).

Many of the participants commented on how often they felt they were disbelieved, judged or labelled as dysfunctional in some way because the biomedical physician's relay of information did not match the participant's sense of reality. Some participants suggested biomedical physicians considered them to be mentally incapable of making rational decisions. Such sentiments lead to CAM use, as shown in these comments:

They [biomedical practitioner] couldn't understand why I kept getting sick. I felt like they [biomedical practitioner] didn't believe me because they thought I wasn't taking them [prescribed medicine]. I was taking them and they [biomedicines] weren't working...and they were trying to make me feel like I was making things up (P13).

They [biomedical practitioners] kept telling me I was depressed and that I should see a psychologist. Well, I didn't need a psychologist, what I needed was to be checked out properly, because I was already on anti-depressives. I needed him [biomedical physician] to tell me the truth that the drugs were causing the depression. After years of taking that crap I'm finally free of them because of him [CAM practitioner] (P18).

Some participants reported using CAM because they felt abandoned by biomedical physicians, as illustrated in these responses:

They [biomedical physicians] give you no support they just expect you to get on with it. How can you get on with it when you've been told you've got a disease that is going to kill you and they [biomedical physicians] won't help you (P3).

[Biomedical doctor said] "Well, um pay your last respects to your parents and to your family, because I don't think you're gonna make it tonight," and ah that sort of pushed me and I thought no way this is not happening. Yeah...I was angry at the time. I felt like they were just giving up on me, like a piece of crap that you throw away...yeah, so I had to do something (P5).

Some participants reported a loss of trust occurred when the biomedical physician's advice was at odds with the treatment outcome, as this response illustrates:

When they [biomedical physicians] tell you things that aren't true you can't trust them [biomedical physicians] anymore....they [biomedical physicians]told me if I didn't have hep C treatment... that I would die, that it was my only chance and I believed them, so I did it. But it didn't work. I got even sicker than before, then they wouldn't help me, it was like they washed their hands of me...after that I don't trust them [biomedical physicians] (P19).

First-order theme: Loss of confidence in treating physicians' advice. This theme is about the use of CAM because of misgivings about biomedical practitioners' counsel, which was often considered to consist of mixed messages. Some of the participants' reported their belief in biomedicine was negated when biomedical physicians recommended a drug that was known to be harmful. Some participants suggested that such difficult situations were a tactic used by biomedical physicians to exonerate themselves if a drug/treatment caused harm. Some participants considered that they had been put in a de-facto relationship of responsibility because ultimately it was they who had to decide whether or not to take the drug. Some participants reported such situations were untenable because, if they didn't take the treating

biomedical physician's advice, they would be labelled as "difficult" and, if they did take the drug and something went awry, then they would have to bear the responsibility and consequences. These reasons for CAM use are typified in these comments:

The medicine he [biomedical physician] suggested [for migraines] wasn't going to stop them coming back. It was only to cover up the pain, and what is worse, like I said before; I would have to be on them for the rest of my life. Apart from that, it was a really dangerous medicine. I just doubted them [biomedical practitioners] after that. I mean how could they [biomedical practitioners] offer me something like that? I mean I've got children to think of (P3).

I'd like to see them do half the things we have to do, and put up with all the crap we go through...[biomedical physicians] got no idea how bad you feel and when they don't understand or try to make out like it's nothing then you get really annoyed and stop talking to them, I think 'why bother you don't understand'...when they tell you take something [a drug] and when it makes you sick, they just say well we'll try something else", but when they were going to get you on the medicine in the first place, they make you feel like you have to take it, because if you don't then they think you are being difficult, and a bad patient. I got so annoyed with their [biomedical physicians'] attitudes I thought I should see someone who could at least provide real advice that was going to help me live my life, not shit that was just putting me down, and giving me shit that was making me sick (P20).

Some participants reported they formed negative views when biomedical physicians attempted to make light of a problem that the participants considered was of grave concern.

Some participants suggested such situations made them feel indignant, and typically CAM use ensued, as this statement shows:

I can't believe [biomedical physician] sometimes. If it weren't serious it would be funny. Does he think we don't have any feelings or something? My hair was falling out, and I told him [treating physician]. He leaned back in his chair and said "you've got enough hair on your head, I wouldn't worry about it". I was worried that my hair was falling out in clumps and he made me feel like I was stupid. Why didn't he tell me the Desferal was was part of the reason I was losing my hair. She [CAM practitioner] told me what was happening when I asked for something for my hair. It's not right that she should tell me and he [biomedical practitioner] wouldn't. How can you respect them [biomedical physicians] when they treat you that? I can't, I just don't trust them [biomedical physicians] because they're like car sales men only worse because they get you when you're weak (P8).

Many participants felt aggrieved by their perceptions of the sense of injustice and unfeeling manner by which biomedical physicians dealt with unsuccessful treatment outcomes. As illustrated in the following comment, CAM use was triggered by an unproductive encounter with a biomedical physician:

After I became very ill from a treatment I started using alternative medicine because of what happened...the gastroenterologist greeted me with these words “what have you been doing to yourself”, ...I became furious and said it’s not what I’ve been doing it’s what your treatment’s been doing. “You can stop [the treatment] for now and go back on it in three months” he said. Like he hadn’t heard a thing I said. F...k you I thought, you’re f...king with my life and then blaming me. I wasn’t having any of that, I told him exactly what I thought, and told him never to come near me again. I then told my haematologist and he just looked at me like I was lying, and said, “I don’t know”. What was that supposed to mean? I mean they knew the drug gave me made me very sick. Anyway, that made me even angrier, because he wasn’t going to support me, he was going to back his mate, and I was suffering real bad (P15).

Second-Order Theme: Loss of Confidence Because of the Adverse Effects of

Biomedical Treatment

In this theme the reasons for CAM use stem from the undesirable consequences of biomedical treatment, which resulted in a loss of confidence in both biomedical treatment and biomedical physicians. Undesirable consequences of treatment refer to any treatment capable of producing a therapeutic effect and producing unwanted or adverse effects (Edwards & Ralph, 2000). An adverse effect is an unplanned or detrimental reaction to a drug administered at normal dosage, or to a diagnostic test, or to a therapeutic intervention (Anderson, Anderson & Glaze, 1998). Hence, this second-order theme is broad in its categorisation of adverse effects and takes in all manner of undue and undesirable outcomes of biomedically-prescribed therapeutic regimens, which the participants reported as having a major influence on their decision to use CAM.

This theme is also about the use of CAM treatments because the adverse effects that resulted from biomedical treatment lead to unease. This theme is also about CAM use brought about by the unpleasant effect some prescribed medicines had, which the participants suggested affected their quality of life and health. This theme is about CAM use because some adverse affects could not be treated with biomedicine. This third-order theme is also about CAM use provoked by the damaging effects of some biomedical procedures/treatments, for which further biomedical treatment was implemented to attenuate or ameliorate the problem. Thus, this second-order theme is also about the use of CAM because biomedicine was considered harmful and because biomedical physicians reportedly refused to acknowledge

adverse effects. As typified in the following statement many participants reported turning to CAM because of the frustration and anger they felt toward biomedical adverse effects:

I get pretty angry when I think about the hep C because it came from the blood...it is a real piss off when you get something like hep C from the blood that is supposed to keep you alive and yet it is going to kill you. It's a joke really. It gets worse, because it [hepatitis C] can't be treated, well not properly...not at all...[CAM] helps me overcome some of the tiredness and things like that and that's more than they can do [biomedical physicians] but I am so angry that I got hepatitis C...I now know that our [biomedical] treatment is shit. It makes me feel like giving up, which I would have if it wasn't for my [CAM] practitioner...I cry a lot (P17).

There were four first-order themes; *loss of confidence in biomedicine because adverse effects caused co-morbidities, loss of confidence because biomedically prescribed medicines had unpleasant adverse effects, loss of because biomedical adverse effects/events caused irreparable damage and loss of confidence because the adverse effect/event caused by biomedicine required treatment.*

First-Order theme: Loss of confidence because adverse effects caused co-morbidities.

This first-order theme refers using CAM when biomedical treatments used to attenuate or cure co-morbidities resulted in more illness. Such adverse effects of biomedicine caused a loss of confidence in biomedicine. This theme is about using CAM because biomedical treatment caused life-threatening adverse effects. This theme is about using CAM because foreknowledge and personal experience that biomedical treatment had undesirable outcomes. Such sentiments caused disaffection for biomedicine. Many participants reported they used CAM because they could not reconcile that biomedical treatment had unhealthy outcomes. Many of the participants reported using CAM to overcome adverse effects because they felt a sense of nervousness and unease about the prognosis of iatrogenic illnesses. These reasons for using CAM are illustrated in these comments:

Like I said I got cardiomegaly from the iron overload when I was young. It's annoying when the treatment you have makes you sick and can kill you. I don't want to go down that road again so I do what I can to help myself. Like I said I take extra folic acid and vitamin E and other things because you just don't know what else it's [iron overload] going to cause, I mean this [cardiac arrest] has shortened my life for sure (P4).

How bad is that? You get what I mean you can't live without it [biomedical treatment] and you don't get to live because of it. Because we get infections, bad bones and eyes

from the injections...you have to find things [CAM] to help your health, so that you don't become really sick from the [infections] because it's the treatment that is making us sick too (P 3).

My hearing's not the best because of Des [Desferal]...there is nothing they [biomedical practitioners] can do except take you off the Des or reduce the dose. That means my iron levels would go up which could do more damage. So I was trying to overcome the bad things we get from Des [iron chelator]. It just seems like we are tiptoeing on glass all the time. I mean what sort of medicine is it that makes you sick?...if my [CAM] practitioner caused half as many of the bad things that happen to us, he would go to gaol, but they [biomedical practitioners] get away with it. If I didn't need the blood transfusions I would never go to a doctor again (P13).

Some participants reported using CAM when adverse effects from blood transfusions occurred. A few of the participants reported being very upset when blood transfusions had adverse effects because such treatment was essential to their survival. Many participants reported they felt vulnerable during a blood transfusion because the adverse effects of such treatment could be lethal. Hence, when blood transfusions had adverse effects most participants reported they felt "betrayed". This led to CAM use, as shown by this statement:

We go in [hospital] to get better and we get sick. You get pretty annoyed really, because it's frustrating, it's like you're standing in front of a truck waiting to be gunned down. Your trust goes because you feel like you've been betrayed....I go in [biomedical hospital] to be saved and then when I have a blood reaction I wonder about what it really means, you know, did I get a serious infection, was the blood not cross matched properly, did I get some else's blood? All those sorts of things (P8).

Most participants considered adverse effects were inexcusable given their delicate state of health and reliance on biomedicine. Most participants reported feeling aggrieved by biomedical treatment used to ameliorate an adverse effect because they felt that they had to suffer the consequences for something that should not have arisen in the first place. Many participants felt 'let down' by biomedicine when subsequent treatment to ameliorate adverse effects caused further adverse effects. These reasons for using CAM are illustrated in this statement:

When the antibiotics caused the irritable bowel I went along with their [biomedical practitioners] decision to use more antibiotics but I wasn't getting any better. Instead I was getting other things like, thrush and upset tummy, which meant I needed more drugs. In the end, I just gave up on all of it and saw a [CAM] practitioner because I was getting really f...d off by it because I felt used and abused. If you can understand what I mean, here I trusted them [biomedical practitioners] to do the right thing and

they were letting me down by giving me things that didn't work for things their drugs caused (P10).

First-order theme: Loss of confidence because biomedically prescribed medicines had unpleasant adverse effect. This first-order theme is about CAM use because adverse effects interfered with the participants' physical and psychological wellbeing. Some participants reported contaminated biomedicines caused adverse effects. Such events triggered a loss of confidence in biomedicine because not only did participants have to suffer the consequences of the adverse effect, participants also commented they often were blamed for the adverse effect that made them ill. These reasons for using CAM are typified in this comment:

You just get sick of the things that happen with the treatment, especially when they try to blame you...when I used to get infections from the needles they would try and blame my technique and they did that to everyone who got ulcerations and infections...but they knew that the Desferal was dirty and that made me so mad to know that they [biomedical health-care workers] are so dishonest, so of course I looked elsewhere where I could communicate openly without feeling like I was some sort of freak that didn't know what was going on (P1).

Most participants acknowledged that biomedicine was a necessary intrusion on their lives, but when the intrusion was perceived to be unwarranted they lost confidence in biomedicine. This led to CAM use, as this response typifies:

The heart medications I'm on caused migraines...they [biomedical practitioners] tried to treat them...wanted to give me something [biomedical medication] hideous and as I said before I went to a Chinese medical practitioner, because I just couldn't function from the migraines. They made me violently ill and I had to take days off work. What was I supposed to do stop the heart medications or take something lethal? I just couldn't believe the heart medications were causing me so much grief and that they wanted me take something that was going to make my life even more miserable (P3).

Many participants reported adverse effects impacted on their physical wellbeing by causing unpleasant sensations. Many of the participants reported they felt their wellbeing was jeopardised twice because further biomedical treatment used to treat the first adverse effect had adverse effects. The following statement exemplifies these reasons for CAM use:

I couldn't stand the pill, because it made me bloat and when that happened I couldn't breathe...I didn't see the point in taking stuff to cover up the things the pill was doing to my body so I thought I better get it fixed once and for all, because the more drugs you are on they cause other things to happen and I didn't want that (P1).

Many participants reported they felt a sense of loss occurred when side effects impinged upon their ability to fulfil their social roles. Some participants felt biomedicine encroached on their personal lives sufficiently, but when the intrusion involved their immediate family, particularly their children, they considered such situations unbearable. Some participants suggested unbearable situations that biomedicine put them in were disparaging and unacceptable, as this statement illustrates:

I stopped it [biomedical treatment]. I just stopped it I said I'm pulling out and they were like why this and that and I said "I can't function like this my little one you know is bringing me his milk in bed so I can pour it in the bottle and get him to take it the microwave to heat". Ah, they [biomedical practitioners] didn't like it they tried to say "oh go a little more maybe you'll get a little bit better you know its early stages" No it's not early stages you're in on this drug for five months so far and its making you feel like this everyday. I don't get any help from anyone, "are you willing to come in look after my child while I lay in bed and you know try get out of it in the morning?" So I just to said them "I can't do it", [and] I got off it [the drug] (P4).

Many participants suggested adverse effects of medications that challenged their coping abilities lead to CAM use. Many participants reported when biomedical treatment impacted on their coping abilities and biomedical practitioners were less than sympathetic they lost confidence in biomedicine and turned to CAM, as typified in the following response:

What sort of a mother was I? I couldn't go on like that. Not only wasn't I able to look after my baby, I couldn't work...I had to get help because the medicine made me very unwell because I couldn't do anything...well I stopped taking the medicine and I went to one of those alternative type doctors because I hated them [biomedical physicians]. They [biomedical physicians] were just the pits, cruel and the treatment was torture (P1).

First-order theme: Loss of confidence because adverse effects/events caused irreparable damage. In this theme, the reasons for CAM use centre on adverse effects that could not be reversed either by withdrawal of the offending drug, or by subsequent biomedical treatment. This theme is about CAM use because some adverse treatment events were considered by the participants life threatening. In this theme the participants' negative views and subsequent CAM use centred on adverse effects, which reportedly might possibly shorten their life span. Thus, adverse effects that could not be treated and threatened the participants' life caused a loss of confidence in biomedicine. Many of the participants who had acquired

hepatitis C from blood transfusions reported using CAM because they had given up hope and because they had lost confidence that biomedicine could do anything about this life-threatening side effect, as shown in this statement.

I came to use Chinese medicine for lots of reasons and one of them was because I wanted to stop the damage from the hepatitis C. I did go on the trial as I said before, and I went through hell for nothing. But I still begged them [biomedical practitioners] to do something, to help me, because I didn't want to die or get liver cancer...I gave up in the end because their treatments are only a pipedream (P18).

Biomedicines that were prescribed and were known to potentially have lethal consequences were unacceptable to many participants and this led to CAM use, as shown in the following response:

The medication suggested for migraines has serious adverse effects. I wasn't at all happy because what they offered was lethal. They [biomedical practitioners] said that was all they could give me for the migraines; I wasn't even going to try it after being told that (P3).

Many of the participants reported they used CAM because biomedical adverse effects caused untreatable and serious pathologies, which resulted in a sense of desperation, as typified in the following comment:

They [biomedical practitioners] can't do anything for it [hepatitis C], except experiment on you and that's really dangerous. I wasn't going to have any of that. No matter how desperate I am I won't have stuff that is going to make me worse and if that means using stuff they [biomedical practitioners] don't like that's tough because I'm not stupid enough to just listen to everything they say. I know some thals [people with TM] that have gone crazy from the [biomedical treatment for hepatitis C] treatment (P3).

First-order theme: Loss of confidence because adverse effects/event required treatment. This first-order theme is about the use of CAM because biomedical treatment was required to ameliorate or alleviate adverse effects and this led to a loss of confidence in biomedicine. This theme is about CAM use because biomedical adverse effects required ongoing biomedical treatment. This meant the adverse effect was incurable and this led to a loss of confidence and CAM use. Some of the participants reported their CAM use was motivated by adverse effects that required further biomedical treatment, as shown by the following comment:

I had to have a tracheotomy because they [anaesthetists] used the wrong thing when they were operating on me. This left me with a scar that shortened my neck and made me very uncomfortable, so I used Vitamin E to soften the scar. A nurse suggested I try it and it helped a little. I'm still not happy because I had to have more treatment and I've been left with an ugly scar (P15).

Many of the participants reported that when biomedical treatment was required infinitum for an adverse effect, they turned to CAM as illustrated in this comment:

I'm having to have stuff [biomedical treatment] to get me off the morphine which they made me addicted to, because I had to have it day in, day out for the pain. But I found out that I would have to be on this drug for the rest of my life, because every time I tried to come off it I got sick...I had to get off it, because it was just another addiction and they [biomedical practitioners] didn't help me, so I saw a naturopath and I told them [biomedical practitioners] (P11).

Third-Order Theme: Rejection of Biomedicine

In this third-order theme rejection of biomedicine refers to avoiding biomedical treatment and/or physicians or using CAM in lieu of biomedicine. Thus, this theme is about using CAM to circumvent biomedicine and as a substitute to biomedicine. This third-order theme shows CAM was used to avoid biomedical treatment and biomedical physicians. In this study, it meant selected aspects of biomedicine were rejected because of the negative connotations associated with taking some biomedicines/treatments and/or the advice of biomedical physicians. This theme refers to rejecting some biomedicines and rejecting biomedical guidance in favour of CAM treatments. This third-order *theme had two second-order themes; avoiding biomedicine and rejection of biomedicine.*

Second-order Theme: Avoiding Biomedicine

This theme is about the instances where the participants reported they used CAM to avoid biomedicine because of the negative views they had formed of biomedicine. In this theme, the reasons for CAM use centred on the attempts the participants made to evade biomedical treatment and/or biomedical physicians. Shunning biomedical treatment meant using CAM in lieu of biomedicine. Some of the participants reported using CAM to avoid some biomedicines because they were considered "bad", as shown in this statement:

I wanted to try [CAM] before starting IVF, because I knew it [IVF] was bad. Bad? Oh, it's bad because it makes you really sick, mad and it's very time consuming...mostly

because it [IVF] is bad, it makes you mad and bloats you, you know it plays around with your hormones and that is bad (P2).

This second-order theme had two first-order themes; *avoiding biomedical treatment* and *avoiding biomedical physicians*.

First-order theme: Avoiding biomedical treatment. In this theme CAM was used to avoid medications for co-morbidities, to avoid blood transfusions, and to avoid the need for biomedical treatment and/or interventions for manifesting pathologies. CAM was used to avoid medication for serious and lesser problematic co-morbidities. Some of the participants with blood-clotting abnormalities reported they feared some biomedically prescribed drugs and used CAM to avoid their use, as shown in these responses:

He [biomedical practitioner] told me my platelets were too high and that I should have some aspirin but that can make you bleed so I told my [CAM] practitioner and he looks after that for me, because I wasn't going to take aspirin (P10).

I'm on too many drugs. I'd rather not have warfarin...[because it] is a rat poison ...I'm not going to take rat poison (P17).

Many participants reported they used CAM to avoid biomedical treatment because they considered some biomedical drugs addictive, as shown in this statement:

I don't want to take sleeping tablets because they're addictive. I mean why would you encourage someone to take that...it is so bad...my CAM practitioner told me you don't really sleep anyway. It just knocks you out (P2).

Many participants reported they used CAM because they did not want to take some biomedicine and/or they wanted to avoid further biomedical interventions, as shown in these statements:

I'm using some herbs, partly because I want to try and avoid having a splenectomy, which I was told I would have to have if my blood keep falling (P1).

I want to avoid having insulin, because at the moment, my diabetes is diet controlled and that's how I want it to stay (P9).

I was sick of taking Panadol for headaches...I wanted to avoid having to use them (P10).

First-Order Theme: Avoiding biomedical practitioners. This theme is about using CAM to sidestep seeing biomedical practitioners. This theme is about using CAM to avoid or

lessen the need to interact with biomedical practitioners because the participants considered biomedical practitioners did not enable productive communication and time spent with them was not beneficial. Some participants used CAM to bypass biomedical practitioners to avoid hearing contradictory information and unpalatable news, as this statement typifies:

I do everything I can to avoid them...because one minute they say you're doing really well and then they say you need to have some more tests or this drug or that drug (P6).

Some participants suggested they used CAM to avoiding biomedical practitioners because they were "wasting time", as illustrated in the following comment:

When we are having a blood transfusion, the doctor sees us for about one minute. When we see our main doctor [treating specialist], we see him for about 5 minutes max, how can that be right? How can they say we are fit for a transfusion or whatever in one minute? I have to travel and lose time from work to see prof [treating specialist] and sometimes I have to wait, and I can't see why I should waste my time, I never come away from there feeling that he has answered my questions properly, or explained things to me. So I'd rather spent the time with someone who does (P3).

Most participants considered CAM practitioners more likely than biomedical practitioners to listen and explain. The following statements show the reasons the participants avoided biomedical practitioners:

The more I stay away from them [biomedical practitioners] the better off I am, they [biomedical practitioners] do my head in. I find them [biomedical practitioner] really sneaky the way they don't answer questions properly or tell you to ask some-one else and that infuriates me (P8).

They [biomedical practitioners] don't do much for me, except upset me, because of their double talk and the way they talk down to you, like you don't understand or something. That doesn't happen with him [CAM practitioner] he talks and explains and goes over things (P21).

Second-Order Theme: Rejection of Biomedicine

This theme is about using CAM in lieu of biomedicine. Rejection of biomedicine typically did not mean total rejection and permanent termination and cessation of all biomedicines. Thus this theme is about using CAM because some aspects of biomedicine did not sufficiently deal with the health needs of the participants.

This theme refers to CAM because some of the medicine/s had been rejected because they did not provide satisfactory outcomes or were potentially going to cause the problem for

which they had been prescribed. Rejected drugs were thought to worsen rather than prevent adverse outcomes of prescribed treatment or they were thought to be ineffective. This theme is also about the rejection of biomedicine drugs in general. This meant CAM was used as a replacement for some biomedicine.

This theme also refers to using CAM when biomedical advice/guidance had been rejected. Some encounters with biomedical practitioners precipitated CAM use because the information, which led participants to believe they were being “abandoned” by biomedical physicians, angered them. Some participants reported when they considered biomedical information was contradictory they chose to not adhere with biomedical advice because the information in the context of the situation, did not make sense. These statements reflect these reasons for using CAM:

There are some things I don't take ever. Well I used to take them but not anymore because I don't think they're any good... I don't take penicillin...because penicillin doesn't work and it probably suppresses your immune system...I don't take hydrocortisone because...that stuff [hydrocortisone] breaks down your skin (P3).

They [biomedical physicians] were telling me they were abandoning me like a piece of crap that you throw away because they couldn't do anymore, and that I had to prepare for death. “Say goodbye to your family” that's what she [biomedical physician] said.... they didn't think I was going to make it through the night and at the same time they were telling me shit like what to eat and not eat. That made me really angry. We didn't give up; my wife rang him [CAM practitioner] and I reckon he saved my life (P5).

Many participants considered biomedicine that did not perform as expected was harmful and ineffective. Such biomedicine was described as having “no benefits”. Many participants reported they used CAM as a substitute for rejected biomedicines because they considered it was the safer option. Many participants' reported CAM use was preferable to the rejected medicines, because it was safer and beneficial. These reasons for using CAM are illustrated in the following comments:

I use herbs instead of HRT and penicillin because I was just sick of not seeing any benefits from them; in fact I had no benefits. All I had was a never-ending vicious cycle of bad effects, like bloating, coughs, colds and the flu. I'll never go back to those drugs...they were so bad (P1).

It's better not to take something that is harmful...it only makes you sick; it doesn't do you any good. You see when I was taking penicillin I was always sick, I kept getting

infections and felt awful. I know they [biomedical practitioners] gave me the penicillin because I haven't got a spleen, but I can do without it. I've proven I can do without it. I don't feel sick anymore and I don't get as many infections, so it [CAM] must be working (P10).

I won't take everything they tell me to. I think sometimes less is best to the drugs they give, because they aren't safe and they're not always that good [effective] anyway (P12).

I only take the [biomedical] medicines that keep me alive; you understand the absolute minimal I can take without causing myself grief. Because they [biomedical medicines] eventually end up doing damage...natural medicines can't hurt you (P13).

There were two first-order themes for rejection of biomedicine; *rejection of biomedical treatment* and *rejection of biomedical guidance*.

First-order theme: Rejection of biomedical treatment. This theme is about using CAM in preference to biomedical treatment, which had been discarded. This theme is about why the participants considered CAM use was preferable to biomedical treatment. Many participants reported they used CAM as substitution therapy, as this comment shows:

There is no way they [biomedical practitioners] will ever get me to have some treatments. No, never again because I can tell you the treatment is worse than the disease. No, I will find something instead...to take its place (P12).

Many participants reported they rejected some biomedical procedures because they were unsafe, caused undue pain and discomfort or brought no relief from the symptoms for which the treatment/investigation had been instigated. Thus, participants' prior bad experiences with biomedicine caused them to reject biomedical treatments in favour of CAM, as this comment illustrates:

You know before I went on the hep C trial I had to have a liver biopsy and other tests...the liver biopsy was so painful...I had to spend a couple of days in hospital, just to make sure I didn't bleed or something. Then I stupidly went on the trial, which meant I had to give myself injections and boy did they make me sick. I lost weight; I got depressed and my hair started to fall out in clumps. In the end, I was so sick I couldn't breathe. I thought I was going to die, and all that for nothing. I mean I've still got hep C and I can tell you I am worse than before, after what they did to me. I been having trouble recovering from it, that's why I turned to the alternative stuff to get stronger and hopefully to help my hep C (P18).

First-order theme: Rejection of biomedical guidance. This first-order theme is about using CAM practitioner advice, when biomedical guidance was rejected. This theme is about

implementing the advice of a CAM practitioner over the guidance offered by a biomedical physician because the participants perceived biomedical advice was given in an unfeeling manner and/or was inaccurate. Many of the participants rejected biomedical advice because they considered the biomedical advice unhelpful, as these comments show:

They [biomedical practitioners] can lecture you like a mother is going to lecture to her child, but I don't want to hear the negativity that comes out of them (P4).

Everything they [treating physicians] said was bad. But he [CAM practitioner] was different you know he encouraged me and he helped me a lot by sorting out the things I should eat instead of just saying "No" to everything (P5).

Some participants reported they used CAM when biomedical practitioners delivered information in an insensitive manner and because they considered the information was inaccurate, as shown in these statements:

I wasn't going to listen to him [biomedical practitioner]...he was wrong... He [biomedical practitioner] was telling me to use the stuff for my migraines and just two minutes earlier, after I asked him [biomedical practitioner] he told me how dangerous it was and he was insisting I have that. How caring is that? Giving me something deadly (P16).

I gave up all hope; I just wanted to die when I kept telling him [biomedical practitioner] I wasn't well. He [biomedical practitioner] thought it was in my head and told me to see a psych [psychiatrist]...they found I had an infection in my spine and then when they were taking some fluid from my spine they punctured my kidney and I collapsed and they told me I collapsed because I was anxious...but the doctor who did the test told me they punctured my kidney and that's why I collapsed... he [haematologist] finally apologised but I don't think that is good enough. I lost my job...and I lost my benefits because he [haematologist] told me society didn't owe me a living...I mean I wasn't bludging I'd paid for my benefits and my work advised me to go for a payout, but he wouldn't sign. I was told by the psychiatrist to "stop this nonsense, you're expandable [expandable]"... they just don't care (P19).

Summary of General Dimension 2

The general dimension negative view of biomedicine reflected the participants' use of CAM when disillusionment with their health care occurred, leading to a negative opinion of one or more components of biomedical treatment. According to the participants, disappointment with biomedical care often transpired when such care failed to deliver positive health care outcomes.

Participants considered health care outcomes had failed when treatment expectations were not met, when treatment failed to provide the relief and comfort that was promised or expected. In such instances, the participants frequently used CAM.

The participants formed a negative view of biomedicine and turned to CAM when biomedical therapies had unintended effects that harmed their health. In instances where treatment created additional health problems, the participants considered this unacceptable and turned to CAM, particularly if the biomedical treatment caused a life threatening illness or had life threatening adverse effects.

The participants lost confidence in biomedical drugs, procedures and the advice from prescribers of such treatment, when the participants' recognised biomedicines did not possess the ability to cure or provide effective treatment for particular diseases/disorders, or when the biomedical treatment created additional health problems.

This general dimension shows negative views of biomedicine triggered CAM use because biomedicine did not cure. Additionally, the interaction between the participant and health practitioners was perceived to be less than satisfactory. Also, participants' perceptions about biomedical practitioner knowledge were considered inadequate and therefore unable to meet the participants' needs.

This general dimension illustrates CAM was used to avoid biomedical treatment and health care-givers when delivery of biomedical treatment or the interaction with health care givers was considered by the participants as having impinged upon their dignity. This occurred when information being provided by biomedical practitioners was used to avoid taking responsibility for adverse drug reactions. This general dimension suggests CAM use became the preferred therapy when particular biomedicines were considered harmful. Rejection of biomedical guidance occurred when the participants considered such direction was misplaced, inaccurate or delivered in a manner not commensurate with the participant's expectations of a carer. For these reasons, the participants chose to seek the guidance of a CAM practitioner in lieu of that offered by their treating physician.

General Dimension 3: Self Determination

The general dimension self-determination refers to the use of CAM as a way of making autonomous decisions, considered appropriate in dealing with a never-ending cycle of biomedical treatment. Self-determination is about biomedical experiences, convictions and knowledge of thalassaemia major (TM), which provided the motivation to engage in CAM treatments/therapies considered beneficial. This general dimension is about using CAM because it was a treatment chosen, rather than imposed, as biomedical treatment for TM was perceived to be. This general dimension is about using CAM to be proactive in caring for oneself. Most of the participants reported they used CAM because they considered they knew what was best for them. Most of the participants reported they knew what was best because they were acutely aware of their body and its needs. Many of the participants reported they used CAM because they were determined to take action and not sit and wait for biomedical practitioners to prescribe treatments. These reasons for using CAM, which typify self-determination, are illustrated by the following comment:

I only do what I think is right for my body because no-one knows it like I do. I don't sit around waiting for them [biomedical physicians] to make me better because they can't always do it because they can't possibly know what it is like to live with thal (P21).

There was one third-order theme, *taking control*.

Third-Order Theme: Taking Control

This theme is about using CAM because it was a voluntary health care choice that was different to biomedical care, which did not allow for flexibility. Taking control is about using CAM because biomedicine was a predetermined necessity, which was considered to not take into consideration individual characteristics. In this theme, CAM use was undertaken because it allowed for self-determination of the biomedicines that would be taken by decreasing the need for some of them. This theme is about using CAM to determine the course of TM. Some participants suggested that CAM use was a decision based on their unique understanding of their illness. The following comments exemplify taking control with CAM:

So after all we go through. I now do what I think is best. I know my body better than anyone, and when I don't do as I am told by them [biomedical practitioners] it isn't because I don't want to have anymore [biomedical] treatment, it is because I am doing

the best thing for myself, because I know from what has happened, that you have to help yourself. It's like, you know, you can't just wait and hope that they [biomedical practitioners] have all the answers because they don't (P9).

You have to be responsible for yourself, you can't wait for them [biomedical physicians] because they can only do so much and sometimes what they do isn't right because we are not all the same. The rest is up to you. No one knows unless they've got that, what a horrible thing it is because it never ends, never gets better, only worse. If you want the best you have to go out and find it, you know try things (P15).

There were two second-order themes; *actively engaging* and *taking control to attain quality of life*.

Second-Order Theme: Actively Engaging.

This theme is about using CAM to overcome biomedical limitations. This theme is about using CAM when biomedicine could do no more. This theme is about taking control of adverse situations. Some participants reported they used CAM to prove to biomedical practitioners that more could be done, as this statement shows:

I showed them [biomedical practitioners] when they told me there was nothing else that could be done, I took over and got help and I'm still here...that's proof [that CAM worked] and I'm better than I've ever been (P16).

Many of the participants suggested that improved health meant the CAM measures they had taken to enhance their physical condition, gave them control over their biomedical treatment and TM. Many of the participants suggested that taking control over biomedical treatment was necessary to their survival. These reasons for using CAM are illustrated in this statement:

I wanted to be able to be in control because when you have to have treatment like we do all your life, you haven't really got much of a say, like other people. Well, it means there are certain things you have to do, like I told you the blood transfusions and the needles and things. But I can do things to help myself. The things [CAM treatments] ...not having things [biomedical drugs] I don't think are right for me, things like that. I do it so I don't get really sick and have to have more and more treatment, stay in hospital and things like that, because if you just rely on them [biomedical practitioners] you won't live to be old, that for sure and you won't be well for most of your life. Well I don't think being well is having to take lots of [biomedical] drugs like some thals do (P2).

Many participants considered the use of CAM assisted them in controlling the natural progress of TM and other illnesses. This statement illustrates this reason for using CAM:

I do my best to not to let that ruin my life. I don't accept that there is nothing that can be done to prevent the bad things that that [TM] does. Like wreck our heart and liver. I just try and limit the poisons that go into my body, and try and get rid of the ones that come with having that (P17).

This second-order theme had two first-order themes; *doing what is best* and *doing something*.

First-order theme: Doing what is best. This theme is about using CAM because participants considered it was the correct health-care decision. Some of the participants considered CAM use was “doing what is best”, as this statement shows:

You know what your body's limitations are and I think we're the best doctor for our bodies. Well I know when I'm sick, I don't need to wait for some test or doctor to tell me that I'm sick, because I know before they do. When I'm sick I just do what is best. Well, I might take some herbs or increase my fruit, if I think that is what my body needs (P5).

First-order theme: Doing something. This theme is about using CAM as a means of taking charge in the face of health crisis. Some participants suggested taking charge meant, “fight[ing]” back and not accepting that all avenues for life-saving treatment had been explored. Some participants did not accept that because biomedical treatment options had been exhausted that they should do nothing, as this comment illustrates:

You just have to fight, because if you don't you're dead. They [biomedical practitioners] only know what's in the books [medical textbooks], if it's not there they think there is nothing that can be done...in my case they were wrong (P5).

Many participants suggested the use of CAM was a way of overcoming passively having to rely on biomedicine. This quote illustrates how many participants used CAM as a way of demonstrating that they could actively undertake steps to relieve their health concerns:

I wasn't going to sit back and just take it [negative prognosis] because they're [biomedical practitioners] not God. I knew in my heart that there was something that could help me, even if they [biomedical practitioners] couldn't or didn't want to. I got onto the net and started searching and then I saw a naturopath and then I had acupuncture by a [biomedical] doctor, which by the way didn't work and hurt like hell, and finally I found someone who practised traditional Chinese medicine...I proved to myself they [biomedical practitioners] were wrong, because I got better (P1).

Second-Order Theme: Taking Control to Attain Quality-of-Life (QoL)

This second-order theme refers to using CAM treatment to sustain wellness, improve health and enhance health. This theme is about using CAM to limit the episodes of sickness that interfered with life. This theme is about using CAM to maintain and improve health to avoid being a burden to people significant to the participants. This theme is also about using CAM to increase the life span of participants. This statement illustrates what taking control to improve quality of life (QoL) meant to most of the participants:

You can't ever be normal, even though they [biomedical physicians] tell us we are, when you have to have treatment all the time...I don't want to have to have treatment all the time because it is sick making and you have to plan your whole life around it...our treatment is part of our lifestyle because we have it every day, you know what I mean? We live not only with that [TM] every day; we live with medicines...at least I can feel better...I suppose that's why I do it [CAM use]...to have a life (P18).

There were three first-order themes; *taking control to sustain wellness*, *taking control to maintain and improve health* and *taking control to increase longevity*.

First-order theme: Taking control to sustain wellness. This theme is about using CAM as a means of taking control to sustain wellness, to feel better, to be better, and to have the physical and mental resources necessary to live a normal life. This theme is about using CAM to save valuable time to spend on life instead of hospital and biomedical treatment. This theme is about using CAM to limit and/or decrease the burden and responsibility families had in caring for the participant. Many participants reported they used CAM to improve health because they wanted "to be better" so they could fulfil their societal responsibilities.

Some participants reported they used CAM because it gave some respite from acute illnesses. Many participants suggested through CAM they attained QoL because CAM treatment made them feel better by providing the energy needed to fulfil their social roles.

These reasons for using CAM are typified in these statements:

I really want to be able to just be, and not have to have blood transfusions and things interfering with my life. It is really hard being normal when you have to go to the hospital every three weeks and a ten-hour injection every night. No the alternative stuff doesn't stop that from happening but it makes me feel more normal because it has helped me get over some things, like I told you before. You know now I don't have to have so many drugs and I don't have irritable bowel and things like that (P 3).

I need to be doing things with my child...to do that you need to be well. Being well to me means not being sick, not needing hospitals and things. I know that is impossible but with the stuff I use [CAM] I feel better, I don't get so sick and I've got more energy (P 8).

First-order theme: Taking control to maintain health and improve health. This theme is about using CAM to provide some relief from the chronic nature of TM. This theme is about using CAM to maintain and improve health to minimise the participants' exposure to biomedicine because it interfered with everyday life. This first-order theme is about using CAM to be well because biomedical treatment did not sufficiently deal with the health needs of the participants. This first order-theme is about using CAM to "feel healthier". This theme is about using CAM to overcome the stresses of living with a chronic illness. This theme is about preserving and improving health with CAM. This theme is about using CAM to minimise health crises, such as those that might lead to more biomedical interventions and possible hospital stays. Many participants reported biomedicine was time consuming and the use of CAM was a way of reducing the time spent in hospital and/or visiting biomedical practitioners. The following statements typify these reasons for CAM use:

I want to stay healthy so when we decide to have children I don't have to use IVF and I can spent the time with them instead of [biomedical] doctors (P1).

You do what you can to keep your health; you understand to be OK, like not to be sick. If you just do what they [biomedical physicians] tell you do, you will always be in and out of hospital, you know like having this test or that test, and it all takes time. I just try and do other things, because just thinking about what has to be done takes a lot of effort and sometimes you feel it is just a waste of time...I just want things that will stop things [illnesses] from beginning in the first place (P11).

Many participants reported they used CAM because biomedical treatment insufficiently maintained health and did not improve health, as shown in this statement:

Being well to me means not being sick, not needing hospitals and things...they just can only do the blood [blood transfusions] and not the other things to stop you getting sick and things that will make you feel good. Yes, you're right blood transfusions make us feel better, but we also feel sick from them. We just need more things to make use feel really good (P18).

Some participants commented about the "need to be doing things" with the family and how CAM was seen as way of improving energy levels, which would enable them to attend to

family responsibilities. This theme is about using CAM to integrate into society. These reasons for using CAM are typified in these statements:

I need to be doing things with my child and family. You need lots of energy for that. To do what everyone else does you need to be well. Clean, cook work, look after the baby, go shopping. Everything that normal people do, we have do it too (P 8).

I wasn't very pleasant to be around before I went to the Chinese practitioner, because I used to throw wobbles...you know I would scream and carry on...I was on anti-depressives but that made me worse...I shut myself off from the family...I was desperate as I said I needed help...I thought I would never work again (P 18).

Some participants commented they often had to spend time in hospital for the purpose of stabilising severe co-morbidities and/or treating infections. As suggested by the participants, CAM use was a way of minimising such events, which they considered interfered with their role of caregiver, and took away their freedom. CAM was a way of gaining time; time to spend on other aspects of the participants' lives. These statements illustrate how the participants used CAM to influence the course of their illness:

I don't want to go down that road again [cardiac arrest] so I do what I can to help myself to be well. Like I said I take extra folic acid and vitamin E and other things (P5).

I don't want to be sick in the future; it is such a waste of time. You know I have more important things to be doing. Like I have to look after my children and to do that properly I have to earn money. People don't think that you have a life outside of the hospital, but we do and we can't do everything, if we are sick and in hospital or having to go for this test and getting this treatment. That's why I use alternative medicines to help me stay healthy and give better energy levels, which means I won't need it [biomedical treatment] so much (P10).

Many participants reported using CAM because they considered it essential to avoid the harsh and hard hitting biomedical treatments, as this statement shows:

When I used to get depressed, I was thinking I was going to have a heart attack. They [biomedical practitioners] did all these tests and said my heart was good and that there was nothing to worry about, but that didn't stop me getting depressed, because I kept thinking about what happens when our heart gets sick. I didn't want to have all those horrible drugs and pace makers and things, so I thought about the things that I could do to help myself (P 9).

First-order theme: Increase longevity. This theme is about using CAM when issues of life expectancy were impacting on participants' QoL. Some participants suggested that CAM use was a way of halting the progression of thalassaemia major. As noted earlier, life-

threatening co-morbidities were particularly worrisome to the participants. CAM use was seen as a way of overcoming such adversity, as these statements typify:

I want to be around for my child for a long time and not as an invalid. I might have thalassaemia major, but I want to do everything that other people can do, and that means looking after my family properly (P9).

Alternative medicine to me is a way of stopping the need for some really bad drugs, which ruin your health. You know some of the things I take are for detoxifying, and general increase of energy. But I suppose the detoxifying is the most important to me, because I have Hep C, and that is something I don't want to be the cause of my death (P11).

To avoid being burdensome to those nearest to them, some participants considered CAM was a way of preventing the types of health crises that would lead to their demise and cause grief. This statement illustrates the reasons some participants used CAM to increase their life expectancy:

I do what I can so my parents don't have to bury me or look after me for the rest of my life. My parents have probably gone through just as much pain as I have, I want to reward them, because they stuck by me and helped me a lot...the best reward for them [parents] is showing them that I am going to be okay and by not dying. Well, really no-one knows when they are going to die, but you can do things that help you stay well...like the stuff I do, which I take, stop me getting sick...if you stop getting sick you will probably live as long as someone who is healthy. What I mean is, if you keep scratching something you will end up eroding it away, even a stone, but if you leave it alone by doing the right things then everything else will look after itself (P10).

Summary of General Dimension 3

The general dimension of self-determination refers to the participants' desire for autonomy that gave rise to CAM use. This general dimension shows CAM was used as a tool to maintain health, to improve health, to prevent health crises and to increase longevity, to live with as little disruption and dependence upon biomedicine as possible. The participants used CAM as a way of not acquiescing to biomedical treatment, which they felt was not meeting their health needs. Passively acquiescing to biomedical treatment was not an approach the participants considered appropriate to their wellbeing, whereas the capacity to choose CAM treatments was considered an action that could improve their situation. The participants considered the use of CAM was a way of helping themselves to health care that was not available through usual biomedical treating venues. CAM use was a way of taking control of

some aspects of health care that the participants suggested were not being attended to, or were being inappropriately attended to by biomedicine.

In this general dimension many participants perceived CAM use was a way of showing or doing what they felt was in their better health interests. The reasons the participants gave for CAM use in this general dimension centred on active participation in health care. As suggested by the participants active participation was essential to their survival and wellbeing. This general dimension showed that the participants used CAM because they considered it improved their chance of survival by improving their health.

This general dimension shows CAM was used because the participants considered CAM contributed to maintaining their health and wellbeing, which enabled them to cope with their daily activities such as rearing a family and maintaining some form of paid work. This general dimension indicates CAM was used to improve health to avoid or delay the natural progression of thalassaemia major. Hence, the reasons the participants gave for CAM use related to their intention to increase prospects of life expectancy.

General Dimension 4: Attributes of CAM

This general dimension, attributes of CAM, refers to the qualities that the participants considered CAM treatments possessed. The participants suggested CAM characteristics, which they found appealing, were that CAM is capable of providing positive outcomes, and such outcomes did not jeopardise their life or their health, because CAM is safe. CAM was safe, because it is natural. This general dimension is about the characteristics of CAM that the participants credited CAM treatment as having. This general dimension also related to the perceptions the participants held of CAM practitioners.

The positive characteristics, which the participants ascribed to CAM practitioners, motivated them to use the services provided by such practitioners. Hence, this general dimension is about the qualities the participants attributed to CAM products and CAM practitioners. These qualities are reasons the participants gave for CAM use, and as motives for continuing with such treatment. Whilst this general dimension is about the positive

attributes of CAM, the participants were not concerned with the name given to a particular form of treatment and as these participants' comments show, many made no differentiation between treatments:

Doesn't matter what you call it, it works it's good medicine if it doesn't it's not and you don't use it (P3).

You know, all medicines doesn't matter what you call them, because that's just away of talking really, are treatment and that means it makes you better, if it can't do that then it's not medicine (P 6).

Really it's all medicine to me (P14).

The features with which participants credited CAM are detailed in the third-order and lower-order themes. In this general dimension, there was only one third-order theme; *attributes of CAM treatment and attributes of CAM practitioners.*

Third-Order Theme: Attributes of CAM Treatment

The third order-theme, the attributes of CAM, refers to the positive characteristics the participants considered CAM possessed. These attributes motivated CAM use. Many of the participants commented that, because CAM was good for health, it would be used as a continuing pattern of health behaviour, as these statements show:

I am not sure how I would describe it basically I feel, I feel that it is just a natural way, method. It can't do any harm it actually helped me improve my general health and wellbeing. I feel everyone should use it. I will always use it from now on because it's been good for me (P1).

I am still using herbs because they've helped my blood a lot and they cured my sinus problem (P10).

This third-order theme had one second-order theme, *CAM harmless*, which represents the participants' view of CAM as a benevolent and innocuous form of treatment that healed and prevented illness.

Second-Order Theme: CAM Harmless

This theme is about the beneficial attributes the participants considered CAM had. This theme is about the use of CAM because it was considered harmless. Most participants considered CAM beneficial because it was effective and safe and attributed these attributes to

perception that CAM was ‘natural’. All participants considered CAM was a helpful form of treatment because it was harmless, as typified in these statements:

My blood is higher, my iron is down and I don’t get sick. What more can you ask...I don’t get sick from it [CAM] because it’s not dangerous like drugs (P10).

I’ve only seen benefits from it [CAM] helped me a lot. Well, I don’t get bloated...bloating is bad because it stresses your heart...CAM doesn’t do that (P12).

It’s OK to use it [CAM] because it’s harmless; it never did me any harm. It only helped me (P15).

If it wasn’t for the herbs I don’t know where I would be. They’ve helped me a lot. Improved my blood, my diabetes and best of all got me off the antidepressants... basically saved my life...before I was a zombie...because those drugs [antidepressants] are bad (P17).

Now I don’t get headaches...it’s [CAM] much safer and it does good... I’ve got more energy and I’m much calmer and happier. My blood is about ten [pre-blood transfusion], so there’s improvement and my iron is the lowest it’s ever been ...so it’s not increasing the iron...that means its harmless (P20).

This second-order theme had three first-order themes; *CAM beneficial*, *CAM safe* and *CAM natural*.

First-order theme: CAM beneficial. This theme is about CAM use because CAM provided positive health outcomes. Participants reported they measured their health outcomes by how they felt, by noted improvement in haemoglobin levels and other biochemical assays such as liver function tests, a decrease in episodes of acute illness and improvement in chronic illnesses. All participants reported CAM was beneficial and some participants reported proof of the benefits of CAM was measured by the ability of CAM to “make you better”, as this statement exemplifies:

When you are trying to improve him [person with an illness taking CAM] and you make him better in the sense you are trying to make them feel healthier then its good, and they should keep doing it, if they think it is making them better. That’s what happened to me and that’s why I think it [CAM] has a place in medicine and I don’t think anyone should try and stop you using it if it’s proven to be doing you good. Proof, what does it mean? It means you get better, and if something makes you better, you know like cures you of something, or help brings you back from nearly dying like it for me, I think that’s proof. I don’t care what anyone says it [CAM] helped me so in my books it’s [CAM] good (P5).

First-order Theme: CAM safe. The first-order theme, CAM safe, is about the perception that CAM was not harmful, which provided the rationale to participants' utilisation of CAM. In using any form of treatment, the participants considered underlying principles such as safety of treatment, as being of paramount importance. Because the participants considered CAM as a treatment that was not "dangerous", its use was justified. The participants suggested that that they considered a therapy to be safe, if it was a treatment that no deleterious outcomes. This theme is about the associations the participants made about CAM safety. Some participants suggested CAM was safe because it provided positive outcomes. Most of the participants reported because CAM had been therapeutically beneficial. Thus, safety was an inherent component of CAM and indicative of its capacity to produce positive outcomes, as these statements show:

Some of it tastes bloody awful but so does western medicine, only this stuff is safer, because I've never seen any bad from it. I've only see benefits from it. I have to say it has helped me a lot. I don't believe its [CAM] harmful because I know it helped me (P2).

I got better, I didn't suffer and I keep getting stronger, so of course it's [CAM] safe. If it wasn't I would have gotten sick and I wouldn't be still using it [CAM] (P16).

First-order theme: CAM natural. This theme is about the perceptions the participants held about the origins of CAM products. It was their beliefs about these origins that led participants to assume they were safe. This theme is about CAM products being organic substances. Some of the participants suggested CAM was safe because it was not a refined and manufactured product. Many participants considered CAM products as "natural", and natural meant that CAM was safe. These perceptions of CAM are illustrated in this comment:

It's natural you are putting something natural into your body, and that's good. That means it's can't do you any harm like drugs (P4).

Many participants considered CAM products were unrefined products that had originated from the soil, which was associated with being organic. These perceptions of CAM validated CAM use. The following statements illustrate how participants reasoned that CAM use was appropriate because it was "natural":

I wanted something more natural than what was being recommended to me for migraines by the hospital that worked. I wanted something more natural. Something that wasn't made from chemical and things like that, you know the whole plant (P2).

It's natural you are putting something natural into you body, so it can't hurt you it can only help you (P4).

There are no chemicals added to them because they aren't made, you know they're natural things from the ground. Because they're organic they're safe (P10).

It's like grown, organic so it's natural. If I had it my way I wouldn't use anything else (P15).

Third-Order Theme: CAM Practitioner Attributes

This third-order theme, CAM practitioner attributes, refers to CAM use motivated by the positive qualities that the participants considered CAM practitioners had. This theme is about CAM use because CAM practitioners were considered to be open and honest. This theme refers to the use of CAM practitioner services because CAM practitioners provided the time and dignity for the participants to make decisions about their health. This theme is about using CAM practitioner services because the practitioners were respectful of individual needs. Many of the participants reported that CAM practitioners were better able to treat an illness effectively because they treated the underlying cause as well as the symptoms. Participants perceived that this was central to wholistic care, and was given as a reason for CAM use, as this statement shows:

They [biomedical practitioners] love band aides whereas I think they should be doing more to fix things up properly, you know like looking for the cause like natural medicine does. You know I am more than a person with thal. I have the same problems and more than healthy people do (P6).

Many participants suggested that the CAM consultation was an interaction that kept them coming back to CAM, because it fulfilled the criteria they expected of a session with a health professional. Many participants stated that the time spent with a CAM practitioner made them "feel good". The following statements reflect the positive attributes that the participants held of CAM practitioners:

So I prefer to see my Chinese doctor because she treats me like a human being, guides me and give me honest information. But more than that, like she never looks at me as if she is judging me (P8).

But my other doctor [CAM] talks and explains and goes over things all the time, I'd rather see her any day...I always feel good after seeing her (P18).

This third-order theme had one second-order theme, *CAM practitioner desirable qualities*.

Second-order Theme: CAM Practitioner Desirable Qualities

This second-order theme is about using CAM because CAM practitioners were perceived to have skills and abilities, which were conducive to healing. Many participants reported they found CAM practitioners were responsive to their needs. Most participants reported CAM practitioners enlisted them in the healing process by encouraging and providing health care information. Many participants reported their health needs were met by CAM practitioners and these were often measured in the positive health outcomes, such as healing irritable bowel an illness that biomedicine had failed to cure. Most participants reported CAM practitioners approached and conversed with them openly. This gave the participants confidence in CAM because it indicated to them that CAM practitioners understood their expectations for coming to see them. Many participants reported CAM practitioners were able to explain things that biomedical physicians either refused to answer or said they could not. These reasons for using CAM practitioners in preference to biomedical physicians are illustrated in these comments:

I never come away from there [biomedical consultation] feeling that he [biomedical physician] has answered my questions properly, or explained things anyway. So I'd rather spent the time with someone who does (P3).

Everything they [treating physicians] said was bad...can't do this, can't do that. But he [CAM practitioner] was different you know he encouraged me and he helped me a lot by sorting out the things I should eat instead of just saying "No" to everything (Ps5).

I prefer to see my Chinese doctor because he treats me like an equal, guides me and give me honest information (P8).

He [biomedical practitioner] was wrong because the advice I got from the [CAM] practitioner proved to be right (P16).

My other doctor [CAM] talks and explains and goes over things all the time, I'd rather see him any day...I always feel good after seeing him (Ps18).

There were two first-order themes; *CAM practitioners are caring and empathetic* and *CAM practitioners have better skills*.

First-order theme: CAM practitioners are caring and empathetic. This theme is about the type of service CAM practitioners provided to the participants, which they found attractive. This theme refers to CAM practitioners as practitioners who offered wholistic care. This theme is about perceptions that CAM practitioners were non-judgemental. This theme refers to the importance the participants allocated to the manner in which CAM practitioners approached and treated them and to the time given during a consultation. Many participants suggested because CAM practitioners treated them appropriately they were more trustworthy and capable. Some participants suggested CAM practitioners were better able to treat a person because they treated the whole person, as illustrated in these statements:

Alternative medicine looks after all of you, but western medicine just focuses on the body. I think medicine should do both (P3).

It [biomedicine] can't heal the soul. When the soul is sick so is the person. So you should look after that side too because it means you are thinking it's not just a body, it's more than that. Alternative doctors always ask about how you are feeling and they don't just mean how your body is, they mean how your soul is (P7).

The participants considered CAM practitioners to be "special people" because they never bullied or threatened them, as these statements show:

When they [biomedical practitioners] told me I had hep C and that I had to go on this trial because if I didn't I would die, when I look back on it now, they were threatening me. You know like bullying me to do this [trial] or else. My [CAM] practitioner is so nice and gentle, always explains things and guides me and doesn't get upset when I don't do things right (P3).

She [CAM practitioner] has never once, looked at me as if I'm a failure or as if I'm lying. Ah, [biomedical] doctors and nurses sometimes give off really bad vibes, especially when you know they're not happy with you. Oh, yes they can be real bullies when they want to be (P18).

First-order theme: CAM practitioners have better skills. This theme refers to CAM practitioner skills that made CAM use attractive. CAM practitioners were considered to be able to treat appropriately because practitioners made accurate diagnoses, practitioners tailored treatment plans specifically for the participants, and involved participants in the planning of

treatment, treatment was effective, and practitioners spent ample time with participants explaining, answering questions and giving advice, in an open and honest manner. These positive attributes, considered were characteristic of CAM practitioners, motivated participants to use CAM, as these comments illustrate:

When I went to the [CAM] practitioner I spent over one and half hours there. I have never been asked so many questions in my life, but I was also asked if I had any questions and if I understood. Whenever I didn't understand something; he went over the information again and again, until I got it, and he made me take notes about what I had to do. I have to say I was pretty impressed because everything he said happened just like he told me (P9).

[CAM practitioner] he is the best... talks to you like you're really special; makes me feel really good. I can ring whenever I have a question and he never puts me off, he never gets mad with me. When I first went to him, he told me about the treatment and said that it was difficult because I would have to change my lifestyle, and that I would probably fall in the shit sometime, but that didn't matter. I wasn't to give up because I'm only human and I'm allowed to make mistakes...he has never once, looked at me as if I'm a failure (P 18).

[CAM practitioner] taught me so much. Never once looked at her watch, I mean I was there for two hours and she encourages me to ring her whenever I need to. I've been seeing her now for four months and already I can see a big difference (P19).

As shown in the following statements most participants reported CAM practitioners provided positive health outcomes, because they were concerned with the causes of disease, as well as the manifesting symptoms:

He [CAM practitioner] was different you know he encouraged me and he helped me a lot by sorting out the things I should eat instead of just saying "No" to everything. That means he [CAM practitioner] knew what he was doing, and he didn't think I was wasting his time because I was telling him how I just wanted to eat fruit because I just felt like I needed it. He said that was all part of helping him to help me (P5).

He [CAM practitioner] is more interested in how I got the cold or flu or whatever I go to him for, than the symptoms....treats the my sore neck, runny nose and things like that...gives me guidance on what I should and shouldn't be doing so I can get better and stay better....asks me millions of questions about how it happened, because that helps him make up his mind about what he is going to give me. The other [biomedical] doctors don't do that, they just write prescriptions and they don't care that your liver or whatever is shot, whereas my other doctor [CAM practitioner] does, he tries to prevent more damage (P11).

As shown by the next two statements, many participants reported that CAM practitioners provided information about biomedical processes, whereas treating biomedical physicians often failed to do so. This gave the participants the confidence to use CAM:

Why didn't he tell [biomedical practitioner] me the Desferal was taking it out of our bodies, and that was part of the reason I was losing my hair. I had to find that out from a natural [CAM] doctor. She told me what was happening when I asked for something for my hair. It's not right. Whenever I need to find out anything I now just ask her [CAM practitioner], I don't even bother with him [treating physician] (P8).

I had stopped chelating and I wasn't taking any [biomedical] medicines because I just couldn't cope anymore after everything that had happened. I now take my folic acid ... have my pump [chelate] every night because I know now that things can change because she [CAM practitioner] explained how my body works and why I needed to take folic acid...I reckon she's knows more than they [biomedical practitioners] do. When I stopped chelating he [biomedical practitioner] told me that it was my choice and that I could even stop blood transfusions, because he knew of people who had and they were doing OK. She [CAM practitioner] said that wasn't a good idea because it would stress my heart and it was her who helped me get back to using the pump (P19).

Many participants suggested positive treatment outcomes were evidence of CAM practitioner skills. Most participants considered CAM practitioners accurately predicted the treatment outcome. These reasons for using CAM are illustrated in the following statements:

My [CAM] doctor told me my irritable bowel and sinus would get better if I changed my diet. I had to take some herbs for a while to give me a helping hand, and that's what happened, it all worked out like I was told it was going to happen. I think when you are told something, and it happens it shows they know what they are doing (P1).

The advice I got from the [CAM] practitioner proved to be right. Everything he [CAM practitioner] said was right. Well, he told me the herbs would improve my haemoglobin and that I wouldn't feel so awful after eating and that happened, so he was right (P16).

She told me I would have more energy and she told me my blood levels would increase and that's what happened. Oh! From 8 to 8.9, I now go in and my haemoglobin is 10-11... I feel much better (P19).

Summary of General Dimension 4

The general dimension, of positive views of CAM, portrays the characteristics attributed to CAM. Characteristics such as beneficial, safe and natural attributed were to CAM products. These characteristics ascribed to CAM, motivated CAM use. The participants associated the safety of CAM products with the notion that CAM was organic, hence natural. The participants associated natural with harmlessness, which was a prime reason for using CAM. This general dimension showed the reasons for CAM use centred on the participants' treatment criteria and notions of safety and beneficence. In addition to the positive

characteristics that participants accorded to CAM products, were the positive attributes that they stated that they observed in CAM practitioners.

Participants considered CAM practitioners as having interpersonal and treatment skills that facilitated healing. The participants suggested that CAM practitioners showed a caring attitude because they were open and honest in their dealings with participants. This general dimension showed the participants considered that because CAM practitioners practised holistic care, they were better able to treat successfully. These views of CAM provided participants with sufficient reasons to initiate and maintain CAM use.

Discussion

This discussion reviews the findings of Phase 2 of the thesis, which focused on the reasons for CAM use provided by the participants in conversational style interviews. This discussion presents and compares the reasons for CAM use, with those found in other studies where the participants were selected on other criteria. Conclusions drawn from each of the general dimensions are discussed. As shown by the general dimensions, the decision to use CAM often was not made on a dichotomous basis of 'to use CAM or not use CAM', or because of one over-riding reason. Rather, as indicated by the findings the decision to use CAM was associated with particular health related experiences that participants drew upon to inform their decision to use CAM. Thus, this discussion considers the relationships between the general dimensions. To end this discussion future research is addressed that derives directly from the findings of Phase 2.

Relationship of Findings to Previous Research

Phase 2 illustrated that CAM was used with intent to treat and because CAM gave the participants control over their choice of treatment. Phase 2 also showed CAM was used because it possessed qualities that participants considered were missing from biomedical care.

General dimension 1(GD1). The findings illustrate CAM was used to treat the main pathology and other illnesses associated with the natural progression of thalassaemia major (TM) or biomedical treatment. The findings indicate CAM treatments were used to address

both psychological and physical symptoms. Other studies have shown people with a chronic illness use CAM to attenuate symptoms that might be associated with the primary illness (Fairfield et al., 1998; Oneschuk et al., 2000; Wolsko et al., 2004; Shinto et al., 2005). While many studies found that people with psychiatric disorders used CAM (Druss et al., 2000; Kessler et al., 2001a. Knaudt et al., 1999) they had not indicated whether such use was for the psychiatric disorder. In contrast, GD 1 illustrates some participants used CAM to treat depression and to prevent suicide when they felt biomedical treatment was futile. This is a new and important finding for CAM use because it suggests that allied health practitioners, such as psychologists, or biomedical practitioners are failing to recognise that “not all is all right” and that their clients are either suffering in silence or electing to use CAM. Therefore, treating biomedical practitioners are not treating wholistic, as they might believe.

The findings show CAM was used to increase life expectancy, by improving health. This finding suggests participants were anxious about their health status and used CAM as a coping mechanism. This finding is similar to that by Söllner et al. (2000) who found in people with cancer used CAM in conjunction with biomedicine as a way coping with feelings of hopelessness (p. 878). People with TM have been found to exhibit high levels of hopelessness and anxiety because they were trying to cope with the fear of a premature death (Aydin et al., 1997; Sadwoski et al., 2003). Similarly, most participants in this research reported they were anxious and desperate to overcome illnesses, failure of treatment or both. Therefore this finding suggests CAM use was a last resort treatment (Caspi, Koithan & Criddle, 2004) motivated by a state of hopelessness. These findings also suggest that some participants were in a state of denial and grasped at CAM as a last resort treatment.

These findings also suggest CAM use was a coping strategy (Cartwright & Torr, 2005; Davidson, Geoghegan, McLaughlin & Woodward, 2005; Verhoef, Best & Pocobellis, 2003; Honda & Jacobson, 2005; Söllner et al., 2000) used to actively overcome the limitations of the participants’ illness and or treatment. The findings suggest that the seeking out of other treatments (CAM) might be associated with better psychological adjustment to adversity

(Davidson, Geoghegan, McLaughlin & Woodward, 2005; Richardson, Graham & Levine, 1986). In addition, because the participants were aware of the assessment by biomedicine of their condition and pragmatically chose to find what was appropriate for presenting problems, even when informed by biomedical physicians 'nothing else could be done' suggests that the health behaviour of the participants' is consistent with an internal locus of control because they did not assign validity to outsiders others perceived to be informed (Guadagnoli & Ward, 1998).

The findings indicate participants' use of CAM to return normal physiological status to an organ to meant to reverse damaged organs, such as the heart. Hence, seeking treatment to normalise damaged organs suggests the participants wanted to cure disease. Whilst, some research supports the observation that people with a serious illness, such as cancer (Gupta et al., 2002) and those terminally ill used CAM for curative purposes (Oneschuk et al., 2000) in Phase 2 the findings suggest all participants sought treatment for most illnesses because they wanted a cure. This finding is unlike other studies, which have shown, for example that only a small proportion of people use CAM with curative intent (Kappauf, 2000; Vandecreek et al., 1999; Verhoef et al., 1999; Yeh et al., 2002). In addition, whilst all participants expressed that a cure for TM was what they hoped for and most did not say they used CAM for such a purpose, analysis of the treatments used by many of the participants, such as wheat grass to switch on foetal haemoglobin, suggests participants were actively seeking a cure for TM. These findings indicate that using CAM with curative intent should be viewed in context of the meaning of what treating an illness means to people.

The findings show the participants were motivated to use CAM because they wanted treatment to have no adverse effects, be effective, prevent illnesses and act as an alternative to biomedicine in some circumstances. For example, the findings illustrate that CAM was used to boost the immune system, to provide protection against viral and bacterial infections. CAM was also used to prevent co-morbidities. This finding is similar to other CAM studies that found people with a compromised immune system, such as those undergoing chemotherapy,

used CAM to bolster their immune system (Boon & Brown, 1999; Canales & Geller, 2003). The findings of this study were also consistent with the results of other qualitative studies, which found CAM was used for prevention of further illness and/or recurrence of cancer in women diagnosed with breast cancer (Adler & Fosket, 1999; Boon & Brown, 1999; Maskarinec et al., 2001).

The findings point out that CAM was used to provide effective treatment. Effective treatment meant ameliorating the illness for which the treatment was sought. This again shows CAM was used for curative purposes.

Effective treatment had to mitigate and/or compensate against further damage, which, in effect, was also preventive treatment. Effective treatment also meant the treatment had to have no adverse effects. The findings show CAM was used as a first treatment option to treat some co-morbidity, such as infertility and to avoid the perceived harmful effects of IVF and/or invitro fertilisation biomedical treatment.

The findings suggest that CAM was used as an alternative treatment in lieu of biomedical treatments known to have adverse effects. Many studies have shown that people with serious illnesses used CAM to attenuate the adverse effects of biomedicine (Boone et al., 2000; Bullock et al., 1999; Cronan, Kaplan & Kozin; 1993; Sleath et al., 2001). No CAM study, however, was found that indicated, as this study has, that CAM was used to avoid the perceived and known adverse effects of biomedicine that might emanate from the projected long-term effects of biomedical treatment. Thus, in this research the findings show that avoiding the adverse effects of biomedicine was another example of using CAM for preventative purposes and that CAM was used as defence against foreseeable harm and the possible consequences of both treatment and illness.

General dimension (GD 2). The findings show CAM use was prompted by negative views of biomedicine treatment and biomedical encounter/s with physicians and/or other health care workers.

The findings show CAM was used when biomedicine failed to provide relief from symptoms or failed to cure an illness. Hence, as indicated in GD 1, CAM was sought to find effective treatment. Although this finding is consistent with those of many studies, which found the participants sought CAM treatment because biomedicine had not provided a satisfactory solution or had been ineffective (Boon et al., 2000; Bullock et al., 1999; Oneschuk et al., 2000; Sleath et al., 2001) some researchers suggested this did not contribute to dissatisfaction with biomedicine and subsequent CAM use (Furnham & Smith, 1988; Kappauf et al., 2000). Despite finding CAM users were critical about the efficacy of biomedicine, Furnham and Smith (1988) suggested this was not the reason for using CAM; rather dissatisfaction with biomedical practitioners was the reason. In contrast, the findings illustrate that ineffective biomedical treatment was a major factor that contributed to CAM use and was associated with other negative views of biomedicine.

It must be noted that the findings point out that illnesses considered curable by the respondents, such as irritable bowel and sinusitis not cured by biomedicine often after numerous attempts contributed to a loss of confidence in biomedicine because biomedicine was seen to be ineffective. Such negative views of biomedicine were associated with a loss of confidence in the biomedical physicians' ability because the biomedical physician failed to prescribe treatment "that worked".

Moreover this finding indicates as others have found that CAM was used as 'a second resort' treatment in people with medical conditions that biomedicine cannot cure or did not provide symptom relief (Oneschuk et al., 2000; Berg & Arnetz, 1998; Conroy et al., 2000). This finding suggests CAM, in addition to being a second resort treatment was also used a last resort treatment when biomedical treatment options had been exhausted. In accordance with other studies (Barram, 2001; Boon & Brown, 1999; Nayak et al., 2003; Peter et al., 2002) these findings show that CAM use was a last resort treatment driven by illnesses for which there was no known treatment and/or had a bleak prognosis.

A loss of confidence in biomedicine also occurred because participants felt biomedicine had abandoned them. For instance, CAM use was triggered when biomedical physicians advised nothing else could be done to treat a disorder and that the person should prepare for death. This, in effect, was perceived as withdrawal of biomedical treatment because biomedical physicians advised that no further attempts would be made to turn the situation around. This suggests CAM was used as a last resort treatment to survive and as a source of comfort because biomedicine could offer neither physical nor emotional support. GD 2 suggests as other studies found of such phenomena (Baruch, 1981; Hyden, 1997) participants had difficulty in reconciling the withdrawal of medical services, which they perceived as threatening and shocking.

In addition, GD 2 indicates the participants reported they could not reconcile nor understand, that whilst biomedicine had abandoned them, health practitioners were resolute in controlling health behaviour by persisting in giving biomedical advice, such as prohibiting particular foods. Such advice appeared out of proportion to the news of impending death, perplexed participants and triggered CAM use because the biomedical physician was perceived to want to control the client's behaviour for no apparent reason. This finding as Street, Krupat, Bell Kravitz and Haidet (2003) (p. 609) found suggests communication in medical encounters is influenced by the physician's and client's beliefs about control in their relationship.

Moreover, participants who perceived they were being forced to comply with biomedical interventions that they did not fully understand, and/or which they did not believe to be beneficial (Corrigan & Garman, 1997; Hornung, Klinberg & Feldman, 1998; Rogers et al., 1998) led to CAM use. These findings are similar to studies (Boon & Brown, 1999; Chao-Hsing et al., 1999) that found confusing and conflicting information affects the decision-making process.

The findings illustrate, unlike other studies, that the decision to use CAM was inextricably associated with a loss of confidence in biomedicine, which was the culmination of

a chain of events. Hence, as indicated biomedical advice delivered in an uncaring manner and/or information that made no sense, lead to a loss of confidence in the biomedical physician's ability and abandonment of biomedical advice. These findings draw attention to and add to the empirical data of the significance of "assessing the client's perception of information at various stages in the illness" (Davidson & Mill, 2005, p. 90).

In particular, the findings of this research illustrate that there is an association between the perceived quality of biomedical information and care. Such negative feelings toward biomedicine emanated from negative encounters with biomedical physicians and so from prescribed biomedical treatments that had adverse effects. Biomedical adverse effects/events were a major cause of discontent amongst the participants and this lead to CAM use because many of these adverse effects were untreatable, unpleasant or caused other illnesses.

Phase 2 illustrated CAM was used to overcome biomedical adverse effects, and/or to minimise the harm from such adverse effects. Other research has consistently shown CAM was used to treat symptoms associated with treatment (Boon et al., 2000; Mizdorf et al., 1999; Palinkas & Kabongo, 2000).

GD 2 points out the way in which biomedical physicians dealt with the issue of adverse effects that were life-limiting or life threatening caused a loss of confidence in the both in biomedical treatment and in the physician. For instance, when biomedical physicians prescribed medicines known to be "lethal" to treat an adverse effect of a prescribed drug, this led to a rejection of biomedicine and to CAM use, as an alternative. The presentation of harmful medicines by biomedical physicians resulted in a loss of confidence in the biomedical physician's ability/knowledge because the participants could not understand why their health/life was being put into further jeopardy. In addition, adverse effects of biomedicine triggered CAM use for numerous other reasons.

Participants who used CAM in lieu of hormone replacement therapy (HRT) did so because they were aware of the association between cancer and HRT. This meant CAM was

used to avoid some biomedical treatments. These reasons were linked to the reasons for using CAM as preventive treatment and as treatment without adverse effects, as shown in GD 1.

More importantly, adverse effects/events motivated CAM use predominantly for five reasons. The first reason was that some adverse events such as hepatitis C were untreatable. This was perceived as a biomedical failure, so CAM was used to find effective treatment, as shown in GD 1. This shows that CAM was used to compensate biomedical inadequacies. The second reason was that biomedical attempts to treat adverse events, such as iron overload, caused physical and emotional discomfort, such as pain caused by nightly injections of prescribed medicine. Thus, as noted CAM was used for relief and comfort. The third reason was that biomedicine failed to cure illnesses, such as heart disease and hepatitis C, the adverse effects/events of treatment. This reason again adds to the concept that CAM was used for curative purposes. The fourth reason for CAM use was that biomedicine was not capable of treating subsequent co-morbidities, such as hepatocellular carcinoma, arising, for example, from adverse events, such as hepatitis C. This reason shows CAM was used because of a loss of confidence in treatment because it was limited. The fifth reason for CAM use was the perceived lack of care and the absence of a caring manner that treating biomedical physicians displayed during and post treatment for adverse effects, such as hepatitis C. This reason shows CAM was used because of a loss of confidence in biomedical physicians.

GD 2 shows CAM use was motivated by adverse effects and it also shows that the rationale to use CAM was associated with biomedical failure, a loss of confidence in treatment and dissatisfaction with biomedical physicians. GD 2 suggests CAM was used to avoid biomedical treatment and biomedical physicians and as a substitute treatment when biomedicine was rejected because of dissatisfaction with biomedical treatment, and/or physicians.

Kappauf et al. (2000) concluded dissatisfaction with biomedicine was not a contributing factor to the use of CAM and that the use of CAM might be related to a person's perception of the disease's unfavourable diagnosis, rather than to its medically expected

outcome, and efficacy of treatment. Conversely, GD 2 illustrated dissatisfaction with biomedicine was a major contributing factor to CAM use because biomedicine was not effective. Such dissatisfaction was related to experience of ineffective treatment, rather than to the person's perception of efficacy as suggested by Kappauf et al. (2000). The findings illustrate that failure of biomedicine lead to a loss of confidence in biomedical physicians often because the information they relayed to participants confused them or was perceived as not being accurate. Such perceptions were given momentum by illnesses that CAM 'cured'.

The findings show that whilst feelings and beliefs contributed to CAM use, such perceptions were based on knowledge such as; treatment was known to have adverse effects and personal experience of adverse effects from biomedical treatment. GD 2 indicates bad experiences with biomedicine, rather than perception was a prime motivator of CAM use. This finding is supported by many other studies of people with serious illnesses (Adler & Fosket, 1999; Boon & Brown 1999; Standish et al., 2002) that found CAM was used because of adverse effects of biomedicine.

GD 2 points out that dissatisfaction with biomedicine was a prime reason for using CAM because biomedical treatments made participants often feel worse, rather than better. This finding illustrated that in people with chronic illnesses who must have biomedicine to survive, such treatment, which effectively is palliative, was not sufficient because it harmed and was often ineffective.

General dimension (GD 3). Illustrates the use of CAM was about self-determining health-care by participating actively in treatment decisions. GD 3 was about being a proactive participant, rather than a submissive recipient of health care. Hence, self-determination, in this study meant using CAM to take control over health care decisions, which is supported in the findings of GD 2. GD 3 indicated CAM was used to do "what is best", when, as shown in GD 2, biomedicine had failed to provide relief or to cure an illness. GD 3 points out CAM was used to do "something", when biomedicine could do not more, as opposed "to sit[ting] back and just take[ing] it", despite biomedical physician advice to the contrary.

In this general dimension participants expressed their determination to use treatments considered “best” for overcoming illnesses and the biomedical treatments with which they would comply. For example, participants who reported using CAM in lieu of biomedical pharmaceuticals considered lethal, as shown in GD 2, illustrate “doing what is best”. GD 3 confirmed the findings of GD 1 and GD 2 by demonstrating that a desire to control health matters was related to a loss of confidence in biomedical treatment and/or physicians, because participants considered some of the treatments and the practitioners’ decisions threatened their health. GD 3 indicated that participants stated that CAM use was a way of overcoming threatening biomedical situations and events such as hepatitis C and terminal illness. These findings show as found by Scheier and Carver (1992) that proactive health care behaviour motivated the drive to seek out the most appropriate treatments.

GD 3 suggests as found Davidson, Geoghegan, McLaughlin and Woodward (2004) found CAM users have notably higher levels of anxious preoccupation and fighting spirit. Whilst people displaying anxious preoccupation have been described as being persistently anxious, seeking information about their illness and tending to interpret this information negatively (Greer, Moorey & Watson, 1989). The findings of GD 3 suggest that pre-occupation with health matters and subsequent CAM use is not necessarily a morbid phenomenon, reflecting anxiety and depression (Burstein et al., 1999; Vandecreek et al., 1999), rather it reflects frustration with limitations that chronic illness presents. Therefore, CAM is used to overcome such limitations and not used as an expression of anxiety but a way of improving physical well-being, which as found in this thesis was measured by the participants as change in physiological indicators, improved emotional well-being and cure for some co-morbidities. These findings coincide with those of Verhoef, Mulkins and Boon (2005) who found CAM users identified values of quality of life such as, effective pain management and increased physical well-being, as end goals for CAM use.

GD 3 indicates the use of CAM was a display of fighting spirit because taking control was associated with finding treatments that could improve illness. Such behaviour is not

consistent with a fatalistic attitude. Hence, this study suggests as Davidson, Geoghegan, McLaughlin and Woodward (2004) found in people with cancer who used CAM had a more internal locus of control than non-CAM users. This is consistent with the research of Marks, Richardson, Graham and Levine (1986) who reported that internal locus of control was associated with a variety of positive health practices and improved physical and psychological functioning.

The findings of GD 1, 2, 3 indicated CAM was used to preserve, maintain health and to treat specific ailments. Researchers have generalised that CAM used for preservation and health maintenance are lifestyle practices, rather than treatment for specific ailments (Kessler et al., 2001b; Oldendick et al., 2000). For those with serious/chronic illnesses the findings of this study suggest CAM is not a lifestyle decision, but a form of treatment.

General dimension 4 (GD4). The findings illustrated as other studies have shown that CAM was used because it was effective and safe and CAM practitioners had interpersonal and diagnostic skills, which participants valued (Boon et al., 2000; Oldendick et al. 2000; Shumay et al. 2002; Biddle, Simpson & Wilkinson, 2003; Spiegel, Stroud & Fyfe, 1998; Standish et al., 2001). GD 2 indicated CAM was used because these attributes were lacking in biomedical care and this caused a loss of confidence in biomedicine. GD 4 shows CAM was used because it provided effective relief of symptoms and signs such as shortness of breath and pain, which as shown in GD 2 biomedicine failed to do.

In an American national study participants reported CAM therapies were more helpful than biomedicine for the treatment of headache and neck and back pain (Eisenberg et al., 2003). The participants of this present study considered CAM was more effective than biomedicine for treating recalcitrant illnesses such as chronic infections, irritable bowel and migraines, which biomedicine failed to treat after numerous attempts, as shown in GD 2.

The findings of GD 4 also suggest that participants considered CAM was better at maintaining and improving their health post blood transfusions and better able to deal with the psychological distress, as GD 2 and GD 3 showed. GD 4 showed the participants pursued

CAM treatments because they did not have adverse effects associated with biomedical care.

GD 4 shows that CAM was considered safe and beneficial treatment.

GD 4 indicates CAM practitioners did not patronise participants and expected them to be proactive recipients of care rather than passive takers. GD 4 illustrates participants considered CAM practitioners provided correct advice, “honest information”, and that they had good clinical skills that were reflected by the treatment they prescribed, which participants believed they had benefited from. GD 4 shows CAM practitioners had the skills, which encouraged participants to continue with biomedical treatment.

GD 4 illustrated that the participants considered CAM practitioners offered consultations in an environment that was not time limited. This finding contrasts with the finding in GD 2 that showed participants considered some biomedical consults a waste of time because they were not friendly and conducive to open dialogue. Whilst a study of 435 people with cancer reported they spent too much waiting in hospital (Davidson & Mills, 2004) this current research showed ‘a waste of time’ referred to the quality of the consult.

GD 4 indicates participants were compliant with CAM treatments because of the skills of CAM practitioners, but more so because outcome of treatment was accurately represented.

Future Research

The findings suggest CAM improved the health status of the participants. Future research could examine and evaluate those CAM that reportedly benefited the participants.

This research points out that people are more likely to adhere to treatments that are considered safe and that safety was often associated with outcome of treatment. Future research could evaluate and examine whether such an association is only made for CAM treatments or also held for biomedicine.

It would also be interesting to examine if a CAM treatment had adverse effects as some biomedicines, such as chemotherapy, whether CAM would still be considered safe and effective. This is important because this study has shown that participants hold the view that

CAM medicines are natural and therefore safe, despite evidence showing adverse effects can occur with CAM.

The findings suggest that CAM was used for curative purposes. Future research could delve deeper into the belief held by participants that CAM could provide a cure. The question of a cure could be followed through by not only examining what people with a chronic illness seek from CAM, but also by investigating what they seek from biomedicine because as suggested by the findings people seek the same outcomes and have the same expectations of CAM as they do of biomedicine.

The findings suggest fighting spirit and taking control of health matters was associated with seeking better treatment outcomes and higher locus of control. It would be interesting to examine further the impact of “fighting spirit” versus “fatalistic attitude” and whether these relate to locus of control. Future research could examine survival rates in people with chronic illness and/or serious illnesses who use CAM and biomedicine and compare them with those who only use biomedicine.

The findings suggest that some participants were in denial when faced with poor prognosis and this made them rally against biomedical advice and triggered CAM use. It would be interesting to examine the concept of denial in relation to health behaviour. This is important because denial is usually seen to be a negative aspect that inhibits or leads to a rejection of biomedicine. In contrast in this research ‘denial’ motivated a search for something that might have benefit.

This research illustrated that people are more likely to comply with treatment when the treating practitioner was forthright and empathetic. Future research could examine the consultative techniques used by CAM practitioners and compare them with those of biomedical practitioners.

In this research the findings illustrate that people who require biomedical treatment from birth rely on practitioner skills, not only treatment to make them better. Future research needs to evaluate the value personal interaction plays in healing. This research indicates that

people with a life-long illness who undergo intensive biomedical treatment are highly subjective to the kind of consultative process that is not rushed. Future research could examine and compare the outcome of treatments prescribed in a rushed manner with those prescribed in an environment that is not time driven.

The findings illustrate that the participants perceived CAM practitioners were better able to treat effectively because they treated the cause and the symptoms of an illness. Future research could examine how CAM practitioners incorporated this praxis into the treatment regimen and whether this accounted for the perceived success of CAM treatments. It would also be interesting to examine the views held by CAM practitioners and biomedical practitioners of causative factors because this research showed the participants did not believe that biomedicine treated the cause of an illness.

This research showed the participants believed CAM practitioners at times had better biomedical knowledge and/or were prepared to share it with participants. Future research could examine whether people's perceptions of CAM practitioner skills are in part based on CAM practitioner knowledge of biomedicine or whether perceived biomedical knowledge is based on associative factors such as the efficacy of CAM.

The findings suggest CAM was beneficial and improved the participants' health status. Future research could examine and compare the health status of people with a serious illness who use biomedicine and CAM concurrently with those that only use biomedicine.

Conclusion

Phase 2 of this research indicated that people with TM recognise that TM is an incurable illness and that pathogenesis of the illness means they will eventually succumb to the sequelae of TM. The findings of Phase 2 suggest people with TM use CAM to avoid an early death and a life complicated by more illness. Thus, Phase 2 indicated CAM was used as treatment to survive and decrease morbidity.

The findings show that CAM use was encouraged rather than discouraged by the negative views biomedical practitioners held toward CAM. This is an important and unique

finding because it highlights the importance of assessing patient perception of the quality and information content of communication.

Whilst, Phase 2 showed that a loss of faith in biomedical practitioners motivated CAM use, often because biomedical practitioners were perceived as being “less than open and honest” or “threatening”, the findings suggest, that CAM use was first motivated by need. This meant prevailing health problems that did not respond to biomedical care and/or when biomedical treatment threatened health, were prime motivators for CAM use. Thus, negative interactions with health-carers motivate CAM use, only when the treatment they prescribe was considered harmful or ineffective. Thus, the findings show CAM use was motivated by a loss of faith in biomedicine. Hence, the findings in Phase 2 suggest a loss of faith in biomedicine and subsequent CAM use in this context was associated with defensive behaviour.

CHAPTER 6: PHASE 3 REASONS for CAM DISCLOSURE by PEOPLE with an HAEMOGLOBINOPATHY

In this chapter, I present the third part of the analysis and interpretation of data gathered in this thesis, addressing the reasons for CAM disclosure. As discussed in chapter 3 the purpose of Phase 3 was to understand why people choose to disclose/not disclose their use of CAM to treating biomedical physicians. In Phase 1, 12 of the participants reported they were CAM users and only one person reported disclosed CAM use. Data gathered in Phase 1 on the substances and therapies the participants used suggested all were CAM users. Subsequently, all participants were interviewed in Phase 2, which confirmed the finding of Phase 1 that there were 21 CAM users. Hence, all of the participants were interviewed in Phase 3.

The general dimensions and themes are presented in Table 6.1 and represent the concepts and their relationship to one another.

Illustrated in Table 6.1 is the hierarchic development of the themes for reasons for CAM disclosure. As shown in Appendix 7, 90 raw data statements were identified and grouped into first-order themes. There were 20 first-order themes, which were further classified into nine second-order themes. Finally, the second-order themes were grouped under 4 general dimensions. The four general dimensions are disclosure of CAM, attempted CAM disclosure, abandoned CAM disclosure and non-disclosure to treating physician(s). Each general dimension is addressed in turn. The description of the general dimension includes identification of the second-order themes, within which the lower-order themes are discussed.

General Dimension 1: Reasons for CAM Disclosure

The general dimension, disclosure of CAM use is about the reasons participants gave for informing their biomedical practitioners about their CAM use. This general dimension

reflects how the participants used CAM disclosure as a way of trying to engage biomedical physicians in discussion about the use of CAM.

Table 6.1: *Hierarchical Development of Reasons for CAM Disclosure*

First-Order Themes	Second-Order Themes	General Dimension
Wanted to gauge biomedical practitioner's view of CAM	Wanted information about CAM	Disclosure of CAM use
Wanted specific information about CAM		
Continued CAM disclosure because of loss of confidence in biomedicine	Disclosed because of dissatisfaction with biomedicine	Disclosure of CAM use
Continued CAM disclosure because of loss of confidence in biomedicine		
Wanted biomedical physician to know		
Participant wanted guidance about CAM	Tried to discuss CAM use	Tried to disclose CAM use
Participant did not receive information about CAM	Biomedical physician against CAM use	Abandoned CAM disclosure
Negative feedback from B/M practitioner inhibited future CAM disclosure		
Biomedical physician against CAM use		
Denial of CAM use		Non-disclosure of CAM use
CAM use would make treating physician angry		
Avoid negative interaction with biomedical physician		
Biomedical physician discouraged CAM use		
Continued CAM disclosure because of loss of confidence in biomedicine	Disclosed because of dissatisfaction with biomedicine	Disclosure of CAM use

Table 6.1: *Hierarchical Development of Reasons for CAM Disclosure*

First-Order Themes	Second-Order Themes	General Dimension
Wanted biomedical physician to know	Disclosed because of dissatisfaction with biomedicine	Disclosure of CAM use
Participant wanted guidance about CAM	Tried to discuss CAM use	Tried to disclose CAM use
Participant did not receive information about CAM	Biomedical physician advised against CAM use	Abandoned CAM disclosure
Negative feedback from B/M practitioner inhibited future CAM disclosure		
Biomedical physician against CAM use		
Maintain privacy to prevent negative consequences	Maintain privacy	Non-disclosure of CAM use
Unhappy with past encounter biomedical practitioner	Unhappy with biomedical practitioner	
Treating physician advised against CAM	Biomedical physician never asked about CAM	
Biomedical practitioners not concerned about CAM use		
Participant never thought to disclose CAM use	CAM not discussed with treating physician	
No point in discussing CAM with B/M practitioner		
CAM not discussed with treating physician		
No mutual sharing of information		

Table 6.1: *Hierarchical Development of Reasons for CAM Disclosure*

First-Order Themes	Second-Order Themes	General Dimension
None of the biomedical physician's concern	Biomedical physician does not need to know	Non-disclosure of CAM use
CAM not harmful		
CAM does not interfere with biomedical treatment		

This general dimension is about seeking advice about CAM use as a method to inform biomedical practitioners of CAM use and proposed CAM use. This general dimension is also about the reasons the participants gave for continuing to disclose the use of CAM. The themes that reflect the participants' reasons for disclosing the use of CAM are represented in the second-order and lower-order themes. CAM disclosure had two second-order themes; wanted information about CAM and disclosed because of dissatisfaction with biomedicine.

Researchers have never previously questioned the definition of CAM disclosure. I found during the analysis of CAM disclosure that it was difficult to categorise people who instigated CAM discussions with their biomedical practitioner. I decided that people who asked their biomedical practitioners about CAM were disclosers because to disclose is "to make known or reveal" (Sykes, 1982, p. 273). Hence, there were five CAM disclosers who asked their biomedical physician for information about possible alternatives to biomedicine and about CAM products that could possibly help them. I decided that seeking information from a treating biomedical practitioner about treating or helping to improve the health of participants with CAM was one of the methods chosen to disclose CAM.

There is validation for attributing the seeking of CAM information from a biomedical practitioner as disclosure because all of the participants who sought CAM information decided to abandon further discussions about CAM and not to disclose CAM

use in the future. More importantly these participants considered they had disclosed their use of CAM.

There were two second-order themes, *wanted information about CAM* and disclosed because of dissatisfaction with biomedicine.

Second-order Theme: Wanted Information about CAM

This second-order theme is about disclosing the use of CAM because the participants wanted biomedical practitioner to provide information about CAM products and therapies. Many participants considered they had disclosed CAM use when they “mentioned” CAM and asked for information about CAM, as these statements show:

I have actually like, I have mentioned. I felt that for instance supplements and so forth can help improve the condition but basically I just briefly discussed that with him [biomedical practitioner] (P1).

I did tell like I said before. I wanted to know if they [CAM] could be OK and not dangerous that sought of thing (P3).

I did mention it [CAM]. I felt that for instance supplements and so forth can help improve the condition [TM] (P8).

There were two first-order themes: *Wanted to gauge biomedical practitioner’s view of CAM* and *wanted specific information about CAM*

First-Order Theme: Wanted to gauge biomedical practitioner’s view of CAM. When participants were asked again if they directly disclosed their use of CAM to their biomedical practitioner, most of the participants were guarded as shown in these statements:

Yes I did tell him [biomedical practitioner] when I asked him if there were some natural things we could use to help us (P1).

We were just having a general conversation about it [CAM]. I wanted to know if there were natural things that could help (P7).

I just asked him about it [CAM] because I wanted to know if it [CAM] could help (P10).

First-Order Theme: Wanted specific information about CAM. The first-order theme, wanted specific information about CAM is about disclosing the use of CAM because

participants wanted information about the products they were using. This theme is about seeking information about CAM to gauge how biomedical practitioners would react to CAM use prior to making a full disclosure. Some participants wanted to inform the treating physician about those CAM therapies they considered as possible biomedical replacements for 'lethal' drugs, as this statement shows:

I told him [treating biomedical practitioner about wanting to use [CAM] when I was looking for something other than the lethal drug they wanted to prescribe for my migraines (P3).

Some participants disclosed CAM use by asking the treating physician's opinion of a particular CAM treatment, as these statements show:

I asked him [biomedical practitioner] if he had heard of Bromelain [pineapple extract] because I didn't want to take Warfarin. I told him I wanted to take it instead of Warfarin (P3).

Before I started using the wheat grass I asked him [biomedical practitioner] what he thought and he just said it was up to me (P17).

Second-Order Theme: Disclosed Because Dissatisfaction with Biomedicine

The second-order theme refers to disclosure of CAM use or proposed use of CAM because the participants were dissatisfied with biomedicine. Many of the participants reported biomedical dissatisfaction was a reason for CAM disclosure, typified by the following responses:

Like I told you before, I was unhappy about one of the prescribed medicines I was being prescribed [by biomedical practitioner] because once you're on it, you're on it for life and it is really dangerous. I wanted an alternative and I told him (P3).

They couldn't help me with their [biomedical practitioners] drugs so I told them. I told them I was using it [CAM] (P11).

There were two first-order themes, *continued CAM disclosure because of loss of confidence in biomedicine* and *wanted biomedical physician to know*.

First-order theme: Continued CAM disclosure because of loss of confidence in biomedicine. The first-order theme refers to ongoing CAM disclosure motivated by

dissatisfaction with biomedicine. Only one person continued to disclose CAM use to the treating biomedical practitioner to express the negative feelings held toward an adverse event of biomedical that had caused harm, as this statement shows:

I kept telling them [about CAM] because everything they [biomedical practitioners] did, didn't work and I was mad because they caused the problem in the first place (P11).

The participant continued to disclose CAM use because biomedicine could not help and because the biomedical physician did not believe the participant that CAM was being used. This caused further dissatisfaction with biomedicine and provided the impetus for continued CAM disclosure, as shown in the following statement:

I keep telling them I use it [CAM] because they didn't believe I had a tumour on my kidney and by the time they found it I was really sick and had to be operated on, and I ended up in intensive care...given pain killers all the time I got addicted to morphine and they [biomedical physicians] couldn't help me. They [biomedical practitioners] didn't believe me when I said I was using it [CAM]. I just keep telling them that I do, because like I said they couldn't help me and because they didn't believe that I was using it [CAM] (P11).

First-order theme: Wanted biomedical physician to know. This first-order theme is about informing the biomedical practitioner about proposed CAM use. This theme is about informing biomedical physicians about CAM treatments proposed as alternatives biomedical treatment. Some participants reported they disclosed CAM because they were dissatisfied when biomedicine could only prescribe pharmaceuticals considered unsuitable, because they were "lethal" or "dangerous". Some participants chose CAM disclosure as a way of informing biomedical practitioners about the discontent they felt toward biomedicine. These reasons for CAM disclosure are expressed in the following response:

I did tell him I wanted to try something instead of warfarin I wanted something more natural...I gave my doctor the name of an alternative when I was looking for something other than the lethal drug they wanted to prescribe for my migraines because I thought he should know that I was looking for something else. Basically I wasn't happy with some of the drugs they were prescribing and suggesting I take and I wanted him know. All they [biomedical practitioners] could do was to give me lethal drugs, and I wasn't happy about that. So I told him [biomedical practitioner] and that's when I gave him the name of an alternative (P3).

General Dimension 2: Tried to disclose CAM use

The general dimension, *tried to disclose CAM use*, refers to participants attempting to inform biomedical practitioners of their CAM use. In this general dimension the themes reflect the reasons the participants gave for attempting to disclose CAM and why such attempts never reached their main objective, which was to inform the biomedical practitioner of CAM use. The themes of this general dimension reveal that those participants who attempted to disclose CAM did so by using the topic of CAM in discussions with their biomedical practitioner. The themes show that the participants tried to keep CAM discussions at a level that did not actually imply to the biomedical physician that they used CAM. This general dimension had one second-order theme, attempted disclosure of CAM use.

Second-Order Theme: Tried to Discuss CAM use

This theme, *tried to discuss CAM use*, is about attempting to disclose CAM use by engaging the biomedical physician in discussions about CAM. Many participants were reluctant to fully disclose CAM use until the biomedical physician's views about CAM were known. Many participants reported they asked their biomedical practitioner for guidance about CAM because the participants wanted the biomedical physician to know about their CAM use. These reasons for CAM use are illustrated in these statements:

I tried to tell him because I wanted him [biomedical physician] to know I was going to use it (P1).

I tried telling him by asking him [biomedical practitioner] if Chinese medicine or naturopathy could help (P9).

I tried to tell him because I wanted him [biomedical physician] to know...I had to find out what he [biomedical practitioner] thought of it [CAM] first, because I heard he against it. So I just asked him about things [CAM] that could help us (P12).

I was already using it [CAM] but I wanted to know what he thought before actually telling him. You know, like I asked him if there were things we could use to help us (P21).

Some participants who attempted to inform the biomedical physician of intended CAM use suggested that they were thwarted by the negative response they received. Hence, they never disclosed CAM, so CAM disclosure remained an attempt to disclose, as this statement exemplifies:

When I asked him [biomedical practitioner] if Chinese medicine or naturopathy could help, he [biomedical physician] just told me it was a waste of money to use it [CAM] and that I shouldn't use it. So we never spoke about it [CAM] again (P21).

The second-order theme, tried to disclose CAM use, had two first-order themes; *wanted biomedical practitioner to know about CAM use* and *participant wanted guidance about CAM*.

First-Order Theme: Wanted biomedical practitioner to know about CAM use. This theme is about attempts to disclose CAM use because participants believed it was important biomedical physician to know about such use. Many participants considered practitioners should know about CAM use for their individual benefit and for the benefit of other people with TM, as these statements show:

I tried to tell him because I wanted him [biomedical physician] to know because I wanted to make sure that it was going to interfere with my other treatment (P1).

I tried telling him [biomedical physician] because I thought it was important for him to know...because it [CAM] could benefit others. I wanted other patients to try too because I saw real benefits from it and I thought by talking about it [CAM] with him [biomedical practitioner] he would be open to it [CAM] (P9).

First-order theme: Participant wanted guidance about CAM. This theme is about the attempts the participants made to disclose CAM because they were looking for guidance from their biomedical practitioner about the use of CAM. By seeking guidance about CAM use some participants reported they had made an attempt to disclose CAM use, as these statements show:

Well I did once try [to disclose CAM use] because I wanted him [biomedical practitioner] to guide me. You know tell me which ones [CAM treatments] might be dangerous and that sort of thing (P9).

I was trying to tell him [biomedical practitioner] when it [CAM] up in general conversation. I wanted him to give me some information...that's what I expected...you know some information about it [CAM] (P10).

Some participants suggested they attempted to disclose CAM because they wanted reassurance that CAM products were not harmful, as these statements show:

I tried to tell...I was expecting him to give me some guidance about which things I could have and which ones I couldn't (P12).

I was trying to tell him [biomedical practitioner]. So I've asked him [biomedical practitioner] about the natural medicines so I would know what was good and what wasn't. I really wanted to find out if what I was using was OK. Not dangerous and that sort of thing (P20).

General Dimension 3: Abandoned CAM Disclosure

The general dimension, abandoned CAM disclosure refers to the reasons the participants gave for not persisting with CAM disclosure. This general dimension is about abandoning CAM disclosure because the participants perceived biomedical physicians held negative views toward CAM. The themes of this general dimension refer to the reasons the participants gave for abandoning CAM disclosure after disclosing CAM use or attempting to disclose CAM use. This general dimension had two second-order themes; *biomedical physician advised against CAM use* and *biomedical physician against CAM use*.

Second-order theme: Biomedical Physician Advised Against CAM Use

The theme, *biomedical physician advised against CAM use* is about abandoning CAM disclosure because biomedical physicians advised the participants not to use CAM. This theme is about abandoning CAM disclosure because biomedical physicians did not provide CAM information when asked. Some participants' reported they became 'annoyed' with biomedical physicians who ignored initial requests for information about CAM and this triggered the decision to abandon any attempt to disclose the use of CAM. Many participants reported they were annoyed because they could not be open with their treating physician. In this context, 'open' meant participating in health-care decisions by having

questions about CAM answered. Some participants suggested when biomedical physicians communicated their distrust of CAM as a way of advising them not use CAM, they were viewed as controlling health health-behaviour and this was given as reason for abandoning CAM disclosure. These reasons for abandoning CAM disclosure are illustrated in these statements:

He told me not use anything. We never talked about it [CAM] again because he annoyed me the way he was just telling me what to do, instead of explaining things (P 6).

I was told not to go there [not to use CAM] because it wasn't good. I came out of there [consulting room] thinking hey, he didn't answer your questions, as usual. So I decided then and there that if that was how it going to be I wouldn't say anything again (P 18).

The second-order theme, *biomedical physician advised against CAM use* had four first-order themes; *participant did not receive information about CAM*, *negative feedback from biomedical practitioner inhibited future CAM disclosure*, *biomedical physician advised against CAM use* and *biomedical physician against CAM use*.

First-order theme: Participant did not receive information about CAM. This first-order theme is about abandoning CAM disclosure because many participants reported they did not receive the information they sought about CAM from their biomedical physician. This theme is also about abandoning CAM disclosure because the information the participants sought about CAM was dismissed by biomedical physicians, and was replaced with advice about not using CAM.

Some participants reported they decided to abandon CAM disclosure when the information they sought about CAM was an admission by the biomedical physician that he/she "didn't know enough about it". Some participants reported they decided not disclose CAM to their treating physician in the future because the advice they received about CAM was prefaced with a self professed lack of knowledge about CAM. These reasons for abandoning CAM disclosure are exemplified in the following statements:

I wanted to know about it [CAM] that's not what I got...he just told me not to use it [CAM]. So I wasn't ever going to bring up talking about it [CAM] again (P 1).

He said [biomedical physician] he didn't know enough about it [CAM]. When I pushed for more information he told me not to use it and started carrying on about not being able to control the dose and those sorts of things....So like I said there was no point in discussing it with him, so that was it, I decided never to talk about it [CAM] (P 3).

I felt that for instance supplements and so forth can help improve the [TM] condition. He[biomedical physician] didn't answer my questions just told me not use it...if he was going to be like that then I wasn't going to tell him anything again (P8).

Many participants reported they wanted to be informed rather than told because they wanted to participate in health-care decision-making. Some participants reported one of the ways of achieving this was by having their questions about CAM answered by the biomedical physicians. Some participants reported when biomedical practitioners failed to answer questions about CAM they were considered to be seeking to control their health-care behaviour. Some participants explained such perceptions as another example of how biomedical physicians "want to know everything", and "control everything". These views for abandoning CAM disclosure are illustrated by the following statements:

When I tried to tell him about what I was going to do he just went into the crap about not knowing this and that about it [CAM], which like I told you was his way of saying "don't use it". But one of things that really annoyed me was the way they want to know everything about you, but even won't share information with us that is about us and I just thought if 'that's how you are going to be I won't ever tell you anything again' (P13).

They don't answer our questions about anything and I got zilch about alternative medicine except "don't use it" because they want to control everything. So I decided if they weren't going to answer my questions I was never going to mention it again [CAM] (P14).

First-Order Theme: Negative feedback from biomedical practitioner inhibited future CAM disclosure. This first-order theme is about not pursuing CAM disclosure because CAM discussions with the treating physician were not constructive. Some participants suggested that unconstructive discussions about CAM were those that focused on

disapproving of CAM, rather than offering an objective and balanced point of view.

Some participants considered such counsel biased because biomedical physicians did not provide enough information with which to make decisions about health-care. Some participants decided to abandon CAM disclosure when biomedical physicians commented negatively about CAM and at the same time delivered counsel not to use CAM, as these statements show:

Basically pretty negative I could feel basically that he [biomedical physician] didn't agree with that [CAM] or that he felt it was like a waste of time or whatever that it was just up to the individual but it [CAM] didn't really do anything so that was basically as far we went and I don't think I've ever discussed it ever since (P7).

You can only try but when they [biomedical practitioners] don't answer your questions but order you not to use it [CAM] you give up. Especially when they tell you that it's [CAM] crap and you know that's not true (P19).

Some participants considered negative CAM information that came from biomedical physicians was biased because it was based on "his opinion", and contrasted with their experience of CAM. Some participants considered this was reason to abandon CAM disclosure:

I decided I would never talk or try to talk about alternative medicine again after he just bagged it and bagged it without even considering that it could be good, or even saying that he had evidence that such and such was bad. No he just bagged it. It didn't make me feel good because here I was getting benefit out of it. Anyway it was only his opinion...you can't rely on that if you want to stay alive (P7).

Look the reason I said I would never talk about it to him again is because he is basically unfair toward it [CAM]...if I went to my boss and gave him a report on why we should do something and didn't back it up with some hard cold facts, he would just laugh at me or worse sack me. Well I reckon, telling someone they shouldn't do something because you don't like it [CAM] is even worse when you are dealing with peoples' lives. I don't consider myself so stupid that I would keep using something if it weren't good for me...it [CAM] wasn't making things worse and he [biomedical practitioner] went off at me...so what chance have you in dealing with someone who can't see what is in front of them. Whenever he speaks about it [CAM] it's all doom and gloom, there's never an upmarket beat about it ever (P 10).

Some participants reported CAM disclosure came to a halt when biomedical physicians were perceived as being 'rude', as shown in these comments:

He said [biomedical practitioner] that it [CAM] as a whole was harmful and that we shouldn't use it. I didn't agree. They [biomedical physicians] just said I should take advice and not to use [CAM] and that was it we never talked about it again. That's pretty damned rude I reckon. I don't just take advice. I wanted information and he [biomedical physician] was telling me what to do and he didn't even know if what I was doing was good or bad. He didn't wait or ask me if I had improved because of what I was using (P 10).

I tried to tell them about what I do because it might important and it might help others but when he [biomedical practitioner] laughed, how bloody rude is that and insensitive

...I just thought why bother if he thinks it's [CAM] a joke...he was sort of telling me that I didn't know what I was doing...but I've only seen good from the [CAM] treatments I've used so I know what I am doing...he's so stuck on one way of treating. He only thinks his medicine is good everything else is bad (P13).

First-order theme: Biomedical physician advised against CAM use. This theme is about the participants resolve not to disclosure CAM use in the future because biomedical physicians advised against such use. This first-order theme refers to the abandoning CAM disclosure because biomedical physicians were not sympathetic toward the use of CAM. Many participants considered biomedical physicians who advised against CAM use were not interested in what they had to say but rather they were interested in controlling their behaviour, which they did not consider was in their best interests. Many participants suggested that attempts to control their decisions about health care provided the impetus to abandon CAM disclosure, as this statement shows:

He [biomedical practitioner] just told me not to use it [CAM] so I never mentioned it again. Because he wasn't really interested in what I had to say he just wanted to know what I did outside the hospital and if it didn't measure up to what he wanted then he was against it (P1).

When he told me not to use it [CAM] and ignored the questions I asked him about natural things, I thought to myself he is a control freak. So I just thought I won't even try and talk about it anymore. I mean there's no good reason for them to stop you using it [CAM] except maybe it means they don't really know what is working and what isn't, which means they don't really care about us, only about using us a guinea pigs. Well you know what they do with experimental animals they control everything that is done to them, and that's what we are (P10).

Many participants irrevocably decided to abandon CAM disclosure when they considered biomedical physicians were against CAM. These statements illustrated these reasons:

What more can I say he was against it is against it [CAM]. I will never even try to talk to him about it again (P7).

You can't communicate with someone who has one point of view. He was so against it [CAM]. He just made no sense, talking about how bad it was and all that crap and that we shouldn't use it. I decided not to talk about it [CAM] ever again (P9).

General Dimension 4: Reasons for Non-Disclosure of CAM Use

The fourth general dimension, reasons for non-disclosure of CAM use refers to the non-disclosure of CAM use because biomedical practitioners were considered by the participants to hold negative sentiments about CAM, to be intolerant of CAM use and because they discouraged CAM use by various tactics, such as not facilitating open discussions and providing information about CAM. In this general dimension the negative responses that the participants suggested biomedical physicians made and held toward CAM were central to many of the reasons the participants gave for non-disclosure of CAM use. For instance, some participants reported that they did not report CAM use because biomedical physicians were against CAM use, a notion that was triggered by hearsay from other people with TM who attended the same biomedical practice and from personal communication with biomedical physicians. How these two central assertions informed the reasons given by the participants for non-disclosure are elaborated on in the second-order themes. This theme is also about denying the use of CAM as method of not disclosing such use. This general dimension refers to non-disclosure of CAM use because the participants wanted to maintain a separate life away from biomedical care and because CAM disclosure was considered not necessary because it was not relevant to their biomedical treatment. There were six second-order themes in this general dimension; *biomedical physician against CAM use, maintain privacy, unhappy with biomedical practitioner, treating physician never asked about CAM, CAM not discussed with treating physician* and *biomedical physician does not need to know*.

Second-Order Theme: Treating Physician against CAM Use

This second-order theme, treating physician against CAM use is about the participants not disclosing CAM use because treating physicians were considered to be unenthusiastic and unsupportive about such use. Many participants reported hearsay and

personal experience about how biomedical physicians felt about CAM use were the basis for their non-disclosure of CAM use. Many participants suggested biomedical physicians who held and expressed negative opinions of CAM, gave them reason not to disclose CAM use. Some participants explained that such opinions reflected that the biomedical physician did not want to discuss CAM. Some participants reported negative statements made by biomedical physicians included suggestions that the participants should not use CAM and this was given as a reason for not disclosing CAM use. These reasons for not disclosing CAM use are reflected in this statement:

He just started to say how bad it [CAM] was. That it was dangerous and all that sort of crap and then he said “but you know that of course, and wouldn’t use it, would you?”. I didn’t answer him to be honest because I just thought, if he really wanted to know he should have been prepared to talk about it properly (P14).

Some participants reported that when they heard the treating physician berating other people with TM about CAM use, this gave them the resolve not to disclose CAM because they felt if they did disclose CAM use, they would be admonished, as this statement typifies:

I’ve heard him [biomedical physician] going off at others [people with TM] who were using stuff [CAM] to help them, and I so I don’t say anything to him because I don’t want to be told off like a child (P18).

This second-order theme had five first-order themes; *biomedical physician against CAM use, denial of CAM use, CAM use would make treating physician angry, avoid negative interaction with biomedical physician* and *biomedical physician discouraged CAM use*.

First-order theme: Biomedical physician against CAM use. This first-order theme is about not disclosing the use of CAM because biomedical practitioners were against CAM use. This theme is about not disclosing CAM use because some participants considered biomedical practitioners were unjustified in the way they represented CAM. Some of the participants suggested that most of the people with TM knew the treating biomedical

physician was against CAM and gave this as a reason for not disclosing CAM.

These statements reflect these reasons for not disclosing CAM use:

We, well when I say we, most of us know he doesn't like the alternative stuff so we don't tell him (P4).

Yeah, I reckon that most people don't tell him [treating physician] about what they use because they know he's against it (P5).

Some participants who were advised not to use CAM by their biomedical practitioner did not disclose CAM use because the biomedical physician was against CAM use. Some participants did not disclose CAM use because of the manner in which biomedical physicians spoke about CAM, which the participants considered unprofessional and "not true". These reasons for not disclosing CAM are shown in these statements:

We all know he is against CAM, or whatever you called it, because he tells everyone not to use it. I've actually heard him go ballistic at someone about alternative medicine. I don't tell him about what I do because of that (P4).

I could feel basically that he [biomedical practitioner] didn't agree it [CAM]. I don't talk about it [CAM]. You know he doesn't like it [CAM] by the way he speaks about it (P7).

He [biomedical practitioner] didn't seem to like the idea...I don't want to tell him anything about what I do because he just is not professional when he talks about it [CAM] (P8).

He [biomedical physician] started saying how someone became very ill because they were using some alternative medicines and that the person risked their life...I knew he was against it [CAM] because he had just told me about this other person, for all I know it was probably not true anyway (P16).

First-order theme: Denial of CAM use. This theme is about denial of CAM use by participants in instances where the biomedical physician did ask about CAM use. Some participants reported that they denied using CAM because they knew or perceived that the treating physician was against CAM use. Some participants reported they denied the use of CAM because they did not want to be berated by the biomedical physician for using CAM. These reasons for denying CAM use, is exemplified in this statement:

He asked me once, but I denied it because I heard he's against it. I couldn't see the point in telling him, if all he was going to do was tell me off (P5).

Some participants denied their use of CAM because they suggested the biomedical physician indicated how opposed they were to CAM use prior to asking whether or not the participant had used CAM. Some participants reported such incidences influenced their decision to deny CAM use, as typified in this response:

He [biomedical physician] started saying how someone became very ill because they were using some alternative medicines and that the person risked their life. Then out of the blue he [biomedical physician] asked me if I was using alternative medicine, and I said “No” (P16).

Some participants suggested the biomedical physician’s questions about CAM use reflected the response the biomedical physician wanted to hear, and this led to a denial of CAM use, as this statement shows:

He [biomedical physician] sort of asked me about it [CAM] in a funny way, he just said, “Of course you wouldn’t use it, would you?” and I said “No”. If you go away and think about the time you spend with the doctor you soon realise they act like the police or lawyers. That means they ask you a question in the way they want it answered (P12).

First-order theme: CAM use would make treating physician angry. This theme refers to none disclosure of CAM use because disclosing the use of CAM would upset the biomedical physician. This theme is also about not disclosing CAM because CAM disclosure would jeopardise the manner in which participants were treated. Some participants reported they did not disclose the use of CAM because they had noticed a change of behaviour, or could feel the “vibes” toward people who used CAM. These statements reflect these reasons for not disclosing CAM to treating physicians:

Well they [biomedical physicians] don’t tell you they’re mad at you but you feel the vibes when you go in [for treatment]. So if you don’t want to cop it then it’s best not to say anything about what you do. It is best to keep it [CAM use] to yourself (P6).

I can’t see the point in upsetting them [biomedical practitioners]. It is best to say nothing. People who stand up to them [biomedical health care professionals] get treated differently. You know like, they don’t sort of treat you right and they’re rude when they talk to you (P16).

Some participants did not disclose their CAM use because they reported that biomedical physicians would be “furious” about CAM use because they did not want the participants to use CAM. Some participants reported that they did not disclose the use of CAM because biomedical physicians were against CAM because they did not believe CAM “worked”. These reasons for non-disclosure of CAM as provided by the participants were based on the participants’ perceptions and hearsay and are illustrated in the following statements:

They [biomedical practitioners] get pretty upset if we want to use other things [CAM]. What more can I say he’s against it so I’m not going to tell him (P15).

He would be furious, so I just don’t say anything because he thinks it doesn’t work. I know he doesn’t think it works because he has said it others (P17).

First-order theme: Avoid negative interaction with biomedical physician. In this theme, the reasons for non-disclosure of CAM centre on how the participants reported biomedical physicians did react when informed about CAM use. This theme is somewhat different to the previous one, because it does not focus on the perceptions and hearsay of participants, but on the experiences that the participants reported they had with biomedical physicians about CAM use, which triggered non-disclosure of CAM. Some participants reported they did not disclose CAM use because they wanted to avoid a repetition of previous unpleasant encounters with the biomedical practitioner when they did discuss CAM use, as this statement shows:

Well we have actually discussed it [CAM] in a round about way, now that you ask. I can’t exactly remember when, but he started to go on and on about how bad it was and that we shouldn’t use it... so I just avoid talking about it [CAM] (P14).

Some participants reported they did not disclose the use of CAM because they recalled how biomedical physicians reacted when their parents reported CAM use. In the following statement the participant recalls an incident about CAM disclosure from childhood that left an indelible effect, which triggered non-disclosure of CAM in adult years

because the biomedical physician's encounter with the parent threatened the family unit. The participant reported that this memory served to remind that biomedical physicians were against CAM use and gave this as a reason for not disclosing CAM use, as shown below:

When I was younger my mum told our other doctor [haematologist/ paediatrician] that she was giving me something to strengthen my blood and she was threatened. They told her that if she continued to give it to me, they would have me taken away. So, I know he would be upset and would tell me off, so why tell him something he doesn't believe in and would only get upset about? I can do without the aggro (P9).

First-order theme: Physician discouraged CAM use. This theme refers to some participants' non-disclosure of CAM because biomedical physicians never condoned the use of and/or disparaged CAM. This first-order theme is also about how biomedical physicians' represented CAM therapies as having no scientific validity. It is also about how biomedical physician's represented CAM as useless, harmful and dangerous, and or a waste of money. Some participants reported that they did not disclose CAM use because the biomedical physician would discourage such use, which was against their wishes. Some participants considered biomedical physicians were insensitive to their need for proactive decision-making. Hence, some participants reported they did not disclose the use of CAM because biomedical physicians attempted to dissuade participants from using CAM rather than allow them to decide whether or not to use CAM, as these statements show:

He [biomedical physician] just said I should take advice. Oh, by saying I should take advice he [biomedical physician] was telling me not to use it. Just because he [biomedical practitioner] doesn't like alternative medicine doesn't mean I shouldn't use it...it's me who decides what to do (P10).

I prefer not to tell them anything because they don't like [CAM]. They try and talk you out of it and I didn't want that. I wanted to have some say in what was going on...you know I wanted to discuss it [CAM] properly, so I could decide, not just be told what to do (P16).

He's against it, so why tell him? If you don't tell them what they want to hear, they don't want to hear it. Conversations with [biomedical] doctors is [are] a one-way street. That means shut up and do as you're told (P18).

Some participants reported one of the ways biomedical physicians discouraged CAM use was by saying they did not know enough about CAM. Some participants reported biomedical physicians often said they did not know enough about CAM and at the same time advised or implied they should not use CAM. This indicated to the participants that the biomedical physician was not prepared to put in the time to find out about CAM and this triggered non-disclosure, as this statement shows:

He [treating physician] said he didn't know enough about it [Bromelein] and that he couldn't control the dose. He wouldn't even put in the effort and time to find out about it. Well he [biomedical physician] just doesn't want us to use it [CAM] and so he just said he didn't know enough about it. If he were for it [CAM] he would have looked into it, instead of saying what he said. (P3).

Many of the participants considered biomedical physicians who suggested they knew little about CAM were actually expressing that they were against CAM use. Some participants reported biomedical physicians feigned a lack of CAM knowledge as a ploy to discourage CAM use, as exemplified in this statement:

They say [biomedical physicians] they don't know enough about the alternative medicines and things...well that's what they say. It's their way of telling you not to use it. Well because if the [biomedical] specialist doesn't know then it mustn't be good, that's what they want you believe...they just expect you do what they tell you to do, so it's better not to say anything (P17).

Some participants reported biomedical physicians prefaced advice about not using CAM by portraying CAM as "bad". Some participants reported that such information about CAM was not sufficient and when the biomedical physicians were challenged about such views, they responded in a defensive manner. This triggered non-disclosure because such comments reinforced participant's views that biomedical physicians disparaged CAM use to discourage such use, as shown in the following comments:

He [biomedical physician] was so against it [CAM]. He just made no sense, talking about how bad it was and all that crap and that we shouldn't use it. I decided not to talk about it [CAM] (P9).

It was all about how bad it [CAM] was and all that. When I didn't agree with what he was saying about it [CAM]. He [biomedical physician] just said I should listen

and not to use it [CAM]. So he wasn't really saying anything except "don't use it" because he is against it [CAM] and not because he had good reasons (P20).

Some participants reported they did not disclose CAM use because they did not want the biomedical physician to criticise or belittle them for using CAM, as these statements show:

I just don't bring it [CAM] up because he [biomedical physician] will just lecture me about why I shouldn't use it. Like I've heard him do to others (P4).

I prefer not to tell them anything because they don't like [CAM]. They try and talk you out of it by making you feel stupid (P6).

Many participants reported not disclosing CAM because biomedical practitioners offered little or no evidence to back up their claims that CAM was harmful when discouraging such use, as this statement shows:

I don't feel that a doctor is doing the right thing by telling you not to use something because they don't believe in it. Well what you believe in is not good enough in medicine, I mean they believe in the drugs they use and they are really harmful sometimes, and they never tell you that they are harmful. They [biomedical physicians] just make up the rules to suit themselves instead of finding out about it [CAM]. What they should be doing is encouraging us to do things and report back so they can learn and perhaps others [people with TM] will benefit (P3).

Just because he [biomedical practitioner] doesn't like alternative medicine doesn't mean I shouldn't use it. So we don't talk about it because I expect him to back up his statements rather than say things like that (P21).

Some participants considered treating physicians' negative stance against CAM use as unjustified because they were discounting experiential knowledge, and this triggered non-disclosure of CAM, as these statements show:

What more can I say? He's [biomedical physician] against it [CAM] so I'm not going to tell him because he is plain wrong in being so against it [CAM], because I know it [CAM] does good. Telling them [biomedical practitioners] it [CAM] is good is not good enough for them they want proof. Proof to them means tested in laboratories and that sort of thing, but look at all the bad drugs that have been tested, so what is proof? (P15).

We know our body better than anyone, and if we say it [CAM] is working they [biomedical practitioners] should listen, not put us down, because how many times have we told them their drugs are making us sick or that we are sick and they haven't believed us until we've been on death's door. It's the same for the alternative stuff.

They don't want to believe that it could be doing good. They just don't want us to use it...I'm not going to tell them what I do (P18).

Many participants reported not disclosing their CAM use because comments made by biomedical physicians were perceived to be biased and lacked foundation, as shown in these responses:

He told me it was a waste of money to use it [CAM] and that I shouldn't use it. After that I decided to shut my mouth because as far as I'm concerned I've paid excessive amounts of money to doctors for a five-minute consultation, where they haven't done anything (P1).

I'm a scientist and he knows that and when he said that there was no proof that it worked, I lost all faith in him...so I won't discuss it [CAM] with him ...I mean what is proof? Look at all the drugs and treatments we have, there is no proof they work. You know there are no scientific trials backing up our treatment. They know blood transfusions work because we live. I know CAM works because it makes me better, so what is the difference? (P3).

He said there was no scientific evidence to prove it [CAM] worked and that it is harmful. I never found it [CAM] harmful. I've been harmed by [biomedical] medicine but never by alternative stuff. So I just don't tell him because he's stuck on one way of treating (P4).

Second-Order Theme: Maintain Privacy

This second-order theme, maintain privacy, refers to non-disclosure of CAM use because the participants wanted to separate home and hospital care. The participants suggested separating home activities from hospital care was a way of maintaining their privacy. In this theme the participants considered CAM a separate matter from hospital care, and this was given as a reason for not disclosing CAM use, as shown in these statements:

What I do away from the hospital is my business...I'm not going to tell them what I do in the privacy of my home (P1).

You can't tell them everything. It's [CAM] a private affair. Well, because they [biomedical physicians] having nothing to do with it. I mean it [CAM] has nothing to do with the hospital because they [biomedical physicians] don't prescribe it (P2).

Some participants reported they did not disclose their CAM use to protect the sanctity of their home and family, as these statements illustrate:

We have a life outside the hospital. So what we do away from there is for us to know (P8).

I don't think he needs to know what teas I drink...really what I do at home stays home (P16).

They want to know everything...I like to keep some things private. Yes, my other medicines [CAM] and home life are my business (P18).

This second-order theme had one first-order theme that was *Maintain privacy to prevent negative consequences*

First-order theme: Maintain privacy to prevent negative consequences. These exemplars show illustrate this theme is about not disclosing CAM use because the participants wanted to protect their families and themselves from negative consequences that might occur as a result of disclosing. Some participants reported they did not disclose the use of CAM because disclosing CAM use to biomedical physicians would cause them to “stress” and possibly create conflict with the home by upsetting their partners, as this statement shows:

If I told them I used alternative medicine they would just stress me out because that would put thoughts in my head and even worse my husband's head that it is bad and then we would probably argue (P8).

Some participants did not disclose CAM use because informing the biomedical physician about what they did at home made them feel as though they were “always” in hospital. Some participants reported they did not disclose CAM use because they considered such private information should not be handed over to biomedical physicians who could use it against them in the future. These reasons for not disclosing CAM use are illustrated below:

Because if you tell them everything, you have no other life, you know it's like you are always there [in hospital]. Nah, I won't tell them about what I use or do at home, which they always want you to, it's just not on, it's my business...it's best not to tell them everything because they use it [information] against you. Well if you get sick they straight away blame the herbs or whatever, never what they are doing (P7).

I don't tell them about what I do...they only use it against you if something goes wrong. Yes, I think I can explain what I mean. There have been times when I've complained that something they [biomedical physicians] have given me has made me sick, and they just tried to blame me. You know like I didn't use the silly drug properly or didn't use it and that type of rubbish....even when it's their fault you get the blame. So imagine what they would do if they knew I use it [CAM] and I complained about some drug, they would blame the alternative stuff. What you do at home is best left at home if you want to stay sane (P18).

Second-order Theme: Unhappy with Biomedical Practitioner

This second-order theme, unhappy with biomedical practitioner is about not disclosing the use of CAM because biomedical physicians responded to participants' CAM use in negative fashion. This theme is about not disclosing CAM use because the biomedical physician's behaviour toward CAM and/or the participant was upsetting. Some participants reported they did not disclose their use of CAM because they did not like the manner in which biomedical physicians reacted toward CAM. Some participants reported they did not disclose CAM use because they did not like the way biomedical physicians handled their pleas for help. These reasons for non-disclosure are illustrated below:

It pisses me off they way they react about alternative medicines...I'm not going to tell them (P17).

He [biomedical physician] can be pretty evasive at times. You know like he will say something like "you're doing really well" and then go and order tests, that he hasn't told me about? So why should I discuss what I do with him? If he won't tell me what is going on with my body, I can tell you I am not happy and I will do everything not to co-operate. Yes, not telling him [biomedical practitioner] that I use alternative medicine is one way (P3).

This second-order theme had one first-order theme and this was *unhappy with past encounter with biomedical practitioner*

First-order theme: Unhappy with past encounter with biomedical practitioner. This theme is about not disclosing the use of CAM because past biomedical events and/or communication with the biomedical practitioner were objectionable and/or left the participant wondering what the consultation was all about. This theme is about not disclosing CAM use because a memory of a past encounter with biomedical practitioner was

so disagreeable it made some participants unhappy with the biomedical practitioner. Hence, this theme is about not disclosing CAM use as a form of reprisal. Some participants did not disclose their use of CAM because the biomedical practitioner's actions/words humiliated and angered them. Some participants reported they would not disclose their CAM use because biomedical physicians withheld information from them. These reasons for not disclosing the use of CAM are typified in the following responses:

After the way I was treated when I begged them for help there is no way I will tell them who [CAM practitioner] helped me (P18).

I don't want to tell them anything because they treat us like idiots. I had seen my doctor and then when I went to have my blood, the nurses said they were going to take some blood. When I asked what it was for they [biomedical nurses] said he [treating specialist] had ordered them. When I asked them to explain they said that he [treating specialist] should explain and I said he told me nothing. By this time I was becoming very angry, so I told them that I wanted the results and they said I couldn't have them, then I demanded they send them to my GP...I went ballistic and I now treat them the same way they treat me, they give me shit I give it back...no I will never ever tell them anything (P17).

Second-Order Theme: Treating Physician Never Asked About CAM

This second-order theme is about the not disclosing the use of CAM because biomedical physicians never asked about such use. This theme is about not disclosing CAM use because biomedical practitioners were not concerned about its use. The treating physician never asked in the context of this theme refers to biomedical physicians not asking about CAM in a direct manner, it is not about implied asking as discussed under the theme, denial of CAM use.

Some participants reported they did not disclose their use of CAM because the biomedical practitioner did not ask, as shown by these comments:

He [biomedical physician] never asked. They [biomedical physicians] never talk about it [CAM] (P2).

He [biomedical physician] never asked anyway (P9).

Some participants reported they did not disclose their CAM use because biomedical physicians who did not ask about such use were considered to be not concerned about CAM use, as shown by this comment:

But he's never asked anyway, so he is not fussed about it (P14).

The second-order theme had two first-order themes; *treating physician Treating physician advised against CAM* and *biomedical practitioners not concerned about CAM use*.

First-order theme: Treating physician advised against CAM. This theme is about not disclosing CAM use because the participants were not asked about such use but instead, were advised not to use CAM by the biomedical practitioner. Some participants reported biomedical physicians who advised against CAM use without asking first if CAM use was taking place were not deserving of a response, as shown in these statements:

They [biomedical physicians] never talk about it [CAM] properly, so why should I tell him after he ordered me not to use it? Besides he [biomedical physician] never asked, just told me not to use it (P2).

No one asked me. Anyway we know he doesn't want us to use it so he just makes snide remarks about how its bad and things like that (P4).

I'm not going to tell him [biomedical practitioner] because he [biomedical physician] told me not to use it without finding out if used it [CAM] (P9).

First-order theme: Biomedical practitioners not concerned about CAM use. This theme is about not disclosing the use of CAM because biomedical physicians did not ask about such because they were not interested in whether the participants were using it. Some participants suggested biomedical practitioners did not ask about CAM use because they were not interested in their welfare, as these comments show:

They're [biomedical practitioners] not really interested in us. In fact they don't care at all about us. We are just a number to them. If they were worried they'd ask but they don't ask (P18).

They're not worried about it [CAM]...so they don't talk about it [CAM] because they just don't really care about us (P20).

Some participants considered biomedical physicians did not ask about CAM use because they couldn't do anything about it, and if they couldn't control CAM use then they were not going to concern themselves with it. The following statement shows how these views triggered non-disclosure of CAM use:

They don't want us to use it...they are dead set against it, but they know they can't stop us from using it, so they just don't ask because then they can just pretend it's [CAM] not happening...you know why worry about something you can't do anything about? Not that they worry about it really (P15).

Second-order theme: CAM not discussed with Treating Physician

This second-order theme, *CAM not discussed with treating physician*, is about not disclosing the use of CAM because CAM disclosure was not an issue that preoccupied participants when consulting with biomedical practitioners because the time spent with the biomedical practitioner was limited and did not allow for discussions about CAM. This theme is about not disclosing the use of CAM because the participants never thought CAM was an issue that should be discussed. Some participants reported they did not disclose CAM because CAM as a topic had not come up during the biomedical consultation, as this comment shows:

We just never speak about it. Even when I wanted to talk about it, time was up and I was out the door (P12).

Some participants did not disclose their CAM use because they were preoccupied with other health issues, which they suggested biomedical physician brushed aside, as this comment shows:

I always go in with lots of questions for him [biomedical practitioner] but he never answers them, so how am I going to get answers about alternative medicine? My thoughts just aren't there at the time, anyway, so I suppose I just never thought about it [CAM disclosure] (P19).

The second-order theme, *CAM not discussed with treating physician*, had four first-order themes. The first-order themes were, *participant never thought to disclose CAM use*,

no point in discussing CAM with biomedical practitioner, CAM not discussed with treating physician and no mutual sharing of information.

First-order theme: Participant never thought to disclose CAM use. This theme is about not disclosing the use of CAM because some participants never thought to disclose CAM use because CAM was not a topic that could/should be discussed with the biomedical practitioner. Some participants suggested the decision to not disclose CAM use was made easy if they did not go into the consulting room with an agenda to discuss CAM, as this comment shows:

It's [CAM] not their area of expertise, so I don't really go in to see him [biomedical practitioner] to talk about it [CAM]. So if I don't bring it up then we don't have to talk about it. You know I'm not forcing him into an area, which is not his cup of tea, if you know what I mean (P16).

Some participants reported they did not disclose their use of CAM because they never thought disclosing such use was not an appropriate topic to discuss with the biomedical physician, when biomedical problems were being addressed, as this comment shows:

I don't really think about talking to him about it when I go to see him because I have a difficult enough time getting him to talk about the other things that he is supposed to know about and help me with (P17).

First-order theme: No point in discussing CAM with Biomedical practitioner. This theme is about not disclosing the use of CAM because there was nothing to be gained by informing the biomedical practitioner about such use because CAM was not their area of expertise. This theme is about not disclosing CAM because previous encounters with the biomedical physician left participants with the impression that there was no point in talking about CAM. Many participants reported not disclosing their CAM use because there was nothing to be gained because biomedical physicians did not know enough about CAM, as these comments show:

There's nothing good going to come out of talking or telling them about it [CAM]. I just don't think about it anymore after my experience. Like I told you he didn't know enough about it, so that's it (P3).

What's the use of telling them...it's not a point of discussion. They [biomedical physicians] only know one type of medicine and that's it, so they're against it, so there's no point in talking about it. We all know that, so why go there? (P4).

First-order theme: CAM not discussed with treating physician. This theme is about avoiding CAM discussions with biomedical physicians. Some participants reported they did not disclose their CAM use because they wanted to avoid talking about CAM and deliberately set out to avoid such conversations because talking about CAM was a fruitless exercise. This view for not disclosing the use of CAM is shown in the following comments:

It's [CAM] a no go zone and so I just avoid talking about it [CAM]. Like I will change the subject by talking about something totally different just like he [biomedical physician] does to us. Because there is no point in talking to him about it, so we just don't discuss it. I won't talk about it (P11).

It's just not talked about. You can't win any argument with them [biomedical practitioners] they're only going to upset you, so why bother if you can't get anything sensible out of them [biomedical physician] (P18).

First-order Theme: No mutual sharing of information. This first-order theme, no mutual sharing of information, refers to not disclosing the use of CAM because biomedical practitioners did not reciprocate information. This theme is about not disclosing the use of CAM because participants considered biomedical physicians held a tight reign on the information they were prepared to share. Some participants reported they did not disclose their use of CAM because biomedical physicians refused to answer their questions, as this comment shows:

They want to know the ins and outs of the cat's bum when it comes to us, but you just try and ask them a question and see what you get. Oh, I've asked him things about my health and even about alternative medicine and he [CAM] just ignored me. He ignored my questions by telling me not to use it [CAM]. I don't think that is fair, if I ask a question I expect it to be answered properly. I don't give them any information anymore. Not about me and definitely not about alternative stuff [CAM] see how they like it. I can tell you they don't like it but that's just bad luck because if they're not going to give me information I'm not either (P1).

Second-order theme: Biomedical Physician Does Not Need to Know

This theme, biomedical physician does not need to know, is about not disclosing the use of CAM because the participants did not consider that it was relevant for the biomedical physician to know about such use. This theme is about not disclosing the use of CAM because CAM was considered by the participants to be not harmful. This theme is about not disclosing the use CAM because the participants considered CAM did not interact with their biomedical treatment and therefore there was no need to for the biomedical physician to be informed about CAM use. Some participants reported not disclosing the use of CAM because they considered it was not relevant information, which should be shared with the biomedical practitioners, as this statement shows:

I don't think he needs to know what teas I drink. Yes, I know I told you I drink Camomile and things like that to help me sleep but is that really important? I don't think so. How ridiculous, that I should tell him about things that don't concern him (P16).

This second-order theme had three first-order themes; *none of the treating physician's concern*, *CAM not harmful* and *CAM does not interfere with biomedical treatment*.

First-order theme: None of the treating physician's concern. This first-order theme is about not disclosing the use of CAM because the participants did not believe CAM use was an issue biomedical practitioners should be concerned with. These statements reflect this reason for not disclosing CAM:

What I do at home is shouldn't concern them [biomedical] physicians]. I mean if he isn't worried about some basic things like my diet, which he should be interested in. Why should he be worried about alternative medicine because that is what a lot of it is, I mean it was a alternative doctor that told me which food to avoid because they had lots of iron in them, he didn't. So why should I tell him? (P15).

How ridiculous, that I should tell him about things that don't concern him (P16).

First-order theme: CAM not harmful. This theme is about not disclosing the use of CAM because participants considered CAM products were innocuous and therefore the

biomedical physician did not need to know if they were using CAM. These reasons for not disclosing CAM use are reflected in the following statements:

[Biomedical physician] don't need to know [about CAM use]. It doesn't make you sick. It doesn't do anything bad to you (P2).

What I take is not hurting me so I don't tell him (P5).

Some participants did not disclose CAM use because such use was beneficial they did not consider that the biomedical physician should be informed. Some participants felt some unease about not disclosing CAM because they felt that other people might be missing out on the benefits of CAM. The following statement represents these views:

What I take is not hurting me so I don't tell him. I have improved because of it, like I told before. I feel guilty for not telling 'em right that I'm doing something different and it's actually it's actually working and it might help some other patients (P5).

First-order theme: CAM does not interfere with biomedical treatment. This theme is about not disclosing the use of CAM because participants considered CAM did not interfere with their biomedical treatment. The following statements reflect this reason for not disclosing CAM use:

Well it doesn't interact with our other drugs so he doesn't have to know [biomedical practitioners] don't need to know about it [CAM use]...it doesn't affect our treatment (P2).

It doesn't affect the other drugs, so that's it...I won't tell him (P17).

I mean it doesn't interfere with my other [biomedical] treatment...so why should they know [CAM] (P18).

Most participants considered CAM use did not interfere with their biomedical treatment, but one person did report that if CAM was having a deleterious effect then they would disclose their use of CAM, as shown in the following statement:

I would...tell him [biomedical practitioner] if it [CAM] was affecting my treatment...it doesn't so he doesn't need to know (P3).

Discussion

This discussion reviews the findings of Phase 3 of the thesis, which focused on the reasons for CAM disclosure or non-disclosure provided by the participants of this study. This discussion compares the reasons for CAM disclosure reported in this study with those from other studies. There have been no studies of CAM use in people with thalassaemia major and consequently there is no previous knowledge of such peoples' level of CAM disclosure. Therefore comparisons are made with studies of people selected on the basis of other criteria. Conclusions drawn from each of the general dimensions are discussed.

Phase 3 showed that the decision to disclose was based on a number of factors and not on one reason. Some of the factors were linked, that is the findings of Phase 3 showed the decision to disclose CAM use was a process whereby participants drew upon particular experiences to inform their decision. Thus, this discussion considers the associations between the general dimensions. This illustrates the relationship of each general dimension to the reasons given for CAM disclosure/non-disclosure. Finally, in this discussion, future research is addressed that derives directly from the findings of Phase 3.

Relationship to Previous Research

Four general dimensions (GD) emerged from the inductive content analysis in Phase 3 of this thesis. The four general dimensions were CAM disclosure, attempted CAM disclosure, abandoned CAM disclosure and non-disclosure of CAM use.

General dimension (GD 1). This dimension was about disclosing the use of CAM to biomedical physicians because the participants sought information about CAM. The findings of GD 1 show that seeking CAM information from biomedical physicians was one of the methods chosen to disclose/broach CAM use. In the truest definition of revealing something, it could be said that seeking information about CAM is not CAM disclosure. As noted in the comments provided by the participants, however, they considered that by

seeking CAM information they had disclosed their CAM use to their treating physician. So, for the purposes of analysis, seeking information about CAM was considered disclosure because the meanings people assign to their behaviour are intrinsic to inductive methods of analysis.

GD 1 illustrates one of the ways participants tried to disclose their CAM use was by seeking information about CAM from biomedical physicians. GD 1 showed, as found in a study of women with cancer Powell et al. (2002), the participants initiated CAM discussions because they wanted information about CAM and their possible interactions with biomedicine. The findings of GD 1 showed some of the participants disclosed their CAM use because they wanted their biomedical physician to know about such use or intended use of CAM.

GD 1 indicated only one person was forthright in disclosing CAM use. In this case CAM disclosure was made for three reasons. The reasons the participant gave for CAM disclosure were anger toward biomedicine because of biomedical failure, because biomedicine could not help and because biomedical physicians did not believe what the participant was saying. CAM disclosure in this context was a way of showing a loss of confidence in biomedicine.

GD 1 illustrates dissatisfaction with biomedicine was a reason for CAM disclosure. GD 1 indicated CAM disclosure was a way of informing biomedical physicians informing biomedical physicians that an alternative to biomedicine was being considered. These are new findings for CAM disclosure.

GD 1 showed participants disclosed their CAM use because they wanted the biomedical physician to know about CAM use because they thought it was important for the treating physician to know about proposed and/or current use of CAM. This finding for disclosure of CAM use directly contrasted with results reported by other researchers who

found people with cancer (Adler & Fosket, 1999; Balneaves et al., 1999; Powell et al., 2003), attending primary physicians (Busse, Heaton, Wu, Wilson & Mills, 2005) and parents of children with asthma (Shenfield et al., 2002) did not feel it was important for the physician to know about CAM use.

GD 1 shows open communication with biomedical physicians about CAM was driven by biomedical failure, which was associated with dissatisfaction with biomedicine. In contrast, whilst research has shown (e.g. Sleath et al., 2001) communication with biomedical physicians restricted CAM disclosure and that biomedical dissatisfaction was not the reason for such non-disclosure. I could not find a study that examined whether dissatisfaction with biomedicine was a reason for disclosing CAM use. Hence, this appears to be a new finding for CAM disclosure. It is possible that the feeling of disillusion with biomedicine that was reported by participants in this research reflects the character of thalassaemia. Living with a lifelong illness, which does not improve and, typically, deteriorates despite frequent and intensive biomedical treatment, is likely to wear down even resilient individuals.

General dimension 2 (GD 2) was about attempting to disclose the use of CAM. GD 2 shows attempts to disclose CAM use to biomedical physicians were made because the participants wanted some guidance about CAM use and because they thought it was important for the biomedical physician to know. This is similar to the findings of GD 1, which showed that seeking information about CAM was a way of disclosing CAM use.

GD 2 is different because the participants recognised that they had attempted to disclose CAM but had not actually disclosed CAM use, on the basis of their perception that the biomedicine practitioner failed to recognise the attempt. In reviewing the literature I could not find a study that explored CAM disclosure in this context. GD 1 and GD 2 highlighted that when participants' concerns were dismissed or not taken seriously they considered biomedical physicians were being obstructive toward their attempts to access

information to help support or guide their health-care decisions. GD 2 showed the participants considered such behaviour as counterproductive to empowering them. This finding is associated with those of Phase 2 that indicated the participants had a hopeful attitude toward their illness, which they could influence despite biomedical advice to contrary. This finding is also similar to that of Furnham and Forey (1994) who found participants believed despite their circumstances they could improve their condition.

GD 2 suggests participants considered behaviour that was perceived to threaten this belief was about power and control. Hence, non-disclosure of CAM was one of the ways the participants chose to maintain control. Many studies of chronic illness, which have examined self-care decision-making, have found that although biomedical physicians proffer patient participation they overtly and covertly work against it (Arksey & Sloper, 1999; Chapman, 1994; Opie, 1998) and as GD 1 and GD 2 indicated this is often done by withholding information and/or ignoring requests for information. Hence, the findings suggest in some instances biomedical physicians are either not interested or that they hear, but choose to ignore CAM disclosure and attempts to disclose CAM.

General dimension 3 (GD 3) was about abandoning CAM disclosure because when participants asked about CAM the biomedical physician advised against such use. GD 3 shows CAM disclosure was abandoned because biomedical physicians made negative comments about CAM, as shown in Phase 2 negative comments about CAM made by biomedical physicians lead to a loss of confidence in the biomedical physicians' ability and knowledge, and this was a contributing factor to CAM use and rejection of biomedical advice.

Similarly, GD 3 shows in instances where biomedical physicians made negative comments that suggested CAM was dangerous and/or a waste of time, rather than answer questions about CAM caused even more dissatisfaction with biomedicine, which motivated

participants to abandon CAM disclosure. This indicated CAM disclosure was abandoned because participants felt disappointed that the biomedical physician was not supportive or at least, neutral.

Similarly, in a qualitative study Tasaki et al. (2002) found the participants' perceptions of the physicians' attitude toward CAM discouraged them from initiating or continuing with discussions about CAM and contributed to non-disclosure (Powell et al., 2002). Similarly, Wynia, Eisenberg and Wilson (1999) found biomedical physicians that positively viewed CAM increased communication about CAM use.

The findings for GD 3 show biomedical physicians who perceived CAM as dangerous discouraged discussion about CAM use. Whilst, the finding in GD 3 support that there is an association between how much information a person will reveal to their biomedical physician and how the biomedical physician reacts to such information, none of the participants' reported positive responses by biomedical physicians about CAM, so full disclosure was minimal.

General dimension 4 (GD 4) was about not disclosing the use of CAM because biomedical physicians were against such use. GD 4 showed non-disclosure of CAM occurred because participants could "sense" or "knew" the biomedical physician was against CAM. GD 4 showed participants did not disclose CAM because conversations about CAM with biomedical practitioners gave participants the impression they were against CAM use. GD 4 indicated CAM was not disclosed because the biomedical physician advised that CAM was harmful and/or did not work, and that CAM should not be used. Hence, GD 4 showed biomedical physician opposition and antipathy toward CAM impeded CAM disclosure.

The difference between GD 3 and GD 4 is that in GD 3 participants made the decision not to continue a current attempt to disclose because of the perception of a negative

response by the biomedical physician at that time. In GD 4 participants decided not to disclose based on a perception they had previously gained of the biomedical practitioner's negative view of CAM, so they did not even attempt to disclose.

Many studies found the rate of CAM disclosure fell dramatically in cases where the treating physician did not recommend healing therapies (Busse et al., 2005; Oldendick et al., 2000; Wynia et al., 1999). GD 4 showed denial of CAM use occurred because the participants "knew" or "heard" that the biomedical physician was against CAM use. GD 4 showed denial of CAM use occurred when the biomedical physician asked about CAM use by using rhetorical language, for example, "but of course, you wouldn't use CAM, would you", which suggested that CAM should not be used. This finding suggests non-disclosure of CAM was triggered by "opposition [to CAM] from their physicians on a scale from hidden disapproval to active opposition" (Tasaki et al., 2002, p. 215). GD 4 illustrated such interactions lead to non-disclosure of CAM because the participants felt the biomedical physician was patronising and had not offered the opportunity or acknowledged they had a right to be actively engaged in decisions about their health-care.

No other studies were found that had reported denial of CAM use in instances where the biomedical physician had asked about CAM use. GD 4 shows that CAM non-disclosure was associated with a sense of not being allowed by biomedical practitioners to actively participate in health-care decisions. Whilst this is a new finding for non-disclosure of CAM, in a study of chronic illness and empowerment, participants reported "attempts to assume an active role in decisions about their care were met at times with...anger" [by biomedical physicians] (Paterson, 2001, p. 577). Similarly, in GD 4 participants reported biomedical physicians met the issue of CAM with anger and this made the participants resolute in their decision not to disclose their CAM use.

GD 4 showed participants did not want to upset their biomedical physician and so did not disclose their CAM use because they wanted to avoid unpalatable interactions with the biomedical physician. GD 4 showed anticipation of being reprimanded for CAM use inhibited CAM disclosure. Similarly, Vallerand et al. (2003) found fear of being criticised and misunderstood was a reason for non-disclosure of CAM. GD 4 indicated participants considered the manner in which biomedical physicians expressed their stance about CAM use was often aggressive and threatening.

Although, participants sometimes reported that their experience of negative interactions with biomedical physicians occurred many years ago, the manner in which CAM use was dealt left an indelible mark that inhibited CAM disclosure years later. Hence, GD 4 shows non-disclosure of CAM was motivated by self-preservation, which is a new finding for non-disclosure of CAM.

GD 4 also showed that sometimes participants did not disclose their CAM use because they “did not want to be told off like a child” (P4). Hence, CAM was not disclosed did not occur because participants anticipated a negative response from their physician. Fear of a negative response has often been cited in the literature as a reason for not disclosing CAM use (Powell et al., 2003; Rao et al., 1999; Shenfield, Lim & Allen, 2002; Tasaki et al., 2002; Tan, Uzun & Akçay, 2004). GD 4 showed that negative responses from biomedical physicians were considered threatening and demeaning, which is a new finding for not disclosing CAM use. Findings, such as CAM use is not disclosed because people felt threatened, could be interpreted that people feared that biomedical treatment would be withdrawn if they disclosed their CAM use. In a national U.S. study, Eisenberg et al. (2001) reported this concern among a sample of the general population who used CAM and biomedicine. In this thesis, however, fear of withdrawal of biomedical services was not

found to be a reason for not disclosing CAM, but it was a reason for CAM use, as shown in Phase 2.

GD 4 showed, when biomedical physicians depicted CAM as useless because it lacked scientific proof, was harmful and/or a waste of money, this inhibited CAM disclosure but not CAM use. These reasons were also given in GD 3 for abandoning CAM disclosure. Similarly, Busse et al. (2005) and Tasaki et al. (2002) found that when biomedical physicians insisted on scientific proof, this inhibited CAM disclosure.

GD 4 showed that participants rejected negative depictions of CAM because they were considered to be unfounded. For example, some participants commented that their biomedical treatment was based on clinical experience and not on scientific data and hence was equal to experiential knowledge, which biomedical physicians were quick to dismiss. This made the participants angry and lead to non-disclosure of CAM because biomedical physicians were perceived to hold representations of CAM that were biased.

Similarly, Tasaki et al. (2002) found participants perceived biomedical physicians held biased views toward CAM, which made discussions about CAM difficult and at times triggered non-disclosure of CAM. GD 4 showed such perceptions generated a sense of anger. GD 4 suggests the emotion of anger was associated with non-disclosure and this is a new finding.

GD 4 showed that some participants did not disclose CAM because they wanted to maintain their privacy. Thus, GD 4 indicated non-disclosure of CAM was a way of showing that participants had another “life outside of the hospital”. No other study has shown that people did not disclose their CAM use because they wanted to maintain their privacy.

GD 4 showed some of the participants did not disclose their CAM use because they were unhappy with their biomedical practitioner because the biomedical practitioner failed to provide information about their medical condition. I could not locate a study that

reported biomedical physicians failing to provide medical information to a participant as a reason for non-disclosure. I found research that described people's different coping styles. People who wanted as much information as possible about what was wrong with them were described by Miller and Mangan (1983) and Miller et al. (1988) as 'monitors' and those who wanted to know as little as possible were called 'blunters'. Miller and Mangan (1983) and Miller et al. (1988) found that when the volume of information did not conform to one of these coping styles, there appeared to be an adverse psychophysiological affect.

The findings of GD 4 suggested a lack of information had affected the participants' behaviour and feelings toward their biomedical carer. Whilst there is evidence that shows people have a desire for information and want to be involved in healthcare decision-making with their biomedical physicians (Deber, Kraetschmer & Irvine, 1999) this thesis adds to this knowledge because the findings suggest the withholding of information by biomedical physicians affects health-care behaviour. The findings of GD 4 also indicate non-disclosure in some people is an adverse psychological effect of medical encounters that provide limited information, and this is a new finding.

GD 4 showed some participants did not disclose their CAM use because the biomedical practitioner failed to answer questions about CAM and/or CAM was spoken about in negative terms. Hence, it could be said that non-disclosure of CAM reflected of a loss of confidence in the biomedical practitioner, which as Phase 2 showed was a reason for CAM use.

Many researchers have also found that CAM disclosure was inhibited by perceptions that biomedical physicians were not interested in CAM use (Busse et al., 2005; Sleath et al., 2001; Tasaki et al., 2002), because they did not ask about such use (Busse et al., 2005; Eisenberg et al., 2001; Powell et al., 2002; Rao et al., 1999; Shenfield et al., 2002). GD 4

showed the participants did not disclose their CAM use because the biomedical practitioner did not ask about such use, which they perceived was a lack of care. The association between a biomedical physician not asking about CAM and the perception of a lack of care has not previously been reported; hence this is a new finding.

Participants considered biomedical practitioners who did not ask about CAM use were not interested in such use. The literature provides four possibilities for physicians not asking about CAM and GD 4 shows all impacted on the participants' perceptions of the biomedical practitioner and their decision not to disclose CAM. The first reason was because physicians were possibly time-constrained which meant they had to give precedence to other issues (Wynia et al., 1999). Participants reported that a five minute, "if lucky" consultation was inadequate given the gravity of their illness, and this caused dissatisfaction with the biomedical practitioner who was perceived to be money-orientated rather than caring, and this contributed to CAM non-disclosure as shown in GD 4 and to CAM use, as shown in Phase 2.

The second possibility was based on Wynia et al. (1999) finding that only 3% of physicians considered CAM harmful but drew no conclusion about what effect viewing CAM as dangerous would have on communication. This thesis has shown that depicting CAM dangerous has a profound negative effect on CAM disclosure.

The third reason was that physicians might not feel adequately trained to discuss the risks and benefits of individual CAM therapies (Eisenberg et al., 1997). In this present study participants perceived biomedical physicians lacked CAM knowledge and therefore their advice was invalid and this was a reason given for not disclosing CAM, and for using CAM as shown in Phase 2.

The fourth was that physicians might have legal concerns about appearing to recommend CAM therapies, while discussing them (Studdert et al., 1998). In contrast, the

participants in this present study reported that biomedical physicians rarely recommended CAM use because “they don’t believe in it”. The participants considered biomedical practitioners divulged little about biomedical treatment and its impact on them for legal reasons, and this caused great concern and was given as a reason for not disclosing CAM. Whilst, GD 4 showed the participants considered biomedical physicians who did not ask were not interested in CAM, it also showed that not asking about CAM was perceived as “they don’t care about us” (P17) and reflected a lack of perceived care which was a reason for CAM use, as Phase 2 showed.

Although, no study was found that explored the association between non-disclosure and perceived lack of care, in a study of the strategies used by people with serious illness, Dewar (2001) found participants retaliated against biomedical physicians. GD 4 shows non-disclosure of CAM is a form of retaliation against biomedical physicians who were perceived not to care.

GD 4 showed some participants “never thought to” disclose their CAM use because there “was nothing to be gained by it”. Hence, there was no “point in discussing” CAM use with the biomedical practitioner because biomedical physicians were perceived to have negative feelings toward CAM. This finding suggests withholding information about CAM use was another way of showing dissatisfaction with biomedical practitioners.

GD 4 showed that CAM disclosure was related to the reasons found in Phase 2, which showed that CAM use is linked to the communication experience with biomedical practitioners. Phase 2 showed CAM use was motivated by negative feelings toward biomedicine. Similarly, GD 4 showed such negative feelings inhibited CAM disclosure. Taken in the context of the reasons given for non-disclosure because of information not being reciprocated and perceptions that biomedical physicians were against CAM use, non-disclosure was shown to be a protective strategy against negative exchanges.

GD 4 also showed CAM was not disclosed because participants considered the biomedical physician did not need to know because CAM use was none of the treating physician's concern, which meant it was not necessary for the biomedical physician to "know what teas I drink" (P16). Although, this finding is similar to other studies, which found non-disclosure of CAM occurred because participants thought it was "none of the biomedical physicians business" (Busse et al., 2005, p. 618), GD 4 showed that *none of the physician's business/concern*, as a reason for not disclosing CAM is linked with two other findings of this thesis. Firstly, not disclosing CAM because it is none of the biomedical physician's business is a way of maintaining privacy, as noted earlier. Secondly, not disclosing CAM, because it is none of the biomedical physician's business was linked to dissatisfaction with biomedical physicians because they failed to provide necessary information, such as dietary advice. The participants considered that the provision of information about foods low in iron was the biomedical physician's responsibility. Thus, when such information was not forthcoming from biomedical physicians, but was accessed through CAM practitioners, participants developed the attitude *that it was none of their biomedical practitioner's business*. Hence, non-disclosure of CAM displayed the thought process by which an anti-biomedical physician attitude and a pro-CAM practitioner attitude were developed, at least with reference to disclosure of CAM.

GD 4 also showed that participants claimed that it was not important to disclose CAM because CAM was considered harmless and non-interfering with biomedical treatment. These findings are somewhat similar to those of other researchers, who found CAM disclosure did not occur because participants did not consider it was important for the biomedical doctor to know about such use (Eisenberg et al., 2001; Powell et al., 2002; Sleath et al., 2001; Vallerand et al., 2003). The results of the present study expand on

previous research because they show why the participants considered it was not important for the biomedical physician to know about CAM use.

GD 4 showed non-disclosure was common and had a range of causes. Some of these were consistent with previous research, but there were several original findings, including denial of CAM use when biomedical physicians asked about such use, perceptions that biomedical physicians were aggressive and/or threatening, failing to provide CAM information and withholding personal medical information prevented disclosure. Many of the findings of GD 4 show that reasons for CAM disclosure are associated with the findings for CAM use in Phase 2, and such an association has never previously been explored. The findings of GD 4 and Phase 2 suggest the reasons for CAM use and CAM non-disclosure frequently are coping and protective strategies. Other new findings for are; non-disclosure of CAM is motivated by self-preservation and anger, and non-disclosure in some people is an adverse psychological effect of medical encounters that provide limited information.

Phase 3 shows some attempts to disclose were considered to have failed because biomedical practitioners did not listen, some were abandoned, often due to biomedical advice, which reflected physicians' anti-CAM stance, and there were many cases of non-disclosure. Phase 3 shows the rate of CAM disclosure was very low, and much lower than previous research estimates. Whilst it is widely acknowledged that it is essential for biomedical physicians to be informed about CAM because of the potential of interactions and possible hyper or under dosing of biomedical medicines, Phase 3 shows to improve communication about CAM use, an increased awareness is important. Phase 3 showed participants' anticipation of negative interactions based on past experience inhibited CAM disclosure. Phase 3 shows physicians need to be aware that disagreeing with patients' decisions to use CAM without showing respect and compassion for such decisions encourages non-disclosure of CAM use. Phase 3 shows participants expect from their

physicians the same attitude about CAM and their biomedical treatment. Hence, Phase 3 shows when physicians fail to provide information about CAM or biomedical issues this affects communication, moreover it inhibits CAM disclosure and limits the information participants relay to biomedical physicians about their biomedical condition and treatment.

Future Research

The findings from Phase 3 show CAM disclosure and non-disclosure were linked to dissatisfaction with biomedicine and/or physicians. These findings suggest research examining and comparing whether CAM disclosure and non-disclosure is a predictor of biomedical dissatisfaction and whether biomedical dissatisfaction is a predictor of CAM disclosure and non-disclosure, would be valuable.

The findings of Phase 3 show the reasons for seeking information about CAM and the reasons for CAM disclosure and non-disclosure are associated. This suggests research examining the association between them would be valuable to biomedical physicians.

The findings suggest a study examining the language biomedical physicians' use when talking about CAM and their impact on CAM disclosure could be valuable in enhancing communication about CAM in biomedical consultations. To obtain a complete picture of the underlying causes of the communication difficulty, physicians' perspectives should be examined in future studies.

Research that replicates the findings of this thesis is needed to examine whether the finding that CAM disclosure is motivated by biomedical physicians actively ignoring their clients attempts to disclose CAM, can be generalised.

The findings suggest that the issue of privacy and CAM disclosure are associated. Research would be valuable in exploring the issue of privacy and health behaviour. Such research could compare the findings of CAM users from the general community, who use

biomedicine intermittently, CAM users who are chronically ill, and use biomedicine regularly.

The findings suggest there is an association between CAM non-disclosure and coping and protective strategies. Research replicating this finding and examining whether such strategies jeopardise biomedical care or assist with alleviating the burden of illness would be of benefit to biomedical practitioners caring for people with long-term illness.

The findings suggest non-disclosure is also about the perceived imbalance of power between biomedical physicians and people with chronic illness. Hence, research examining whether non-disclosure of CAM is associated with a sense of vulnerability in people with a chronic illness would be valuable in assessing health-behaviours.

Conclusion

Phase 3 showed the level of CAM disclosure was motivated by the biomedical practitioner communication experience. The findings of Phase 3 suggest CAM disclosure is associated with retaliatory behaviour against biomedical practitioners and defensive behaviour.

CHAPTER 7: GENERAL DISCUSSION

The findings of this thesis adds to the current body of knowledge from other descriptive, epidemiologic and population studies of CAM because the reasons provided by participants for such use, and its disclosure to biomedical physicians, is from the perspective of people with thalassaemia major (TM). The reasons the participants in the present research gave for using CAM when they had ready access to and use high levels of biomedical care provide a deeper understanding of the concurrent use of biomedicine and CAM, and reasons for disclosure of CAM use. Conclusions from each of three phases are discussed as they relate to each other and other research. Methodological issues are discussed as they relate to the thesis. Similarly, future research and implication for practice are also discussed in relation to the findings of this thesis.

Summary of Conclusions

The first phase showed the participants lived their daily lives in an environment of intensive biomedical treatment because of the main pathology. Whilst, such biomedical treatments provide a marked improvement in survival, growth and sexual development if started at the right time and followed diligently, there are associated risks (Porter, 1999).

All participants had co-existing illnesses, such as hepatitis C, reportedly caused by the biomedical treatment for TM. All the participants had one or more co-morbidity, such as osteoporosis caused by the natural progression of thalassaemia major and/or biomedical treatment. The most serious co-existing illnesses reported by the participants were hepatitis C and cardiomyopathy.

Participants reported a greater number of co-morbidities per person than previously reported in CAM surveys (De Visser & Grierson, 2002; Egede et al., 2002). Phase 1 showed the intensity and duration of biomedical treatment including pharmaceutical and

surgical interventions was higher than for people with other serious illnesses, such as cancer (Patterson et al., 2002).

Phase 1 showed estimates for CAM use varied significantly according to which CAM definition was applied to analyse the data. Moreover, this thesis showed dichotomous question formats are problematic. For example, whilst 12 (57.14%) of the participants reported using CAM all participants were found to be CAM users when the data of reported therapies and/or products the participants used was analysed.

The findings suggest that the participants were not familiar with the terms, complementary and alternative medicine and the acronym CAM. This finding suggests participants often guessed an answer when confronted with dichotomous questions about CAM use and CAM disclosure.

Participants defined some biomedical interventions as CAM and some CAM as biomedicine, and or both CAM and biomedicine. This finding suggests that people when using treatments/therapies do not actively differentiate them, as CAM or biomedicine, but as treatment.

In contrast to Williams, Fletcher and Dawson (2003) participants of this research did not consider the practitioner important for differentiating CAM from biomedicine.

The findings support Cassileth (1999) by showing participants' categorisation of individual therapies and CAM in general was often different to how researchers categorise such therapies. Hence, estimating and comparing the CAM estimates found in this research with those of other studies was problematic because of the ambiguous definitions of CAM used by researchers.

The two CAM estimates, the highest 21 (100%) based on the reported CAM substances and therapies used and the one derived from the participants' responses to the dichotomous question, 12 (57.14%) were used for reasons of comparison. Both CAM

estimates for this thesis were much higher than for people with diabetes (25%) (Schoenberg et al., 2004) and for people attending outpatient clinics (35.7%) (Pucci, Cartechini, Taus & Giuliani, 2004). The lower CAM estimate (57.14%) for this thesis was comparable to some studies for people with a chronic illness such as multiple sclerosis (Nayak et al., 2003) and diabetes (Yeh et al., 2002), and higher for people with chronic liver/GIT disease (Yang et al., 2002), and lower than for some other serious illness such as cardiac and bone transplant patients (Huber, 2004) and for arthritis (Rao et al., 1999). The higher CAM estimate, 100%, is much higher than most reviewed studies (Boon et al., 2000; Lengacher et al., 2002; Patterson et al., 2002) and comparable for fibromyalgia where 98% of the participants had used some form of CAM in the previous 6 months (Wahner-Roedler et al., 2005) and for 87% of people with multiple sclerosis who were found to have 'ever used CAM' (Shinto et al., 2006). Both CAM estimates for this thesis are much higher than studies estimating CAM amongst people with serious blood disorders (Gupta et al., 2002; Kappauf et al., 2000).

All participants reported using some form of ingestible CAM product, such as herbs and vitamins and minerals. Whilst this is a common finding amongst many studies of people with a serious illness (Furler et al., 2003; Lengacher et al., 2002; Tan et al., 2004; Tasaki et al., 2003), the degree of use was substantially higher for this thesis. For example, most studies showed the use of herbs ranged from around 25% (Boone & Brown, 1999; Dailey et al., 2003) to as high as 50% (Powell et al., 2002) and the use of vitamins and minerals ranged from 50% (Boon et al., 2000) to 57% (Furler et al., 2003).

Despite the intensive use of biomedicine and CAM, Phase 1 demonstrated that the reported level of CAM disclosure to treating physicians was substantially lower than shown by other studies for people attending tertiary care hospitals (Tan et al., 2004; Welch, 2001;

Yang et al., 2002). Hence, estimates for CAM use and CAM disclosure from other studies show little resemblance to the findings of this thesis.

Comparison between the findings from this thesis and those from other studies suggest people who use tertiary health care are more likely to use CAM and less likely to disclose such use to treating physicians than the general population.

The results of Phase 2 are comparatively similar to the findings of (Huber et al., 2004; Tan et al., 2004; Tilden, Drach & Tolle, 2004; Wahner-Roedler et al., 2005) who found CAM was particularly appealing to people with chronic or life-threatening illnesses, seeking relief of pain and treatment of difficult conditions.

Phase 2 demonstrated that CAM was used for the primary illness and/or the presenting symptoms and those caused by treatment, as was shown in other studies (Boon et al., 2000; Canales & Geller, 2003; Mitzdorf et al., 1999; Rafferty et al., 2002; Read et al., 2002). The findings of this thesis demonstrate as Tan et al. (2004) found that CAM was used for serious illnesses, such as chronic heart failure and anaemia, and chronic illnesses such as migraine headaches, gastric problems and sinusitis.

Unlike this thesis no other study has detailed the signs and symptoms or the illnesses for which participants use CAM. For example, participants reported they used CAM to; relieve bone pain caused by anaemia and osteoporosis; to relieve traumatic pain caused by injection site injuries, to relieve chronic migraine pain caused by biomedicine used for the treatment of cardiomyopathy; to prevent future illnesses such as, optic and aural neuropathy; to abate symptoms such as, chronic fatigue reportedly caused by hepatitis C, to treat the symptoms of thalassaemia major, such as shortness of breath, and to maintain haemoglobin levels.

Phase 2 showed the participants used CAM as treatment simultaneously for multiple illnesses; this is a new finding for CAM use.

The participants used CAM to slow the progression of life threatening and basically untreatable illnesses such as, hepatitis C to prolong their life. Whilst, this finding is not unlike using CAM as a last resort treatment (Boon & Brown, 1999; Gupta et al., 2002; Menniti-Ippolit et al., 2002; Mitzdorf et al., 1999; Peter et al., 2002; Sleath et al., 2001) because there was nothing else biomedicine could do (Menniti-Ippolit et al., 2002) no other study was found that made the association between slowing the progression of an illness and last resort. This finding suggests last resort treatment as a reason for CAM use has been underestimated.

Participants reported they used CAM because “they had do to something” in instances where the biomedical practitioner had told them to prepare for death and because they knew there was no biomedical cure. Again this supports that CAM use was a last resort treatment.

Phase 2 showed as other studies found (Conroy et al., 2000; Rickhi et al., 2003) the participants used CAM as a last resort because they were dissatisfied with biomedicine because biomedical treatment failed.

The finding that participants used CAM to “reverse” conditions, such as cardiomyopathy suggests they were seeking a cure and not merely to treat presenting symptoms, such as palpitations and tachycardia as reported.

The participants used CAM as a form of prophylaxis against bacterial and viral infections and to improve the participants’ immune system, reportedly impaired because they were asplenic. Other studies have shown that people use CAM as a form of prophylaxis (Bode, Müller & Storck, 2001; Palinkas & Kabongo, 2000; Read et al., 2002; Rickhi et al., 2003; Tilden, Drach & Tolle, 2004; Williamson, Fletcher & Dawson, 2003).

Participants reported that they had been prescribed biomedical prophylactics to prevent/lessen the incidence of infection, and chose CAM in lieu. This finding illustrates that participants used CAM as an 'alternative' medicine.

Participants used CAM to treat illnesses because reportedly biomedical treatment was ineffective. Moreover, unlike other studies Phase 2 demonstrated what ineffective treatment meant to the participants. For example, biomedical treatment, which had adverse effects that caused other illnesses, or failed to provide the outcome for which it was prescribed, was considered ineffective.

The results of this research showed when further biomedical treatment was required to deal with adverse effects, such as hepatitis C, often without success, this was considered by the participants to be a major biomedical failure, on two accounts: Firstly, because biomedical treatment caused the illness and secondly because biomedicine could not successfully treat the condition. Phases 2 and 3 showed biomedical failures were associated with dissatisfaction with biomedicine, which triggered CAM use and CAM disclosure and CAM non-disclosure respectively.

This thesis found that biomedical failure was associated with a loss of confidence in biomedical practitioners, because, as reported by the participants, they failed to address the biomedical failures in an effective, safe and caring manner.

Despite many researchers finding that people use CAM because of dissatisfaction with biomedicine (Boon et al., 2000, 2003a; Bernstein & Shuval, 1997; D'Crus & Wilkinson, 2005; Oneschuk, et al., 2000; Paltiel et al., 2001; Tan et al., 2004) some have suggested that such dissatisfaction was not associated with biomedical failure (Astin, 1998; Berg & Arnetz, 1998; Kappauf et al., 2000) or dissatisfaction with biomedical practitioners (Conroy et al., 2000; Furler et al., 2003). Whilst the findings of Phase 2 support the extant literature which shows dissatisfaction or a loss of confidence in biomedicine medicine was

associated with the treatment effect and/or the biomedical encounter (Boon & Brown, 1999; Boon et al., 2003a; Leiser, 2003; Siahpush, 1999; Paltiel et al., 2001), Phase 2 showed that dissatisfaction with biomedical practitioners, dissatisfaction with treatment and dissatisfaction with both were associated. Dissatisfaction with treatment often led to dissatisfaction with biomedical practitioners because the prescriber of treatment was blamed for prescribing treatment that was ineffective or had adverse effects. This is a new finding for CAM use and illustrates that dissatisfaction with biomedicine is a complex issue.

The findings of Phase 2 illustrated that CAM was used to prolong life, to survive (in instances where an illness was said to be terminal) and to prevent further co-morbidities or to prevent/slow deterioration in health. This thesis showed that CAM was used to achieve these goals, which, according to the participants, could only be attained when a condition was ameliorated completely, and this necessitated a cure. This finding is unlike most studies (Tilden, Drach & Tolle, 2004), which found that CAM is not used or is rarely used for curative purposes. Whilst this thesis found that the participants expressed the belief that a cure was what in part constituted effective treatment, this needs to be taken in the context of the illnesses from which they expected to be cured. For example, the participants recognised that thalassaemia major was incurable and did not, in most cases, pursue treatment that would cure it, but they did expect and pursued treatments to cure illnesses that they considered curable, such as migraine headache, irritable bowel and sinusitis.

The findings of this research show biomedical treatment, which failed to cure illnesses they considered curable, was considered by the participants an abject failure, particularly if biomedical treatment had failed several times to treat such disorders and even more so when CAM successfully 'cured' them. This, in turn, triggered in the participants a belief that biomedical physicians were, at times, inept and uncaring for two reasons, which led to CAM use. The first, as discussed, was because biomedical physicians were

considered to have failed to prescribe effective treatment. The second reason, as reported by the participants, was because biomedical physicians never accepted blame for biomedical failures rather they often blamed the participant for such failures.

Participants reported biomedical physicians often either attempted to refer them to a psychologist or told them to “get on with it” or “go elsewhere”, when confronted with biomedical failure, and this led to a loss of confidence in biomedical physicians.

Biomedical care that reportedly failed to understand participants’ desires and expectations of such care were given as reasons for CAM use, CAM disclosure and CAM non-disclosure. In a systematic review of 57 studies, Wensing, Jung, Mainz, Olesen, and Grol (1998) identified humaneness, competency/accuracy, and shared decision-making as the top three priorities of adult outpatients. The findings of the thesis illustrated that the participants reacted negatively to biomedical physicians who reportedly did not practice these aspects of care.

The findings of this thesis illustrate that the participants preferred a patient-centred approach to their biomedical consult. Despite Swenson et al. (2004) finding 31% of participants preferred a non-patient-centered approach much of the literature illustrates participants preferred a patient-centered approach (Kinnersley, Stott, Peters & Harvey, 1999; Kinmonth, Woodcock, Griffin, Speigal & Campbell, 1998; Krupat, Bell, Kravitz & Azari, 2001; Rosenber, Lussier & Beaudoin, 1997; Williams, Weinman & Dale, 1998) that fostered trust and satisfaction in the biomedical encounter. Moreover, Swenson et al. (2004) found 69% participants who preferred a patient-centred approach more likely to be users of CAM and younger. Therefore, the findings of Swenson et al. (2004) suggest as the findings of this dissertation found CAM use was strongly motivated by the biomedical encounter.

This research showed a lack of trust and satisfaction in the biomedical encounter triggered CAM use and it also contributed to CAM disclosure and non-disclosure, as shown in Phase 3. In contrast, Phase 2 showed participants considered CAM practitioners provided

empathy and understanding, and as many studies (Baron, et al., 2003; Huber et al., 2004; Magin, Adams, Heading, Pond & Smith, 2006; Johnson, Bilbao & Graham-Brown, 2003; Quattropani et al., 2003; Shumay et al., 2001) have shown that CAM products were safe and an effective form of treatment.

Phase 2 of this thesis confirmed the findings of Phase 1, which showed CAM was used concurrently with biomedicine at all times as a treatment. This finding directly contrasts with a study of 1,433 people visiting a health centre from which Al-Windi (2002) concluded participants “did not use biomedicine and CAM concurrently” (p. 41). Conversely, many studies have shown that ingestible CAM products, such as herbs, are used concurrently with biomedicine (Maskarinec et al., 2001; Patterson et al., 2002; Sirois, 2002; Tan, Uzun & Akçay, 2004; Wahner-Roedler et al., 2005), but the level of use varies substantially from the findings of this thesis. The data generated by the research in this thesis might differ from those studies because biomedical treatment for the participants of this thesis was a necessary, ongoing process for survival and, hence, could never be abandoned.

This thesis showed participants used CAM concurrently with biomedicine and sometimes used CAM in lieu of some biomedical products considered to be ineffective and/or deleterious to their health. This finding suggests CAM use was associated with rejection of biomedical medicines and/or poor compliance because of safety and effectiveness of a biomedical drug. For example, the participants used CAM in lieu of biomedically prescribed medicines that were known to have adverse effects. This thesis found rejection of such biomedicines was absolute in cases where the adverse effect had failed to respond to additional biomedical treatment. The participants reported they used CAM for such situations and rejected biomedicine and biomedical advice that they considered was not in their best interests. This finding contrasts with those of some researchers who found CAM use was linked to poor compliance with biomedical treatments

because of anxiety and/or depression (Furnham & Smith, 1988; Kessler et al., 2001a; Rickhi et al., 2003).

This thesis showed the participants frequently perceived the need to take control of their own health-care by seeking alternatives to the largely palliative and sometimes harmful biomedical care. This finding supports research evidence, which suggested that CAM use was associated with a desire to control health-care decisions (Adler & Fosket, 1999; Boon et al., 2000; Canales & Geller, 2003; Street, Krupat, Bell, Kravitz & Haidet, 2003). At the same time, this thesis showed the decision to use CAM in lieu of biomedicine was carefully considered. For instance, this research showed CAM was not used in lieu of biomedicine, despite the known adverse effects of some treatments, such as blood transfusions and iron-chelating medicine, because these biomedical treatments were acknowledged as life preserving. The findings of this thesis suggest the participants adopted positive health behaviours, consistent with the research of Marks, Richardson, Graham and Levine (1986), who reported that internal locus of control was associated with a variety of positive health practices and improved physical and psychological functioning. The findings do show that the participants demonstrated a desire to be involved in determining their own treatment and despite some evidence to showing that locus of control with respect to health was no different among users and non-users of CAM (Ramos-Remus, Watters, Dyke & Suarez-Almazore, 1999; Sirois & Glick, 2002) there is contrasting evidence amongst people with cancer that showed those who used CAM had more internal locus of control than non-CAM users (Davidson, Geoghegan, McLaughlin & Woodward, 2004). Locus of control was not measured directly in the present study, but participants' interview responses suggest that most of those who used CAM reflected an internal locus of control with reference to their health care.

Many researchers considered the concurrent use of CAM and biomedicine as complementary medicine and CAM used in lieu of biomedicine as alternative medicine (Hawks & Moyad, 2003; Lengacher et al., 2002; NCCAM, 2003; Söllner et al., 1999). This thesis showed these definitions of CAM could not be sustained because they did not accurately reflect how the participants used CAM. The thesis showed the purpose for which the participants employed CAM was for treatment. Yet most of the participants considered many individual CAM therapies, such as non-prescribed vitamins and minerals and herbal medicine in the form of tea/juice or tablets/capsules, including St John's Wart, St Mary's Thistle, aloe vera, wheat-grass, spirulina, Valerian, and garlic/horseradish, were often considered 'lifestyle' practice. Contrasting the way the participants defined individual substances were the reported reasons they gave for using these CAM products, such as "to be well".

When participants' responses were explored in the context of what "to be well" meant, it was clear that the participants used CAM to treat and or prevent illnesses associated with TM and or its treatment, and to improve their quality of life, as Shinto et al. (2006) found in people with multiple sclerosis. In addition the findings of this thesis show that participants were frustrated with constant ill health and this as Shinto et al. (2006) found motivated CAM use more so because of physical rather than mental impairment.

Treating illnesses for the participants in the present study often meant minimising deterioration of the condition. Hence, the findings of this thesis are different to those of other studies, which suggested CAM use was a lifestyle practice and not a form of treatment (Eisenberg et al., 1993, 1998; Kessler et al., 2002; Oldendick et al., 2000).

This thesis showed some therapies were being used as complementary and, in some, cases as alternative medicine. When the participants' manner of use of the therapies is considered, according to the Cochrane Collaboration (1997) and NCCAM (2002) definitions

of CAM, all participants were found to be CAM users. At the same time, all participants can be categorised as using complementary medicine and most can also be categorised as using alternative medicine. Using the operational CAM definition for this thesis, based on intent of use, all participants were found to be CAM users. In the context of what type of CAM user the participants were the analysis shows all participants were self-prescribers of CAM and utilisers of CAM practitioners, complementary medicine and alternative medicine users. Thus, Phase 2 confirmed the findings of Phase 1 that there were 21 CAM users. Further, Phase 2 showed that the main reasons for CAM use were treatment, negative views of biomedicine, self-determination, and enhancing quality-of- life through CAM and personal control of health.

This thesis has shown CAM disclosure cannot easily be estimated by dichotomous questions. For example, when the findings of Phase 1 are compared with the findings of Phase 3, whilst there is some similarity, because both Phases showed there was one CAM discloser, Phase 3 showed there were degrees of disclosure, such as attempts to disclose and abandonment of attempted CAM disclosure. Phase 3 showed that most of the participants tried to disclose their CAM by seeking information about CAM. The participants considered seeking information about CAM, was CAM disclosure. This thesis showed all participants' who had attempted to disclose CAM use, abandoned CAM disclosure because they were dissatisfied with biomedical practitioners' attitudes toward CAM. This thesis showed there was only one CAM discloser who continued to disclose CAM use and the reason was because of dissatisfaction with biomedicine and the biomedical practitioner. The findings of this thesis show that CAM non-disclosure is associated with biomedical practitioner disinterest and/or negative approach; a lack of opportunity to discuss CAM use; the perception of participants that it was not important for the biomedical physician to know about CAM use; and reports from the participants that the doctor did not ask. These reasons

for non-disclosure are similar to those found in other studies (Adler & Fosket, 1999; Busse et al., 2005; Chen, Bernard & Cottrell, 1999; Crock et al., 1999; Gray et al., 1998; Hilsden, Scott & Verhoef, 1998; Powell et al., 2002; Yang et al., 2002). This research is the first to show that CAM non-disclosure was associated with biomedical physician attempts to dissuade participants from using CAM, and as shown in Phase 2, this was a reason for CAM use. Unlike other studies, Phase 3 showed these reasons for CAM disclosure were associated with dissatisfaction with biomedicine and practitioners. Moreover, Phase 3 showed such dissatisfaction was often associated with the reasons for using CAM. Phases 2 and 3 demonstrated that the participants felt dissatisfied when they perceived that biomedical physicians withheld information, provided inaccurate information or refused to discuss CAM, or the biomedical condition of the participants in what the participants considered to be an appropriate manner. Under these circumstances, participants often reported a loss of confidence in biomedicine and the practitioner, in relation CAM use, which contributed to CAM non-disclosure.

This thesis has highlighted noteworthy similarities between the reasons provided by the participants of this study for CAM use and CAM disclosure with those provided by other people with chronic illnesses, as found in other studies. The findings of this thesis show the participants' reasons for CAM use and CAM disclosure are somewhat different possibly because of the life-long duration of the participants' illness. This does not suggest a reified relationship between lifelong illness and CAM use, rather it suggests the importance of being able to distinguish between the consequences of life-term biomedical care and biomedical care that comes into a person's life at a later stage, because the findings suggest that, whilst such care prolongs life, it insufficiently deals with the repercussions of prolonging life. For example, whilst the participants acknowledged that blood transfusions and iron chelation treatments kept them alive, they also recognised that it was limiting their

life expectancy and quality of life, which impacted on their psychological, social and physical health. Hence, the findings of this thesis show that CAM was used to minimise the diminishing effects of biomedical care. No other study to date has differentiated between the use of CAM to prevent the long-term adverse effects of biomedical treatment, compared to CAM used for the immediate/current effects of biomedical treatment or the current symptoms of an illness.

This does not suggest that people with life-term illnesses do not use CAM for the present treatment of symptoms but, as thesis has shown, in people with a haemoglobinopathy, their use of CAM was equally motivated by the shortcomings of biomedicine which had emerged over many years and the long-term effects of biomedical treatment. This thesis has that shown in turn, these motivators for CAM use were associated with the reported uncaring biomedical practitioner experience, from which the participants garnered additional impetus to pursue CAM and ultimately to not disclose CAM use or to disclose such use, specifically as a defiant message to biomedicine.

The findings of this thesis show the participants' reaction to a life-long condition and the reasons for CAM use and CAM disclosure and non-disclosure are associated with dissatisfaction with biomedicine, and that dissatisfaction with biomedicine is associated with a desire to protect/control personal information and health care decisions. For example, this thesis showed that negative experiences with biomedicine lead participants to withhold information from biomedical practitioners and to take personal control of health care decisions. This thesis provided valuable insight into CAM use and CAM disclosure and non-disclosure amongst people with a chronic blood disorder by showing that health care decisions were not based on a single factor or even a on a number of isolated factors, rather they depended on multiple factors, which are associated with each other. For instance, as shown in by the findings of this thesis, the participants relied on support from those with

whom they had contact, and this included biomedical physicians entrusted with their care. Thus, when participants became disillusioned with biomedical treatment considered unsafe and/or ineffective, this caused disillusionment with biomedical treatment, which was projected toward biomedical physicians because they were the prescribers of such treatments.

This thesis showed a lack of trust resulted when care was perceived to be inadequate or withheld and/or administered in an uncaring manner, and/or when information was withheld or provided with bias. A lack of trusting relationship with biomedical staff was reported as a continual source of biomedical dissatisfaction, which resulted in CAM use by all participants, and non-disclosure of CAM by all but one participant. This thesis showed participants had long memories. Perceived past injudicious actions by medical practitioners were not forgotten, rather they were added to a tally that reached a point where it was expressed as a loss of confidence in biomedical practitioners. Such a loss of confidence led to CAM use which was a way of taking control of situations because biomedical practitioners were perceived to be less than caring and took no responsibility for catastrophic biomedical incidents. Such catastrophic biomedical incidents affected the participants' realm of being, which meant such incidents not only affected their health and life span, they affected how participants functioned in society. Hence, this thesis showed when biomedicine threatened life and/or wellbeing of the participant; it also threatened the social cohesion of the participants' family and/or other social obligations, such as work. Under these circumstances, the participants used CAM and did not disclose such use for self-preservation.

The present research showed the participants adapted to negative situations and took the necessary action they perceived was in their best interests. The findings of the studies undertaken here suggest the participants did not have a fatalistic attitude but rather a positive

attitude, despite their circumstances. The phases of this research illustrated the reported benefits the participants had from CAM, and it showed the participants selected CAM treatments with specific goals in mind. The present research showed the participants also used CAM to protect themselves from the often harmful and ineffective biomedical treatment. Hence, the phases of the present study throughout this chapter suggest CAM use is associated with protective behaviour. Moreover, the findings of the thesis as shown by Salmenperä (2002) show CAM use was associated with a non-fatalistic attitude to life that motivated the participants to do as much as they could for themselves.

The research findings of this thesis illustrated that CAM use was motivated by palliative care. Palliative care at end-of-life has been defined as care that takes place when a cure is no longer possible and disease modification provides diminishing returns (National Institutes of Health, 1997). Although it can be argued that most people who participated in this research are not at end-of-life, their biomedical treatment was not curative and provided diminishing returns. The findings of the present research showed that whilst the participants' acknowledged that the biomedical treatment for the principle diagnosis, β -thalassaemia major was not curative, it was not the prime motivator for CAM use, rather it was the diminishing returns of their long-term biomedical treatment, which was a major reason for CAM use. The findings of this thesis illustrate that CAM use and CAM disclosure can only be understood in relation to the wider context of living and coping with a disorder that is lifelong, complex and a dynamic process. These findings demonstrated CAM use and CAM disclosure for people with β -thalassaemia major together reflect a strategy adopted to attain a sense of normalcy in their lives.

The findings of the research in this thesis identified a number of important aspects of the behaviour of adults with β -thalassaemia major related to CAM use and CAM disclosure. The results of this research are the first to show that the reasons for CAM use are the same

reasons for CAM disclosure and CAM non-disclosure. The findings of this three-phase research suggested that dissatisfaction with biomedicine was associated with dissatisfaction with interactions with biomedical practitioners, and this was a major reason for CAM use and CAM disclosure and CAM non-disclosure. The results show such dissatisfaction was wrought from ineffective treatment/biomedical failure and all its associated factors, which included adverse events and how biomedical physicians dealt with them. Hence, this research has shown the medical encounter was pivotal to dissatisfaction with biomedicine, CAM use, CAM disclosure and CAM non-disclosure.

The results of this thesis have major implications for the biomedical management of people with β -thalassaemia major. The findings also provide valuable indicators for CAM practitioners in relation to people with β -thalassaemia major, as well as other lifelong, life-threatening conditions. Moreover, the findings of this thesis enlarge upon an aspect of health behaviour namely the reasons for CAM use and CAM disclosure, by showing that the issues that affect such behaviour are complex. The findings showed the reasons for CAM use and disclosure of CAM to biomedical physicians centre on the interactional dynamics associated with coping and managing a chronic illness, the effect of biomedical treatment and communication, and participatory decision-making. As shown by this research these psychosocial and physical aspects of treating illness affect the perceived wellness of the individual and their health behaviour.

The World Health Organisation (WHO) defined health as a “state of complete physical, mental and social well-being” (1978). Thus the dominant theme that emanates from this research suggests biomedicine is not able to meet these demands (Barrett et al., 2003). This research shows when these needs are not met people with chronic illness will seek to have them met by using CAM, disclosing CAM and not disclosing CAM.

Future Research

The participants. This thesis was original because there is no previous research of this type describing CAM use amongst people with a lifelong illness, such as β -thalassaemia. This indicates more research with people who have lifelong illness is needed to explore CAM use amongst those who require intensive biomedical care. Research of this kind will be of value for comparative reasons to establish whether and how the need for biomedical care from cradle to grave affects people's decision to use CAM.

The sample for this research was predominantly Caucasian, suburban, young-to-middle aged, adult females, with above average income and education levels. Hence, the sample might not be representative of people with thalassaemia major, or people with a lifelong illness requiring intensive biomedical treatment, in Australia and other developed and developing countries. Research is required into CAM use among people with a β -thalassaemia major from other parts of Australia and the world to evaluate whether the findings of this thesis can be generalised. Research into similar group of people is also warranted within Australia and internationally for comparative reasons. Research into sub-cultural and cultural differences is also important in understanding how culture affects both the reasons for CAM use and its prevalence in various contexts.

CAM definition. Although the aim of this thesis was to determine the usage of CAM, the rate of CAM disclosure and the reasons for CAM use and CAM disclosure amongst a particular group of individuals for whom biomedicine was a necessity, the review of the literature showed that research on CAM use and disclosure has largely been conducted in disciplines other than CAM. During the research process, many articles emerged from non-CAM disciplines, such as psychology, sociology and biomedicine, which indicated that most of the research on CAM use and CAM disclosure has come from those disciplines. Future investigation comparing the findings on CAM use and CAM disclosure that have emerged from those disciplines with those from CAM disciplines would be interesting to examine

how CAM disciplines identify themselves and whether this affects CAM estimates.

Research could then compare the findings on CAM use from the different disciplines and evaluate whether the different philosophical foundations of each discipline affects CAM estimates. The researcher who conducted this study is from a CAM discipline. The researcher devised a CAM definition that was based on intent of use of treatments that had not been prescribed by a biomedical physician. The findings of this research show CAM definitions have substantial influence on CAM estimates and suggest that the operationalised CAM definition is often responsible for substantial variations in CAM estimates amongst apparently similar populations. Research using different CAM definitions, including the one used for this study, in analyses would be valuable in assessing the numerical impact CAM definitions have on the same data.

The findings of this thesis showed the definition of CAM is one issue that significantly affects CAM estimates. This thesis showed that research on estimates for CAM use needs more thought about developing homogeneous and unambiguous terms to describe CAM. This thesis has demonstrated that qualitative research can be especially helpful in clarifying the meaning of CAM and CAM product definitions. Continued research is imperative to develop conceptually sound, as well as reliable and valid, instruments to measure CAM use, based on the understandings that arise from qualitative studies.

Differentiation of CAM treatments. The results of this three-phase study suggest some of the participants used individualised CAM modalities for the treatment of their illnesses, whereas others used standardised CAM treatment. The researcher characterised individualised CAM treatment as CAM treatment based on the individual needs of the person, as determined by a CAM practitioner. In contrast, standardised CAM treatment was characterised as CAM treatment provided by a CAM practitioner, offering the same or similar treatment to all people presenting with a particular illness, such as anaemia,

osteoporosis or Hepatitis C. Standardised CAM treatment was also characterised as CAM treatment that the participants self-prescribed. Hence, standardised CAM treatment, when self-prescribed was characterised by the participants' choice of treatment made on hearsay of efficacy, rather than being prescribed on the differentiation of presenting signs and symptoms by a CAM practitioner. There is little knowledge about differences between reasons for individualised CAM treatment and standardised CAM treatment, because previous research into CAM has focused on the choice between CAM and biomedicine and/or a combination of the two. Research differentiating between individualised CAM treatment and standardised CAM treatment would help determine how people make the decision to use the services of a CAM practitioner or to prescribe their own CAM treatment. Research could determine whether the decision to self-prescribe CAM is analogous to self-prescribing biomedicines, such as over-the-counter medicine.

The present research did not determine whether CAM use amongst people with TM was sustained. Research is needed to show whether CAM practitioner services and or self-prescribed CAM use are sustained and for what reasons. Such research is fundamental to establishing whether CAM use is harmful because as with OTC medicines, a lack of knowledge in administering these products can be harmful. Such research requires participants' behaviour to be monitored over a period of time to observe whether CAM use is continued. At the end of a sufficiently long observation period, participants should be interviewed to identify reasons why they maintained their CAM use, switched to different CAM modalities or stopped using CAM during the time when they are monitored. The results of such research would add to the knowledge of CAM use and could be used to develop educational material for CAM users alerting them to the importance of differentiating signs and symptoms for reasons of safety and efficacy of treatments. The results of such research could also be used to gather anecdotal evidence suggesting which

CAM products/modalities produced benefits to the participants. Such information could be used to test such CAM products/modalities in clinical trials, to provide empirical evidence of their efficacy and safety, and might lead to the development of new pharmaceutical interventions or ways of treating the chronically ill.

This present research did not compare people with TM with any other group. For comparative reasons research is needed to show whether people with a chronic and serious illness are more likely to consult CAM practitioners or self-prescribe CAM than people with acute conditions or the general population. In this kind of research, different groups, such as people with life-long illnesses, people with disabilities, people with chronic illnesses that typically occur later in life (for example, heart disease, arthritis and type 2 diabetes) and the general population need to be compared in the same study, using the same methods, preferably including qualitative techniques. Because of the absence of standard definitions and measures comparisons between various groups examined in different studies cannot be made any confidence.

Safety and efficacy of treatments. The findings of this research suggest people who are intensively biomedically treated for their entire life expect treatment to be safe and effective. As shown from the findings of this three-phase study, treatment that did not meet these expectations was a cause for dissatisfaction, which often triggered CAM use. Equally, the findings suggest that, if CAM treatment were to be found lacking in safety and efficacy, it too would lead to dissatisfaction. That none of the participants reported being dissatisfied with CAM is interesting because CAM was not effective in curing the primary illness. This suggests that whilst the participants reported they wanted CAM to cure the primary illness, they did not expect that it would. Hence, there was no dissatisfaction with palliative outcomes from using CAM. One of the participants did report that CAM was ineffective in treating infertility and attributed the failure to “I didn’t give it long enough”. Therefore, once

again there was no dissatisfaction with CAM. This dissatisfaction with biomedical treatment (any treatment) probably comes with constant failure. The participants in this research reported that the failure to alleviate illnesses such as irritable bowel and sinusitis, which the participants considered should have been cured, particularly after many failed biomedical attempts, caused negative views of biomedicine. Research that explores at which point dissatisfaction occurs would be valuable to biomedical physicians and CAM practitioners, because it would alert them to re-evaluate treatment strategies and to ask clients what course of treatment they would like to pursue, and whether they are happy to continue with the current treatment strategy.

CAM use and Biomedical Safety and Efficacy

A noteworthy contribution of this thesis was that the interviews identified that CAM use was often motivated by the reported lack of biomedical efficacy. This suggests a perceived lack of biomedical efficacy predicts CAM use. Research that explores perceptions of biomedical ineffectiveness specifically in relation to the variable of outcome efficacy would be valuable to determine to what extent, if biomedicine is perceived to be ineffective, people will seek alternative forms of treatment.

The findings showed CAM was often used because biomedicine was perceived to be “dangerous”. Many participants reported how biomedical treatment had made them ill and this caused a loss of confidence in biomedicine and biomedical practitioners. The findings of this research suggest biomedicines that are injurious to health, regardless of the expected outcome are not acceptable to people. The participants expressed anger and frustration at biomedical treatment that was given experimentally as a possible cure for illnesses, such as Hepatitis C, which endangered the participants’ life. The findings show when the expected outcome was not met by experimental treatment this was a major cause of dissatisfaction and loss of confidence in biomedicine, particularly if the experimental treatment was

deleterious to health. Research that explores the responses of people to notionally dangerous treatment, when it is acceptable to people and under what conditions it leads people to search for alternative therapy is a primary step in understanding from where dissatisfaction and loss of confidence in biomedicine comes from is important knowledge for biomedical physicians to have, when they have no alternative but to prescribe “lethal” medicine and to effectively manage the reactions of those exposed to such treatments.

A major contribution of this thesis was the finding that participants often felt they had been deceived and “given no option” but to accept experimental treatment and this was a principal cause of dissatisfaction with biomedicine, which triggered CAM use. The findings show a loss of confidence in biomedicine occurred because participants felt like they “meant nothing to them [biomedical physicians]” and that they had been “used”. This suggests that research on peoples’ views of experimental clinical trials needs to be conducted because there is little knowledge about how people feel before and after they enter clinical trials. Such research also needs to examine whether if the results of this thesis can be generalised to other groups of people who have been through clinical trials. Research comparing the views of people who undergo experimental medicine as a last resort with those who participate for other reasons, (for example, altruism or seeking a cure for a non-terminal illness), would be valuable in understanding from where and at which point dissatisfaction with biomedicine occurs.

Efficacy and Safety of CAM. The findings of this research showed one of the major reasons the participants gave for using CAM was because of its perceived efficacy and because they wanted efficacious and safe treatment. As shown by this thesis, most of the participants blamed the biomedical practitioner for not providing safe and efficacious medicine, and this lead to dissatisfaction and CAM use. Hence, in this context, issues of safety and efficacy are not solely dependent upon the product. This suggests research, which

explores how CAM practitioners treat people with anaemia is a necessary step for establishing safety of treatment, because some people, such as those with thalassaemia major, even though they present with anaemia should not be treated with iron, a common treatment for anaemia. For the same reasons of safety, research into standardised CAM treatment would be valuable in exploring whether people with a serious condition, such as thalassaemia major, are taking products, such as iron fortified foods and/or multi/vitamins with iron, known to be unsafe practice for such people. This kind of research and research into other substances, which might be injurious to the health of people with thalassaemia major has never been undertaken and is one of the step required to establish safety of CAM treatment and health behaviour.

An important conclusion of this research is that continued CAM use was motivated by the reported outcome efficacy of CAM. This suggests that outcome efficacy is a predictor of maintenance of CAM use. One of the variables posited by the health belief model as a predictor of health behaviour is outcome efficacy (Walleston, Walleston & DeVellis, 1978). Research that explores CAM use in relation to the HBM, specifically in relation to the variable of outcome efficacy, is needed to test the prediction that, if CAM is perceived to be effective, people will continue to use CAM.

CAM use and benefits of CAM. The participants in this research reported that they perceived CAM was helping them. Further study of this perception would be interesting. Studies could look at how commonly the perception that CAM is beneficial occurs, what factors affect that perception (for example, personal decision to use CAM, strength of need for a reassuring or positive treatment) and whether it is an accurate perception.

This thesis showed the participants reported that they benefited from CAM and this was given as a reason for not accepting biomedical advice that CAM did not work. Further research comparing the health of people with thalassaemia major who use CAM with those

who do not use CAM would be valuable in establishing whether CAM is actually beneficial, which CAM products/treatments are providing the benefit and whether the benefit is lasting. Such information would assist in developing educational programs for biomedical practitioners who deal with people with thalassaemia major. Such educational programs could indicate which CAM treatments would be valuable to people with thalassaemia major and to biomedical treatment, by showing, which illnesses respond to CAM treatment.

A major finding of this research was that the benefit of CAM was often predicated on the perception that it was efficacious because it provided lasting relief from illnesses, such as irritable bowel and sinusitis, which biomedicine had failed to treat effectively. Research aimed at determining the utility of specific CAM treatments for co-morbidities could provide the basis for incorporating such treatments into the care of people with illnesses that don't respond to biomedical care. Research of this kind could compare the efficacy of CAM treatments believed to be beneficial for people with a chronic illness, who do not need much biomedical intervention, with the efficacy of the treatments for those who require constant biomedical intervention. Research comparing belief in the efficacy of CAM use amongst other people with life-long illnesses, such as haemophilia is required to evaluate whether such beliefs and life-long illnesses are associated. This research could be extended to the general population to evaluate whether there are common beliefs in CAM efficacy, the extent of belief in efficacy in CAM and whether it can be generalised.

A major finding of this research was that participants considered CAM improved their health substantially and helped them to fulfil their social roles, including being well enough to find and secure permanent work. In this way, participants indicated that CAM use was associated with improved quality of life. Research evaluating the effect of CAM on the subjective health of people with a lifelong illness is necessary to examine whether CAM use

can substantially benefit individuals' perceptions of physical and psychological health and to what degree CAM treatments affects subjective health.

The participants in this research reported that CAM practitioners treated them with empathy and respect, looked after the “soul”, found the “cause of the disease” and provided them with health information that helped guide them toward self-reliance, so that they were better able to avoid ill-health. In contrast, the participants considered biomedical practitioners treated them as “numbers” and refused to provide them with the information they needed to make appropriate health decisions. These findings suggest the participants' valued wholistic care. The participants reported they used CAM because their CAM practitioners treated them “more like a friend”, spoke to them in an open and honest way, and listened carefully. The participants also reported CAM practitioners provided them with hands on knowledge to treat minor complaints and offered suggestions and education about proactive care, and proposed strategies which they could undertake on their own to prevent reoccurrence of their symptoms, enhance their health, and, if necessary redirect their lives. Research could evaluate whether people who receive wholistic care are better equipped to cope with adverse events, such as when treatment options have been exhausted. The findings of this thesis suggest that wholistic care actually decreases the need for biomedical interventions, which has many positive outcomes, including that it saves valuable health resources. Research into the value of wholistic care would be interesting to examine whether such care, when incorporated into biomedical practice reduced the need for some biomedical interventions, such as CAM in lieu of antibiotics for treating sinusitis and/or irritable bowel, to see if that finding of this research can be generalised. If some CAM treatments can replace the use of antibiotics in some instances, this would provide the impetus for further research in evaluating which CAM products can be used in lieu of antibiotics. This research would valuable in preventing antibiotic resistance in the community, which is of great

concern primarily for reasons of health and Government health costs which are often exacerbated by antibiotic resistant infections requiring hospitalisation.

CAM safety. Most of the participants in this research used CAM because such practice was believed to be safe. To date there has been no research into specific CAM products and the effect they might have when taken with the biomedical medicines people with thalassaemia are prescribed. Research is needed to evaluate the interactions CAM products might have with the biomedical medicines people with thalassaemia use. The findings of such research are essential for safe prescribing practices for biomedical medical and CAM practitioners.

CAM Use and Health Behaviour

CAM use and positive health behaviour. his research showed the participants did not perceive themselves as risk takers and the findings suggest their health behaviours were positive. Research that compares the beliefs about the CAM they use held by people with a chronic illness with the known properties of those products/treatments would be valuable in determining whether the beliefs of people accurately reflect the value of the CAM treatment/product as it relates to them. The findings of such research could be used to develop illness specific information sheets for people undergoing intensive treatment.

A finding of this thesis suggests many participants displayed an internal locus of control. Internal locus of control is associated with a variety of positive health practices and improved psychological and physical functioning (Marks, Richardson, Graham & Levine, 1986). Previous research on internal locus of control and CAM use was limited to people with cancer ((Davidson, Geoghegan, McLaughlin & Woodward, 2004; Henderson, & Donatelle, 2003; Marks et al., 1986).

Hence, further research exploring whether the association between internal locus of control and CAM use can be generalised to people with other chronic illnesses, such as

those with haemophilia, would add to the knowledge about characteristics of people who use CAM, as well as providing insights into the impact of internal locus of control on health behaviour.

The findings suggested that although some participants had an internal locus of control, their distress did not diminish, despite CAM use, because such distress was the result of their interactions with biomedical practitioners and treatments, which did not change. This suggests internal locus of control might be associated with avoidance behaviour, because some participants reported that they used CAM to avoid biomedical treatment, consults with biomedical practitioners and biomedical advice. Hence, the psychological variables associated with internal locus of control need further exploration, which would add to knowledge about CAM use and internal locus of control by evaluating whether CAM use is avoidance behaviour and whether internal locus of control is a predictor of such behaviour. More importantly, such knowledge is required to generate further research to evaluate whether internal locus of control is the result of individual personality differences, conditioned learning or current/longterm/cumulative environmental prompts, such as distressing biomedical consultations. Such knowledge could lead to more research, which explores whether CAM is the result of internal locus of control or if internal locus of control motivates CAM use.

The participants attributed their positive health practices and improved psychological and physical functioning to their use of CAM. The findings of this research suggest that the participants displayed positive health behaviours because they perceived that their CAM use was not harmful, but beneficial. The participants reported that they measured this by biomedical markers, such as improved haemoglobin levels and the alleviation of disorders, which biomedicine had failed to treat. The findings also suggest the participants' psychological functioning was improved, because they reported less need for

antidepressants and lower levels of stress, and an increased ability to function “as normal”. Research, which compares the psychological functioning of people with life-long illnesses and those with other chronic illnesses who use CAM with those do not use CAM is the first step in determining the utility of CAM for treating the stressors of the natural progression of illnesses, and its treatment.

CAM use and preventive behaviour. The findings of this thesis show most of the participants used CAM to prevent illnesses and many-used CAM instead of prescribed prophylactics such as, penicillin. The participants who adopted CAM as a preventive treatment reported they had fewer episodes of infections and generally felt healthier. Research is required to evaluate whether some CAM treatments are effective in preventing infections. Research is also needed to evaluate which CAM products are effective and whether they can be used in lieu of some pharmaceutical antibiotics used as prophylactic medicine. Such research could provide safe alternative methods of prophylaxis that could reduce the need for antibiotics, saving antibiotics for serious infections and reducing the global threat of antibiotic resistance.

CAM use and protective behaviour. In this thesis, the participants used CAM in the belief that it could prevent illness or deterioration, or promote and maintain health, which suggests such behaviour was associated with protective behaviour. Research that evaluates whether such protective behaviour is generated by fear associated with negative emotional reactions to biomedical treatment, because it is not particularly helpful in some instances, is needed to help understand why people with serious illnesses abandon some biomedical treatments. The findings of such research would provide information on what people with a serious a illness want from treatment, so that biomedical physicians can offer treatment which is in keeping with the expectations of people.

The participants' comments suggest biomedical physicians often added to, rather than allayed, their clients' apprehension by making comments that "make[s] me scared", which motivated CAM use. Knowledge about fear and reactions to it in people with life-threatening illnesses would be valuable for biomedical physicians to help them develop strategies to identify protective behaviour, which occurs as a result of the biomedical consult. Such strategies are necessary to obviate the psychological distress that most of the participants' comments suggest they were experiencing. Teaching programs, which provide biomedical practitioners with the skills to help their clients re-evaluate the need for self-protection and increase acquisitive behaviours, such as self-disclosure and assertiveness, would benefit the client and physicians, by providing an environment that promotes dialogue.

The findings of this thesis suggest that participants were wary of biomedical physicians and reticent to divulge information, which they thought biomedical carers might access. For the purpose of comparison, research examining the reasons people give for CAM use and disclosure should not only be undertaken by those aligned with the biomedical care of the participants, but also by those not aligned with their biomedical care. Such research is needed to validate the findings of this and other research, which suggests participants are intimidated by their biomedical carers and withhold information to self-protect their mind and body. The findings of such research could be used to generate further studies into the reasons people give for feeling intimidated by biomedical practitioners. Research findings from such studies could be applied to the development of training modules to help biomedical physicians to modify their consultative practice, so that it is more user friendly and less "threatening".

CAM Use and Biomedical Attitudes Toward CAM

This research showed the participants' decisions to use CAM were motivated to a great extent by their perceptions of their biomedical physicians' attitudes and beliefs toward CAM. Perhaps surprisingly, a number of participants in this study reported that they resolved to use CAM partly because their biomedical practitioner would not discuss CAM use. Considering that biomedical physicians typically play a major role in influencing the health care decisions of their clients, research that explores such relationships would be valuable in examining how theory about relationships among individuals' attitudes, beliefs, behavioural intentions and actual practices (Ajzen & Fishbein, 1975) influence CAM use and CAM disclosure. In this research, CAM use and non-disclosure, and compliance with some biomedical regimens were associated with physician-patient interaction. Participants frequently reported biomedical physicians were reluctant to facilitate the participants' need for information about their health, biomedical treatment and about CAM. Hence, research that explores and expands on the health compliance model, with regard to physician-patient interaction variables will assist in the development and testing of instrumental skills that could provide biomedical practitioners with the capacity to offer more effective patient/physician communication.

This present research showed that participants had positive attitudes about CAM use, which contrasted with the negative attitudes they perceived biomedical physicians held toward CAM. Research could be derived from Fishbein and Ajzen's (1975) theory of reasoned action theory to assess physicians' CAM attitudes, subjective norms, behavioural intentions, and medical practices. Such research would help to determine whether the findings, which showed CAM use and CAM non-disclosure were motivated by and associated with the negative attitudes biomedical physicians projected toward CAM, can be generalised, and to confirm these novel findings.

CAM Use and Control

A major finding of this research was that CAM disclosure and CAM use was affected by the perceived authoritative power of biomedical physicians, as exemplified in the statement “they [biomedical practitioners] just want to control everything”. In an effort to overcome such authoritative power, the participants reported they used CAM and disclosed (in one case) and did not disclose such use to “take control”. Future research should seek to determine the extent to which CAM use and CAM disclosure are associated with behavioural control. This research showed the participants perceived there was an imbalance of power and that biomedical practitioners showed prejudice regarding other forms of therapy, and that the participants reported they used CAM and did/not disclose such use as a form of retaliatory action. Research is needed to determine whether retaliatory action as a reason for CAM use and non-disclosure or disclosure can be generalised to other populations. There is a need to conduct an in-depth assessment of the interactions about CAM use between those with thalassemia major (and others with a serious/chronic illness) with their physicians. Such research could provide an understanding of the extent to which physicians evaluate CAM risks and benefits, their willingness to discuss these issues and the extent of advocacy for or against CAM use to see if the findings of this thesis generalised to other group.

Interestingly, the findings of this research also show childhood memories of authoritative power wielded by past treating physicians were used as a reason not to disclose CAM use. Research into the health behaviours of people who have been treated since infancy has never previously been undertaken to determine how far back past biomedical experiences affect current health behaviours. Research exploring and comparing the early situation factors, such as treatment received and the memory of the biomedical consult experienced during childhood, and the current situational factors associated with treatment

and the consult, would be valuable in determining whether one or both kinds of situational factor influence CAM use and CAM disclosure amongst people with a chronic illness.

The findings of the present research suggested the participants' CAM use and CAM non-disclosure were motivated by defensive behaviour. This research also showed CAM use was associated with precautionary behaviour. Research using theories, such as the health belief model and the health promotion model (Kaplan et al., 1993; Laffrey, 1990; Palank, 1991), to develop and test hypotheses to evaluate whether CAM use and CAM non-disclosure are defensive health behaviours. This would be valuable for predicting CAM use and CAM disclosure. Similarly, research could be undertaken to evaluate if CAM use and CAM disclosure are precautionary health behaviours, this too would be valuable in predicting CAM use and CAM disclosure in the future.

This research showed CAM use reportedly provided comfort compared with biomedical treatment, which was associated with discomfort, in both a physical and an emotional context. Participants often reported that such incompatible physical and emotional states were associated with anger and hostility toward their biomedical practitioner/treatment and perhaps depression, for which many of the participants reported they had been biomedically treated or which biomedical practitioners had advised them was a condition they needed to treat. The findings of this research in regard to this issue show that these emotional states lead to CAM use, CAM non-disclosure and non-compliance with the biomedical physician's recommendations. Research exploring the relationship between the emotional-motivational characteristics posited by the health compliance model-11 (Frank, 2000) and CAM behaviour would be useful to evaluate if the findings of this research can be generalised to people requiring intensive biomedical treatment.

This thesis has shown that people are sensitive to the manner in which they are treated and react accordingly. Research comparing the sensitivity and behaviour of chronically-ill people, who believe they have been unfairly treated, and those who believe health care was delivered in a caring manner needs to be undertaken to evaluate health outcomes and the impact such outcomes have on behaviours, such as CAM use and CAM disclosure.

In this thesis, there was a strong association between CAM disclosure/non-disclosure and the participants' beliefs that biomedical physicians blamed and shamed them, rather than admitting that biomedical treatment was not always meeting its therapeutic aim. Research is needed to evaluate how CAM disclosure is affected by the perception of non-recognition of biomedical ineffectiveness by biomedical staff and that such non-recognition is "sick making", so it hinders to the biomedical physicians' objectives to heal. Such knowledge would assist biomedical practitioners to incorporate into the biomedical consult information that acknowledges biomedicine might not always have the desired outcome, which might make for healthier emotional responses that assist biomedical physicians in dealing with people with whom they might have a long-term client-practitioner relationship.

A major contribution of this research is the finding that the level of distress, reported by the participants, was contributed to by the handling of their condition by biomedical practitioners and this was a major contributor to CAM use and to non-disclosure. Research is needed on the development of training modules for biomedical practitioners in the handling of people in such circumstances. Research could evaluate the effect of the implementation of such training on the health behaviour and level of distress of people with serious medical conditions. Such research would be valuable in assessing/determining whether training should be implemented and what impact it could have on biomedical practitioners' praxis. There is also a need for research to evaluate whether the findings of

this research, showing the biomedical consult was the cause of much distress, often leading biomedical practitioners to resort to pharmaceutical interventions, can be generalised to other group where regular consultations are necessary over the long-term. The findings of such research could also be used to develop and encourage a wholistic approach to biomedical consults that might lead to more positive relationship that assist in addressing the cause of such distress, rather than to behaviours, such as the dispensing of drugs to mask the problem. There is also a need for the development and testing of various psychological interventions to help people to deal with the biomedical consultation experience.

Another conclusion of this thesis suggested that people who are intensively biomedically treated from a young age and have need for constant hospital care are more likely to use CAM than other group, yet they are less likely to disclose CAM use. More research is needed comparing CAM use and CAM disclosure of people in primary care with those using hospital in-patient and outpatient services to evaluate whether the high level of CAM use in intensively treated people can be generalised.

The findings of this thesis suggest that biomedical palliative care for people with life-long disorders does not sufficiently meet the needs of people who require biomedical care from cradle to grave. Research has never before been undertaken to ask what lifelong, chronically ill people want and expect from their biomedical care. Also no research has been undertaken to discover if biomedical physicians ask what it is the client wants and expects from treatment, whether it be biomedical or CAM or a combination of both. Results from such research could be used to properly allocate health resources to those that fulfil the needs of people with life-long illnesses. Research could then be undertaken to compare the different treatments applied by comparing the health of people for example, receiving CAM with those not receiving them. Such research could examine whether people receiving CAM treatments had less need for prescribed medicines and/or less admissions to in-patient care.

Such an evaluation is necessary to develop government health care policy in relation to treatment of people who require expensive and intensive biomedical care for more efficient expenditure of public monies and allocation of scarce health resources.

This three-phase study showed much research is needed into the health behaviours of people in relation to CAM use and CAM disclosure to more clearly and completely understand the phenomena associated with CAM and the relationship of these factors to biomedicine. The future research generated by this thesis has potential to add knowledge to many disciplines, such as CAM, biomedicine, psychology and sociology. Any future research generated from this thesis could also contribute to Government health policies in relation to health, social services and education.

Implications for Practice

The results of this thesis have major implications for the management of people with thalassaemia major. Although, the focus of the research is CAM, clearly there are some noteworthy implications for biomedicine. These will be discussed, and then the CAM implications will be addressed.

Implications for Biomedical Practice

This research indicated that the encounter between biomedical practitioners and participants was influential in the participants' decision to use CAM (Siahpush, 1999). The medical encounter also affected disclosure of CAM. The implications for biomedical practice include the need for biomedical practitioners to have CAM knowledge, to accurately reflect safety of biomedical and CAM treatment, to respect the autonomy of clients and to display sensitivity toward a vulnerable group of people. The implications predominantly centre on the consultation process. Each of the implications for biomedical practice will be discussed.

CAM Knowledge

Participants reported biomedical physicians often advised them against CAM use, because “we don’t know enough about it”. Hence, biomedical physicians could benefit from the acquisition of knowledge of the various forms of CAM treatments that people might use, because some CAM substances can interact with biomedical treatment (Shane-Mcwhorter & Geil, 2002; Sørensen, 2002). Such an increase of knowledge might enhance the ability of the biomedical physician to differentiate CAM treatments that might be harmful when combined with biomedical regimens, from those that are reported as being beneficial by their clients and which Western “scientific” knowledge suggest do no harm, at worst.

The reports mad by the participants suggested that their respect for biomedical practitioners typically declined, when practitioners reported that they or “we” did not know much about CAM. Given that a range of major CAM modalities have a long and well-documented history as health approaches and ways to treat illness, participants often perceived this kind of response to reflect badly on the biomedical practitioner. Wither their knowledge was perceived to limited due to prejudice about certain health modalities or the impression given was that the practitioners had just not made an effort to widen their understanding of potential treatments. Biomedical practitioners would increase respect for their expertise if they learned enough about major CAM modalities to discuss them and advise their clients in an educated manner.

The participants reported they felt biomedical physicians did not believe them when they tried to inform the practitioners of the CAM benefits that they had experienced, by making comments like “there is no evidence to support it works”. A number of the participants reported such comments diminished their respect for biomedical physicians, rather making them resolute in “telling them nothing” and more determined to use CAM.

Hence, biomedical physicians could maximise and maintain sound relationship with their clients by not summarily dismissing participants' reported anecdotal evidence.

The results of this research showed that, when biomedical physicians dismissed anecdotal evidence reported by the participants that CAM had been beneficial, such as an increase in haemoglobin levels, this reaction by biomedical practitioners caused dissatisfaction because such benefits were easily verifiable. It would be beneficial if the CAM, to which some of the participants attributed an increase in haemoglobin levels, were monitored for any long-term positive or negative effect. Biomedical physicians willing to undertake such monitoring would increase their knowledge of CAM and foster their relationship with clients by engaging them in treatment plans, which include CAM.

Efficacy and Safety of Treatment

This research has shown that participants used CAM because they were concerned about the efficacy and safety of biomedical treatment. Amongst the participants in this research, unsafe and ineffective biomedical treatments were reported to be major causes of dissatisfaction with biomedicine that motivated CAM use. It is recognised that, in response to many of the challenges presented by thalassaemia major, biomedicine faces a two-edged sword in providing optimal treatment to people with thalassaemia major, for many reasons. As reported by the participants, what was often considered optimum by biomedicine was not 'optimum' as perceived by the participants, when it damaged their health or was ineffective. Optimum treatment "includes safe and effective CAM treatments even if they are not within the physician's standard of care or are outside the physician's scope of practice" (Bulen, 2003, p. 332). It is recommended that biomedical physicians should make appropriate suggestions, including some CAM therapies, which might possibly fulfil participants' needs because it is a requirement of informed consent and a requirement of ethically and legally sound treatment (Bulen, 2003; Forrester & Griffiths, 2003).

The participants often considered biomedical physicians feigned ignorance of CAM because “if they don’t know about it [CAM] how come they say they know it’s ‘dangerous’?”. Thus, biomedical physicians should be aware that their clients were perceptive to mixed messages. As shown by this research, mixed messages caused a number of the participants to have negative reactions to biomedicine, by displaying anger toward their health-carer, and retaliatory by rejecting biomedical advice. Rejection of biomedical advice jeopardised the biomedical physician’s responsibility to provide optimum treatment by failing to solicit and answer questions in a manner that considered the client’s understanding and expectations of the consultation process (Bulen, 2003; Forrester & Griffiths, 2003). Hence, it is recommended biomedical physicians should be trained to consult in a manner that does not elicit negative emotions by underestimating their clients’ ability to recall and process information.

Based on the reports of participants in this research, biomedical physicians should be aware that people are using CAM because biomedicine is not providing a cure or sufficient relief, and/or because the adverse effects of some biomedical treatments outweigh the benefits. It is suggested that this would be facilitated for many biomedical physicians, if they became more informed about CAM, and were prepared to make referrals to and communicate with CAM practitioners. Open communication between biomedical physicians and CAM practitioners would be in the best interest of the person being treated.

Participants reported that their motivation to use CAM was increased by situations in which treating physicians dismissed CAM treatments that could potentially benefit the participants and insisted they use biomedical treatments, which the participants believed to be harmful. Hence, it is recommended that biomedical physicians should be aware that by not offering their clients the opportunity to discuss the reasons for wanting to use CAM and what benefits the participants perceived CAM had, biomedical practitioners were potentially

neglecting treatments, which could be advantageous to the participants' health.

Whilst this has potential legal ramifications (Bulen, 2003), a more direct and immediate impact was that the participants perceived such behaviour negatively and it reinforced their commitment to 'safe' CAM use. Thus, it would be beneficial to the consultation process for biomedical physicians to encourage CAM use or at least to be open to it and to ask the client to monitor and report back the benefits and adverse effects, if any. This would add to the biomedical physician's CAM knowledge and indicate to the client that concerns about safety of CAM and biomedical treatment was of mutual interest.

Biomedical treatment provided with the intention of testing its efficacy in people with TM, which was perceived by some participants as being deleterious to the participant's health, was one of the reported causes of anger and rejection of biomedical advice within the present sample. For example, participants who reported they had been recruited to try an experimental treatment felt as though they had been coerced into such trials because, if they did not acquiesce to such "safe" treatment, they were told they would die. The participants reported the "promised" outcomes of trial drug/s never manifested, and in the process of the trial their health was further damaged. This led a number of the participants to claim that experimental treatment was not safe and was therefore misrepresented to them. For these reasons, the participants often stated they used CAM and did not report such use to biomedical physicians, as a form of retaliation against biomedical practitioners. This suggests biomedical physicians should be more thoroughly trained to be mindful not to give their clients false impressions of treatment. It also suggests biomedical physicians need to accept that some treatments are best not given and, if offered, all the adverse effects should be explained from the outset in an honest and open manner, because as shown by this thesis the participants often retaliated against biomedical physicians by withholding not only

information about CAM use from the practitioners but also not reporting other important other health-related information.

Most participants reported biomedical physicians frequently ignored their pleas for help, when the participants perceived that biomedical treatment had adverse effects. The participants claimed that biomedical practitioners refused to accept and acknowledge what had happened. This caused dissatisfaction and lead to CAM use, not so much because the treatment had adverse effects, but because biomedical physicians often attempted to place the responsibility onto the participant by telling them to see a psychologist. Hence, biomedical physicians, who are responsible for such a vulnerable group of people, would benefit by being proactive, rather than reactive, and by accepting responsibility for the ramifications of treatment that they prescribe/recommend. In any event, all recommendations for psychological counselling should be handled with care and sensitivity, given the perceptions that most lay people have of the role of psychology.

The participants of this thesis recognised that biomedical physicians mostly acted out of beneficence, but when physicians ignored the participants' distress, they were perceived to be acting with maleficent intent, which reinforced the participants' pursuit of CAM and, perhaps more importantly, their non-disclosure of such use. Therefore, biomedical physicians should be advised or trained to foster a more caring and nurturing consultative process, one in which the intentions cannot be misconstrued.

Control of Health Behaviour

Portraying CAM as dangerous and ineffective, which is not what the participants reported they experienced in their CAM use, lead the participants to believe the misrepresentation was a deliberate attempt to control their health behaviour. This frequently caused dissatisfaction with the biomedical practitioner. Thus, biomedical physicians would be well advised to establish lines of communication with their clients that acknowledge that they are equal partners in treatment-making decisions.

Participants reported frequently feeling more positive and often gaining more benefits from prescriptions from their CAM consultations, where the consultation was wholistic, compared to the biomedical consult, where the focus was usually on specific physical markers of illness. Hence, biomedical physicians should recognise that attempting to control health behaviour, such as CAM use, which reportedly produced benefits, is likely to fail, because, as the participants said, “why should I stop something that is helping me”.

Controlling health behaviours considered by participants to be beneficial has other implications for biomedical physicians, which are possibly more important. Firstly, controlling a health behaviour, which is beneficial, cannot be, and was not perceived by the participants to be, in their best interests. Secondly, attempts to control health behaviour that was perceived as beneficial, lead to a loss of trust in the biomedical physician and typically reinforced CAM use. The loss of trust in the biomedical physician came about because the biomedical physician was often perceived to be giving advice, which was the antithesis of the goals biomedical practitioners said they were trying to reach for the participants, “to do the best for them”. Thus biomedical physicians would do well to be mindful that contradicting/and or ignoring what their clients are reporting and continuing with a preformed agenda is not going to elicit their expected outcome of changing health behaviour, rather it is likely to do encourage clients to contravene or ignore biomedical advice.

The results suggest that the style of biomedical consultation, which the participants’ commonly reported they experienced, was not conducive to eliciting attitudes that would support adherence to biomedical advice for health behaviours, because it was perceived as an unequal partnership. Hence, the patient-physician interaction reportedly did not facilitate knowledge acquisition by either the practitioner or the client and did not elicit positive attitudes or emotions in the client. Participants stated this occurred because the withholding

of information by biomedical practitioners was perceived as a form of control and misinformation that lead, as a substantial number of participants claimed, to a loss of trust. This indicates there would be value in biomedical physicians being aware that altering peoples' health behaviour by persuasion to a particular point of view requires developing an environment in which the clients feel they are viewed as equal partners in the treatment process.

Autonomy

This research showed biomedical practitioners who could or would not answer the participants' questions or concerns about CAM accurately were perceived by most participants as not being knowledgeable about CAM, and not caring toward participants. This translated to participant dissatisfaction, often for the reason that the participants considered their decision-making autonomy was thwarted because they were not being given the information they sought to make an informed decision. Autonomy is an important and integral part of the treatment process (Forrester & Griffiths, 2003) and so relevant to the maintenance of a successful partnership between client and physician. Thus, biomedical physicians could facilitate their interactions with clients by noting that clients are not amenable to advice when they perceive their autonomy is threatened.

Sensitivity

The results of this thesis showed that attempts by biomedical physicians to dissuade people from using CAM typically encouraged such use and non-disclosure of CAM. Biomedical physicians, thus, could benefit by considering individuals' understanding of the organic factors that motivated, or at least triggered, an interest in CAM use, their ability to understand the language in which advice is given and their emotional state. The results showed all of these factors impeded the biomedical physicians' attempts to alter their patients' health behaviour. A greater understanding or appreciation of these factors, which affect the person's attitude toward the relayed information, might assist biomedical physicians' efforts to alter behaviour the practitioners consider to be adverse to biomedical treatment regimens and, by association, to the health and well-being of the individual. The participants also reported biomedical physicians often acted with maleficence, because, when they asked for help in treating the adverse affects of treatment, they were told, "nothing could be done". Biomedical physicians could benefit by recognising that people

from such a vulnerable population are likely to react by rejecting biomedical advice, when they are exposed to stressful events that worsen their state of health.

One of the significant findings of this thesis showed the participants frequently turned to CAM for help because comments by biomedical practitioners, such as “well that’s just bad luck”, indicated that they were being abandoned by biomedicine. Biomedical practitioners would do well to recognise that such comments, as reported by the participants, elicited emotions of anger and diminished the respect participants held for practitioners.

Some of the participants reported they considered the biomedical physician “part of the family”, because they believed they held their interests of well-being, to be of paramount importance. A number of participants reported, when biomedical practitioners told them “to get on with it”, their illusion of a significant other was shattered and this caused distress. Participants reported that such situations made them believe that “all along they were just pretending to care”, and to negatively re-evaluate their relationship with their biomedical practitioner. Biomedical practitioners could benefit by acknowledging the findings of this research, which shows the words they use in dealing with vulnerable people were linked to dissatisfaction with the practitioners and in turn stimulated participants to turn to CAM use.

The biomedical implications for practice proposed in this section show people with thalassaemia major are using CAM despite their biomedical physicians’ remonstrations that they should not use CAM. Hence, biomedical physicians need to rethink how they approach the issue of CAM with their clients. Furthermore, biomedical physicians who discouraged CAM use usually failed to reach their objective, because the consultation process did not provide knowledge about CAM when it was requested. This often led to participants rejecting biomedical advice. Thus, the biomedical consultative process needs to be modified to consider the educative needs of the client. There is a need for biomedical physicians to become knowledgeable about CAM so they can refer clients who seek CAM to appropriate

CAM practitioners. There is also a need for biomedical practitioners to modify the way they communicate about CAM, to encourage open dialogue about CAM. CAM non-disclosure was equally affected by the physicians' stance and manner toward CAM. This indicates biomedical physicians would benefit from becoming aware that participants often withhold information, because they are either intimidated by the physician, or as a form of retaliation. Such relationship cannot be said to be conducive to appropriate standards of care.

Implications for CAM Practitioners

The research reported in this thesis indicated the participants had high expectations of their CAM practitioner and trusted that the CAM practitioners would provide appropriate treatment. To the participants, appropriate CAM treatment was treatment that was safe and effective. The participants also valued the consultative process, which offered them the time to discuss their needs. The implications for CAM practice include the need for CAM practitioners to have biomedical knowledge, the value of the perception that CAM treatment is safe and beneficial, and the positive impact wholistic practice that emphasised consent, autonomy and sensitivity toward a vulnerable group of people. The implications once again predominantly centre on the treatment process. Each of the implications for CAM practice will be discussed in the following sections.

Biomedical Knowledge

The findings of this thesis show the participants consulted with CAM practitioners for the treatment of a genetic disorder, which presents as anaemia. Thus, CAM practitioners need to understand that, whilst people with TM might exhibit common symptoms of anaemia, the cause of the anaemia needs to be differentiated from that which occurs as a result of some deficiency, such as iron or folate. A consequence of not differentiating common presentations, such as anaemia, are that some treatments might not be suitable, and in the

case of people with thalassaemia major, potentially lethal. Thus, CAM practitioners need to avail themselves to the current literature to understand the complexity of treating people with thalassaemia major.

A noteworthy result of the research in this thesis was that whilst the participants reported some of the symptoms of thalassaemia major (TM) were alleviated by CAM use, it did not negate the need for blood transfusions. CAM practitioners should be aware that, whilst certain kinds of CAM use reportedly improved the health status of people with TM, they should recognise that CAM treatments do not cure TM. Hence, CAM practitioners should ensure their biomedical knowledge of TM and the implications it presents are comprehensive, so that CAM treatments do not give their clients false hope and lead to expectations of outcomes, which cannot be met.

Safety and Efficacy

This research concluded that people with thalassaemia major often use CAM treatments to manage the main pathology and a number of co-morbidities, whilst concurrently being treated intensively with biomedicine. Hence, CAM practitioners would be more effective if they acquired knowledge of the various forms of biomedical treatments that people use, because some CAM substances can interact with, attenuate or potentiate biomedical treatment (Shane-Mcwhorter & Geil, 2002; Sørensen, 2002).

The results of this research show people with thalassaemia major use CAM concurrently with biomedicine. CAM practitioners are obligated to know which CAM might interact with the biomedical regimens their clients are using. Hence, CAM practitioners must ensure their treatment does not interfere with the biomedical treatment of people, such as the participants of this study, who are almost always going to be using some form of biomedicine. The onus on the CAM practitioner is to take an extensive medical history, which includes a list of known, pre-existing medical conditions and prescribed medicines,

for reasons of safety. For example, as reported by the participants, they were biomedically treated for iron overload. Hence, there is a need for CAM practitioners to recognise that some treatments, such as iron supplements, commonly dispensed by CAM practitioners for anaemia, could endanger their client's life. For reasons of safety, CAM practitioners would be advised to provide to people who consult them a list of ingredients contained in any prescription. Such information is required in the event of an adverse effect, to assist biomedical physicians' evaluation of the cause and appropriate course of treatment.

A major finding of this research was that people concurrently using biomedicine and CAM predominantly did not disclose such use to their biomedical physician. Thus, CAM practitioners should explain to participants the importance of divulging such information and encourage them to disclose to biomedical physicians. At the same time, CAM practitioners should appreciate that people might also withhold information from them for various reasons. One of the reasons given by some participants in this research was "to test" the CAM practitioner. It is, thus, imperative that CAM practitioners develop and maintain trusting relationship with their clients to engender open dialogue for reasons of safe and effective delivery of treatment.

Consent

The standards of care and issues of informed consent outlined earlier, which apply to biomedical practitioners, are equally relevant to all health practitioners (Forrester & Griffiths, 2005). Hence, CAM practitioners would be well advised to disclose information about the limitations of CAM and the possible outcomes, if biomedical treatment is delayed or abandoned (Forrester & Griffiths, 2005). CAM practitioners should ensure that they understand the nature, not only of the presenting illness that a client talks about, but also whether there is an underlying pathology, which is chronic. CAM practitioners need this knowledge to ensure that what they prescribe is not going to negatively interact with or

attenuate biomedical treatment. Providing CAM treatment without such knowledge, in the event of an adverse reaction causing harm to a person, is deemed to be negligent behaviour for which a tort of law can be brought forth (Forrester & Griffiths, 2005). CAM practitioners must also relay such information to their clients, so people who consult them can make a fully-informed decision about their health care (Forrester & Griffiths, 2005).

This research showed the participants used CAM to treat some illnesses which biomedicine had failed to manage or could not treat. CAM practitioners should also recognise and communicate to people that CAM has limitations, just as biomedicine does, and that CAM practitioners might need to refer such people back to their biomedical practitioner. CAM practitioners also need to encourage people with a chronic illness to give approval for them to communicate with their client's biomedical physician.

Autonomy

As shown by this thesis, the participants were sensitive to their right to autonomy being threatened or infringed upon. Thus, CAM practitioners are advised to ensure their clients are fully cognisant of the CAM treatments they are recommending and prescribing. This includes providing the participants a list of the ingredients, which they prescribe. Such a list must be presented in a language, which can be understood by the participant.

The findings of this research show the participants used CAM because biomedicine had not developed an effective treatment for some illnesses. CAM practitioners need to ask why people who require intensive biomedical treatment are turning to them, to ensure that any treatment they might prescribe is not going to give the person false expectations of health outcomes; to do otherwise is misrepresentation (Bulen, 2003; Forrester & Griffiths, 2005). This research also showed that when the participants perceived that the effectiveness and safety of biomedical treatment had been misrepresented to them, they turned to CAM.

Hence, CAM practitioners should recognise that their clients often utilise their services because they perceive them to be open and honest.

Sensitivity to a Group of Vulnerable People

CAM practitioners should recognise that people often turn to them because they have exhausted biomedical options. This places the CAM practitioner in a position of power, which must not be abused by portraying their treating ability as superior to that of the biomedical physician. Representation of CAM modalities as having healing properties beyond their real capacities is only likely to lead to expectations, which might not be within the range of the CAM practitioners' abilities to deliver. Thus, CAM practitioners need to explain that CAM and perhaps their ability as a practitioner might also be limited when dealing with people who have TM, or some other complicated and serious disorder.

Perceived exploitation of power was reported by the participants to be a cause of dissatisfaction with biomedical consultations and treatment and often lead to a rejection of biomedical advice. This might often have been to the detriment of the participants' health. Hence, CAM practitioners have a responsibility to ensure that the advice they give people who consult them is not going to further endanger the ongoing relationship the person needs to conserve with their biomedical practitioner. In dealing with people with TM, CAM practitioners should attempt to help such vulnerable people to mend damaged associations and foster healthy relationship with their biomedical carers, as part of their wholistic care regimen. Thus, CAM practitioners need to develop the skills required to counsel and educate their clients in dealing with adverse events that affect their relationship with significant others, including their biomedical physicians, because, for such people, biomedicine is an essential and ongoing part of their life.

CAM practitioners would benefit from appreciating that whilst people with thalassaemia major can go without CAM treatment, they could not forgo biomedical

treatment. CAM practitioners would do well to encourage people with TM to adhere to their biomedical regimens. CAM practitioners have an important role to play in assisting people who seek their help in deriving the greater benefit out of biomedicine. The ways CAM practitioners can do this include reinforcing the positive aspects of biomedical treatment and helping people with TM to overcome the negative aspects of such treatment by providing appropriate CAM treatment, which might include counselling.

This thesis has shown there are many implications for biomedical and CAM practice. Each of the implications is centred to the delivery of safe and effective care. Safe and effective care also carries responsibility, not only for the physical well-being of the individual, but also for their psychological wellness. The implications for practice show how ignoring either of these aspects can have negative repercussions and could jeopardise the safe and effective delivery of treatment, which is what the participants in this research demand and expect of their carers. Any perceived deviation from such care lead to CAM use and increased non-disclosure, as well as withholding of vital information necessary for the safe and effective application of biomedical treatment. Such concerns are relevant to the CAM practitioner for the reasons of safety and efficacy, and to foster healthy patient-physician-CAM practitioner relationship.

The sections covering future research and implications for practice highlighted that the biomedical and CAM professions really need to collaborate on research related to concurrent CAM and treatment for various conditions. They also need to get together to negotiate ways to practice in cooperation for the safe and effective delivery of treatment.

Concluding Remarks

CAM use was common in this sample of people with TM. This thesis showed CAM was used as a form of treatment. The main reasons the people in this research used CAM related to the negative views they held of biomedicine. The findings showed negative views

were associated with perceived notions of the limitations, efficacy and adverse effects of biomedical treatment. This thesis showed CAM disclosure was associated with negative perceptions of biomedical treatment and biomedical physicians. This is the first thesis to show that the reasons for CAM use were associated with those given for CAM disclosure.

This research showed that investigating CAM use and CAM disclosure was difficult because CAM was not easy to define. CAM as a term used to differentiate treatments not considered biomedical has the capacity to create confusion in researchers and participants. Hence, estimating CAM use was difficult, if not impossible. The researcher acknowledges the value of both inductive and reductive methods of inquiry into CAM use and disclosure and realises that both methods can be employed to find out why people use CAM and choose to disclose such use.

The inductive method chosen for this research, however, added new knowledge about CAM use and CAM disclosure by showing how the reasons for such use and disclosure were associated with decisions, feelings and behaviour. The inductive methods also showed that the reasons for CAM use were associated. The decision made by people with TM to use CAM was made by referring to past and present experiences of biomedicine, which formed the rationale for such use and disclosure of CAM. Thus, the decision to use CAM was made mostly to avoid those experiences that initially informed CAM use. These findings illustrate that qualitative methods were crucial to understanding the health-behaviours of people with a life-long illness.

This research was original in its methods and a number of its key findings about reasons CAM use and CAM disclosure. The findings of this thesis showed the issues surrounding CAM use and CAM disclosure are important and have serious implications for people who need biomedicine, for CAM practitioners and for biomedical practitioners.

I hope that the results of this thesis will encourage people to conduct more research into issues related to CAM use in people with TM and chronic illness to understand the factors that lie behind the decision to use CAM and disclosure of such use in people who desperately need supportive healthcare. This kind of research is important because the findings showed that negative interpretations of CAM by biomedical physicians do not deter lifelong CAM use, rather tending to encourage it, at least some people with lifelong illness. At the same time, those negative interpretations discouraged disclosure, producing a dangerous situation, in which people with a life-threatening illness were using various CAM modalities, but their biomedical practitioners were not aware of this additional treatment. The findings also suggest that, if people benefit from CAM, they are not going to be easily dissuaded from such use. Finally, the results reported in this thesis make a strong case for the need for the professions comprising biomedicine and CAM to work together to achieve the most efficacious outcomes for people who seek their services.

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COMPLEMENTARY and ALTERNATIVE MEDICINE DEFINITIONS

**Definition of CAM by the National Centre for Complementary
and Alternative Medicine (NCCAM)**

1. Conventional medicine is medicine as practiced by holders of M.D. (medical doctor) or D.O. (doctor of osteopathy) degrees and by their allied health professionals, such as physical therapists, psychologists, and registered nurses. Other terms for conventional medicine include allopathy; Western, mainstream, orthodox, and regular medicine; and biomedicine. Some conventional medical practitioners are also practitioners of CAM.

2. Other terms for complementary and alternative medicine include unconventional, non-conventional, unproven, and irregular medicine or health care.

3. Some uses of dietary supplements have been incorporated into conventional medicine. For example, scientists have found that folic acid prevents certain birth defects, and a regimen of vitamins and zinc can slow the progression of an eye disease called age-related macular degeneration (AMD).

The list of what is considered to be CAM changes continually, as those therapies that are proven to be safe and effective become adopted into conventional health care and as new approaches to health care emerge.

Complementary medicine is used together with conventional medicine. An example of a complementary therapy is using aromatherapy to help lessen a patient's discomfort following surgery.

Alternative medicine is used in place of conventional medicine. An example of an alternative therapy is using a special diet to treat cancer instead of undergoing surgery, radiation, or chemotherapy that has been recommended by a conventional doctor.

Integrative medicine, as defined by NCCAM, combines mainstream medical therapies and CAM therapies for which there is some high-quality scientific evidence of safety and effectiveness. Accessed August 19, 2002, from:

<http://nccam.nih.gov/health/whatisacam/>

Cochrane Collaboration Definition of CAM

CAM is a broad domain of healing resources that encompasses all health systems, modalities, and practices and their accompanying theories and beliefs, other than those intrinsic to the politically dominant health system of a particular society or culture in a given historical period. CAM includes all such practices and ideas self defined by the users as preventing or treating illness or promoting health and wellbeing. Boundaries within CAM and between the CAM domain and the domain of the dominant system are not always sharp or fixed. (Panel on Definition and Description, 1997, p.50).

CAM Definition as Applied to Landmark CAM Survey by Eisenberg et al.

(1993)

Medical interventions, not taught at US medical schools or generally available at US hospitals. (Eisenberg et al., 1993).

World Health Organization (Who) CAM Definition

A broad set of health care practices that are not part of a country's own tradition, or not integrated into its dominant health care system. (WHO, 2002, p. 7). Retrieved 17/05/02 from <http://www.who.int/inf/en/pr-2002-38.html>

PHASE 1: GUIDING QUESTIONS

Socio-demographics

1. Please tell me about yourself. For example, where you born, how old you are.
2. Where you went to school, what level you reached. Whether you are married and have any children.
3. What type of work you do.
4. Annual family income.
5. Medical History.
6. Age of Diagnosis/commencement of biomedical treatment
7. Known pathologies
8. Surgery
9. Prescribed medicines
10. Anything else
11. CAM Use YES/NO
12. CAM disclosure YES/ NO
13. Please tell me what you do to maintain your health

Knows what CAM is

Explain CAM

14. Please tell me about the types of therapies/treatments/products that you have heard of that people might use for their health- (Devise written list as participant speaks. Add to list psychologist, psychiatrist and social worker, if not already mentioned).
15. Go through list with participant: Please tell me how you would categorise each of these therapies/treatments/products (e.g., CAM, biomedicine, both, don't know, other)
16. Please tell me which of these therapies/treatments/products you have used.

Who prescribed these therapies/treatments/products (Self, B/M practitioner, CAM practitioner).

PHASE 2: GUIDING QUESTIONS

1. Reasons for seeking other therapies
2. Types of illnesses treated with CAM
3. Why use other therapies

Motivators for CAM use

Expectations of CAM Were they met?

PHASE 3: GUIDING QUESTIONS

1. Reasons for Disclosing CAM use
2. Motivators for CAM disclosure

How CAM disclosure occurred

Continued CAM disclosure Not continued Reasons

FLYER SEEKING PARTICIPANTS

Faculty of Human Development

School of Health Sciences



We are seeking people to take part in a study of complementary and alternative medicine.

This study will examine why some people use biomedicine to treat their illness and at the same time use other treatments such as, herbs, diet therapy or other therapies. These treatments are also known as complementary and alternative therapies. We are interested in learning more about the use of complementary and alternative therapies. We are particularly interested in talking to people with a chronic illness that requires ongoing medical treatment.

If you have a haemoglobinopathy such as thalassaemia major, we are interested in hearing your views about the types of treatment and therapies you use and have experienced.

Interviews will take place at a time and venue most convenient to you.

All interviews will be conducted in strict confidence, and measures will be taken to ensure participants are not identified. This study is not a clinical trial and participants will not be requested to take any medications, herbs, other substances or undergo any form of treatment. For further information please ring:

Helen Georgiou on: 9365 2179 or 9347 0940 or Mb: 0407 055 634

PLAIN LANGUAGE STATEMENT

This study will examine why some people use conventional medicine to treat their illness and at the same time use complementary and alternative therapies.

We are interested in learning more about the use of complementary and alternative therapies. We are particularly interested in talking to people with a chronic illness that require ongoing medical treatment. The information will help health practitioners understand the issues that confront people who use conventional medicine and complementary and alternative medicine concurrently. Understanding these issues is critical to the provision of optimal medical and psychosocial support to people facing situations in which they must evaluate treatment options and act in ways that will optimise their physical and psychological well-being.

All information you provide is **STRICTLY CONFIDENTIAL** and at no time will your name appear in the study. For data collection purposes you will be allocated a code number to ensure confidentiality. This code number will only be known to Helen Georgiou and will be stored in a locked cabinet, to which only she will have access. Data will be collected using a tape recorder and notes that Helen might take down during the interview. Your participation in this study is voluntary. You may withdraw from the study at any time, should you wish not to continue without jeopardising yourself in any way. Any queries about your participation in this project may be directed to Helen Georgiou, ph: 9365 2179 or MB; 0407 0550634 or Prof. Tony Morris on ph: 9688 5353. If you have any queries or complaints about the way you have been treated, you may contact the Secretary, University Human Research Ethics Committee, Victoria University of Technology, PO Box 14428 MC, Melbourne, 8001 (telephone no: 03-9688 4710).



CONSENT FORM

Victoria University of Technology

INFORMATION TO PARTICIPANTS

We would like to invite you to be a part of a study into the use of Complementary Medicine/therapies.



We are interested in learning more about the use of complementary and alternative therapies.

CERTIFICATION BY SUBJECT

I.....
of.....

Certify that I am at least 18 years old and that I am voluntarily giving my consent to participate in the study entitled: Reasons for Use and Disclosure of Concurrent use of Complementary Medicine and Biomedical Treatment by People with a Hamoglobinopathy being conducted at Victoria University of Technology by: Professor Tony Morris, Dr Shelley Beer and Helen Georgiou.

I certify that the objectives of the study, together with any risks to me associated with the procedures listed hereunder to be carried out in the study, have been fully explained to me by: Helen Georgiou and that I freely consent to participation involving these procedures.

Procedures:

I understand that I will be interviewed about the types of things I do to for my health, about complementary and alternative therapies and that the interview will be tape-recorded, and that notes will be taken.

My participation will not identify me in any way and I understand the measures taken to safeguard my anonymity.

I understand that I might become upset during the interview and that should I wish the services of a counsellor or psychologist will be provided.

I have been given the interviewer's name and contact details.

I certify that I have had the opportunity to have any questions answered and that I understand that I can withdraw from this study at any time and that this withdrawal will not jeopardise me in any way.

I have been informed that the information I provide will be kept confidential.

Signed:

Participant: date:

Witness other than the researcher:date:

Hierarchical Development of Themes for Reasons for CAM Use

Raw Data Statement	First Order Themes	Second Order Themes	Third Order Themes	General Dimensions
For the depression. Hormone treatment...[it] is making me mad (P2)	Seeks treatment for co-morbidity associated with TM treatment	Seeks treatment for co-morbidity associated with TM	Seeks treatment for co-morbidity	Seeking treatment
Something to help with...and my bones (P7)				
To strengthen my bones because the minerals are going out of them (P17)				
I am having herbs for my bones (P20)				
Wanted something for the hep C (P3)				
I wanted something...for my hepatitis C (P4)				
For the hepatitis (P8)				
I had to do something for the hep C (P18)				
My ferritins [iron level] were really high I had to do more than my needles (P9)				
I needed to get the iron levels down...something else [CAM] that could help me (P15)				

Hierarchical Development of Themes for Reasons for CAM Use (*continued...*)

Raw Data Statement	First Order Themes	Second Order Themes	Third Order Themes	General Dimensions
My liver is huge so I just want to get it down (P4)	Seeks treatment for co-morbidity associated with TM treatment	Seeks treatment for co-morbidity associated with TM	Seeks treatment for co-morbidity	Seeking treatment
Because of...heart medications I get migraines..I wanted something to treat them (P3)				
For diabetes (P13)				
Something [for] the iron levels (P17)				
I use it [CAM] treat because the liver it's got too much iron in it (P19)				
Improve...liver enzymes and make my liver smaller (P19)				
Something to help with that and my bones (P7)				
For the bones... for everything really (P8)				
Strengthen...bones...minerals...going out of them (P17)				
I am having herbs for my bones (P20)				

Hierarchical Development of Themes for Reasons for CAM Use (*continued...*)

Raw Data Statement	First Order Themes	Second Order Themes	Third Order Themes	General Dimensions
Needed something to help [treat] my heart (P10)	Seeks treatment for co-morbidity associated with TM treatment	Seeks treatment for co-morbidity associated with TM	Seeks treatment for co-morbidity	Seeking treatment
For my heart [cardiomyopathy] (P17)				
To start a family...couldn't get pregnant (P1)				
I used...to become pregnant (P6)				
I used...to become pregnant (P6)	Seeks treatment for co-morbidity associated with main pathology of TM			
Wanted to get pregnant...went to a naturopath (P7)				
I wanted to get pregnant (P8)				
To help treat my diabetes (P10)				
To treat kidney stones (P13)				
To stop my spleen from getting any bigger (P1)				

Hierarchical Development of Themes for Reasons for CAM Use (*continued...*)

Raw Data Statement	First Order Themes	Second Order Themes	Third Order Themes	General Dimensions
[Used CAM to treat]...low immune system (P1)	Seeks treatment for co-morbidity associated with main pathology of TM	Seeks treatment for co-morbidity associated with TM	Seeks treatment for co-morbidity	Seeking treatment
I haven't got a spleen... to improve my immunity (P8)				
Basically to build my immunity (P21)				
I wanted something to stop it [depression] (P2)	Seeks treatment for psychological symptoms	Seeks treatment for symptoms		
Treat depression (P3)				
I became very depressed...I needed something because I was going to commit suicide (P8)				
I use it [CAM] to help me stay calm and relaxed (P10)				
[Used CAM] because I used to scream at everyone when I got low... before a blood transfusion (P11)				
I get pretty aggressive and short tempered...I find it [CAM] help...so I use it when I things aren't right (P15)				

Hierarchical Development of Themes for Reasons for CAM Use (*continued...*)

Raw Data Statement	First Order Themes	Second Order Themes	Third Order Themes	General Dimensions
I use camomile and valerian tea to help me sleep...can't sleep...anxious especially before a blood transfusion (P16)	Seeks treatment for psychological symptoms	Seeks treatment for symptoms	Seeks treatment for co-morbidity	Seeking treatment
I was sleeping my life away (P17)				
I used to get anxious every time I went in for blood (P20)				
I used it [CAM] for a vaginal discharge (P1)	Seeks treatment for physical symptoms			
To treat gastric ulcer (P3)				
Desire to treat migraines (P3)				
To treat congestion (P4)				
To treat skin problems (P7)				
To treat stomach upset (P6)				

Hierarchical Development of Themes for Reasons for CAM Use (*continued...*)

Raw Data Statement	First Order Themes	Second Order Themes	Third Order Themes	General Dimensions
[Used CAM for] infections...colds and flu (P14)	Seeks treatment for physical symptoms	Seeks treatment for symptoms	Seeks treatment for co-morbidity	Seeking treatment
I used it [CAM] when I got migraines (P16)				
For...migraines...pain...nausea it was horrible (P6)				
For the sinus pain, it was driving me mad (P7)				
The pain from the kidney stones was unbearable (P10)				
For...back pains (P11)				
For...back pain...came...before every transfusion (P14)				
Back pain, every pain I wanted to fix them (P18)				
For the horrendous back pain (P21)				
I wanted to treat the pain (P12)				

Hierarchical Development of Themes for Reasons for CAM Use (*continued...*)

Raw Data Statement	First Order Themes	Second Order Themes	Third Order Themes	General Dimensions
To be rid of the pains (P14)	Seeks treatment for physical symptoms	Seeks treatment for symptoms	Seeks treatment for co-morbidity	Seeking treatment
(Injection sites) painful...especially if...infected and ulcerate...for pain (P16)				
Get rid of the stiffness in back and shoulders (P17)				
I used to get this horrible tingling...painful sensation, I use it for that (P20)				
I use it for most things. Colds, flu, infections, pain...detoxify my blood everything really (P20)				
For the headaches (P21)				
started using CAM...[for] tired, lethargic, fatigued (P1)				
Not to be so tired, lethargic, fatigued...energy levels (P1)	Seeks treatment for signs and symptoms of blood abnormalities	Seeks treatment for TM	Seeks treatment for TM	
To stop...blood from clotting...it's dangerous (P9)				

Hierarchical Development of Themes for Reasons for CAM Use (*continued...*)

Raw Data Statement	First Order Themes	Second Order Themes	Third Order Themes	General Dimensions
My blood clots real easy... to stop that (P15)	Seeks treatment for signs and symptoms of blood abnormalities	Seeks treatment for TM	Seeks treatment for TM	Seeks treatment
When... blood... low... couldn't do what I wanted... like my life was on hold until the next transfusion (P17)				
So I wouldn't feel really yuk... wanted to feel the same... one transfusion to the next (P20)				
Used to feel really awful before...transfusion. I used to feel [before CAM]..tired (P21)				
Something to help the haemoglobin level (P1)	Seeks treatment to keep haemoglobin high			
Just something that works by keeping the blood higher (P4)				
To have good haemoglobins...I can't function properly (P6)				
I take things that keep my blood up (P8)				
I'm hoping to improve my blood (P11)				

Hierarchical Development of Themes for Reasons for CAM Use (*continued...*)

Raw Data Statement	First Order Themes	Second Order Themes	Third Order Themes	General Dimensions
Just to keep the blood high [haemoglobin] (P12)	Seeks treatment to keep haemoglobin high	Seeks treatment for TM	Seeks treatment for TM	Seeks treatment
I want my blood levels higher (P15)				
To stop my blood [haemoglobin] from falling to crap levels like 8 or 9 (P16)				
I like my blood levels to be higher (P17)				
To have higher blood (P18)				
To have higher haemoglobin (P19)				
To have a decent level [haemoglobin] before (P20)				
I don't want to be sick ever again (P10).				
Want to be well...something...make me better (P8)				
Not to need blood [transfusions] (P16)				

Hierarchical Development of Themes for Reasons for CAM Use (*continued...*)

Raw Data Statement	First Order Themes	Second Order Themes	Third Order Themes	General Dimensions
Want to be able to just be...blood transfusions and things interfering with my life (P3)	Seeks treatment to cure TM	Seeks treatment for TM	Seeks treatment for TM	Seeks treatment
Can't feel good (have quality of life)... so you have to get better (P5).				
I would love to be cured so I'll try most things...I know it's only a dream (P7)				
Something that will make me better (P8)				
Suppose...I want to better period, like forever (P18)				
I don't want to be sick ever again (P10)				
To get rid of the problem once and for all (P9)				
I wanted to stop my blood from clotting because it's dangerous (P9)				
My platelet count was too high...so I wanted something to fix that (P11).				
Something...doesn't have them [adverse effects] (P3)				

Hierarchical Development of Themes for Reasons for CAM Use (*continued...*)

Raw Data Statement	First Order Themes	Second Order Themes	Third Order Themes	General Dimensions
I found [CAM] was good a fixing things but didn't make me sick...that's why I think it's good (P8)	Seeks treatment without adverse effects	Seeks treatment without adverse effects	Seeks particular type of treatment	Seeks treatment
Prevent infections...that didn't make me sick (P11)				
Something that helps but doesn't make you sick (P13)				
I wanted treatment that had no bad effects (P14)				
I...use it [CAM] because it fixes me without making me sick (P15)				
I just wanted something gentle that could help me (P16)				
Wanted something...don't make you sick (P17)				
Things...fix the problem but don't hurt you (P19)				
It's important...doesn't do any damage (P20)				

Hierarchical Development of Themes for Reasons for CAM Use (*continued...*)

Raw Data Statement	First Order Themes	Second Order Themes	Third Order Themes	General Dimensions
Didn't want them to turn...chronic, that's why (P3)	Seeks treatment that works	Seeks effective treatment	Seeks particular type of treatment	Seeks treatment
To get rid of the sinus once and for all (P9)				
Something [treatment] that works (P10)				
Like treatment to work the first time (P12)				
Want to get better...I want things that work (P14)				
I just like things to get better with once go (P21)				
Stop the merry-go-round...wanted ...urinary tract infection gone for good (P8)	Seeks treatment for recurring illness			
To treat things...re-occurring urinary tract infections (P10)				
Treat them [infections]...keep coming back (P19)				
I just wanted to stop the bones...getting worse (P16)	Seeks to prevent co-morbidities	Seeks preventive treatment		

Hierarchical Development of Themes for Reasons for CAM Use (*continued...*)

Raw Data Statement	First Order Themes	Second Order Themes	Third Order Themes	General Dimensions
To stop my bones from getting even worse than they are (P21)	Seeks to prevent co-morbidities	Seeks preventive treatment	Seeks particular type of treatment	Seeks treatment
My immunity was down so I built it up. With herbs and things. I did it because I kept getting sinusitis and things like that. Infections mostly (P8)				
To stop getting infections (P9)				
I am trying to stop getting heart problems (P10)				
Stop my liver from getting any bigger (P7)				
Don't want...liver getting...more damage (P11)				
Hep C...to stop...making things worse (P8)				
Hep C...stop it from making me more sick (P16)				
Stop the hepatitis C from getting worse (P17)				
Hep C...I just don't want things to get worse (P19)				

Hierarchical Development of Themes for Reasons for CAM Use (*continued...*)

Raw Data Statement	First Order Themes	Second Order Themes	Third Order Themes	General Dimensions
To stop the tiredness and breathlessness (P2)	Seeks to prevent co-morbidities			
Sick of ...9's [haemoglobin]...can't function (P6).	Seeks preventive treatment for sign/symptom of TM	Seeks preventive treatment	Seeks particular type of treatment	Seeks treatment
Didn't want to look so pale and sickly...keep...haemoglobin level even. Not to fall so low (P8)				
To keep my blood levels up (P11)				
Wanted... my haemoglobin to stop falling... low (P12)				
Needed...keep my blood from falling to...low levels (P13)				
Something to stop my blood from falling (P15)				
Prevent the pain...every time I needed blood (P16)				
Bad back pain....that's why I went (P17)				

Hierarchical Development of Themes for Reasons for CAM Use (*continued...*)

Raw Data Statement	First Order Themes	Second Order Themes	Third Order Themes	General Dimensions
Stop feeling...washed out before...after a transfusion (P20)	Seeks preventive treatment for sign/symptom of TM	Seeks preventive treatment	Seeks particular type of treatment	Seeks treatment
Hate...medicines...make me sick (P9)				
I just wanted something safer (P10)	Seeks safer alternative to biomedicine	Seeks alternative to biomedicine		
Something different that would hurt me (P12)				
[CAM] that...help me that wasn't harmful (P15)				
Prefer...things around that are safer (P20)				
Wanted to try something natural (P7)	Seeks natural treatment as alternative to biomedicine			
I wanted something else... something natural (P6)				
Wanted...things...natural because...can't hurt (P12)				

Hierarchical Development of Themes for Reasons for CAM Use (*continued...*)

Raw Data Statement	First Order Themes	Second Order Themes	Third Order Themes	General Dimensions
The penicillin doesn't stop infections (P6)	Loss of confidence because preventive biomedicine failed	Loss of confidence in biomedical treatment	Loss of confidence in biomedicine	Negative view of biomedicine
Supposed to stop infections...don't do that (P10)				
Penicillin is useless...doesn't stop infections (P13)				
Supposed to take penicillin but...no point...taking it, it doesn't work (P15)				
Don't take [penicillin]...did nothing (P19)				
Stopped taking the penicillin and use herbs instead. Because I kept getting infections (P20).				
The medicine they gave me didn't stop them [infections] coming back (P3)	Loss of confidence because biomedicine failed to prevent illness from recurring			
The drugs [B/M] didn't stop the irritable bowel from coming back (P7)				
They couldn't treat it [IBS]...but they tried and failed six times (P3)				
The medicines don't...work because you never get over things...like urinary tract infections (P7)				

Hierarchical Development of Themes for Reasons for CAM Use (*continued...*)

Raw Data Statement	First Order Themes	Second Order Themes	Third Order Themes	General Dimensions
They couldn't fix the sinus...it kept coming back (P10)	Loss of confidence because biomedicine failed to prevent illness from recurring	Loss of confidence in biomedical treatment	Loss of confidence in biomedicine	Negative view of biomedicine
The medicines don't always work because it [UTI] kept coming back again and again (P13)				
Tired of taking stuff that only made me better...I was on it. I stopped...would get sick again (P16)				
Sinus kept coming back...tried everything they [B/M practitioners] could think of (P17)				
Always having something for chest infections...they couldn't fix them so they didn't come back (P21)				
B/M treatment] don't make things better (P6)	Biomedicine does not do what it is supposed to do			
It [antibiotics] didn't get rid of the sinus (P9)				
[B/M] wasn't doing what...supposed to do (P11)				

Hierarchical Development of Themes for Reasons for CAM Use (*continued...*)

Raw Data Statement	First Order Themes	Second Order Themes	Third Order Themes	General Dimensions
Medicines...don't do what they are supposed to do (P12)	Biomedicine does not do what it is supposed to do	Loss of confidence in biomedical treatment	Loss of confidence in biomedicine	Negative view of biomedicine
[B/M] didn't work...needed more treatment (P13)				
[B/M] didn't work for me because if it did then I wouldn't have needed more treatment (P15)				
Supposed to get better...instead I got sick (P16)				
[B/M physicians] give you things...then something else because it didn't work (P20)				
[B/M drug] didn't do what they [B/M practitioners] said it would do (P21)				
Antibiotics only work...short periods of time (P4)	Loss of confidence because biomedicine is a band-aide			
Going back for more...[B/M treatment] just band-aide (P11)				
I still need blood and stuff for my bones because it only [B/M] works for a little time (P12)				

Hierarchical Development of Themes for Reasons for CAM Use (*continued...*)

Raw Data Statement	First Order Themes	Second Order Themes	Third Order Themes	General Dimensions
lot of...drugs don't cure you they just patch things up (P13)	Loss of confidence because biomedicine is a band-aide	Loss of confidence in biomedical treatment	Loss of confidence in biomedicine	Negative view of biomedicine
Medicine only works for short time (P18)				
They couldn't treat it (IBS) (P3)	Loss of confidence because of the limitations of biomedicine			
I got the Hepatitis C ...it's not curable they [biomedical practitioners] can't do anything (P3)				
There was nothing else they could do (P5)				
[B/M] can't do anything for it [hepatitis C] (P8)				
They reckon they've done all they can (P10)				
Did they [B/M practitioners] get rid of the hepatitis C? Don't think so (P7)	Loss of confidence because biomedicine failed to cure			
[B/M] didn't cure ...even the simple things (P13)				

Hierarchical Development of Themes for Reasons for CAM Use (*continued...*)

Raw Data Statement	First Order Themes	Second Order Themes	Third Order Themes	General Dimensions
They don't have a treatment for hep C (P13)	Loss of confidence because biomedicine failed to cure	Loss of confidence in biomedical treatment	Loss of confidence in biomedicine	Negative view of biomedicine
Well it [B/M] can't cure the hep [hepatitis C].... can't see the sense in not trying other things (P17)				
They [biomedicine] can't cure anything, not thalassaemia not hepatitis (P18)				
I'm sick of taking drugs that don't cure you (P19)				
The [B/M] medicines haven't worked (P21)				
Hard to keep going when you know the blood transfusions are going kill you (P2)	Loss of confidence in a particular treatment			
[B/M treatment] hopeless; you still need blood and medicines all the time (P6)				
[Suggested medication] is to be taken forever (P3)				
Because of my heart medicines... I need other medication to relieve the migraines (P3).				

Hierarchical Development of Themes for Reasons for CAM Use (*continued...*)

Raw Data Statement	First Order Themes	Second Order Themes	Third Order Themes	General Dimensions
Sick of taking Panadol for headaches (P10)	Loss of confidence in a particular treatment	Loss of confidence in biomedical treatment	Loss of confidence in biomedicine	Negative view of biomedicine
What is the point of taking something that is going to kill you? (P3)				
Hep C treatment...was no help torture (P4)				
They don't have a treatment for hep C they only pretend they do (P13)				
Hep C treatment was torture...I still suffer (P16)				
Had a terrible time on the hep C trial and after all that it didn't work (P18)				
I don't think our treatment is good (P1).	Loss of confidence in TM treatment			
Keep going back for more (P11)				
Our treatment is not that good (P14)				
Not very happy... with treatment [B/M] (P16)				

Hierarchical Development of Themes for Reasons for CAM Use (*continued...*)

Raw Data Statement	First Order Themes	Second Order Themes	Third Order Themes	General Dimensions
It is really hard because nothing gets better (P20)	Loss of confidence in TM treatment	Loss of confidence in biomedical treatment	Loss of confidence in biomedicine	Negative view of biomedicine
It's pretty hopeless really (P21)				
Doctor doesn't know how to guide you about lifestyle (P2)	Loss of confidence treating physicians ability and/or knowledge	Loss of confidence treating physician		
[B/M practitioners] go by books sometimes the books don't work (P4)				
Come to realise...they don't have...answers (P5)				
He didn't know anything about the stuff I wanted to take instead of the Warfarin (P6)				
Been wrong about many things I can't believe what he [B/M practitioner] says (P6)				
[B/M practitioners] only care about the body (P7)				
They [B/M practitioners] don't know about the soul (P8)				

Hierarchical Development of Themes for Reasons for CAM Use (*continued...*)

Raw Data Statement	First Order Themes	Second Order Themes	Third Order Themes	General Dimensions
They couldn't understand why I kept getting sick. In the end I got fed up (P10)	Loss of confidence treating physicians ability and/or knowledge	Loss of confidence treating physician	Loss of confidence in biomedicine	Negative view of biomedicine
I kept telling them I was unwell and they wouldn't believe me so I had to get help (P11)				
They're specialists in the field but they don't know it all (P11)				
[B/M physician] wouldn't believe it was the drug that was causing the infection (P12)				
They [B/M physicians]...they don't know what is going on... send you to the psychiatrist (P13)				
If they can't find what's wrong they think you're mad...can't trust them (P14)				
I don't believe everything doctors tell me because they've been wrong (P16)				
Instead of looking to find out what was wrong with me they [B/M physicians] called the psychiatrists (P17)				

Hierarchical Development of Themes for Reasons for CAM Use (*continued...*)

Raw Data Statement	First Order Themes	Second Order Themes	Third Order Themes	General Dimensions
All they tell me is I'm depressed and should see a psychologist (P18)	Loss of confidence treating physicians ability and/or knowledge	Loss of confidence treating physician	Loss of confidence in biomedicine	Negative view of biomedicine
Told me...say goodbye to...family...still insisted on telling me what I could...could not do (P4)				
[B/M practitioners] can't give you lifestyle advice (P5)				
He wanted to prescribe something lethal...don't think that is good advice (P6)				
He told me I needed a shrink...what I really needed was something for the tumour (P9)				
I was unwell and they wanted to put me on antidepressants (P9)				
I was unwell and they wanted to put me on antidepressants. How ridiculous is that? (P10)				
What [B/M practitioners] did made me not rely on them ever again (P13)				
Told to take Panadol when I had bone pain because that's what his mother takes (P21)	Loss of confidence treating physicians advice			

Hierarchical Development of Themes for Reasons for CAM Use (*continued...*)

Raw Data Statement	First Order Themes	Second Order Themes	Third Order Themes	General Dimensions
He wanted to prescribe something lethal...I don't think that is good advice (P6)	Loss of confidence treating physicians advice	Loss of confidence treating physician	Loss of confidence in biomedicine	Negative view of biomedicine
They wanted to put me on antidepressants (P10)				
Not...happy with the [B/M] advice (P16)				
He wanted...to double my dose...for depression (P18)				
What they say is always that beneficial (P19)				
Hormones make you mad...give you cancer... Infections, bad bones...eyes, from injections, blood can kill (P3)	Loss of confidence because adverse effects of biomedicine cause co-morbidities			
It [Hepatitis C] came from the blood (P4).				
I got the hep C from the blood... My bones aren't that good and..it's from the Desferal (P12)				
[TM treatment] you can get blood reactions Toxins from the treatment...we get other problems (P13)				

Hierarchical Development of Themes for Reasons for CAM Use (*continued...*)

Raw Data Statement	First Order Themes	Second Order Themes	Third Order Themes	General Dimensions
Problems [from treatment]... medicines...poisonous...cause big problems...bones...terrible because of...drugs (P14)	Loss of confidence because adverse effects of biomedicine cause co-morbidities	Loss of confidence in biomedicine because of biomedical adverse effects	Loss of confidence in biomedicine	Negative view of biomedicine
Anti depressives cause depression (P18)				
My heart medicines give me migraines (P3)	Loss of confidence because bio-medically prescribed medicines have unpleasant adverse effects			
It is a real piss off when you get something like hep C from the blood that is supposed to keep you alive...it's a bit of a joke really (P17)				
Penicillin makes you sick (P8)				
Stomach upsets caused by the medicines they give for the depression (P6)				
Medicine [Desferal] gives me palpitations (P10)				
It [penicillin] makes me sick (P9)				
It [penicillin] makes you sick (P10)				

Hierarchical Development of Themes for Reasons for CAM Use (*continued...*)

Raw Data Statement	First Order Themes	Second Order Themes	Third Order Themes	General Dimensions
They [IVF medicines] make you sick (P7)	Loss of confidence in biomedicine because adverse effects/events cause irreparable damage	Loss of confidence because of biomedical adverse effects	Loss of confidence in biomedicine	Negative view of biomedicine
The drugs they give me for my depression make me ill (P6)				
Warfarin is poisonous...it kills (P16)				
We will probably die from the hep C (P17)				
Hep C...it's going to kill me (P18)				
Hep C from...blood...that's a worry...because there's no treatment (P12)				
It's pretty sad when they make you sick and then can't treat it (P16)				
Not much they can do if the iron over load affects your heart (P17)				
I got transverse myelitis when I was about 10...it happened after an injection, now I'm crippled (P2)				

Hierarchical Development of Themes for Reasons for CAM Use (*continued...*)

Raw Data Statement	First Order Themes	Second Order Themes	Third Order Themes	General Dimensions
I had to have a tracheotomy because they [anaesthetist] used the wrong thing (P15)	Loss of confidence in biomedicine because adverse effect/event caused by biomedicine required treatment	Loss of confidence because of biomedical adverse effects	Loss of confidence in biomedicine	Negative view of biomedicine
In the end I ended up having an operation (P9)				
They treated my gastric ulcer gave me irritable bowel and I had to have more treatment (P1)				
I was treated for ..a gastric ulcer I had to have antibiotics, and they gave me irritable bowel and thrush, so I had to have more treatment (P3)				
The stuff they gave me [medication] made me really sick I had to go into hospital (P11)				
[B/M treatment] then caused something and I had to have more drugs (P16)				
Try and avoid splenectomy (P1)	Avoiding biomedical treatment	Avoiding biomedicine	Rejection of biomedicine	
Don't want to take sleeping pills (P2)				

Hierarchical Development of Themes for Reasons for CAM Use (*continued...*)

Raw Data Statement	First Order Themes	Second Order Themes	Third Order Themes	General Dimensions
Wanted to try before starting IVF (P2)	Avoiding biomedical treatment	Avoiding biomedicine	Rejection of biomedicine	Negative view of biomedicine
Before using drugs [IVF] I wanted to try something safer (P7)				
I want to avoid having insulin (P9)				
Sick of taking Panadol for headaches (P10)				
The less I have to do with them the better (P2)				
I do everything I can to avoid them (P6)				
They don't do much for me except upset me, best is when I can avoid seeing any of them (P18)	Avoiding biomedical practitioners			
More I stay awaythe better off I am (P8)				
It's best...not to waste your time with them (P20)				

Hierarchical Development of Themes for Reasons for CAM Use (*continued...*)

Raw Data Statement	First Order Themes	Second Order Themes	Third Order Themes	General Dimensions
It was suggested that I go on some anti viral injections, but I said “no thanks” (P1)	Rejection of biomedical treatment	Rejection of biomedicine	Rejection of biomedicine	Negative view of biomedicine
I won't take it [medication for migraine] (P3)				
I won't take the zinc or penicillin, so I need something else (P8)				
Didn't want...drug...being recommended (P13)				
I don't take penicillin (P10)				
No, I refuse to take it [penicillin] (P11)				
I'm not taking the pill and calcium (P1)				
I don't take everything they tell me to...it's too dangerous (P3)				
I prefer ...not a pharmaceutical medicine as much as possible (P7)				

Hierarchical Development of Themes for Reasons for CAM Use (*continued...*)

Raw Data Statement	First Order Themes	Second Order Themes	Third Order Themes	General Dimensions
If you take everything they want you to take you will be a walking pill box (P10)	Rejection of biomedical treatment	Rejection of biomedicine	Rejection of biomedicine	Negative view of biomedicine
Sometimes it is best not to have the drugs. We know for our bodies what is best (P11)				
I won't take everything they tell me to. I think sometimes less is best when it comes to the drugs they give (P12)				
I only take [B/M] the medicines that keep me alive (P13)				
If you take everything, like I was, you end up taking this for that and that for this...I now take only the bare minimum (P13)				
I won't be going on any trials again (P18)				
I thought about [B/M] doctor's advice about it [CAM] what I was using [CAM] can't be that dangerous (P3)	Rejection of biomedical guidance			
I had to do something... [treating B/M physicians] told me say good-bye to my family (P4)				

Hierarchical Development of Themes for Reasons for CAM Use (*continued...*)

Raw Data Statement	First Order Themes	Second Order Themes	Third Order Themes	General Dimensions
If you listen to them [B/M practitioners] you're not gonna to get any better (P4)	Rejection of biomedical guidance	Rejection of biomedicine	Rejection of biomedicine	Negative view of biomedicine
They [B/M] told me it [CAM] was harmful but I don't agree (P12)				
I was never going to listen to them again after what they did (P 20)				
I just do what I think it is good for me (P3).	Doing what is best	Being proactive	Taking control	Self-determination
You've gotta go you know with your own gut... your instincts can tell you go this way do this do that you know (P4)				
You know what your body's limitations are and I think we're the best doctor for our bodies (P5)				
I just wanted to be the best I could that's why I do extra things [CAM] (P5)				
I don't like not being in control...I have to be doing things that help me stay well (P18)				

Hierarchical Development of Themes for Reasons for CAM Use (*continued...*)

Raw Data Statement	First Order Themes	Second Order Themes	Third Order Themes	General Dimensions
You just have to get do other things...want to stay well (P19)	Doing what is best	Being proactive	Taking control	Self-determination
I wasn't going to sit back and just take it (P1)	Doing something			
I had to do something. You just have to fight (P4).				
I am always trying to find new ways of dealing with the things that happen (P11)				
I really want to be able to just be and not have to have blood transfusions and things interfering with my life (P3)	Taking control to sustain wellness	Taking control to attain quality of life (QoL)		
I don't want to be sick in the future...because they [B/M practitioners] can't do everything (P10)				
You understand to be OK, like not sick (P11).				
I need to be doing things with my child...to do that you need to be well. Being well to me means not being sick (P8)				

Hierarchical Development of Themes for Reasons for CAM Use (*continued...*)

Raw Data Statement	First Order Themes	Second Order Themes	Third Order Themes	General Dimensions
I expect not to be so tired, lethargic, fatigued, have better energy levels (P1)	Taking control to maintain and improve health	Taking control to attain quality of life (QoL)	Taking control	Self-determination
You do what you can to keep and improve your health, you understand to be OK, like not sick (P11)				
I just don't want to....be better (P 18)				
I suppose that means I want to better...so I can be normal (P18)				
I want to be around for my child for a long time and not as an invalid (P9)	Taking control to increase longevity			
I do what I can so my parents don't have to bury me or look after me for the rest of my life (P s 10)				
I just want to be the best I can, not sick all the time because if you're sick you die early (P17)				
It helps you stay well...I want to have grand children like everyone else (P21).				

Hierarchical Development of Themes for Reasons for CAM Use (*continued...*)

Raw Data Statement	First Order Themes	Second Order Themes	Third Order Themes	General Dimensions
I know it [CAM] helped me (P2).	CAM Beneficial	CAM Beneficial	CAM treatment attributes	CAM attributes
It [CAM] was helping me at the time (P3)				
Still using the herbs because...helped my blood a lot...cured my sinus problem (P10)				
I've only seen benefits it [from CAM] (P12)				
To improve him [person taking CAM]... to make them feel healthier (P5)				
I don't believe it's harmful because I know it [CAM] helped me (P2)	CAM Safe			
Well for a start it's [CAM] natural, so it's safe. Like eating food (P1)				
Some of it [CAM] tastes bloody awful but so does western medicine...this stuff is safer (P2)				
I don't believe it's [CAM] harmful because I know it helped me (P2)				

Hierarchical Development of Themes for Reasons for CAM Use (*continued...*)

Raw Data Statement	First Order Themes	Second Order Themes	Third Order Themes	General Dimensions
It's natural you are putting something natural into your body (P4)	CAM natural	CAM Beneficial	CAM treatment attributes	CAM attributes
No chemicals added to them... they must be safe (P10)				
Must be better for you...it's natural... from the ground (P12)				
It's organic...like natural...no chemicals and shit to make you sick (P14)				
I never get treated like I'm dumb (P1)	CAM practitioners are caring and empathetic	CAM practitioner attributes	CAM practitioner attributes	
Always answers my questions...never tries to make out like I'm stupid (P2)				
Was really interested in what I had to say and how I felt (P3)				
They really care about you...they follow up (P7)				
They care about the soul not just the body (P8)				
I never get hurried...[CAM practitioner] spends hours with me sometimes...they just care (P11)				

Hierarchical Development of Themes for Reasons for CAM Use (*continued...*)

Raw Data Statement	First Order Themes	Second Order Themes	Third Order Themes	General Dimensions
You know when they talk to you know they are interested in everything...not just the sickness (P14)	CAM practitioners are caring and empathetic	CAM practitioner attributes	CAM practitioner attributes	CAM attributes
I just love the way they treat like you are human not a number not a disease but a person with feelings (P19)				
It's nice being treated like a person and not a number or a disease (P20)				
You know when you go there [to CAM practitioner] they are not going to look at you like you are mad (P21).				
Got rid of the migraines...so they must know something. (P3)	CAM practitioners have better skills			
She treats me like an equal, guides me and gives me honest information (P8)				
I think they [CAM practitioners] are better able to deal with some things...like irritable bowel (P9)				
Haemoglobin up...got more energy and I don't get colds...that has to say something (P10)				

Hierarchical Development of Themes for Reasons for CAM Use (*continued...*)

Raw Data Statement	First Order Themes	Second Order Themes	Third Order Themes	General Dimensions
Advice I got from the [CAM] practitioner proved to be right (P16)	CAM practitioners have better skills	CAM practitioner attributes	CAM practitioner attributes	CAM attributes
The advice I got from the [CAM] practitioner proved to be right (P16)				
CAM practitioner] always gives me good advice (P17)				
My liver enzymes are down...I'm off the antidepressants...as far as I'm concerned they're [CAM practitioners] the best (P18)				
My [CAM] practitioner is the best...got rid of the sinus...got rid of the irritable...blood is better (P19)				
I have seen the benefits...in my books she's the best because she knows what she's doing (P20)				
Since seeing her [CAM practitioner] I feel normal...not like a washed out rag (P21)				

Hierarchical Development of Reasons for CAM Disclosure

Raw Data Statement	First-Order Theme 1	Second-Order Theme 2	General Dimension
I asked him if there were some natural things we could use to help us (P1)	Wanted information about CAM	Wanted information about CAM	Disclosure of CAM use
I wanted information about the alternatives I wanted to use...if they could be OK and not dangerous that sought of thing (P3)			
I wanted to know if there natural things that could help (P7)			
I have mentioned it [CAM]. I felt that for instance supplements and so forth can help improve the condition (P8)			
I just asked him about it [CAM] because I wanted to know if it [CAM] could help (P10)	Continued CAM disclosure because of loss of confidence in biomedicine	Disclosed because of dissatisfaction with biomedicine	
I kept telling them [about CAM]. I was so angry because they nearly killed me (P11)			
I kept telling them [about CAM] because everything they [biomedical practitioners] did,didn't work...and they didn't believe me (P11)			
All they could do was to give me lethal drugs, and I wasn't happy about that. So I told him [biomedical practitioner] (P3)	Wanted biomedical physician to know		

Hierarchical Development of Reasons for CAM Disclosure (*continued...*)

Raw Data Statement	First-Order Theme 1	Second-Order Theme 2	General Dimension
I wasn't happy with some of the drugs they were prescribing and suggesting I take and I wanted him know (P3)	Wanted biomedical physician to know	Disclosed because of dissatisfaction with biomedicine	Disclosure of CAM use
I thought he should know that I was looking for something else (P3)			
I told them [biomedical practitioners] because... because they couldn't help me and because they didn't believe me (P11)			
I tried to tell him because I wanted him [biomedical physician] to know (P1)		Tried to disclose CAM use	Tried to disclose CAM use
I tried telling him [biomedical physician] because I thought it was important for him to know (P9)			
I tried to tell...I was expecting him to give me some guidance (P1)	Participant wanted guidance about CAM	Tried to disclose CAM use	Tried to disclose CAM use
I tried telling him by asking him [B/M practitioner] if Chinese medicine or naturopathy could help (P9)			
I was trying to tell him [B/M practitioner] when it [CAM] up in general conversation. I wanted him to tell me what he thought about it (P10)			

Hierarchical Development of Reasons for CAM Disclosure (*continued...*)

Raw Data Statement	First-Order Theme 1	Second-Order Theme 2	General Dimension		
I wanted to know about it [CAM] that's not what I got...he just told me not to use it [CAM] (P1)	Participant did not receive information about CAM	Biomedical physician advised against CAM use	Abandoned CAM disclosure		
He [biomedical physician] didn't know enough about it. He [B/M practitioner] was against it [CAM] (P3)					
I wasn't getting the information I was asking for. So I stopped even trying to tell (P6).					
I asked him if there were some natural things we could use...he told me it was a waste of money to use it [CAM] and that I shouldn't... so I never mentioned it again (P1)	Negative feedback from B/M practitioner inhibited future CAM disclosure			Biomedical physician advised against CAM use	Abandoned CAM disclosure
Which is his way of saying...we shouldn't use it [CAM] and that we shouldn't use it...and we never spoke about it again (P3)					
What more can I say he was against it [CAM] so we just never talked about it again...[biomedical practitioner] didn't agree...it [CAM] didn't really do anything so that was basically as far we went (P7)					
[Biomedical practitioner] that complementary and alternative medicine, as a whole was harmful. I don't even try and talk about it anymore (P10)					

Hierarchical Development of Reasons for CAM Disclosure (*continued...*)

Raw Data Statement	First-Order Theme 1	Second-Order Theme 2	General Dimension
Basically pretty negative...after he told me not to use it [CAM] that was basically as far we went (P7)	Biomedical physician against CAM use		Abandoned CAM disclosure
He was so against it [CAM].... made no sense, talking about how bad it was ...that we shouldn't use it. I decided not to talk about it [CAM] again (P9).			
We, well when I say we, most of us know he [B/M practitioner] doesn't like the alternative stuff so we don't tell him (P4)	Biomedical physician against CAM use	Biomedical physician against CAM use	Non-disclosure of CAM use
I could feel basically that he [B/M practitioner] didn't agree it [CAM]. I don't talk about it [CAM] (P7)			
[Biomedical practitioner] didn't seem to like the idea. I don't want to tell him anything about what I do (P8)			
[Biomedical practitioner] said that complementary and alternative medicine as a whole was harmful. I didn't agree he just said I should take advice (P10)			
He's [biomedical practitioner] against it so I'm not going to tell him (P15)			
So I just don't say anything. [B/M practitioner] thinks it doesn't work (P17)			

Hierarchical Development of Reasons for CAM Disclosure (*continued...*)

Raw Data Statement	First-Order Theme 1	Second-Order Theme 2	General Dimension
He's against it, so why tell him? (P18)	Biomedical physician against CAM use	Biomedical physician against CAM use	Non-disclosure of CAM use
He asked me once, but I denied it because I heard he's against it (P5)	Denial of CAM use		
I just tell him [biomedical physician] I don't use it because he doesn't like it [CAM] (P7)			
He sort of asked me about it [CAM] in a funny way, he just said you wouldn't use it would you?" and I said "No" (P12)	CAM use would make treating physician angry	B/M physician against CAM use	
He doesn't like it [CAM]...so I tell him nothing...he would get upset (P5)			
He would be furious, so I just don't say anything (P6)			
He would get really mad, so I just don't say anything because he thinks it doesn't work (P17)			
I can't see the point in upsetting them [B/M practitioners]. It is best to say nothing (P16)			

Hierarchical Development of Reasons for CAM Disclosure (*continued*)

Raw Data Statement	First-Order Theme 1	Second-Order Theme 2	General Dimension
I don't want a lecture about what I can and can't do. I just avoid talking about it [CAM] (P4)	Avoid negative interaction with biomedical physician	Biomedical physician against CAM use	Non-disclosure of CAM use
I know he would be upset and would tell me off, so why tell him (P11)			
[Biomedical physician] isn't open to that [CAM], like I told you before and would probably tell me off (P15).			
I just don't bring it [CAM] up because he [B/M physician] will just lecture me about why I shouldn't use it. Like I've heard him do to others (P4)	Biomedical physician discouraged CAM use		
I prefer not to tell them anything because they...try and talk you out of it (P6)			
Basically he [Biomedical physician] didn't seem to like the idea (P8)			
[Biomedical physician] just said I should take advice and not to use it [CAM] (P10)			
Why tell them something, if they're only going to tell not to use it (P12)			
What I do away from the hospital is my business...I'm going to tell them what I do in the privacy of my home (P1)	Maintain privacy	Maintain privacy	

Hierarchical Development of Reasons for CAM Disclosure (*continued*)

Raw Data Statement	First-Order Theme 1	Second-Order Theme 2	General Dimension
You can't tell them everything. It's [CAM] a private affair (P2)	Maintain privacy	Maintain privacy	Non-disclosure of CAM use
We have a life outside the hospital. So what we do away from there is for us to know (P8)			
I don't think he needs to know what teas I drink...really what I do at home stays home (P16)			
They want to know everything...I like to keep some things private. Yes, my other medicines [CAM] is my business (P18)			
He [biomedical physician] can be pretty evasive at times. You know like he will say something like "you're doing really well" and then go and order tests that he hasn't discussed with me first. So why should I discuss what I do with him? (P3)	Unhappy with biomedical practitioner	Unhappy with biomedical practitioner	
It pisses me off they way they react about alternative medicines...I'm not going to tell them (P17)			
After the way I was treated when I begged them for help there is no way I will tell them who [CAM practitioner] helped me (P18)			
I get treated like a mushroom, kept in the dark and fed bullshit...so I give them [biomedical physician] what they give me, no information (P20).			

Hierarchical Development of Reasons for CAM Disclosure (*continued*)

Raw Data Statement	First-Order Theme 1	Second-Order Theme 2	General Dimension
He [biomedical physician] never asked...you'd have to be mad to volunteer to tell them anyway (P2)	Biomedical physician never asked about CAM	Biomedical physician never asked about CAM	Non-disclosure of CAM use
No one really asked me (P4)			
He [B/M physician] never asked anyway (P9)			
But he's never asked anyway (P14)			
They don't ask (P10)\			
If they cared they would ask (P15)			
Don't tell if they [biomedical practitioners] don't ask (P16)			
They're [biomedical practitioners] not really interested...they don't ask (P18)			

Hierarchical Development of Reasons for CAM Disclosure or Non-Disclosure (*continued*)

Raw Data Statement	First-Order Theme 1	Second-Order Theme 2	General Dimension
They're not worried about it...so they don't talk about it [CAM] (P10)	Biomedical practitioners not concerned about CAM use	Biomedical physician never asked about CAM	Non-disclosure of CAM use
They're [biomedical Practitioners] not worried about it, or they'd ask (P14)			
I suppose. If they cared they would ask (P15)			
They're [B/M Practitioners] not really interested or they'd ask (P18)			
I just never thought about it [CAM disclosure] (P9)	Participant never thought to disclose CAM use	CAM not discussed with treating physician	
I never thought to [discuss CAM with B/M practitioner] I suppose (P15)			
There's nothing to be gained in talking or telling them about it [CAM] (P3)	No point in discussing CAM with B/M practitioner		
What's the use of telling them...it's not for discussion (P4)			
I can't see the point in telling them about what I do...it's just not talked about (P18)			
It's [CAM] not discussed (P2)	CAM not discussed with treating physician		

Hierarchical Development of Reasons for CAM Disclosure (*continued*)

Raw Data Statement	First-Order Theme 1	Second-Order Theme 2	General Dimension
We don't discuss it (P10)	CAM not discussed with treating physician	CAM not discussed with treating physician	Non-disclosure of CAM use
It's [CAM] a no go zone...I won't talk about it (P11)			
It's not something we've ever discussed (P13)			
I don't think we've ever talked about it [CAM] (P14)			
I won't tell them more than I think they need to know...because they keep me in the dark...they only tell you what they want you know (P2)	No mutual Sharing of information	CAM not discussed with treating physician	Non-disclosure of CAM use
They want to know everything. They won't share information with us...why should we tell them anything? (P3)			
I can't even get my results...for my GP so why should I tell them anything? (P18)			
What I do at home is not their [biomedical, physicians] concern them (P15)	None of the biomedical physician's concern	Biomedical physician does not need to know	Non-disclosure of CAM use
I don't think he needs to know what teas I drink (P16)			

Hierarchical Development of Reasons for CAM Disclosure or Non-Disclosure (*continued*)

Raw Data Statement	First-Order Theme 1	Second-Order Theme 2	General Dimension
Why should they be bothered about what help I get and what I am using (P18)	None of the biomedical physician's concern	Biomedical physician does not need to know	Non-disclosure of CAM use
Well it doesn't interact with our other drugs so he doesn't have to know...it doesn't affect our treatment (P2)	CAM does not interfere with biomedical treatment		
I would...tell him [B/M practitioner] if it [CAM] was affecting my treatment...it doesn't so he doesn't need to know (P3)			
It's [CAM] doing you good so why should they know? (P4)			
What I take is not hurting me so I don't tell him (P5)			
It doesn't affect the other drugs, so that's it...I won't tell him...why they should know (P17)			
Why should they know? It [CAM] doesn't hurt you. I mean it doesn't interfere with my other [B/M] treatment...so why should they know. I mean it doesn't interfere with my other [biomedical] treatment...so why should they know [CAM] (P18)			