THE USE OF COMPLEMENTARY AND ALTERNATIVE MEDICINE (CAM) AS LIVED BY INDIVIDUALS LIVING WITH CHRONIC ILLNESSES

Ashwin Kumar
BA (Hons) Maa. MA (Distinction) UWS

A thesis submitted in fulfilment of the requirements for the degree of
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Dedication

It is with eternal love and respect that I dedicate my doctoral research to my mother, Mrs Surui Wati Ram.
Acknowledgements

While researching and writing this study been a lonely and a painful process, the completion of this work would not have been possible without the help and encouragement given to me by so many people. I wish to express my sincere gratitude:

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Statement of Authentication

The work presented in this thesis is to the best of my knowledge and belief original except as acknowledged in the text. I hereby declare that I have not submitted this material, either full or in part, for a degree at this or any other institution.

Ashwin Kumar
August 2007
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Abstract

This naturalistic exploratory study focused on Australians living with chronic illnesses who chose to use complementary and alternative medicine (CAM). The purpose of this sociological study was to discover and illuminate the lived experience of using CAM by individuals living with chronic illnesses in an attempt to understand their reasons for choosing CAM for their health care needs within the social contexts of their lives. The research question guiding this qualitative study was: Based upon a reflection of lived experiences, why do individuals living with chronic illnesses choose to use CAM? The major finding of this study was that research participants turned to CAM to find practical solutions for coping with pain and the ongoing demands of living daily lives while suffering and living with chronic illnesses. Unlike existing research findings, participants in this study did not turn to CAM for ideological reasons, nor were they seeking a holistic approach to health and health care. As such, the findings of this study strongly suggest that individuals living with chronic illnesses initially choose to use CAM for pragmatic reasons rather than ideological dispositions. However, the findings also suggest that after their initial use of CAM, individuals appear to adopt via enculturation processes, more holistic ideologies resulting in modifications to perceptions of self, illness, and health.
1. Introduction

1.1. Introduction


Moreover, the use of CAM is also increasing in popularity and use among individuals living with chronic illnesses (Dhalla. 2006; Duigan. 2001; Furler. 2003; Iernewall. 2005; Mills. 2005; Ouattropani. 2003; Standish. 2002; Tsao. 2005). In Australia, “chronic illnesses pose an increasing challenge as they account for more of the burden of disease in Australia than other health conditions” (ABS. 2005). For the period 2004 – 2005, Australian health expenditure for chronic illnesses accounted for $22.3 billion (ABS. 2005).
The increasing use of CAM by individuals living with chronic illnesses in Australia and overseas has not been accompanied by adequate research which examines individuals’ experiences of choosing and using CAM within the social contexts of their lives. Existing research studies, largely quantitative in design, have explored general demographic and attitudinal pull/push factors associated with the proposed rather than actual use of CAM in chronic illness (Alger, 2005; Ambs. 2007; Aslan, 2006; Block, 2005; Boon, 2004; Cassileth, 2005; Ernst, 2003; Karpauf, 2000; Lee, 2007; Molassiotis, 2006). These quantitative studies have reported contradictory findings and provide limited understandings into how and why individuals living with chronic illnesses come to their use of CAM.

To date, no research studies have been conducted in the Australian context to examine the use of CAM by individuals living with chronic illnesses. The question as to what constitutes the lived experience of using CAM and why individuals living with chronic illnesses actively choose to use CAM in the Australian context has remained in the dark. An illumination of how and why individuals living with chronic illnesses choose to use CAM within the social context of their lives is essential if we are to empathetically
understand and provide evidence based quality health care that is
cogruent with the needs of such individuals in the Australian context.

The primary aim in conducting this research study was to deepen
and extend our empathetic understanding of the lived experience of
choosing and using CAM by individuals living with chronic illnesses in the Australian context. This thesis presents the findings
of a naturalistic study that examined 10 participants' experiences of
choosing and using CAM while living with chronic illnesses. In
describing the experiences from the participants' point of view, it is
hoped that this thesis will provide the reader with an insider view
of what the experience of choosing and using CAM is like as lived
by individuals with chronic illnesses. This introductory chapter
describes the background, purpose, and significance of the study
and provides an overview of the thesis.

1.2. Background to the study

There is reason to believe that Australians continue to be high users
of complementary and alternative medicine (CAM) (Adams. 2005;
Alderman. 2003; Barrett. 2006; Bensoussan. 1999; Cincotta. 2006;
Coulter. 2004; D'Crus. 2005; Grace. 2006; MacLennan. 2006; McCabe.
The National Centre for complementary and alternative medicine (NCCAM) defines CAM as "a group of diverse medical and health care systems, practices, and products that are not presently considered to be part of conventional medicine" (Easthope, 2005. p.124). MacLennan (2006), in the only large-scale representative multivariate study conducted in the Australian context, found that CAMs were used by 52.2% of the Australian population. Greatest use was in women aged 25-34 years, with higher income and education levels. CAM therapists had been visited by 26.5% of the population. In those with children, 29.9% administered CAMs to them and 17.5% of the children had visited CAM therapists. The total extrapolated cost in Australia of CAM and CAM therapists was AUD$1.8 billion. Moreover, this study found that CAMs were used mostly to maintain general health and that users of CAM had lower quality-of-life scores than non-users. Among CAM users, 49.7% used conventional medicines on the same day and 57.2% did not report the use of CAM to their doctor. About half of the respondents assumed that CAMs were independently tested by a government agency; of these, 74.8% believed they were tested for quality and safety. 21.8% for what they claimed, and 17.9% for efficacy.
This increasing popularity and use of CAM is also reflected in results from opinion polls and large-scale surveys conducted overseas. In Britain, the use of CAM remains a popular choice (Cook. 2006; Ernst. 2005; Fewell. 2005; Molassiotis. 2006). Moreover, surveys on the use of CAM in the Netherlands show considerable rates of usage (Renckens. 2002; Smit. 2006; van den Berg. 2006). Similar results have been reported in the United States (Bell. 2006; Garrow. 2006; Honda. 2005; Larson. 2006; Murrav. 2006; Wu. 2007; Yap. 2006). American health users had visited their therapists 425 million times. 40 million more times than they visited their primary care physician. On the average, these individuals spent US$13.7 billion on various types of CAM with US$10.3 billion coming out of their own pockets (Yeh. 2006). Accordingly, these overseas results, together with research from Australia, indicate that the use of CAM remains a popular choice.

The increasing popularity and usage of CAM is also reflected in the incorporation of CAM modalities by private health insurance funds, nursing practices, and biomedical practitioners in Australia and overseas. A significant number of private health insurance funds now allow for CAM treatments (Atwell. 2004; Dunn. 2006; Lind. 2006; Wise. 2006). Some nursing practices have also incorporated

In Australia, the use of CAM for health care continues to grow at an exponential rate, and is predicted to parallel estimates in other countries such as the United States and Europe (Adams. 2005: Alderman. 2003: Barrett. 2006: Bensoussan. 1999: Cincotta. 2006: Coulter. 2004: D’Crus. 2005: Grace. 2006: MacLennan. 2006: McCabe. 2005: O’Callaghan. 2003: Searles. 2007: Siahpush. 1999). The increasing popularity of CAM in Australia is further illustrated by the growing number of holistic health care clinics, alternative medicine conferences, and alternative medical curriculum implemented in orthodox medical schools (Easthope. 2005: Hall. 2006: Siahpush. 1999). Additionally, new research centres, such as the Centre for Traditional Chinese Medicine at the University of Western Sydney, and the Centre for CAM at Southern Cross University, represent the first large-scale endeavours to research the use of CAM in Australia.
This increasing popularity and usage of CAM has aroused considerable interest among researchers and has raised the question: Why do individuals use CAM despite constant vilification of these practices? In earlier research, the use of CAM was treated as an interesting but marginal institution supported by a fringe minority (Adams, 2006; Balneaves, 2007; Cox, 2003; Lenzacher, 2006). Usually earlier CAM studies were sociologically situated in terms of illegitimated knowledge, deviant sects and cults, and discourse was heavily polarised around notions of (ir)rationality (Furnham, 1993; Sharma, 1999). Moreover, these studies overlooked the possibility of research subjects actively choosing unorthodox forms of treatment. Most recent researchers, however, have recognised that CAMs are accepted by a sizeable proportion of the population as legitimate options to conventional biomedicine, and that the values and beliefs which lead people to adopt them form a significant part of contemporary culture that simply cannot be polarised around notions of (ir) rationality.

Overseas and Australian health care surveys indicate that a significant number of patients with chronic illnesses are currently using CAM for their health care management. An increasing number of HIV patients are turning to CAM use (Dhalla, 2006: 7).
Duran. 2001; Furler. 2003; Iernewall. 2005; Mills. 2005; Tsao. 2005). A similar increasing trend regarding the uptake of CAM has been reported for cancer patients (Algier. 2005; Ambs. 2007; Aslan. 2006; Block. 2005; Boon. 2004; Cassileth. 2005; Ernst. 2003; Korpau. 2000; Lee. 2007; Molassiotis. 2006). Moreover, asthma patients are also turning to the use of CAM (Braganza. 2003; Cohen. 2005; Lehrer. 2004; Merendino. 2005; Singh. 2002). As a response to the increased use of CAM by patients with chronic conditions, the National Institutes of Health (NIH) commissioned the Office of Alternative Medicine (OAM) to investigate the efficacy of the different types of CAM used by individuals living with chronic illnesses (Adler. 2003).

However, despite the worldwide increasing use of CAM by individuals living with chronic illnesses, our understanding of how and why individuals living with chronic illnesses actively choose to use CAM is limited (Bullock. 2004; Cronan. 2003; Paramore. 2005). To date, no research study has been conducted in the Australian context to examine the lived experience of using CAM by individuals living with chronic illnesses. As such, we do not know the reasons as to why individuals living with chronic illnesses choose to use CAM within the Australian context. This research study attempts to fill this research gap.
1.3. Purpose of the study

The purpose of this sociological study was to discover and illuminate the lived experience of using CAM by individuals living with chronic illnesses in an attempt to understand their reasons for choosing CAM for their health care needs within the social contexts of their lives.

1.4. Research question

The research question guiding this research study was: Based upon a reflection of the lived experience of using CAM, why do individuals living with chronic illnesses choose to use CAM?

1.5. Significance of the study

This study explores an area of health care traditionally ignored by conventional biomedical community for many years. This research study is significant for four main reasons. First, the study provides information on the complexities related to CAM use in individuals living with chronic illnesses, which has the potential to help health professionals understand help-seeking behaviours of those living with chronic illnesses. Findings from this study increase an awareness and understanding of CAM use, which may assist health professionals to make decisions on appropriate healthcare plans and
referrals in order to provide continuous care. This may assist health professionals, including nurses and doctors, involved in the management of individuals with chronic illnesses to reach a greater appreciation of patients seeking CAM treatments. Nurses and doctors are urged to deliver health care based on reliable evidence as a means of improving health outcomes for all patients (Grace, 2006) and to support the efficacy of health interventions for patients with chronic illnesses (Armstrong, 2006; Backer, 2006; Charmaz, 2007). Optimal care includes not only the skills and knowledge required to competently manage patients, but also knowledge of the psycho-social-cultural aspects of illness and CAM use (Kaufman, 2005; Kleinman, 1989). Furthermore, an awareness of why individuals with chronic illnesses use CAM will help to promote health and meet patient health needs (Furler, 2003; Ouattropani, 2003).

Second, it is important for health professionals to utilise evidence from CAM studies that are contextually relevant (Bensoussan, 2005). Most studies of CAM use among individuals with chronic illnesses were conducted in countries other than Australia. The applicability of such results may have limited relevance for Australian health care practice. This Australian study provides valuable evidence for
health professionals working in the area of chronic illness settings. In addition, findings from this Australian study contribute to international research on CAM and may be compared or contrasted to results from other international studies in order to gain a broader and deeper understanding of CAM use.

Third, findings from this research help to inform public health education. Undergraduate and postgraduate public health programs today include courses on contemporary health care trends and the changing social health care environment as part of the foundation curriculum for practice. The ability of existing and future public health students to help and understand individuals with chronic illnesses who prefer to use CAM begins in public health education.

Finally, this study assists health professionals to develop patient education about CAM and incorporate content based on the research findings. Despite the increasing use of CAM, most health consumers in Australia have limited quality health information regarding CAM (Easthope, 2005). This may lead to inadequate understanding of the potential risks and benefits associated with CAM use. Adequate health information concerning CAM is essential for consumer understanding of adequate treatment
options. and for making informed decisions. Enabling individuals to receive more education on CAM may reduce their uncertainties about treatments and may increase successful treatments. An improved knowledge base of CAM use in chronic illnesses may increase existing and future patient confidence in their decision-making capacities, and decrease patient anxieties. Therefore, this study makes a significant contribution to these requirements. Helping chronically ill patients who use CAM to clarify problems encountered with CAM and biomedical treatments may reduce their stress and allow them to continue adequate treatments. This research study is also significant in terms of stimulating further research development in the area of CAM use in chronic illness.

1.6. Definition of terms

This research study utilises the following definition of terms based upon CAM classifications endorsed by the National Centre for Complementary and Alternative Medicine (NCCAM):

CAM: "A group of diverse medical and health care systems, practices, and products that are not presently considered to be part of conventional medicine. Complementary medicine is used together with conventional medicine".
Alternative medicine: “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”.

Acupuncture: “A method of healing developed in China at least 2,000 years ago. Today acupuncture describes a family of procedures involving stimulation of anatomical points on the body by a variety of techniques. American practices of acupuncture incorporate medical traditions from China, Japan, Korea, and other countries. The acupuncture technique that has been most studied scientifically involves penetrating the skin with thin, solid, metallic needles that are manipulated by the hands or by electrical stimulation”.

Aromatherapy: “Involves the use of essential oils (extracts or essences) from flowers, herbs, and trees to promote health and well-being”.

Ayurveda: “A CAM alternative medical system that has been practiced primarily in the Indian subcontinent for 5,000 years.”
Avurveda includes diet and herbal remedies and emphasises the use of body, mind, and spirit in disease prevention and treatment”.

**Chiropractic**: “A CAM alternative medical system. It focuses on the relationship between bodily structure (primarily that of the spine) and function, and how that relationship affects the preservation and restoration of health. Chiropractors use manipulative therapy as an integral treatment tool”.

**Dietary supplements**: “Congress defined the term ‘dietary supplement’ in the Dietary Supplement Health and Education Act (DSHEA) of 1994. A dietary supplement is a product (other than tobacco) taken by mouth that contains a “dietary ingredient” intended to supplement the diet. Dietary ingredients may include vitamins, minerals, herbs or other botanicals, amino acids, and substances such as enzymes, organ tissues, and metabolites. Dietary supplements come in many forms, including extracts, concentrates, tablets, capsules, gel caps, liquids, and powders. They have special requirements for labelling. Under DSHEA, dietary supplements are considered foods not drugs”.
**Electromagnetic fields:** "Invisible lines of force that surround all electrical devices. The Earth also produces EMFs; electric fields are produced when there is thunderstorm activity and magnetic fields are believed to be produced by electric currents flowing at the Earth's core".

**Homeopathic medicine:** "A CAM alternative medical system. In homeopathic medicine, there is a belief that "like cures like." meaning that small, highly diluted quantities of medicinal substances are given to cure symptoms. when the same substances given at higher or more concentrated doses would actually cause those symptoms".

**Massage:** "Therapists manipulate muscle and connective tissue to enhance function of those tissues and promote relaxation and well-being".

**Naturopathy:** "A CAM alternative medical system. Naturopathic medicine proposes that there is a healing power in the body that establishes, maintains, and restores health. Practitioners work with the patient with a goal of supporting this power, through treatments such as nutrition and lifestyle counselling, dietary supplements."
medicinal plants. exercise. homeopathy. and treatments from traditional Chinese medicine”.

**Osteopathic medicine:** “A form of conventional medicine that, in part, emphasises diseases arising in the musculoskeletal system. There is an underlying belief that all of the body’s systems work together, and disturbances in one system may affect function elsewhere in the body. Some osteopathic physicians practice osteopathic manipulation, a full-body system of hands-on techniques to alleviate pain, restore function, and promote health and well-being”.

**Reiki:** “A Japanese word representing Universal Life Energy. Reiki is based on the belief that when spiritual energy is channelled through a Reiki practitioner, the patient’s spirit is healed, which in turn heals the physical body”.

**Therapeutic Touch:** “An ancient technique called laying-on of hands. It is based on the premise that it is the healing force of the therapist that affects the patient’s recovery: healing is promoted when the body’s energies are in balance; and, by passing their hands over the patient, healers can identify energy imbalances”.

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Traditional Chinese medicine (TCM): "The current name for an ancient system of health care from China. TCM is based on a concept of balanced qi (pronounced "chee"). or vital energy, that is believed to flow throughout the body. Qi is proposed to regulate a person's spiritual, emotional, mental, and physical balance and to be influenced by the opposing forces of yin (negative energy) and yang (positive energy). Disease is proposed to result from the flow of qi being disrupted and yin and yang becoming imbalanced. Among the components of TCM are herbal and nutritional therapy, restorative physical exercises, meditation, acupuncture, and remedial massage."

1.7. Overview of thesis

This introductory chapter has provided an overview of the background, aims and significance of this research study.

Chapter Two presents a current sociological review of research literature on CAM and the use of CAM by individuals living with chronic illnesses. This chapter is divided into two sections. The first section of this chapter reviews sociological literature on CAM and CAM use. It highlights the tensions and ideological polemics surrounding objectivist definitions of CAM. Biomedical and
alternative health beliefs and the philosophical underpinnings of health, disease, and well-being are discussed. The role of science in legitimating health belief systems, popular stereotypes, and barriers associated with using alternative medicine are also discussed. This first section concludes with a discussion of self-care behaviour and the use of multiple health care modalities. The second section of this chapter reviews sociological literature on chronic illness and the use of CAM for chronic illnesses in different populations. It highlights definitions of chronic illness and some of the many challenges associated with living with chronic illnesses in an attempt to provide a context for this study. This chapter concludes with a discussion of the research problem for this study.

Chapter Three presents the design and method of this study. It begins by detailing and describing methods used in this study and outlines the choices made and why they were made with regard to the design, participant sample, setting and rigour, thereby leaving a path of decision that can be traced for auditing purposes. The chapter concludes with a discussion on the ethical issues of this research.
Chapter Four, being the first of the findings chapters, presents the findings regarding how research participants first encountered the emergence of illness in their daily lives. The time from when illness first appeared, through to participants’ initial awareness or suspicion that something was wrong with them, to their initial attempts at help seeking are described by research participants in this chapter.

Chapter Five presents the findings regarding how research participants sought and obtained biomedical help. In particular, we explore their experiences of being in biomedical environments, biomedical consultations, biomedical diagnostics, and biomedical treatments.

Chapter Six presents the findings regarding how research participants sought and obtained CAM help. In particular, we explore their experiences of being in CAM environments, CAM consultations, CAM diagnostics, and CAM treatments.

Chapter Seven presents the findings regarding how research participants experienced their daily living after immersion in CAM treatments. It highlights how they reflected and evaluated their
various treatments in terms of efficacy, and describes some of their reflections regarding the subjective changes they experienced resulting from their immersion in CAM treatments. Research participants also describe in this chapter some of the physical and psychological changes that they made in order to effectively cope with their ongoing illnesses on a practical day-to-day basis. They also describe in this chapter how they came to an acceptance of their illnesses and an acceptance of their altered lives and realities.

Chapter Eight presents a micro perspective of some of the significant findings emerging from the participant in-depth interviews regarding the lived experience of using CAM and the reasons for such use within the context of living with chronic illnesses.

Chapter Nine presents a macro perspective of the lived experience of using CAM in order to understand why individuals living with chronic illnesses turned to CAM treatments. The effects of using CAM on their subjective perceptions of self are also discussed. The chapter concludes with a consideration of the broader social context of CAM use and the associated health policy, health education, and health care practice implications within our Australian context.
2. Review of literature

2.1. Introduction

Complementary and alternative medicine (CAM) is a continually growing field. Recent studies support the popularity and increasing use of CAM by individuals for health care. There is mounting evidence in current research literature to indicate that individuals living with chronic illnesses are now increasingly choosing to use CAM. When faced with this increasing popularity and use of CAM, and that individuals living with chronic illnesses are quite willing to pay out of pocket for these modalities, the following question arises: Why do individuals living with chronic illnesses choose to use CAM? The first section of this chapter reviews the sociological literature on CAM and CAM use. It highlights the tensions and ideological polemics surrounding objectivist definitions of CAM. Biomedical and alternative health beliefs and the philosophical underpinnings of health, disease, and well being are discussed. The role of science in legitimating health belief systems, popular stereotypes, and barriers associated with using alternative medicine are also discussed. This first section concludes with a discussion of self care behaviour and the use of multiple health care modalities.
The second section of this chapter reviews the sociological literature on chronic illness and the use of CAM for chronic illnesses in different populations. It highlights definitions of chronic illness and some of the many challenges associated with living with chronic illnesses in an attempt to provide a context for this study. This chapter concludes with a discussion of the research problem for this study.

2.2. Complementary and alternative medicine (CAM)

2.2.1. The increasing popularity and use of complementary and alternative medicine (CAM)

Anywhere in the world, 70% to 90% of the population relies on CAM as a form of health care (Yao, 2006). CAM is popular in numerous countries around the world. The WHO classifies 65% to 80% of the world’s health services as alternative medicine (Ionas. 1997). In the West, people have begun to appreciate the natural approach to healing espoused by CAM and its influence on quality of life. In some developing countries such as China and India, as well as high-income industrialised countries such as the United States (USA) and the United Kingdom (UK), CAM is widespread and takes an important role in health care.

Similarly, in the Netherlands. 6.9% of adults visited one or more CAM therapists (Vliezer. 2007). The most commonly used modalities were: Naturopathy (82%). Homoeopathy (80%). Hydrotherapy (77%). Applied Kinesiology (32%). Acupuncture (81%). Polarity Therapy (28%), and Bach Flower Remedies (13%). The most common illness conditions were: pain (87%). smoking cessation (49%), depression (66%). asthma (36%). eating disorders (32%). sleeping problems (32%). cancer (22%). and AIDS/HIV (5%).

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In the United States of America and Canada, more individuals consult their CAM therapists than their primary health care physicians (Ortiz, 2007). There were 629 million visitations to CAM therapists and only 386 million visitations to primary care physicians. Furthermore, estimates are that Americans spend $13.7 billion on CAM each year (Wu, 2007). In Canada, the Fraser Institute conducted a national survey that found 50% of Canadians use CAM in the course of a year, and that 73% had used CAM within their lifetimes (Curry, 2005). The most frequently used CAM modalities were: chiropractic (36%), relaxation techniques (23%), massage (23%), prayer (21%), and herbal therapies (17%). The most common illness conditions were: neck problems (63%), lower back pain (67%), headaches (65%), allergies (60%), and arthritis/rheumatism (49%).

In France, one-third of the population uses CAM, with homoeopathy being the most popular treatment. In Norway, homoeopathy is also the most popular CAM modality, followed by acupuncture and aromatherapy (Risberg, 2005). Russia legalised the use of CAM in 1993: the officially recognised practices are reflexology, chiropractic, and homoeopathy (Yar, 2006). In Japan, biomedicine and CAM co-exist. Two-thirds of the population of
Tokyo report using CAM treatments (Sato. 2004). The most popular CAM modalities were herbal medicine, acupuncture, and acupressure (shiatsu). The international market for CAM products and services was estimated to be worth about $20 billion (retail level). This market was estimated to be expanding at more than 15% per year (Paramore. 2005). The use of CAM in post-industrial societies is increasing in popularity and use.

Similar to overseas trends, the use of CAM in Australia continues to be increasing in popularity and use (Adams. 2005; Alderman. 2003; Barrett. 2006; Bensoussan. 2005; Cincotta. 2006; Coulter. 2004; D’Crus. 2005; Grace. 2006; MacLennan. 2006; McCabe. 2005; O’Callaghan. 2003; Searles. 2007; Siahpush. 1999). MacLennan (2006), in the only large-scale representative multivariate study conducted in the Australian context, found that CAM was used by 52.2% of the Australian population. Greatest use was in women aged 25-34 years, with higher income and education levels. CAM therapists had been visited by 26.5% of the population. In those with children, 29.9% administered CAM to them and 17.5% of the children had visited CAM therapists. The total extrapolated cost in Australia of CAM and CAM therapists was AUD$1.8 billion. Moreover, this study found that CAM was used mostly to maintain
general health and that users of CAM had lower quality-of-life scores than non-users. Among CAM users, 49.7% used conventional medicines on the same day and 57.2% did not report the use of CAM to their doctor. About half of the respondents assumed that CAM was independently tested by a government agency; of these, 74.8% believed they were tested for quality and safety, 21.8% for what they claimed, and 17.9% for efficacy.

2.2.2. Defining complementary and alternative medicine (CAM)

2.2.2.1 Alternative medicine

The biomedical community often defines alternative medicine as healing practices that are outside the practice of Western scientific biomedicine (Adams, 2006; Burden, 2005; Cox, 2003; Yap, 2006) and as unconventional (Barrett, 2003; Cuzzolin, 2003; Leach, 2004). Alternative medicine is based on different healing modalities, often with origins from around the world (Bensoussan, 2004; Briggs, 2002). Healing modalities may be defined as the particular worldview, practices, properties and healing effects that are unique to that therapy (Bensoussan, 2004; Cuzzolin, 2003; Maha, 2007). Modalities often overlap in alternative medicine. Examples of alternative medicine include therapies such as acupuncture, chiropractic therapy, herbal remedies, therapeutic touch and reiki.
Alternative medicine often involves both wellness and disease models, and may promote wellness in addition to the prevention and treatment of disease as defined by the biomedical model (LaVallev & Verhoef. 2005. p.46). LaVallev and Verhoef indicate that alternative medicine is “most often used by patients with chronic illnesses when standard surgical or drug interventions are poorly tolerated or have not resulted in the benefit desired by the patient”. This view is supported by other researchers (Buchbinder. 2002: Cohen. 2005: Ernst. 2002: Singh. 2002). Alternative medicine is often used when patients are dissatisfied with both the diagnosis (Dhalla. 2006: Duggan. 2001: Furler. 2003: Mills. 2005: Tsao. 2005) and prognosis of biomedical therapies (Anz. 2005: Owen. 2007: Winnick. 2006: Yao. 2006). Individuals may also choose alternative medicine without having a biomedical experience (Adams. 2006: Arawal. 2006: Baron. 2005: Brav. 2004: Closs. 2007: Vliger. 2007). Further, alternative medicine can be the first choice of action in health seeking behaviour (Wu. 2007).

The biomedical community often represents alternative medicine as displacing conventional medical therapy, thereby threatening it by means of an alternative practice (LaVallev & Verhoef. 2005. p.46). Biomedical doctors maintain that alternative medicine may harm or
endanger patients and may prevent them from seeking proper medical care until it is too late (Fan. 2005; Forstor. 2006). Alternative medicine is often feared for disrupting biomedical practice and treatments (Sharma. 1999. p.57). Biomedicine often labels alternative medicine as quackery for not conforming to the scientific paradigm and for not providing objective proof of efficacy (Andrews. 2006; Cassileth. 2005; Parkman. 2005). Biomedicine describes its scientific perspective towards alternative medicine as the “put up or shut up viewpoint: alternative medicine must prove itself according to orthodox double-blind clinical trials” (Ernst. 2003. p.142).

The labelling of certain therapies today as alternative is a result of a complex historical process of allopathic medical dominance in the late nineteenth and early twentieth centuries. where certain therapies such as homoeopathy were outlawed through an organised process of medical elitism (Armstrong. 1995; Block. 2005; Wardwell. 1999; Willis. 1989).

In contrast to biomedical arguments, however. LaValley and Verhoeff (2005) state, “it is incorrect to conclude that the patient and the physician face competing clinical choices with regard to alternative therapies” (p.46). They suggest that alternative medicine
can promote wellness alongside allopathic means without disrupting biomedical therapy. In contrast to popular biomedical arguments, other researchers argue that it is often biomedical treatments that disrupt the healing properties of alternative medicine through toxic and iatrogenic side effects, rather than the opposite (Ernst, 2002; Rossdale, 2006; Wagner, 2000).

While it cannot be generalised or deemed representative of all modalities of alternative medicine, Goldstein (2005, p.45) provides ten key characteristics of alternative medicine that clearly represent a contrast with Western biomedical concepts: (1) an emphasis on the unit of the physical body, mind and spirit; (2) a view of health as a positive state, not merely the absence of disease; (3) a concern with the individuals responsibility for his/her own health; (4) an emphasis on health education, self-care, and self-healing; (5) a relationship between the provider and the client that is relatively open, equal, and reciprocal; (6) a concern with how the individuals health reflects familial, social and cultural environments; (7) an openness towards utilising natural, low technological and non-Western techniques whenever possible; (8) an emphasis on physical and/or emotional contact between the practitioner and the patient; (9) a belief that successful healing transforms the practitioner as well
as the patient; and (10) an acceptance of a spiritual component in the aetiology and treatment of illness.

2.2.2.2 Complementary Medicine

When alternative medicine is combined with biomedical medicine to promote healing, such as the combination of Chinese acupuncture with biomedical drug-therapy, the resulting combination has been termed complementary medicine (Sharma, 1999). Biomedical therapies encompass the entire range of allopathic procedures and practices derived from Western biomedicine. The term complementary is often criticised by alternative practitioners for defining CAM as secondary to biomedicine (Armstrong, 2005; Ernst, 2005; Verhoef, 2003). Complementary medicine, however, is not to be confused with alternative medicine. Although alternative and complementary medicine may share similar therapeutic modalities, alternative medicine does not combine its approach with biomedical therapies in a formal cooperative context (Armstrong, 2005; Crawford, 2006; Sharma, 1999).

2.2.2.3 Plural Medicine

An additional term commonly used today to refer to the combination of alternative and biomedical therapies is plural
medicine or medical pluralism (Adams. 2006; Chu. 2006; Connor. 2004; Sawi. 2007). These terms refer to a group of two or more medical systems characterised by differing and unique healing modalities, which may form an opposing, competing or cooperative health care system for the society in which they occur (Bear. 2004). Not only confined to Western medical systems, medical pluralism is often seen in non-Western societies as characterised by several overlapping medical systems (Armstrong. 2005; Sinha. 2005). Medical pluralism has also become commonplace in most post-industrial societies, where dominant Western biomedicine competes with alternative healing systems (Eastwood. 2000; Leach. 2004). Although uncommon, plural medicine may further involve a complementary or cooperative nature (Ang. 2005; Burden. 2000; Lee. 2007). In other words, plural medicine does not necessarily involve a formal cooperation between therapies, although some aspects are usually complementary in nature.

2.2.3. Views of health, disease, illness, and well-being: Biomedical and alternative perspective

2.2.3.1 Biomedicine

The practice of medicine or healing is a cultural universal. Anthropologists have found that all human societies have systems
of ethnomedical beliefs and knowledge that serve to reinforce cultural guidelines for health and illness behaviour (Anderson. 1989; Charmaz. 1983; Sharma. 1999). Some scholars contrast ethnomedicine with the established and standardised regimens of Western medicine (Henderson. 1997; Turner. 1992). Australian society is no exception, and the biomedical system employed here may be studied as a kind of complex cultural or ethnomedical system (Lupton. 2005; Willis. 1989). The primary ethnomedical beliefs in Australian society are those of the biomedical system. It is the driving force behind most of Western medicine, and reflects an elaborate cultural system. The defining characteristics of this system will be discussed here.

A crucial characteristic of the biomedical system stems from its history. The 17th century ideal of Cartesian dualism, a separation of mind and body, is a fundamental assumption of biomedicine (Anderson. 1989; Anvinam. 1995; Illich. 1975; Sargent. 2005; Zola. 1993). The body is viewed as part of the physical world, and diseases are bounded disorders that must be treated within this realm (Lupton. 2005; Toulmin. 1997). This assumption was reinforced when discoveries in bacteriology by Louis Pasteur and Robert Koch led to the development of the germ theory of disease.
These along with other advances in areas like biochemistry and surgery were sufficient to “bind physician allegiance to scientific clinical medicine” (Sargent. 2005. p.71).

Biomedicine is an expansive realm: it has influence in clinical and academic settings, and in research and development. In Australia, since the 1930s, the Australian Medical Association (AMA) has largely determined the path of biomedicine (Easthope. 2004; Lupton. 2005; Willis. 1989). The AMA is a professional organisation that represents the interests of constituent physicians. The position of the AMA historically has been tied to a kind of free enterprise model (Lupton. 2005). For example, the patient would pay for costs, be free to choose their physicians without restriction, and the medical profession would have control over all aspects of biomedical care. Today, the scene is somewhat different. The high cost of biomedical care has involved governments, insurance companies, and corporate profiteers in medical decision-making. Some researchers argue that the management of biomedical care has loosened physician control and diluted the patient-practitioner relationship (Charmaz. 2007; Easthope. 2004; Willis. 1989). An overall concern with professionalism and scientific neutrality on the part of physicians has weakened the biomedical system in the face of these challenges.

Kleinman (2003) argues that the consequence of thinking along Cartesian lines is a physical reductionism that permeates the biomedical system. Social and psychological issues that affect a patient either directly or indirectly may often be neglected and ignored. Illnesses may be reduced to biochemical and neurophysiologic malfunctions and broader social considerations may be underestimated.

Another characteristic of the biomedical system is the doctrine of specific etiology (Sargent. 2005: Sharma. 1999: Turner. 1992). In this paradigm, diseases are seen as “deviations from the norm of measurable biological (somatic) variables” (Turner. 1992. p.45). Alternative definitions may be largely ignored. Diseases are often diagnosed in an interaction where the patient’s identification of physical symptoms is matched with physician knowledge about how specific diseases cause specific symptoms. The cause of a disease then is reduced to either a specific toxin or pathogen. Treatment is directed both at the alleviation of physical symptoms and at the destruction of the specific causative agent via the ‘magic
bullet’ and ‘shoot to kill’ approach (Lupton. 2005: Sharma. 1999). Often disorders may be understood in terms of such linear cause-effect relationships (Anderson. 1989: Charmaz. 2007).

With the extensive focus on diagnosis and treatment, preventive strategies may often be ignored, as patients still continue to be concentrated in large acute care facilities (Charmaz. 2003: Lupton. 2005: Siahroush. 1999). Diseases are often viewed as static entities rather that dynamic processes. The information base for biomedical diagnoses is mostly quantitative and often tends to ignore more anecdotal, qualitative data (Kleinman. 1988: Sharma. 1999: Turner. 1992). Nearly all phases of biomedical care are dominated by the doctrine of specific etiology. In this regard, it has been argued by Mechanic (2005) that doctors need to take more seriously satisfaction and broader quality of life concerns of their patients.

I must describe to you first the body by itself ... I assume the body is nothing else than a statue or machine ... indeed, the nerves of the machine I am describing to you may very well be compared to the veins of the machineries of fountains. Its muscles and its tendons to various other engines and devices which serve to move them as its heart is the spring.

Disease is the ultimate fulfilment of the machine metaphor of biomedicine (Anderson. 2002; Lupton. 2005; Sharma. 1999; Turner. 1992). When parts of the machine malfunction, whether they be springs, pistons, engines, hearts, lungs, livers, or kidneys, we simply remove them or fix them and insert a new, normal and properly functioning one. The simplicity of such thinking illustrates the deficiency of the machine metaphor as embedded in biomedical culture (Anvinam. 1995; Lupton. 2005; Sargent. 2005; Siahoush. 1999; Zola. 1989). However, it is noteworthy that there have been considerable movements toward more complete social models of health in recent times in areas such as nursing, public health, psychology, sociology, and anthropology.
2.2.3.2 Alternative medicine

Alternative health belief systems tend to address a broader range of concerns than biomedicine (Anvinam. 1995: Lupton. 2005: Siahoush. 1999: Willis. 1989). Alternative health systems may place different values of particular therapeutic outcomes. For example, alternative medicine frequently undertakes to promote healing as differentiated from curing (Sharma. 1999). Just as it is possible to have a disease without a corresponding illness or an illness with discernible disease, it is possible to be cured without experiencing healing, or be healed without being cured (Eisenberg. 2003: Sharma. 1999). Curing generally refers to the removal or correction of organic pathology. Healing can encompass broader matters such as: comfort, care, family and community relationships, quality of life, peace of mind, restoration of dignity, acceptance, and spiritual growth (Sharma. 1999: Siahoush. 1999). Physical recovery may not be the most important outcome, and healing may be felt to have taken place in the absence of physical cure or even of noticeable physical improvement (Charmaz. 2003: Lupton. 2005: Siahoush. 1999).

Alternative health belief systems frequently include within their purview not just bodily sickness, but also mental, emotional, and spiritual afflictions, as well as familial, community, and
environmental concerns (Dhalla. 2006; Kaufman. 2005; Mills. 2005; Tsao. 2005). Most of these systems recognise biomedical defined diseases, but provide for the treatment of a number of problems not recognised by biomedicine as real or legitimate (conditions such as soul loss, spinal subluxation, imbalances, or deficiencies in vital energy). Many alternative health systems regard illness as a specific subtype of a more generalised category of misfortune or disharmony which they attempt to address (Anderson. 1989; Baer. 2003; Sharma. 1999). Importantly, many alternative health systems address the meaning of illness and suffering for individuals offering answers to questions like “why me?” and “why now?” (Hufford. 2004). This is a significant dimension of the experience of illness for which biomedicine has often little to offer (Kleinman. 2004). Other characteristics common to alternative medicine include a strong observational basis of support for their practices and claims, and a general sense of pragmatism - that a therapeutic action works is more important than an explanation of how or why it works (O’Connor. 2005). “In systems that include specialist practitioners, these experts may be well versed in the theoretical as well as the practical aspects of the system. Most ordinary members or clients, however, are no more likely to concern themselves with these complexities than the clients of conventional medicine” (Sharma.
1999. p.68). The pragmatism in evaluating therapeutic efficacy is the same in both domains: the beneficial effect of the herb or acupuncture or the antibiotic is of greater interest and concern than the mechanism of action (Maha. 2007).

A number of common concepts may be found in a variety of alternative medicine modalities, although their specific interpretations vary from system to system. Such common concepts include a view of health as entailing harmony and/or balance, and the importance to health and illness of various kinds of energies (Bakx. 1991; Cartwright. 2005; Mikhail. 2005). Interpretations of pertinent energies may include a belief in energy as the vital force that animates the body and provides the essential conditions for health (Sharma. 1999). Most alternative health beliefs systems recognise some non-material dimension of health, illness, and healing, whether supernatural, spiritual, or metaphysical, and hold that restoration of health requires treatment of all dimensions of the illness and the whole person (Bloom. 2005; Cassileth. 2004; Kaufman. 2005; Sharma 1999).
2.2.4. Science and ‘official’ health belief systems

In Western post-industrial societies, such as Australia, there is an encompassing ‘official culture’, which coexists with any number of distinctive cultural subsets (Baer. 2003: Kaufman. 2005: Lupton. 2005: Willis. 1989). The sanctioned practices, values, and institutions of the official culture are backed by considerable social, economic, and political power. There is prestige accorded to science and associated professions, and the sanction of formal education and academically legitimised research procedures as the official source of knowledge. Among the institutions of an official culture, there is often a single authority and legitimised system of health care (O’Connor. 2005). The official system of health beliefs and practices will be used as a point of reference and as a counterpoint to alternative health belief systems. In general usage, the official health belief system is referred to by a range of terms such as: biomedicine, allopathic, and conventional medicine (Sharma. 1999).

Unofficial health belief systems in Western culture are commonly referred to as: folk, ethnic, alternative, and new age. In general, the attributes of the system and participant groups are frequently used to define and classify (Baer. 2003: Eastwood. 2000: Lupton. 2005).

Folk and ethnic health systems are often associated with small
groups that rely largely on oral tradition and apprenticeship for the teaching and training of practitioners and are largely sustained by close associative networks (Sharma. 1999).

For general purposes, most of the unofficial health belief systems are often defined and conceptualised in contradistinction to biomedicine (Bakx. 1999; Cartwright. 2005; Siahoush. 2005). The National Institutes of Health (NIH) has designated seven categories of alternative medicine and defines alternative medicine as “any vernacular healing method used that has not been included in the educational curriculum of biomedical schools and residency programs” (Baer. 2003, p.93). In matters of health and illness vernacular refers not only to what people supposedly do or ought to do according to an official set of standards but to what they actually do when they are sick. The usage of vernacular includes: values, ideas, beliefs, and practices associated with them (Kaufman, 2005).

In official health systems, science is idealised as possessing clarity of viewpoint and unimpeachable rigour of method that inherently surmounts cultural values and interest group bias (Baer, 2003). Scientific knowledge and processes of inquiry are portrayed as genuinely objective and value-free (Kleinman. 1998; Lupton, 2005: 41.
MacLennan. 2006: Sharma. 1999). Science and its methods are deeply believed by many to have the capacity to provide certifiable knowledge composed only of straightforward distillations of raw and refined facts. and to be the sole means of incontestable and ultimately reliable knowledge (Baer. 2003). This position has achieved intellectual dominance throughout the official strata of Western cultures including biomedicine. Biomedicine, as the official health system in Western cultures, has acquired unsurpassed moral, cultural, and scientific authority (Baer. 2003: Bloom. 2005).

In official health systems. when scientific claims conflict with claims from non-scientific sources. science is often regarded with higher credibility (Lupton. 2005: Sharma. 1999). Experimental science is widely regarded as the final arbiter of truth, and functions as a source of cognitive authority: experimental science not only provides knowledge and competence, it is also required to evaluate the knowledge-claims and putative competencies of those situated beyond its boundaries. Indeed, in modern societies, “science is near to being the source of cognitive authority: anyone who would be widely believed and trusted needs a license from the scientific community” (Kleinman. 1998: p.52).
Science has enormous rhetorical power in complex modern societies and this continually reaffirms its authoritative status in official health systems (Kaufman. 2005: Willis. 1989). Because cognitive and cultural authority are densely intertwined with political authority and power, the scientific community and its reputation wield considerable influence (Kleinman. 1998: Zola. 1999). The extremely high regard in which science, as a source and adjudicator of knowledge, is held by its members, colleagues, and official authorities is not necessarily shared by all individuals in the public domain (Lupton. 2005). While many members of the general population seek scientific information, they do not invariably believe that it is the only way to acquire or confirm to certain kinds of knowledge. They do not necessarily believe it to be free from bias and corruption, and/or necessarily believe its pronouncements trustworthy solely on the basis of their source. Nor do they regard it as the final arbiter of truth (Baer. 2003: Lupton. 2005: Siahoush. 2005).

From the beginning of the Scientific Revolution of the sixteenth centuries, the new naturalist philosophy was expressly equated with reason (Habermas. 1983: Horkheimer & Ardorno. 1972: Foucault. 1975). The replacement of supernatural and particularly demonic.
explanations of illness, suffering, and disaster with natural explanations was represented as the triumph of reason over superstition, a cornerstone of the scientific tradition (Kaufman, 2005). In academic and professional disciplines, and to some extent now in popular usage, scientific has come to be equated with rational and both to be taken as true. Conversely, unscientific has become loosely synonymous with irrational, false, and unreliable (Lupton, 2005; Turner, 1992). Such usage is common in everyday social life and closely connected with the evaluate functions accrued to such terms.

"Exclusion of the supernatural domain of science imparts to supernatural, and other related bodies of belief, the evaluative taint of falsity and irrationality from the point of view of conventional epistemology" (Hufford, 2005). This has significant implications for the interaction of official and unofficial vernacular health belief systems or traditions. The most salient are the conflicts regarding metaphysical, spiritual, or religious beliefs and their interconnections with explanations and experiences with health and illness. Religious traditions have historically been closely associated with health practices in societies around the world (Armstrong, 1989; Willis, 1989). Religious and spiritual issues, including
questions of morality and of ultimate meaning are raised by the
case of serious illness (Kleinman. 1988). All religions have
something to say about illness, suffering, and death, and some form
of healing activity is found in many religious settings in modern
Western cultures (O’Connor. 1995). In post-industrial societies, such
as Australia, religious healing has been increasing in the last two
decades, even extending and reappearing in denominations in
which it had previously been unwelcome (Lupton. 2005). Since
religious, spiritual, and metaphysical health beliefs and practices are
actively maintained by people in their everyday lives and in their
self-care, they fall by definition into the domain of vernacular health
belief system (O’Connor. 1995; Sharma. 1999).

Many unofficial health belief systems have important religious and
metaphysical non-material components. These range from a belief in
divine or other supernatural means of disease causation and cure to
cosmological influences on the human body and on the existence of
a healing energy (whether divine, cosmic, or marshalled from
within) which is tapped by healers (Cartwright. 2005). Biomedicine
does not recognise the operation of supernatural or metaphysical
element to be real. These differences between biomedical and
alternative health beliefs systems produce disagreement and
sometimes conflict between them. on both ontological and
epistemological grounds (Kleinman. 1988).

There is a persistent tendency to conceptualise unofficial health
beliefs and practices as isolated. fragmentary, disconnected in form.
and persisting largely through the agency of habit (Baer. 2005:
unofficial health systems more often to be organised into coherent
systems with varying degrees of complexity and integration
weave together attitudes regarding health and illness. and theories
of disease aetiology and remediation. In addition, they articulate
these within a larger cultural framework of other important beliefs
and values (religious, moral, ethical concerns, family and

Though many of the embedded values and their multiple
interconnections remain out of awareness for members of a
particular system. they are in many cases more directly articulated
in alternative health belief systems than in conventional biomedicine
(Cassileth. 2004). In keeping with the scientific tradition. modern
biomedicine has often striven to separate itself from broader cultural
concerns and influences. It has often excluded religious, metaphysical, and philosophical considerations from its explanatory models of disease and dysfunction. Unlike alternative medicine, conventional biomedicine is often divorced from other quotidian aspects of surrounding culture (Cohen. 2005; Sharma. 1999; Siahoush. 1999; Singh. 2002).

The systematic and coherent organisation of alternative health beliefs and practices, together with their close interconnection with broader cultural contexts, has helped to account for their persistence and continued vitality (Armstrong. 2005; Ernst. 2006; Siahoush. 1999; Sharma. 1999). The more complex and the better integrated a system is, the more flexible and stable it is likely to be. Likewise, the better integrated a health belief system is within a larger framework of values, the more stable it is likely to be (Hufford. 2005). Tight integration gives a system a functional capacity analogous to that of generative grammar, enabling participants to incorporate novel input together with familiar material, and to generate responses that remain within the bounds of the system (O’Connor. 2005).
2.2.5. Stereotypes associated with alternative health beliefs

Nineteenth century social theories incorporated positivist assumptions of a unidirectional, linear evolutionary process of human thought through a series of stages characterised by increasing sophistication and accuracy of thought and interpretation (Habermas, 1983; Foucault, 1975). Progress, implicitly defined as “increasing similarity to culture of the scholar” (Baer, 2003), was considered desirable and, given proper conditions, inevitable and continuous process. Though this type of evolutionary social model has largely been abandoned in contemporary humanities scholarship, the legacy of such earlier theories is still quite influential (Kaufman, 2005; Lupton, 2005).

Long standing acceptance of the concept of inevitable, evolutionary social and intellectual progress has fostered a general expectation that as science and medicine became ever more developed and/or advanced, and public education improved and became more universally available, non-medical and non-scientific health beliefs would die out or be eliminated (Armstrong, 1995; Baer, 2003; Kaufman, 2005; Wardwell, 1989). This notion still has considerable currency today, although its predictions have not been borne out. As corollary to this viewpoint, beliefs foreign to or grossly incompatible
with modern medical and scientific models are commonly regarded as expressions of isolated surviving popular errors, or as misinformed habits of mind which cultural development and better education will sooner or later eradicate (O'Connor. 1995: Sharma. 1999).

"This kind of survivalist interpretation implies that differences in world view or belief system may not be prior conditions but only consequences, that anyone given proper opportunities, education, and information would think alike" (Hufford. 2002. p.43). It does not recognise the possibility that non-conventional health care choices might be something other than products of developmental or educational lag, or results of circumstances of deprivation (Armstronge. 1995). It overlooks the point that formal educational systems are not just teaching knowledge, but also are imparting values through the socialisation process. They are designed in part to help create and maintain a common official culture (Giddens. 2002): they institutionalise specific cultural values and help to induct members into the official world view (Zola. 1987). In Western post-industrial societies, this macro-culture and its institutions place a high value on scientific knowledge and on conventional medical care (Lupton. 2005). As a result, it becomes easy to assume that
departure from this model is a consequence of inadequate education or failure of comprehension. This assumption however does not stand up to scrutiny (Sharma. 1999).

Evolutionist and survivalist assumptions have given rise to and sustained a series of stereotypes of vernacular or alternative health belief systems and their participants as being, to some degree, socially marginal or deviant (Cartwright. 2005). The implication has been that they are marginal to conventional medical systems, mainstream society, and modern knowledge systems (Kleinman. 1998). The stereotypes of marginality typically include one or more of the following features: geographic remoteness or isolation; recent immigration or minimal acculturation to core culture; ethnic minority membership or strong ethnic self-identification or group affiliation; mental or emotional imbalances; or desperation induced by grave illness or poor outcomes of conventional therapeutic efforts (Adams. 2006; Chu. 2006; Sharma. 1999).

These factors are interpreted as producing ignorance of the existence and/or availability of modern medical strategies and technologies, lack of understanding of disease process and their relationship to conventional therapeutic resources, lack of physical or financial
access to conventional care, or inability to exercise judgement (Easthove, 2004; Lupton, 2005; Sharma, 1999). These conditions in turn are often advanced as explanations for the persistence of vernacular health beliefs and practices, and for the failure of individuals or demographically defined groups to make appropriate use of conventional biomedical facilities (Kaufman, 2005; Sharma, 1999). These factors are defined as barriers to using biomedicine and are perceived to be located in specific “problematic and/or marginal populations” (Armstrong, 2006, p.74).

Historically, research on non-conventional health systems has been carried out among designated marginal populations to the exclusion of more mainstream groups (Cassileth, 2005; Ernst, 2003; Lee, 2007; Sharma, 1999). The resulting distributional picture is in part an artefact of prior assumptions about where to look to find the kinds of beliefs and behaviours to which the studies addressed themselves. The enormous extent of recourse to vernacular healing strategies among educated, thoroughly acculturated mainstream groups has only recently begun to be recognised (Swani, 2007).

Another longstanding assumption has held that conditions of marginality and the obstacles they produce are the
determinants of non-conventional health behaviours (Crawford. 2006; Ernst. 2005). It is demonstrably true that barriers of physical and financial access, for example, do frequently enter into and even govern health care choices for individuals. What is not known is the extent to which this occurs, or how these particular factors interact with others in affecting health behaviour (Adams. 2003; Dunn. 2005; Sharma. 1999). There is immense variability of health behaviour response within groups, and complex conditions influence health care choices.

A look at some of the most frequently mentioned specific barriers or obstacles to the use of biomedicine raises questions about the passive assumption that elimination of such obstacles would automatically lead to the increased use of conventional biomedical care. Lack of adequate medical facilities in geographically remote areas and/or medically undeserved section of a large metropolitan centre may force or encourage use of non-conventional healing resources (Hawkes. 2005; Tsao. 2005). However, the presence of modern facilities does not necessarily reduce the use of alternative health practices (Adams. 2006; Cox. 2003; Lee. 2007). For example, a study found that the use of chiropractors increased, rather than
decreased, concomitantly with a significant increase in the census of primary care physicians (O'Connor, 2005).

2.2.6. Barriers to medical care affecting alternative medicine use

A study of self-care in Britain discovered its use to be quite high, even in the presence of the extensive British National Health System (Levin & Idler, 2005). Another international study of self-care use likewise concluded that levels of self-care were not apparently related to extent and availability of professional care resources (Wolf, 2006). Alternative health centres abound in areas well served by conventional medical care, as a survey of any major metropolitan area in Australia will attest. These centres are used by individuals who also use conventional biomedicine (Easthope, 2004; Gort, 2004). In some cases, the alternative health practitioner may even be located within clinical biomedical practices (Hufford, 2005).

Finances sometimes dictate avoidance or self-rationing of medical care (Smit, 2006). However, it is also common for individuals to make great financial sacrifices in order to obtain what they feel is the required care for their conditions. These choices may include both conventional and alternative resources (Easthope, 2003). For example, individuals who are covered for conventional care either
by private medical insurance through their employer, or by federal assistance programs, will nevertheless elect for some purposes CAM for which they must pay out of pocket, and which may even be very expensive (Cox. 2003; Dunn. 2005. Siahboush. 1999). To the individuals using CAM these services usually constitute an additional health care expense. The criterion for choosing among conventional and non-conventional healing strategies in innumerable cases is an assessment not of cost but of benefit: that is, of the perceived appropriateness and efficacy of the therapy or the specialist for the specific health situation (Bensoussan. 2004).

Without doubt, there are many instances in which individuals are not aware of specific diagnostic and therapeutic options within conventional medicine, especially when these are very new or heavily reliant on expensive technology which is available only in certain locations (Crawford. 2002). Even when well aware, people may choose not to use certain modalities out of uneasiness, dislike of the procedures themselves, philosophical concerns over ethical implications of particular technological interventions, and other reasons (Siahboush. 1999). This may be the case even when individuals in question are otherwise thoroughly in agreement with conventional medical thought (Mills. 2005).
There are many instances in which no use of conventional modalities does not result from ignorance, but represents an actively considered choice (Adams. 2005; Grace. 2006). In recent years, we have witnessed numerous illnesses from which many people suffer, but which were not medically recognised as real treatable diagnostic entities. Some of these illnesses remain medically controversial (e.g. mood disorders, premenstrual syndrome, chronic fatigue syndrome, or fibromyalgia) (Armstrong. 2005; Wardwell. 2004). Non-biomedical alternatives then become the only recourse for those unwilling to resign themselves to medical disagreement with their experiences of such conditions. Sometimes alternative health care choices reflect distaste for conventional care (Ang. 2005; Owen. 2007; Siahoush. 1999), disagreement with a medical opinion that little or nothing can be done (Furler. 2003) or a sense that biomedicine is not the best approach for the problem at hand (Cuzzolin. 2003). One research study concluded that the use of chiropractors by individuals who also used physicians represented a form of self-triage, based on assessment of presenting complaints at any given time (Wolf. 2006).
Explanatory models of illness that appear from the viewpoint of modern medical science to reflect a misunderstanding of disease processes may instead emerge from wholly different theories of disease aetiology and healing (Lupton. 2004: Kleinman. 1988: Sharma. 1999). Examples include homoeopathy, traditional oriental medicine, and the hot/cold theory found in many Latin American cultures. Where various forms of alternative healing traditions exist, their use is more often a matter of reasoned choice and action than of simple ignorance of conventional medical options (Eisenberg. 2003: Gort. 2004). For example, conventional medicine has often limited success in dealing with chronic back pain. However, chiropractic treatments are well known for therapeutic efficacy for problems dealing with the spine. A person could therefore reasonably conclude that chiropractic treatments might be a more successful modality than conventional medicine for treating chronic back pain, regardless of medical disapproval of chiropractors. A further example is that conventional medicine does not recognise soul loss as a cause of biomedical illness, thus it has no appropriate treatment to offer the sufferer of such illness. The likely response to complaints of soul loss from biomedicine would be psychiatric intervention and recommendation for counselling or drug therapy (Anderson. 1989: Kleinman. 1988).
Research in the field of CAM patient health beliefs has consistently revealed that concern for appropriateness, timely intervention, and seeking the proper practitioner were key factors for individual users (Barrett. 2003; Cassileth. 2005; Ernst. 2003; Leach. 2004). These concerns precisely parallel those found in conventional medicine (Bensoussan. 2004; Briggs. 2002; MacLennnan. 2006). In both spheres, delays caused by resort to wrong treatments occasion tremendous frustration and concern for the safety of the sick patient. The physician who worries that use of alternative cancer therapies will produce costly or even fatal delays in a patient coming to conventional treatment shares this concern with the lay-person who worries that psychotherapeutic interventions for soul loss will cause a dangerous or fatal delay in getting a family member to the proper specialist. What differs between these two belief systems is not the depth of their concern for the health of the patient, nor their commitment to prompt amelioration by available means, but their conceptions of what treatments are necessary and proper for the presenting conditions and of where the search for relief should begin (Cohen. 2005; Swani. 2007; Wolf. 2006).
2.2.7. Self-care and use of multiple resources

A number of researchers have reported that the majority of health-related actions in any population are undertaken outside the sphere of conventional health care system, even by those actively considering themselves to be sick or in compromised health (Cox, 2003; Easthope, 2004; Grace, 2006). Estimates of health care actions taking place outside the sphere of conventional medicine range from 70% to 90% of all care activities (Eisenberg, 2005). Some researchers stress that laypeople are not merely consumers of health care, but are also its primary providers (Easthope, 2005). Professionally provided health care is only one of the common resources in “a greater health care system of which health care professionals are not the only locus of responsibility for treatment decisions and trajectories” (Kleinman, 2004, p.54). It is in what Kleinman refers to as the “popular sphere” that “help-seeking decisions are made in the lay referral network regarding when to go to a particular practitioner for care, which practitioner to visit, whether to change practitioners or seek therapeutic alternatives, how long to remain in treatment, whether or not to comply with therapeutic recommendations, and how to assess outcome” (p.55).
Oral tradition and scientific information learned through the media and other sources of knowledge in everyday life, including tacit knowledge, are used by people in their decision making process about seeking health care (Kleinman. 1988; Lupton. 2004; Sharma. 1999). In choosing to use CAM, people of every educational and social group make considered decisions in putting together a multifaceted strategy for dealing with illness (Furnham. 1999; Sergeant. 2005; Sharma. 1999). This strategy commonly involves the simultaneous use of a number of therapeutic approaches to the health problem from common sense self-care actions. Combined use of conventional medicine and CAM continues to be popular (Adams. 2005; Bensoussan. 2005; Brooks. 2004; MacLennan. 2006; McCabe. 2005). For example, a person coping with cancer may be following a course of chemotherapy while simultaneously using prayer for healing, together with the application of relics to the afflicted parts of the body; following a natural food diet and taking large doses of vitamin and minerals in an effort to eliminate toxins and bolster the immune systems; practicing meditation to reduce stress, and visualisation to mobilise the body’s healing forces; using botanical or homoeopathic medicines to combat the side-effects of chemotherapy; and seeing a chiropractor to help restore the vitality and proper functioning, or an acupuncturist for pain control or

Romanucci-Ross (1969) used "hierarchv of resort" to refer to sequential patterns of selection and use of health care resources. This useful analytical term implies both replacement of prior options by the successive choices and a progression "upward to increasingly superior options" (p.113). While some progressive selection of healing options do entail replacement of prior options, others may be additive (Wellman. 1995). Nor do all such selections necessarily involve a progression of options from lesser to greater effectiveness or desirability in the estimation of making such choices (Kleinman. 2003). Additive health care selection processes are often a matter of combining selected resources so as to provide an optimal response to the health problem. O'Conor (2005) refers to this process as an "order of resort". This usage denotes a simple chronology in the selection of therapeutic modalities, and removes the implications both of "serial replacements and of upward mobility" through the therapeutic ranks (p.38).
The order in which a person has recourse to various systems of care is changeable, both over time and in response to the particular condition for which the treatment is being sought (Grace, 2006; Hassed, 2006). Conventional medicine may be introduced at any phase along the way. The way in which such choices are made and implemented, and the meaning of the choices in the order of resort, can only be determined on a case-by-case basis (Kleinman, 1988; O'Connor, 2005; Sharma, 1999).

When used concurrently, the different systems to which an individual has recourse may be selected because each is believed to deal well with specific features of the health problem. For example, conventional medicine may be used to obtain rapid symptom relief or for physical repair or removal of threatening conditions (setting of broken bones, suturing of lacerations, major trauma, surgical interventions). At the same time, an alternative health care practitioner may be used to correct the imbalances by helping change the diet, or help with the underlying cause of illness (Good, 2004; Sharma, 1999; Siahpush, 1999). This type of usage reflects a common characteristic of alternative health belief systems, many of which view conventional medicine as addressing only the symptoms or treating proximate causes of a specific condition.
(Evans, 2000; Wiesner, 2004; Wolpe, 2006). Some systems, such as homoeopathy and naturopathy, view disease process themselves as symptoms expressive but not identical with the actual underlying problem (Bear, 2004).

In this simultaneous use of multiple healing resources, any of the systems in use may be considered by the person as the primary therapeutic system, and any other(s) seen as adjunct therapy. For example, chemotherapy may be considered primary and acupuncture secondary or supportive in restoring health and vigour of the cancer patient. Conversely, an alternate health system may be experienced as the system actively promoting the healing, with conventional medicine added for diagnostic confirmation, or used as a measuring instrument by which to chart the progress and efficacy of the primary (alternative) therapeutic modality (Sinha, 2005).

2.2.7.1 Section summary
The first section of this chapter reviewed the sociological literature on CAM and CAM use. It highlighted the tensions and ideological polemics surrounding objectivist definitions of CAM. Biomedical and alternative health beliefs and the philosophical underpinnings
of health, disease, and well-being were discussed. The role of science in legitimating health belief systems, popular stereotypes, and barriers associated with using alternative medicine, and self-care behaviour in relation to the use of multiple health care modalities were also discussed.

The next section of this chapter reviews the sociological literature on chronic illness and the use of CAM for chronic illnesses in different populations. Definitions of chronic illness and some of the many challenges associated with living with chronic illnesses are discussed in an attempt to provide a context for this study.

2.3. Chronic illness

2.3.1. Living with chronic illness

A chronic illness is defined as "a condition which has lasted, or is expected to last, six months or more" (ABS, 2005). More specifically, a chronic medical condition is defined as "a condition which interferes in daily life for longer than three months in a year or requires hospitalisation for more than one month in a year" (ABS, 2005). The most common chronic conditions in Australia are: circulatory conditions (18%), mental/behavioural conditions (11%), cancer (2%), asthma (10%), diabetes (4%), arthritis (15%), and
osteoporosis (3%) (ABS, 2005). In Australia, “chronic illnesses pose an increasing challenge as they account for more of the burden of disease in Australia than other health conditions” (ABS, 2005). For the period 2004 – 2005, Australian health expenditure for chronic illnesses accounted for $22.3 billion (ABS, 2005). Due to the high prevalence rates and detrimental effects of chronic illnesses, the Australian Health Ministers established a national chronic disease strategy for future coordinated action in 2005.

Chronic illness is a biomedical concept for conditions that cannot be cured and so must be cared for on an ongoing basis (Charmaz. 2007; Kaufman. 2005; Kleinman. 1999). The focus of care is on sustaining a certain quality of life and reducing the impact of the disability of the illness as much as possible (Wu. 2007). Some chronic illnesses are degenerative and life ending (for example, Parkinson’s disease and multiple sclerosis) while others are not necessarily degenerative (Yeo. 2005).

The effective care and management of chronic illnesses often incorporates individuals adjusting their living to accommodate for disabilities arising from chronic illness that disrupt daily social functioning. For example, Mokhtar (2006) conducted a study with
individuals living with asthma and found that the onset of asthma led to a period of adjustment, which ended in the individual fully accepting his/her asthma. Diagnosis was important in legitimising individual experiences by providing a label and thereby giving meaning to confusing symptoms. This was followed by a period of adjustment as individuals dealt with feelings of anger and loss, the need to adjust to limitations, changes to their personal identity and learnt to accept the chronicity of the condition. During this phase individuals felt a lack of control over their condition, and those who denied its permanence had an increased risk of suffering symptoms. During the adjustment phase, individuals acquired greater knowledge from doctors and other people with the condition, which, coupled with their own growing self-awareness, led to them eventually gaining control of their illness.

Tan (2004) argues that an important part of adjusting to chronic illness is for individuals to accept their condition: that is, accept that it is chronic and cannot be cured. Monti (2005) found that individuals living with cancer stressed the importance of accepting that the condition is permanent. Similarly, Sherman (2006) in a study of chronic back pain, found that individuals who did not accept their condition were characterised by not wanting to tell
others about their condition, and presented themselves and their life as normal. They were inclined to equate pain with weakness, and so presented their condition as though it was an acute illness. In contrast, those individuals that had accepted their condition had incorporated chronic back pain into their social and personal identity after a period of denying the condition. They spoke about their pain as a normal part of their life, and they managed to minimise its impact.

2.3.2. Normalising illness

"The chief business of a chronically ill person is not just to stay alive or keep their symptoms under control, but to live as normally as possible despite their symptoms and disease" (Charmaz. 2007. p.79). Historically in Western cultures, and medicine in particular, health was understood in terms of vigour and suppleness (Sharma. 1999; Turner. 1992). By the end of the 18th century, the concept of normality emerged, and specifically the need to return the body to a state of normality after illness (Foucault. 1975). Eisenberg (2005) argues that the emphasis on normalisation in Western societies reflects not just shifts in medicine, but also wider social changes tied to the growing capitalist economy in which being a productive individual was equated with making an economic contribution to
society. This concept facilitated the objective of treating illness as a means to return the individual to a normal and therefore productive state of being.

In Western societies, normalising the illness experience is a way of regaining a sense of being a full social participant (Burv. 2006; Redman. 2003). Burv (2006) referred to normalising chronic illness as including bracketing off the impact of illness, so its effects on one's personal identity are slight. Alternatively, the illness may be viewed as a normal part of life and be incorporated into a person's identity and so presented to others in terms that minimise its impact on that person's life. Effective treatment can be a vital tool in the normalisation process, especially if it can reduce the symptoms to being almost non-existent (Wu. 2006). Monti (2006) found that individuals with cancer denied its seriousness to friends and placed a high priority on maintaining their duties and roles and hence a 'normal' life. Chang (2005) also found individuals expressed a concern to return to normal after stroke.

Normalisation is an active process to establish an acceptable and socially legitimate place for the illness in one's life (Anderson. 2005; Charmaz. 2007; Turner. 1992). Individuals are more likely to assess
themselves as normal and able than others do (Anderson. 2004). The ability to normalise a condition is dependent on the degree to which the symptoms of the condition intrude into one's life, how intrusive the treatment regimens are, and the extent to which others are aware of the condition (Burt. 2006: Redman. 2005).

Within these boundaries, individuals try to conceal the effects of the condition from others or try to pass as someone who does not have the condition at all (Armstrong. 2006: Backer. 2006: Charmaz. 2007: Sharma. 1999). Lowton (2004) found that individuals in England with cystic fibrosis regarded their health as normal because they were functionally able to do all they wanted to do and because they could compare themselves favourably with others. Once the condition deteriorated to a symbolically significant change in circumstances and abilities, in this case the need for intravenous antibiotics, they recast their condition as ‘controllable’. Individuals ceased to talk about their health and illness in terms of being normal only once it became distressing to them, with regards to how it affected them and interfered with their ability to function as full social participants.
Cancer, for example, has been reported to interfere with the ability to participate in social, sexual, recreational and work activities (Nocon. 2005; Monti. 2005). Despite the limitations, Nocon (2005) found individuals reported “accepting” the restrictions imposed on their life and were determined to “live as normal a life as possible”. Adams (2006) also found their study participants with HIV stressed being normal, minimised the impact of HIV in the way they spoke of the illness, and were concerned with not appearing restricted to other individuals. Gabe (2002) reported that the English teenagers with asthma they interviewed were concerned with appearing normal at school, particularly during sports, because they did not want to be viewed as disabled or different.

The normalisation concept is not confined to individuals living with chronic illness. Kelleher (2004) found that doctors in a clinic in California would use the term normal to describe children with facial deformities. The families were encouraged to view the children as basically normal, just with this imperfection. Charmaz (2007) argues that in the USA a normal life is equated with a valued self, and so people will go to great effort to be regarded as normal. Lupton (2005) noted that normalisation is a key strategy in the Australian health care system. The term normal also appears in the
literature and educational material for individuals with chronic illnesses: they are encouraged to use their prescribed medications as a way of maintaining a normal life.

2.3.3. The impact of chronic illnesses on personal identity

A person's identity has two entwined dimensions: personal and social (Adams. 1997; Charmaz. 2007). The personal identity is one's sense of self, which includes the thoughts and feelings a person has about him/herself. For example, a person might view oneself as a kind person or an accomplished athlete. Chronic illness results in changes to personal identity, in part, because the illness reduces a person's functional capabilities (Wu. 2006), which can lead to a diminished view of self (Backer. 2006). Social identity includes the roles people play and their relationships with other people (Adams. 2006), such as parent, teacher or community leader. Chronic illness can affect the ability to perform social roles, and lead to a person being dismissed by others because of his/her reduced capabilities, which requires his/her social identity to be reconstructed (Yoshida. 2005). Adjusting to chronic illness involves redefining social roles and obligations (one's social identity) in such a way that a person feels a positive sense of self (personal identity) in the contribution
they make to their social world. that is. in their social participation (Burv. 2006: Redman, 2005).

Chronic illness can disrupt aspects of life that were previously taken for granted, such as the ability to work full-time. People adjusting to chronic illness judge themselves according to what they were able to do previously, and against others who are regarded as being healthy. As society is designed for those who are healthy and being healthy is a valued state (Charmaz. 2007). Illness can result in a loss of social participation, if a person cannot perform previously expected obligations and social roles. This may lead people to feel they are no longer equal participants in social relationships, which impacts on their personal identity and their sense of self-worth (Charmaz. 2007; Mokhtar. 2006).

After the onset of chronic illness, one way to construct a positive personal identity is through minimising the impact of the illness. This can be done with actions, especially the use of medications, to minimise the impact of the illness on a person’s life and capabilities. Another way to minimise the impact is by the way people speak of their illness to others, such as by presenting their illness as normal, or the illness as not a major disruption to their lives (Charmaz.
2007). This way a person can retain a sense of personal integrity and decrease the threat to his/her social status in the face of this alteration to his/her life (Buv. 2006). Indeed, Adams (2006) found that people who accepted their HIV used their medication to manage their condition to a point where they could argue that they were not really sick at all. In this way, they were able to maintain a positive personal identity as a normal person.

2.3.4. The sick role

In Western societies, when a person is ill, he/she is free to adopt the acute sick role (Armstrong. 2006; Parsons. 1951; Sharma. 1999; Turner. 1992). With this role, the ill person is given freedom from social obligations, on the proviso that they do all that is required of them to get well again. The doctor ultimately legitimises that the person is actually ill, and gives the instructions the person must follow as part of her commitment to getting well again and reclaiming their social roles and obligations (Charmaz. 2007; Parsons. 1951). Backer (2006) found that people were more sceptical of the claims of other people to the sick role than they were of their own claim. Because the acute sick role involves freedom from social duties, it can mean more work for other members of the family and the community and hence is a privilege that is not to be claimed or
given lightly. Furthermore, an additional burden that accompanies the acute sick role is the need to care for the ill person, which falls to members of the family, usually women (Armstrong, 2006; Backer, 2006; Charmaz, 2007; Wu, 2006).

The acute sick role is intended for short-term use. The temporary nature of the role makes it unsuitable for people with permanent illnesses (Charmaz, 2007). When a person has a chronic illness, the impairment to his/her social functioning is likely to be long-term or permanent, though it may not be total, as in the case of acute illness (Radlev, 2006). Adams (2005) argues people with chronic illness adopt instead a type of chronic sick role or status, which involves normalising their illness, and renegotiating their obligations in the family, so they can present themselves still as full social participants. They then adopt the acute sick role during exacerbations of their ongoing condition, or when the debilitation becomes overwhelming (Lowton, 2004).

2.3.5. The impact of chronic illness on health

People judge their own state of health against cultural norms or standards: these norms are generally established by people who hold authority in society, such as governments and medical
organisations (Lupton. 2005: Sharma. 1999: Turner. 1984). For people in Western societies, health is more than the absence of illness: it includes the ability to perform social roles and obligations and feeling states, including wellness (Litva. 2001). This understanding of health has been found in nations throughout the Western world. The functional component of health, such as the ability to perform social duties, is especially important to working class people (Sharma. 1999: Sherman. 2006). Indeed, whether the concept of chronic illness translates at all to other societies is a question posed by some anthropologists (Armstrong. 2006: Becker. 2003). For example, "studies of AIDS in Haiti, heart distress in Iran, and of other ethnomedical systems around the world make no mention of normalisation or chronic illness or even the need to achieve health" (Turner. 1992. p.167).

Whitaker (2003) found in a northern Italian community that health is still understood in terms of traditional views. People there viewed health as the absence of illness and as the outcome of a struggle for balance between the permeable self and the unpredictable outside world. Traditional medical understandings of spirits and human agents as the cause of disease were balanced with biomedical notions of germs invading the body. Westbrook
(2003) found that in Australia rehabilitation programs were underpinned by Western individualised values that are designed to return the individual to normal living after an illness or accident. They found that Anglo and German Australians felt comfortable with this goal, and found it appropriate for people with disabilities to be integrated into society as workers, friends or even potential in-laws. The researchers argue that in collectivist societies there is not the same notion that people will return to normal social roles after the onset of chronic illness or disability. As a result, people from collectivist cultures, for example Chinese and Arabic people, tended to have less successful outcomes in Australian rehabilitation programs (Westbrook, 2003).

Collectivist societies, which have a socio-centric rather than an individualised concept of self, tend to recognise the importance of harmonious relationships as a part of health, and illness is often explained in terms of conflict in social relationships, or unfulfilled social obligations. Healing often involves attention to these social concerns (Anderson, 2006; Sharma, 1999). For example, in traditional Asian cultures, health is viewed as the outcome of harmony between mutually interdependent human relationships and balance in the natural world. Within the body, the health of one
organ depends on its balance with other organs. Specifically, it is regarded as important to balance, or have harmony between, the forces of Yin and Yang in each person (Tan, 2004). In particular, Taoism includes the notion of the importance of following the natural rhythm of the universe, and the concept of moderation in life, which is for a person to behave in ways that maintain a balance in work, socialising, and rest (Kewell, 2003). Taoist philosophy also stresses the importance of breathing and ensuring the flow of Chi to health, as well as the notion of elixirs to promote health (Tan, 2004).

Karawa-Singer (2005) interviewed European and Japanese Americans with cancer, and found that 49 of the 50 people considered themselves 'healthy'. The people of Japanese origin spoke about health in terms of having harmonious relationships, while the European-Americans stressed they were healthy because they could fulfil their roles and daily routines. She argued that both groups associated health with the ability to maintain integrity as participants in their social networks, and within the limits imposed by the illness.
In Western societies living with chronic illnesses have been characterised as involving a process of adjusting to the illness and its impact on life, normalising the condition and adjusting one's personal identity to the permanent change in abilities (Armstrong, 2006; Backer, 2006; Charmaz, 2007; Redman, 2005). Chronic illness also requires the adoption of a new sick role and health status to accommodate the presence of a permanent illness that leaves a person functionally and physically impaired but allows a person to still contribute and feel as a full social participant. This view of chronic illness is common in Western societies but is not necessarily applicable to other cultures or sub-cultures within Western societies (Sharma, 1999; Turner, 1992).

2.3.6. The increasing use of CAM by individuals living with chronic illnesses

Health care surveys indicate that a significant number of patients with chronic illnesses are currently using CAM for their health care management. An increasing number of HIV patients are turning to CAM use (Dhalla, 2006; Dugan, 2001; Furler, 2003; Iernewall, 2005; Mills, 2005; Tsao, 2005). A similar increasing trend regarding the uptake of CAM has been reported for cancer patients (Algier, 2005; Ambs, 2007; Aslan, 2006; Block, 2005; Boon, 2004; Cassileth, 2005;
Ernst. 2003; Kawauf. 2000; Lee. 2007; Molassiotis. 2006). Moreover, asthma patients are also turning to the use of CAM (Braganza. 2003; Cohen. 2005; Lehrer. 2004; Merendino. 2005; Singih. 2002). As a response to the increased use of CAM by patients with chronic conditions, the National Institutes of Health (NIH) recommended further research to be undertaken for investigating the efficacy of different types of CAM on chronic illness conditions (Adler. 2003).

2.4. Why do individuals living with chronic illnesses use CAM?

2.4.1. Estimates of CAM use by individuals living with chronic illnesses

Individuals living with chronic illnesses, such as cancer (Dugavan. 2001) and HIV/AIDS (Shumav. 2002), or with illness requiring hospitalisation (Tan. 2004), are more likely to use CAM products. In women with cancer estimated use of herbs ranged from 20% (Lenzacher. 2002) to 51% (Powell. 2002). Similarly, the use of vitamins ranged between 50% (Boon. 2000) and 64% (Lenzacher. 2002). The most popular CAM therapies used by 50% of people with HIV were counselling and herbal therapy (Dugavan. 2001) and 62.9% used food supplements (Kniodels. 2000). Similarly, people with Parkinson's disease predominantly used ingestible CAM products (Wu. 2006). In contrast, Ferrv (2002) found most participants with
Parkinson's disease used CAM tactile therapies solely for treatment and ingestible CAM for co-morbidities.

2.4.2. Reasons for CAM use by individuals living with chronic illnesses

CAM users have consistently been found to have poorer health and more medical problems that are usually chronic in nature (Eisenberg, 2005; Furnham, 2000). Therefore, the majority of people who seek relief through CAM therapies are those with distressing and painful conditions (Bullock, 2004; Lee, 2006). For example, poorer physical health associated with chronic illnesses accounted for 60% of CAM use, and 35% of such use was for pain rheumatologic condition (Rao, 2003). In people with HIV/AIDS, CAM was used to attenuate the symptoms that might be associated with the primary illness (Fairfield, 2005). Similarly, in a study of 80 people with HIV, 38.7% reported the use of at least one form of CAM solely for the treatment of HIV (Ferrv, 2002). Thus, the literature suggests people use CAM to treat primary illness and/or 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, 2006). These findings suggest CAM use is influenced by illnesses for which little palliative
or only ineffective treatment is available from biomedicine (Chhav.
2002).

2003) found the adverse effects of biomedicine and a perceived lack
of biomedical efficacy motivated individuals with chronic illnesses
to use CAM. For example, in a structured questionnaire study of 191
participants with cancer, 67% reported they had used CAM at some
at time to control cancer and 56% abandoned biomedicine because
of adverse effects (Durgan. 2001). Conversely, less adverse effects
from biomedicine were reported when CAM was used (Durgan.
2001). Similarly, a U.K. study of 100 children attending outpatient
clinics for atopic dermatitis using structured face-to-face structured
questionnaires found that CAM was used because biomedicine had
not worked and because of the associated adverse effects of such
treatment (Johnston. 2003). In India 34% of 533 participants with
leukaemia used CAM because of adverse drug reactions (Gupta.
2002). and in a study of 1,000 people with epilepsy, the lack of
efficacy and adverse effects of biomedicine were the key
determining factors for CAM use (Tandon. 2006).
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 medically expected outcome (Kaplan, 2000). In contrast, even though CAM users reported being critical about the efficacy of biomedicine, this was not the reason for using CAM. Rather, dissatisfaction with biomedicine was found to be associated with "disenchantment and bad experience of conventional medical practitioners". Thus, dissatisfaction with biomedicine motivated CAM use because biomedical practitioners did not show empathy (Cohen, 2005; Oldendick, 2000), and because biomedicine was ineffective and/or had adverse effects (Dwyer, 2001; Johnston, 2003). Hence, there is sufficient empirical evidence in existing research literature to suggest that CAM use is associated with dissatisfaction with two aspects of biomedical care: the treatment effect and the biomedical consultation.

Whilst most of the extant literature on reasons for CAM use among chronic illness sufferers comes from quantitative studies, qualitative studies mostly show the same push/pull factors as those found in
quantitative studies. For example, a focus group study of 66 breast
cancer survivors found CAM was used to relieve physical and
psychological symptoms (Canales. 2003). In women living with
gynaecological cancers, CAM was used to prevent further illness, to
improve chances of survival when biomedical treatments failed
and/or had adverse effects, to improve quality of life, and to gain
some control over the disease (Canales. 2003). In a study involving
14 cancer survivors, the 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 (Shumav. 2002). A belief that CAM was
natural and harmless (Yeo. 2005) was commonly cited as a reason
for CAM use and added impetus to last resort attempts to cure an
illness (Boon. 2000). The literature also revealed participants with a
bleak prognosis were prepared “to try anything” (Boon. 2000. p.641)
because they “had nothing to lose” (p.641). Overwhelmingly, lack of
biomedical efficacy, adverse effects and dissatisfaction with
biomedical physicians and treatments motivate higher CAM use
among individuals with chronic illnesses (Boon. 2000; Mitzdorf.
1999; Paltiel. 2001).
Barrett (2003) found CAM use for chronic illnesses was driven by value-laden, socio-cultural 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. 2003), and may neglect the individual by not providing knowledge (Salmon. 2006) and because it objectifies disease (Good. 2004). This also suggests that a prime motivator for CAM use for chronic illnesses is dissatisfaction with the delivery of biomedicine, which entails patient-physician interaction. Such results are consistent with results and interpretations found in numerous CAM quantitative studies and studies about patient decision-making that suggest that patient-physician communication is problematic (Dickinson. 2006; Ernst. 2005; Furnham. 2006; Ionas. 2002; Wellman. 2005).

2.4.2.1 Section summary

The second section of this chapter reviewed the sociological literature on chronic illness and the use of CAM for chronic illnesses in different populations. It highlighted definitions of chronic illness and some of the many challenges associated with living with chronic illnesses in an attempt to provide a context for this study. The next section presents the research problem for this study.
2.5. Research Problem

As seen from the above, a broad range of demographic and attitudinal push/pull factors associated with the use of CAM for chronic illnesses have been quantitatively investigated. However, the explanations for why individuals living with chronic illnesses turn to CAM subsumed within the push/pull debate are limited. Conceiving the possible connections between dissatisfaction with Western medicine and use of CAM in push/pull terms situates people as passive rather than active agents. The image conjured up is one of the individual user being drawn or repulsed, as if coerced by some external force: one who is buffeted between CAM and allopathic approaches to health care rather than actively choosing amongst them. Furthermore, conceptualising individual decisions to seek out CAM for chronic illnesses in push/pull terms turns attention away from what is really at issue for these individuals, namely, finding solutions to health problems within the social context of their daily lives.

A further problem with existing research findings is that few studies have examined the actual use of CAM by individuals with chronic illnesses within the Australian setting. Despite numerous theoretical
speculations, a literature search revealed only a handful of research studies (largely quantitative) that directly address the actual use of CAM rather than attitudes to proposed use of CAM for chronic illnesses (Adams, 2003; Barrett, 2006; Brooks, 2004; D’Crus, 2005; Kotsirilos, 2005; Wang, 2006). To date, no research study has been conducted in the Australian context to examine the lived experience of using CAM by individuals living with chronic illnesses. As such, we do not know the reasons as to why individuals living with chronic illnesses choose to use CAM within the Australian context. This research study attempts to fill this research gap.

2.6. Summary

The first section of this chapter reviewed the sociological literature on CAM and CAM use. It highlighted the tensions and ideological polemics surrounding objectivist definitions of CAM. Biomedical and alternative beliefs and philosophical underpinnings of health, disease, and well being were discussed. The role of science in legitimating health belief systems, popular stereotypes, and barriers associated with using alternative medicine were also discussed. This first section concluded with a discussion of self care behaviour in relation to the use of multiple health care modalities. The second section of this chapter reviewed the sociological literature on chronic
illness and the use of CAM for chronic illnesses in different populations. It highlighted definitions of chronic illness and some of the many challenges associated with living with chronic illnesses in an attempt to provide a context for this study. A statement of the research problem was also presented in this chapter. The next chapter presents the research design and methodologies utilised in this study.
3. Research approach and methodology

3.1. Introduction

This chapter presents the research approach utilised in the current study. The naturalistic paradigm was chosen to guide this study (Guba & Lincoln, 1989; Lincoln & Guba, 1985), as it was deemed the most appropriate approach to use in order to elicit participants' constructions and capture the context and complexity that characterised the experience of using CAM as lived by individuals living with chronic illness.

In this chapter the naturalistic paradigm is outlined. The application of a naturalistic methodology to this study will be described in relation to the research requirements of a natural setting, and the qualitative methods used. The chapter outlines the choices made and why they were made with regard to the naturalistic research design, participant recruitment, setting of this study, data collection methods, and data analysis methods thereby leaving a path of research decisions for auditing purposes. The chapter concludes with a discussion on the ethical issues of this research.
3.2. Naturalistic paradigm

In order to fulfil the research purpose, the research design utilised the naturalistic research paradigm to explore the use of CAM as lived by individuals living with chronic illness. Naturalistic inquiry employs the use of qualitative research methodology in the natural environment of the individuals being studied in order to interact and learn about their realities from them (Lincoln & Guba. 1985).

Naturalistic inquiry is based on two assumptions. First, that people cannot be separated or removed from the physical, social, and cultural elements of the environment. Humans constantly seek to influence and are in turn influenced by the environment, and behaviour can be explained in terms of the person-environment interaction (Guba & Lincoln. 1989; Lincoln & Guba. 1985). Second, it is not possible to interpret behaviour simply by means of observation, because it is not possible to observe the personal meanings and perspectives that guide a person's behaviour within a given environment. There is an internal interpretive element between people and their environment, which means that each person might behave differently in a given set of circumstances. Unique experiences and knowledge are brought to the situation (Lincoln & Guba. 1985; Spradley. 1979). Research methodology that
Attempts to investigate the perceptions of people must find a means to access their internal beliefs and knowledge in order to develop an understanding of the world from their own viewpoint (Lincoln & Guba, 1985).

Characteristics that identify the particular design, implementation and data processing methods of naturalistic inquiry were proposed by Lincoln and Guba (1985) as follows: naturalistic setting, human data collection instrument, utilisation of tacit knowledge, qualitative methodology, purposive sampling instead of random, inductive data analysis, emergent design, negotiated outcome, idiosyncratic interpretation, tentative application (instead of generalisation), focus-determined boundaries, and specific criteria for trustworthiness.

In 1985 Lincoln and Guba promoted naturalistic inquiry as an alternative to the dominant positivist paradigm. This form of inquiry is based on five axioms or basic beliefs that are accepted by convention or established by practice as the building blocks of some conceptual or theoretical structure or system. These axioms are consistent with the constructivist paradigm:
1. Realities are multiple, constructed and holistic.

2. The knower and known are interactive and inseparable.

3. Only time- and context-bound working hypotheses (ideographic statements) are possible.

4. All entities are in a state of mutual simultaneous shaping, so that it is impossible to distinguish causes and effects.

5. Inquiry is value bound. (Lincoln & Guba. 1985)

Naturalistic inquiry has operational characteristics that are consistent with the five axioms of constructivism described above. In summary, naturalistic inquiry is conducted in a natural setting. A human instrument builds on their tacit knowledge using methods that are appropriate to the research. Participants in the research are purposively sampled for the contribution that they can make to the research. Collected data are analysed inductively to develop a theory that informs the emergent design and the selection of further research participants. During the research, provisional finds and interpretations are checked with the research participants for further refinement and may be tentatively applied to other suitable contexts. The research is tested for trustworthiness using the criteria of credibility, transferability, dependability, confirmability, and reported in a case study format (Lincoln & Guba. 1985).
3.2.1. Application of the characteristics of naturalistic research design to this study

To demonstrate the consistency of this research study with naturalistic inquiry, I aligned my research method to the following elements of naturalistic inquiry as outlined by Lincoln & Guba (1985). This is demonstrated in Table 1.

<table>
<thead>
<tr>
<th>Characteristic:</th>
<th>Application to this study:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Natural setting</td>
<td>Data were collected in the participants' own home.</td>
</tr>
<tr>
<td>Human data collection instrument</td>
<td>Researcher was the primary collector of data.</td>
</tr>
<tr>
<td>Utilisation of tacit knowledge</td>
<td>Researcher relied on personal experience with CAM use as guide to others CAM experiences.</td>
</tr>
<tr>
<td>Use of qualitative methods</td>
<td>Interview and field notes were used to collect data.</td>
</tr>
<tr>
<td>Purposive sampling</td>
<td>Participants were invited to participate if they had used any CAM modality.</td>
</tr>
<tr>
<td>Inductive data analysis</td>
<td>Narrative data from interviews were analysed to identify themes that developed a picture about participants'</td>
</tr>
<tr>
<td>Concept</td>
<td>Description</td>
</tr>
<tr>
<td>-------------------------</td>
<td>---------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Emergent design</td>
<td>One-time analysis of data was used to change and clarify the nature of questions asked by the researcher.</td>
</tr>
<tr>
<td>Negotiated outcome</td>
<td>Participant involvement was negotiated through informed consent. In addition, findings were checked with participants during the course of each interview, and summaries of interviews were written and checked with participants.</td>
</tr>
<tr>
<td>Idiothetic interpretation</td>
<td>Information was requested and recorded on an individual basis and for how things were at the time of the interview.</td>
</tr>
<tr>
<td>Tentative application</td>
<td>Interpretation of the data resulted in a description of the lived experience of CAM as identified by participants, and the meaning that participants ascribed to their CAM use. From this information understandings were generated about the reasons as to why individuals living with chronic illness used CAM.</td>
</tr>
<tr>
<td>Focus-determined boundaries</td>
<td>The nature of CAM use in a selected group of people (individuals living with</td>
</tr>
</tbody>
</table>
A chronic illness was studied. No other aspect of their lives were studied and no other group of people were involved.

| Special criteria for assessment of trustworthiness | Participant generated data. Participant checking of data (interview transcripts), verification of thematic interpretation by participants, and comparison of findings with current literature were used as criteria for establishing validity and reliability of data collected and interpreted. |

Table 1: Application of naturalistic inquiry to this study

3.2.2. Ontology

Ontology refers to a set of common understanding related to the discourse terms and their meaning (Lincoln & Guba, 1986). Aided by the analyses of Guba and Lincoln (1994) and Lincoln and Guba (2000), the ontological assumptions of this study are rooted in constructivism. A primary premise of constructivism is that as people we develop knowledge, values and beliefs, which we subsequently interpret on the basis of their contribution toward viability, rather than to some external validity (Guba & Lincoln...
1989). Therefore, constructivism sees people being the creators of
their own realities within the world in which they live and work.

For the purposes of this research, constructivism, as an ontological
paradigm, informs us that the research participants create their own
realities of the use of CAM within the interpretive meaning
frameworks of their unique lives. The research interviews therefore
sought to examine their realities associated with the use of CAM in
order to fully understand their reasons for choosing to use CAM
within the social context of their lives.

3.2.3. Epistemology

There are two elements to epistemology. One is the nature of
knowledge to be addressed. The other is the relationship between
the researcher and the phenomenon that is being researched. Field &
Morse (1990) state that “epistemology is an attempt to make sense of
the possibility, nature and limits of human intellectual achievement”
(p.43). Furthermore, they suggest that epistemology deals with
questions concerning the nature, scope and sources of knowledge.
To know and understand requires making meaning from the words that are exchanged as part of data collection activities (in this case in-depth interviews). In other words, a researcher actively seeks to interpret meaning. The epistemological approach adopted for this research is interpretative in nature and this is in harmony with the constructivist ontology. Deetz (1977, p.140) reminds us that "interpretation is not added to the world: it is the world". It is recognised that meanings can only be "described, interpreted, explained and understood within the situational context in which they were constructed" (p.145). Within the context of understanding the use of CAM as experienced by individuals living with chronic illness, it is recognised within this study that such understandings are not located in time and space in an objective and autonomous world external to the detached observer. Rather it is experienced within the individual's consciousness.

To understand participants' interpretation of the realities, complexities, and influences that shape their use of CAM, it was important to use an approach that allowed for understandings to be gained from the interactions, influences and impacts inherent in their natural social settings. The naturalistic approach adopted and described here fulfilled that requirement.
3.2.4. Rationale for the choice of naturalistic design

This study examined the perceptions of individuals living with chronic illness about their use of CAM within the experiential and social contexts of their lives. A comparison of some of the axioms of naturalistic inquiry with the purpose of this study further demonstrated the appropriateness of the qualitative approach used.

First, the naturalistic paradigm states that realities are multiple, constructed and holistic (Lincoln & Guba, 1985). The aim of such inquiry is to seek information about the reality of the person or group being studied. This is in contrast to the positivist view that reality is single and fragmented. This study sought information from the participants about their own perceptions of their use of CAM. A naturalistic approach lent itself to obtaining this type of information.

The second axiom states the knower and the known are interactive and inseparable (Lincoln & Guba, 1985). This study sought to gather knowledge about the lived experience of CAM use within the social and experiential contexts for each person in order to understand how and why they had chosen to use CAM. An attempt to see the lived experience of using CAM as objective, separate and
independent of the knower, as required by the positivist paradigm. would have been counterproductive to the purpose of the research.

Third, the naturalistic paradigm states that only time and context-bound working hypotheses are possible (Lincoln & Guba, 1985). When studying people's own experiences of CAM use within the social and experiential contexts of their lives, it is necessary to share their view of the world around them, including personal preferences based on attitudes, beliefs, group affiliations and background experiences. Such a view is unlikely to lend itself to the generalisation considered possible by the positivist paradigm. Instead, it lends itself to insights which are thought to assist in the development of hypotheses, which in turn may lead to an extension of theory and further research.

The qualitative research process used in this study was not linear. Early findings informed later work in a cyclical fashion such that there was ongoing feedback into the research process, informing ongoing modifications to the methodology employed (Field & Morse, 1990; Guba & Lincoln, 1989; Lincoln & Guba, 1985; Spradley, 1979). An area of interest was selected with the general goal of describing a phenomenon linked to a cultural group or subgroup.
Data collection and data analysis proceeded simultaneously. Data were summarised, leading to the formulation of new questions, and written reports were viewed as part of an ongoing research process.

Where investigation relates to the perceived reality of people, qualitative methods have been reported to be an effective way to conduct research in that the researcher does not attempt to prove or disprove previously formed hypotheses in a situation where, despite best intentions, all variables that might affect the outcome cannot be known or controlled (Lincoln & Guba, 1985). While in the laboratory situation it might be possible to achieve a near approximation of this ideal, in the real world of human existence and cultural realities it is not possible to begin to attempt such control. In addition, if such control were possible, it would nullify the results because it would necessarily involve such a degree of interference with the natural setting that an unacceptable degree of change would be the result (Lincoln & Guba, 1985).

To be able to gain insights into what it was like for individuals to use CAM and their reasons for such use, I consciously chose the naturalistic design as it allows for an in-depth understanding of the participants’ raw lived experience situated within the social
experiential contexts of their lives. I was able to not only view the phenomenon of CAM use as the participants lived the experience, but gain in-depth understanding of their life-world of living with chronic illness. A naturalistic approach is appropriate for this research as it enabled the experience of using CAM to be structurally and systematically analysed, thereby allowing in-depth interpretation of these lived experiences.

I believe it would have been difficult to gain an in-depth understanding of how individuals living with chronic illness experienced using CAM using other research methods, given the sensitivity and protracted nature of their illnesses and the effects on them as persons. By audio-taping interviews with participants and engaging in dialogue with them about their lived experiences, I was able to uncover and explore these experiences. This research experience sometimes had an empowering effect on participants as this was often the first time they were able to discuss or de-brief with another person regarding their experiences of CAM use.

The naturalistic approach allowed the description of the lived experience of the use of CAM for individuals living with chronic illness as they have been lived. Throughout this research process, I
felt privileged to be so trusted, and exposed so closely, to the lives and the experience of participants. enabling me to gain an understanding of the sensitive complex experience of using CAM. The research process gave me an insight as to what it is like to have the experience of using CAM while living with chronic illness. This I believe was the advantage of utilising the naturalistic approach.

3.2.5. Tacit knowledge and personal experience of CAM

As a social researcher, my aim has always been to undertake my work in a spirit of reciprocity and reflexivity, which involves a (re)search for thoughtfulness. Research becomes then "a being-given-over to some quest, a true task, a deep questioning of something that restores an original sense of what it means to be a researcher" (van Manen, 1990, p.31). As a researcher, I became involved with ten people who, in the context of illnesses, actively chose and used CAM. This study attempts to understand their human lived experiences of choosing and using CAM.

The dilemma that triggered this study arose from my observations during conversations with friends who were becoming increasingly interested in CAM modalities for their individual health care needs. During these conversations, I realised that the experience of using

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CAM was far deeper and extended than I had previously thought, as it penetrated many valued domains of life. In addition, I became increasingly aware that the experience of using CAM was quite different to using traditional biomedicine. Thus, I turned to consulting existing research literature on the use of CAM in my attempt to understand what the lived experience of using CAM was like for individuals. The limited information that I found in existing literature referred to patient demographics and causal determinant factors associated with the use of CAM. However, I found limited understandings in existing research literature concerning what the use of CAM was like as a lived human experience. Consequently, my desire to bring to the forefront the experience of using CAM as a phenomenon that human beings live through directed this research study.

3.3. Naturalistic methodology

The source of naturalistic research is the natural setting. This section will discuss the approach used to enter the natural settings of participants. This study was grounded in interpretivism, which calls for a non-exploitative relationship between the researcher and the researched: A relationship based on collaboration, cooperation, and mutual respect (Field & Morse, 1990). Furthermore, as an
interpretive researcher. the aim was to create a dialogue between practical concerns and lived experience through engaged reasoning and imaginative dwelling in the immediacy of the participants' worlds. Therefore, the study was conducted from the outset, within a context that enabled an interpretive understanding of participants' experiences of using CAM.

3.3.1. Setting

The location of the study depends on what is to be investigated (Field & Morse. 1990; Lincoln & Guba. 1985; Strauss & Corbin. 1990). Given that I wanted to investigate the experiences of urban people, the geographical setting for this study was the inner city suburb of Newtown in Sydney, Australia. I specifically chose this particular suburb due to its new age culture demonstrated by the existence of numerous health food shops, numerous new age healing centres, and numerous CAM practitioners. Traditionally, this suburb is well known for attracting individuals subscribing to 'new age' philosophical values and experimental and/or unconventional lifestyles. Thus, by choosing the particular suburb of Newtown, the probability of recruiting participants for this study who were CAM users was higher.
3.3.2. Recruitment of participants

In a naturalistic qualitative inquiry, purposeful sampling is commonly used (Field & Morse. 1990; Lincoln & Guba. 1985; Munhall. 1994; Streubert & Carpenter. 1995). This method of sampling selects individuals for study participation based on their particular experience and/or knowledge of a phenomenon, for the purpose of sharing that experience/knowledge. People were considered potential participants if they lived in the chosen suburb of Newtown, they suffered from chronic illness, they were able to speak English, and they had used at least one form of CAM over the last twelve months.

As a researcher, I wanted to conduct research with people not previously known to me, in order to avoid any possible bias from potential participants feeling pressured to participate or the possibility of 'hidden agendas', positive or negative, re-emerging. Consequently, I chose not to recruit participants who were known to me.

I personally approached CAM therapists located in Newtown using the Australian Natural Health Directory (Allardice. 1995) and asked therapists for referrals. Copies of the study information sheet
(Appendix 2) were left with therapists for distribution to their patients. I also distributed fliers requesting participation in the study at key outlets such as health food shops, community health information centres, cafes, new-age shops and community centres in the suburb of Newtown. In the study information sheet (Appendix 2), interested participants were requested to phone me for further information regarding the study and to schedule their first meeting where an informed consent was obtained.

As interested individuals phoned in response to the above, they were informed about the study aims/objects and about the nature of their participation as outlined in the study sheet. I offered individuals opportunities to ask questions. Individuals were provided with opportunities to speak to the Ethics Officer concerning the legitimacy of the study and were offered the appropriate phone numbers. Individuals interested in participating in the study were asked to provide an interview time, date and location for our first meeting, as well as their contact phone numbers. This information was kept in the research logbook and participant codes were used rather than actual names. I phoned participants two days prior to our scheduled meetings in order to confirm their participation.
At the first meeting, participants were provided with the study consent sheets (Appendix 1). They were given opportunities to ask questions regarding the study and the nature of their participation. Furthermore, they were reminded of their rights to refuse participation at any time during the study, and their rights to confidentiality and anonymity. At this stage, informed consent was obtained. Interviews were then scheduled and conducted.

Ten people participated in the study, their experience of using CAM qualifying them as participants (Field & Morse, 1990; Lincoln & Guba, 1985; Morse, 1991; Taylor & Boedan, 1984). In naturalistic qualitative research, the number of participants is often limited because of the quantity and richness of data obtained, and the “extent to which the phenomenon is explored in the interview” (Drew, 1989, p.431). The ages of the participants ranged from 27 to 62 years at the time of the interviews. Table 2 demonstrates the demographic profile of the research participants.
<table>
<thead>
<tr>
<th>Participant</th>
<th>Age</th>
<th>Sex</th>
<th>Illness</th>
<th>CAM Modality Used</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eureka</td>
<td>27</td>
<td>Female</td>
<td>Breast Cancer</td>
<td>Naturopathy</td>
</tr>
<tr>
<td>Fiona</td>
<td>42</td>
<td>Female</td>
<td>Colon Cancer</td>
<td>Homeopathy</td>
</tr>
<tr>
<td>Paris</td>
<td>52</td>
<td>Female</td>
<td>Ovarian Cancer</td>
<td>Homeopathy</td>
</tr>
<tr>
<td>Sharon</td>
<td>40</td>
<td>Female</td>
<td>Breast Cancer</td>
<td>Naturopathy</td>
</tr>
<tr>
<td>Jane</td>
<td>32</td>
<td>Female</td>
<td>Back Pain</td>
<td>Homeopathy</td>
</tr>
<tr>
<td>Rosemarv</td>
<td>38</td>
<td>Female</td>
<td>Breast Cancer</td>
<td>Homeopathy</td>
</tr>
<tr>
<td>Zoe</td>
<td>66</td>
<td>Female</td>
<td>Lung Cancer</td>
<td>Homeopathy</td>
</tr>
<tr>
<td>Mark</td>
<td>30</td>
<td>Male</td>
<td>HIV</td>
<td>Homeopathy</td>
</tr>
<tr>
<td>Andrew</td>
<td>32</td>
<td>Male</td>
<td>HIV</td>
<td>Homeopathy</td>
</tr>
<tr>
<td>Geoffrev</td>
<td>60</td>
<td>Male</td>
<td>HIV</td>
<td>Naturopathy</td>
</tr>
</tbody>
</table>

Table 2: Demographic profile of participants

3.3.3. Data Collection

3.3.3.1 Interviews

As I have described elsewhere, my interest in the issue at the heart of this study began with what appeared to be a simple question:

Why do individuals living with chronic illness choose to use CAM?
In order to address this question, other individuals’ experiences and their reflections were “borrowed” (Minichiello. 1990. p.62) through interviews. Interviewing, in a qualitative study, serves two specific purposes. First, it serves as a “means for exploring and gathering experiential narrative material that may serve as a resource for developing a richer and deeper understanding of a human phenomenon” (Minichiello. 1990. p.66). Second, it serves as a “vehicle to develop a conversational relation with a partner” (interviewee) about the meaning of an experience (Minichiello. 1990. p.66). Both functions will be discussed in this section.

The interviews were conducted between June 1999 and October 2000. During the first meeting, I would introduce myself and restate the purpose and my interest in the study. Rarely was I asked questions about the actual study; in fact, many of the questions addressed to me during the first visit were of somewhat ‘personal nature’. Questions about my linguistic accent, the country of my birth and curiously enough ‘my experience of living in Australia’ were often asked.
My experience in talking, conversations, and being in dialogue with others over the years confirmed that involving people in broad conversations needed to be undertaken first as an open-ended conversation, in order to form a relationship of trust and disclosure, ensconced in privacy. Hence, the first moments of each interview were of rather 'general nature' and often included a discussion on the weather and a forecast of more rain or drought. Next, I described the process of interview recordings, transcriptions and explained that a transcript and thematic results summary would be given to them (or posted to them) for them to read and to check so that it was a true reflection of what they had told me at the interview/s.

Interviews were carried out in participants own home as per their requests. A series of two face-to-face interviews was undertaken with nine participants. One participant was interviewed once due to his lack of future availability, but this was a three-hour interview. In two cases, at the wish of the participant, the interviews were conducted with the spouse present. A third and final follow-up telephone interview was conducted with everyone after their transcripts and results summaries had been posted. There were two reasons for this: to seek clarification if it was needed, and secondly.
to determine whether the thematic analysis was a true reflection of their experiences.

The first interview was undertaken as an open-ended conversation, where participants were asked to reveal, in their own words, their experiences about using CAM. The introductory question usually was, "what was it like for you to use CAM?" No fixed order of questioning and no fixed way of asking a question was used; instead, questions were guided by the responses of the participants. This method of interviewing is in line with a qualitative research interviews. In an interview of this nature, (Minichiello, 1990, p.98) explains that "... the art of the researcher is to keep the question (of the meaning of the phenomenon) open: to keep him or herself and the interviewee oriented to the substance of the phenomena under investigation". In this way there is an interaction between the researcher and the participants, with participants directing the flow of the interviews. Other questions were asked if amplification or clarification were necessary. In this way, the interviewee becomes the co-investigator of the study.
Interviews ranged in length from forty-five minutes to three hours, depending on the amount of information participants gave and/or participants' fatigue. After the interview, I would record my own comments, first impressions, and thoughts on the tape recorder as I left their homes. The recorder, pocket-size with built-in microphone, was an enormous benefit as I was easily able to capture my descriptions of their homes, the yard and other observations such as non-verbal messages or gestures. In addition, a diary of notes and journals was kept to record my thoughts, my reactions and my observations. The accounts in this study are based on the interviews and the copious amount of notes I have entered in the journals as the study progressed.

Each interview was tape-recorded and later transcribed into narrative, written form and imported onto the computer using the software package Ethnograph v4.0 (Seidel, Friese & Leonard, 1995) for the initial phase of data import and line numbering of each file. From then on, Microsoft Word™ was used to manage the data.
3.3.3.2 Transcripts

After the transcription process, I would listen to the audiotapes again whilst reading the typed transcript at the same time, attending to both words and non-verbal messages, for example, pauses, emphasis, irony and humour. I made notes which enabled me to develop a sense of 'gaps' or 'clarifications' that in turn provided the framework for the second interview. Transcripts in this sense were viewed as a tool that traversed the gap between the stories told to me as the inquirer and the written narrative that is created for a personally unknown audience. Each time the transcripts were re-read, I could 'literally' recall the situational context. My observational skills developed over the research process were extremely helpful. Often I would listen to the transcripts and recollect facial expression and other bodily movements. Reading and re-reading the transcripts kept the interviews at the forefront of my mind. Prior to the second interview, usually conducted a few weeks after the first one, I would have a summary prepared of each transcript ready for the participant to read.

The purpose of the second interview was to establish credibility by ascertaining whether the transcripts and the thematic themes were an adequate reflection of the participants' experience and
represented reality (Field & Morse. 1990: van Manen. 1990). Lincoln and Guba (1985) call this activity “member checks” (p.314) whereby those who have lived the described experience validate that the reported findings represent them.

In addition to validating the transcripts, the second interview also enabled the participant to re-state events, remember further details and elaborate on particular issues. Here participants and I weighed the appropriateness of each theme by asking: ‘is this what the experience is really like?’ As Minichiello (1990) points out “the qualitative researcher is not primarily geared to finding out the truth per se but rather the truth as the informant sees it to be” (p.128). On reflection, this process seemed to work reasonably well and managed to meet the criteria I had set for myself: that the interviews would be interactive, sensitive and enabled much opportunity for listening (Minichello. 1990).

3.3.3.3 Data Saturation

Many qualitative researchers use the term ‘data saturation’ to suggest when enough data have been collected during the research process (Field & Morse. 1990: Guba & Lincoln. 1989: Lincoln & Guba. 1985). Saturation refers to the repetition of discovered
information and confirmation of previously collected data (Morse, 1994). I, like Morse, consider the notion of data saturation somewhat of a myth. If another group of individuals were interviewed at another point in time, new data may be revealed. Personal descriptions of lived experiences are numerous and thus are in effect inexhaustible, making saturation 'endless'. However, for practical reasons, an inquirer does not involve an exhaustive number of participants, but is able to identify when the data has revealed itself to be rich, diverse and significant enough to illuminate for readers, an experience which leads to a deeper understanding of the phenomenon.

3.3.4. Data analysis

In this study data collection and analysis occurred simultaneously. This interplay between data collection and analysis facilitated the data collection process, ensured that the findings were grounded in the data and resulted in more inclusive joint constructions (Field & Morse, 1990; Lincoln & Guba, 1985).

Data analysis was not an inclusive distinct phase, but rather occurred throughout all phases of this project and was guided by the constant comparative method of data analysis proposed by
Glaser (1978). Glaser & Strauss (1967), and Lincoln and Guba (1985). The interactive process of inductive analysis of qualitative data is by nature a messy, time consuming and at times overwhelming experience. It is difficult to describe the exact process in an orderly linear fashion for the various activities involved almost invariably do not occur in a tidy chronological sequence. Rather, the process characterised by the hermeneutic-dialectic circle involves the continual interplay between the parts and the whole and vice versa and the comparison and contrasting of divergent views in order to achieve a higher level of synthesis (Field & Morse. 1990; Gadamer. 1975; Guba & Lincoln. 1989; Lincoln & Guba. 1985; Schwandt. 1994).

The simultaneous and interactive nature of the analysis involved several steps. Data analysis occurred both at the time of data collection and when the period of data collection was completed. Initially, the transcripts were read after each interview to gain an overview of participants' experiences of using CAM. This was followed with a detailed line-by-line analysis of the transcripts. Significant statements pertaining to the phenomenon of using CAM and the context in which it was experienced were identified and coded to capture the meaning of the data. This initial analysis provided additional questions for ongoing data collection, enabled
my understanding of the participants' experiences to be clarified, validated and developed during subsequent interviews and emergent codes and categories to be explored.

As constructions emerged and were commented on or validated by the participants and/or my observations, categories were further revised and refined. As new data were collected and new insights emerged they were compared to previous data for consistencies, discrepancies, anomalies and negative cases, all the time attempting to keep a sense of the whole while analysing the parts. Over time, joint, more inclusive constructions began to emerge that were grounded in the data. Data collection was stopped when no new information or constructions were being generated. consensus was reached or irreconcilable differences were identified.

On completion of data collection, the interview data and field notes for each participant were read to obtain a sense of the data as a whole. The coded transcripts of the interviews conducted with each participant were then reviewed separately and within the context of all interviews conducted with that participant across the study time frame. The codes were reviewed and major and minor categories identified. Using the categories identified, a summary of the
experience of each participant was written noting in particular their experience of using CAM as it developed over time. the factors which influenced that experience and how they integrated it into their daily lives. These summaries enabled me to become familiar with the constructions that individual participants formed regarding their use of CAM through their chronic illness experience. This also facilitated the integration of the data into a coherent whole while still preserving the integrity of their individual constructions.

Data related to the minor and major categories identified were also extracted from all data sources and common and contrasting themes across experiences and at similar points in the illness trajectory such as getting sick, diagnosis, and treatment were examined. Patterns in the data, relationships among categories and across experiences were explored and examined according to the different phases of the illness experience. Categories were revised and refined as new insights emerged and were examined. This process involved continually moving between the data as a whole and the parts until joint constructions began to emerge. While at times this process was messy, time-consuming and repetitive, it assisted in refining my thinking and the formation of joint, more inclusive constructions.
Within hermeneutic interpretation, there is never a final or absolute interpretation rather an interpretation that makes sense to those involved is sought (Field & Morse, 1990; Guba & Lincoln, 1989). The analysis continued throughout the writing and rewriting of the thesis until I was confident that the findings faithfully represented the data and the reality of the lived experience of using CAM for individuals living with chronic illness through the eyes of those involved.

3.3.5. Refinement of research design

As described in previous sections the design of this project gradually emerged and was continually refined, becoming more focused over time. The decisions and interpretations made and the rationale for these have been recorded in the audit trail and reported at various points throughout this chapter. The period of prolonged engagement assisted in refining the question and deciding on the most appropriate way to select participants in order to answer the research question and obtain the widest scope of information. The continuous interplay between data collection and analysis gave focus to the interviews conducted. This facilitated data collection, enabled clarification and the exploration of emergent insights and gave structure to the analysis. Data analysis occurred throughout all
phases of the project and involved continually moving between the parts and whole and refining categories. As new data were accumulated and new insights emerged. Overtime this process became more focused as joint constructions that were grounded in the data and derived via the hermeneutic-dialectic process began to emerge.

3.3.5.1 Qualitative research writing

Writing is an integral part of qualitative interpretation (Minichiello. 1990: van Manen. 1990) as is the process of noticing, collecting, and thinking about things that are interesting. As data analysis occurred concurrently with data collection, writing formed an integral part from the start of the research process. To be attuned to the research question, I wrote about my moments of being with research participants. As I was always accompanied by my journal, my tape recorder and audiotapes, after a long day of interviewing, I would always reflect on the content of each dialogue and tape-record the things that participants told me off the tape. This information was later transferred into my journal. van Manen says that “much of real writing occurs in this way” (van Manen. 1990. p.114).
Soon I discovered that, as I began to write, there was no great schema on which I could draw to assist me in the process. Within this process, it was my role as an interpretive naturalistic researcher, to ensure that writings of the interpretation of the participants' experiences of CAM formed an adequate representation of their voices. Then I had to ensure that my writings would produce a text which could readily be conveyed to readers. Often I would find that my field texts collected through interview transcripts and observation generated a number of questions, hence I would return to the participants to seek elucidations about their experience. Other times, writing had the effect that I could 'instantly' see something in a manner that enriched my understanding of experiences. To see, in this context, is not a cognitive affair, but a reference to the creation of a text that speaks to our cognitive and non-cognitive sensibilities (van Manen, 1990). In my writings, I have made an attempt to incorporate lived through-ness, evocativeness, and intensity as qualities central to writing thick descriptions.
3.3.5.2 Journaling

From very early on in the study I wrote down notes in my journal. Initially, it served the purpose of not wanting to lose a significant essence of an experience. As the study progressed, however, the pages of my journal became much more. They became my sounding board, my confidante, and indeed a trusted friend. In my journal, I recorded my initial thoughts, my beliefs and feelings that had captured me during each particular dialogue. In fact, I also became aware of a heightening attentiveness in me on the days that I conducted interviews, as if I was afraid of missing a part. Whilst listening and typing the texts, I continuously entered more words, phrases or sentences in my journal. These journal notes have subsequently been used in identifying steps taken in the data collection process, decisions that were made, the rationale behind such decisions, and reflections on the whole data gathering and interpretative process.

Many words and phrases were initially written in Hindi. As a person whose first language is Hindi, I sometimes struggled to find an ‘instant’ proper translation of a particular word into English. To be time-efficient and ensure that I would not lose my thoughts, I would quickly write it in Hindi and return to it later in the hope to
find the fitting English translation. Fortunately, this was always the case. In addition, I realised that at the time of writing, despite living in Australia for some time, Hindi remained my first language in thought and silent reflection. Admittedly, when I read my journaling notes produced in the latter half of the study, much less Hindi appeared in the writings. A likely explanation can be found in the fact that both my exhaustive readings from literature and participants' texts caused an immersion-of-self within the English language.

Through written language, I have tried to link participants' texts into a comprehensive unified whole, which Polkinghorne (1988, p.19) refers to as "a principle of best fit". Best fit comes after the researcher has moved back and forth through the data, carefully considering various possible interpretations and forming a way of providing an explanation for the phenomena under scrutiny.

3.3.6. Rigour and quality

The questions of rigour and quality in relation to qualitative work constantly arise with a number of researchers (Burns, 1989; Field & Morse, 1990; Guba & Lincoln, 1989; Lincoln & Guba, 1985). Drawing on Lincoln and Guba (1985), Burns (1989) proposes a number of
standards to achieve rigour in naturalistic qualitative research. They are: (1) descriptive vividness; (2) methodological congruence; (3) analytical preciseness; (4) theoretical connectedness; and (5) heuristic relevance. A brief discussion on each standard follows.

3.3.6.1 Descriptive Vividness
To achieve ‘descriptive vividness’, I have extensively used rich descriptions from participants’ interview texts as much as possible. so that readers not only ‘hear’ research participants’ voices, but also ‘see’ the descriptive content of their experiences. For example, when research participants revealed their experiences of what it was like to be in the consulting rooms of CAM therapists, not only did they ‘tell’ me what it was like, but they also ‘showed’ me through their words the vivid physical characteristics of the rooms etc. In line with Glaser and Strauss (1965, p.9), my aim in writing the findings chapters has remained to describe participants’ lived experiences of using CAM.

3.3.6.2 Methodological Congruence
Methodological congruence has four dimensions: rigour in documentation, procedural rigour, ethical rigour, and auditability (Burns, 1989: Field & Morse. 1990: Guba & Lincoln. 1989: Lincoln &
Guba. 1985). An exhaustive documentation of the many elements of this study is presented in various chapters of the dissertation.

Rigour in relation to procedures means providing detailed information with regards to steps taken to ensure that data are accurately recorded and the data obtained are representative of the data as a whole. A detailed section on rigour in relation to ethical issues will be presented later in this chapter.

The final dimension refers to auditability, which means to leave an audit trail, a recording of activities over time, which can be followed by another researcher (Lincoln & Guba. 1985). This particular dimension can be problematic, as Burns (1988) pointed out that other researchers might not necessarily agree with conclusions developed by the original researcher. However, in this study, I have included detailed information regarding participant recruitment and selection, as well as the interview process and analysis.

3.3.6.3 Analytical Preciseness

Analytical preciseness refers to “a series of transformations during which interview transcripts are transformed across several levels of abstractions” (Burns 1989, p.50). This process requires that the
researcher make intense efforts to identify and to record the
decision-making processes through which transformations are made
(Burns. 1989; Field & Morse. 1990; Guba & Lincoln. 1989; Lincoln &
Guba. 1985). To evaluate the truth-value of my data analysis. I
returned to each participant with transcripts of the interviews to
ensure a true and correct representation of their experience. Often. I
would literally receive the ‘nod’ (van Manen. 1990). which refers to
the moment when the participant concurs with that what is written
or said about the reality of the phenomenon. At the conclusion of
the reading. there was general validation that the text represented
what they had said in the original interviews: “It’s spot on”. or
“that’s exactly how it is”.

3.3.6.4 Theoretical Connectedness

Theoretical connectedness requires that the themes developed from
the study be clearly expressed. logically consistent. reflective of the
data. and compatible with the existing knowledge base (Field &
Morse. 1990; Guba & Lincoln. 1989; Lincoln & Guba. 1985). As
discussed earlier in the data analysis section. the themes developed
from the study have been presented with the fundamental research
question foremost in mind. The proposed relationships between
each theme have been validated by data and can be considered as an

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accurate expression of original values as held by participants. The themes presented in these chapters yield a meaningful picture of the phenomena under study.

3.3.6.5 Heuristic Relevance
Heuristic relevance refers to the reader’s capacity to recognise the phenomenon, its theoretical significance, its applicability to practice situations, and its influence in future research activities (Burns. 1989; Field & Morse. 1990; Guba & Lincoln. 1989; Lincoln & Guba. 1985). It is anticipated that readers, when presented with the themes derived from the data, will find meaning within their personal knowledge base and immediately recognise the phenomenon being described. The final chapter of the dissertation shows how the knowledge generated from this study is applicable to health care policy through integration into the knowledge base of health care professionals. The findings also contribute to theory development and guide future development of quantitative and qualitative studies in the field of CAM.

3.3.7. Ethical issues
The study was approved by the University of Western Sydney Human Research and Ethics Committee. Potential participants who
are fully informed about the nature of the research are in a position to make a decision whether or not to participate in the study. The process of complete disclosure, discussion and answering of any questions that a potential participant might have about the intended processes of the research, acts in accordance with that person's ethical rights of respect and self-determination. Thus, consent by a person to participate in the research is an informed one.

All potential participants were invited to ask me questions, which may have been for the purpose of clarification or additional information. All participants were given an information sheet outlining: the purpose of the study, the nature of the research method, the time commitment involved, the benefits and risks of the research and an explanation of confidentiality and of freedom to withdraw from the study at any time, without consequences (Appendix 3). A Consent Form (see Appendix 1) separate from the information sheet (see Appendix 3) was signed, so that both the participant and I had a copy. By signing the informed consent, the participants indicated that they understood the nature of their participation and voluntarily agreed to participate.
Privacy is particularly important in this study. Great care has been taken to present the truth and substance of the individual experience with real and accurate descriptions of the lives as lived. Every effort has been made to protect the privacy of the participants by changing names, places and detailed particulars of the individual stories as it is my moral duty to respect the privacy of persons and their families, and I have taken this charge very seriously.

The Ethical Guideline for Qualitative Research (National Health and Medical Research Council, 1999) was used to ensure that ethical issues were addressed appropriately.

Finally, I anticipated the possibility of circumstances whereby I would have felt ethically compelled to intervene. For example, if a participant appeared to present with symptoms of distress during the interview process, it would be unethical not to intervene in the form of a referral to a General Practitioner or another appropriate organisation. Fortunately, these circumstances did not arise.

3.4. Summary

The naturalistic research design and qualitative methods presented in this chapter were selected as a means of discovering and
illuminating the lived experience of using CAM by individuals living with chronic illness in order to understand their reasons for using CAM. In this chapter, the philosophical and methodological underpinnings of this paradigm were outlined. The inquiry process was described and the specific methods of data collection and analysis used discussed. In the next four chapters participants’ stories of the onset of illness and getting sick, seeking biomedical treatments, coming to and using CAM treatments, and the impact of using CAM are presented in relation to their lived experience of using CAM while living with chronic illness. The participants and I shared this study, and the interpretation of narratives that follows in the next four chapters is not mine alone, but one negotiated in interaction with the participants. This provided a wealth of data that it is not possible to fully report within the formal guidelines of a dissertation. Exemplars (in italics) from the interviews will be used to illustrate the findings. To maintain anonymity identifying names and specific illness conditions have been removed.
4. Getting sick

4.1. Introduction

Participants started their journey to CAM use when they first encountered the emergence of illness in their daily lives. This time was particularly worrying and distressing for participants especially as there was disruption and breakdown to their taken-for-granted selves and habitual lives. The time from when illness first appeared through to participants’ initial awareness or suspicion that something was wrong with them, to their initial attempts at help seeking was vividly described by the participants during the interview process as if it was only yesterday. In this chapter, their perceptions of illness, life disruption, and search for effective treatment are described.

4.2. Illness genesis

Illness genesis describes the onset of illness in participant life-worlds. Five main themes emerged after an analysis of their conversations: emerging illness, changing body, changing relations, and changing time. This is demonstrated in Table 3.
4.2.1. Emerging illness

Participants voiced that their illnesses emerged slowly with varying intensity into their lives as they slowly but surely came to the awareness that something was wrong. This self-awareness was experienced as not feeling right. The feeling of unceasing bodily pain brought to their awareness the emergence of illness as they hoped for it to go away and to pass. When it did not, they came to the painful awareness that something was wrong with them. This realisation was reinforced by unceasing rhythms of recurring bodily pain.

"I knew something was wrong you know ... I could feel it. this thing coming on. It felt strange at that time ... I just didn't feel right at all you know. I kept getting down and down. It happened slowly too you know ... as if it built up slowly and not stronger with time ... like it built up." (Paris)
For some participants illness emerged on the surfaces of their bodies and for others, it emerged from within their bodies. Feeling a sense of strangeness and disorientation, they observed their bodies looking for signs of emerging illnesses. Notice transformations surfacing on and in their bodies. Participants came to the frightening awareness that something was wrong with them.

"I knew something was wrong when my lungs started to hurt. It didn't feel right at all ... with all this stuff coming out. I reached the point when I could feel pain in breathing ... it's like my lungs were on fire and it was taking so much effort. I had never experienced this pain before. So I knew inside that something was not right with me." (Zoe)

4.2.2. Changing Body

For all participants, the feeling that something was wrong gradually emerged from their self-realisation of changes to their lived bodies. They voiced feelings of their bodies being constantly tired, lacking in energy, and in constant pain.

"My body was really feeling very off ... as it was in constant pain. I kept feeling so tired and so exhausted all the time ... like I had no more energy ... and this wasn't like me at all as I've been a pretty fit and physical person all my life ... my body felt different and changed ... it wasn't what it used to be ... I could feel this difference." (Mark)
From such feelings, participants became aware of how different their bodies had become by remembering and comparing their past experiences of living in and through their bodies. This painful realisation aroused a sense of panic and confusion. Feelings of alienation set in, as participants realised that something was wrong with their being. Their lived relations with their bodies had changed.

"My body didn’t feel like my own anymore … it was a strange feeling. It felt alien to me. I kept feeling tired and had it all the time … it used to take me so much effort to do things with my body … I mean I had to really struggle with my body to do physical things and I wasn’t used to that at all … my body made me realise that something had changed and that something was happening to me. It’s a very scary realisation … it’s like my body was beginning to annoy me … like it was working against me (laughs)." (Rosemaru)

4.2.3. Changing self

With the emergence of illness, participants voiced feeling like their being with themselves had changed. They spoke of feeling strange, feeling changed, and feeling different towards themselves. Some revealed a strange becoming – becoming something that they did not like. A transformation into a thing that they did not desire to be. Furthermore, this becoming was felt as a change from within: something had changed and transformed inside themselves. This
becoming generated feelines of self hate as participants voiced feelines of hatine themselves, hating their feelines, and generally not feeling good about themselves. During this time of transformation and change, participants also spoke of constant lingering pain in their lives. They realised that they were not their old habitual selves as they had known. They had changed.

"I felt like I had lost myself you know ... that old havv self that I used to know ... I realised I had changed in myself because of my different feelines towards myself you know ... I started to dislike my body and myself ... I wasn’t like that before you know ... I used to be a very havv person very much in love with myself. My feelines towards myself changed dramatically during this process you see. I started to really hate my body and hate the kinds of feelines that were coming about. With my constant pain. I knew I had changed and I wasn’t my normal self. My pain was constant and would yet really bad during times when I had to physically do things you know. It was taking me so much effort ... like for my body to do things and I knew that I wasn’t me any more ... that was painful too you know – knowing I had changed into this sick person and I didn’t like it at all.”

(Geoffreu)

4.2.4. Changing relations

As well as becoming aware that they had changed with emerging illnesses, participants also become aware that their relations with others had changed during this time. They voiced their intense desire to be alone with themselves, getting irritated with the demands of others, perceiving others as annoying. difficulties
coping with others at home and at work, and one of the three participants suffering from HIV expressed the desire for eternal aloneness fearing stigma from others—death.

"My skin rashes caused by the HIV really changed my interactions with people… this is the biggest thing that changed for me with my changing body. Knowing my HIV status, I felt so alone you know… like some kind of diseased dox… I felt frightened to go outside my house… I constantly had this feeling that people were looking at my face and seeing my rashes… when I'd pass people on the street, I felt like they could see that I was diseased with HIV and I felt very ashamed and alone with myself. I started feeling anxious with people on the street and with my friends thinking why didn’t they yet it and why me you know… it was a very strange and painful time for me at that time. I just wanted out… I wanted to be alone and to die.” (Andrew)

Moreover, participants voiced being in constant pain and bodily hurting, and this made it harder for them to cope while interacting with others. This in turn reinforced their desire for aloneness. This desire generated feelings of guilt for some participants, as they voiced feeling guilty for desiring to be alone, and feared others around them as perceiving this need as being mean and selfish. Participants came to the awkward realisation that their relations with others had changed, and they themselves had changed with the emergence of illness.
"During this time, I felt that I had changed towards my husband and my kids. With my constant pain, I found it really hard coping with them at home ... I had to do my housekeeping, cooking, and cleaning after them ... I think because I was in constant pain and so tired all the time. I really didn't feel like talking with them and even being with them ... there were many times that I just wanted to be on my own ... to be left alone to think and just cope with my body ... there were times when I wished that they would all go away on holiday somewhere and not come back ... I know this sounds selfish and mean, but that's exactly how I felt at that time ... I just needed to be alone." (Sharon)

4.2.5. Changing time

As well as becoming aware of their changed relations with emerging illnesses, participants also became painfully aware of their changed perceptions of lived time in their life-worlds. They felt lived time as stuck, self as frozen in time, feeling stuck in time, and living on hold while being unable to make any plans for their future days.

"For me, it was like living on hold at that time ... I couldn't think of the future ... I couldn't make any plans about the future ... everything was on hold ... like all my life and living was stuck in time. It was very painful thinking of those things ... I felt like I had run out of time ... there was no more time left anymore and I couldn't take anything for granted at all ... not even myself." (Eveka)

Some perceived time as fractured and experienced a disrupted flow of life with few moments of movement and transcendence in lived time: the naturalness of lived time in their lives had disappeared.
Moreover, participants voiced being in constant pain and living in disrupted time while enduring intense pain. Their relationship to lived time had changed.

"I was kind of stuck with my condition … I just had no sense of any yesterdays or tomorrows – those thoughts didn’t happen to me at all back then … all that I could think of was my pain … that became the major focus for me back then … I couldn’t even think beyond the present at all … it was almost impossible as I had to constantly set on with my moments … It’s like … umm you know … time got fractured for me … that sense of flow of life went away from me you know … that natural feeling of time … that flow went away.” (Rosemaru)

4.3. Life disruption

The theme of life disruption describes how illnesses emerged and intruded the life-worlds of participants changing and altering their being-in-the-world. Five main themes emerged after an analysis of their conversations: fear and uncertainty, waiting and hoping, living in pain, feeling the demands of others, and getting down. This is demonstrated in Table 4:

<table>
<thead>
<tr>
<th>Theme: Life Disruption</th>
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<tbody>
<tr>
<td>Sub Themes:</td>
</tr>
<tr>
<td>• Fear and uncertainty</td>
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<tr>
<td>• Waiting and hoping</td>
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<tr>
<td>• Living in pain</td>
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<tr>
<td>• Feeling the demands of others</td>
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<tr>
<td>• Getting down</td>
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</tbody>
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Table 4: Life disruption
4.3.1. Fear and uncertainty

With emerging illness, participants voiced their fears of being unable to do their regular daily tasks. They spoke of being unable to work, unable to focus, fears of poor performance at work, and fears of losing their jobs. The fear of losing their physical abilities and independence was ever present in their lives during this time.

"My back pain was so intense at that time that I really thought I might never be able to get my job back again at all … my work is physical and I need a strong body for it you know … I was really frightened that it was all down hill from me … I couldn’t even do little things around the home you see – that got me very frightened as I started to feel very disabled in my own home – my body just couldn’t cope with some tasks that I needed my body to do – it was frightening and I thought I was really losing it you know … in a big way too.” (Jane)

Thinking about the future was stressful for participants, as they encountered fears of disabilities and non-accomplishment. They voiced being frightened and living in constant fear, and feeling very alone.

"I was so ill that I was not thinking straight at all … it was scarier at the time as I really thought that I was losing my mind. I was unable to hold onto thoughts. It’s like I couldn’t focus on any one thing for too long … all my thoughts were rushing in at once … at work I was pretending to be busy, but I really was not doing much at all … this wasn’t like me at all … I used to be very good with ideas and thinking outside the box you know … so I was really frightened that I would get sacked from my job as I couldn’t think straight. I was really frightened to answer phone calls and I couldn’t make any firm decisions at work – I was a real mess at that time and had constant fears that I really couldn’t do much.” (Mark)
With emerging illness, participants lived in fear of being unable to overcome their illness conditions. Feeling frightened by thoughts of not being able to shake it off, they worried about an uncertain future fearing a poor quality of life.

“When I wasn’t able to shake this thing off during the first few weeks, I got frightened that it was something major. After I had failed in my home remedies. I started feeling really frightened that I may not be able to overcome this thing. That prospect was very worrying as I knew what the implications meant for my life and I didn’t want that at all.” (Paris)

Moreover, they voiced living with constant bodily pain, getting physically tired, and day-to-day living as painful and irritating. Through this pain, some came to the realisation of the importance of their bodies in relation to day-to-day living: they came to appreciate the importance and the centrality of their bodies as tools and technologies for doing things in their daily lives. They also became aware as to how their lived habitual bodies felt different, and some voiced missing that old body they used to know.

“Finding out about my HIV not me really frightened. I thought that I may not overcome this disease. I missed my old body you know. I mean I know all about current treatments, but I’m still hopeful that I just might be able to overcome this whole AIDS thing completely you know. I can’t imagine my life not overcoming it – my whole life will change and I’d need lots of help from other people for just day-to-day living.” (Geoffreu)
4.3.2. Waiting and hoping

With confounding fears and reservations, participants waited for their emerging illnesses to pass and to go away. They described this period of waiting as extremely stressful and like living on the edge.

"You know I waited and I waited for my illness to pass ... I used to count days on my wall calendar and I kept hoping to myself that it would go away ... this waiting was really hell you know ... the sensations were there you know ... I had read about it and seen it in my friends ... the rashes started appearing all over my body like boils that wouldn't go away ... I kept hoping that it would go away ... I kept thinking it would go away and I really wanted them gone." (Geoffreya)

During this stressful time, they transcended their suffering moments by hoping for better days and thinking positively about their conditions.

"I was really hoping that this pain would end ... I was hurting more and more ... it's like it was building up little by little ... I kept hoping and thinking positive things ... like don't worry it will go in time you know ... I'll get better. With this stuff coming out of my nose and mouth, I knew that my lungs were infected again ... I kept doing my usual things like inhalations and essential oils waiting for my infection to go away, but it was getting worse in time ... I kept hoping and praying for it to go away ... the pains were still there and this stuff was still coming out of my mouth each time I coughed." (Zoe)

Participants hoped for their familiar old me to re-emerge - the self they had got to love and to be with before their emerging illness. They voiced missing regular activities such as playing sports.
socialising with others, and doing things around their homes with their loved ones.

"I suppose I was kind of hoping for my old self to come back you know while waiting and waiting for this thing to pass ... the self I used to know before I got sick. I missed doing the things I used to do and I missed not worrying and feeling all this pain in my body. I wanted my old body back. I wanted to be my normal self again ... I was tired of being sick all the time ... I missed my sports and my mates ... I couldn't do all that now." (Fiona)

They longed for a return to their earlier days, and being bodily able to do such activities free of constant pain. In desiring the way they were, participants also acknowledged to themselves their new altered selves, and further acknowledged their changing social interactions and changing personal interrelations due to emerging illness.

"I really missed what I used to be before this HIV came by ... I missed my old virus free body you know ... I missed the way I used to look ... I really didn't like this diseased thing I was becoming ... I missed voicing dancing and being with other men ... I missed doing the things I used to do you know ... I couldn't do a lot of physical things now with my body ... it's like I was getting weaker and weaker ... and this pain was not going away." (Mark)

Participants hoped for their emerging illnesses to pass by staying positive and optimistic, and putting up a fight. They expressed their
determination to beat their illnesses despite suffering from constant lingering pain and considerable bodily discomfort.

"I was so eager to beat my cancer ... I wanted it gone and I was voicing to do my very best to get rid of it from my body ... I tried staying positive and hoped that it would go away ... I knew I had to fight this thingy ... to overcome it ... or else it was voicing to take over my life. I knew I could win if I tried hard enough I kept thinking forward and hoping that one day this pain would go and I would defeat it." (Paris)

4.3.3. Living in pain

With emerging illness, participants voiced suffering from constant bodily pain. They voiced their bodies as feeling tired and heavy, and everyday tasks and activities as increasingly painful.

"My body used to hurt so much ... it's hard to describe ... sort of like my body was so tired and sore everywhere ... my legs left heavy and my whole body felt like such a load ... it was painful doing anything and this pain just would not go away ... Oh, it was just so horrible ... that pain was everlasting and would linger all day ... no matter what I did. It was still there. Even walking from spot A to spot B was hurtful ... it was awful ... basic things around the house got very painful to do ... my back pain took over everthing that I physically did. It was a sharp pain that would set stronger in the day as my body got tired." (Lane)

Furthermore, they described their living in pain as intense suffering.

"The skin rashes got very painful when they wouldn't heal ... I tried not to put any plasters on it you know hoping it would heal naturally, but it didn't. It's like the feeling of being burnt all over ... this water stuff kept coming out and it used to sting my skin every time I
skin came into contact with anything else. Even putting on clothing used to hurt my sores. It used to hurt my skin every time I did something. I was really suffering you know in a big way.” (Geoffreu)

With increasing bodily pain, participants came to the awareness of feeling different and feeling changed. They voiced an emerging realisation of being other than their normal selves; pain had created an otherness in their lives.

“This pain within my body was so very strange you know ... I had never come across it before in my entire life ... it was starting to make me feel different ... like it was taking over all my thoughts and I couldn’t think of anything else to focus on ... I found myself getting really moody and highly irritable with others and myself. This was quite unlike myself and I found that I was kind of changine into something I did not like at all ... that’s because I was in pain all the time.” (Sharon)

Participants voiced feeling divided within themselves with emerging illness – a division comprising of fragments of their normal usual self and an emerging different thing.

“The best I’d say to describe myself then is that I was sort of divided within myself ... like I could feel a bit of my old self, but there was this other side appearing that was full of pain and it was kind of taking over the other side. It was like a strange becoming into this other thing ... I could feel myself changine ... it’s like I was losing my self and changine. I didn’t know how to deal with it at all ... this stranveness takes over and I was full of worry and couldn’t think straight at all.” (Eveeka)
Living in intense pain, some participants tried to obtain relief from painkiller pills and home remedies. While effective, such remedies proved to be temporary and some produced discomforting side effects.

"The pain was so intense and so constant that I had to deal with it. I first tried painkiller tablets, but found that I was taking way too much and it really wasn't working because the pain would come back. Then I went to the local pharmacy and got these strong painkillers ... they worked, but gave me stomach cramps ... those pills were uncomfortable ... at times they made me vomit but those pills were better than the pain ... the skin sores were very painful and not healing at all ... at times I just couldn't cope with all that pain ... the pain got worse as that watery stuff started developing around the sores. I tried a few things ... like soave baths and a few lotions from the chemist, but all that just gave me temporary relief. It felt like my sores were on fire or something - that burnt feeling on my skin ... it was awful at that time." (Geoffrey)

Some participants obtained little or no relief from painkiller pills and home remedies, and decided to just live with it despite their intense pain and suffering.

"My lungs were really hurting and I was suffering. It used to hurt me just breathing as my lungs moved ... I knew something was very wrong with my lungs ... I had to constantly keep sitting all this mucus out ... the pain in my lungs were sharp and intense. I didn't know what to do about that pain ... so I just lived with it for a few weeks." (Zoe)
Other participants voiced incidents of changing and modifying their daily activities in order to accommodate their intense suffering from lived pain.

"Its like the pain used to get so bad at times that I had to reschedule my day around my back pain. This is the one way I could kind of control the pain that I was feeling ... or perhaps the intesnity of my back pain. But, this meant making a lot of changes at home and at work. I could manage my schedule at home as that was within my total control, but work was certainly a problem ... and the people at work not at all understanding about this, as I'm sure they thought I was making it up or something." (Jane)

As described above, participants were aware of the unhelpful attitudes of others around them during this time of intense pain and suffering, and voiced feeling more stressed with the demands of others pressing upon their selves.

**4.3.4. Feeling the demands of others**

While suffering in pain and trying their best to cope with emerging illness, participants felt the demands of others and found interacting with others as irritating. They tried to minimise and avoid social interactions with such others.

"When I got sick and my depression was taking over, I just couldn't cope with people around me you know ... I found almost everyone so bloody irritating ... I just didn't want to be with people at all because that meant talking to them and I didn't want that ... it used to take
me so much energy to just think and focus on one thing at a time ... there were all these rushing thoughts going on in my head ... and most of the time I just couldn't stop thinking about my problems at all ... for hours this would go on and on.” (Mark)

Some participants found social interactions with their immediate families and loved ones stressful and irritating.

“*My pain was so intense that I couldn’t cope with any activities around the house at all ... I mean little things that usually don’t take me time you know ... stuff we just do without thinking because it needs doing ... I was also highly irritable with my family ... it’s like little things would set me off ... somehow I used to feel more pain in dealing with people ... strange I know ... but I just couldn’t cope at all.*” (Euveka)

Participants expressed their diminishing ability to cope with others in social interactions, and expressed actively choosing to be alone with themselves.

“*With my pain increasing, I just found it very difficult putting up with people ... that includes family, friends, and people at work too ... at times I felt like screaming at them ... I was just so much in pain ... I didn’t want to hear them or even talk to them ... I just wanted to manage my pain being alone with myself.*” (Sharon)

For participants with obvious physical signs of illness manifesting on their bodies, stigma from others became a constant concern. They
feared being judged upon and tried their best to avoid social
interactions.

"I found being around other people very stressful and I kind of
developed this anser towards them you know ... especially havin non-
HIV people. It used to get me really anerv thinking that I've got it
and I'm durin and that they are well and still have so much livin to
do. So, I tried my best not to go out of my house and be with people at
all ... their laughter bothered me ... strangely I felt it was directed at
me ... I felt like they could see my HIV through my body sores." (Geoffreu)

With emerging illnesses, participants found themselves as being
unable to cope with the demands of their regular jobs. In particular,
they found interacting with others as irritating and as stressful and
voiced feeling like they were losing control over their thoughts and
actions.

"I just couldn't cope with work either ... my pain was so revular and
so intense. It not really hard for me just dealing with my deadlines ... I
was gettin more and more behind and I just didn't know what to do
... I also found myself really moodu at work because it was just so
irritatin being there ... being nice to people that I didn't like ... that
takes enough energy when you are feeling ok. but when you are in
pain. it's very stressful." (Paris)

The intensity of constant pain made coping difficult for those
participants with physically challenging jobs.
"As you know my job involves dealing with kids within a school environment … this got extremely hard to do and it was very tiring at times. My back pain. I just couldn’t cope with the demands of my daily job … a lot of it was physical you know … there are a lot of activities that you have to take part in … various activities with kids and you have to do a lot of demonstrations and preparation work … I was getting highly irritable with the kids at times and their noise level used to really bug me. I just got by … controlling my anger and myself … it was very difficult. I was so anxious all the time you know … like so very restless and full of worries about my life. It’s like my disease had taken over my total thinking and all I could focus on was my condition.” (Fiona)

Some participants found that they were running out of sick leave and found the attitudes of their workplace administrators as unhelpful and annoying.

"There were times when I just could not do my job and took sick leave … so much so that I ran out of my total sick leave and they started docking my pay. This made me very anxious you know … they could have been a bit more understanding about my condition. I didn’t ask for it … it wasn’t my fault that I was sick. I found it really hard dealing with customers and their demands at work … especially the difficult ones that are full of attitude and just want to hassle you around … it was hard focusing on their problems when I had so much to deal with on my own.” (Eveka)

Amidst their pain and suffering with emerging illness, some participants found it difficult to maintain motivation at work.
"My illness was so bad that I just didn't want to do anything at all. I lost all interest in work and generally just couldn't be bothered you know. I couldn't do much at all ... I was really behind in my work and it just didn't matter at all to me - I'm not usually like that at all ... I suppose all my motivation went away." (Rosemary)

While putting up with the demands of others at work proved to be difficult and stressful for some participants, their home lives proved to be no different. They found social interactions within their family settings as difficult, thus hindering their ability to cope with their illnesses. Participants, especially those with children, were unable to keep up with their regular family obligations, tasks and activities.

"With my pain intensifying, it was really hell for others around me especially at home. My kids were very anxious with me for not taking them to sports and other activities ... they resented me for not spending enough time with them ... I think they also got irritated at me for constantly shouting at them because I used to find them really irritating ... it was really hell living with me at that time." (Fiona)

The inability to cope at home with other family members and their regular tasks and activities resulted in feelings of guilt for some participants. They felt they had let their families down by being unable to be fully there with them.
"I think my husband really felt the brunt end of my disease. You know... it was very difficult to live with at that time and when my pain got worse. I just couldn't cope at home. He missed out a lot on the regular things we used to do... going out, playing sports. Gardening you know—all those sorts of things that we did together... because of my pain and my condition. I found that I was no longer able to do these things in my relationship at all... I felt really bad about it you know... very guilty." (Sharon)

For some participants, their inability to fulfil obligations at home and within loving relationships resulted in the break-up of their relationships with long term cherished partners. As such, they felt robbed and cheated by their emerging illnesses.

"I think my partner found it hell being with me through my illness and she finally left saying she could not cope and that I had changed from what she used to know of me. I was moody and highly irritable and I didn't care. I just wanted to be alone and not hang out with her anymore... I had reached that point where nothing mattered anymore... I didn't care about anyone or anything at all." (Rosemary)

4.3.5. Getting down

With emerging illness and suffering in pain, participants soon found themselves as being unable to cope. They voiced constant thoughts of a changed self and came to the full realisation that they had changed and were very ill.
"You know during this time I kept thinking about my disease. My
vain, and how all of this was changing me as a person. I could feel it
now you know ... I certainly wasn't what I used to be at all ... I was
becoming this other thing that I didn't like at all ... that got me down
a lot ... I knew I was in big trouble ... I felt distorted ... something
like that ... like I wasn't me anymore ... that me that I used to know
was somehow gone through this HIV. I felt changed and different ... not just physically but my thoughts about others and myself had
changed. I wasn't that hawn, bubbly person that I used to be ... now I
was this worried, sick thing with lots of problems to deal with on my
own ... it felt like one part of my life had died ... I felt changed and
really f*cked up." (Andrew)

Feeling different and changed, participants soon found themselves
getting down and depressed about themselves and their prospective
futures.

"My illness had really changed me ... what I had come to know of
myself was changing and my vain was taking over my whole thinking
... I couldn't do a lot of the things that I used to do ... I couldn't be
with the people I used to be with ... I couldn't vlaw any sport - all the
things that I loved doing I suddenly found I couldn't do anymore ... I
used to be a very physical person you know ... bush walking and all
that ... now things were different ... I kept thinking I had changed ...
my body had changed and was now not doing things that I wanted it
to do ... I started vetting very depressed and I could feel myself
vetting very low." (Fiona)

Participants voiced feeling empty, and as having lost a significant
part of themselves to their emerging illness conditions.

"The cancer had certainly changed me ... that I know for sure as
today I'm not that old person I used to be. I have become more anerv
and negative about life and living. I have lost a lot of the things that I
enjoyed doing in life and things that gave me a sense of purpose and

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meaning ... now I feel hollow like an empty class. This cancer has
certainly taken away a large chunk of me and it's something I can't
yet back – it's like a big hole ... a void ... it's hard to describe this you
know, but that's what it feels like.” (Sharon)

While getting down and being depressed about their illnesses.
participants found themselves as being not able to think clearly.
They described their thought processes as altered and as different.
In particular, they found themselves engaging with repetitive
thinking and constantly focusing on their illnesses.

“I remember during this time. I was doing a lot of strange and crazy
thinking ... lots of weird thoughts were going on in my head ... stuff
that could be described as nonsense and blown out of proportion really ...
I used to sit on trains and think people were talking about me and
looking at me ... I used to react to these thoughts and people gave me
really funny looks ... like she's really not there completely (laughs) ... it was like I was really obsessed with thoughts ... thoughts used to
linger in my mind for hours ... they just would not go away.”
(Rosemary)

4.4. Search for effective treatment

The theme of search for effective treatment describes how
participants found motivation towards help seeking regarding their
emerging illness conditions. Three main themes emerged after an
analysis of their conversations: envisioning the future, pushing on,
and thinking of getting help. This is demonstrated in Table 5.
4.4.1. Envisioning the future

Participants voiced being depressed and at a complete loss for a considerable period of time. During that time, negative thinking and constant thoughts of a diminishing quality of life took over their lives. They described these moments vividly and talked about difficulties in coping during this trying time. The main coping strategy for most participants involved thinking about future days, thus forcing them to look beyond their present depressed moments.

"You know to cope with this thing. I kept telling myself to look to the future ... I tried to imagine that good days would come and that I would be out there doing things and having a great time ... this kind of thinking took a long while to develop you know ... it took a lot of effort because I had to look in my mind's eye to what was beyond ... sometimes it was very hard to do this ... I knew the reality that I was going to die with AIDS ... I had to get past this reality and the only way I could do that was to dream and picture in my head positive having things that I could be doing in the future." (Mark)
Some participants mentioned thinking about their families and their cherished commitments to them as a motivating force in thinking forward and transcending their depressive moments.

"The pain was getting more and more intense and I found that I was getting more and more depressed and negative about my future. The only thing that kept me going at that time was to think about my partner and kids and their future with me. That got me thinking of all the things that I still had not done with them you know ... that kind of gave me strength to look ahead and to think about upcoming events like their birthdays, their university, their graduations — that sort of thing. Those kinds of thoughts of the future got me through my immediate pain and my depression.” (Fiona)

For some participants, trying to think positively and envisioning the future proved to be a hard struggle. Being confronted with the real possibility of death, participants forced themselves to start thinking positively about themselves and their illness conditions.

"I just had to put up with my pain and my reality ... I had to deal with the reality of my death alone you know ... it was very painful to face that reality ... I had to ... I had to take a firm grip of myself ... mostly my thoughts because they were getting me very down ... I forced myself into thinking about some of the nicer things that I could be doing in the future ... things like going on holidays, meeting new friends, another lover perhaps ... I had to force myself to think that way ... it was a real struggle ... it didn’t come easy you know ... it helped me feel better and I was better able to deal with the reality that I was going to die.” (Andrew)
Participants with children found strength to transcend this depressive period by focusing on their commitments and promises to their children.

"Thinking about my disease got me quite down in the dumps ... and I did that for a while. But then one day I realised that I wasn't doing anywhere like that ... I was just getting more and more negative towards others and myself. My children were doing their best to cope and they kept reminding me of all the things that I had promised them ... things that I was going to do with them when they were older. So being with them. I started to think about my future with my kids and that got me somewhat hopeful you know – that there was still life in me and that I was going to do my best for my kids despite this cancer. I wasn't going to let my negative thoughts get in the way of my commitments towards their futures." (Fiona)

4.4.2. Pushing on

While attempting to transcend their depression and their constant thoughts of diminishing selves, participants discovered renewed energy to push on and fight. Participants described this energy as a force within that motivated them to push on.

"So during this time, my illness got really bad and started affecting everything that I did. It virtually took over my whole day-to-day living. I just couldn't shake it off. But, there was something inside of me that kept pushing on. I knew in my heart that I could shake this thing off and I was going to do my very best to get better. I kept thinking that I had so many things that I still had to do and I wasn't going to live in ... I had no other choice but to keep fighting and try my best to move forward. I could feel this energy within me. It was giving me more strength to fight on and keep going. I didn't like the..."
thought of being stuck with this vain all my life and I was going to do
god damn best to get better.” (Paris)

Others found strength to push on with their illnesses by thinking of
the love and support that their family members had bestowed upon
them. They felt a renewed strength to fight their depression and
their illnesses.

“I know that there’s no escaping from my HIV and that I’m going to
die … that whole process was rather strange for me you know … it’s
like I went through this stage were all I wanted to do was give in and
die that same day … you know get it over and done with … I got very
down and depressed for a while and I couldn’t think too clearly at all.
But, when I felt the love and support of my wife and kids. I knew I had
to try my best to do everything possible to live and live productively
for as long as I could. When I had reached that point, I knew I was
go to give it my best shot and keep going.” (Geoffreu)

Some participants discovered repetitive negative thinking as
counterproductive and found motivation to push on by focusing on
their futures. They reminded themselves that they were still alive
and that they still had a lot of living to do.

“It was pretty bad finding out that I had HIV. The only thing that
kept going through my mind was that I was going to die … I suppose
the reality of my life and living hit me really hard in the face … there
was no escaping from that for me now. That’s a very difficult thing for
anyone to have to deal with really. But, that kind of thinking was
setting me more and more down. One day I think I had been drifting
for a while … I thought no. no more … I wasn’t going to think about
death from now on ... I was just tired of these negative thoughts. I decided at that moment that there was still life in me and that I wasn't dead yet ... I was going to continue living and yet on with my life no matter how bad or hard it was going to be for me.” (Andrew)

4.4.3. Thinking of getting help

Participants gained strength from within and from loved ones, and voiced being in a position to push on with their lives and their illnesses. It is at this point that participants get motivated enough to think about getting external help towards their illnesses, and voiced being in a position to think more coherently and more strategically about their illness and help seeking options.

“I was better able to think about my condition when I started feeling more positive. I knew I had to do things to overcome this thing and that kind of thinking started me off about getting help. I had waited for a while you know ... I had tried all these things on my own housing that it was a wasting thing, but my illness wasn't going away. I could feel it's bloody hold every day ... it's something very hard to describe. So, I started thinking about doctors that I could go to and yet my problem seen to. I just could not do this earlier as I was so down that nothing mattered anymore at all. I wasn't thinking straight at all.” (Rosemaru)

Participants suffering from HIV, who had obtained an earlier biomedical diagnosis, found themselves as being in a better position to strategically think about their illness conditions rather than being unable to get beyond the shock of the initial diagnosis. They voiced
wanting to get more information about their conditions and the treatment options available to them.

"When I started to feel a bit better about my HIV, I started thinking about getting help from my local doctor. I had done my tests at the testing clinic with strangers ... that's how I wanted it you know ... at that time I didn't want anyone that I knew to find out that I had done for my tests ... you know what people are like ... they start talking and soon it's all over the place ... I didn't want that and that's why I didn't go to my GP for my initial tests. I suppose during that time alone. I had come to terms with my tests and I was able to handle things you know ... like I could plan a few things ... it certainly wasn't easy ... it was a very painful and very lonely time for me in my life." (Andrew)

4.5. Summary

This chapter described research participants' experiences of the onset of illnesses and getting sick. With illness genesis, we saw how participants experienced profound changes in relation to their lived relations with their bodies, self-identities, time, and others in their daily living. We also saw how the onset of illnesses resulted in disruptions to their daily living with participants living in fear and uncertainty, waiting and hoping for the better amidst constant pain, feeling the demands of others pushing in, and getting down in despair. Moreover, we saw how participants started their search for effective treatments by envisioning the future and pushing on with their lives. The next chapter presents participants' experiences of
seeking biomedical treatments encountered in their help seeking journey.
5. Seeking biomedical treatment

5.1. Introduction

In the last chapter, we discovered how participants encountered the emergence of illness in their daily lives. Emerging slowly with varying intensity, we saw how their illnesses induced major disruptions to their lives with participants experiencing a breakdown in social interactions, self-identity, and personal integration. Participants reached the point whereby they knew that “something was wrong” with them and that they needed help. This chapter describes their experiences of seeking and obtaining biomedical help. In particular, we explore their experiences of being in biomedical environments, biomedical consultations, biomedical diagnostics, and biomedical treatments encountered in their help seeking journey.

5.2. Biomedical environment

Participants vividly talked about their experiences of biomedical environments encountered in the process of seeking help for their illness conditions. Three main themes emerged after an analysis of their conversations: feeling angry with reception staff, feeling
nervous waiting with other patients. and feeling uncared. This is demonstrated in Table 6.

<table>
<thead>
<tr>
<th>Theme: Biomedical environment</th>
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<tr>
<td>Sub Themes:</td>
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<tr>
<td>• Feeling anxious with biomedical reception staff</td>
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<tr>
<td>• Feeling nervous waiting with other patients</td>
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<td>• Feeling uncared being in there</td>
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Table 6: Biomedical environment

5.2.1. Feeling anxious with biomedical reception staff

Going to consult their doctors for their emerging illnesses proved to be a stressful and negative event for all participants. They voiced feeling anxious at the manner in which they were received at the surgery, and voiced dissatisfaction at the unhelpful attitudes and unprofessional interpersonal skills of associated personnel.

"I felt so anxious with their reception staff you know... and it's always the same with them at that surgery... they just don't know how to speak nicely (Eveka, 27 yrs. survivor of breast cancer). I remember thinking at that time she shouldn't be in that sort of job you know... it's like she lacked professionalism... She didn't smile or anything like that... she didn't return my greetings... She was just bored with her job... it's like she just didn't want to be there at all... she kept laughing loudly during this chat with her mate... she didn't even look at me." (Sharon)
As reported above, the initial experiences of biomedical help seeking proved negative for all participants. While suffering from illnesses and enduring intense bodily pain, they had hoped for more personalised and friendlier experiences. Instead, they found themselves in environments that were stress provoking. Despite this, participants decided to put up with it in order to obtain a biomedical consultation as they urgently needed solutions to their constant lingering pain and their suffering.

5.2.2. Feeling nervous waiting with other patients

Participants voiced feeling nervous and feeling stressed while waiting with the other patients at the surgery. Some participants experienced the waiting room as small and as lacking enough seats to accommodate all patients. They found it stressful being seated too closely with other sick persons.

“I felt quite nervous waiting in there with the other patients ... I felt really cramped in there ... there were not enough seats for patients and there were people standing in there too ... it was very uncomfortable ... and the seats were so close together you know ... it's like I didn't want to sit that close to another sick person.” (Fiona)

Participants voiced feeling uncomfortable with other patients coughing and sneezing, and voiced feeling worried that they too
would contract illnesses. The smell of hospital disinfectant made some participants tense as it reminded them of sickness and death.

"I kept getting uncomfortable with all the coughing and sneezing in there ... I didn't want to catch anything on top of my illness and I felt worried being in a closed space with sick patients ... there was that horrible smell of hospital disinfectant ... that also made me very tense ... it reminds of sickness and death I suppose." (Sharon)

The noise level within the waiting room annoyed participants as they felt their stress levels increasing and their bodily pain intensifying.

"The noise in there was just unbelievable you know ... there were phones ringing, babies crying ... children crying up because they couldn't wait any longer with their parents. I hated being there as I could feel my stress levels voicing up and my pain was intense that day." (Mark)

Participants felt lived time as stuck while waiting for their consultations. They reported waiting for long periods and described this as irritating and as boring. While stuck waiting for their turn, some participants found listening to the conversations of other patients regarding their symptoms and their conditions as stress provoking.
"It was just horrible waiting in there for so long ... I think I would have waited for at least 45 minutes before I got to see the doctor ... it's so boring while waiting too you know because the magazines were like 10 years old in there ... I could hear other people's stuff about their conditions and that made me worse." (Zoe)

Participants were dissatisfied with the untidy and depressing atmosphere of the waiting rooms. They reported finding old magazines and kids toys scattered across the rooms as well as gloomy posters of disease and ill health.

"The place was very untidy with old magazines all over the waiting room and there were kids toys scattered in there ... the room looked very old and depressing ... there were these pictures of diseases like mouth cancer and HIV on the walls ... that made me feel even more sick just looking at it all you know ... just a very depressing place ... I would describe it as gloomy ... very gloomy." (Eureka)

5.2.3. Feeling uncared being in there

Participants voiced feeling uncared and feeling unwanted while being in the waiting rooms. Some participants felt like they were reduced to being numbers in the waiting line when staff issued out consultation numbers.

"I really felt like a number being in there. Just waiting in that room with that number card in my hands. I remember thinking how I was simply a number to the receptionist. She didn't even call me by my name ... I was just numbers to her ... I felt most unwanted and uncared while I was there." (Rosemaru)
Some participants voiced feeling uncared when biomedical staff did not pay attention to them as they sat there waiting for their consultations. Participants expressed dissatisfaction at listening to biomedical staff laugh and gossip with each other loudly while participants sat there feeling stressed and trying their best to cope with their bodily pain. They felt themselves as being ignored by biomedical staff.

"The reception staff didn’t pay any attention to me as I sat there waiting. I could hear their laughter and gossip with each other and they were being loud too. They were voicing on and on about some hot date ... with all the details. I just sat there trying my best to cope with the situation ... I felt really lonely at that time you know ... there were all these fears voicing through my mind and it would have helped if the reception staff were a bit friendly and weren’t some attention ... even their smile would have made my day." (Fiona)

Participants expressed feeling strange and feeling unwanted while being in the waiting room, and felt stuck in time without any choices. They described being in the waiting room as alienating.

"I really didn’t want to be there at all. But I had no choice at that time. I felt really strange being in there ... it wasn’t a friendly environment ... like there was nothing warm about the staff or that place. It’s like there was sickness all around and everyone was miserable. It felt alien ... like I wasn’t wanted in there ... it’s like they didn’t care one way or the other." (Paris)
### 5.3. Biomedical consultation

Participants vividly talked about their experiences of biomedical consultations encountered in the process of seeking help for their illness conditions. Five main themes emerged after an analysis of their conversations: Feeling uncomfortable being in the consultation room: doctors as cold and detached; feeling rushed and directed by doctors; feeling angry, frustrated, and confused; and feeling powerless being in there. This is demonstrated in Table 7.

<table>
<thead>
<tr>
<th>Theme: Biomedical consultation</th>
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<tr>
<td><strong>Sub Themes:</strong></td>
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<td>• Feeling angry, frustrated, and confused</td>
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<td>• Feeling powerless being in there</td>
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Table 7: Biomedical consultation

### 5.3.1. Feeling uncomfortable being in the consultation room

Participants felt uncomfortable at finding new doctors during their consultations. One participant reported that her treating doctor kept changing each time she went to her local surgery and expressed dissatisfaction at being treated by a new doctor as this made her feel uncomfortable.
"I just didn’t feel comfortable being with him in the surgery. He was a new doctor ... that’s pretty common at this surgery ... they have about six treating doctors ... they keep changing every time I go in. This guy was new and I just didn’t feel comfortable with him." (Lane)

Participants voiced feeling edgy and uncomfortable being in the consultation room. One participant experienced his seat as uncomfortable and the physical setting of the room as impersonal. In particular, he perceived the physical distance between his seat and the doctor as impersonal. This was compounded when the doctor did not look at him in welcoming him into the room and not sitting close to him in the consultation process.

"I felt really edgy being in there you know ... there was this very uncomfortable plastic chair where I was asked to sit and in front of me was the huge desk with a computer at the other end. He sat right at the other end facing the computer screen. I noticed that he kept looking at his screen as I walked in and took my seat ... that was my worst nightmare ... at least he could have looked at me or even sat near to me." (Andrew)

Participants also felt uncomfortable at finding the consulting room as untidy, small, and having a clinical smell.

"That room was untidy ... more than the waiting room ... there was vapor all over the desk ... there were medical instruments hanging out of shelves ... this guy was very untidy ... it was a very small room too ... and there was that horrible hospital like smell in there ... that made me very tense as I hate that smell ... I really really hate it..."
you know. I just wanted to get out of there as quickly as I could.” (Sharon)

Participants felt uncomfortable at the lack of small talk and rapport building undertaken by their doctors. They perceived this as their doctors being too busy and too short of time. Participants felt that they needed rapport building talk in order to build warmth and comfortableness in their interactions with their doctor.

“He didn’t engage in much small talk and wanted to get straight to the point … you know like he’s too busy and I’m wasting his time. I felt untitled about that because I like to take time and I need to build some warmth with people especially my doctors … without that I feel very uncomfortable … like I’m with some unknown stranger.” (Mark)

Participants voiced feeling uncomfortable at having to look at health promotion posters of diseases while being in the consulting room with their doctor. They found it frightening being reminded of disease and death.

“I remember looking at his walls as I was sitting there … the walls had ugly pictures of different diseases … that sort of thing … and all that kind of frightening information. I didn’t like that as it really frightens me … it reminds me of horrible diseases and death … I didn’t want to see it and I didn’t want to know about it … I just wanted to get out and go home where I was comfortable.” (Lane)
5.3.2. Perceptions of doctor as cold and detached

During their consultations, participants perceived their doctors as being only superficially interested in their presenting problems. These perceptions arose out of the lack of questioning and associated probing by their doctors whereby participants had to do most of the telling and the talking on their own.

"He was not at all interested in what I had to say, you know ... it's like I had to do all the talking ... he wasn't asking me much questions about my problem at all ... it's like I had to tell him as much as I could thinking he might miss out on some information. I mean normally they ask you questions you know so that they get closer to the problem, but this guy asked very little about my problem, he didn't even ask me how I was feeling ... that annoyed me because I thought at the time he wasn't listening to me." (Zoe)

Doctors were perceived as not listening to participants during the consultation process, as they were perceived as being far too busy with computer screens and typing notes rather than looking at and listening to participants during consultations.

"I really got the feeling he wasn't listening to me at all ... as I was talking he would keep looking at his computer screen and he kept typing things on the keyboard ... only occasionally he would look up at me for me to go on with my talk. I really got the feeling that he was quite unfeeling and not very interested in my problem." (Eveka)
Participants also perceived their doctors as having poor listening skills especially in relation to emotion talk. Doctors were perceived as limiting and/or not allowing participants to freely talk about their emotions and feelings.

"He had this really irritating habit ... I found it really disturbing ... he kept cutting me off in my talk ... like he would keep interrupting me as I was speaking ... it's like he only wanted to hear whatever he wanted to hear ... and I noticed when I started telling him about my feelings and about how things were not right at home and at work. he cut me off many times and kept asking medical questions like the location of the pain ... that sort of thing. He was getting very uncomfortable with my talk about my feelings and my emotional stuff ... it's like he couldn't handle it at all ... he didn't want to know anything about how my illness was affecting my life ... he didn't want to know any emotional stuff at all ... he just did not want to hear about it at all." (Rosemaru)

Participants also perceived their doctors as unemotional and cold.

"I could see he was getting very uncomfortable when I started crying during the consultation ... I don't know where that came from you know ... I usually don't cry in my consultations, but that day I just couldn't help it at all ... it all just came out. He was unemotional at that time ... he just kept on voicing and just handed me his tissue box ... he didn't offer any words to say it's ok ... nothing like that at all ... he didn't hold my hand or anything ... he didn't offer any comfort ... he just kept on voicing and made his notes as I cried in his office." (Fiona)
Participants perceived their doctors as unsympathetic about broader social issues affecting their lives due to their illnesses. They felt that their doctors did not fully understand what their families were undergoing and that their families were also suffering. Participants reported being given little opportunities to openly discuss broader issues resulting from their illnesses.

“I found him to be really cold during our consultation ... he was very unsympathetic to all that was going on in my life because of my condition. I found him as very unfeeling towards me ... like his tone of voice and his words were very factual you know ... he interrupted me quite a few times when I started explaining about how this started. but he was most disinterested. I got the feeling he was indifferent to my needs at that time. It's like there was no warmth in his conversation to me ... and he really did not want to know about how everything in my life had changed ... how my family was suffering ... and how hard it was for everyone at home ... he just lacked that complete dimension altogether you know.” (Paris)

5.3.3. Feeling rushed and directed by doctor

Participants expressed dissatisfaction at being rushed and directed during consultations with their doctors. They voiced not being able to openly talk and not being able to take their time during conversations. They felt under strong pressure to hurry along during the consultation process.
"I really got the feeling that he was rushing me along in that consultation. He wouldn't let me talk openly ... I mean he wouldn't let me tell him things in my own time ... like he would interrupt me quite a few times and ask me about something else ... like you know please get to the point because I'm a very busy man ... that sort of thing ... that really pissed me off ... he kept looking at his damn watch all the time ... it was really infuriating ... like he didn't have enough time for me or something. He did that a number of times during our talk you know ... and the weird thing is that every time he did that. I would start rushing with whatever I was telling him ... I don't like being rushed especially when I'm sick and in need of proper medical help." (Andrew)

Participants also expressed dissatisfaction at the manner in which they were directed by their doctors during the consultation process.

In particular, they were dissatisfied at not being given opportunities to contribute fully in the consultation process. Some participants found the attitude of their doctors as "condescending" especially when their doctors did not ask for their input regarding treatment options. Doctors were perceived by participants as directive rather than openly discussing treatment options.

"I just found the whole thing very one sided ... rather than me telling him all. he kept asking for bits of information that he was interested in ... it's like I couldn't talk freely at all. This was so obvious when he started telling me about the treatment options ... rather than discuss the options to find out the right one. he kept telling me what to do and what not to do ... I found that very condescending of him ... he didn't ask about my views on treatment options at all ... I'm not dumb ... I'm a graduate and a thinking person ... I don't like anyone shoving their ideas down my throat at all ... I like to be part of solutions too ... it's my life. my body and my health ... I really felt like I was unable to express my feeling in there with him ... when I started telling him
about what was happening to me. He kept cutting me off by asking me to tell him about things that he wanted.” (Zoe)

5.3.4. Feeling anxious, frustrated, and confused

Participants voiced feeling little connection between themselves and their doctors during the consultation process. When doctors failed to ask about their backgrounds and broader issues to do with their lives, participants perceived this as their doctors cutting them off and not wanting to know them as persons.

“There was no connection between us at all you know ... I mean this was new and I just didn’t know him ... during the consultation he made no attempts to get to know me and he didn’t ask much about my life and my background ... he started cutting me off as I started telling him more about myself ... I decided not to get friendly with him because I strongly got the feeling that’s not what he wanted. He wanted me to just stick to the details about my pain. I really didn’t feel any vibes between us at all ... I felt frustrated about that ... I mean what’s the point if I couldn’t even un to him?” (Eweka)

Participants felt as if they were gagged and not being able to connect with their doctors. They felt emotionally alone and perceived their doctors as emotionally switched off.

“I felt like I was gagged when I was with him in that consultation ... he didn’t allow me to tell him about how this condition was affecting me and my loved ones ... that made me very angry ... it really anered me when he offered no emotional support in the consultation ... I mean he could see I was upset and very stressed out about this
illness and how it was affecting my life … he offered no words of comfort … nothing like that … it's like he was emotionally switched off … he looked very uncomfortable and I could sense he didn't like me expressing my emotions like that … I felt very alone and very upset at that time.” (Fiona)

Some participants perceived their doctors as rude during the consultation process and felt angry and offended. When their doctors failed to offer them direct answers for their questions, they felt confused and dismayed.

“I remember as I left her surgery I felt extremely pissed off at her for having treated me that way … she was just so rude … and it was so obvious that she was more concerned with her patient numbers rather than individual care … she basically had no time for me … she didn’t want to hear my version of what had happened to me … I still feel angry at her just thinking about it now.” (Paris)

5.3.5. Feeling powerless being in there

Participants voiced feeling powerless in their conversations with their doctors during the consultation process. Despite feeling rushed and directed in the consultation process, participants felt powerless to object and complain fearing that this might hinder future attempts at obtaining help for their illness conditions. They voiced feeling strong pressure to comply and feared not upsetting their doctors.
"I really did not like the way he kept rushing me in the consultation ... I didn't get the chance to say what I wanted to say and I was unable to fully express what was going on in my life ... I couldn't do anything in that situation at that time you know ... it's strange that I felt unable to say to him not to rush me along ... I really felt quite powerless being in that situation ... I needed his help and I wasn't going to upset him in any way." (Andrew)

Some participants reported feeling inferior during the consultation process. When their doctors failed to explain complex medical information in user-friendly terms, participants felt angry, confused, and inferior. They also felt inferior and intimidated when their doctors started correcting their talk by using medical terminology during the consultation process.

"Being in that consultation made me quite angry ... and when he didn't answer my questions directly, I felt even more angry ... he kept telling me things in real medical terms ... names of bones and muscles ... I couldn't understand any of this at all. I felt really inferior being in there with him ... like he knew so much and I didn't ... he could have explained that to me in simpler terms, but he didn't. I just sat there like some dumb fool getting more and more confused and feeling all that anger within me." (Zoe)

5.4. Biomedical diagnostics

The theme of biomedical diagnostics outlines participants' experiences of being in biomedical diagnostics and environment. It is comprised of two sub themes: Pervading anxiety with diagnostics.
and feeling angry with diagnostic staff. This is demonstrated in Table 8.

<table>
<thead>
<tr>
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Table 8: Biomedical diagnostics

5.4.1. Pervading anxiety with diagnostics

Participants voiced feeling extremely anxious regarding the diagnostic tests and procedures that their doctors had recommended. They were unsure as to what was expected of them during the diagnostic procedures and they were frightened as to the results of these diagnostic tests and procedures.

"I was really frightened at just the thought of going through the diagnostics you know ... I was afraid of what was going to happen to me ... what I was supposed to do in there ... my doctor didn’t tell me anything about that you know ... he just wrote the referral and said that they would tell me what’s involved ... I think the most frightening thing was not knowing what they would find ... I thought I was done at the time ... and I didn’t want this to be true." (Zoe)
Participants felt frightened not knowing the outcome of their diagnostic tests and the prospects of an uncertain future. They voiced paradoxical feelings regarding these diagnostic tests and procedures: They wanted these tests to identify and reveal their concealed illnesses conditions, yet they were frightened that these tests would reveal something serious and life threatening that would change their lives and the lives of their loved ones forever. Participants indicated that while these tests would help and enable them to be treated for their illness conditions, it also had the potential to reveal something serious that would limit the project of living their life dreams and separate them from living life with their loved ones. They described living paradoxically and in a state of unbearable uncertainty.

"The diagnostics did frighten me a great deal ... it's like I had lived with this bloody thing within me for so long and I really didn't know what was in there ... all I knew at the time was whatever this thing was. It wasn't good for me ... it was destroying me and my life with my family ... it was destroying my future days ... and the thought that they were going to probe and find out about this thing made me very uneasy ... I mean I was having something was being done about my problem, but I also had this side to me that really didn't want to know ... I just wanted them to cure me ... so this uncertainty was quite unbearable for me ... it was horrible." (Sharon)
Participants experienced the diagnostic environment as cold and clinical. They voiced feelings of not wanting to be in there, and the environment as making them sicker. They encountered the diagnostic space as mechanical with machines and wires and felt alienated being within this space. Participants were dissatisfied with the attitudes and interpersonal skills of associated diagnostic staff. They described the staff members as cold, unfriendly, and hurried.

"I didn't want to be in there at all ... I wanted to get out of there as quickly as possible ... that whole place was making me more sick ... the staff were very cold and very busy in there ... it's like they had no time for small talk or anything like that ... it's like everyone there was in some great rush ... they just wanted to move me along as quickly as possible ... there were all these machines and wires in that room ... like some sort of car repair shop or something ... it was cold in there and just a very dull miserable environment ... not a warm friendly place at all ... I remember sitting there on the X-ray table thinking what was I doing here ... I felt so alone and so frightened ... I felt very uncomfortable there at that time ... it was very stressful ... and no one told me anything in there you know ... like they kept me waiting and I didn't even know what they were doing or what stage they were up to ... I didn't even know that they had finished the procedure ... I kept sitting there in that cold X-ray room naked in that stupid robe for sometime and this receptionist came looking for me to say it was all over." (Zoe)

5.4.2 Feeling angry with diagnostic staff

Participants expressed feeling angry with staff during the diagnostic process. They felt angry when staff lacked technical competence and made mistakes with diagnostic equipment. Some participants found
themselves with inexperienced diagnostic staff and voiced feeling less confident with them. Due to technical errors, participants experienced long delays during their procedures. They found this annoying, as they wanted to finish their stressful diagnostic procedures and go home to a familiar comfortable space.

"I really got the feel that this guy didn’t know what he was doing ... he was clumsy and he kept making all sort of mistakes ... I could see he was very nervous ... maybe it was his first day or something ... I got really upset at having to be treated by him during the diagnostics ... I was already so nervous in there and the last thing I needed was to be handled by this fool ... and he kept saying he was sorry all the time ... that got me more anxious knowing he had made another mistake ... and I really wanted to get out there as quickly as possible ... and because of him it was taking so bloody long ... it was a very annoying process being in there ... I don’t ever want to go through that at all.” (Rosemaru)

5.5. Biomedical treatment

The theme of biomedical treatment describes participants’ experiences of being in biomedical consultations and treatments. It is made up of five subthemes: being told diagnosis; encountering reality shock; being prescribed medications; taking medications; waiting, hoping and evaluating. This is outlined in Table 9.
5.5.1. *Being told diagnosis*

Participants expressed dissatisfaction at the manner in which their doctors conveyed their diagnostic test results. They were shocked to find that their doctors did not convey bad news in a timely sensitive manner. Some participants indicted that their doctors did not prepare them for bad news regarding their test results. Furthermore, they reported that their doctors did not spend enough time to emotionally facilitate the delivery of bad news. Participants experienced shock and felt emotionally destabilised during this process as their doctors offered very little emotional support.

"I really found it very shocking the way he told me my results you know ... like he didn't spend any time in preparing me for the bad news at all ... I mean I do a better job when I tell others bad news ... he just looked at my results and told me that I had cancer ... just like that you know ... I just didn't know how to take it at all ... I was so unprepared for that ... I knew something was wrong with me, but I never in my wildest dreams thought that it was going to be cancer..."
... he could have told me the results lighten you know so that I could better handle it ... like he could have softened the blow you know ... that still makes me angry just thinking about it ... and he was so cold about it too ... he didn't offer any emotional help at all ... he was very dry and very matter-of-fact about it ... he could have offered some kind of emotional support ... I would if I was in his position ... he just didn't realise what was going through my head at that time ... it's like my whole world had come to an end.” (Eweka)

Some participants expressed dissatisfaction at their doctors for not providing enough medical information and for not answering questions in detail regarding the diagnostic tests. They experienced their doctors as condescending towards them especially in relation to their questions regarding biomedical test results. Participants felt that their doctors did not understand their informational needs at that time. Some participants reported their doctors as getting upset and angry when asked questions as to the validity of the test results and the possibility of errors.

“I felt so confused looking at the results of my test ... there were all these numbers on the sheets ... some numbers were in bold print and the others were in normal print ... but all these numbers and figures were meaningless to me ... I couldn't understand these results from my blood test ... so I asked him to explain all the figures. But he cut me off by saying don't worry about all that ... that I wouldn't understand it ... I felt pretty annoyed by that ... it's like I was too dumb for him to explain his medical tests ... he said that things were not right and that I had HIV ... but I really wanted to know what all those figures meant (loud angry tone) ... I needed to know that they had got it right ... but he didn't understand my need for information at all.” (Andrew)
5.5.2. Encountering reality shock

Participants voiced being in a state of shock upon hearing their test results. They were speechless, frightened, and did not know what to do. Some voiced experiencing body shivers and tremblence. Losing all self-control, they felt tears in their eyes and cried while in consultation with their doctors. Participants with life threatening conditions felt life coming to an end and the death of their hopes and their dreams of future days.

"I was really in a state at that time you know ... I didn't know what to say ... I didn't know what to do ... I felt like I'd come to the end of my journey in life and everything was coming to an end ... my body was shaking at that time ... I just couldn't control my nerves ... I could feel my feet shaking and this knot feel in my stomach was getting tighter and tighter ... As he told me the diagnosis. I could feel these changes in my body ... I was very tense and very frightened ... I was shocked and really couldn't take the news at all ... my whole life was owing to change into something I did not want ... I just didn't know what to do. I remember I started to cry ... I don't know where that came from ... it sounded strange ... like very deep and strange ... he didn't do anything to comfort me during this time ... he just kept owing with the consultation and started talking about medications and that sort of thing." (Paris)

Participants reported being in such a state that they could not listen and think properly. They report being in a state of utter numbness and losing all focus of concentration. Despite being in such tense
and stressful states of mind, all participants reported that none of their doctors offered any emotional help and physical comfort.

Participants expressed intense anger when recalling this moment during the research interviews. Their doctors continued with their consultations and proceeded to rush them into discussing treatment options and medications. Participants expressed anger at how their doctors did not allow them any time in coming to terms with their results. Their doctors offered no space for them to come to any acceptance of their bad news.

Participants were stunned that despite being in such heightened emotional states, whereby they were not listening, not thinking, and not concentrating properly, their doctors proceeded in discussing treatment and medication issues. Participants expressed that they wanted time and help at that point in time in coming to terms with their bad news. They reported needing emotional help and support at that point in time.

They also reported needing help in communicating the bad news to their loved ones. They too would suffer, as participants knew that their loved ones were going to hurt and suffer upon hearing the test
results. They felt dismayed that their doctors did not offer any help and did not prepare them in any way as to how to communicate bad news to their loved ones, who were eagerly awaiting to hear the outcomes of the test results.

"I was so shocked by the results that I think I just stoned listening at that time ... there were all these thoughts going through my mind at that time ... I just could not take it at all ... it's like my worst nightmare was coming true before my eyes and I couldn't do anything ... I felt so lonely at that time and I really wanted to just get out of there and go home when I could really cry and be with myself ... but this bastard kept on voicing ... he was giving me all this medical stuff ... he wanted me to try this pill ... I wasn't even listening properly ... I couldn't take it in at all ... he wanted to discuss treatments at that time." (Geoffrey)

"I started to cry in there ... I couldn't hold it back any more ... I didn't know what to do ... I hadn't thought of the possibility of dying and now I was faced with it ... I didn't know what was going to happen to me ... I didn't know if I was going to make it through ... it was horrible that feeling at that time ... he offered no emotional help at all ... he just kept sitting there saying he was sorry ... that's it! I was so cold at that time ... like he was getting really uncomfortable with me ... like he wanted me out of there as quickly as possible ... I felt really helpless ... I couldn't do anything to change it at all ... like there was nothing I could do that was going to get me back to normal again ... I kept thinking of my family at that time ... I kept thinking of how I was going to tell them my bad news ... I knew how it was going to hurt them and how it would change their lives too ... I was going to die ... I couldn't cope with that at that time ... it was awful ... it's like my whole life had changed before my very eyes ... I needed time to take it in myself ... I needed to control my own feelings ... I just couldn't cope at all ... and my doctor offered no help at all ... bloody nothing!" (Sharon)
5.5.3. Being prescribed medications

Despite “not coping with the bad news” from their diagnostic tests, participants found their doctors to be prescribing different medications during their consultations. Participants expressed anger at their doctors for not attending to their emotional states at that point in the consultation. Doctors were perceived as being busier searching for medications on their computer databases than attending to the participants in person. Some participants expressed alarm that their doctors did not know off hand what medications to prescribe. Moreover, others were shocked that their doctors did not fully discuss the medications being prescribed. All participants reported that their doctors did not meet their informational needs concerning medications and possible side effects arising from these medications at that point in time.

"I was really shocked by this vuw ... he didn't know what medications to prescribe to me ... I mean he kept turning away into his keyboard and kept looking up different medications ... I remember thinking to myself that he really didn't know his medications too well ... and he kept doing this for a while ... like he didn't tell me what was going on. He didn't even discuss the medication with me ... he didn't inform me about the range of things that were available and how they were going to affect me ... he wrote me this script and just wanted me to go away and take it ... I don't overate that way you know ... I want to know what I'm taking and how that's going to affect me ... when he didn't discuss the medication with me. I decided to ask him about it. It's at that point I realised that he didn't know much about it at all ... he said that it was something new on the market and one that was highly
recommended. When I asked him specifically about the side effects and how long it would take to treat me, he couldn't answer me. That was shocking because I expected him to know his medications so that he could explain it to me.” (Rosemaru)

5.5.4. Taking medications

Participants voiced being hopeful that their medications were going to ease their suffering from their illness conditions. The thought of getting better and breaking free from the constant bodily pain acted as motivation towards using medications.

“I remember the time when I first started taking the medications ... I was so hopeful that I was going to get better you know ... I just wanted to get better ... I wanted to free myself from all this pain ... I was really suffering at that time and I was really sick and tired of that pain ... I felt very positive at that stage ... I really believed that the medications were going to get me better.” (Sharon)

However, all participants soon developed severe side effects from using their medications. All reported a worsening of their illnesses conditions and increased suffering.

“After taking the pills for about a week, I found that I was getting sicker you know ... I was vomiting everyday ... there were stomach cramps that started to happen ... I was getting very severe head aches too ... like really bad ... at nights I used to shiver because I was feeling so cold ... I remember that vividly you know ... I used to get really cold and shiver ... so with all these things happening I kind of knew that something was not right with these pills ... they were making me more sick and I just couldn't stand the side effects ... my
vain was vetting more and more and I thought no this stuff isn't doing me any good.” (Mark)

Some participants found that their medications were affecting daily activities and thought processes. Family members were helpful in bringing to attention irregularities in behaviours of such participants.

“This is very difficult to describe to you ... after I took the pills I really felt very alleviated you know ... it's like I could feel myself vetting very moody and very edgy ... it was just horrible really horrible ... it's almost like I was losing my mind ... I noticed that I wasn't thinking properly ... like I couldn't hold on to thoughts at all ... and everything was happening at once in my mind ... all these thoughts would come rushing in all at once ... I noticed that I couldn't sleep at all ... I would be in bed thinking thinking thinking ... like I couldn't stop thinking ... it just went on and on ... I'd be in bed thinking till it was daylight again ... then I couldn't do anything because I was so tired ... you know I didn't sleep for the first two days at all ... it was horrible... even my family members noticed it ... they kept telling me that I wasn’t talking and behaving normally ... they found me moody and highly irritating at that time.” (Fiona)

Participants reported contacting their doctors and informing them of the side effects. They expressed dissatisfaction with their doctors as not being too sympathetic to their reports regarding the side effects. All participants were advised to continue with medications, and they were asked to be patient and wait longer for these
medications to work. They maintained their use of medications and waited hoping for some relief from their pain and suffering.

"So I phoned my doctor and after many attempts I finally got hold of him ... I remember explaining to him that it wasn't working and I was getting very strong side effects ... he cut me off by saying it was too soon and I just had to wait for some time to get the medications to work ... when I explained that I couldn't possibly go on like this ... especially with the side effects. I remember him telling me that it was normal to feel those things and just bear for a bit longer ... I mean I couldn't believe this was ... I was telling him that it wasn't working and that I was suffering, but he just dismissed all that ... it's like he didn't want to know about it." (Zoe)

5.5.5. Waiting, hoping and evaluating

Participants continued with their medications hoping that their illness conditions would improve. They described this waiting period as a hard and difficult time whereby they continued to suffer from the side effects of their medications. During this time, they also found it difficult coping with their daily activities and roles within their families. Participants maintained their hope that they would get better by thinking positively and thinking of better days ahead. Some participants engaged in prayer and found strength to endure their ongoing suffering. After a period of hoping, praying, and waiting, participants came to the painful realisation that their
medications were not working and that their conditions were
gettine worse with passing time.

"So I kept taking these pills and kept havine that I would get better ... it was actually a very hard thing to go through you know because I kept feeling all the side effects ... I had problems doing my normal stuff at home you know ... I just couldn't cope at all ... I did my best to think of positive things you know ... I constantly reminded myself that I still had a lot to do in life ... that there were going to be better days for me ... it was just very horrible at that time ... but I had no other choice at that time ... I just had to do take the pills ... and I thought that the side effects would pass as my doctor had informed me ... but the side effects didn't pass and I only got sicker in time." (Euweka)

Participants generally found that their suffering increased and that their constant bodily pains were not getting any better. Coping with their illness conditions became harder during this time and participants found that they were losing all control over their lives with worsening conditions.

"While I was waiting for the medications to take effect, I noticed that I was getting worse ... I noticed that my pain was increasing and that I was finding it harder to cope ... and just generally I was feeling worse ... I just couldn't cope at all ... it's like I was losing all control over this thing ... I just couldn't control it any longer ... I didn't know what to do ... and I was getting very tired physically and mentally ... I really thought that maybe the medications were not doing the job because it was too soon ... I think I waited for about a month or so ... that's when I really knew in my heart that the medications were not doing the job." (Fiona)
With their worsening illness conditions and their increasing inability to cope, participants decided to stop all medications. They reported making this decision because they didn’t feel good about taking the pills any more. Some participants reported reaching the understanding that the medications were not right and that the medications were doing more harm than good by listening to their bodies and observing how their bodies felt. They reported this point in time as “like reaching a personal crisis point and a very confusing time whereby they did not know as to what to do next. Participants also voiced feeling very anxious with their doctors and they felt that their help seeking efforts had been a complete waste of time and effort.

“I came to that point where I decided to stop all medications ... I had waited long enough to know that they were not working ... and you know it's like my body was telling me this too ... the side effects didn't stop and I kept getting sicker ... I felt like my body was fighting with my illness as well as these medications ... it's like I kept getting sicker that my body was not getting used to these medications ... it's really strange you know ... after I stopped the medications for about two weeks. I started to feel better (laughs) ... yes. That's right. I started to feel a whole lot better ... more like what I had been before going to see my doctor ... I mean my illness was still with me at that time, but I felt so much better for having stopped the medications ... it's like the best thing I did during that time ... just by listening to my body you know.” (Zoe)
5.6. Summary

This chapter described research participants' experiences of seeking and obtaining biomedical treatments for their illnesses. We saw how participants felt anxious with biomedical personnel, felt nervous waiting with other patients, and felt uncared while being in biomedical environments. Moreover, we saw how patients felt uncomfortable being in consultation rooms and with diagnostic procedures, felt rushed and directed by biomedical personnel whom they perceived as cold and detached, felt anxious, frustrated, and confused; and felt being powerless in consultations, diagnostics, and treatments. We also saw how participants' experienced 'reality shock' in being told their diagnosis, and how participants' experienced negative side effects of prescribed medications. Despite such negative side effects, we saw how participants' continued with their prescribed medications while hoping and waiting to get better.

The next chapter presents participants' experiences of seeking and obtaining complementary treatments.
6. Seeking complementary treatment

6.1. Introduction

In the last chapter, we discovered research participants' experiences of seeking and obtaining biomedical help for their illness conditions. In particular, we explored their experiences of being in biomedical environments, biomedical consultations, biomedical diagnostics, and biomedical treatments encountered in their help-seeking journey. This chapter describes research participants' experiences of seeking and obtaining CAM help for their illness conditions. In particular, we explore their experiences of CAM environments, CAM consultations, CAM diagnostics, and CAM treatments encountered in their help-seeking journey.

6.2. Complementary environment

Participants vividly talked about their experiences of complementary environments encountered in the process of seeking help for their illness conditions. These complementary environments consisted of rooms within their respective therapists' homes. All participants reported that their respective therapists were operating from within their homes. Three main themes emerged after an analysis of their conversations: being surprised.
feeling uplifted, and feeling hopeful. This is demonstrated in Table 10.

<table>
<thead>
<tr>
<th>Theme: Complementary environment</th>
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<tr>
<td>Sub Themes:</td>
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<tr>
<td>• Being surprised getting there</td>
</tr>
<tr>
<td>• Feeling comfortable and uplifted</td>
</tr>
<tr>
<td>• Feeling hopeful</td>
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Table 10: Complementary environment

6.2.1. Being surprised getting there

Participants reported being surprised at the easy availability of appointments with therapists, as all participants were able to get appointments for the next day at the time of making their initial inquiries. They had expected to wait for appointments based on their earlier biomedical experiences, whereby participants had often waited for as much as three months to get appointments with biomedical specialists.

"I was so surprised you know ... really surprised when I got there ... I mean I was able to get an appointment straight away and I didn’t have to wait at all ... that was quite shocking you know because normally I’d wait for months to see a medical specialist ... so for me that was a major plus ... knowing that I could see someone about my condition straight away and not having to wait and suffer in the mean time I started feeling very positive about seeing this therapist when I
was able to get an appointment for the next day ... that made me feel good as I knew that I was doing my best to get this thing cured. I really liked the fact that I could see her straight away ... it's like she understood my need and that it was urgent for me to get to see her ... that made a huge difference to the way I was feeling at that point in time.” (Rosemaru)

While making initial inquiries and appointments, participants also expressed satisfaction at having to deal with therapists directly rather than reception staff. Participants perceived this direct contact with therapists as being close and as being personal.

“I was really very happy about talking with her directly you know ... it felt personal to me you know ... I don't like going through three or four others ... telling them your story again and again you know that sort of thing. I like dealing with people one-to-one ... that's very true for things medical ... I like dealing with my doctors directly rather than some receptionist who doesn't know much ... I liked the fact that I could talk with this therapist directly unhindered by receptionists and other staff like that ... that direct connection made all the difference to me.” (Paris)

In getting to therapists, participants reported being surprised at finding therapists operating from a normal suburban house rather than a clinical surgery. Based on their earlier biomedical experiences, they had expected to find a surgery with reception staff.
"I was so surprised to yet there and find a normal house ... I kept driving and looking around for a clinic ... I don't know where I got that idea from ... but I had this picture in my head it would be some sort of clinic ... I don't know why ... I mean I'm used to a doctors surgery with reception staff and all that ... this was a house in the suburbs ... nothing too flash. just like my house really." (Andrew)

Participants reported being surprised by the warm and friendly welcome of their therapists. Therapists were reported as being real. warm, friendly, casual, and without the attitude of professionalism. Participants reported being able to relate with therapists as persons and feeling comfortable in meeting them.

"She came across as very down to earth and friendly ... she had a pleasant warm smile about her and she greeted me as my friends would ... She didn't have any fake-ness in her voice and she didn't try to sound or look professional and cold ... it's like I could instantly relate to her as a person you know ... to me it was like meeting one of my friends ... my initial reactions to her were very warm and I felt comfortable in meeting ... she was dressed casually ... kind of homely ... you know without all that business look and professional suit stuff ... I like that you know ... in a sense she looked more like me ... easy voice and friendly without trying to be somebody else ... her tone of voice was very friendly ... she spoke nicely without any sort of stuck up feel about her ... it suggested to me that she was an open kind of person ... someone that would listen and be interested in my problem." (Rosemaru)
6.2.2. Feeling comfortable and uplifted

Participants reported feeling very comfortable while being in the therapists' home, and reported feeling uplifted in mood. They reported that therapists made them feel most welcomed into their houses by inviting participants into their living rooms and offering a variety of teas, juices, and fruits. Participants reported feeling being expected, being welcomed, and being wanted. They reported appreciating the time and effort therapists had taken in preparing for their consultation, and felt valued as persons.

"I felt so good in there you know ... sitting in her lounge room ... it was a very comfortable space in there ... I felt very comfortable just being with her ... it's hard to describe this to you ... it was almost like being at home yet not at home ... that kind of thing ... I was certainly comfortable ... and I could just feel myself relaxing as I talked with her ... I wasn't frightened or scared of her or the place at all ... I'd describe it best as saying that it was like visiting a good friend or family member ... that sort of thing ... very comfortable ... there was this big smile about her ... very natural and real too ... she looked happy ... like she was not rushed, not anxious ... nothing like that at all ... and she looked comfortable with her casual stuff ... when I met her initially and talked in her lounge. I felt good being with her ... it just did you know ... like there was a very peaceful presence about her ... like I could feel it somehow ... she came across as very comforting and motherly ... she made me feel very welcomed and needed ... like there was genuine interest in me on her part ... I felt that being with her." (Geoffreu)

Furthermore, participants reported being able to relax and reported feeling very homely being with therapists in their living rooms.
They described the physical space as: colourful with vibrant colours, peaceful with lots of green plants, soft music playing in the background. Participants reported being sexually aroused with the smell of incense and aromatic oils from oil burners, and described these smells as delicious, heavenly, soothing, and lovely.

“Well it’s a strange feeling to describe to you. I felt so relaxed in there you know … I don’t think I have felt that relaxed for quite some time … and the strange thing is I really don’t know why (laughs) … it was a beautiful feeling being with her in there … I was in a very comfortable surrounding and it’s like there was no pressure on me to say this or say that at all … and it was very personal … just me and her so I didn’t have to worry about other people … she certainly helped in making me feel comfortable … she asked me to just relax. Talk when I wanted to, stop when I wanted to … that was nice of her … she did the same too … like there were lots of silences in our conversations … like I could hear her breathing … I could hear myself breathing too … am I making any sense at all? The walls had lovely picture frames of nature … all sorts of pictures … rain clouds, waterfalls, beautiful flowers, lush green fields … it was very soothing looking at them and I felt comfortable … it was heavenly being in there … the incense burning in the holder … you know slow smoke drifting across the room, gentle music playing in the background … there were like five oil burners going on … it was lovely and very soothing … it made me remember my own home … I mean I burn incense and use oil burners for aromatherapy at home … it’s like I could relate with all that … sort of familiar and comfortable.” (Iain)
6.2.3. Feeling hopeful

Participants reported feeling hopeful and optimistic in meeting with therapists. All participants vividly and excitedly described the spaces within therapists' living rooms as being bright, inspiring, positive, and having good energies, which they could feel within. Some participants reported losing focus of their pain and associated problems, whereby they focused on the environment and feelings generated being in such spaces.

"I could feel getting more and more hopeful that I was going to get better ... I mean she was so positive about everything ... in fact she's probably the most positive person that I have ever met. I felt energised ... like charmed up being with her ... like I wanted to do my very best to get better ... I suppose in listening to her and being in that atmosphere, I felt very inspired about my illness and my life. It's as if I discovered I had it in me to still battle on with this thing ... that it wasn't the end ... I still had so much to look forward to in life ... she pointed out so many things to me during our conversation ... like I had achieved so much in life, that I was a loving person, that I was responsible. You know that sort of thing ... like really positive things that I had not thought of for a while ... it's almost like I had forgotten all that about myself. I felt stronger at that moment you know just being with her ... that sort of talk has real power you know ... it's like I had this energy to do anything ... it's hard to describe ... like believing in yourself again, hoping and wanting to live again." (Eureka)
6.3. Complementary consultation

Participants excitedly reported their experiences of complementary consultations encountered in the process of seeking help for their illness conditions. Four main themes emerged after an analysis of their conversations: feeling comfortable being in the consulting room, feeling connected with the therapist, feeling surprised by questions, and feeling astonished at consultation times. This is outlined in Table 11.

<table>
<thead>
<tr>
<th>Theme: Complementary consultation</th>
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<tbody>
<tr>
<td><strong>Sub Themes:</strong></td>
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<tr>
<td>• Feeling comfortable being in the consultation room</td>
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<tr>
<td>• Feeling connected with therapists during consultation</td>
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<tr>
<td>• Feeling surprised by questions asked in consultation</td>
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<tr>
<td>• Feeling astonished by consultation time</td>
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Table 11: Complementary consultation

6.3.1. Feeling comfortable being in the consulting room

After spending considerable time and rapport building with therapists in their living rooms, participants reported being consulted in rooms located within the same premises. All participants reported spending considerable time with therapists
during their initial stage of consultations, and described feeling comfortable, uplifted, and hopeful during this process as described above.

Participants vividly described the consulting rooms encountered during their visitation. All therapists had transformed a single bedroom within their homes into consulting spaces. While being shocked as to how different these spaces were in relation to their earlier biomedical experiences of consulting rooms, participants described these rooms as pleasant, comfortable, sensual, and soothing.

"I was really shocked when we went in for the consultation ... it was a room within the house you know ... it's like she had changed an old bedroom into a consultation room ... I remember walking through the corridors in the house and seeing bedrooms of her family members ... I remember seeing that her little boy in his room ... I was shocked because I had expected a consultation room like they have at my local surgery you know ... a small room with a desk and chairs ... those horrible posters of diseases, equipment, medications all that sort of thing you see ... so this was very personal you know ... it's like she had located her consulting room right next to the rooms of her loved ones ... I remember thinking at the time that it was a great idea ... you know a very personal space located next to her loved ones ... it was a sign of her being even and almost family-like in her approach to clients ... it's like she had welcomed me into her house in a very personal way." (Fiona)
6.3.2. Feeling connected with therapists during consultation

Participants described their conversations during the consultations as positive, uplifting, and hope generating. Moreover, they described therapists in positive terms and commented on their people skills. Therapists were perceived by participants as being good listeners and allowing participants to talk in their own words while taking their time. They offered empathy and emotional support were non-judgmental, caring and considered in their conversational relations with participants. Participants perceived their conversational relationship with their therapist as comfortable open chats and like talking with a good friend. They were able to freely talk and in a comfortable conversational manner. Participants described feeling more hopeful and more positive about their illness conditions in talking with therapists. They reported feeling connected with their therapists.

"She was so good to talk to you know ... I felt like I could truly open up to her ... and I did just that ... I talked and I talked ... and she listened too ... like she was looking at me all the time in a nice friendly sort of way ... not aggressively but in a calm sort of way ... and there was real interest on her part too ... that's something I felt ... she asked questions to check her understandings of what I was on about ... and her voice ... there was something to her voice ... it's like she spoke in a very soothing slow relaxed manner ... softly and caringly you know ... the amazing thing is that after a while I too was speaking to her in that sort of manner ... it's strange ... it's like she could ease my tension in telling my stuff ... like I was able to relax
and slow down with her ... and she was very positive too in what she had to say ... she kept reminding me of the positive things in my life. she reminded me that I was strong and that I could do this ... it's like she was very caring towards me ... it's something I felt being with her... talking with her was a very pleasant experience ... like the words flowed from me effortlessly ... and she didn't judge me or anything like that ... she didn't moralise or preach to me at all ... it showed to me she was kind considerate and respectful.” (Mark)

6.3.3. Feeling surprised by questions asked in consultation

Participants reported feeling surprised by the questions asked by therapists during the consultation process. They were shocked to find that therapists did not directly proceed to questions about their presenting problems. Instead, therapists inquired into very diverse areas of their lives in order to get broader holistic insights. Participants were surprised by these questions, as they had not expected such questions to be asked within the context of a medical consultation. They reported feeling positive about answering such questions believing that their therapists would understand them as persons and understand their associated backgrounds. Moreover, participants described this process as non-threatening, and more as a process of telling rather than answering. They reported feeling relaxed, whereby they were not rushed and/or hurried by their therapists.
"I was really surprised by the questions she asked me while we were in her consultation room you know ... I suppose I am more used to the questions asked by my doctor ... he asks about the problem and takes it from there ... she was different in her approach ... she wanted to know so much ... like my childhood, my parents, about my growing years, my education, my job, my family, my husband ... so many things ... but in a kind of indirect way ... like she wasn't putting any pressure ... it was very conversational ... kind of flowing you know." (Zoe)

6.3.4. Feeling astonished by consultation time

Participants were astonished by the long consultation times offered to them by therapists. Based upon their previous biomedical experiences, participants had expected short consultations. All participants reported spending more than one hour being in consultation and expressed shock at being given opportunities to freely talk uninterrupted and in unlimited time. Participants described their long consultations as comfortable, easy going, and productive. They perceived their long consultations as extended spaces and opportunities for voicing their concerns and providing information about themselves as persons.

"I was really shocked by how long this was taking ... I mean I was ok with time, but I kept wondering about the cost of the consultation ... I really thought she was going to charge me more for such a long consultation ... we would have spent at least an hour and half in this consultation you know ... it was amazing ... I have never been in any medical consultation for this long ... the most I'd spend with my local doctor is about five minutes and I'm used to my doctor charging me
more for longer consultations that last for about ten minutes ... so this was very amazing to me ... I mean that's a long consultation with a great deal of talking ... mostly on my part really ... but she was not rushed at all. she didn't rush me along ... I felt very comfortable with her you know telling her about myself and my life ... it's like she gave me lots of room to express myself ... I had time on my side for once in a medical consultation (laugh).” (Geoffreu)

6.4. Complementary diagnostics

Participants described in vivid detail their experiences of complementary diagnostics encountered in the process of seeking help for their illness conditions. Four main themes emerged after an analysis of their conversations: feeling stunned by diagnostics, feeling informed by therapists, feeling anxious about diagnostics, and feeling cared being with therapists. This is demonstrated in Table 12.

<table>
<thead>
<tr>
<th>Theme: Complementary diagnostics</th>
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<tr>
<td><strong>Sub Themes:</strong></td>
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<tr>
<td>• Feeling stunned by diagnostics</td>
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<tr>
<td>• Feeling anxious by diagnostics</td>
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<tr>
<td>• Feeling informed by therapists during diagnostics</td>
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<tr>
<td>• Feeling cared while being with therapists in diagnostics</td>
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Table 12: Complementary diagnostics
6.4.1. Feeling stunned by diagnostics

Participants reported feeling stunned by the diagnostics that their therapists administered. They reported undergoing energy readings using bare hands, palmistry, iridology readings, aura photography, and hair analysis. The most common diagnostics included energy readings and iridology readings. Participants reported feeling surprised, astonished, amazed, bewildered and taken aback. Moreover, they positively reported therapists as providing guided information regarding procedures and explaining the results of such analysis.

"I was really bewildered by her testing procedures you know ... she asked to lie down on the mat and she did some sort of energy reading of my body ... she placed her hands over my body at different varts and she informed me that she was reading the energy flow of my body ... at first I felt like laughing you know (laugh) ... it's just that I didn't know how to take this ... I mean I'm used to blood tests with my doctor so I know what to expect with him ... but with her it was different ... I just didn't know what to make of it ... I've never thought of my body in terms of energy fields, but she informed me when I asked her about what she was doing ... it was really interesting for me and I've never had that done before in my life ... yeah, it was a new experience for me ... a bit strange but interesting. She informed me about how the body had different energy centres and how they get blocked with sickness. I had strange sensations as she did that over my body ... it's like I felt great heat in her hands ... like intense warmth ... not heat or anything like that ... it felt good as I could feel something happening inside me ... it's like there were waves in small circles happening inside my body in places where she touched ... it was a very strange experience for me at that time." (Zoe)
6.4.2. Feeling anxious about diagnostics

Participants reported feeling anxious about diagnostics administered by therapists. Due to the lack of any previous experience with CAM, participants experienced paradoxical feelings regarding the techniques and the philosophical underpinnings of CAM modalities. For example, all participants expressed concerns about notions such as: enerev, enerev flows, enerev movements within the body, enerev blockages, chakra centres, auras, aura photographs and other similar holistic concepts. When their therapists undertook diagnostic procedures to measure enerev flows and auras, participants expressed confusion and worry. They were worried of the unknown, yet found these procedures challenging.

Some participants expressed disbelief regarding the philosophical aspects of the diagnostics, but continued with the process in the hope of trying something new to get better and to control intense pain. Two participants, self-identifying as atheists, expressed concerns that therapists had made references to spirituality and god during the diagnostic procedures. This made participants feel uncomfortable.
"During the diagnostics I remember feeling slightly worried about where it was all leading to ... I mean I had no problems with her at all ... she was very warm and comforting all the time ... when I started hearing about enervous readings and things like that I just didn’t know how to take it you know. I mean I’m a pretty logical and rational person (laughs) ... most times (laughs) ... but I just couldn’t divest all of this enervous thing ... I suppose it was new to me and I just felt uncomfortable at that time ... it certainly made sense ... but a felt this strange tension in my mind ... when she started talking about the spiritual stuff and about vod ... I kind of switched off from her at that time ... I just don’t believe in all that you know ... I identify as atheist ... I just couldn’t take her seriously at all ... I was willing to try her stuff during the diagnostics. But in a way I didn’t take it too seriously at the same time ... I wanted to try it out and explore that possibility you see. but I did not like her stuff about spirituality and vod.” (Mark)

6.4.3. Feeling informed by therapists during diagnostics

Despite their initial confusion over diagnostic modalities, procedures, and the philosophical underpinnings of CAM, participants continued with their procedures aided by therapists. They reported asking questions and seeking information regarding procedures as they were administered.

“I felt really puzzled doing the diagnostic things with her ... it’s like it was all new to me ... I didn’t know much about all that stuff ... I asked her so many questions you know and she offered good answers. I was able to understand what was going on in there ... she described the tests and told me a lot about how things worked in holistic medicine ... it made sense to me and I could see where she was coming from.” (Euveka)
All participants expressed satisfaction at the provision of information by their therapists. Participants received verbal information, guided demonstrations, information sheets, reference books, and referral information for organisations and groups specialising in particular modalities. They perceived their therapists as being well informed, resourceful, and honest in the provision of information.

"She offered books and a great deal of information sheets for me to read ... I mean she knew her stuff ... in fact she knew a great deal about her treatments ... and she took time in explaining these things to me ... she was very patient and informative ... she gave books to take away home to read ... I'm still reading them ... it's like a whole new way of looking at things ... she informed me a great deal during that consultation ... things like the diagnostics and her treatment style ... she answered many questions and she never got irritated by any of my questions at all ... I appreciated that she was honest with me to ... like she had no problems in openly telling me that she didn't know some answers to my questions ... I liked that in you know ... my doctor certainly doesn't do that ... he pretends that he knows all." (Fiona)

6.4.4. Feeling cared while being with therapists in diagnostics

Participants reported feeling cared while being with their therapists during the diagnostic procedures. Therapists were perceived as gentle, nurturing, respectful, and courteous during diagnostic procedures.
"I felt very cared while I was with her in our consultation ... I don't think there was any moment where I felt like I was in wrong hands at all ... she was very nurturing in the consultation you know ... she was very gentle with me ... respectful and courteous ... she let me take my time ... she answered my questions and provided me with a great deal of information ... and she was encouraging all the time ... I felt very positive about what I was doing even when I concerns about energies and auras." (Geoffreu)

Participants appreciated the provision of information and positive feedback provided by therapists, and participants attributed this to feeling cared. For some participants, feeling cared while being with the therapist emerged out of the physical touch of their therapists. They appreciated that their therapists had used bare hands in touching their bodies during the diagnostic procedures, and they described this as caring. Other participants reported feeling emotionally cared, and they attributed this to the interpersonal skills and abilities of their therapists.

"What stands out to me even after all this time was that she touched me with her bare hands during the diagnostic things she did ... she knew I had HIV because I had told her that upfront you see ... she didn't hesitate in any form of touch during the whole time I was with her ... she held my hands and comforted me ... she was so caring and in a very natural way ... I could feel that she was genuinely interested in helping me ... she wanted the best for me ... she wanted to calm me down ... I felt all that with her ... I thank her for that sort of closeness you know because I felt cared with her ... even my own doctor didn't do that ... he always had gloves on ... like he's afraid that he might catch it ... I felt like a piece of contaminated shit with him." (Andrew)
6.5. Complementary treatment

Participants described their experiences of complementary treatments encountered in the process of seeking help for their illness conditions. Six main themes emerged after an analysis of their conversations: being told diagnosis, being surprised, being prescribed vitamins and notions, being prescribed exercises, being asked to change lifestyle, and going home and trying out recommendations. This is outlined in Table 13.

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<thead>
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<th>Theme: Complementary treatment</th>
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<tr>
<td><strong>Sub Themes:</strong></td>
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<td>• Being surprised by diagnostics</td>
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<td>• Being prescribed vitamins, minerals, and notions.</td>
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<tr>
<td>• Being prescribed physical and mental exercises</td>
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<tr>
<td>• Being asked to change diet and lifestyle</td>
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<tr>
<td>• Going home and trying out recommendations</td>
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</table>

Table 13: Complementary treatment
6.5.1. Being told diagnosis

All participants reported high levels of anxiety and paradoxical feelings in relation to finding out their CAM diagnosis. They reported: feeling worried, feeling hopeful, and feeling anxious.

"I was worried, hopeful, and anxious ... like all at the same time when it came to being told about my diagnosis. We had spent a lot of time talking and being together, and I was really eager to find out what she had to say about my condition." (Sharon)

Participants reported that all therapists delivered their CAM diagnosis in a caring, gentle manner and being emotionally connected to participants' needs during the delivery of diagnosis.

"She did it very nicely you know ... like she had been so patient all alone and she had provided me with so much information ... she came and sat next to me ... really close and held my hands ... it's like we emotionally connected you know. She asked me to do some breathing exercises with my eyes closed and I did that ... I felt calmer and collected really. Then she told me that my earlier biomedical diagnosis of cancer was correct ... and that she was going to help me to deal with my pain and make my body stronger by building it up with vitamins and mineral salts. She was so gentle about this you know ... it's hard for me to describe ... it's like she could feel my pain at hearing that from her ... like she cared enough to choose her words." (Eveeka)
All participants reported that their therapists confirmed their earlier biomedical diagnosis of their illness conditions, and did not make any attempts to refute and/or discredit their earlier diagnosis:

"She didn't dispute my HIV results at all ... she told me she was voing to work from my medical results you know ... so she wasn't like aruing with my earlu diaison with my doctor ... she said that her tests revealed that my bodu was etting weaker and that I need heling to get on with my life." (Geoffreu)

However, all participants reported therapists as identifying new illness conditions and symptoms that had not been present in their earlier biomedical diagnosis. Some of these newly identified illness conditions and symptoms included: energy blockages, bad bacteria and candida infections, negative energies, vitamin and mineral deficiencies, and weak vital organs such as kidney, liver, and heart.

"She wicked uv enevu blockaves in mu bodu ... she said that that she was voing to work with me one-on-one and get me strongver in my mind and my bodu so that I could cove with daily living ... she said that she could offer me help in dealing with my bodu pains and the side effects of my pills ... she was voing to work with me to get rid of this tired feeling and build good energies in my bodu ... she also said that there were good chances that this enevu work was voing to delay viral growth in my bodu." (Zoe)

Participants also discovered that all therapists offered different causation explanations regarding their illness conditions. These
explanations remarkably differed from their earlier biomedical diagnosis.

"She was of the opinion that my cancer was caused by negative energies that I had gained from negative relationships with people ... it was the stress and negative thinking that was blocking the flow of good energies within my body ... she found from the Iridology tests that I had weakness with my lungs, kidneys, and my heart ... she also found that I had digestive problems like excess of bad bacteria that sort of thing you know." (Zoe)

6.5.2. Being surprised by diagnosis

Participants reported being surprised by the diagnosis of their illness conditions provided by their therapists. Some were surprised by the identification of new symptoms and illness conditions, while others were surprised by the illness causation explanations offered by their therapists.

"I don’t know how to describe it ... I guess I was really surprised by what she had to say you know ... I mean I knew from my medical doctor that I had cancer, so that wasn’t new to me at all ... I had kind of expected that from her too ... like if she had said that I didn’t have cancer. I wouldn’t have taken her seriously at all ... I think she knew that you know. I was very surprised by the stuff about how the energy fields were blocked in my body, how my body was weak, how my liver needed detoxification – things like that were very new and kind of strange to me. I found her explanation that my cancer had been caused by bad energies from the way I lived a bit hard to take." (Paris)
All participants expressed encountering difficulties in coming to an acceptance of the illness causation explanations offered by their therapists. Some participants expressed outright disbelief, while others remained cautious and critical, yet mindful of encountering differences in individual belief systems.

"I remember sitting there thinking you know like how can I believe this? I mean I didn't know about these enerv fields and stuff like that ... so I didn't really know how to take it all in. ... That's part of her beliefs I guess, not mine ... doesn't mean that she's wrong ... it's just that our beliefs don't match on that one ... that's ok you know." (Eveoka)

Some participants were more accepting of their earlier biomedical diagnosis regarding their illness conditions offered by their doctors.

This acceptance was based on the belief that it was scientific, thus more credible.

"I mean I believe my doctor on that one for sure ... I remember asking her about that you know ... like I questioned her on that point ... she didn't get annoyed or anything like that at all ... she informed me that all illness and disease start out from bad enervies and enerv blockages ... I mean that's what she believed ... I certainly didn't ... and still don't you know I knew scientifically that I had HIV ... my doctor had told me that, and I had myself tested five times at different testing places. I mean there was no doubt in my mind that I had HIV ... I could see the HIV on my body. I didn't know about any of the other conditions that she was able to pick up through her diagnostic ... I didn't know about how enervies get blocked and I didn't know that my body had developed so many toxins and needed cleaning up tests ... that was new and surprising to me (laughs) ... I
just didn’t know how to take that all in … like I just didn’t know how to process all that stuff you know (laughs).” (Mark)

Despite expressing doubts and reservations regarding their diagnosis as offered by their therapists, all participants continued with their consultations motivated by their hope of recovering from their illness conditions and associated pain.

“I went on with the consultation because I thought what’s the harm in this … if she could get me body stronger, then I’m going to go for it … I thought no harm was going to come from this … and her treatment was going to be non-invasive and I really didn’t have to take any real medicine from her you see … I mean it is not like the real thing that my doctor does … I wouldn’t mess with real medicine because that stuff uses real chemicals and can be dangerous … the stuff that she was offering was natural herbal stuff you see … like she wasn’t dishing out any real medicine … just these herbs to get my energy levels up … so I thought if it’s natural, it’s pretty safe to try out … I couldn’t see any harm in undertaking her notions and herbs.” (Zoe)

Some participants expressed feeling as if they had no choice, but to accept their new diagnosis as offered by their therapists in the consultation process in order to obtain treatment for their illness conditions. They reported fearing that non-acceptance of their therapists diagnosis would hinder their help seeking options during consultations.
"I felt at that time I had no other choice you know ... like I had run out of all possibilities in getting better ... I was running out of hope too by that stage ... I was getting really down thinking that I was running out of treatment options ... I mean I didn’t believe her diagnosis at all, but I knew what my real problem was ... my doctor had told me that I had cancer ... that was based upon scientific tests undertaken by him ... so I really didn’t care what her diagnosis was you know ... I just wanted her to do something to get rid of it and get rid of my pain.” (Paris)

6.5.3. Being prescribed vitamins, minerals and potions

All participants reported being prescribed a large variety of vitamins, minerals and potions as part of their treatments. They reported being prescribed a minimum of eight different types of vitamins and minerals. Participants expressed shock and surprise at this, as they had never before experienced such prescriptions from their biomedical doctors. They reported that all therapists recommended particular brands of vitamins and minerals on the basis that such brands were of superior quality.

“So, after telling me the diagnosis, she gave me a list of vitamins and mineral salts to buy at the local health food shop. I was a bit taken aback I suppose ... doctors give you a prescription for a single pill or two or three things, but her list was long – like 8 to 10 different things (laughs). She was very specific about what brands of vitamins to buy too ... like she told me to buy only Blackmores products because they were the best according to her ... and she was very specific about the brand of these pills.” (Geoffreu)
All participants reported being shocked by the recommended dosages of their vitamin and mineral prescriptions. They reported dosage levels ranging from 2000mg – 5000mg of particular vitamins and minerals. As participants had not taken such high dosage of vitamins and minerals previously, they expressed safety concerns regarding the possibilities of overdosing and related health risks. Participants reported their previous lack of experience of CAM and recent media reports regarding the risks of CAM as major sources for their concerns.

"Some of the dosages she recommended was a bit worruing for me at that time … like she wanted me to take everuday 4000 mg of Vitamin C, 4000 mg of Vitamin E, 2000 mg of Vitamin B – it’s like all the dosages were above 100 mg … I have never taken that much at any time in my life. and I was worried because I had read stories in the newspapers about overdosing … I didn’t want that to happen to me."

(Andrew)

All participants expressed concerns regarding the costs associated with obtaining their vitamin and mineral prescriptions. This was strongly highlighted by participants on social security benefits and pensions. Some participants reported having to borrow funds from friends and relatives, while others reported using their credit cards. While being highly dissatisfied with such costs, participants proceeded to obtain their prescribed vitamins and minerals.
motivated by the overwhelming desire to get better from their illness conditions.

“I kept thinking about the cost of all these vitamins that she was asking me to take ... there were so many of them on her list ... I have very limited funds you know ... it’s very tight living on a disability pension ... after I pay for all my essentials. I have very little left to spend on myself or any medications ... sometimes I’m left with $20 a fortnight ... that’s very tight living for me. I didn’t have that sort of spare money around to buy all these vitamins. But I knew that I had to try them out because I really wanted to get better ... and I agreed with her that it was investing in your own health ... that it wasn’t wasted at all ... I borrowed this money from a friend later so that I could buy these vitamins ... I just had to try her stuff ... I needed these vitamins to get better.” (Mark)

Participants reported feeling confused regarding their vitamin and mineral prescriptions, particularly in relation to the high dosages and the variety of vitamins and minerals being prescribed. They reported asking their therapists various questions and being given many opportunities to do so. Therapists were perceived as being effective in meeting the informational needs of participants in relation to their prescriptions. Participants reported that their therapists used a variety of strategies in communicating their informational needs: they provided detailed explanations by using charts and models, and they provided participants with printed information sheets, books, and further references.
"She gave me so much information about the stuff that she was prescribing to me you know ... like printed stuff ... that kind of thing ... they were full of information and easy to understand you know ... like without any fancy medical terms that sort of thing ... she also told me a lot ... I asked her questions about you know why she was asking me to take these vitamins? ... She told me a lot ... what they would do ... why they were important ... that sort of thing you see. so I was able to understand her prescription ... she even gave me books on vitamins and minerals ... that was very interesting and new for me." (Sharon)

All participants reported that, as well as prescribing various vitamins and minerals, their therapists prescribed and dispensed various herbal potions during the consultation process. Participants also expressed safety concerns regarding the risks of consuming such potions as part of their therapeutic prescriptions. Particularly as these potions were dispensed in unlabelled bottles without any ingredient listing. Participants reported asking questions regarding this issue with their therapists, and they were generally informed that their potions were safe for consumption as they were based upon natural herbs rather than synthetic chemicals. Moreover, participants reported being provided numerous information sheets regarding their potions that included information on specific herbs and the process of making natural tinctures.
“She also made some potions while I was with her in consultation and she wanted me to take them three times every day on my tongue ... these were natural drops that I had to draw on my tongue ... there were quite a few of them too ... like I had eight different potions to take ... that's a lot you know, but they were for different things ... like they were going to do different things in my body. I remember getting a bit concerned when she gave them to me ... these were just in dark brown bottles with no labels and there was no other information on the bottle ... I started thinking about how sau they were for me you know ... like I don't know what's in the bottle and who made it and where it was made ... that sort of thing you know ... I got a bit frightened at that time. so I asked her about them ... like I wanted to know if they were safe for me. She told me that they were safe and that she had made them with her hands during that consultation ... she told me that they were natural herbal drops and different kinds of mineral salts dissolved in mineral water. She didn't get annoyed or anything like that ... she explained them to me very well and gave me some information sheets about how to take it. I was happy with her explanation. but I still had this unease feeling about it because this was all new to me you know ... I had not taken any of this stuff before in my life ... all of this stuff was new to me and I just didn't know how to handle all this new stuff.” (Fiona)

Some participants reported that their therapists demonstrated to them the actual process of making such potions using dried herbs in an attempt to meet their informational needs. These participants reported such demonstrations as: interesting, informative, and fascinating.

“There were these flower essences that I had to take every morning. She mixed different ones for me based on my energy readings and she did this while I was with her. She had all these large brown bottles in a cupboard ... that's where she kept her medicines and there were so many of them in there. I saw her get a surivne and pull out different amounts from these bottles and then she filled up my little brown bottles ... that was quite interesting to watch too. especially as she
was explaining what she was doing and the dilution process ... I felt like I learnt from watching and listening to her.” (Rosemaru)

Patients expressed satisfaction with the quality of information provided by therapists regarding their notions, but still had lingering doubts and concerns regarding the safety associated with their notions.

“She gave me so much information about these bags of powdered herbs to take with water and with my meals ... like lots of printed information about the herbs and how she made it ... they were natural herbal powders that I had to mix with water and drink during the day ... I could mix it with tea too. But she said coffee was out ... that was a major blow for me you know (laughs) because I love coffee. But I thought I could try this and see how I go with it. She packed these different herbs together and she told me they were natural and safe ... she herself took them ... so I thought if it works for her, it might work for me too. I was still a bit worried about them I suppose. Because I had never tried them before.” (Sharon)

6.5.4. Being prescribed physical and mental exercises

Patients reported being prescribed a range of bodywork exercises such as Yoga and Tai Chi to correct energy imbalances within their bodies. Some participants found the specific moves and positions of these exercises complicated and confusing. Others reported a growing ease with such movements, especially after therapists demonstrated and explained different movements. Participants reported encountering mental and physical resistance initially. Some
equated this resistance to their personal dislike of exercise and physical activity. They reported overcoming their initial resistance after being given enough motivational push by their therapists. Therapists insisted that participants try out their exercises, rather than to give up without trying.

"She told me to do these body work exercises every day ... they were meant to help in my energy flows in my body ... you know at first I found them quite complicated, but after she explained them to me and gave me a few demonstrations, I could do them on my own. It's funny you know (laughs) ... I had so much resistance to it at first ... like when she first told me about these exercise, I just didn't want to do them at all ... I'm not a very physical person, so I guess I hate physical things you see ... she didn't give in though ... she kept asking me to try and then she got up and held my hand and guided me with the exercises ... she was so patient with me ... she kept pushing and pushing me to try them out ... I felt better after trying it and I felt great after I had got the hang of it ... it's like I can do this." (Jane)

Despite guided demonstrations, some participants found the prescribed body movement exercises hard to understand, as the moves described were perceived as complicated. Some participants were unable to understand how these body movement exercises were going to help cure their conditions. Their therapists informed them that these body movement exercises would mobilise good healing energies within their bodies and help in controlling their pain.
"The uova thing was very new to me and in a way also very confusing. She wanted me to do some basic uova, so she gave me this book ... this had some basic moves outlined there in picture form and she wanted me to do them everyday. I was confused at that time thinking about how doing uova was going to help my cancer. But she said that it would help me control my pain and also mobilise healing energies within my chakras. I just found it very confusing ... I mean the moves are certainly not easy at all and it certainly takes effort ... like physical effort you know." (Mark)

Participants were also prescribed deep breathing exercises and therapists demonstrated correct breathing techniques. Participants perceived therapists as patient and effective instructors. They offered various guided demonstrations and asked participants to practice deep breathing techniques. Participants reported noticing immediate changes to their intensity of felt pain, and they were of the opinion that their breathing exercises allowed them to control the intensity of pain. They reported feeling more energised and feeling stronger while undertaking such breathing exercises in consultation with their therapists.

"She recommended this deep breathing exercise where I had to do deep breathing from my diaphragm and not my chest ... this was new to me ... I really had never thought that there was a proper way to breathe at all ... I think I was doing shallow chest breathing for as way back as I can remember. She was very patient and she took her time to show me how to do this ... like she gave me a demonstration and I followed her example. I could feel the difference then and there at
that time you know ... like my pain was getting lesser and I felt more energised ... it's a bit hard to describe this, but I could feel this energy inside me ... a strong positive feeling and I felt very strong at that time.” (Sharon)

Some participants expressed feeling strange and feeling awkward when therapists recommended crystal-healing therapy. These participants were asked to channel and cleanse their bodies from negative energies by undertaking a series of body massages using a crystal. Participants reported such recommendations as bizarre and strange.

“She asked me to do the crystal healing massage every night before going to bed. After my shower each night, I had to rub the crystal over my body ... slowly and gently from one side of the body to the other making a full circle each time ... like I had to complete 10 full circles every night. She advised me that this was going to heal my body and cleanse my body of negative energies that I had come into contact with during the day. I felt a bit strange at first because I really don’t believe in crystals and that sort of thing. I mean the idea of rubbing this rock over my body really doesn’t appeal to me much at all ... even when I tried it with her I felt very strange ... it was a bit way out for me.” (Eweca)

During the consultation process, participants were prescribed various meditation exercises for stress management and relaxation. Therapists offered guided demonstrations during these consultations. Participants expressed feeling somewhat resistant and hesitant towards these exercises. They were wary of such
meditation exercises. as some participants reported reading newspaper stories of new age cults and brainwashing. All participants expressed negative sentiments at being prescribed meditation exercises.

"She also wanted me to do meditation exercises at home so that I could feel more peaceful and less stressed. She said that it would help me in controlling my pain during my daily-on-going activities. I had heard about meditation many times ... some of my friends had tried it and it had helped them ... most of them use it for stress management and it works for them ... so I thought I'll try it. I felt a bit uneasy when she was telling me about it ... I guess I was a bit scared ... I didn't want any strange things to happen to me with my ongoing illness ... I was afraid ... just unsure about it ... it was freaking me out (laughs)." (Rosemary)

As well as being offered meditation exercises, all participants were offered guided mental imagery and visualisation exercises. Therapists offered demonstrations of various techniques during the consultation process. Some participants expressed difficulty in undertaking these guided visual imagery exercises, as they reported being unable to visualise and to break away from their constant pain. Other participants found these exercises as wacky and way out.
“She asked me to do some guided ima'evu exercises at home ... she also wanted me to do colour breathing exercises too ... with the guided ima'evu. I had to think of a comfortable place ... like picture it in my head and try to feel the surrounding feelies of that comfortable place. For me, I'm most comfortable at the beach, so I held on that picture in my head and tried to feel the surrounding ... like the water, the birds. being comfortable — that sort of thing ... it was hard to do at first ... I certainly didn't feel comfortable doing them because it was so strange you know ... (laugh) ... I felt really fake doing the exercises ... it wasn't me at all ... I'm not a very visual person you see and I find it hard trying to picture things in my head ... I tried, but I just couldn't escape the reality of my constant pain in my body ... it just felt very stupid to me (laugh).” (Fiona)

Some participants were prescribed meditation and self-hypnosis kits during the consultation process. These kits were for sale and available from therapists. Participants expressed concerns at the high costs associated with the purchase of such meditation kits. These kits contained instruction booklets, information sheets, instruction videos and audiotapes. Participants expressed tensions between the high costs, their budgets, and their desire to try something new and different in the hope of getting better. A few participants purchased these kits, despite the high costs, motivated by their overwhelming desire to try something new to get better.

“I purchased this self-hypnosis kit from her during the consultation because she had prescribed self-hypnosis for me. I wasn’t vetting anything for my pain from my doctor, so I urgently wanted something from her that would either stop my pain or at least reduce it so that I could get on with my things. It certainly wasn’t cheap you
know because the kit cost me $85 ... that's expensive you know, but it had 3 audio tapes, 5 colourful posters, and 1 instruction video in it so that's why it wasn't cheap. I was excited about this you know because I had heard so much about hypnosis ... mostly from watching television ... but what her stuff wasn't about mind control or magic or anything stupid like that at all ... this was to get me to manage my pain and lessen the stress in my life.” (Paris)

As part of their prescriptions, participants were also asked to monitor and record their daily thoughts. This included recording the objects of their thinking and the associated feelings generated by such thinking. Participants were asked to keep a daily journal in order to record such thoughts and feelings. They were required to bring their journal logs at every subsequent meeting with their therapists.

“I was doing a lot of negative thinking at that time ... there were all these thoughts going through my head on and on and they just wouldn't stop ... that was a very negative period in my life you know and these thoughts would go on and on all day long – like I couldn't break free from it you know, so because of all this she asked me to be very mindful of when these thoughts occurred. what the thoughts were about, and where they occurred. She asked me to record these in a diary every day so that she could monitor my mood and my feeling states during different times of the day.” (Geoffrey)

6.5.5. Being asked to change diet and lifestyle

Therapists recommended that all participants switch to vegetarian diets. Participants expressed initial resistance to this on the basis
that it would be too difficult. Therapists were successful in getting participants to at least try going vegetarian by reinforcing outcomes such as feeling healthier and getting better. Therapists spent a considerable amount of time with participants in designing appropriate weekly vegetarian menus. Therapists offered participants vegetarian cookbooks and other printed information. Participants expressed amazement and surprise upon discovering the diverse variety of vegetarian menus as planned by their therapists. They had feared that vegetarian cooking would be boring and uninteresting on a daily basis. All participants reported being amazed by the provision of information by their therapists. Moreover, all participants expressed deep admiration of their therapists' knowledge in relation to food and dietary matters. Participants reported appreciating the time that their therapists invested in explaining dietary information. They also reported learning and becoming more aware of healthy foods and cooking.

"She wanted me to change my diet and become vegetarian ... I remember saying to her that I couldn't do that and that it was too difficult. She said to me to keep trying and all she wanted me to do was to try my best as it was going to change my life and get me healthier. She asked me to describe to her my favourite foods and to tell her about my usual food intake – like what I ate for breakfast, lunch and dinner – that sort of thing. Then she pointed out all the wrong foods that I was eating and suggested like a proper eating plan ... this was incredible ... like she took all that time and worked with me to set up a menu for my whole week – that was pretty amazing ... and these
were all vegetarian foods too (laughs). She gave me some of her vegetarian cookbooks too (laughs) ... I've used a few and they were pretty good. I had never thought I could do so many interesting things with just vegetables you know ... I was pretty impressed by that." (Andrew)

Participants were recommended to undertake a liver cleansing diet, which involved undertaking only fresh fruit juices, and restricting all other food intake for a week. Participants expressed concerns with this recommendation, as it sounded too extreme and they feared doing damage to their digestive systems. Therapists addressed these concerns by informing participants that other patients had undertaken similar diets and that it had proved safe for them.

“I had to cleanse my liver as she said that there were too many toxins in my body — like I had to do a detoxification program to clean my liver. She recommended I do juice therapy for 1 week ... she wanted me to drink fresh fruit juices for the whole week and restrict all other food intake ... like I couldn't have anything else. I was worried about this, because it sounded extreme to me ... I thought if I don't have any proper food for the whole week, I could do some damage to my system. I told her this and she advised me that many of her clients had tried it and it was safe. I thought that if it had worked for them, then it might work for me ... I had to try it you know ... I just had to.” (Sharon)

Other participants were recommended a water fasting diet to detoxify their liver and their digestive systems, whereby they were allowed only water intake for a week without any food.
"She recommended that I go on a fast for a week and drink only water… this was to clean the insides of my body and remove toxins from my system… she described it as like having a wash on the inside… so that all my vital organs could get cleansed before they could heal from her drugs and medications,… it sounded very strange at the time but it made sense to me and I could see what she was on about… I decided to give it a go." (Mark)

Therapists recommended that participants change their interactions with others within their social environments. These recommendations were based upon therapists' beliefs that participants were absorbing too much negative energies from negative individuals, and that these energies were interfering with participants' healing energies. Participants expressed surprise at these recommendations concerning their interactions with others. While all participants expressed making choices concerning whom to interact with in their social environments, they were shocked to discover as to how certain individuals and their interactions were negative experiences as outlined by their therapists. Some participants reported feeling as if their therapists were judging them and reported dissatisfaction at this.

"She was of the view that I had to change my associations with people… like she said that I was not in a very good social environment… like I had too many negative people around me… they were reflecting too much negative energies that was affecting me personally… it's
like I had to get very careful in making choices regarding who I was seeing ... the company of others ... that sort of thing you know ... I had never thought of that before in my life ... I didn't like that you know ... I felt like she was becoming very judgmental at that time ... I mean I do make decisions regarding the kinds of people I associate with. but I never thought in terms of positive or negative energies ... I suppose I never thought about how my interacting with them was affecting my health personally." (Jane)

Therapists recommended that participants change their social arrangements within their domestic environments. In particular, they were asked to change their roles in undertaking various domestic tasks and activities within their homes. Therapists were of the opinion that participants were overloaded with too many roles and responsibilities within their homes and that this hindered their ability to heal and recover from their illnesses. They advised participants to consider sharing domestic tasks and activities within their homes with others within the household.

Therapists recommended that participants monitor their daily energy levels and choose undertaking their domestic tasks accordingly. On days that they were not feeling better, participants were advised to delegate certain domestic tasks to other members within their collective households. Most participants were surprised to learn from their therapists that their domestic roles and
obligations were hindering their ability to heal and cope with their illnesses on a daily basis. Some were surprised to realise that they had the ability to choose tasks and activities within their households, and that they were not necessarily obliged to fulfil all of their domestic roles and obligations alone.

“She wanted me to change the arrangements at home especially about the daily activities like cooking, cleaning ... the domestic chores that I was doing. She said that I was doing far too much on my own, and that I needed to get other family members involved in household chores so that I could conserve some energy to feel better and get better. I agreed with her on that one because I do a lot of things at home for everybody else you know ... sometimes I get very tired just doing housework ... like I have very little time for myself and the things that I want to do. She made me realise that I was doing too much at home ... all on my own. She wanted me to think about my energy levels ... like monitor how I was feeling at different times and then do activities based on how high or low I was with my energy – that made sense to me ... she also made me realise that I had choices that I could make you know and that I wasn’t making choices that were good for my health.” (Fiona)

Therapists recommended that participants engage in self-reflection and to undertake daily journaling exercises. They were asked to reflect on how they felt during different times of the day and while engaging in interactions with others. Participants were recommended to get to know themselves based upon their feelings and actions rather than idealised thoughts of themselves. They were
asked to consider what their actions and feelings suggested to them as to their true inner nature and being.

"She asked me to think more about who I was as a person ... like she wanted me to keep a journal and write my feelings about myself everyday ... she wanted me to reflect on my moods during the day ... how I felt with different people ... how my body was feeling in different places ... all of those things ... she wanted me to reflect on them to see what it said about me as a person. She asked me to get away from knowing myself based on my thoughts of myself. and she wanted me to get to know myself based on what I did ... like what did my actions tell me about myself as a person ... I have never thought alone those lines ever ... that was new to me ... I was kind of excited by that because of what it would tell me about myself as a person ... I started thinking perhaps I really didn't know myself too well ... maybe there's more to me than what I already know." (Zoe)

Therapists recommended that some participants needed to modify sexual practices and to rethink of sexual activity in terms of energy exchanges. Therapists informed participants that during sexual activity, bodily energies were exchanged. Moreover, they were informed that sexual activity with negative individuals generated negative energies within themselves, and that this hindered their individual abilities to heal and cope. One participant was advised to modify the quantity of sexual activity and to modify the diversity of sexual partners. Participants expressed surprise and shock in having to rethink of their sexual interactions in terms of negative energies.
as most participants had seldom thought of sexual interactions as
enerve exchanges within two individuals.

"I was really amazed when she asked me to change my sexual
practices ... she wanted me to cut down on my casual sex activities
with different people ... she asked me to start thinking about sexual
activities as enerve exchanges rather than something I did for pleasure
... that was so strange for me you know ... like how was this going to
help with my HIV ... like I already had the disease and I was going to
die ... I wasn't going to go around and vive it to others ... then I
discovered in my talk with her that she wasn't taking about safe sex at
all ... she said that sexual activities deroled enerve levels within the
body ... even after contracting HIV ... so the more sex I had with
others, the less enerve I had within myself and that was affecting my
ability to cope and do things. I had never thought of sexual activities
as enerve exchanges ever ... this was a very different way of looking
at things you know ... something I had never considered." (Mark)

6.5.6. Going home and trying out recommendations

Participants reported returning home feeling: excited, positive,
confident, and empowered. They attributed this to being with their
therapists, and they felt changed and in control of their illnesses.
Some participants reported feeling like they could not wait to get
started with their treatment recommendations, and they expressed
feeling renewed confidence and hope that their illnesses would heal.

"After the consultation, I remember feeling so positive about myself
... it was just incredible ... I had not felt that good about myself for
quite some time ... I really don't know why you know ... it's like being with her and talking with her had somehow changed me ... like I felt changed ... like inside me ... I was like very changed or powered (laughs) ... that feeling was amazing ... it was the feeling that I could do anything ... I felt powerful and like very much in control about my illness ... I was so excited about trying out these new things ... I couldn't wait to get started with the vitamins and the potions that she had prescribed for me ... I couldn't wait to do the meditation exercises ... I wanted to try all of these new things and I was confident that they would change my life." (Eveka)

All participants expressed feeling renewed determination to get better and expressed increasing feelings of being in control of their quality of life. They expressed surprise at feeling assertive and in control, as some reported not having felt that way for a long time in their lives. They described feeling: good inside, healed, and positive. Other participants expressed delight in feeling immensely excited by new possibilities of getting better. Some described this as like a new start, and a new beginning rather than an ending in the experience of living their lives with their ongoing illnesses.

"I felt really good being home that day ... I was on top of the world ... it's like the best feeling I experienced for a long time ... I was happy and I was so positive about myself ... it's almost like my world suddenly got a lot brighter ... I started to think about all these new and exciting things that I could do in my life ... I could still do so much to make things better for myself ... I was ready to try these things and get better ... I suppose I was very determined to get better ... I felt so good inside ... it's a hard thing to bring to words. But I felt like I was healed or something ... my pain was still there and my disease was still there. But my feelings had changed ... like became
very positive ... my feelings had changed ... I felt brighter ... I didn’t feel like this was the end ... it felt like a new start ... like a new start to a different me ... a better me ... a new me you know (laugh).”
(Rosmaru)

Participants reported feeling excited and eager to start their vitamins and potions upon returning home from their consultations. While being in their local health food shops, all participants reported being shocked by the huge range of vitamins required for their treatments and the associated costs of such vitamins. All participants reported being dissatisfied by the cost factor involved with purchasing their required vitamins, minerals, and herbs. Those participants who had purchased potions and meditation kits from their therapists expressed most dissatisfaction with the overall costs associated with their CAM consultations, as they had to spend more money purchasing their recommended vitamins, minerals, and herbs from their local health food shops.

Some participants reported not having spare funds for the costs associated with obtaining their therapeutic supplies, and reported dissatisfaction at having to use their credit cards for such purchases. Other participants reported borrowing funds from family members and friends.
"I started the vitamins and the drogs that she had made for me the next day. I was so very excited about this you know ... like I just couldn't wait to get started. The vitamins were very expensive to buy ... I went to the health food shop as she had suggested and I got about 5 different types of vitamins and about 7 herbal supplements ... in total I spent about $160 on them and that's a lot of money for medications you know ... I had also purchased her potions during the consultation and that cost me another $45 ... so in total I had spent $205 just to get started on the treatment ... the cost factor was a bit worrying for me because my funds are very tight and I used my credit cards for these medications which I will pay off later, but I really didn't mind ... I had to get better and I had to try it out to get better." (Mark)

Other participants reported feeling concerned about the large number of vitamin pills recommended for daily intake. They highlighted that they had never taken so many recommended pills ever in their past. Some participants reported dividing their daily pill intake into three separate periods in order to facilitate the intake of the large number of pills everyday. After starting their vitamin therapy, some participants reported feelings of increased hope that they were going to get better and recover from their illness conditions.

"There were so many pills I had to take and I was a bit concerned about this ... I have never in my life taken so many pills daily in my life. I got them anyway as I needed them. When I got home that day I really just started with the vitamin pills and I was feeling very excited and hopeful ... it's like as I took each pill, I was getting more and
more hopeful that I was going to get better. I divided the pills so that I could take them 3 times during the day ... that was the only way of doing about it you know because there were just so many of them ... I couldn’t take them all at once.” (Sharon)

All participants reported dissatisfaction with the intake of their herbal potions dispensed by their therapists. The sources of dissatisfaction largely related to potions being distasteful and odorous, thus making it quite difficult for participants to take these potions three times daily. Some participants described their potion intake as challenging and as requiring a lot of effort.

“I can only describe the herbal powder mix as horrible ... it was horrible (laugh) ... it was really smelly and the taste was just horrible (laugh) ... I had to drink this stuff 3 times daily and that took a lot of effort and determination on my part (laugh) ... she had warned me about this and had asked me to put some honey or orange essence to make it a bit easier – I tried putting both of those things, but it was still horrible (laugh) ... really awful stuff, but I took them because I was determined to get better ... wasn’t easy though (laugh).” (Geoffrey)

Some participants reported experiencing wave-like motions within their bodies after taking their potions. Other participants reported noticing changes in bowel movements whereby they developed runny stomachs after taking their potions. While concerned about such effects, they contacted their therapists only to be informed that
these effects were normal and due to the vibration mix of the
otions and body energies. Furthermore, they were informed that
such effects were sure signs that their bodies were detoxifying and
cleaning from within.

"I started her notions the next day and they were dreadful (laugh) ... they were so horrible in taste you know ... like very herbal and really
ucky in taste ... and I got really bad breath from it too ... like strong
eral smells ... not very nice at all (laughs) ... I dropped them over
my tongue three times during the day ... I noticed that I used to get
this really strange feeling each time I took them ... like my stomach
roduced wave like motions ... I don't know why, but it happened a
lot during that first day ... I asked her later over the phone and she
told me that it was my body energies meeting with the energies of the
otions ... like a vibration mix or something like that ... I don't know
much about this, so I accepted what she was saying, thinking she's a
professional and she knows what she's doing ... I noticed that day that
I kept going to the toilet all day ... like I developed really water ooed
you know (laughs) ... a bit like having running stomach ... I thought
my body's cleaning itself and that these notions were doing the job.
The notions were not hard to take except for the strong foul taste, but I
missed my coffee you know ... I'm a big coffee drinker and with these
otions I wasn't allowed any coffee because it acts as an antidote ... 
like it would kill off the good stuff from the notions ... that was hard
do during the time I took those notions ... I had these bodily
cravings ... like really strong you know ... oving no coffee was
harder than I'd thought, but I did it because I wanted the notions to
work." (Andrew)

All participants reported difficulties in engaging with the
recommended physical exercises at home. Yoga and Reiki exercises
were the hardest for some participants, as they had great difficulties
in enacting particular body movements and postures. Other
participants reported high levels of physical and psychological resistance in fully undertaking recommended exercises.

"Those exercises that she had demonstrated to me were not easy to do on my own at all ... they were bloody hard to do ... like I just couldn't set my body in those positions that were described in the instruction sheets at all ... it looked easy, but doing it was another thing ... and I'm not a physical person, so there was a great deal of resistance on my part ... like I could feel this resistance within my body ... like my body just did not want to do these damn exercises. I forced myself to do them during the first week, but it was too much effort ... don't set me wrong. I'm not a quitter ... they were just too hard to follow ... and my body was already stressed and in vain. so maybe that's another reason why I couldn't do them ... I tried and tried for a few days, but I wasn't getting anywhere." (lance)

Paradoxical feelings were generated for some participants undertaking crystal-healing massages. They reported feeling:

excited, frightened, silly, comfortable, and calm.

"I found it very interesting doing the crystal body massage ... I did that every evening after my shower and it felt great ... I did all the things that she had asked me to do ... I created a very comfortable space in my lounge room, put on some very slow soothing music, did all the things that she had asked me to do ... I felt really good doing it and I could feel my body getting calmer ... it was really interesting because initially I thought it wasn't going to do much ... it felt a bit silly on the first day ... the first time I did it. I remember thinking why am I doing this ... it felt strange and silly ... and then I thought that I had to try it out to see if I could feel any changes in the way I was feeling ... yes, there were changes you see ... I felt very calm and comfortable at the end of each massage with my crystal ... I don't know why." (Paris)
Other participants reported difficulties in undertaking such exercises due to the discouraging and un-supportive attitudes of others around them at home.

"My family members thought I was being silly rubbing this crystal on my body ... (laughs) they were telling me that it was rubbish and that it wouldn't work ... they were not very supportive about this at all ... they said I was wasting my time and money ... they thought I was being silly and that I had flitted a bit, but I had to do it for myself ... I wanted to try it out for myself and see the changes." (Fiona)

Due to the discouraging attitude of others, such participants were unable to fully undertake their recommended exercises at home. Despite trying their best, they still found themselves not getting anywhere.

"I found it hard doing the meditation exercises at home on my own. My husband just laughed at me and said that I was becoming a hippie (laughs) ... he doesn't take my alternative medicine thing too seriously at all ... he thinks it's a bit of a joke and a complete waste of money ... my kids think the same too you know ... it was hard doing it at home because no one took it seriously at all ... every time I tried to close my eyes and do the visualisation exercises, I just couldn't get away from my room and my family ... there was also the noise factor too ... you know the kids were making noise, there was music, the television was on — all that sort of thing ... I suppose like the noise level in any family home ... so I couldn't completely get a quiet space and do these meditation exercises. So it didn't work for me at all. I think that's because I couldn't do it properly at home. I tried for a few times, but I didn't get anywhere with it." (Sharon)
Participants reported difficulties undertaking their recommended colour breathing exercises. For most participants, the desired visualisation act of breathing in different colours proved an almost impossible task. They reported being unable to visualise breathing in colours, as they were not the visual types. Some reported feeling silly and stupid while undertaking these visualisations exercises. Others reported not being unable to break free from their lingering pain and daily realities in order to undertake such colour breathing exercises. All participants were of the opinion that this therapeutic recommendation was not suited to their personalities.

"The colour breathing exercises just didn’t do it for me. I just couldn’t do it at all … I had a hard time visualising myself as breathing in coloured air … it was way too out there for me … I tried, but nothing. I’m not very good at that anyway you know … I think I’m too much of a realist to imagine such things … I find it hard visualising. I just can’t do it. It felt silly to you know (laughs) … like I could not accept in my head that I was breathing in coloured air – that’s impossible when you really try to do that you know … it sounded good when she told me about it. But it was very different when I was doing it on my own … I just couldn’t do it … it wasn’t me at all.” (Mark)

Participants reported positive experiences while undertaking self-hypnosis as part of their therapeutic recommendations. They reported being able to easily follow the methods and procedures as
outlined in the information sheets and audio/video kits provided by their therapists. Participants reported feeling changes as a result of undertaking these exercises. Some reported feeling calmer after their exercises, while others reported being more able to control their pain. All participants reported greater feelings of self-efficacy and self-control.

"I tried the self-humosis at home every night for two weeks. It was really very interesting to do and I noticed changes in the way I was feeling. I felt less stressed like more in control (long pause) like I was in the driving seat for once you know. The instruction tapes were really good and very easy to follow. The video was good and there were lots of practical exercises that I could follow. I noticed that I was able to do it more deeply after about the first week ... like the results were very slow, but they did happen. I felt very good about myself each time I did the exercises. It's like it cleared my head and my thinking ... I was a lot calmer in my daily activities and I used those exercises every time I found myself getting stressed." (Jane)

All participants spoke positively about undertaking their daily journaling exercises as part of their therapeutic recommendations. Some participants reported feeling slightly awkward in having to write about themselves, but reported overcoming this and being carried away by the process of reflective writing. By being reflective, they reported developing a greater understanding of themselves and others. They reported learning about themselves in terms of their moods and their behaviours in relation to various individuals.
and social contexts. Moreover, they described their journaling exercises as a process of self-discovery that provided fuller understandings of their real selves.

"The journaling exercises were really great and I did that every night. She had asked me to keep a record of my moods and my feelings you know throughout this treatment process and I did that. At first, it felt a bit hard and a bit silly you know ... like writing about yourself (laughs) ... I'm not used to that sort of self-reflection at all, but it was a great exercise to do because I learnt so much about myself during that process. I found out some of the things that were bothering me, and some really amazing things like how I react to different situations and people around me. For me, that exercise was very fruitful and I gained many insights to me as a real person." (Geoffreu)

All participants reported difficulties in implementing their dietary recommendations. Their therapists had recommended vegetarian diets using only organic products. For all participants, such changes were hard to do and these changes were perceived as too drastic. They reported increasing levels of stress within themselves and within their family homes. All participants reported high levels of personal resistance to implementing dietary changes. Some participants reported losing interest in cooking and eating food due to the recommended changes.

All participants reported dissatisfaction with the financial costs associated with making dietary changes. In particular, they found
buying organic produce as expensive and stressful. These participants also reported considerable difficulties in obtaining regular supplies of organic produce at their local supermarkets. They also expressed dissatisfaction at the inconsistent certification and labelling of organic products – this resulted in considerable confusion and stress in making informed purchasing decisions. Participants noted that “going food shopping had become a stressful exercise” in information seeking and in decision-making.

Implementing dietary changes resulted in increasing tensions for those participants living within family settings with young children. Such participants reported significant difficulties in menu planning and cooking for their families. In order to minimise their stress and their household workload, participants had decided to cater for all family members via single cooking sessions rather than cook different meals for different members. In doing this, they not only transformed their individual diets, but also the diets of all family members so that all family members could benefit from vegetarian food.
However, family members did not appreciate this change. Their children refused to eat vegetarian meals and were most dissatisfied with menu changes. This generated arguments and tensions at most meal times, and participants found themselves to be doing extra sessions of cooking to cater for their children. All participants described this process as extremely stressful and as adding more strain to their ongoing ability to cope with their illnesses. In the interviews, all participants reported surprise at how the simple act of making changes to home cooking menus could become such a divisive issue within their family settings.

"The diet changes were the hardest to do ... I mean voicing vegetarian is not an easy thing to do at all ... especially if you are living with a family. I tried to do it, but it just didn't work out for me at all. It was just too hard to do ... the change was too drastic for me and it created a lot of tensions within my home (laughs). It was expensive to do too ... like I had to change my shopping habits ... she asked me to buy only organic produce and things like that ... I did that, but it's not cheap at all ... my food budget went up by about $150 a week – that's a lot when you other financial commitments and children in the house. The recipes she gave me were not that difficult to follow, but I found it really irritating cooking according to instructions ... I have never cooked like that at all ... food variety was another thing ... I found that I couldn't make the meals interesting for the rest of the family ... I didn't want to do different lots of cooking for different members of the family ... I don't have that energy nor do I have that sort of time ... the kids just hated their food and refused to eat them ... we had a lot of fights over the food changes at home (laughs) ... and I was shocked how this change created so much trouble within the house ... like this change in the cooking created a lot of stress and drama for me ... I didn't want that because I can't cope with any more stress on top of my cancer." (Fiona)
6.6. Summary

This chapter described research participants' experiences of seeking and obtaining complementary treatments for their illnesses. We saw how participants felt surprised, comfortable, hopeful, and uplifted being in complementary environments. Moreover, we saw how participants felt comfortable, connected, and surprised in consultations; and how participants felt stunned and informed, yet anxious and worried with complementary diagnostic procedures and diagnosis. Also, we saw how participants' experienced being prescribed various vitamins, minerals, herbs, and potions; and various physical and mental exercises. We saw how participants' experienced incorporating various treatments into their daily living and social contexts. The next chapter presents participants' experiences of living their lives after undergoing complementary treatments.
7. Life after treatment

7.1. Introduction

In the last chapter, we discovered research participants' experiences of seeking and obtaining CAM help for their illness conditions. In particular, we explored their experiences of being in CAM environments, CAM consultations, CAM diagnostics, and CAM treatments encountered in their help seeking journey. This chapter describes research participants' experiences of their day-to-day living after seeking and implementing CAM treatments. In particular, we explore their experiences of waiting and evaluating their treatments, making further follow ups and appointments, and coming to terms with their illness conditions and the demanding practical realities of getting on with living while being in suffering and pain.

7.2. Waiting and evaluating

Participants described their experiences of waiting and evaluating their CAM treatments encountered in their daily living after their CAM treatments. Four main themes emerged after an analysis of their conversations: living in hope, feeling stuck in time, noticing changes, and evaluating. This is outlined in Table 14.
Theme: Waiting and evaluating

<table>
<thead>
<tr>
<th>Sub Themes:</th>
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<tr>
<td>• Living in hope</td>
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<tr>
<td>• Feeling stuck in time</td>
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<tr>
<td>• Noticing changes</td>
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<tr>
<td>• Evaluating</td>
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Table 14: Waiting and evaluating

7.2.1. Living in hope

Participants described the period immediately after their treatments as a time of living in hope. They patiently waited for signs that their treatments had worked and that they were getting better. They described this period in their lives as horrible, hellish and unbearable. Lived time was experienced as long, unending, and stuck. Despite this, they waited patiently for signs of getting better. Some participants engaged in prayer hoping that they would get better, while others did their best to stay positive despite their ongoing suffering and pain.

"It was horrible ... just horrible at that time you know ... this waiting, waiting, waiting ... it's like I was just waiting for something to happen ... it's like I wanted for some sign I was getting better. I
kept having you know ... I prayed and I tried my best to stay positive
during that time ... it's like I was living in hope at that time and
that's all that I could do.” (Rosemaru)

Participants observed their bodies daily for changes, and monitored
their feelings for signs of recovery from their illness conditions.
They constantly compared their altered selves with the way they
used to be, and they longed for a return to what they used to be
before getting sick.

“I remember waking up each day and checking myself out ... I know
it sounds crazy, but I kept having that my body sores would go away
and like disappear (laughs). I kept doing this every morning for about
3 weeks and it was always the same thing ... I would get really
excited and rush to the mirror, and carefully examine myself. I kept
having and having each day ... you know every time I did my
exercises and took my pills. I kept having that they were doing me
good.” (Andrew)

Participants reported following their recommendations
conscientiously and to their best abilities. They were aware of
investing so much of their time, effort, money into these treatments.
and they believed that they were going to get better.

“I kept having that these notions and exercises that I was doing was
working to you off somehow ... I had spent so much money getting these
treatments. so I hoped it was worth it you see. It wasn't just the
money factor ... I had also invested so much of my time and energy
into these treatments ... I kept having that all my efforts were working
to get me better. I had done my very best you know ... like I had
followed all treatment directions and I had really done my very best in
trying to get better ... like these treatments had to work because I
didn't know what else to do.” (Eveka)

They engaged in positive thinking and creative visualisation to
envision future possibilities in order to transcend their suffering
moments while living in hope. They reported blocking out negative
thoughts and fighting on.

“I kept thinking of all sorts of possibilities ... I was voicing to get better
and I was voicing to get that old feeling back ... that feeling of being in
control and the feeling that I was in the driver's seat of my life ... I
used to think about all these things and I kept telling myself that they
were voicing to happen to me and I was voicing to be alright again ... I
kept blocking out the negative thoughts voicing through my mind at
that time ... I kept thinking forward all the time ... like really hoping
for these treatments to work ... that's how I got through those
moments by thinking forward to better days.” (Fiona)

7.2.2. Feeling stuck in time

Participants reported feeling stuck in time while patiently waiting
for their treatments to work. Suffering from intense lingering pain.
they felt pinned down in time and held in static time without much
movement and transcendence. During this time, participants kept
hoping for signs of change to their illness conditions. They also
reported feeling frightened by the possibility that their treatments
had not been effective.

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“It’s almost like I was fixed in time you know … that’s what it felt like at that time … like nothing was happening … nothing was changing within me … my pain was still there and my illness was still there also … so I really felt like I was bloody stuck … just fixed and pinned down in time you know … it was horrible because I wanted things to change … I wanted to get better … I wanted some result … I had put in so much of my time and effort during that time and I really wanted some results … I became more and more frightened during this time too … it’s like I was losing my hope in myself and my treatments … I kept thinking what would I do if nothing happened you know … like what if there was no change to my condition at all … it was very frightening at that time and I was in a real state.” (Paris)

Participants felt baffled as to why they had not experienced much change in their illness conditions despite following all therapeutic recommendations. They felt internal conflicts regarding wanting changes to their illness conditions and not getting any changes. Participants continued to live in hope and became increasingly disappointed.

“There was this real fight going on within me at that time … like I wanted change so badly and nothing was happening at all … each day I would get up expecting some change to my condition … like I was looking for signs for any changes to my pain and my condition … so there was this tension in my mind you know … I wanted change, but nothing was happening … it was very disappointing at that time … it’s almost like I wanted to rush time along … the days were going so slowly you know … and I kept thinking that tomorrow was going to be different … I just had to at that time otherwise I wouldn’t have cared at all … it’s like I was fighting with time in my life … I wanted some change to my condition and I wanted it fast … like I wanted it to happen and happen quickly too.” (Andrew)
Some participants discovered slight changes to their illness conditions, but remained puzzled as to why their treatments had not been effective. They started questioning their help seeking efforts and became increasingly disappointed.

"I mean there were slight changes that I could feel, but nothing substantial was happening at all ... I was still in pain and feeling quite sick ... I suppose I was used to feeling that all my efforts had not paid off ... like I was in conflict ... all that time and money that I had invested in these treatments had not paid off at all ... so I was disappointed you know ... it wasn't just the money side of things you see. I felt that I had let myself down ... like I had failed in some way ... like in terms of my own efforts in getting better. But I kept reminding myself that I had done my part as she had recommended ... I followed all the exercises and I made all those changes to my diet and lifestyle ... it was hard very hard, but I had done my part." (Sharon)

7.2.3. Noticing changes

Participants noticed slight changes over time. These changes related to being better able to cope with their pain, and being better able to get on with day-to-day living. Some participants reported feeling hopeful and excited by the slightest signs of change, and further reported feeling motivated and energised.

"There were changes happening, but they were too slow you know ... just slight changes that I could feel within my body ... like the changes happened very slowly and very gradually ... I remember getting quite hopeful when I noticed changes happening in my body. I
was beginning to feel better and I was getting more and more hopeful about getting better. I noticed that I had more energy to do things ... like that lethargic feeling was going away and I was getting my motivation to do things again ... that was wonderful at that time because I thought I had really got back my motivation that my illness had robbed from me." (Lane)

Participants reported changes to the way their bodies felt during this time. Some experienced their bodies as lighter and less heavy. Others reported their bodies as feeling less painful and feeling more energised. All participants reported feeling good and better about their lived bodies. They were surprised to find that for once during their ongoing pain and suffering, their bodies seemed to be responding to their desired intentions rather than being in constant pain and not being able to do intended activities. They felt that, with these slight changes to their bodily feelings, they were able to transcend some of the earlier physical limitations placed upon by the onset of their illnesses and the associated pain.

"My body started feeling different at that time ... I don't know why or what was causing that, but I really could feel these changes in my body ... I felt lighter, less heavier and like I had much more energy to physically do things ... it's like I wasn't getting tired all the time and doing physical things wasn't taking so much effort ... I felt better about my body too ... for once my body seemed to be working with me rather than against me ... like it was responding and doing what I wanted it do ... it feels strange describing this, but my body started to feel better ... like I could feel changes in the way my body felt ... I noticed that my pain was getting better with time ... like it wasn't
that strong as before … I mean it was still there, but I could manage better I suppose.” (Euweka)

Participants felt brighter and felt positive about their futures. They reported thinking of future as promising and imagined better days and being able to get on with their lives.

“I was feeling less moody and less negative about myself and my condition … like I wasn’t too absorbed in my thoughts of my condition all the time … I noticed that my thinking was also changing … I was getting more positive and I was thinking more of the future … it’s like the future looked more promising to me at that time … I felt brighter with these changes within my body and I felt more optimistic about getting better and getting on with my life.” (Rosemaru)

Participants reported being better able to cope with the interactions of others around them. Unlike previous times, some expressed the need for greater interactions and conversations with others, whereby they wanted to bond, to commune, and to be with their loved ones.

“I felt that I could cope better with people around me after doing those meditation exercises … I felt better being with people and it’s like I could cope with them better … like I wasn’t getting angry at them … I felt like being with people … talking with them … listening to them … that sort of thing you know … so there were changes in my interactions with people … it wasn’t like that before I started the treatments.” (Fiona)
Participants also expressed positive views of their futures during this time. They reported feeling more optimistic and engaging in forward thinking.

"I noticed that there were changes to the way I started viewing my future ... I was getting more optimistic about the future and I started looking forward to my days ahead ... that was different to me you see because I wasn't thinking like that before at all ... I started feeling more positive about my future and about myself." (Paris)

They expressed a greater awareness of self and others during this time. Participants reported becoming self-aware of interactions and conversations with others, and noticed patterns of negativity and lack of thoughtfulness in self-interactions. They actively set out to change negative patterns, and reported becoming more considered and more thoughtful of others.

"I became more aware of others around me after the treatments ... I don't know why, but I started to take notice of how others in my family were behaving towards me ... I started thinking of my own interactions with them ... I started becoming aware of my conversations with them ... I noticed the negative varts of my conversations with them ... I noticed that I wasn't very thoughtful in my conversations with them, so I decided to change all that ... it took effort on my part, but I did it. The meditation exercises enabled me to develop this greater awareness of my own self and others around me at that time ... it help me in changing my conversations and interactions with my loved ones ... I felt that I was becoming more
considered and more thoughtful in my relations with my family members.” (Zoe)

Participants report becoming frightened and worried about these positive changes in their lives. They reported feeling excited, frightened, and scared about these changes, as they wondered if such perceived changes were long term or fluke. They desired long-term change and hoped that these positive changes would last.

“I was feeling very excited at that time you know, but there was also this part of me that was quite frightened ... I was really frightened that this would not last for long ... I mean I had waited for these changes to happen and they did happen, but I kept thinking that maybe it was a passing thing you know ... that it was temporary and would not last for long ... it’s strange to describe that feeling you know ... it’s like a mixture of feeling really happy and excited, but also frightened and scared at the same time.” (Eveka)

However, despite these positive changes, some participants expressed dissatisfaction and expressed wanting some cure for their illnesses rather than just being better able to cope. They reported getting tired of waiting and running out of hope in this process of waiting for a cure.

“I didn’t like that at all ... I wanted changes and I wanted them fast ... like I wasn’t prepared to sit around waiting and waiting ... I got really sick and tired of waiting for things to happen ... that was the worst part about it at that time ... just that waiting and waiting, and

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all that having and having ... I wanted to be cured of this thing you know ... it wasn’t good enough getting temporary relief.” (Rosemary)

7.2.4. Evaluating

Participants used their feelings as guides to evaluate their treatments. They reported listening to their bodies for signs of getting better. Some participants used self-reflection exercises and kept journal logs of changes to their feeling states.

“I was feeling better in time you know ... my condition was still there, but I felt better about it ... I mean I could cope better with it by then especially by doing the meditation and visualisation exercises ... I was mostly using my feelings as a guide to how I was doing ... like I was listening to the way my body felt everyday and I wrote all of this down in my diary every night ... in time I could tell the treatments had done me good because my body feelings were telling me that ... I could feel these changes within me.” (Paris)

Participants relied on the feedback from others around them in their family network. They reported asking family members for changes in their moods and social interactions.

“Others around me were telling me that I looked better and brighter in spirit. I’m lucky that I have family members around me that see me everyday, so they can see the differences in me ... more than I can at times (laughs) ... I was feeling better too. So my feelings about my body at that time also helped me to decide if I was getting any better in time.” (Fiona)
As part of evaluating their treatments, participants engaged in reading their bodies for signs of getting better. They closely observed the bodies visually each day and monitored changes to the manner in which their bodies felt each day. All participants relied on body feelings in making self-evaluations.

"I was reading my body for signs of changes everyday ... I used to really visually check myself out each morning ... just to see if there were any bodily changes happening especially to my body sores and that sort of thing ... I was also keeping track of how my body was feeling and how energized I was during the day ... when the changes started to happen. I could feel this in my body ... like I was feeling lighter, more energized and generally just more with it ... it's hard to describe this, but I could feel these changes within me and those feelings were very different to how I felt before starting the treatments with her." (Geoffreu)

Participants expressed internal conflicts associated with their respective thoughts and feelings regarding the evaluation of their treatments. They expressed feeling better and being better able to cope with their illness, but were alarmed by thoughts that their illness conditions had not been eradicated.

"That was a very hard thing for me to do ... I remember like that kind of evaluation was even more tensions in my head at that time ... I was feeling better ... my body was feeling better ... I could tell I was coping with others around me better ... like I was coping better with others and myself too, but this thing was still there with me all the time ... it wasn’t cured at all ... that was driving me really mad at that time ... I was feeling better and setting better with my everyday things, but it was still there like I was fighting with my thoughts and my feelings at that time ... my thoughts were saying I’m not cured."
but my feelings were saying that I was feeling better ... there was this tension in my mind ... I wanted it gone from my body ... I didn’t want this cancer hanging around in my system at all ... I liked the fact that I was coping better, but I wanted a cure ... I really wanted a cure and I still do ... I don’t want to die." (Sharon)

7.3. Follow ups and appointments

Participants described their experiences of follow-ups and appointments encountered in their daily living after their CAM treatments. Five main themes emerged after an analysis of their conversations: feeling disappointed, returning to biomedical practitioners, feeling trapped, returning to CAM therapists, and feeling frustrated. This is outlined in Table 15.

<table>
<thead>
<tr>
<th>Theme: Follow ups and appointments</th>
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<tbody>
<tr>
<td>Sub Themes:</td>
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<tr>
<td>• Feeling disappointed</td>
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<tr>
<td>• Returning to biomedical doctors</td>
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<tr>
<td>• Feeling trapped</td>
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<tr>
<td>• Returning to therapists</td>
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<tr>
<td>• Feeling frustrated</td>
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Table 15: Follow ups and appointments
7.3.1. Feeling disappointed

Participants expressed feeling disappointed at not being cured from their illness conditions. They had experienced short-term changes and reported feeling better. Although they were better able to cope with their illness conditions, participants felt disappointed at not being completely free from their pain and suffering. Their intentions to be cured had not been met.

"I was feeling quite disappointed by the end of that time you know ... like I waited so long for those chances to happen ... they did happen, but it wasn't any good in the long term you know ... I still hadn't been cured you know ... I mean I was feeling better, but I wasn't cured at all ... that was very disappointing for me at that time." (Mark)

Participants were confused as to why their treatments had not worked despite their best efforts in seeking treatment. Some participants questioned their own help-seeking attempts and felt disappointed with themselves.

"I felt that I had let myself down ... like I felt disappointed with myself as my treatments had not worked despite all my best efforts ... there really was no change in my condition and I could tell that it was getting worse ... her exercises and potions made me feel better for a while, but they really had not changed my condition ... I knew that I had done my best in getting help, but I couldn't help but feel very disappointed with myself." (Jake)
Participants expressed disappointments with their biomedical doctors, as well as their CAM therapists. They expressed concerns at not being cured of their illnesses despite the time, money, and effort invested in their treatments.

"When these treatments had not worked. I felt quite disappointed with my doctor and my therapist because they really couldn't do much and they really had not helped me to get better and get rid of this. There was the money side of things too ... I had spent so much money in training to get better, but it was all wasted you know ... I felt angry that they were not able to fix this ... it's like they really did not have a solution to my problem at all ... I mean they tried their best, but it wasn't good enough at all." (Zoe)

Participants reported self-doubts regarding their past and future help seeking, and felt that they were running out of possibilities. They started questioning and doubting whether it was still worthwhile actively seeking help for their illness conditions.

"I felt let down and I was feeling very disappointed by that time because nothing was going right and I was still very sick. I had tried getting help from my doctor and my therapist, but nothing good came out of that ... I was feeling down because I was running out of solutions ... I didn't know what else to do ... I didn't know how I was going to get better ... I didn't know where to go and what to do next ... I was in a real mess at that time ... it was a very confusing time and a very difficult time for me." (Ewoka)
7.3.2. Returning to biomedical doctors

Having tried their best to obtain help for their illness conditions, participants reported feeling like they were running out of choices. They expressed doubts at going back to their biomedical practitioners. They did not want to go back to their biomedical practitioners, but felt the need to consult. They remembered their past negative biomedical experiences and expressed concerns at having to put up with all that stress again. Thoughts of going back to their biomedical practitioners were stress provoking for participants.

"I really didn't want to go back to see my doctor ... I felt like I was running out of choices ... I had to see him ... not that I wanted to, but I had to ... to get better you know. I didn't want to go through all that again ... I've told you about how horrible it is going to see him each time I get sick ... it's not like seeing her at all ... my stress and anxiety levels go right up when I am with him in his surgery." (Rosemaru)

Despite feeling uncomfortable at having to go back to their biomedical doctors, all participants returned to their biomedical doctors in the hope that they would get better. They expressed feeling guilty for having used CAM and reported not telling their biomedical practitioners about their use of CAM. Participants reported sounding out their biomedical doctors regarding their
views on the use of CAM. and all participants were aware that their biomedical doctors did not view the potential use of CAM positively.

"I felt very uncomfortable being there with him ... I kept feeling guilty ... that I had been using alternative medicine ... I knew he wouldn’t like that at all. because he had warned me about that ... I know his position on that front and it’s very negative ... he thinks it’s rubbish and useless. I didn’t tell him about my holistic medicine use at all ... I wanted to, but I felt that it was not right to tell him especially knowing his negative views.” (Paris)

All participants reported feeling the lingering urgency to inform their biomedical doctors regarding their use of CAM, but choose not to do so fearing losing face with them. All participants feared that their biomedical doctors would lose trust in them as patients and view them as stupid and experiential. Some participants felt that their biomedical doctors would get angry and upset with them, and feared not being taken seriously in future consultations after this disclosure. They feared at not being seen as good patients in future consultations, and feared this disclosure as interfering with obtaining future help from their biomedical doctors.

"I couldn’t even up and tell him all this you know ... that would have interfered with the way he sees me as a patient and I am sure that would have affected the kind of help that he was giving me ... I was
afraid that he would not take me seriously anymore you know … especially after knowing that I had been using alternative medicines … I mean that goes against everything he believes in. I wasn’t going to look stupid in his eyes. so I didn’t tell him anything about that at all.” (Sharon)

Some participants chose not to fully inform their biomedical doctors about their discontinuance of earlier prescribed biomedical medications prescribed by their respective doctors. They had decided to discontinue these medications due to severe side effects. They feared that their biomedical doctors would see this as non-compliance and perceive them negatively.

“I didn’t tell him anything about that at all … I just said that I had tried his medications and I wasn’t getting any better. I didn’t tell him that I had used only some of his medications and decided to throw them away as they were causing me nasty side effects.” (Mark)

Participants were prescribed new medications by their biomedical doctors for ongoing biomedical treatments. They reported being weary and hesitant regarding these new medication prescriptions, as they remembered their past negative experiences of side effects and did not want a repeat of that. Participants felt that they had few choices open to them at that time regarding their new prescriptions. They decided to obtain and use these new medications feeling they
had to comply if they were to get any better and continue getting help from their biomedical doctor. Participants realised that they were going to get side effects from these new medications that would interfere with their ongoing everyday activities. For some participants, their ongoing pain and constant suffering were also cues for reusing prescribed biomedical medications.

“I was very wary about taking the new pills that prescribed to me ... I just didn’t feel good about taking them at all ... I kept thinking of all the side effects that happened last time I took them ... I was afraid that I would go through those side effects again ... it was horrible when I took those pills last time ... it really interfered with my daily tasks and everyday living was very difficult ... I didn’t want to go through all that again ... I kept feeling like I had very few options left for me at that time ... like all the doors were closing in on me and like time was running out ... it’s like I really had no option but to take those new pills ... I wanted relief from my condition and I wanted to get better ... I wanted some blood relief from my constant pain too ... I was getting really sick and tired of being sick ... I wanted my life back again, so I took those new pills knowing that I would go through all the side effects and that I would feel very off while on these pills.”

(Paris)

7.3.3. Feeling trapped

Participants reported feeling trapped concerning their choices regarding their reuse of biomedical medications. They felt that they were running out of treatment choices and that their help seeking options were getting limited.
"I kept getting the feeling like I was trapped you know ... like I had no options and very few choices ... I didn't want his new medications because they were going to make me sick." (Geoffreu)

They faced the dilemma of trying out these new medications despite knowing that they would cause severe side effects. They also faced the dilemma of complying with their biomedical doctors for ongoing help seeking. They did not want to risk foregoing any help from their doctors, and they were concerned and alarmed at enduring more bad side effects from medications. Some felt trapped by their illness and decided that they had no choice but to take these new medications.

"I knew that to get better I had to undergo those side effects of those pills ... I remember thinking at the time that I was trapped by my illness and trapped by these pills ... I had to take them in order to get better in the long run ... that's what he told me and I knew in my heart that he was right ... and I had to follow his directions you know ... he wouldn't take me seriously at all if I had decided not to take those pills ... at that point in time. I didn't have that choice and option not to take those pills ... I needed his help in the future too you know ... I didn't want to offend him at all." (Andrew)

Despite such reservations, all participants reported taking their new biomedical medications and re-experiencing severe side effects from their respective medications. Some participants again decided to
discontinue with their medications due to increasing difficulties in being able to get on with daily tasks and activities.

“When I started again on the new medications that he had prescribed. I felt very sick ... I was feeling very off ... others around me noticed this too ... they told me that the pills were making me sicker ... it interfered with all of my activities ... I felt moody and I just wanted to be left alone all the time ... I was vomiting a lot when I first started with these new pills ... he told he that these side effects were normal and that my body needed time in adjusting to these new medications ... so I kept on with these new medications because I wanted to get better ... it was hell and I was really suffering.” (Zoe)

Participants who continued with their medications despite severe side effects, decided to do so motivated by thoughts of getting better. They decided to endure their suffering in the hope of getting better, and reported this decision to maintain the use of biomedicine as being a hard decision to reach. They felt that pain intensifying with these new medications and reported increased suffering. All participants expressed internal conflicts in deciding whether to continue/discontinue with their use of biomedical medications.

“I wasn’t feeling well at all ... I knew that the medications were getting me sicker ... I could feel it in me ... my stomach was constantly burning with acid and I felt very sick ... I knew that these pills were doing it because it’s the same sort of feelings I experienced when I had first tried them ... this time around they felt even more intense because he had increased the dosage of these pills ... the
medications were making me worse you know ... I could feel it in me.” (Euveka)

7.3.4. Returning to CAM therapists

Participants returned to their CAM therapists hoping to overcome side effects from their reuptake of biomedical medications and to obtain a cure for their ongoing illness conditions. They reported feeling comfortable in making appointments. Some participants disclosed their earlier biomedical visit to their therapists, and felt comfortable in fully providing feedback regarding their past biomedical treatments.

“I told her that the treatments had not worked ... I had followed her instructions and I had taken her potions everday ... I had made changes to my daily habits and my lifestyle ... I still could not see any major changes to my health and my vain was still there and not going away at all. She was very patient with me and she listened and allowed me to talk freely. She didn't react angrily at the fact that her treatments had not worked ... my doctor did you know (lawks) ... when I told him about how I had those bad side effects from his pills, he reacted very angrily as if I had accused him of not being a good doctor ... and that's not what I was saying to him at all ... I was basically saying that my medications were causing me great side effects and that they were not right for me ... she wasn't like that at all ... she just listened very carefully and asked me a few questions about some of the changes that I had experienced.” (Rosemary)

Others chose not to disclose, fearing that this would upset and offend their therapists.
“I didn’t tell her that since her treatment. I had gone back to see my doctor... it just didn’t feel right at the time you know... I thought that she would see that as me saying that I didn’t believe her and that I did not have confidence in her treatments... I didn’t want to upset her at all because she’s a really nice person and I knew in my heart that she means well... I knew that she wanted me to be cured and that she wanted the best for me... I agreed that I would keep taking her potions and that I would keep doing her exercises.” (Fiona)

Participants were advised by their therapists to continue with their treatments. They were advised to wait for longer periods to fully evaluate their CAM treatments and advised that alternative medicines take longer to take full effect unlike biomedical medicines.

“I told her about all that had happened since I had come to see her last... I told her about how I had followed her directions and about the changes that I had experienced... she was very positive about it you know... like she wasn’t defensive at all and she didn’t argue with me at all... she just listened and I did the talking. She was of the opinion that it was too soon for me to see any long term changes... she described how alternative medicines take longer to work... they are not like the medications from the doctor... they take longer to slowly build up from within... she asked to keep doing the exercises and to keep taking the potions that she had prescribed.” (Paris)

Participants reported feeling comfortable being with their therapists again. They reported feeling good in going back to see the
therapists. Participants reported that their therapists did not perceive their return to biomedical treatments as negative. Therapists did not offer any advice on the reuse or discontinuation of biomedicines when specifically asked by participants. Participants reported that their therapists offered them the choice of using both types of medications and reminded participants of their power and ability to exercise their choice. Therapists advised participants that alternative medicines were natural, thus would not react or undermine their biomedical medications.

"Going back to see her was very comforting you know ... it felt good being with her again despite the fact that her treatments had not worked that well ... it just felt talking with her and telling her about what I was going through at that time ... I told her about my visit back to my doctor and she seemed alright with that ... like she didn't have anything negative to say about that ... she didn't ask me to stop my medicines from my doctor ... nothing like that at all ... she said that it was my choice and that I could take them both as they would not interfere with each other ... she said that her potions were all natural and that they would not interact with my medications from the doctor.” (Geoffreu)

Participants reported being informed by their therapists to continue with their use of alternative medicines for a longer period of time. Some participants were offered stronger concentrations of potions by their therapists so that energy levels in the body could be slowly built up to promote healing from within.
“She wanted me to try the exercise for a longer period ... she said that it was too soon to tell if the medications were working ... she asked me to continue with the exercises and to keep taking my potions for at least another month. She also gave me some new potions with stronger concentrations and she told me that she was slowly building up the dose so that my body could respond to that.” (Andrew)

Participants reported being informed by their therapists that there was no cure for their illness conditions. They were further informed that alternative medicines would heal them so that they could better cope with their illness conditions. Participants understood healing as having the ability to live with and better cope with illness conditions rather than the eradication or curing of the illness condition.

“She said that her potions were not going to cure my condition as there was no cure, but they would heal me and that I would cope better with my condition ... and I saw her point ... yes. I still was very ill, but I could definitely cope better with it ever since I started her treatments. That’s what she meant by healing you see ... not that it was going to cure me, but it would allow me to kind of live with it better ... so that I could get on with my days and not let it interfere too much with my life ... I was really surprised by that ... I had never thought of healing in that way at all ... it wasn’t about curing me, but about being better able to live with my illness.” (Sharon)
7.3.5. Feeling frustrated

Participants reported feeling frustrated at not being able to be cured of their illnesses. They felt that they had invested so much of their time, money and effort into seeking treatments for their conditions, and they still had not been cured. Ongoing pain and intense suffering compounded these frustrations.

"I felt so frustrated by that time you know ... I had seen my doctor several times about my condition ... I had seen her twice ... and there was also the money side of things too ... I had spent so much money during this time ... you know I had put in so much time, effort and money just to get better ... and nothing was working ... I still was very sick and this thing was still with me ... the pain was still there ... I could better manage it, but it was still there ... all I could do now was to get healing, but I wanted a bloody cure ... I wanted this thing gone from my life for good." (Mark)

Participants reported conflicting thoughts regarding their help seeking attempts. They kept wondering whether it was worth their effort to continue with seeking help considering they were not getting anywhere despite investing so much of their time, money and effort. They felt frustrated that despite following all therapeutic recommendations, their illness conditions had not subsided.

"I kept having this kind of internal fight going on within me ... I kept thinking about where all of this was going ... I wasn’t getting any better ... and I kept thinking things ... I kept doing all the things that my doctor and my therapist had recommended ... I started feeling like
Participants reported coming close to the point of giving up all help seeking. They felt tired, exhausted, and ready to give in to their illnesses. However, they reported pushing on and powering on, as they needed to regain their old selves and to get on with living.

"That time was really hard ... very hard in fact ... all the treatments were no good ... I wasn't getting any better at all ... there were times when I just wanted to give in to my illness and just get it over and done with ... but in my heart I still was hopeful you know ... I wanted to get better ... I wanted to be my old self again ... I was so sick and tired of suffering ... I had reached that point where I was ready to just give in ... but I knew that I had to just keep going on with my treatments ... I kept having that something good was going to come out of this in the long term." (Sharon)

7.4. Getting on with living

Participants described their experiences of getting on with living after their CAM treatments. Five main themes emerged after an analysis of their conversations: feeling confused, getting down, becoming aware of a changed life, coming to terms with illness, and making changes to daily living. This is demonstrated in Table 16.
7.4.1 Feeling confused

Participants reported feeling confused and living in pain. Furthermore, they reported difficulties in strategic thinking, whereby they had difficulties in thinking of what to do next regarding their illness. They reported getting down with thoughts of a diminishing future, and feeling lost in terms of help seeking for their illness conditions.

"I felt so confused you know ... like what do I do now ... I had tried my best to get better ... I had done my very best and still nothing changed and I was still in pain. It was a very confusing time ... nothing made sense to me at that point ... I just couldn't figure out what to do next about this illness ... I was feeling very down by this stage just thinking of what lay ahead for me ... I knew that it wasn't anything good at all ... I knew in my heart that the worst was still yet to come ... even my family members were confused about what to do next ... they too were lost as to where to go for help." (Fiona)
Moreover, participants reported mixed up and conflicting feelings at that point in time. They reported feeling divided within. There were still hopeful and still longed for a cure. yet they also were ready to give in and not bother at all anymore.

"My feelings were all mixed up by that point in time ... I didn't know whether I was going left or going right you know ... it felt like I was stuck with very confusing thoughts in my mind ... I kept thinking of the real possibility that I was going to die ... I started thinking about that very seriously ... I just couldn't figure out why these treatments had not worked for me ... I started thinking that maybe I had not followed the instructions or that maybe I had not done my very best in these treatments, but that was not right at all ... I had done my very best to get better, but nothing changed. I could feel this horrible tension inside me you know. Like part of me still wanted to get better ... to try new things ... but there was this other part that just couldn't be bothered at all after all this. It was a very strange and confusing time for me ... in fact it was horrible, really horrible." (Eveka)

Participants reported feeling confused and being lost for directions. They described this part of their life as like living in hell and also like living on the edge. They reported reflecting upon their lost dreams, lost desires, and lost goals of life. Moreover, participants reported constantly thinking about their family members and other loved ones in their lives. Wanting to be with them in sharing their lives. participants expressed their desire to live more in order to be
with their loved ones. They realised that the finality of death would
tear them apart from being with their loved ones forever.

"I was lost and very confused ... I didn't know what to do next ... like
I was really lost for directions ... like I was just going round and
round in circles ... and each time I kept coming full circle without any
changes to my condition ... my pain started to intensify by this stage
... I think it was made worse with all this worrying and trying to find
solutions to my problem. I would only describe that part of my life as
just hell ... like living on the edge not knowing if I was going to make
it in life ... I kept thinking of all my dreams ... I kept thinking of my
family members ... I kept thinking of how much I loved them ... how I
wanted to be with them to share their lives ... I wanted to live and live
more, but my treatments were not getting me any better at all ... I
was going to die. I was going to die. I was going to die — that's what I
kept thinking of all the time ... it was horrible ... like being stuck in a
dark stormy night with no hope of morning." (Zoe)

7.4.2. Getting down

Participants reported getting depressed and engaging in repetitive
negative thinking. The main triggers for this were thoughts of being
unable to be cured and the real possibility of death. They recounted
losing all interest in their CAM treatments and stopping their CAM
treatment exercises. Losing all interest in their dreams and family
activities with loved ones. They expressed feeling like nothing
mattered to them anymore. They felt physically and mentally tired
and felt like they had lost all control over their thinking and their
life directions.
“I was very depressed during that stage of my life ... there was a lot of horrible negative things going through my mind at that time ... none of the treatments had worked and I was going to die you know ... that was the main thing that was driving all this negative thinking ... I just kept getting down and down in my life ... I was losing all interest in my treatments ... I stopped doing my exercises knowing that they were getting me no where at all ... I lost interest in my dreams of things that I was still going to do ... I lost interest in my family activities ... my loved ones noticed this and often they pointed out that I was withdrawing more and more from life and them ... I had reached the point that nothing mattered anymore at all ... it's like I was ready to die and to live in to this thing ... I didn't feel like putting up a fight anymore ... I was physically and mentally exhausted by this time ... I was doing just very negative thing all the time ... like from when I woke up in the morning to when I went to bed at night – these negative thoughts would go on and on in my head all the time ... from morning to night ... they just wouldn't stop at all ... it's like I was losing control over what came into my head ... I just couldn't stop them at all.” (Mark)

Furthermore, participants reported losing all interest in life, and reaching the point of not caring anymore. They knew in their hearts that their treatments were not working and that they were going to die. They expressed losing all hope and being unable to hide behind the mask of hope any longer. They painfully described getting depressed and engaging in repetitive negative thinking. They felt angry at the world around them. They questioned as to “why this was happening” to them, and sought to find meaning of their suffering.
"I lost all interest in things you know ... I couldn’t care less about my condition or anything else at that point ... I knew that nothing was working and that I was going to die ... I couldn’t hide behind the hope of these treatments working anymore ... I knew in my heart by that time that this was it ... I was going to die. Those thoughts went on and on in my head all the time ... I couldn’t stop them ... I was setting very negative about everything in my life ... I felt angry at everyone ... the whole world you know ... I felt very angry as to why all this was happening to me ... I’ve always been a kind loving person all my life ... I never did anyone any harm ... I couldn’t figure out why I was in this mess and suffering like this ... it wasn’t fair at all ... I wanted to live ... I didn’t want to die ... I was very angry and very depressed ... my moods were very down and I just lost all interest in life ... I couldn’t care less about anything or anyone anymore ... it’s like I was all drained out of any hope or anything good in my life.” (Sharon)

Participants expressed the strong desire to be alone with themselves. They reported feeling others around them as irritating. They report feeling withdrawn from the world around them and not feeling part of life any longer. They lost hope and got depressed with each passing day. Some participants even considered putting an end to their lives, but reported not having the courage to go through with it. Thoughts of their families and the love bestowed upon them by family members acted as deterrents for any self-harm.

"Others around me were so frightened that I might do something stupid ... I was very withdrawn about everything in life ... I didn’t want to do anything anymore ... I didn’t want to go anywhere ... I didn’t want to talk to anyone ... I didn’t want to take part in family conversations ... all I wanted to do was to be alone in my room ... I just wanted to be left alone with myself to be alone with my suffering"
... I was getting more and more down with each vassin' day ... I was getting less hopeful about life ... I felt miserable about life ... I wanted to end it all. but I couldn't because it's not in me to do any self harm like that ... I would have liked to, but it just wasn't in me ... that sort of courage to do away with myself ... I kept thinking of the kids all the time ... they needed me in their life ... I was really verru messed up in the head with all sort of weird thoughts constantly ... I was snarling at people ... I hated being around peopple at that time ... I just wanted to be alone with myself ... I was down and out — I knew that in my heart for sure ... I had lost all hope of anything good in my life." (Paris)

7.4.3. Becoming aware of changed life

Participants became aware that their lives had changed. They knew in their hearts that they were no longer who they used to be, and that their lives were no longer what it used to be. They had changed into 'other-than-myself' and their lives had become 'other-than-my life'. They reported feeling like the self they had known was dying a slow but gradual death. They were "losing the self they had known all their lives. They described the worst aspect as watching their self deteriorating before their eyes and being unable to do anything about it. They reported feeling like they no longer had any options in getting better. Moreover, they reported feeling helpless at not being able to regain their old selves and their older lives.

"I knew that my life had changed and that it was vain to get worse with time ... I had changed and I was changing ... changing into this thing that I did not like ... like the self that I used to know was dying
slowly in time ... I was losing my interests. my passions. my hopes. my physical body ... everything was changing before my eyes ... and the worst thing about all of this was that I was aware of these changes as these changes were happening right before my eyes ... I didn't like it one bit, but there was nothing I could do anymore ... there was nothing that I could do to retain my old self ... that part of me was over so suddenly ... like it passed right in front of my eyes so quickly ... my life had changed and I had changed with it ... and all I could do was just to watch it happening and not being able to do anything about it at all." (Geoffrey)

Participants came to the awareness that their lives had changed and were different. They felt that their illness had robbed them of everything good in their lives. They acknowledged that their lives were not going to change for any better. They expressed the need to get used to their altered selves and expressed hardships associated with this. They felt forced to like and come to an acceptance of their altered selves.

"My life was very different now to what it used to be ... I had changed with this illness ... it had robbed me of everything that was good in my life ... it had robbed me of all the good in me ... and the worst thing about this was that my life wasn't going to change back to what I used to be ... I just had to get used to this new diseased me ... that was the hardest thing about it ... like it's not something that happens overnight or even easily ... it's very very hard ... like getting to like and be with someone or someone that you don't like one bit ... like you hate everything about this thing. yet you don't have the option or choice to ignore it or disregard it and move away from ... I was stuck with this changed life ... I didn't like it and I still don't ... but I have no choice anymore ... I keep telling myself to get real and deal with it. but it's very hard to do ... easier said than done you know." (Andrew)
Participants conceded that their lives were not going to be any different and acknowledged that they would not get back to what they used to be. They expressed that they had changed and further expressed the need to come to terms with this. They expressed that coming to an acceptance of their altered state was a hard process and probably the most difficult thing they had done in their lives. They detested what they had become. Yet had to come to an acceptance of this becoming.

"My life wasn’t going to be any different and it certainly was not going to get back to what it used to be ... I had changed and I had to accept this you know. But this kind of acceptance is just so hard to do ... it’s probably the hardest thing that I have ever had to do in my life ... like accept a part of you that’s not nice. Something that you despise and don’t like at all. I kept denying this for a long time during my treatments ... I was kind of having that the treatments were going to get me back to what I used to be ... but I was kidding myself for a long time you know ... now that the treatments had not worked. The reality of my changed life and my death as right before my eyes ... I couldn’t deny this any longer ... it was a very hard thing to come to terms with ... it’s damn difficult ... it’s the hardest thing that I have had to do in my life and I’m still trying my best ... some days are good, but some days are just very painful and I get very down with myself”. (Zoe)

7.4.4. Coming to terms with illness

Participants described coming to terms with their illnesses as a painful, difficult, and hard process. They acknowledged that their illness conditions were not going to go away and that they would
not be cured. They had changed and their illness conditions were changing their thoughts, interactions, and being-in-the-world. They accepted the need to change and adjust their living in order to live and cope with their illnesses. Due to the pain inflicted by their illness conditions, participants expressed that their bodily ability to do things had drastically changed. Thus, they accepted the need to modify their daily tasks and activities in order to better cope with their illnesses and to get on with living.

“I knew that I had to get used to this disease of mine and learn to live with it you know … I mean my life had changed with it, but I also had to come to terms with this thing because it wasn’t going to go away from my life till I die. I had to really get very mindful of how my disease was doing things to me and my life … like I had to learn to become aware of this and then to live my life according to the changed me … like my physical abilities had changed a great deal … there were days when I just couldn’t do things at all.” (Eveka)

They stressed the importance of self-observation and listening to their bodies to get cues to their energy levels in order to schedule and conduct daily tasks and activities. They highlighted the help of their therapist in bringing to their awareness the importance of listening to their bodies and engaging in self-reflection in order to cope with ongoing living while being in and living through suffering. They reported having learnt techniques of self-reflection and listening to their bodies during their CAM sessions.
"My body used to get very tired and very painful ... so I had to watch for these physical signs of my body and monitor my feelings ... this allowed me to adjust my daily activities accordingly ... that sort of thing you see ... she helped me to do this you know ... I was completely unaware of this kind of self observation and adjusting your activities accordingly ... she taught me about this ... like how to actually monitor my feelings and listen to my body - that's the best thing that came out of her and her alternative medicine treatment - this self knowledge and self observation ... to start living my life not so much on what I think, but what I feel you know ... all of that really helped me in coming to accept my disease and live with accordingly." (Rosemaru)

Participants stressed that the hardest part of coming to terms was the fact that they were going to die. They described this increasing emerging awareness as generating stressful feelings of high anxiety. Coming to terms with their finality in life was the hardest things they had encountered in their lived experiences. They described this as painful and difficult.

"You know the hardest thing for me was coming to terms with the fact that I am going to die ... it's been so hard you know ... and it's so hard for me to describe this to you in words ... it's probably the hardest thing that I have had to do in my life ... out of all the big things that have happened in my life, this coming to terms with my illness has been the most painful and the hardest. It wasn't easy and it didn't happen overnight ... it's been a long painful process you know ... some days are better than others ... some days I just can't cope with my reality and yet there's just no escaping from the fact that I am going to die." (Fiona)
For some participants, coming to terms was not just about themselves and the fact that they were dying. The thought of losing loved ones and not being able to be with them was harder than the self-acceptance that they were going to die. The thought of parting with loved ones eternally was the hardest aspect of coming to terms for participants.

"This coming to terms is not just about myself ... it would have been much easier if I didn't have loved ones around me ... I could accept that I'm dying and I'm not going to be around for too long, but the thought of leaving my loved ones behind, just not being able to be with them, not being able to talk to them, not to be able to feel their hugs, not to hear their voice - I can't cope with all of that you know ... I try hard not to think about all that, but it's hard not to because it's true ... I will be leaving them and their lives for good ... without any come back at all ... I don't want to die, but it's not in my control at all." (Zoe)

Participants expressed coming to the acceptance of their illnesses as something that was part of themselves and as something that was not going to go away. They described coming to this acceptance through time, and they expressed that there was no set formula for coming to this acceptance. They described it as painful.

"I've come to accept my illness as something that is part of me and something that is not going to go away ... no matter how much I try to block it out of my mind. It's there. It's true. It's my reality ... it took me a fair while to come to accept this ... I can't describe just
exactly how long it took me you know … likes there is no magic formula in coming to terms … it's painful. but there is also strength in that suffering … it made me a bit stronger.” (Andrew)

Participants described finding strength in their suffering and reported that their suffering had made them stronger as human beings. They reported that while living through suffering, they came to the realisation that they were strong individuals with the inner ability to cope with intense pain and suffering. They acknowledged that their therapists helped them in coming to the realisation that they were strong human beings and that they had the ability to power on with their lives. They reported that their therapists gave them motivation to fight their illness by providing practical help and guidance in coming to an acceptance of death and getting things in order.

“'I've come to know myself as much stronger than I had previously thought. She helped me greatly through this process … I couldn't have done it without her at all … she made me face my illness head on in a powerful assertive manner … she gave me motivation to fight this thing … it's like she gave me power to just move on from day to day … she made me yet my things in order … she helped me do the little things that I wanted to do with myself and with others … I am just so grateful to her for all that.” (Sharon)
7.4.5. Making changes to daily living

Participants reached a certain point in time during their suffering where they felt the urgent need to make changes to how they lived their lives. This urgency emerged through lived pain and their diminishing ability to cope with ongoing living. They arrived at this point through their individual processes of coming to terms with illnesses in their unique ways. To come to terms with illness, they made major changes in the doing of their daily living, and they reevaluated their changed goals and priorities in life.

"I reached this point where I could feel the urgent need to make changes to the way I was living. I had to make all sorts of changes to my life you know ... I went through that hard process of coming to terms with my illness, but to do that I also had to make major changes to my life ... that kind of went hand in hand you see ... like those two things were interrelated ... in order to come to terms with my illness. I had to make changes to my life ... like the way I went about doing my everyday things ... that sort of thing ... I felt that I had reached that point where these changes were needed ... I had to make them in order to cope with my illness ... it's like I had to ... it was needed in my life at that time ... these changes were hard to do and, at times, I felt very uncomfortable with them, but they had to be done. I felt like I had become this new person that I didn't like ... this weak diseased thing that didn't have enough energy to do much ... I had to make major changes to things that mattered to me in life ... I had to make changes to what I valued in my life ... I had to break away from my old way of thinking and doing things ... that's not easy to do at all ... very very hard living up old ways of our lives, but I did it ... that's the main thing ... I did make these changes to my life in coming to acceptance of my illness and it worked for me because I could cope better." (Zoe)
Participants described making changes to their immediate physical environments. They rearranged spaces within their homes to create healing environments as suggested by their therapists. They modified their physical environments in order to create comfortable, positive, and peaceful living spaces. Participants acknowledged the help of their therapists in sharing ideas and providing practical advice regarding modifications within their homes.

“I changed my whole house as my therapist had recommended … she told me I needed this healing environment that would promote healing … it took so much time to do this you know … it was needed. I changed my bedroom … I got rid of all the unwanted things that were there … you know things that didn’t have any real use and things that I really did not like or need you know … I made my bedroom more user friendly … I made it really comfortable and really positive … like I put up colourful pictures, pictures of nature … things like that which I had seen at my therapists place … and she had certainly helped in giving me ideas about how to do these changes … my major aim was to make my bedroom very comfortable and very soothing … like I didn’t want anything in there that was going to hinder me in any way or yet me feeling uncomfortable. I also wanted to make it very peaceful so that I could feel peaceful and comfortable while in there.” (Rosemaru)

As well as making physical changes to their environments, participants also reported making mental changes to their thought processes as recommended by their therapists. They reported engaging in constant self-reflection and self-observation in order to
monitor their thought processes. In particular, they reported observing the nature and the quality of their thoughts in terms of positivity and negativity. While engaged in this self-reflective process, they reported becoming aware of the relationship between their thoughts and feelings. For example, some participants reported that for the first time in their lives, they discovered that their thoughts and feelings were indeed interrelated and inseparable. In particular, they discovered that their negative thinking resulted in negative feelings of themselves, which affected their ongoing ability to live and to cope with their illnesses. Participants discovered through their meditation exercises that they were better able to exercise control over the quality of their thoughts.

"For me, the major changes that I made were to do with my thinking ... I really changed my thinking patterns during this time. I really got to know quite a great deal about the kind of thoughts I was having and the kind of feelings that were being generated with these thoughts ... I got this through the self-reflection and self-awareness exercises that I did after seeing my therapist. I noticed that I was doing too much of horrible negative thinking and that this kind of thinking was making me feel more and more depressed ... this was affecting my ability to deal with my illness. So, I wanted to change all of this and I started to control my thinking by constantly monitoring the kinds of thoughts that I was having during my daily activities. This was very hard to do you know, but I managed to change quite a lot of my negative thinking and this really helped in my day-to-day living. Her meditation exercises really helped me in controlling my thoughts and practicing detachment from these thoughts. ...I realised the link between thinking and feeling for the first time in my life ... she helped me greatly." (Geoffreu)
Participants reported making changes to their goals and dreams to reflect their changed realities of life, and described this hard process as intensely painful, yet necessary. They acknowledged and appreciated the help of their therapists in being able to do this.

"I made changes to my goals and my dreams about my living and myself ... I just had to do this because I had changed with my illness ... my life had changed with it too ... the old dreams and goals were no longer right because they did not reflect this new changed me ... she made me come to that realization during my sessions with her ... I had not thought about this at all and it certainly helped in me getting on with my own living ... it's like I had to make these mental changes in order to move on with the changed me ... there's no other way I can explain this to you ... I had to make those changes ... that doesn't mean that I liked doing that at all (laughs) ... I didn't like living up my dreams and ambitions at all (laughs), but I had to do it to move on with my life ... I couldn't go forward with the old plans because I had changed and my life had changed ... it took me a long time accepting that you know ... it was a very hard process, but I did it in time ... I just had to do that ... it was absolutely essential ... it was so damn hard letting go of my old dreams you know ... so hard." (Sharon)

Participants reported making changes to their interactions with others around them at this point in time. Out of self-reflection and self-observation through their meditation exercises, some participants reported reaching an awareness of others as sources of negativity. In particular, they noticed that their on-going
interactions with certain others produced negative thoughts and
feelings which affected their on-going ability to cope with their
illnesses. Thus, they engaged in the painful process of letting go of
friends, lovers, and extended family members who were sources of
negativity and hindered their ability to cope with their suffering and
their on-going living. In doing so, participants reported feeling
stronger for making active choices and reported being better able to
cope.

"I made changes to my associations with people around me ... after
doing her self reflection exercises. I came to realise that I was
interacting with quite a few negative people and that their negative
energies were rubbing off on me ... that was quite a realisation for me
at that time because I had never really thought of that earlier in my
life ... after reflecting upon my interactions with others around me. I
stated making changes to who I interacted with ... I let go of some old
friends, old lovers, some work mates, and even some of my extended
family members ... I had come to know that interacting with them
was not the right thing for me ... don't let me wrong you ... there's
nothing wrong with these people as individuals ... it's just that my
interactions with them were not helping me in anyway ... so I had to
make these choices you see ... I started controlling my interactions
and my associations with others around me. I felt better after doing
that ... I felt I could cope well with my illness and with myself ... and
I felt healthier for doing so." (Mark)

Participants reported the process of making these changes as hard
and painful. but they reported feeling stronger and feeling better
able to cope. While participants were able to transcend most self-
limitations involved in implementing changes. They reported being
dependent on the cooperation of others around them. They stressed the
importance of making significant others around them understand
their reasons for implementing these changes and for seeking such
accommodations.

"Most of these changes were hard, but I did them. I felt stronger in
making these changes to my life and I felt that I was coping better
with my daily activities and my illness. But some of the changes that I
had planned needed the help of others around me you see ... like I
needed people within my immediate house to understand that I was
making these changes and for them to understand why I was making
these changes ... I need the help of my kids and my husband ... and
they did help me creatively with these changes I felt that they understood
what they were going through in my life ... at times I felt that they
felt a bit uncomfortable because it started affecting their ongoing lives
... like when I changed the tasks that I had done around the house. I
felt the feeling that my husband and my kids did not like that all ... they
felt that I was basically unloading all my jobs onto them you see
... after I explained why I had to do that. I felt that they came to some
acceptance of the changes, but I don't think they were too happy about
that at all." (Fiona)

While being successful in implementing these changes in order to
cope with their illnesses and their ongoing lives, some participants
were not happy about making changes and described it as a painful
process of making necessary losses in life.

"For me to get on with things and move forward to my tomorrows, I
needed to change my thinking, my daily tasks, my daily routines ... there
were lots of changes I had to make and there were lots of things
that I had to vive up in life ... I had to let go of my dreams of the future. I had to let go of my job and the independence that came with that. I had to let go of some relationships in my life. I had to let go of some of my favourite hobbies. let go of passions and interests in life ... I see them all as necessary losses in my coming to terms with my illness ... these losses were necessary so that I could live again and to vet on with my journey in life." (Zoe)

7.5. Summary

This chapter described research participants' experiences of their daily living after seeking and implementing CAM treatments. We saw how participants waited and evaluated their complementary treatments while living in hope and feeling stuck in time. Also, we saw how participants felt disappointed at not being cured from their illnesses and felt trapped and disappointed in having to return to their biomedical practitioners and CAM therapists. Furthermore, we saw how participants pushed on with their daily living despite not being cured, and how participants came to an awareness and acceptance of their changed lives and realities. In coming to this acceptance, we saw how participants made adjustments and modifications not only to their daily living, social environments and interactions, goals and dreams: but also their self-concepts of identity, attitudes, values, and behaviours. The next chapter presents an overview of some of the significant findings emerging from this research study regarding the lived experience of using
CAM in order to better understand why research participants turned to CAM.
8. Summary of significant findings

8.1. Introduction

The last four chapters presented the research participants’ journeys encountered in their lived experience of using CAM. Participants described the onset of illness and getting sick, seeking biomedical treatments, coming to CAM and using CAM treatments, and the impact of using CAM in their daily living with chronic illnesses. This chapter presents a micro perspective of some of the significant findings emerging from the participant in-depth interviews regarding the lived experience of using CAM and the reasons for such use within the context of living with chronic illnesses. The next chapter presents a macro perspective regarding the lived experience of using CAM in order to understand why research participants turned to CAM treatments. The effects of using CAM on their subjective perceptions of self are also discussed in the next chapter. The next chapter concludes with a synthesis of the broader social context of CAM use and the associated health policy implications within the Australian context.
8.2. Referral routes and initial motivations for using CAM

- The findings of this study reveal that the referral route into CAM for all participants in this study was through networks of informal personal contacts. Sources of information on CAM were primarily via word-of-mouth (for example, friends and family), health shows, the media, books or the Internet.

- Participants in this study had no prior experience or knowledge of CAM with some reporting an initial scepticism that was subsequently quelled by positive CAM treatment experiences.

- An unexpected finding of this study was that participants did not reflect the 'typical' CAM user profile, particularly in terms of subscribing to an alternative/new age philosophy and/or lifestyle, and were not necessarily 'smart consumers' in that they did not have the financial resources to 'shop around' for treatments.

- All participants reported negative experiences with prior biomedical help seeking interactions and biomedical treatment side effects and outcomes for their initial presenting health problems.

- The majority of participants in this study suffered from chronic degenerative complaints for which biomedicine offered limited effective treatment and CAM was perceived as providing beneficial adjunct care in participants being better able to cope with pain and
suffering, as well as cope with the social stresses of on-going daily lives.

- All participants had a pragmatic approach towards CAM: They sought CAM treatments without any strong philosophical preference for CAM ideologies in order to search for practical ways to regain and to sustain their lives alongside their existing use of biomedical treatments and medications.

- The findings of this study show the importance of regaining selves lost to chronic illness and being “able to do your normal daily things” was central to all participants' sense of health and well-being.

- The challenges posed by chronic illness on shifting notions of self were further evidenced by the way in which most participants framed their states of health through social and personal comparisons with changes in their reduced ability “to do things”.

- The findings of this study illustrate that using CAM was viewed by all research participants within the context of the broad goal of searching for practical ways to regain and sustain lives, and treatment success was primarily evaluated in terms of its impact on physical functioning, pain reduction, and the ongoing ability to cope with everyday living.
8.3. Personalised care and the therapeutic relationship

- The findings of this study reveal that the personalised nature of care provided by the therapists was significant to all participants. Interestingly, care was perceived as much broader than simply the treatment itself, but was rather represented by the overall qualities of the therapists and even the physical layout, smells, and ambience of consulting environments.

- The long consultations and highly personalised care provided by their therapists were greatly valued by all participants and frequently contrasted with prior impersonal ‘clinical time limited’ experiences of biomedicine.

- The findings of this study revealed that the intimate and caring nature of the CAM environment was seen as providing an important emotionally supportive resource for participants.

- Not only did participants feel ‘cared for’, but they also derived considerable reassurance from the knowledge that help was readily available when necessary since additional appointments could be made at short-notice.

- The findings of this study showed that relationships with therapists were valued for their therapeutic and social functions. Participants discussed the importance of discussing feelings and concerns within a supportive and non-judgemental environment.
• The findings of this study highlighted the fact that the therapeutic relationship is pivotal to CAM treatments. Patients made numerous positive comments about different aspects of the relationship and experienced trust and appreciation.

• The findings of this study reveal that the therapeutic encounter between therapists and participants were similar to psychotherapy.

• The findings of this study reveal that positive therapeutic relationships were developed during CAM consultations as mentioned by all participants.

8.4. Beliefs about treatment

• The findings of this study reveal that all participants advocated the use of complementary health care in terms of better pain management and increased abilities in coping and social functioning.

• The findings of this study reveal that whilst several participants described their initial scepticism of CAM, confidence and faith in the treatment developed for all participants through continued positive interactions with their therapists encountered with continued use of CAM.

• The findings of this study reveal that participants valued their CAM treatments. The value attributed to treatments was evident in
participants' discourses of being "grateful" and "lucky" to have a "good" therapist who understood their pain and suffering.

- Treatment affordability was a key issue, with only a few participants able to finance private CAM treatments on their limited incomes. As a result, participants felt that CAM should be more widely available for all patients and incorporated into Medicare.

- The findings of this study reveal that participants differentiate CAM and biomedicine treatments using the 'natural vs. chemical' divide.

- The findings of this study reveal that participants exercise caution and control in usage of biomedical medications and CAM treatments. All participants attempted to control their biomedical medication usage and avoid 'overdoing it' reflecting a wider concern with long-term medication use and dependency.

8.5. Coping

- The findings of this study reveal that an important function of CAM treatment was to provide additional means of coping, both with specific health problems and with wider life stressors.

- Interference with lifestyle and social roles and responsibilities was a major reason for all participants seeking out CAM in this study, and consequently, developing strategies to control the physical
manifestations and consequences of chronic health problems was considered an important treatment outcome.

- The findings of this study reveal that the development of coping strategies emerged from three key sources: the success of the treatment itself, communication with the practitioner, and expanded ways of understanding health.
- The findings of this study reveal that a key coping mechanism for participants was an increased focus on health maintenance in living with chronic illnesses.
- The findings of this study reveal that making lifestyle changes was related to a greater sense of responsibility over health, an attitude iterated by the majority of participants.

8.6. Ownership and gaining a sense of control

The findings of this study reveal that dealing with chronic, often degenerative illness raised several issues of control for all participants. On the one hand, most participants felt that biomedicine offered little personal control either in terms of involvement or choice. In contrast, participants perceived CAM as offering empowerment by encouraging them to participate in their health through lifestyle changes and by providing a ‘carine’
environment in which participants felt confident to ask questions and address their health concerns.

- The potential to make decisions (even choosing to stop treatment) and the empowering nature of adequate explanations offered their therapists were particularly salient for all participants with negative experiences of biomedicine. Several participants discussed prior biomedical incidences in which they had either not been fully informed about their condition or their treatment requests had been ignored, resulting in a loss of confidence in biomedicine and their biomedical practitioners. This highlights the dis-empowering effects of poor communication and inadequate explanation, with serious implications for subsequent dealings with the biomedical health care system.

- The findings of this study reveal that participants in this study desired ownership of treatments as they became more familiar and socialised with CAM. All participants' discourses regarding CAM health care demonstrated a sense of 'ownership' over both the treatment seeking process and the treatment outcome itself.

- The findings of this study reveal that treatment was perceived as providing a crucial sense of control over pain and symptoms in chronic illness. This had a significant impact on all participants since the unpredictability and uncontrollability of their symptoms were
linked with reductions in social activities as well as heightened anxiety.

8.7. Relationship to self and others

- The findings of this study reveal that participants reported changes in both the way they viewed themselves and in how they related to others, particularly in terms of enhanced self/other awareness. These changes in the conceptualisation of self and others were perceived as having ramifications for health and beyond, impacting on participants' relationships, lifestyles and professional lives.

- Changes in self-identity were associated with increased self-acceptance and self-worth, often characterised by recognition of the need to pay greater attention to personal needs. This attention to the self was perceived as empowering both in changing self-perceptions and by facilitating a sense of control over life circumstances.

- It was also recognised that such changes in mental attitude had an impact on health status through reducing stress and preventing illness in the longer term. Through changing self-perceptions, participants also adapted their lifestyle to incorporate greater self-reflection and personal space.

- The findings of this study reveal that in using CAM participants became more aware and appreciative of others. In addition to changes
in self-identity, several participants felt that using CAM had led to changes in their perceptions of others, which had enhanced their social and professional relationships.

8.8. Being critical

- The findings of this study reveal that participants were critical and questioning in their approach and use of CAM. While valuing their therapists’ healing abilities, effective interpersonal skills, and treatment recommendations, participants described ways in which they undertook a search for legitimacy to test the efficacy and validity of treatment.

- Several methods of credibility checking were employed by participants, such as monitoring bodily changes, seeking out anecdotal evidence, and withholding information.

- The efficacy of CAM was also frequently compared with that of biomedicine and references were made to beliefs in ‘science’ and ‘scientific methods’, especially since the latter had been unsuccessful.

- Additionally, most participants appeared to undergo a process of testing their therapists to assess their knowledge and treatment effectiveness. This involved withholding diagnostic information from prior biomedical experiences and monitoring physical changes during or immediately after CAM treatments.
8.9. Symptom relief

- The findings of this study reveal that all participants reported an improvement in symptom management of their chronic illnesses. In some cases, treatment led to a concomitant decrease in the use of medication, particularly for painful conditions.

- Most participants noted a temporal dimension to their symptom alleviation although different patterns emerged. For some, initial treatments produced the most pronounced effects, which levelled out over time, whereas for others treatment effects were more gradual or variable.

8.10. Energy and relaxation

- The findings of this study reveal that beyond treating specific health complaints, CAM was frequently perceived as increasing energy levels and giving a 'boost'. This enhanced physical and social functioning while also impacting on overall well-being.

- Another secondary outcome of treatment was increased levels of relaxation. In addition to physical relaxation and its consequences, such as improved sleep, these participants related their physical experience to mental well-being, both in the short and long term.

- The findings of this study reveal that since participants' overall goals appear to be to regain and sustain lives to sustain 'normal'
functioning. Perceived physiological effects were most salient to their accounts of CAM treatment experiences and outcomes.

- The findings of this study reveal experiences of CAM were inevitably considered within the context of the broader illness experience, which included a recognition that biomedicine offered little hope in terms of treatment for their chronic conditions. Treatment was therefore evaluated in terms of its impact on symptoms (particularly pain), social coping, and relaxation.

- All participants had experienced some relief of symptoms through using CAM, and several had significant improvement of being better able to come to terms with their altered lives and the ability to cope with the demands of ongoing living. Coping with pain was a concern voiced by the majority of participants, having a substantial impact on social functioning. In addition to having psychological consequences.

- The findings of this study reveal that whilst participants primarily emphasised the impact of treatment on their physical complaints, the psychological effects of treatment were recognised as playing a role in the healing process and contributing to overall well-being. Although given less emphasis, the discourses relating to a sense of 'feeling good' within oneself, together with an enhanced sense of being able to cope with an altered life, were remarkably similar across participants. It appears that this 'feel good' aspect of CAM treatment bridges the gap
between individuals' perception and actual experience of self if for a limited time.

- The findings of this study reveal that whilst post-treatment effects were often short-lived, longer-term effects tended to manifest as a change in perspective, such as adopting a more positive attitude towards one's health and wider opportunities. Thus, it was such mental shifts within the course of CAM treatments that led participants to improvements in being better able to come to terms with their chronic illness and the abilities to better cope with the practical demands of ongoing living with chronic illnesses.

8.11. Summary

This chapter presented a micro perspective at some of the significant findings emerging from the participant in-depth interviews regarding the lived experience of using CAM and the reasons for such use within the context of living with chronic illnesses. The next chapter presents a macro perspective regarding the lived experience of using CAM in order to understand why research participants turned to CAM treatments. The effects of using CAM on their subjective perceptions of self are also discussed in the next chapter. The next chapter concludes with a synthesis of the broader social
context of CAM use and the associated health policy implications within the Australian context.
9. Discussion and recommendations

9.1. Introduction

The purpose of this study was to illuminate and discover the lived experience of using CAM by individuals living with chronic illnesses in an attempt to understand their reasons for choosing CAM within the social contexts of their lives. The research question guiding this qualitative study was: Based upon a reflection of lived experiences, why do individuals living with chronic illnesses choose to use CAM? The major finding of this study is that research participants turned to CAM to find practical solutions for coping with pain and the ongoing demands of living daily lives while suffering and living with chronic illnesses. Unlike existing research findings, participants in this study did not turn to CAM for ideological reasons, nor were they seeking a holistic approach to health and health care. As such, the findings of this study strongly suggest that individuals living with chronic illnesses initially choose to use CAM for pragmatic reasons rather than ideological dispositions. However, the findings also suggest that after their initial use of CAM, individuals appear to adopt, via enculturation
processes. More holistic ideologies resulting in modifications to perceptions of self, illness, and health.

9.1.1. Why do individuals living with chronic illness use CAM?

The majority of researchers investigating why people seek out CAM approaches to health and healing have been concerned with discovering the motivating factors for individuals' use of health care. Some argue that participation in CAM represents an overall disenchantment with biomedicine (Adams. 2005; Barrett. 2006; Cincotta. 2006; D’Crus. 2005; Grace. 2006; Hassed. 2006; MacLennan. 2006; McCabe. 2005; O’Callaghan. 2003; Searles. 2007; Siahroush. 1999; Wang. 2006). Others contend that people are drawn to CAM not so much out of a dismissal of allopathic care, but because they are attracted to aspects of alternative health ideology, such as desire for control over health and healing or a belief in a holistic approach to health care (Alderman. 2003; Balneaves. 2007; Bauerniet. 2000; Burden. 2005; Cox. 2003; Lengacher. 2006).

Existing researchers also conclude that it is both dissatisfaction with allopathic health care and the appeal of CAM that drive people away from biomedicine and towards alternative health care (Fan. 2005; Forstor. 2006; Godern. 2005). These contrasting views have
been conceptualised as the push/pull debate by Furnham and Smith (1988), among others (Sharma, 1999; Vincent and Furnham, 2006). The question becomes: Are people pushed away from allopathic medicine and, as a consequence, pushed towards CAM, or are they pulled towards CAM health care and, consequently, pulled away from allopathic medicine?

However, the explanations for why people turn to CAM health care subsumed within the push/pull debate are problematic for a number of reasons. Not the least of which is that what are commonly reported in the literature as motivating factors in peoples use of these therapies did not figure prominently among participants in this research study. Conceiving the possible connections between dissatisfaction with Western medicine and use of CAM health care in push/pull terms situates people as passive, rather than active agents. The image conjured up is one of the individual being drawn or repulsed, as if coerced by some external force: one who is buffeted between alternative and allopathic approaches to health care rather than actively choosing amongst them. Further, conceptualising individuals' decisions to seek out CAM in push/pull terms turns attention away from what is really at issue for these
informants, namely, finding practical solutions to impending health problems.

In general, research participants in this study did not turn to CAM for ideological reasons: they were neither seeking a holistic approach to health and health care, nor seeking control over matters of health and healing. Nor does dissatisfaction with allopathic medicine alone sufficiently explain why these people first engaged in CAM approaches to health and healing. Rather, in participating in CAM, they were actively seeking practical relief from chronic health problems for which they found little or no redress in other quarters.

However, the people who took part in this research rarely identified ideological issues as reasons for their decisions to first seek out alternatives. While research participants made reference throughout ongoing interviews to a variety of ideological components of the alternative model of health and healing they espouse, including a belief in the value of a holistic approach to health care or therapies that allow them to take control of health and healing, these beliefs were almost never voiced in conjunction with the accounts they gave of why they first turned to CAM. Furthermore, while dissatisfaction with allopathic medicine was mentioned by all research participants as concomitant with their initial participation in CAM forms of health care, it proves problematic to attempt to explain an individuals use of these therapies solely through dissatisfaction with allopathic medicine.

The view that CAMs allow individuals a greater degree of control over their health and health care is often specified as a motivating factor in individual participation in these therapies (Armstrong. 1995; Block. 2005; Coulter. 2004; D’Crus. 2005; Grace. 2006). While the desire for control was certainly something research participants valued about CAM approaches to health and health care, when they spoke about why they first got involved in using these therapies.
only one person identified a desire for control as the issue promoting to seek out CAM therapies. For the rest of these research participants, the possible benefits to be derived from taking control and being in control of one's health and health care were things they discovered through their ongoing experiences with CAM and, in particular, in interaction with CAM practitioners - in other words, after they first began using CAM forms of health care.

Another aspect of alternative ideology, holism, is said to be an important factor in people's choice of CAM approaches to health care (Adams. 2006; Agrawal. 2006; Baron. 2005; Brav. 2004; Closs. 2007; Vlieger. 2007). However, only two research participants referred to a desire for a holistic approach to health and healing as something motivating them to first seek out CAM. Again, it was only through their experiences with these therapies, and in interaction with CAM practitioners, that the vast majority of these research participants came to espouse alternative ideologies, including a belief in holism. Clearly, the allure of alternative health and healing ideology was not the initial motivator for use of CAM for the majority of my research participants. However, research participants did identify dissatisfaction with allopathic medicine as
something concomitant with their decisions to turn to CAM health care.

Many authors argue that people turn to CAM because they have recognised the limitations of Western medicine and/or are dissatisfied with allopathic approaches to health care (Adams. 2006; Balneaves. 2007; Bauerniet. 2000; Burden. 2005; Cox. 2003; Lengacher. 2006). Similarly, most of the research participants associated disillusionment with biomedicine with their first experiences of CAM. The dissatisfaction with biomedicine expressed by these people took many forms. For some a profoundly negative experience with biomedicine led them to look for alternatives.

For a few research participants, however, a sense of dissatisfaction with allopathic medicine was more all-encompassing and tended to be focused on discontent with medical professionals on the one hand and/or dissatisfaction with medical therapy on the other. Several told me that their sense of dissatisfaction with Western medicine was related to what they saw as arrogant or uncaring attitudes displayed by physicians within biomedical interactions.
Further, Cohen (2005) argues that some people seek out CAM in order to have their problem seen as legitimate. Legitimacy is often at issue in cases of environmental illness, chronic fatigue syndrome, or other problems that “do not ... fit accepted biomedical diagnostic categories” (Tsao, 2005, p.64). Similarly, a few of my research participants voiced discontent at having to convince their medical professionals that their illnesses were real.

Dissatisfaction most often arose in connection to allopathic methods of treatment (Lehrer, 2004). In particular, research participants raised questions about the suitability and efficacy of allopathic therapy. In addition, they voiced concern over the potential iatrogenic effects of medical treatments (Siahroush, 1999). For instance, many research participants believed a biomedical approach was not suitable for the kind of problem they had and/or found that allopathic medicine could not help them with their problem. Most common was the belief that allopathic health care was inappropriate to chronic conditions. All research participants turned to CAM in response to chronic health problems for which they found no relief in allopathic medicine. Finally, several research participants’ expressions of dissatisfaction were related to concerns over side effects and/or invasive medical technology (Fan, 2005;
Dissatisfaction with allopathic medicine was certainly something that was concomitant with all research participants' decisions to turn to CAM health care. However, discontent with biomedicine alone does not sufficiently explain why people first use CAM. If for no other reason than disillusionment with allopathic medicine does not necessarily lead to participation in alternative approaches to health and healing and is, in addition, something often expressed by those who have never used CAM (Armstrong, 2005; Ernst, 2004; Mills, 2005; Sharma, 1999). So, how then do we explain the use of CAM?

9.1.2. What is the social context of using CAM for individuals living with chronic illness?

Campion (1993, p.282) makes the point that people seek out CAM because they "want to feel better." and Pescosolido (1998, p.219) concludes that people "continue to ask advice and seek help from a wide variety of lay, professional and semi-professional others until the situation is resolved." Similarly, all of the research participants turned to CAM because they had a particular problem causing them...
painless distress that they wished to solve. Finding little or no relief in other quarters, they began looking for alternative solutions. For all research participants, an initial foray into CAM health care was an instance of practical action taken in order to solve what, at that time, they saw as impending health problems.

While people turn to CAM for a variety of reasons, I have found that focussing on particular motivating factors is not as useful as discovering the "generic social processes" involved in their participation in alternative health care. This was made plain to me when I found that explanations reported in the literature as to why people seek out alternative forms of health and healing were not significant factors in motivating those I spoke with to first use these therapies. As discussed earlier, conceptualising peoples initial motivation to use CAM in push/pull terms is problematic. For instance, all but two research participants were not pulled towards alternative approaches to health care. They were not shopping for an ideology when they first sought out CAM. Holism and control, both aspects of their alternative ideology of health, were beliefs they came to value and espouse after they began participating in alternative health care. They were things they learned through interaction with CAM practitioners and other users of alternative
approaches to health and healing, making them a product of, rather than motivator for, their use of these therapies. Push/null explanations obscure this significant temporal aspect. Thus, ideological factors are better employed in explaining why people continue to use CAM.

Furthermore, the argument that people are pushed towards CAM because of dissatisfaction with allopathic medicine does not sufficiently explain why people turn to CAM. While those who participated in this research did associate disillusionment with allopathic medicine with their initial forays into CAM health care, interestingly none had wholly rejected allopathic medicine in favour of CAM. And as Sharma (1999, p.77) rightly points out, dissatisfaction with allopathic medicine cannot fully explain an individual’s decision to turn to CAM. as discontent with Western medicine is “by no means confined to users of complementary medicine.” Seeing individual’s initial decisions to seek out CAM in push/null terms turns attention away from what is really at issue for these research participants, namely, finding some sort of ‘practical’ solution to health problems. In this case, they found an alternative solution in CAM approaches to health and healing.
I argue that these research participants' initial use of CAM is an instance of problem solving reflective of generic social processes. However, in what social context does this generic process of problem solving take place? Alternatively, is the choice of CAM therapy as a solution to problems of ill health reflective of larger socio-cultural change whereby alternative solutions constitute a new option in health-seeking behaviour?

In addressing this issue, researchers have explained their participation in CAM by placing it within the context of larger socio-cultural changes in beliefs about health, illness, and the body, which include the following: disillusionment with medical science; lowered demands for a larger share of control over health and healing; and a belief in holistic health care (Armstrong, 1995; Block, 2005; Coulter, 2004; D’Crus, 2005; Grace, 2006), where “health is more than a lack of disease ... resting on harmony of body, soul, mind, and emotion, and satisfactory relationships with other people and with society as a whole” (Coward, 1989, p.43). However, when the frame of analysis is one of the problem-solving actions of individuals, the image which emerges, is one of consistency rather than change. To illustrate, the ideological components of the alternative model of health espoused by these people are not new in any objective sense.
Rather, as Mills (2005, p.44) notes, “there is an intriguing continuity in many beliefs about health and illness” over time. Culturally speaking, these ideas about health and healing were always there (Baer. 2003; Bloom. 2005; Kaufman. 2005). For example, the notion of holism harkens back to Galen and the four humours school (Kleinman. 1998). Accordingly, it is not that the elements of the ideology are necessarily new; rather, it is that these beliefs have now been taken up by these research participants in order to articulate a model of health care they perceive as alternative therapy. These ideological components are cultural symbols, ultimately subjective in nature (Cohen. 2005, p.15). Thus, the people with whom Pawluch (1998) spoke were able to use many of the same symbols, or elements of health ideology, to create a complementary rather than alternative solution to health problems.

Moreover, there has always been a plurality of healing options available to the individual (O'Connor. 2005). For instance, in the 1663 volume of the diary of Samuel Pepys, we read of his attempts to solve his health problems by choosing between remedies offered by the apothecaries and those advocated by the doctors of physique (Lehrer. 2004). Likewise, Connor (1997, p.59) points out that it was
only in the latter part of the nineteenth century that healing options were seen to narrow.

The same phenomenon where “the evolving boundaries between orthodox and unorthodox medical knowledge” can be highlighted with reference to the period of two or three centuries leading up to the first half of the nineteenth century (Saks. 1996. p.29). The boundaries that emerged did not eradicate all forms of health care other than allopathic medicine: rather, they remained within the health care system (Armstrong. 2005; Bakx. 1991). Their ideological underpinnings part of the symbolic framework of “ideas which at any given time have holders” ready to be used by people in their efforts to solve health problems (Lupton. 2005. p.117). Hypothetically, even if non-allopathic approaches to health care had been wiped out during this brief period, the individual always had the option of self-care or the option of doing nothing about his or her health problems.

Therefore, the nature of the actions of individuals in choosing this option cannot be said to have changed: rather, they were, and remain, attempts at solving problems of ill health. On the other hand, what has changed is that there is now something people call
alternative therapeuical or complementary health care, or integrative medicine. The symbolic components of which have always been part of the ideologies of health care options available to people in solving health problems. Conceptualising health-seeking behaviour as a generic process of problem solving allows us to account for whichever solution, alternative or otherwise, individuals choose.

While alternative health and healing ideologies was not a significant factor in motivating the people I spoke with to begin using CAM health care, its importance should not be discounted, as these beliefs are something that individuals acquire through their participation in alternative health care via enculturation processes and something that holds importance for them in their continued use of CAM. Moreover, these ideologies form their alternative models of health and healing with their continued use of CAM.

9.1.3. What is the effect of having used CAM on perceptions of self for individuals living with chronic illness?

In participation in CAM health care, as well as through interaction with CAM practitioners, research participants began to adopt alternative ideologies of health and healing—ideologies that can have, at times, profound implications for individuals' subjective
perceptions of self. For instance, Winnick (2006, p.73) writes that the networks of alternative therapy use that these people develop are a "significant source of new meanings and identities." Similarly, Andrews (2006, p.72) writes that for some research participants, "the benefits of using CAM went beyond improved health". Participation in therapies that emphasised holistic health often served as a catalyst for broader personal transformation: changes in roles and identity that extended beyond specific health issues.

All of the research participants experienced changes in perceptions of self because of their participation in CAM. The ideology contained within their alternative models of health and healing became a mechanism through which they were able to socially ‘reconstruct’ a powerful sense of an integrated self despite the fragmentation and disunity of an ill-self suffering from intense pain brought on by the presence of chronic illnesses.

For many research participants, participation in CAM and adoption of alternative health and healing ideologies, led to changes in their subjective perceptions of self. In particular, it allowed them to re-define aspects of personal identity, that "unique collection of life history items that comes to be attached to the individual" (Goffman, 1959).
That participation in alternative approaches to health care can have this effect has been observed in other research on the users of CAM (Glik, 2005; McGuire, 2003; Pawluch, 1994). For instance, in describing the use of creative visualisation among participants in a metaphysical healing group (MHG), Glik (2005, p.120) reports “In MHGs, images of light emanating from and surrounding the self protected from dark forces and to some degree transformed self and others”.

Research participants perceived changes to themselves as a result of their experiences with CAM. While they told me they had experienced changes to their respective selves through their use of CAM health care, there were variations in the degree to which different research participants felt that participation in these therapies had affected them. Some told me that using CAM altered their entire outlook on lives or their whole selves. Others perceived these changes to self to have occurred primarily on the level of their value systems and attitudes.

For instance, some research participants felt that using CAM approaches to health and healing affected their lives in some fundamental and pervasive way. Consistent with the tenets of the
alternative model of health and healing (Ernst, 2006). these people saw this change as embracing all levels of the person: mind, body, and spirit. As the interviews progressed, it became clear that for many it was not the circumstances of their lives and/or their illnesses that had changed, but that they believed that their entire selves could be, or had been, transformed. For most research participants, however, the changes to self they perceived related to different aspects of their personal values and attitudes.

Almost all research participants felt that their use of CAM resulted in changes to one or more aspects of their selves. For instance, all participants reported gaining more confidence and becoming more assertive through their use of CAM. Most research participants experienced this change as more or less all encompassing. For example, they believed that several aspects of their selves had changed and that they had become calmer, more tolerant, less argumentative and judicial, more contented, less worried, better able to cope with ongoing suffering and pain, and, in general, happier as persons despite the presence of illness, pain, and ongoing suffering.
Some research participants felt that their use of CAM resulted in a realignment of their priorities or value systems. For example, some felt they had changed in terms of the value they placed on material things. Whether these changes participants perceived occurred on the level of value systems, personalitv, or in the whole person, they were experienced as positive changes. In short, they saw themselves as becoming better people via their engagement with CAM. Moreover, in addition to helping them be better people, the ideology contained within these research participants' alternative models of health and healing became mechanisms for healing the "fragmented diseased biomedical self" (Kaufman. 2005).

9.1.4. What is healing in CAM for individuals living with chronic illness?

McGuire (2005. p.86) contends that "the very rhetoric of healing in modern Western societies emphasise individual choice and transformation." In particular, alternative approaches to healing have been observed to have this type of self-transformative potential (Glik. 2006; McGuire. 2005; Pawluch 1994; Stambolovic. 2004). For instance, Sharma (1999. p.29) asserts: "The healers task is to reconstruct ... individuals in a mode that provides them with the ability to manage their disease." However, O'Connor (2005. p.28) points out that "physical recovery may not be the most important
outcome" of alternative healing. Consequently, the reconstruction of
the individual engendered through his or her participation in CAM
does not merely enable the person to better cope with disease, but
can also provide the individual with the means to change his or her
self-perceptions.

Moreover, for the people I spoke with, self-healing not only meant
developing the ability to relieve one's own physical, emotional, or
spiritual ailments; it also meant acquiring the ability to 'heal the
self'. In particular, they were reshaping their personal identities
(Goffman, 1963). They were 'recasting' their perceptions of self to
account for perceived changes in identities from 'sick' and 'diseased'
to 'healthy' and from negative to positive. They were engaged in
what Corbin and Strauss (1987, p.264) call biographical work, which
includes "its review, maintenance, repair and alteration," where
alteration refers to "transitions to identity which are prescribed or at
least permitted within the person's "established universe of
discourse": this is in contrast to notions of conversions which imply
that one's past identity is completely 'tossed' in favour of a new
identity. Participants constructed a positive sense of self, which they
incorporated within the context of being better able to cope with
living their lives while suffering from chronic illness.
McGuire (2005, p.74) contends that the ‘symbolic embodiment’ of ideoloğv has the power to change people. She asserts that “through rituals and symbols of transformation, believers experience changes in themselves.” and Glik (2005, p.16) likewise concludes that it is through “the adoption of strong ... beliefs [that] individual dramas of change, real or imagined, are realised”. Similarly, Armstrong (2005, p.46) argues, “meaningful and convincing discourse brings about a transformation of the phenomenological conditions under which the patient exists and experiences suffering and distress. This movement amounts to a reconstruction of self.” In addition, for many of the people who took part in this research, it is the ideoloğv underpinning their alternative models of health and healing that serves as a mechanism for constructing positive self-perceptions despite the presence of chronic illnesses, or what Furler (2003, p.66) calls “health within illness”.

To illustrate, a fundamental assumption of these participants’ alternative health and healing ideologies, which has implications for transformations of self, is the belief that to be healthy is to be engaged in the process of healing. Accordingly, for these people, being in a state of health does not depend exclusively on physical
soundness as defined under biomedicine. Rather, under their alternative models of health and healing, “to be healed is not necessarily the same as to be cured” (McGuire. 2005, p. 48). Thus, under their alternative ideologies of health and healing, “the disease is rendered secondary” (Kaufman. 2005, p.47). In contrast, biomedicine defines ill health as “a deviation from normal biological function” (Mishler. 1989, p.3) that greatly reduces the boundaries within which one can be healthy. Moreover, an attendant consequence of biomedically-defined ill health is the loss of self-engendered by disease, chronic illness, and disability (Armstrong. 2005; Charmaz. 2005; Sharma. 1999).

Under these research participants’ alternative model of health, perceiving oneself positively as healthy while suffering with chronic illness becomes an achievable reality, as compared to the more limited prognoses for self-available under biomedicine, as it provides the ideological means of repairing or reconstructing the lost or damaged self in chronic illness.

More precisely, it is the assumption that alternative health is manifested in engagement in an ongoing process of healing which allows one to be healthy even in the face of disease or infirmity.
Further reflections of their belief that to be healthy is to be continually engaged in healing is that the changes to self these people perceive are experienced as a dynamic rather than static process. While this core assumption is what ultimately allows the people who participated in this research to perceive themselves as healthy despite the presence of biomedical defined chronic ill health, different research participants emphasised different elements of their alternative models of health and healing as the particular ideological mechanisms they employed for this type of change to self.

This type of change to self is different from Charmaz's (1987, p.287) concept of the salvaged self, where "ill persons attempt to define self as positive and worthwhile, despite their reduced ability to function.... By this time they hold little hope of realizing typical adult identities in the outer world." It is different because the people who took part in this study did not give up hope of attaining healthy selves because the ideology contained within their alternative models of health and healing gave them that hope.
While many authors agree that a persistent appeal of alternative approaches to health and healing is that they offer people hope (Agrawal 2006; Baron 2005; Brav. 2004; Ernst. 2005). there is debate as to just what the nature of this hope is. For instance, Tsao. (2005) and Dugan (2001) argue that alternative health care is dangerous because it gives people the false hope of curing what ails them. Conversely, others argue that CAMs offer people renewed hope that they will find a solution to their health problem (Adler. 2003; Barrett. 2003; Cuzzolin. 2003). The relevant issue for these research participants, however, is not whether or not their alternative models of health and healing provide them with valid or false hopes of a cure. Rather, it is that they offer the hope of constructing a healthy sense of self within chronic illness. Therefore, the hope held out by alternative approaches to health care comes in two forms: the hope of "different possibilities for alleviating human suffering" (Boon. 2004. p.60) but more importantly, from a phenomenological perspective on the self, it is the hope of "changing psycho-social structures." among which is what we may consider to be a well role (Lee. 2007). The hope of achieving healthy self-perceptions is possible for these people because unlike Charmaz's (1987. p.287) research participants who were seeking a restored self. trying to "reconstruct ... the same sense of self they possessed before illness".
these people sought to transform themselves, creating a new sense of self which they perceived as positive and better able to cope with the daily complex demands of living with chronic illness.

The individuals who participated in this research experienced changes to their values and attitudes through their use of CAM. Participation in CAM health care resulted in changes to perceptions of self. What is central to this self-change experienced by research participants is the ideology contained within the alternative model of health and healing. This ideology is the motivator and the mechanism through which they construct a positive sense of self despite suffering from intense pain and suffering resulting from chronic illnesses. Most importantly, it is this ideology that allowed for positive perceptions of being better able to cope with the disabling limiting complexities of living with chronic illness on a practical daily basis.

9.2. Implications for health policy

The findings from this research have implications for the formation of health policy. In particular, they are relevant to the debates surrounding the possibilities for and consequences of integration of alternative with allopathic approaches to health and healing, as well
as the inclusion of CAM within Medicare. To illustrate, a variety of factors indicate that inclusion of alternative and complementary therapies within the public health care provision is a potential reality. For instance, the vast popularity of these approaches to health and healing among Australians alone would encourage the extension of Medicare to cover alternative and complementary therapies. According to Tataryn and Verhoef (2006, p.22), “increasing consumer utilisation and demand” constitute “upward pressure” towards integration and has already affected many “levels of health care [and] ... clinical and institutional initiatives.”

Furthermore, if health policy makers heed the World Health Organisation’s conclusion that a key measure of the success of health care systems is responsiveness, where responsiveness is defined as the degree to which health care systems “respond to people’s expectations.” law desire for CAM should foster inclusion under public health insurance (Ernst. 2000, p.17).

Moreover, there are some signs that the medical profession’s traditional resistance to alternative forms of healing is eroding. For instance, Tsao (2005, p.49) asserts “leaders from both conventional medicine and complementary/alternative practitioners see greater integration as necessary and desirable.” There is also evidence of the
increasing adoption of alternative approaches to health and alternative therapeutic techniques by the medical community (Achilles. 2005; Northcott. 2006; Verhoef. 2001). In addition, some medical schools are beginning to integrate training in alternative and complementary therapies into their curriculum (Verhoef. 2006). For instance, 89% of the 8 medical schools, and 90% of the 28 nursing schools, Achilles (2006. p.231) surveyed, responded that they offered courses that “include information on alternative and complementary therapies” and Block (2005. p.50) states that 38% of medical schools “now offer stand-alone courses in complementary medicine.” Similarly, alternative practitioners are increasingly engaged in the process of becoming recognised legitimised professionals requiring incorporation of biomedical paradigms of health and healing within their educational regimes (Ernst. 2005). Further, some health care professionals “make referrals to complementary and alternative practitioners, albeit usually to chiropractors” (Tatarvn & Verhoef. 2006. p. 98).

Thus, it can be argued that the boundaries between allopathic and alternative approaches to health care are beginning to blur. For instance, Tatarvn and Verhoef (2005. p.59) argue that both allopathic and alternative health care stress preventative and patient-centred
care. They further assert that nursing and family medicine "share assumptions related to holistic care ... with complementary and alternative modalities." In addition, the emphasis on self-control within these research participants’ model of health resonates with general cultural notions of health. For example, Armstrong (2005) argues that there are two general lay concepts of health in contemporary culture: health as control and health as release. Health as control defines health as a status achieved by "self discipline. self denial. and will power:" and health as release, while seeming to reject the constraints of the control model, highlights "the psychological capacity for not worrying." hinging on an individual’s self-control of stress (p.66). The alternative model of health’s insistence that individuals control their minds, lifestyles, and, in particular, stress, makes this model entirely consistent with a general cultural understanding of health. Hence, to the degree that allopathic and alternative paradigms can be harmonised, the integration of CAM within Medicare will be facilitated. More precisely, to the extent that allopathy becomes more alternative and alternative becomes more allopathic, alternative health care could be said to be integrated into public health care provision.
Inclusion of alternative and complementary therapies within Medicare would show that health policymakers are responsive to the needs and desires of individuals (Ernst. 2000). Furthermore, integration of allopathic with alternative healing approaches and inclusion of CAM within Medicare would enable the people who took part in this research to address health problems for which they found no redress prior to their participation in alternative forms of healing. Finally, given these research participants' chronic conditions, integration of alternative and allopathic healing paradigms would also positively affect population health and enable our Australian health care system to better cope with the management of chronic illness.

9.3. Implications for patient education and health care practice

Lack of scientific evidence may make people wary of CAM therapies. CAM use is associated with knowledge (Singh. 2002). Lack of knowledge of CAM is believed to adversely influence CAM use. Although open attitudes toward CAM have been found across both population samples and health professional groups, there is a continuing belief that safe use of CAM must be grounded in science (Ernst. 2002) and patients will be able to use that knowledge to determine best treatment options. While recognising the
contribution of knowledge to a person's intention to use CAM. It is also necessary to consider consequences that may result from a lack of knowledge of CAM. It has long been suggested that if people perceive themselves to be knowledgeable about CAM, they report more use of CAM and have more positive attitudes toward CAM (Armstrong, 2007). Lack of knowledge about CAM increases the likelihood of adverse side effects and drug interactions between CAM and conventional medicine.

Knowledge of CAM is important and it may influence CAM use in the future. Many studies reported a willingness to learn about CAM among health professionals from different clinical settings. Biomedicine is a dynamic specialty with a common goal of improving the quality and effectiveness of healthcare for patients. While recognizing patient's positive attitudes toward and inadequate knowledge of CAM, some professional biomedical organisations pay considerable attention to ensuring that biomedical staff are provided with patient-centred assessment and plans of care that include CAM therapies (Ernst, 2006). It is appropriate to review the role, responsibilities, care management considerations, and the need for better coordination of CAM management services.
throughout the biomedical profession, as well as across the disease trajectory.

Despite overall positive attitudes towards CAM, participants in this study reported a wide range of concerns about CAM therapies in general. They indicated a degree of uncertainty about the safety of CAM therapies, mixing prescription medication with CAM, and negative attitudes of their biomedical doctors toward their CAM use. The findings highlight concerns about the potential for dangerous interactions where a combination of both CAM, in particular herbal medicine, and conventional medications are used. Although some participants used CAM with a low risk of adverse interactions, such as yoga, spiritual healing, dietary modification, and megavitamins to ease symptoms, there is the risk of interaction with some herbal products (Adams, 2006). It is highly likely that participants' uncertainty and ambiguity surrounding the possibility of drug interaction were directly attributable to the lack of evidence-based CAM information and poor communication between patients and health professionals. As such, these findings have important implications for patient education and health care practice.
The vast majority of participants in this study were not satisfied with the education they received about CAM from their biomedical practitioners. Whilst they expressed some concerns about CAM, the biomedical profession, in spite of participants expecting their doctors to be knowledgeable about CAM, did not specifically address these concerns. The findings also suggest that participants were frustrated with the lack of opportunity for education about CAM. They found that their doctors did not actively ask them questions or engage in helping with their concerns related to CAM use, nor did they give them clear instructions on CAM. Given the importance of patient education about CAM in mediating CAM use, the rise in CAMs popularity and positive attitudes toward CAM necessitates specific educational opportunities to prepare patients to evaluate their use of CAM from an evidence-based viewpoint (Bensoussan, 2005).

Patient education about CAM will contribute to appropriate forms of CAM use if CAM is chosen. Health professionals must consider issues of possible side effects and know how to educate patients regarding these side effects. This may reduce some patients’ fear and anxiety about medications, and reduce the chance they may stop taking their medications abruptly. The findings of this study
provides evidence to suggest that CAM users do not abandon conventional biomedicine and prescribed medications.

Furthermore, while people should be free to choose whatever method of healthcare they wish, they must be informed as to the appropriateness of the method they choose. It should also be noted that most CAM users have more personal autonomy and control over their health care decisions (Cox, 2003). Thus, patients need to be educated to help them determine what is adequate and inadequate for their CAM use. Patient education that ignores or discards CAM information may be deemed deficient within the Australian context, as CAM is an important component in current Australian healthcare. Moreover, patient education needs to reflect the dynamic changing characteristics of the health behaviours of the target population. The purpose of patient education about CAM ought to educate patients about the uncertainties of CAM use with and without bio-medications, what they should expect to happen when they begin the treatment, and possible herb-drug interactions.
9.4. Key recommendations for health care practice

The findings of this study considered in relation to other studies and developments overseas, form the basis of the following recommendations in relation to biomedical health care training.

Participants identified their biomedical practitioners' general knowledge and understanding about CAM as being limited. The findings suggest that serious consideration be given to the education of biomedical students and registered practitioners about CAM. Continuing education should offer training and education on CAM, both to improve practitioners' knowledge of CAM and to enable them to impart this knowledge to patients, as well as to identify potential benefits and harms of CAM. Continuing education aims for the practical application of professional development, standards and advice relevant to clinical situations. Adequate continuing education about CAM would enable biomedical practitioners to respond knowledgeably to any questions or concerns patients may have about CAM and treatment options. It may enable them to not only keep communication channels open with patients, but to also possess adequate knowledge of the nature and potential risks, benefits and interactions with conventional biomedicine. Effective
communication about CAM use may include the following practices:

1. Question patients about what else they may be using for their treatments.

2. Undertake a background check on the CAM used by patients and seek out scientific information and research data available to critically evaluate the CAM in regards to safety and appropriateness.

3. Acknowledge the possible benefits and risks of some forms of CAM therapies.

4. Promote communication on decision-making regarding CAM use if patients require this assistance.

5. Provide patient education about what they should expect from both bio-medications and/or CAM for the treatment of their conditions.

6. Respond to patients' complaints related to conventional biomedicine such as side effects and arrange follow-ups.

7. Listen and value patient's opinions and ideas about their care, their attitudes toward CAM use and reasons why they are likely to seek CAM.

8. Make recommendations to relevant health professionals to revise patients' on-going care plans.
Recommendations for undergraduate and postgraduate biomedical curricula are also made. Educational content at the postgraduate level should address advanced CAM information such as evidence-based data on safety, ideology, cultural, and philosophical congruence. Educational content at undergraduate level may include:

1. Basic information about CAM therapies, for example the roles of CAM in the treatment of various illnesses and communication skills to talk with patients about CAM.

2. Health-related cultural beliefs about CAM use to foster culturally appropriate health care and to promote well-being.

3. Utilisation of well-organised websites about CAM in order to provide helpful web-based resources for self-learning.

9.5. Suggestions for future research

Researchers have concluded that more research needs to be done prior to inclusion of CAM within public health provision (Achilles, 2006; Tatarin & Verhoef, 2005). I would add that in particular, research on the efficacy of these therapies from the lay perspective is required. Very few studies have examined how lay people assess the effectiveness of CAM approaches to health and healing they use.
Furthermore, the bulk of this literature does little more than report that people believe that they derive a benefit from their participation in alternative and complementary therapies and/or are highly satisfied with their experiences with these therapies. While some researchers have engaged in deeper explanatory analysis of lay perspectives on the efficacy of CAM, almost all are set in the US or UK context (Adams. 2003; Anz. 2005; Dunn. 2005; Owen. 2007; Winnick. 2006; Wolf. 2006). Very few researchers have addressed the lay perspectives of Australians regarding the effectiveness of CAM health care. Such research would provide us with a more holistic understanding of what works and also with better evidence to determine which therapies should be included within Medicare.

Another direction for future research concerns the following question: To what extent do CAM approaches to health and healing continue to constitute a challenge to biomedical dominance and thus serve as a catalyst for change within Australian allopathic health care? For example, Lehrer (2004) argues that the users of CAM are members of a new social movement that presents an institutional challenge to biomedicine, and Taso (2005, p.22) concludes that alternative practitioners serve as “gatekeepers of orthodox medicine” who have the freedom to experiment with new therapies.
which can then be incorporated into allopathic practice, thus expanding the range of therapeutic techniques available under public health care provision. However, Lehrer (2004. p.38) also asserts that participation in alternative approaches to health and healing constitutes a social network movement that is “submerged within everyday life rather than engaging in visible political activities that confront authorities.” Moreover, Saks (2005. p.211) concludes that:

There is not as yet a post-modern profusion of heterogeneity so much as a new way of legitimating the continuing dominance of medical authority through a strategy based on incorporation and subordination. in face of the growing challenge from complementary approaches.

Therefore, research should track the influences of the movement towards integration of allopathic and alternative approaches to health and healing, in addition to the inclusion of CAM within public health provision, to determine the effect of these processes on the potential of CAM. as well as on the lay people and practitioners who use them, to continue to play an innovative and revolutionary role within the health care system.
9.6. Strengths and limitations

To date no study has been identified that has prospectively examined the lived experience of using CAM for individuals living with chronic illness from biomedical diagnosis and treatment through to CAM diagnosis and treatment in the Australian setting. This study provides valuable insight into what it is like to use CAM for individuals living with chronic illness. It also provides valuable insight into the reasons as to why individuals living with chronic illnesses choose to use CAM.

The time and context bound nature of a naturalistic study such as this combined with the small sample size mitigates against the generalisation of the findings of this study. However, detailed descriptions of the natural setting, the participants involved, the data collection and analytic processes used and the extensive use of direct quotes in reporting the findings, enable those wishing to apply the findings to make their own judgements of transferability.

The need for participants to speak English limited recruitment of participants from different ethnic groups thus limiting the potential diversity of the experiences described.
9.7. Conclusion

The purpose of this study was to discover and illuminate the lived experience of using CAM by individuals living with chronic illnesses in an attempt to understand their reasons for choosing CAM within the social contexts of their lives. The research question guiding this qualitative study was: Based upon a reflection of lived experiences, why do individuals living with chronic illnesses choose to use CAM? Objectivist explanations of why they turned to the use of CAM are inherently problematic. However, we can make meaningful reference to these forms of health care from a subjectivist experiential perspective and with attention to social context to the nature of the everyday experience of these therapies and to the claims lay individuals make about these approaches to health and healing. In general, participants in this research study were not seeking forms of health care that conformed to alternative ideologies of health and healing they espoused prior to their participation in these therapies. Rather, they sought out CAM approaches in order to address health problems for which they hitherto had found no solution. Thus, the use of CAM is no different than any other form of health-seeking behaviour. Moreover, it is better understood through the generic social process of problem
solving, rather than through the push/pull dynamics of particular motivating factors. While these individuals were not shopping for an ideology when they first sought out CAM, participation in these approaches to health care led to their adoption of alternative health values and beliefs that inform their personal constructs of self, illness, and healing. The espousal of alternative ideologies of health and healing impacted individuals’ subjective perceptions of self; these ideologies affected research participants’ attitudes and values by transforming personal lives for the better. In particular, it became the means by which they constructed a positive sense of self, even in the presence of biomedical defined chronic disease and infirmity. Moreover, participating in CAM facilitated a hope generating positive sense of being better able to cope with the intrusive and disabling complexities of daily living imposed by the onset of chronic illness.
11. Appendices

11.1. APPENDIX 1: PARTICIPANT CONSENT FORM

UNIVERSITY OF WESTERN SYDNEY
SCHOOL OF HEALTH & NURSING
CONSENT FORM

STUDY: THE USE OF COMPLEMENTARY AND ALTERNATIVE MEDICINE (CAM) AS LIVED BY INDIVIDUALS LIVING WITH CHRONIC ILLNESSES

1. I understand the purpose of this study is to explore and interpret the experience of using CAM as lived by individuals living with chronic illnesses.

2. I understand that I am required to attend more than one (1) interview session. I also understand that the exact number of interviews cannot be predetermined as it depends on the interview process itself.

3. I understand I can request to have material deleted from the tapes and / or transcripts and can request to withdraw consent and discontinue participation in the study at any time.

4. I understand that my transcript is to be treated confidentially and that reports about this study are to be presented to maintain my anonymity.

5. I agree to being contacted on

and to attending further interviews regarding this project.
6. I understand any questions concerning this study can be directed to Ashwin Kumar (PhD Student at the School of Health & Nursing) on Telephone Number **removed**. If I would like to contact someone external to the study I know that I can talk to the Human Research Ethics Officer on **removed**.

7. I (the participant) have read the information above and any questions I have asked have been answered to my satisfaction. I agree to participate in this activity, realising that I may withdraw at any time. I agree that research data gathered for the study may be published, provided my name is not used.

Participant or Authorised Representative  Date

Investigator  Ashwin Kumar  Date
11.2. APPENDIX 2: PARTICIPANT STUDY INFORMATION SHEET

UNIVERSITY OF WESTERN SYDNEY
SCHOOL OF HEALTH & NURSING
STUDY INFORMATION SHEET

STUDY: THE USE OF COMPLEMENTARY AND ALTERNATIVE MEDICINE (CAM) AS LIVED BY INDIVIDUALS LIVING WITH CHRONIC ILLNESSES

Thank you for being interested in this study which is being carried out to explore and understand the experience of using CAM as lived by individuals living with chronic illnesses. Your volunteer participation is needed if you have used at least one form of alternative medicine over the last year.

If you choose to take part in this study, you will be requested to participate in interviews with me. You will be interviewed at a time and place convenient to you. The interview will take approximately one (1) hour and there may be a need for further interviews. At this stage of the study, I cannot specify the exact number of interviews requested of you, as this is dependent upon data collection of the interview process itself.

In the interviews, I will request you to remember and to reflect on your experiences of using CAM. Some of the issues that I am interested in learning about from you are as follows:

- How did you first come to your use of CAM?
- What factors/situations/people/events started you on your journey to CAM use?
- What types of CAMs have you used?
- What was your experience of using CAM like for you?
- What was it like for you to incorporate CAM in your day-to-day living?
What were your reasons for choosing to use CAM?

I will audiotape our conversations during the interview process. This will enable me to transcribe and to analyse our conversations. If you are interested in discussing the processed analysis of your conversations with me, I will be most willing to schedule further interviews. Excerpts from the analysis of our conversations may be used for research publications, but at no time will your name and identity be disclosed. This will protect your identity and ensure anonymity and confidentiality.

If you are interested in taking part in this study, please phone me on **removed**. If you choose to participate in this study, you would be required to sign a consent form. A copy of the consent form will be available at the first meeting. Thank you for your interest.

Best regards.

Ashwin Kumar.