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**COGNITIVE DETERMINANTS OF  
TREATMENT CHOICE AMONG  
CANCER PATIENTS**

**A thesis presented in partial fulfilment of the requirements  
for the degree of Doctor of Philosophy in Psychology  
at Massey University**

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**2001**

## ABSTRACT

Decisions about whether or not to include non-conventional therapies in a cancer treatment regimen are potentially critical. An illness such as cancer, perceived to be life-threatening, inevitably raises existential questions which, in the present study, were posited to underlie the cognitive approach to treatment choice for cancer patients. The hypotheses tested in the study were that those who use non-conventional medicine will be more knowledgeable and have a more positive belief system about cancer, will be more interested in and motivated about health matters, will desire more personal control and assume more responsibility for their health and its treatment, and will be more intrinsically oriented in terms of meaning in illness and life. It was further hypothesised that the differences between those who use only conventional treatments and those who include non-conventional treatments will become more marked as the boundary between the two is altered to incorporate more non-conventional treatments in the conventional category, suggesting that patients' perceptions of the distinction varies from the medical establishment's view. An important underlying objective of the study included the exploration of the conceptualisation of meaning in life and its events in terms of intrinsic and extrinsic orientations. 212 adult participants, all having been diagnosed with any form of cancer for at least three months, volunteered and completed a postal survey.

Overall, the results indicated that the conceptualisation of meaning as intrinsically or extrinsically oriented was an appropriate basis for exploring the role of existential issues in treatment decision making. The combination of constructs in the study was also confirmed as appropriate. In terms of the specific hypotheses, the expectation that users of non-conventional medicine would be more knowledgeable and more positive in their beliefs about cancer was supported only when conventional treatment was deemed to include certain physical and natural types of treatment usually labelled as non-conventional. Users of non-conventional medicine were found to be more interested in and more motivated to be involved in health matters than those who used only

conventional medicine. They were also found to be those who desired more personal control over their health and its treatment and were also prepared to assume more responsibility. The results also supported the hypothesised difference between conventional only and non-conventional users in terms of intrinsic life meaning, but results for extrinsic life meaning only partially supported the expectation that this would be associated with conventional medicine use. These were discussed in terms of measurement issues and the reconceptualisation of the religious, spiritual and philosophical derivations of extrinsic meaning. No difference was found between users of conventional only and users of non-conventional medicine in terms of illness meaning, suggesting that conceptualisation in intrinsic and extrinsic terms was inappropriate for this sub-construct. There was also support for the view that treatments are viewed by many as being on a continuum from conventional to non-conventional, rather than being in defined dichotomous groups.

Multivariate results (from a series of 2-group discriminant analyses) confirmed that health interest and motivation, attributions of control, responsibility and blame, and intrinsic and extrinsic meaning in life were the most important contributors to discrimination. Internal control attributions were consistently the most important relative discriminator. These results also showed that the influence of the discriminating variables in combination, including sociodemographic control variables, explained variances ranging from 25.4% to 33.6% across the altered groupings of treatment type.

The results are discussed in relation to the conceptualisation of meaning and attributions of control and responsibility as pivotal concepts, and in relation to the indication that the greatest separation between conventional and non-conventional use was found when certain physical and natural treatments were classified as conventional rather than non-conventional. Psychometric, and conceptual limitations of the study are discussed, suggestions for future research are made, and some applications of the findings for health professionals are offered.



## ACKNOWLEDGMENTS

I extend my sincere thanks to my supervisors. My chief supervisor, Associate Professor Kerry Chamberlain's extensive knowledge and experience in the diverse area of health psychology and in research in psychology in general was invaluable.

Associate Professor John Spicer's research skills and particularly his ability to identify statistical issues and impart his knowledge in this area clearly and concisely contributed significantly to the learning process during this project.

I also sincerely thank my family and friends for the considerable space they gave me to carry out the research and complete this dissertation.

Finally, I am indebted to the many participants who gave much of themselves in contributing to this study. Some, indeed, have passed away after their battle with cancer, and without hearing of the findings of the study.

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## CHAPTER ONE

### INTRODUCTION

#### **Broad objectives of the research**

“Who uses alternative medicine? A hypothesis which seems to have informed some research ..... is the idea that users of alternative medicine are possibly marginal *people* as well as users of marginal *medicine*” (Sharma, 1995).

The present study was not about the desirability or efficacy of any treatment or type of treatment. It was also not concerned with categorising or ‘judging’ people based on their treatment choices. The primary objective of the study was to explore, empirically, the influence that a particular set of cognitions has on treatment choice decisions (between conventional and non-conventional medicine) that people make in relation to a serious illness such as cancer. Underlying this objective is the importance of broadening our understanding of the health-related cognitions of those confronted with a life-threatening illness and how these might influence their health-related behaviours. The early approach to understanding health-related behaviour focused on demographic and socio-cultural factors as determinants (Bishop, 1991). As King (1983) pointed out, however, while there is considerable evidence of the predictive value of demographic and psycho-social factors for health behaviour, cognitive factors, such as health beliefs, have recently been shown to be more predictive of health behaviour. The present study explored a group of cognitions that was considered likely to be important for those facing a threat to their life, such as cancer, and which also could be expected to influence treatment choice behaviour.

In its broadest sense, the research question addressed was: What are the differences in the health related cognitions between those who choose conventional medicine only and those who use non-conventional remedies and therapies in addition to

or in substitution for conventional medicine in the treatment of a life threatening condition such as cancer? The cognitions explored as potential determinants of treatment choice were comprised in a set of four constructs. These constructs were: Knowledge and understanding of cancer; approach to health; attributions of control, responsibility and blame; and meaning in illness and in life. A brief description of each follows.

Knowledge and understanding of cancer comprised two dimensions. One was information-based knowledge and the other concerned the beliefs that surround cancer. Health interest and motivation was the primary dimension of the approach to health construct. It relates to the level of interest and motivation a person displays in knowing about and being involved in their own health care and the beliefs that underlie this. Two other dimensions of the approach to health construct were biomedical versus biopsychosocial orientation, and dispositional optimism. The primary focus of the attributions of control, responsibility and blame construct addressed the question of where (i.e., internally or externally) control, responsibility and blame should rest. Meaning was conceptualised in terms of intrinsically and extrinsically oriented meaning. Intrinsically oriented meaning was conceptualised in an existential frame and extrinsic meaning was cast in a powerful other religious or spiritual frame.

Exploring this conceptualisation of meaning was in itself a secondary, yet important objective in this study. Existential concerns and beliefs are particularly important and prevalent in the context of a life-threatening situation, but surprisingly little research has investigated the influence of this major element of life in situations where life itself is threatened. Acknowledgement and exploration of fundamentally different conceptualisations of life's meaning for different people and the potential of this is one area in which research horizons can be broadened and expanded. A case is made in the present study for the need for psychology to address the effect of different philosophical approaches to life's meaning, including being more prepared to explore religious type variables where these represent a philosophical approach. Historically there is foundation and precedent for this in the sense that medicine, psychology and religion were originally intertwined. The religious context in which Western medicine

developed saw health and illness as being influenced by spiritual factors (Potts, 1998). The original meaning of *psychology* was “the study of the soul”, a sub-discipline of pneumatology, or the study of spiritual beings (Vande Kemp, 1996). Spiritual beliefs are rarely accounted for in either psychological or medical research, however (King, Speck & Thomas, 1995; Larson, Pattison, Blazer, Omran, & Kaplan, 1986; Craigie, Liu, Larson, & Lyons, 1988).

A further objective involved exploring the perception of what is conventional and what is non-conventional treatment. Conventional medicine as a treatment modality is reasonably definitive. It may be described as those methods employed by the conventional medical profession being those who, in New Zealand, are registered as such under the Medical Practitioners Act. It might also be described specifically by its methods, for example, surgery, radiation therapy and chemotherapy. Non-conventional medicine, on the other hand, includes a raft of over 200 therapies and treatments. While there are some fundamental differences between conventional treatments, they are perceived as similar by virtue of their being practised by the recognised medical profession. Within non-conventional medicine, however, the huge number of therapies are not organised in any recognised fashion. Furthermore, they comprise a diverse set of methods that, unlike conventional treatments, are not underpinned by or derived from a single basis such as the biomedical model. They have their bases variously in philosophy, psychology, especially para-psychology, religion, and beliefs about biological, chemical and physical “sciences” that are substantially untested. This gives rise to the need for a means of classifying these treatments to enable exploration of the likelihood that there are differences in the health related cognitions among those who utilise different types of non-conventional therapies.

This was done by classifying non-conventional treatments into groups based on their conceptual approach and how far removed from conventional they were considered to be. The first group comprised physical type therapies where there is already recognition that many are closely allied to conventional medicine and are possibly headed towards being subsumed by the latter (e.g., Thomas, 1995). The second group comprised

therapies based on nutritional and natural remedies, often perceived as being complementary to conventional approaches. The third category included psychological and mind/body type approaches such as imagery and visualisation. The furthest removed from conventional approaches were seen as the psychic and metaphysical therapies where there is a mystical component, although may include a physical component (eg., Yoga). (Detailed lists of treatments included in each category are provided in table 5).

From these groups four pairs of treatment grouping were created. The first represented the traditional division between conventional and non-conventional. In the second grouping those who indicated that prayer was part of their approach to treatment were added to the conventional group. In the third grouping treatments classified as physical and natural were shifted from the non-conventional to the conventional group, and in the fourth grouping treatments classified as mind/body and psychological were shifted from non-conventional to conventional, leaving just the psychic and metaphysical treatments in the non-conventional grouping. This was effectively changing the boundary between what was defined as conventional and non-conventional, enabling investigation into whether cancer patients' cognitions varied depending not only on whether they used conventional or non-conventional as traditionally defined, but also depending on what types of non-conventional medicine they used and how far removed from "conventional" they were.

### ***The treatment choice process***

The study was predicated on the notion that in a life-threatening illness context the treatment choice decision is not a decision made perfunctorily but is one made within a reasonably complex cognitive frame. Figure 1 depicts the process towards treatment choice that was explored in this study and as such is a diagrammatic representation of the framework of the study. The study was concerned mainly with those parts of the diagram contained in the branches. The stem of the diagram provides a suggested background to the point where decisions about treatment become relevant, and bears some resemblance

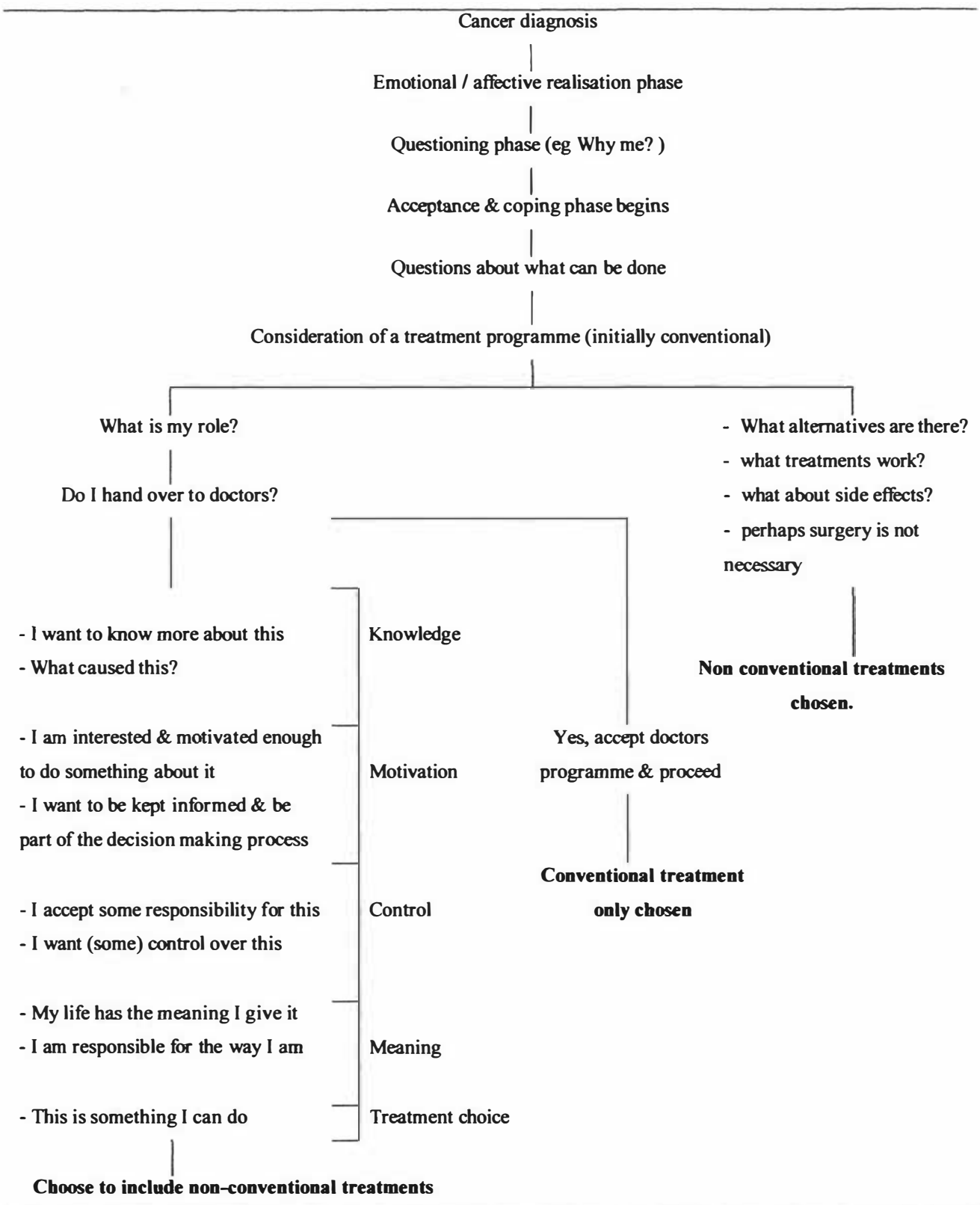


Figure 1. A process towards treatment choice



to Eliopoulos' (1999) emotional response to diagnosis of a chronic illness process.

### ***The nature of the choice***

It is generally recognised that a cancer diagnosis is an especially aversive event bringing with it a fear that death is inevitable. For most people in this situation what to do about the disease, namely how to treat it, becomes a question of urgency. While there are a variety of choices available, there seems to have been a polarising between conventional and non-conventional medicine that often results in the presentation of a dichotomy to patients over treatment. Nevertheless, a range of possibilities is available through various channels which, ipso facto, results in the patient facing a decision making process. Treatment choice is often made, however, within a climate of conflicting claims, many unsubstantiated and with little or no demonstrable scientific basis. Maddocks (1985), for example, expressed the widely held view within the medical profession with the observation that "common to all the alternative therapies is an inadequate theoretical basis, a lack of standardized techniques, and a failure to demonstrate a therapeutic outcome superior to placebo in the majority of trials. And yet, they continue to increase in popularity" (p.548). Possibly the most common claim against non-conventional medicine is its failure to carry out proper clinical trials of its procedures and remedies. Only a "handful" of such studies have appeared in peer-reviewed journals (Verhoef, Hagen, Pelletier, & Forsyth, 1999). This has led to the generalisation that these therapies are ineffective. As Ernst (1995) pointed out, however, as long as a remedy has not been tested, it cannot be labelled effective or ineffective. It has also been estimated that 85% of conventional therapies do not meet this criterion either (Smith, 1991).

### ***Understanding the basis of treatment choice is important***

There are a number of reasons why it is important to understand the bases upon which the decision to use non-conventional medicine or not is made. Clearly the foremost

is that choices made about the treatment of cancer are potentially critical and these choices are made in a context where the options available are extremely diverse with many fundamental practical and conceptual differences. In a general sense the understanding of the determinants of treatment choice is important from the patient's perspective as well as from the perspective of health care providers and educators, if all decisions made are to be in the best interests of the patient.

The availability and use of non-conventional therapies and remedies, for which there is, as yet, little empirical evidence of efficacy or even safety, is increasing at a phenomenal rate (Watkins, 1996; Mitzdorf et al., 1999; Easthope, 1999). The implications of this for health care providers and recipients alike are considerable. Indeed, many see the development of a pluralistic medical system in which conventional medicine shares and competes with non-conventional medicine for patients (Pietroni, 1990). Knowing and understanding the determinants of choice between conventional and non-conventional treatment may provide important information for the medical profession, for patients, and for the health care system itself. Better communication and improved relationships between doctor and patient is always beneficial. Overuse of the health care system is also likely to be reduced through an understanding of patients' concerns and the determinants of their decisions to utilise non-conventional treatments, and by an openness between patients and their doctors about treatment options.

A pluralistic medical system (at least an unofficial one) seems likely and access to and use of non-conventional medicine seems likely to continue to increase. The prediction of, but more importantly, the understanding of the propensity to utilise non-conventional medicine is crucial for conventional medicine professionals if they are to ensure the more effective delivery of their treatment regimens, and is an important part of their concern for their patients' well being. Non-conventional medicine is frequently attractive to certain patients and may in fact be complementary. In both cases there is a strong argument that a well-trained health professional should be in an overall management role of a patient's treatment, but such a role cannot coexist with antagonism

and secrecy. Understanding of the patient's motivations and other relevant cognitions may be critical in this management and guidance process.

Apart from potential diagnostic and disease monitoring issues, there are also concerns about potentially deleterious interactions in the concurrent use of conventional and non-conventional modalities. There is also a potentially negative influence on adherence to conventional regimens and the counteracting of the advice of well-trained conventional practitioners by often untrained non-conventional practitioners, and by patients themselves based on conclusions drawn from anecdotal accounts. The potential for patients to be discouraged from accepting effective treatment for their dangerous disorder is a further concern (Lowenthal, 1994).

The foregoing are justifications based on clinical considerations. Cassileth (1989) summed up, in a psychological frame, the justification for research such as the present in her comments about why cancer patients are turning to non-conventional medicine. "We want attention to ourselves, our souls and our emotions, as well as to our disease. We want a display of concern for us as people, and we want the inclusion of healing methods, such as nutritional attention and spiritual and emotional support, that displays such concern..... We want to believe that thinking the right thoughts enables the individual to control his own cancer. We want to believe that we can do better by designing our own treatment plan. The use of today's questionable cancer therapies is a natural extension of these beliefs. Patients are attracted to therapeutic "alternatives" that reflect social emphasis on personal responsibility" (p.1250). The present study acknowledged and addressed these types of issues.

On the other hand, for some, the choice may focus on questionable aspects of conventional medicine. For example, approximately 20% of illnesses that lead to hospitalisation are iatrogenic in that they are caused by the biomedical care itself (Greenwood & Nunn, 1994). In addition, results of scientific research showing that non-conventional treatments can be as effective or more effective than biomedical treatments, or valuable as complementary treatments, are beginning to accumulate (Cassidy, 1994).

There is also evidence that for specific illnesses non-conventional treatments can be genuinely complementary to conventional medicine and beneficial (e.g., Schwartz, Laitin, Brotman, & LaRocca, 1999).

## Terminology

The intention in this study was to avoid any value judgements about either modality. Attention to the terminology used helped achieve this. In both common parlance and in research, terminology varies among *alternative*, *complementary*, *unconventional*, *non-conventional*, *unproven* and *unorthodox* or *non-orthodox* for medicine that is other than allopathic. The latter is generally referred to as *orthodox*, *conventional*, *Western*, or *biomedical*. Orthodox tends to validate the approach in some way, while unorthodox tends to make a judgement about that approach as being invalid. Similarly, alternative may connote something that is less acceptable. It amounts to a validation of that which it is alternative to in the sense that allopathic medicine lays claim to the term *medicine* leaving anything else to be referred to as alternative medicine. The term *complementary medicine* conveys the notion that this is medicine that operates in tandem with or in addition to allopathic medicine. Some types may in fact work in this way, but even practitioners of non-allopathic medicine would be unlikely to presume this as a general rule. This terminology is, therefore, at best somewhat limiting.

In the present study *conventional* and *non-conventional* was settled on as being nomenclature that seems to be relatively non-partial and free of connotations. Conventional simply means customary or having grown out of tacit agreement, which is generally accepted as to what the term *medicine* refers. Non-conventional means something that is more spontaneous and not necessarily the result of consensus. In this case it connotes simply non-allopathic.

## **Thesis structure**

The thesis is structured around what were essentially the dual objectives of the study. The primary objective concerned the empirical exploration of certain cognitive determinants of treatment choice. The other related to conceptual and measurement issues associated with certain constructs included in the study, in particular the concept of meaning.

The following chapter provides brief detail of cancer and its treatment and introduces previous research into treatment choice decision-making. Chapter three justifies a cognitive approach in health behaviour research generally, reviews various social cognition models commonly used as frameworks for understanding cognitive determinants of health behaviour and provides justification for why they were not adopted in this study. In chapter four, attribution theory and the control and meaning constructs are justified as the theoretical bases of the present study. This includes a review of literature on the construct of meaning. It was included in chapter four rather than chapter five where treatment choice research is reviewed. Meaning, as conceptualised in this study, has not previously been explored in research of this nature. Chapter five applies the cognitive approach specifically to treatment choice behaviour, describes the constructs upon which the present study is based, and reviews previous research into cognitive determinants of treatment choice. Chapter six attempts to clarify aims and objectives and how the variables and constructs were expected to combine as a meaningful approach to understanding and explaining treatment choice decisions. The chapter concludes with a statement of hypotheses. Chapter seven describes the research methodology and presents demographic details of the sample. Chapters eight and nine report the results of the study. The preambles to those chapters set out their format. Finally, chapter ten provides a general discussion of the findings of the study.

## CHAPTER TWO

### CANCER AND ITS TREATMENT

This chapter provides a brief overview of the nature of cancer, its prevalence and treatment methods. It then outlines treatment alternatives before introducing the question of treatment choice among cancer patients. The chapter concludes by examining how previous research has often approached the question of choosing between conventional and non-conventional treatment comparing this to the approach taken in the present study.

#### **The nature of the disease**

The term *cancer* refers to a group of over 100 diseases, which are broadly classified into three main groups. Two of these are carcinomas and sarcomas, which are represented by solid tumours. The third group consists of leukaemias and lymphomas, which arise from blood and lymph forming cells (Geffen, 2000). Cancer is characterised by abnormal regulation of cell growth and reproduction. This disorderly growth is the result of cell nuclei losing their ability to regulate and control growth, disrupting cellular metabolism and reproduction. This leads to the production of mutant cells, which eventually develop into a neoplasm, which may be malignant or benign (Anspaugh, Hamrick, & Rosato, 1994). Cancer cells may also invade surrounding tissue and move throughout the body via the lymph and circulatory systems. Metastasis is a complex and dynamic process (Fidler, 1997) in which cancer cells must proceed through a number of stages without being destroyed by immune responses. The microscopic beginnings and the insidious spreading of cancer combine with the frequently destructive course of the disease to produce the common perception of cancer as a relentless disease that eats away at the sufferer.

## **Cancer prevalence**

Cancer is the second leading cause of death in New Zealand (and in most developed countries) accounting for over 20% of all deaths every year since 1974 and increasing (Abdelaal, 1992). Over 12000 New Zealanders are diagnosed with cancer annually. In 1993 there were 6579 new male cancer registrations and 6185 new female registrations (New Zealand Health Information Service, 1997). Across cancer types the five year survival rate is below 50% (Abdelaal, 1992). In terms of both incidence and survival, cancer is a serious illness in both the developed and developing world. The frequent claim that cancer is a disease of the western lifestyle and can be treated accordingly is unsubstantiated. In 1985 56% of the world's recorded cancer deaths occurred in developing countries (Pisani, Parkin, & Ferlay, 1993). Many more cancer deaths may go undetected or unrecorded in developing countries.

## **Conventional cancer treatment**

Conventional treatment comprises surgery, radiotherapy and systemic therapies, including chemotherapy, hormone therapy, and immunotoxin therapy. The use of a particular conventional treatment depends on the cancer site, the type of cancer and whether there has been any metastasis. Treatment is commonly multi-modal involving various combinations and sequences of the various treatments (Knight, 1998) in a carefully researched and specialised programme.

Surgery is the most common conventional cancer treatment in New Zealand. For example, Abdelaal (1992) reported that 70% of cancer patients received surgery and for 60% surgery was the only method of treatment. Surgery may comprise definitive surgery, generally recommended for a tumour type cancer where no secondary growths are expected. It may also consist of surgical reconstruction, the creation of artificial stomas and palliative surgery (Clarke, 1992). The latter may be used to place catheters for the

administration of drugs or nutrient or for the excision of tumours to reduce pain, obstruction or pressure. Laser surgery, although not surgery in the customary sense, is used to remove blocks of tumour tissue especially in head and neck areas, in some early cervical and pre-cancer situations, and increasingly in lung and oesophageal cancer (Tobias, 1995). Surgery is also often used as a means of diagnosis in the form of surgical biopsy and exploratory surgery.

Like surgery, radiotherapy is most effective if all the cancer cells are within a definable area, since it is a localised treatment. It is generally used to treat tumours by ionising critical molecules within the cancer cell. This inhibits the replication of malignant cells by impairing mitosis or DNA synthesis. The exact mechanisms through which radiation operates are not clear, however, with a number of potential pathways resulting in cell death (Hellman, 1997).

A number of types of radiation therapy are used. At the lower end of the scale is superficial radiation, which is a low energy form that does not penetrate the skin. Teletherapy or mega-voltage radiation uses either x-rays from a linear accelerator or gamma rays from cobalt 60. These penetrate tissue in a reasonably directional fashion. Electron beams produced from a linear accelerator are sometimes used, having the advantage of defined depth penetration. Brachytherapy involves the implantation of a device emitting radiation, usually in the form of caesium, within or close to a tumour site (Clarke, 1992). Disadvantages of radiation treatment are frequent side effects and the destruction of surrounding healthy cells. Side effects may include nausea, diarrhoea, immunosuppression, taste deficit, alopecia, radiation fibrosis and sterility (Johnson, Lauver, & Nail, 1989; Holland, 1989). There is also a small risk of radiotherapy-induced cancer, especially leukaemia. Cancers that are more suitable for radiotherapy include cancer of the larynx, cervix, oesophagus, testicle and Hodgkin's disease (Clarke, 1992).

Chemotherapy is a systemic treatment that utilises a combination of cytotoxic drugs designed to gain maximum destruction of cancer cells with minimum side effects (Tobias, 1995; Knight, 1998). It acts by chemically inhibiting DNA replication at an early



stage of cell division or by interfering with protein synthesis (Clarke, 1992). Each drug is effective against different types of cancer cells (Knight, 1998), mainly actively dividing cells (Clarke, 1992). Not all cancer cells are responsive, therefore. Those cancers in which a large percentage of cells are dividing are especially responsive (e.g., testicular cancer and leukaemia), even when the disease is widespread (Clarke, 1992). The dosage and combination of drugs is guided by established principles (Knight, 1998) based on extensive clinical trials (Tobias, 1995). An important factor in determining this is the time required for recovery of the patient's bone marrow. Typically, treatment will be over one or more days followed by a three to four weeks recovery period (Knight, 1998; Clarke, 1992).

Chemotherapy is used as the principal treatment when surgery and radiation are ineffective or unsuitable. It is also used as an adjuvant treatment after a primary tumour has been controlled by localised treatments (e.g., surgery or radiation) (Knight, 1998). Side effects are frequently severe and some are permanent, often affecting a patient's lifestyle and appearance (Byrski, 1989). They include gastrointestinal disturbances, mouth sores, hair loss, fatigue, diminished concentration and immunosuppression, although in recent years advances in supportive technology have reduced the impact of side effects (Knight, 1998).

Hormone therapy is another systemic treatment based on the knowledge that some cancers respond to hormone levels in the blood. This therapy has the effect of slowing cancer cell growth and regressing tumours, with fewer side effects than chemotherapy. It has application mainly for cancer of the breast, endometrium and prostate (Clarke, 1992).

Biologic response modifiers and immunotherapies are more recently developed treatments which are used for certain lymphomas, melanomas and various other uncommon cancers, such as hairy cell leukaemia. These therapies utilise antibodies and cytokines secreted from the immune system. These are proteins with particular tumour cell destruction capabilities (Rosenberg, 1997). "Active" approaches, which create an immune response, include treatment with interleukin – 2, interferon, and vaccination with

antigen vaccines. "Passive" approaches include treatment with monoclonal antibodies, which are sensitised immunologic reagents. Treatment is complex and often toxic with reasonably severe side effects. These may include nausea, vomiting, diarrhoea, anaemia, cardiac arrhythmia, concentration deficits and flu-like symptoms (Knight, 1998). A particularly useful type of immunologic treatment is colony-stimulating factors (e.g., granulocyte and granulocyte macrophage colony stimulating factors) which are used in the reduction of side effects of chemotherapy (Speechly & Rosenfield, 1996).

### **Conventional medicine advances in detection and treatment**

Conventional bio-medicine has made considerable progress over the last decade or so in identifying carcinogens, developing prevention and early detection strategies and in treating many forms of cancer. Recent progress in oncology and haematology is responsible for dramatic reductions in death from a number of cancers including cancer of the cervix, Hodgkin's disease, testicular tumours, and most types of childhood cancers including acute lymphoblastic leukaemia (Lowenthal, 1994). Early detection, for example, is becoming a major thrust in cancer treatment research (Weinberg, 1998). This is closely allied with diagnostic processes that, for cancer, are likely to remain the preserve of conventional medicine. Examples of these advances include the detection of inherited mutant alleles in genes, which has raised the possibility, for example, that some breast cancers are associated with mutant BRCA1 and BRCA2 genes (Weinberg, 1998). Another example is research with monoclonal antibodies that have been found to be "homing devices" that react with specific cancer cell surface receptors. These potentially could have radioactive atoms and specific toxins attached to them for transporting to a tumour site with a "smart bomb" effect (Weinberg, 1998).

Another recent discovery has been the programmed suicide of cancer cells by chemotherapeutic drugs (apoptosis). The p53 protein, for example, has been found to render many cells susceptible to apoptosis inducing drugs. This discovery means the oncologist could ascertain the genetic status of the p53 gene in a tumour to direct the

planning of the treatment protocol (Weinberg, 1998). Research has also found that biochemists may be able to modify the common cold virus to selectively kill only cells that lack a functional p53 protein, which is known to be a distinction between malignant cancer cells and normal cells (Swisher et al., 1999).

### **Treatment alternatives**

The hundreds of non-conventional treatments used for cancer appear not to be organised according to any biologic or other theoretical or methodological basis. It has been suggested, however, that they share certain common features. Walters (1993), for example, suggests these features are non-toxicity, detoxification, immune stimulation, dietary regimens, nutrient supplementation and psychological or spiritual regimens. At a more fundamental level Walters (1993) suggests that non-conventional medicine regards cancer as a “systemic” disease that involves the whole body, whereas conventional medicine treats cancer as a “localised” disease. Presumably this notion underlies the holistic approach of non-conventional medicine. It would also appear to be using the notion of “systemic” in a broader sense than the conventional description of chemotherapy as a systemic treatment.

In the absence of any overarching theoretical model or organisational structure for non-conventional cancer treatments, and with no way of deriving a definitive list of the therapies used, description of non-conventional cancer treatments, other than in a generic philosophical sense, is beyond the scope of this thesis. Some indication may be gained, however, from the way authors have organised therapies for descriptive purposes. Walters (1993), for example, identified eight therapy groups. These groups, with some examples of each were: biologic and pharmacologic (e.g., antineoplaston therapy, hydrazine sulphate); immune (e.g., imagery and visualisation, Livingston therapy); herbal (e.g., Hoxsey therapy, Pau D’Arco); nutritional (e.g., Pritikin diet, wheatgrass therapy); metabolic (e.g., Gerson therapy); adjunctive (e.g., oxygen therapy, chelation); energy

(e.g., Bioenergetics, homeopathy); and mind/ body (e.g., bio-feedback, psychotherapy). This organisation seems reasonably representative of publications in this area.

### **Prevalence of non-conventional treatment use**

In countries for which statistics are available non-conventional medicine is used by 20%-50% of the population and growing rapidly (Fisher & Ward, 1994). Eisenberg et al. (1993) reported that in 1990 Americans were estimated to have made 425 million visits to non-conventional therapy providers compared to 388 million visits to primary care physicians. Australians, in 1993, spent \$621 million on non-conventional medicines (and another \$309 million on therapists) compared to patient contributions for all classes of pharmaceutical drugs of \$360 million.

Furthermore, Eisenberg et al. (1993) confirmed that non-conventional therapies are frequently used by cancer patients. Cassileth, Lusk, Strouse, and Bodenheimer (1984) reported that over 50% of US cancer patients used non-conventional medicine. In New Zealand the Clinical Oncology Group (1987) reported that 32% of cancer patients had received non-conventional medicine advice and 68% of those intended to follow it in some way. In Australia 46% of children with cancer were found to have used at least one non-conventional therapy (Sawyer, Gannoni, Toogood, Antoniou, & Rice, 1994). In Switzerland, 53% of patients surveyed in an outpatient oncology clinic reported some experience of one or more non-conventional cancer treatments (Morant, Jungi, Koehli, & Senn, 1991). In a British sample of 415 cancer patients 16% had used non-conventional therapies for their cancer (Downer et al., 1994).

### **Some factors underlying the choice of treatments**

A choice that the cancer patient often confronts is whether to use non-conventional medicine, and if so, which one(s). This is likely to be a difficult and

potentially critical choice for the person in a life-threatening situation. A cancer diagnosis is an event that will raise a number of questions for the patient. Morris, Blake, and Buckley (1985) suggested that these would include questions about what will happen in the long run, the speed with which the disease may progress and the possibility of death. A likely behavioural response to these questions would be in the form of taking steps towards treatment. While there is evidence of delay in seeking a cancer diagnosis (e.g., Anderson, Cacioppo, & Roberts, 1995), it has been found reasonably consistently that where symptoms are perceived to be serious the decision to proceed with treatment is made (e.g., Haug, Wykle & Namazi, 1989; Cameron, Leventhal, & Leventhal, 1993; Tan & Bishop, 1996). For many this will likely create a dilemma as to what form of treatment(s) to use. For many patients, an integrated one-stop professional care regimen utilising what the patient might see as an appropriate range of treatments would be the ideal. The reality, however, is what appears to be a polarising between conventional and non-conventional medicine so that the climate is frequently one of mutual distrust and conflicting claims. The depth of this division is illustrated by the following statements. "Holistic medicine is a pabulum of common sense and nonsense offered by cranks and quacks and failed pedants who share an attachment to magic and an animosity toward reason" (Glymour & Stalker, 1983 p.963) and "Doctors are now doing more harm than good ..... patients are now more likely to be made ill by a doctor than they are to be made ill by heart disease or cancer!" (Coleman, 1994 p.28). Even at a more political level there appears to be animosity. For example, the American Cancer Society has been accused of corruption, incompetence, deliberate suppression of cancer therapies that work, the rigging of clinical trials and as being in league with the pharmaceutical industry (e.g., Walters, 1993; Lynes, 1989).

A major obstacle confronting the cancer patient considering non-conventional treatment is where to obtain objective informed advice on treatment options. Within conventional medicine the health professional is able to provide or refer to treatment information covering any options. Indeed, it has been found that often cancer patients prefer to leave the decision to the physician (Sutherland, Llewellyn-Thomas, Lockwood, Tritchler, & Till, 1989). In non-conventional medicine, however, an individual

practitioner is unable to provide objective advice about options because any training they have had will have been specific to the particular method(s) they practice. The major source of information has been found to be relatives and friends (Morant et al., 1991; Sharma, 1992; Fulder, 1988).

Conventional medicine practitioners may sometimes have some positive input regarding non-conventional options. In Britain, for example, Perkin, Percy, and Fraser (1994) found that 93% of GPs and 70% of hospital doctors had suggested a referral for non-conventional treatment on at least one occasion. This was for a limited range of five non-conventional treatments, however, (acupuncture, chiropractic, homoeopathy, naturopathy and osteopathy) and no indication was given as to what the patients' illnesses were. Bernstein and Shuval (1997) found that Israeli doctors frequently referred patients to non-conventional practitioners at patients' request, but were generally sceptical and felt that the 'placebo effect' was operating. In Canada 73% of GPs felt they should have some knowledge of the most important non-conventional therapies but did not seek much more involvement (Verhoef & Sutherland, 1995).

In New Zealand there is a relatively high level of interest in non-conventional therapies by doctors (Dew, 1997). Marshall et al. (1990), for example, found that 30% of Auckland doctors practised one or more forms of non-conventional medicine and Hadley (1988) found a rate of 27% among Wellington doctors. However, referring patients to a specific non-conventional practitioner, or administering a specific therapy themselves does not constitute advising patients about options. It is also important to note that there is no evidence that doctors are facilitating non-conventional treatment for patients suffering from a life-threatening condition such as cancer. It is possible that the attitude of the New Zealand medical profession is reflected in the view of the Clinical Oncology Group (1987) that "It is understandable that cancer patients who do not have time to wait for science to produce a cure and may not understand their disease should turn to pseudoscience. It is harder to understand why anyone who is medically trained should do so" (p.113).

Furthermore, the legal position affects doctors' involvement with non-conventional medicine. In New Zealand conventional medicine practitioners must hold the appropriate degrees in medicine and be registered under the Medical Practitioners Act, 1995. The Act states, as one of its intentions, the imposing of various restrictions on the practice of medicine. The type(s) of medicine that doctors may or may not practise is not legally codified, although the legislation appears to place restrictions on the use by doctors of treatments that are outside conventional scientific medicine. It would appear, for example, that a doctor could be charged with professional misconduct and/or conduct unbecoming a practitioner for undertaking "fringe medicine" (Cole & St George, 1993). Depending on the adjudged extent of deviation from prudent and competent care of a patient, practising non-conventional medicine per se would be unlikely to result in deregistration which flows from the more serious charge of disgraceful conduct. For many doctors the question of where to draw the line remains unanswered both legally and ethically. As in most developed countries, New Zealand authorities (e.g., the Medical Council) are concerned with the misleading of patients that can arise through the offering of cures, particularly for the likes of cancer, via non-conventional therapies. In the United States, for example, medical practitioners who become involved in non-conventional treatments, particularly in the field of cancer therapies, risk their reputations, and even their medical licenses (Lerner, 1994).

### **Treatment choice research**

An increasing number of researchers have recognised the need to understand the determinants of choice of treatment between conventional and non-conventional modalities. Frequently, however, research that has set out to explore the question 'why do people use non-conventional medicine' has turned on the question 'who uses non-conventional medicine'. This has often resulted in studies that have described the sociodemographic characteristics of non-conventional medicine users in comparison to conventional medicine users (Sharma, 1992). It also confirms Bishop's (1991) view that the traditional approach to health-related behaviour research has focused on demographic

and socio-cultural factors. These studies have documented the socio-demographic characteristics of users of non-conventional treatments in most Western countries. Typically, the user of this type of treatment has been profiled as being of middle or upper socio-economic status (Fulder, 1988) and of a higher level of education (Murray & Shepherd, 1993; Bernstein & Shuval, 1997). They are also more likely to be a woman (Downer et al., 1994, MacLennan, Wilson, & Taylor, 1996; Bernstein & Shuval, 1997; Yates et al., 1993) and to be between the ages of 25 and 50 (Eisenberg et al., 1993; Fulder & Munro, 1985; Thomas, Carr, Westlake, & Williams, 1991).

There is evidence, however, that this profile may not be as well defined as the above studies suggest. Loehrer (1993), for example, found that a belief that cancer could be successfully treated by non-conventional treatments is more likely to be held by the elderly and those with less formal education. Gender has also produced varying findings. A number of studies, as mentioned above, have found that women are more likely to use non-conventional medicine, but others have reported no difference (e.g., Cassileth et al., 1984; Verhoef, Sutherland, & Brkich, 1990). Gender differences have also been found to be affected by treatment type with women being more likely to use homoeopathy and herbalism and men preferring massage and osteopathy (Sharma, 1992).

Research exploring treatment modality decision making has often also comprised the collection and cataloguing of factors that patients report as having a causal influence on the decision making process. These have often been judgements about efficacy and delivery of different types of health care. Studies concentrating on these situational judgements about the efficacy of different types of health care have often explored the level of satisfaction or dissatisfaction with non-conventional and conventional medicine in terms of how they are delivered. A common conclusion has been that a decision in favour of non-conventional medicine is best explained by the various failures of the biomedical model and a dissatisfaction with conventional medicine (e.g., Cassileth et al., 1984; Liebrich, Hickling, & Pitt, 1987; Sutherland & Verhoef, 1995; Verhoef et al., 1999; Furnham & Smith, 1988). It has also been suggested that the disenchantment is with conventional practitioners rather than their medicine (Furnham & Smith, 1988),



although Moore, Phipps, and Marcer (1985) found that most thought they had received satisfactory treatment from conventional doctors.

Studies that have specifically targeted cancer patients, however, have demonstrated the equivocal nature of findings that have relied on self-reports of reasons for non-conventional use. For example, Morant et al. (1991) found that disappointment with conventional medicine was the least common reason for the use of non-conventional medicine. Similarly Himmel, Schulte, and Kochen (1993) found no significant link between cancer patients' satisfaction with their doctor and their demand for non-conventional therapies. This suggests that what is at work, particularly among those in a life-threatening situation, may be something more fundamental than what is tapped simply by enquiring of people why they have chosen non-conventional therapy. Clearly, people's perceived reasons are important, but it would also appear that the experience of a serious illness may influence people's thinking in ways that are not recognised or are not enunciable or explainable by them. Previous research, in general, has not explored or accounted for this.

The present study avoided asking participants directly why they had chosen to use non-conventional medicine or not in relation to their cancer. A reason for this was that the study was not designed simply to investigate why cancer patients chose to incorporate non-conventional treatments. The primary aim was to investigate whether users of non-conventional medicine differed on a specific set of cognitions that were hypothesised to be associated with having a life-threatening illness.

Beliefs about treatment efficacy are commonly among the reasons given when patients are simply asked why they chose a particular treatment. It is suggested, however, that for cancer patients the question of treatment efficacy is less prominent. The reasons for this view are as follows. Conventional medicine has made notable, well publicised progress in the treatment of cancer, whereas evidence of success with non-conventional medicine is largely anecdotal and non-specific. Secondly, cancer patients know their illness is serious and that it must be treated with "seriousness". They are, therefore, less

likely to be attracted to a method of treatment that does not match the seriousness of their illness. A decision to use a non-conventional treatment that lacks backing from the “serious” scientific establishment as to its efficacy reinforces the (incorrect) notion that the problem is not serious (Alper, 1984). For cancer patients, therefore, treatment efficacy is less likely to be an issue until, perhaps, conventional medicine has given up.

Previous research that has approached the question of the choice between conventional and non-conventional treatment by asking participants to give their reasons is depicted in figure 1 (chapter 1) by the right branch that often leads to non-conventional use. This type of research has focused more on decisions people make about the nature of the treatment itself. In the present study, which is depicted in the left branch, the focus was more on the questions people have and the decisions they make about themselves and their own role, rather than directly about the treatment. In a sense this distinguishes the present study from those that have been directly focused on people’s perceptions of the differences between the modalities.

## CHAPTER THREE

### THE COGNITIVE APPROACH IN HEALTH BEHAVIOUR RESEARCH

The fundamental aim of this chapter is to provide justification for the adoption of a cognitive approach to understanding treatment choice among cancer patients. Having referred to this as a “cognitive approach”, it is most appropriately described in terms of social cognition. Social cognition is concerned with how individuals make sense of themselves and other people and the situations people find themselves in (Kunda, 1999). It is also concerned with how individual cognitions or thoughts intervene between specific events in people’s lives and their behavioural responses to these situations (Fiske & Taylor, 1991). The chapter is structured as follows. First, a broad definition of ‘health behaviour’ as it is referred to in this study is provided. Justification for a cognitive approach in general is then offered, followed by a description of the social cognition approach. The remainder of the chapter essentially describes areas that the study did not specifically include, and offers some justification for this. These are afforded a reasonable amount of attention in this chapter because they are matters that, arguably, could be relevant and might be expected to be specifically incorporated in a study such as this. The first of these details why social cognition models, which commonly provide a basis for exploring the relationship between cognition and health behaviour, were not utilised. The second concerns potential determinants of treatment choice that could be described as social determinants, and the third concerns the role of affect in the treatment choice process.

#### **Health behaviour defined**

A considerable amount of research in psychology in recent years has focused on identifying the factors that underlie a wide range of health behaviours (Conner & Norman, 1996). Categories of health behaviour investigated have included preventative

behaviours (e.g., diet and exercise regimens), protective behaviours (e.g., undergoing screening procedures and performing self examination), health enhancing behaviours (e.g., quitting smoking), treatment compliance behaviours, and care seeking behaviours.

As Conner and Norman (1996) have pointed out, these behaviours have in common the fact that they have an effect, either immediate or long-term, on the individual's health, and are at least partially within the individual's control. These are important aspects of health behaviour that tend to have been unaccounted for in earlier definitions. Kasl and Cobb (1966) (cited in Conner & Norman, 1996), for example, defined health behaviour as "Any activity undertaken by a person believing himself to be healthy for the purpose of preventing disease or detecting it at an asymptomatic stage" (p.246). Such a definition fails to encompass lay behaviours and excludes the behaviours of those already diagnosed with an illness (Conner & Norman, 1996). In the context of the present study, arguably, choosing to use non-conventional cancer treatment is likely to be a decision based on lay beliefs and attitudes, often made with little or no professional input. It is also a behaviour often undertaken beyond the prevention or detection stage. Accordingly, the present study proceeded on the basis of a definition of health behaviour which accounts for lay behaviours, an element of individual control, and broadens out health behaviour to 'health-related behaviour', to use Schwarzer's (1999) terminology.

### **Justification for a cognitive approach**

Various researchers and writers have pointed to the benefits that have accrued to health psychology from the cognitive school (see Rodin & Salovey, 1989 for a review). Seeman (1989) said of the cognitive subsystem that it is "a domain that is so powerful in its impact on health that it would be difficult to overstate its many facets of health behaviour" (p.1105). Conner and Norman (1996) suggested that the factors underlying who performs health-related behaviours may be broadly grouped into factors 'intrinsic' to the individual (e.g., sociodemographic factors, personality, social support, cognitions)

and factors that are 'extrinsic' such as health promoting incentives provided, and restrictions imposed by communities and governments. They suggested that it is the intrinsic factors that have particularly interested psychologists and, furthermore, that within these, the cognitive factors have been viewed as "the most important proximal determinants" (p.2). Other researchers also have shown that cognitive factors such as health beliefs have more predictive and explanatory value for health behaviour than psychosocial factors (e.g., King, 1983) and personality variables (e.g., Pendleton, 1983).

In the specific context of research among cancer patients, the value of the cognitive approach has been recognised. For example, Taylor's (1983) theory of cognitive adaptation to threatening events, based on research among cancer patients, demonstrates that a cognitive approach to understanding the response to being faced with a life-threatening situation is particularly appropriate. For example, it seems implicit in Taylor's (1983) account of her findings that the severity of personal tragedy evokes or is dealt with by a cognitive response, not necessarily by an affective response, which might be expected intuitively. Taylor (1983) identified three cognitive processes by which individuals achieve an impressive level of adjustment and adaptation to this type of personal tragedy. The first is the search for meaning in the experience, which involves understanding why one has cancer and what its implications for one's life are. The second cognitive element is the gaining of a sense of control over the situation. Taylor (1983) found that patient's efforts at control were both of a psychological nature (e.g., believing in the importance of a positive attitude) and behavioural (e.g., dietary and lifestyle changes). Thirdly, Taylor's (1983) theory proposed that cognitive efforts to enhance the self and restore self-esteem commonly follow the experience of a threatening event. The second and third of these themes were also identified by Seeman (1989) as being dominant motifs in the literature that explored the ways in which cognitive processes influence health.

Conner and Norman (1996) also suggested that it has been cognitive factors (e.g., beliefs, attitudes, knowledge) that have been central to a number of models of the determinants of health behaviours (for reviews see Cummings, Becker, & Maile, 1980;

Becker & Mairman, 1983; Mullen, Hersey, & Iverson, 1987; Weinstein, 1993). They considered that cognitive factors have demonstrated their ability to discriminate between individuals in terms of their propensity to perform certain health behaviours. Justification for this, and for the interest in cognitive factors generally, is found in the considerable research that has explored their role as determinants of various health-related behaviours. Much of this research has involved both the development and utilisation of social cognition models that describe important cognitions and their roles in behaviour regulation (Conner & Norman, 1996; Conner & Waterman, 1996; Abraham, 1999). These models are reviewed below.

Conner and Norman (1996) provided a number of justifications for the concentration on cognitive factors, one of which is particularly germane in the context of the present study. That is, that “These [cognitive] factors are enduring characteristics of the individual which shape behaviour and are acquired through socialization processes” (p.5). It is suggested that the three elements of the above reason are satisfied in the present study. First, the existential component, particularly represented by the meaning variables, and the attributional component, represented by control, responsibility and blame, were conceptualised as enduring cognitive characteristics. They are enduring both in the sense that they are likely to pre-exist the illness experience and, it is suggested, are likely to remain substantially unchanged (without specific intervention) by the experience.

The second element of Conner and Norman’s (1996) reason for focusing on cognitive factors (that cognitive factors shape behaviour) essentially concerns the empirical basis of the present study. In the following chapter the theoretical basis of this, in relation to the specific cognitions of interest, is addressed. Studies that have explored the way cognitive factors shape treatment choice behaviour are also reviewed in the following chapters. The third element concerns the social aspect of social cognition models and is addressed below.

## **The social cognition approach**

Social cognition is a particularly broadly based concept, so much so that, as Fiske and Taylor (1984) commented, it does not rely on any one theory. Generally, research in this area is concerned with how people make sense of others and/or themselves (Fiske & Taylor, 1984). Making sense of oneself is the focus when applied to health-related behaviour. In the context of the present study, how people make sense of themselves is intertwined with how they make sense of their situation and their world, in this case, having a life-threatening illness. This reflects Stainton Rogers' (1991) definition of social cognition as "the study of how people explain and make sense of the world around them, the events in it and how it works, their experiences, their own actions and those of others" (p.42).

A number of theoretical models, referred to as social cognition models, have been developed either in response to the cognitive approach to health behaviour research or as more general social cognition models which have been adapted by researchers in this field. As Conner and Norman (1996) have pointed out, the self-regulation approach, which underlies social cognition models, is derived from a clinically oriented behavioural change process designed to eliminate dysfunctional thinking and behaviour patterns. This underlying basis, evidenced in the various social cognition models, suggests that they may not constitute entirely appropriate frameworks for the exploration of treatment choice decision-making. This type of health behaviour is not seen as involving dysfunctional thinking or behaviour requiring cognitive restructuring or behaviour modification interventions.

Another distinction between the approach taken in the present study and social cognition models is that these models tend to focus on cognitions relating to the health behaviour and its outcomes and to the illness itself. The present study, however, explored cognitions expected to be associated with the particular issues that a threat to ones life usually raises, and the role of the individual in terms of accepting responsibility for, and

### *Social cognition models*

While the social cognition models that are derived from models of decision-making are primarily aimed at predicting health behaviours and outcomes, they are frequently seen also as providing a general framework for understanding the determinants of behaviour (e.g., Conner & Norman, 1996). The more common of these models include the health belief model (Rosenstock, 1966), the theory of reasoned action (Fishbein & Ajzen, 1975), the theory of planned behaviour (Ajzen, 1988), protection motivation theory (Rogers & Mewborn, 1976), and self-efficacy theory (Bandura, 1977; Schwarzer, 1992). Other models that are less widely used nowadays, include the health locus of control model (Wallston, Wallston & De Vellis, 1978), the self-regulatory model of health and illness behaviour (Leventhal, 1970; Leventhal, Meyer, & Nerenz, 1980; Leventhal & Diefenbach, 1991), and the implicit illness model (Turk, Rudy, & Salovey, 1986).

The health belief model (Rosenstock, 1966) (HBM), for example, which remains a popular model in health behaviour research, has limited usefulness among those already diagnosed with the likes of cancer. The underlying theory of the HBM is that behaviour is dependent on two main variables. These are the desire to avoid or recover from illness, and the belief that given illnesses will be overcome by given behaviours. The dimensions of the model, which operationalise these variables are perceived susceptibility or vulnerability, perceived severity, and perceived benefits from and barriers to one's action.

In the context of the present study there are some problems associated with the HBM dimensions. For example, cancer brings with it a feeling of relative permanence. Unlike those with everyday ailments that come and go, most cancer sufferers are past wondering about their susceptibility and vulnerability. Similarly, perception of severity is less relevant for cancer patients because a cancer diagnosis is accompanied by an almost automatic perception of extreme severity. The benefits and barriers dimension, when



applied to treatment issues, has usually been interpreted as beliefs about efficacy and aversiveness or inconvenience of treatment. These are the self-reported treatment focused aspects that the present study aimed to avoid.

The theory of reasoned action (Fishbein & Ajzen, 1975) (TRA) is a general social psychological model of behaviour that has also been widely used to provide a theoretical perspective in health behaviour research. The underlying concept in the TRA is that attitudes and subjective social norms determine intentions, which in turn determine behaviour. Attitudes are the result of beliefs about the consequences of the behaviour and subjective norms are beliefs about how others expect a person to behave. These are attitudes and beliefs that relate to future consequences of the behaviour, so are outcome focused rather than being attributional type beliefs, which are appropriate in the context of the present study.

Furthermore, the TRA has often been used and is particularly suited in investigating preventative behaviours among healthy populations. In such circumstances the information-processing basis of the model is appropriate. Individual's who are not suffering from a life-threatening condition would likely have a greater capacity to be objective, and could make their decision without the pressure of knowing it was critical and probably urgent. An information processing approach may be an ideal approach, particularly in the context of conventional medicine, and may reflect the approach of conventional health professionals. It may not, however, be so useful in exploring the actual decision making process of cancer patients. Concerning beliefs about consequences of behaviour and subjective norms, as Stainton Rogers (1991) commented, asking a person as they are about to perform a behaviour whether they think it is a good idea and whether others will approve, is likely to be fairly predictive of whether they are going to perform the behaviour, but getting consistent answers does not mean that much understanding about their thinking, except at a trivial level, is being gained.

In many research settings an inherent limitation of the TRA is its restriction to behaviours that are under the complete volitional control of the individual (Stroebe &

Stroebe, 1995). Ajzen (1988) developed the theory of planned behaviour to overcome this, incorporating perceived control over the performance of a given behaviour as an additional dimension. The concept of control is an important dimension in the present study, but is seen as rather different from the notion of controllability, which this model is concerned with. In the context of the present study controllability goes more to the question of freedom of choice about treatment, rather than whether a person has a fundamental desire to be in control of treatment decisions or to vest control elsewhere.

Protection motivation theory (Rogers & Mewborn, 1976; Rogers, 1983) is a theory of persuasive communication incorporating fear arousal as one of the main cognitive processes for predicting and influencing behavioural change. Protection motivation involves threat appraisal and coping appraisal processes that result in adaptive and maladaptive coping with a health threat (Boer & Seydel, 1996). The components of threat evaluation (perceived vulnerability and susceptibility and perceived severity) originated from the HBM and so, in the context of already diagnosed cancer patients, protection motivation theory has the same limitations as the HBM. Coping evaluation involves response efficacy in terms of the expectancy that the behaviour will work, and self-efficacy as the expectation that one can carry out the behaviour. Response efficacy is essentially the essence of the treatment choice process itself rather than being a cognitive process. Self-efficacy as defined, is not particularly relevant in the context of the present study, in the sense that performance of the behaviour is not dependent on the ability of the individual.

Self-efficacy itself has been referred to as the key construct in social cognitive theory (Bandura, 1977, 1992; Schwarzer & Fuchs, 1996) and as a construct that should be incorporated in future social cognition models (Norman & Conner, 1996). One of the reasons for this is because it concerns the translation of intentions into action, something which is generally not well accounted for in social cognition models (Abraham & Sheeran, 1993). Even though it has been referred to as a key social cognition construct, Bandura (1977) developed self-efficacy as a key component of cognitive behaviour modification, which perhaps, explains why the construct does not take the value

expectancy approach of most social cognitive variables. It is concerned more with personal control or agency over one's actions than it is with outcome expectancy. Self-efficacy expectancy is the belief that performance of a given behaviour is or is not within one's control (Schwarzer & Fuchs, 1996). While the concept of personal control is important in the context of the present study, behavioural change, which is facilitated by personal control (Schwarzer & Fuchs, 1996) is not so relevant. Making a decision about treatment modality does not constitute behavioural change. As Schwarzer and Fuchs (1996) point out, self-efficacy beliefs are relevant when it involves taking personal action and using personal skills to change a risky behaviour. Giving up smoking to enhance health or as a preventative measure, for example, is a somewhat different scenario to making a decision about what type of treatment to pursue, even though outcome expectancies may be similar.

Of the models that are less widely utilised nowadays, two are worthy of description because they help to demonstrate some of the conceptual limitations of social cognition models in relation to the context of the present study. In utilising the self-regulatory model of health and illness behaviour (Leventhal, 1970; Leventhal et al., 1980; Leventhal & Diefenbach, 1991), Leventhal and Nerenz (1983) identified four dimensions in terms of which they found most people thought about their disease. These were: Identity - identifying the presence or absence of disease and labelling it; consequences - perceived physical, social and economic consequences and emotional response; causes; time frame - its progression and duration. A fifth dimension, curability, including what the individual can do to recover, was added to the model by Lau and Hartman (1983).

The Leventhal model suggests that upon symptom appearance, diagnosis, or during the illness experience, a person constructs a representation of their health threat or illness experience which then influences illness behaviour. As Schiaffino and Cea (1995) interpreted this approach, it is through a person's own illness that he or she comes to understand illness. Certainly, symptoms or diagnosis would initiate a thinking process specifically about now having that particular illness, and no doubt about treatment possibilities. In the present study, however, the cognitions that surround the illness

experience are seen as the bringing into focus of various pre-existing fundamental ontological issues that are inevitably associated with a life threatening experience. While Leventhal and colleagues acknowledge that pre-existing cognitive factors influence the cognitive response to an illness episode (Leventhal & Nerenz, 1983), this is in a limited sense, however. It refers to pre-existing conceptions of illness in terms of cognitive memory schemata generated by previous illness episodes or experiences.

The implicit illness model (Turk et al., 1986) is another example of a model that has some limitations when used with those already diagnosed with a serious disease such as cancer. In developing the Implicit Models of Illness Questionnaire, Turk et al. (1986) factor analysed various existing scales and produced four factors. These were: Seriousness - knowledge about curability, duration and contagiousness; personal responsibility for cause and cure - beliefs about who or what caused the disease and will cure it; controllability - either by the ill person or an outside agent; and changeability - of symptoms and other aspects of the disease. At least two of the dimensions of this model would be inappropriate in the context of the present study. For those already diagnosed with a serious disease such as cancer the seriousness dimension is unnecessary because cancer is always perceived as serious. Similarly the changeability dimension adds little to the understanding of a cancer patient's cognitive approach to their disease. Cancer is frequently perceived as permanent, being changeable only in the sense of worsening.

The dimensions of the implicit illness model may also reflect two restricting methodological aspects of the Turk et al. (1986) study from which they were generated. One was that apart from some diabetes patients, the raters were healthy subjects. As Skelton and Croyle (1991) have pointed out, researchers in this area must use individuals who face genuine threats to their health. The other was that differences in perceptions among the participants may have been attributable to the special circumstances of any of the three disparate diseases the study was based on - the flu, diabetes and cancer.

In a general sense, in the context of treatment choice as a health related behaviour, some additional considerations arise. Firstly, behavioural decision-making theory, as the

underlying theoretical basis of many social cognition models has been used among already diagnosed breast cancer patients with emphasis on the life-threatening nature of the illness (e.g., Siminoff & Fetting, 1991). The approach in that study, for example, was predicated on the notion that behaviour deviates from rationality because people are unaware of alternative frames in which to make their decisions, and have imperfect access to information (Siminoff & Fetting, 1991). In recent times, however, information about non-conventional treatment alternatives has become readily available and making treatment decisions outside of the biomedical doctor-patient frame has become more common. A behavioural decision-making approach may be useful among a cancer population, but possibly only when the field of decision making is based within the biomedical model as it was in the Siminoff and Fetting (1991) study.

Another difficulty is that in the context of making a decision between conventional and non-conventional treatment, the question of what is rational is difficult to answer. In the context of health behaviour the concept of rationality may be less appropriate than it is in general decision-making applications. In a sense, this links back to the restrictions of the biomedical model in which biomedicine and its practitioners are deemed to know what is best and what is rational for an individual. Subjectivity, however, may be important in health matters. Perhaps the individual knows best, in some instances at least, about how to respond to their health situation. For example, the decision to accept palliative treatment rather than definitive treatment may seem irrational in a biomedicine context but may represent the best decision for a given individual in a given situation.

Furthermore, there appears to be support for the suggestion made in this study that health related cognitions are likely to vary at least between non life-threatening and life-threatening situations, if not between specific diseases. This distinction has been confirmed at a health behaviour level by various researchers. For example, Haug et al. (1989) found that people sought professional care for serious symptoms but relied on non-prescription medicine or self-care for symptoms they perceived as less serious. Tan and Bishop (1996) found that Chinese Singaporeans would be more likely to visit an

allopathic doctor for a life threatening condition than a traditional Chinese medicine practitioner or use home remedies or Chinese medicines. Given that health behaviours flow from health-related cognitions, the evidence indicates that people approach life-threatening illness somewhat differently to the way they think about other illness. The stated intention of the implicit illness model (Turk et al., 1986) to act as a generic illness representation model that was consistent across different populations and different diseases may have introduced an inherent weakness to that model.

Finally, in relation to health, there is support for the view that beliefs which influence health behaviours are changing. They are demonstrating greater complexity (e.g., Dines, 1994) and they are influenced by cognitions beyond what has traditionally been accepted within biomedical ideology. Thorne (1993), for example, argued that traditions other than Western biomedicine influence much of our decision-making and behaviour about our health care. For example, in biomedical logic naturalistic theories of disease and cure predominate. When the newly diagnosed cancer patient asks "why me?", and searches for answers in the spiritual realm of their life, they are looking for a personalistic explanation. Models that facilitate the exploration of beliefs and attitudes do not seem to account for beliefs that derive from the so-called spiritual or philosophical realm where questions about meaning have their origin for many people and where behaviours may have their origin as well. The cognitions explored in the present study, it is submitted, take account of these concepts.

Abraham (1999) concluded that social cognition models are useful for understanding individual differences in health-related behaviour and differences in action regulation, although perhaps more in the prediction of health-related behaviour than in its explanation. Abraham (1999) also observed, however, that the application of these models has not gone unquestioned (see Abraham, Sheeran & Orbell, 1998 for a review). In the context of the present study various social cognition models have contributed useful theoretical reference points and some relevant variables. None, however, has provided a suitable conceptual framework on which the study could have been based.

### **The social and cultural aspects of social cognition**

The enduring nature of cognitive characteristics (Conner and Norman's (1996) first justification of the cognitive approach, referred to above) may in part be due to the way they are acquired. An individual's approach to life's existential issues, such as meaning in life, for example, comes from values and beliefs (Reker, 2000). These are learned or derived through socialisation processes – the third element of Conner & Norman's (1996) reason for concentrating on cognitive factors. As Kenyon (2000) points out, humans are 'relational entities' who are involved with other persons and a social environment. Values and beliefs of an ontological nature, for example, are likely learned or acquired through parental influence and various other social processes (e.g., religious involvement). The way in which an individual attributes control and responsibility will often be influenced by social processes as well. For example, a review by Deaux (1976) of studies concerned with attributions of success and failure among men and women showed that men's success and women's failure were attributed to internal factors (e.g., ability) whereas the unexpected failure of men and the unexpected success of women were attributed to external situational factors. There is considerable evidence suggesting that attributions of this nature are acquired through socialisation processes (e.g., Miller, 1984).

Nevertheless, the question of what is social about social cognition models is still debated. For example, these models have been criticised for their inability to capture the social and cultural context of health-related behaviour (Joffe, 1996; Abraham, 1999). On the other hand however, it has been acknowledged that they have various underlying social aspects (Abraham et al., 1998; Abraham, 1999). Some examples of what is social about social cognition models, identified by Abraham (1999) are: They are derived from lay theories of motivation and action; they are used to categorise people in terms of socially shared behaviours; depending on the research setting they are employed in, they often distinguish between population subgroups along social and cultural difference lines;

they permit account to be taken of social context; and they enable beliefs individuals have about other people to be categorised.

In terms of the constructs explored in the present study, in a sense these were derived from underlying cultural and social values and beliefs. As Cassileth (1989) pointed out, such values and beliefs translate directly to what people believe and do with regard to medical choices. This was confirmed by the findings of two studies among patients of non-conventional cancer therapies (Cassileth et al., 1984; Cassileth, 1984) in which five main themes that reflect widely held values and beliefs about medicine and culture were identified. These were: Belief in the power of the individual; the need to understand and control the unknown; how people react to research data; views about contemporary cancer treatment; and how society views illness and particularly cancer.

These socially and culturally derived themes are represented in various elements of the constructs of interest in the present study. For example, belief in the power of the individual sees the individual as capable of triumphing over the enemy cancer (Cassileth, 1989), a concept reflected in the intrinsic approach to illness meaning. The need to understand and control is reflected in the knowledge and control constructs. Cassileth (1989) describes this as the tendency to “fill in gaps in knowledge in order to rid ourselves of uncertainty, disharmony and the unknown” (p.1248). This contributes to the tendency in our culture to seek control – even to reduce biology to controllable events (Cassileth, 1989). The third theme – how people react to research data, is related to knowledge and control and is also reflected in attributions of responsibility and blame. It concerns a cultural tendency to ignore data, in this case about cancer, that is inconsistent with ones own observations and beliefs as well as attributing responsibility for remission or cure to the individual’s own actions, often resulting in the attribution of blame to those who have succumbed to biology (Cassileth, 1989).

The way contemporary cancer treatment is viewed (the fourth theme) was not explored in the present study because of the expectation, based on previous research, that only a small proportion of cancer patients would abandon conventional medicine. The



social component of this, namely the way information is spread through society, was however, an underlying component of the knowledge, and health interest and motivation constructs. Cassileth's (1984) fifth theme describes the Western cultural sense of how to behave when faced with illness – in an “aggressive, optimistic and active-role” manner. Similarly, this is descriptive of various concepts of interest in the present study.

In one sense, therefore, socio-cultural factors can be seen as having a role in health-related behaviour but they are embedded in the more proximal cognitive determinants and to that extent are accounted for in the present study. Studies in which patients have been asked directly why they made the choice of treatment that they made have revealed various psychosocial and socio-cultural reasons for the choice. These have included relying on information about treatment efficacy and the perceived reliability of the source of information. Understandably these are goal directed reasons, but they do not necessarily reveal the underlying bases for the decision. Furthermore, they do not offer any explanation for differences between patients in the choice made. Presumably cancer patients will each have the same goal when embarking on a treatment regimen. Also, with a high prevalence of non-conventional treatment usage and a generally high level of information available, it is reasonable to assume that there is not a wide differential in access to information about non-conventional medicine of one form or another. Certainly it is to be expected that most cancer patients would receive a commensurate amount or quality of conventional professional advice about their condition. A reasonable assumption is, therefore, that there are concomitants of treatment other than what are tapped or represented by social context. A fundamental premise of the present study is that some of these are likely to be cognitive in nature. Conner and Norman (1996) put it as follows: “these [cognitive] determinants are assumed to be important causes of behaviour which mediate the effect of many other determinants (e.g., social class).” (p.2).

### **Affect as a potential determinant of health related behaviour**

Social cognition models have been criticised also for focusing on rational decision-making and ignoring the role of affect (Abraham, 1999). Like motivation, affect historically occupied a central position in social psychology until in the 1960s and 1970s it tended to be overshadowed in the so-called “cognitive revolution”. In one sense, both motivation and affect were absorbed within cognitive approaches. More recently, however, a renewed interest by social and health psychologists in affect as a potentially important variable in understanding health-related behaviour suggests that its omission, or apparent omission, in the present study should be addressed.

The classic work of Schacter and Singer (1962) suggested that an affective response consists of physiological arousal followed by a labelling of that arousal. The ‘feeling’ that follows results from that cognitive process of labelling. Researchers such as Lazarus (1984, 1991, 1993) expanded on this approach. He suggested that a given situation is appraised in stages. In primary appraisal the potential consequences of what is happening are determined. Secondary appraisal consists of deciding what to do, followed by a reappraisal stage as the situation develops. Each appraisal determines the affective response suggesting that cognition precedes affect. Zajonc (1980, 1984), however, argued that affect operates independently of cognition. He found that the affective response to a stimulus situation may occur independently of cognitions about that situation. This suggests that affect may precede cognitive appraisal. Sternberg (2001) refers to these as temporal-sequence theory approaches to the relationship between affective and cognitive factors

The approach taken in the present study was that affective and cognitive aspects are intimately interrelated, certainly within the context of life-threatening illness. The focus of the present study was on the cognitive factors that are involved at all stages of the treatment choice process. Affective responses are likely at various parts of the

process, but how these can be separated and their respective roles teased out is not at all clear. The cognitive constructs explored in the present study contain, at least implicitly, the affective aspects of the process, but no attempt was made to separate them. Whether a meaningful separation would ever be possible would require considerable further investigation. As Taylor (1990) observed, “Just as emotional factors are involved in the experience of health and illness, cognitive factors influence how people appraise their health and cope with the threat of illness” (p.43). Strongman (2001) also commented that even “in everyday life, there is a complex interplay between emotion and cognition occurring simultaneously and in rapidly developing sequences” (p.6.44).

This approach of non-separation of cognition and affect taken in the present study is aligned more with the psychological models of coping with serious illness found in health psychology. In a staged approach the affective component is still reasonably clearly delineated. For example, in Shontz’s (1975) model the first stage is one of shock including various affective responses but also the cognitive response of questioning why this has happened. The second stage is labelled ‘encounter’ in which various affective responses, such as feelings of despair, loss and hopelessness, are mixed with cognitive processes such as thinking the situation through and solving or attempting to solve problems. In Shontz’s (1975) third stage, ‘retreat’, individuals will address their situation by denying the problem or its implications. Finally, in the ‘adjustment’ stage, the individual will determine what adjustments are necessary to live with the disease and decide whether or not to make them.

Taylor’s (1983) model of cognitive adaptation avoids the staged model problem that not everyone goes through all the stages in the specified order (Sternberg, 2001). Furthermore, it is suggested that this model sees the affective component of the serious illness experience embedded in the adaptation process, notwithstanding that this process is labelled “cognitive adaptation”. It is suggested that the way in which Taylor’s (1983) model achieves this reflects the reality of the serious illness experience.

According to Taylor's (1983) model, patients search for meaning in the illness experience. This may lead them to look to causative factors and possibly make behavioural changes. They may simply rethink their own attitudes and priorities (Sternberg, 2001). Another phase may see patients trying to gain a sense of control over their illness and their life. This may include information gathering about the illness and its treatment. A third component of the model concerns the restoration of self-esteem, which may include, for example, a patient comparing her or his situation with those of others.

As in models such as Taylor's (1983), in the present study the response to having cancer was not conceptualised specifically in affective terms, neither were specific measures of affect included. The affective component of the cancer experience was not, however, ignored. The argument is that relevant affective components of the response to a cancer diagnosis were embedded in and accounted for in the constructs explored in the study. In the context of the present study the question to be addressed was whether the affective concomitants of a cancer diagnosis would likely influence important decisions about treatments, and if so, how? The potential role of affective factors was acknowledged and accounted for within the constructs investigated in the study – they were acknowledged in the measurement process and are explainable in terms of the mechanisms inherent in the constructs which account for influences on treatment choice.

Firstly, in relation to the knowledge and understanding of cancer construct, this was measured initially in terms of information-based knowledge. Level of knowledge acquired, either in terms of the quest to gain knowledge, or in terms of purposely avoiding knowledge, is a coping mechanism among cancer patients (Perez, 1992) as they deal with the affective issues surrounding their situation. The expectation in the present study was that level, accuracy and type of knowledge resulting from this coping strategy, would likely be an influencing factor in treatment choice. Furthermore, the second cancer knowledge and understanding dimension measured beliefs, including in affective terms, generated by the individual's subjective experience of cancer. This belief-based understanding of cancer was assessed in terms of positive or negative beliefs about 'my

cancer'. Similarly for this dimension, the mechanism by which the underlying affective nature of beliefs about 'my cancer' might influence treatment choice, was framed in terms of beliefs which have an affective component but are described as cognitions.

A practical example of the inter-relatedness of affective and cognitive aspects in the context of the present study is the way in which the affective response to the knowledge of having cancer is likely to be moderated by the influence of the 'medical machine' that inevitably swings into action providing information and generating treatment activity. As Fiske and Taylor (1984) have pointed out, the depth of an affective response to something can be influenced by the complexity of one's knowledge about it. That is, "complexity encourages the moderation of affect" (p.338). The practical application of this is that since formal cancer diagnosis takes place within the conventional medicine context, it is made within a frame that reflects a cognitive rather than an affective approach to the situation. Initially at least, treatment choices are usually made in this context.

In relation to the attributions of control, responsibility and blame construct, affective factors were acknowledged both in the measurement process and as underlying the attributions of control and responsibility as determinants of treatment choice behaviour. In terms of measurement, in the instrument utilised (Stainton Rogers, 1991) emotional well-being was one of the factors in the orthogonally-rotated 8-factor structure (Furnham, 1994). In a conceptual sense it was posited that it would likely be through the attributional process (described in some detail below) that the affective response would influence treatment choice behaviour. Research using the same instrument has found that users of non-conventional treatments report emotional well-being factors as influences on their current health situation more than users of conventional treatments (e.g., Furnham & Beard, 1995). The affective component is one of the factors the Stainton Rogers (1991) instrument assesses as an underlying component of the attributions of control and responsibility construct. In the present study, the thesis that the nature of attributions of control and responsibility would influence treatment choice acknowledged and subsumed, therefore, an affective component.

Similarly, the meaning construct arguably subsumes affective responses as contributors to underlying important existential questions. For example, as Dunlop (1992) points out, anger as a common affective response, typically is coupled with the ‘why me?’ and ‘what have I done to deserve this?’ type of questions. Dunlop (1992) suggests too that affective responses such as fear of death and the unknown, sometimes coupled with information or misinformation, contributes to the related concept of a sense of losing control. Fear of death particularly invokes existential questioning, and was specifically addressed in the measurement process. The present study explored how orientation in and treatment of these existential issues was associated with treatment choice. In a sense, therefore, the role of underlying affective factors associated with existential issues was accounted for.

Finally, in the specific context of the present study, the view that affect and cognition should not be treated separately is supported by the argument that affective responses in isolation are unlikely to clearly differentiate between users of conventional and non-conventional medicine. That is, all cancer patients are likely to have affective responses. For example, a response such as anxiety, resulting from concerns about whether treatment is working, will still be focused on curing the disease. There appears to be no theoretical basis for suggesting that a particular affective response will necessarily result in a particular choice of treatment. It may, for example cause a conventional medicine user to investigate conventional medicine in more depth, or try non-conventional, and vice versa for a non-conventional user. That is, it may influence factors such as commitment to treatment and a treatment regimen more than the type of treatment chosen. Evidence of behavioural implications of affect in the context of care seeking behaviours seems to be limited to the decision about whether to seek treatment at all (e.g., Easterling & Leventhal, 1989), and whether to delay treatment (e.g., Dracup et al., 1995) rather than decisions about type of treatment. It is possible that the affective response would add strength to a treatment decision already made, rather than influence its direction.

## CHAPTER FOUR

### THEORETICAL FOUNDATIONS OF THE COGNITIVE APPROACH ADOPTED IN THIS STUDY

#### Conceptual framework

Understanding the links between health-related cognitions such as health beliefs and action/behaviour has long been a problem for researchers. As Calnan and Rutter (1986) pointed out, behaviour can often be predicted from beliefs, but what kinds of belief are the most significant is an elusive question. Furthermore, Fiske and Taylor (1984) have shown that the question of how direct the relationship is between cognitions and behaviour is also a difficult one to answer. They suggested that researchers may expect too many and too varied behaviours to be related to any given cognition. This is, perhaps, an underlying difficulty with the social cognition models identified in the present study. That is, that treatment choice as a specific health-related behaviour may be related to a specific group of cognitions, especially when applied in the context of life-threatening illness. Social cognition models may not always relate to the specificity of the behaviours they are expected to predict or explain.

Another consideration in developing the conceptual framework was the way existing health behaviour models tend to comprise cognitions that are generated mainly by the experience of illness, which in a sense, reflects the illness focused biomedical approach. In the present study it was posited that the determinants of illness-related behaviour are not necessarily derived from the cognitive response to the fact of illness. This underscores the rationale, as previously mentioned, for using the Schwarzer (1999) terminology of 'health-related cognitions' rather than illness cognitions. Health-related cognitions may have their basis in the wider belief systems that generally pre-exist illness. They include beliefs that address the 'why' questions ('why me?', 'why this

illness?' etc.) that inevitably lead to existential questions about life itself, and about death, which are especially relevant issues for those in a life-threatening illness situation.

In the present study the investigation of health and illness behaviours was approached in this wider context wherein possible influencing factors were drawn from a larger and more expansive pool. It is larger in the sense that, arguably, people are embracing a wider variety of health related concepts (e.g., philosophical and spiritual aspects, and holism in general), have more knowledge and understanding about health and illness, and are prepared to incorporate these in their health care, than was the case even two decades ago. It is more expansive in the sense that these philosophical and spiritual concepts are pervasive of the lifespan, existing during both well and unwell phases. In this sense, they are not only products of the illness experience.

These 'wider belief system' concepts are operationalised in the present study through the meaning construct, and as such are addressed in some detail later in the chapter. However, the psychological processes that explain how a belief system may influence cognitive functioning and eventually behaviour, can be described in terms of attribution theory. It is attribution theory therefore, that underpins the psychological theoretical basis of the present study.

From this point the chapter first distinguishes this theoretical approach from that taken by social cognition models and then explains the attributional basis of the study. The conceptual link between attribution theory (operationalised in the attributions of control, responsibility and blame construct) and meaning in life and its events is addressed before the particular conceptualisation of meaning in this study is explained.

There are a number of distinguishing features between the theoretical approach adopted in the present study and previous approaches to understanding the relationship between cognitions and health-related behaviour. For example, social cognition models are deliberative models which may only be applicable when individuals have the opportunity to engage in systematic information processing about performing a behaviour



(Norman & Connor, 1996), which may or may not be available to a given cancer patient. Norman & Connor (1996) contrasted that approach with the automatic or spontaneous processes that may influence health behaviour, which is the approach underlying Fazio's (1990) (cited by Norman & Conner, 1996) model. In that model certain cognitions, such as highly accessible attitudes, may guide behaviour in an automatic, non-conscious way. This approach, which Norman and Conner (1996) recognise needs further exploration, has a certain congruence with the approach taken in the present study, particularly in relation to belief structures and attitudes towards existential matters. Enduring belief systems and attitudes, for many people, may guide behaviour in a non-conscious way.

The point was made in the previous chapter that there are three main types of social cognition theory. These are: attribution theory, models of decision making, and schema theory (Stainton Rogers, 1991). Also as indicated in that chapter, social cognition models, particularly those that have been found to be useful in the field of health and illness related behaviour, have been mainly based on decision making theory and have focused mainly on the health enhancing and compromising behaviours of otherwise healthy individuals, particularly in the context of prediction of future health-related behaviours (Conner & Norman, 1996). On the face of it, it would seem reasonable to use a decision-making model as a framework for exploring treatment choice decision-making. The present study, however, was based on an attribution theory approach, the reasons for which are addressed below. As Conner and Norman (1996) pointed out, health behaviour researchers have employed social cognition models that have been based on an attributional approach. However, they have been utilised mainly in explaining response to treatment (Conner, 1993) and in particular, their use has focused on people's responses to a range of serious illnesses (e.g., for cancer, Taylor Lichtman & Wood, 1984; for diabetes, Tenner, Affleck, Allen, McGrade, & Ratzan, 1984; for coronary heart disease, Affleck, Tenner, Croog, & Levine, 1987; for renal failure, Witenberg et al., 1983) (Conner & Norman, 1996). The value of an attributional approach in the context of serious illness has, therefore, been recognised.

Before explaining the role of attribution theory as proposed in the present study, it may be helpful to reiterate at a theoretical level, albeit at the risk of being repetitious, why the decision-making theory approach of social cognition models was not adopted. The opportunity is also taken to briefly review another theoretical model that appears to have developed along similar decision-making theory lines but also takes account of social and cultural background. This theory of behavioural diversity (Cohen & Machalek, 1988) is of particular interest as it has been suggested to be a useful basis for understanding the decision to use non-conventional treatments (e.g., Clavarino & Yates, 1996), although, as demonstrated below, the dimensions of the model are of limited usefulness in the context of the present study.

Firstly, with reference to decision-making theory and models that take that approach, these have their roots in expectancy-value theory (Peak, (1955), cited in Conner & Norman, 1996) and particularly in subjective expected utility (SEU) theory (Edwards, 1954) (Conner & Norman, 1996). This approach assumes that individuals make deliberate choices on a rational basis that take account of the volume and probability of the consequences expected from choosing either of the alternatives (Janis, 1989). The methods for decision analysis that have been developed from these theories are difficult to apply to decision making by patients because in maximising the expected utility of the decision they require quantitative estimates of the benefits of the outcomes of each alternative and of their corresponding probabilities (Janis, 1989). In the treatment choice decision making arena there seems to be no theoretical basis or any evidence pointing to such a rational and “mathematical” cost-benefit analysis process such as might be expected, for example, in the business world, where these approaches tend to be particularly applicable. Furthermore, the subjective utility aspect of these approaches is somewhat lost on cancer patients. There is an underlying assumption of the need for efficacious treatment, so ascertaining whether a cancer patient cares about or wants a cure is likely to be of less relevance.

Cohen and Machalek’s (1988) theory of behavioural diversity, which was advanced to explain the selection of specific behaviours, was considered by Clavarino

and Yates (1996) in the context of the decision to use non-conventional treatment. This would see the use of non-conventional therapies as a variation of normal behaviour. That is, a behavioural option “performed by normal individuals in unexceptional social circumstances” (Cohen & Machalek, 1988, p.466). The model is based on four assumptions. The first is that individuals are predisposed to act in terms of their own interests as they perceive them. In the context of illness, self-interest is reflected in the desire to get well or find a cure. Behaviours or strategies are refined or altered until this goal is achieved, which corresponds with the evidence that non-conventional medicine is often turned to after conventional approaches have failed (Clavarino & Yates, 1996). In the present study, however, patients at all stages of the treatment process were surveyed, including those whose decision was to use both conventional and non-conventional treatment, and not just those who believed that their conventional treatment had failed.

Cohen and Machalek’s (1988) second assumption was that behaviours are acquired through social interaction and socialisation processes rather than being of a dispositional nature. This is picking up on the suggestion of Becker (1974) and Fabrega (1974) that symptoms are interpreted subjectively and that the factors influencing response to them include social and cultural background and past experience. Cohen and Machalek (1988), however, argued against decision-making theory, suggesting that instead of rationally calculating advantages and disadvantages of a strategy, people often choose a strategy that has been successful in the past either for themselves or others. Yates et al. (1993), for example, found that those who were encouraged by family or friends to use non-conventional cancer treatments were up to four times more likely to do so than those who were not so encouraged. In the present study the potential influence of cultural and social factors and socialisation processes was seen in terms of moderating effects on the central constructs of control attributions and meaning, rather than as these factors having a direct effect on the decision, as was proposed in studies such as Yates et al. (1993).

Cohen and Machalek’s (1988) third assumption concerned the perceived success of a given strategy based on frequency of use by others and how it compares with the

alternatives. Notwithstanding the way the model tends to avoid the SEU approach, this component comprises elements of that approach in the way that it proposes a weighing up of the potential “success” of the behaviour. For reasons already mentioned, the present study also avoided the SEU approach. Furthermore, perceived efficacy was not explored as a potential determinant.

The fourth component involved the assessment of factors that Cohen and Machalek (1988) considered affected the extent and range of use of the behaviour decided upon. In the context of the present study questions of adherence, continued use, or extent of use of non-conventional treatments were not seen as determinants of the choice, and treatment choice was not conceptualised in terms of extent and range of use.

### **Attribution theory as an underlying theoretical perspective**

In its broadest sense attribution theory deals with how people explain and make sense of the events they experience in their lives (Kelley & Michela, 1980) and provides a framework for explaining people's actions and behaviours associated with these events. It is important to acknowledge, however, that attribution theory is by no means settled. There are no well-accepted assumptions or hypotheses, nor is there a coherent logical network of conclusions about attributional processes (Weary, Stanley, & Harvey, 1989).

Attribution theory assumes that people are likely to look for causes, and to make causal attributions when something untoward occurs in their life (Howitt et al., 1989; Semin & Manstead, 1983). This underlying focus on cause or perceived causation was inherent in the earliest formulations of the theory (e.g., Heider, 1958). Kelley (1967), who contributed to the expansion of attribution theory in the 1960's, saw threat or change in a person's life as provoking a search for causes and reasons in order to understand, control and predict the future of the situation. Situations of high uncertainty have also been found to encourage the search for causal attributions (Turnquist, Harvey, & Andersen, 1988), as has salience of the event for the individual (Weiner, 1986),

particularly for cancer patients (Taylor, Lichtman, & Wood, 1984). The concept of causal attribution comprises a number of dimensions. These dimensions are drawn together to form the particular attributional approach adopted as the theoretical basis of the present study. They include the notion of locus (internal or external), controllability and the attributing of control, and the attribution of responsibility and blame either to self or another. If the search for causes of one's cancer results in self-responsibility or self-blame, this represents the regaining of a sense of personal control (Taylor et al., 1984).

In terms of locus, the question that arises is: Does this illness originate with me or from some external cause? Attribution theory suggests that when faced with an illness situation most people tend to search for an external cause, and when no plausible external attribution is possible, internal dispositional attributions are searched for within themselves (Sensky, 1997). For Heider (1958), locus of causality was either in the person (personal) or in the environment (impersonal), or both. Kelley (1967) introduced the notion of attributions of causality to other people as part of the focus of external locus of causality. The making of attributions to others has been found to be a particularly relevant concept in the context of serious illness (e.g., Turnquist et al., 1988; Tennen & Affleck, 1990) and the potential for this as an external attribution was acknowledged in the theoretical basis of the present study.

Blaming others is a dimension that arises out of the making of an attribution to an external cause. Tennen and Affleck (1990) identified three conditions that are usually necessary for blaming of others to occur in serious situations. These are that someone else is available to blame, that that person is in a position of authority, and thirdly, that the person blamed is not well known to the patient. A distinction must be made, however, between blame and cause (and responsibility) (Tennen & Affleck, 1990; Sensky, 1997; Weary et al., 1989). Sensky (1997) illustrates the difference between cause and blame with the example of the family who blames the surgeon (in whom the three conditions may be fulfilled) for a patient's death, although acknowledges that the surgeon did not directly cause the death. On the other hand, attributing blame or responsibility for a situation presupposes some attempt at attributing causality (Shaver, 1985), demonstrating

that while causation and responsibility and blame are conceptually distinct, they are still related (Weary et al., 1989).

Janoff-Bulman and Lang-Gunn (1988) found that self blame linked back to control as well. It was either behavioural (because of one's actions), which implies controllability, or characterological which is uncontrollable. Health behaviour research involving self blame (an internal attribution) has been less consistent in its findings, however (Sensky, 1997; Christensen et al., 1999). In a sense, the concept of self-blame reveals the distinction between responsibility and blame. Blaming, it is suggested, tends to be a negative attribution whereas attributing responsibility often has a positive connotation. That is, attributing responsibility, in effect, amounts to the individual finding a plausible explanation and regaining control (Sensky, 1997). It also often results in the demonstration of greater motivation in controlling the course of the disease (e.g., Michela & Wood, 1986).

Another way of viewing the distinction between blame and responsibility is in terms of cause and solution of the problem. Blame and responsibility may be attributed to the cause but responsibility is the appropriate attribution for the solution. Typically, in a medical model neither blame for cause nor responsibility for treatment or cure is by the individual to self, whereas it is suggested that in a non-conventional model or a holistic health model both of these attributions are common and frequently encouraged. Nevertheless, as Weary et al. (1989) noted, studies have generally considered the terms 'responsibility' and 'blame' as interchangeable. Concerning the distinction between self blame and attributions of causality, Christensen et al. (1999) found that behaviour-specific self blame predicted health behaviour but a more generalised attribution of causality to one's own actions or behaviour did not. They suggested that patients distinguish between blaming their behaviour in general and blaming a particular action on their part as the cause of their illness.

“The concept of control is a dominant theme in Western culture and a major component of the practice ideology of the health professions” (Lewis, 1987, p.277). In

our postmodern society, where many aspects of life are outside the control of the individual, people are seeking control over their own bodies (Easthope, 1999). Easthope (1999) also commented that “People seek to control their own bodies through jogging, gymnasiums, vitamins, and alternative medicine. Healers give people the ability to manage their own disease by giving them the ability to reconstruct themselves” (p.274). In the context of the understanding and explaining of health behaviour there appears to be a general acceptance of the salience of the construct of control. In the present study this is acknowledged in the way control is seen as underpinning the theoretical basis of the study. Its role in relation to each of the constructs of interest is implicit and often specifically delineated. In the context of a particular health-related behaviour and for the purposes of measurement, however, the particular conceptualisation and focus of control must be distilled.

In the present study control was cast in an attributional theoretical frame rather than approached from a social learning theory perspective. Rotter’s (1954) social learning theory assumes that learning results from being rewarded or punished. For example, if a behaviour resulted in a reward, the associations between the stimulus and the behavioural response would be reinforced (Howitt et al., 1989). Applied to a social situation, social learning theory suggests that people approach their lives and its events according to the rewards and punishments they have received, particularly in childhood (Stainton Rogers, 1991). The health locus of control construct, which is one of the most widely researched and utilised constructs in relation to health behaviour prediction (Wallston, 1992; Norman & Bennett, 1996), can be traced back to Rotter’s (1954) social learning theory wherein Rotter had distinguished between internal and external locus of control beliefs. Internals were seen as believing that events are a consequence of their own actions and so under their control, whereas externals were seen as believing that events are unrelated to their actions and so beyond their personal control (Norman & Bennett, 1996).

The difference between the social learning / locus of control approach and the attributional approach to control is suggested to be as follows. In the former, both internal and external loci are, in a sense, self-focused. Internals focus on self – my actions will

result in attaining the goal, while externals take the negative position – my actions cannot control goal attainment. In the context of health-related behaviour these positions would lead to the following decisions respectively: ‘I will take action since I am in control’ or ‘I will not take action since I am not in control’. This is why the locus of control approach is most applicable in preventative situations where the decision is either to engage in preventative behaviour or not.

In the attribution approach, on the other hand, a distinct and positively focused action is taken by both internals and externals. This approach is applicable in the treatment choice decision context where the decision is not whether to take action or not, but which type of action (treatment) to take. This is posited to work as follows: If an individual attributes responsibility (or blame) for their illness to self, then it may be to self that they will look for responsibility for the cure. If a person owns the cause they will likely want to be part of the remedy. Those who want more control over treatment are likely to look for treatment options that are less authoritarian and more empowering of the individual (Astin, 1998). Non-conventional medicine permits personal autonomy to a greater extent than does conventional medicine. As Lowenberg and Davis (1994) pointed out, non-conventional medicine moves the locus of causality away from impersonal agents back towards the self, returning the responsibility for health and illness and cure to the individual. The internal has attributed control to herself or himself and so takes the treatment option that is congruent with this, whereas the external has vested control in another and so chooses the treatment that permits another to be in control. Furthermore, non-conventional medicine encourages this self-responsibility. It is often a self-prescribed and self administered regimen, whereas the common perception of conventional medicine is that control is vested in the practitioner and the system, frequently resulting in the obeying of "orders".

The original formulation of the health locus of control construct followed the Rotter (1966) internal/external concept of dividing people into those who attribute their health situation to their own behaviour, which is internal control, and those who attribute it to chance (external control). The original Health Locus of Control Scale (Wallston,



Wallston, Kaplan, & Maides, 1976) developed along these lines, produced inconsistent results, however. In a reformulation (the Multidimensional Health Locus of Control Scale (MHLC)), Wallston, Wallston, and De Vellis (1978) included a 'powerful others' dimension. A conceptual difficulty with this instrument, however, is that it imposed what Stainton Rogers (1991) described as the authors' "liberal-humanistic vision of the world" on the conceptualisation of 'powerful others', focusing "exclusively upon the *benign* influence of orthodox medicine and family and friends" (p.170).

The MHLC and the conceptualisation of locus of control that it represents has probably been the most widely used approach to health locus of control, yet discouraging and sometimes paradoxical results have been obtained by numerous researchers, particularly during the 1970's, who explored its relationship with a wide variety of health behaviours (Stainton Rogers, 1991). In terms of the expectations of the authors of the MHLC scale and their conceptualisation of internality and externality, internality would be the best predictor of 'healthy' behaviour. Findings showed, however, that it was frequently the self-motivated internals who were least likely, and the 'fatalistic' externals who were most likely to engage in healthy actions. This expectation of the effects of internal control paralleled what Watson, Greer, Pruyn, and Van Den Borne (1990) described as a consensus that perceptions of personal (internal) control are associated with a good outcome psychologically. Seligman's (1975) learned-helplessness construct, which holds that passivity, helplessness and depression result from learning that events are beyond personal control, supports this expectation. This has been questioned, however, (Wortman & Dunkel-Schetter, 1979) and it remains unclear whether perception of personal control over health is related to a good outcome in either psychological or physical terms (Watson et al., 1990).

Watson et al. (1990) reported on the development of an English version of the Dutch Cancer Locus of Control Scale (Pruyn et al., 1988 cited in Watson et al., 1990). This scale was developed along the lines of the MHLC scale but to be illness specific for use in prediction of illness-related behaviour of cancer patients. Of interest are the factors revealed by Watson et al. (1990) in a principal components analysis. The three factors

were internal control over the cause of illness, internal control over the course of illness and religious control, the latter presumably representing an external approach. This approach represents a broadening of the conceptualisation of externality, compared to the MHLC approach, by incorporating a religious aspect. For the purposes of the present study, it is limiting in another way, however, in that the conceptualisation of externality seems to be limited to a religious approach without accounting for a broader spiritual aspect. Degner and Russell (1988) made a salient point in suggesting that the MHLC scale and its cancer-related version (Dickson, Dodd, Carrieri, & Levenson, 1985) measure expectations about control over the outcomes of treatment and, as such, were not designed to elicit preferences for control over treatment decisions. It is suggested that the Dutch Cancer Locus of Control Scale and its anglicised version, referred to above, also do not account for the difference between control over outcomes of treatment and control as it relates to treatment decisions.

References above to the conceptualisation of 'powerful others' and externality as religious aspects introduces a further difference between the locus of control approach and what is permitted of an attributional approach in terms of the conceptualisation of externality. In the present study externality, operationalised as 'powerful others', incorporated religious and spiritual concepts with references to God and supernatural power. This was effectively incorporating existential concepts in the concept of control, notions that are further developed and addressed below.

### **Control and meaning as separate but related constructs.**

Those who view events in general as contingent upon their own behaviour are making internal attributions of control and will believe that their health status has resulted essentially from their own actions. Those who make external attributions are likely to believe that their health status is due to external forces (Lewis, 1989). This parallels the intrinsic/extrinsic dichotomy which in the present study, it is suggested, characterises the meaning construct where intrinsicness is associated with focusing on self and seeing the

meaning in one's life and its events as being derived from within, and extrinsicness is associated with an outward focus on another agency, usually a powerful other expressed through a spiritual or religious approach to life.

The approach to the concept of control in terms of attribution theory rather than social learning theory is also applicable to meaning. The social learning approach sees health-related behaviour as resulting from learning processes wherein a person learns whether to vest control in themselves or not as a result of rewards and punishments. The derivation of meaning (either intrinsically or extrinsically), however, is conceptualised in the present study as resulting from an individual's philosophical or spiritual approach to life. This may be the result of various developmental influences or experiences, such as religious experiences, but is in the form of a belief system rather than a learned behaviour such as characterises social learning theory. A belief system may have arisen, for example, out of religious instruction during upbringing, or from what Astin (1998) referred to as a "transformational experience that changes a person's worldview". Such a belief system will likely provide an object to which or to whom external attributions, both of a causative nature and in terms of responsibility for treatment and cure, may be made. This object may be God, for example. This, it is suggested, comprises a true external and alternative focal point, rather than being simply the internal focus expressed negatively.

The assertion that the search for meaning among the seriously ill is related to attributions of control, responsibility and blame has been well documented in the literature. Thompson (1991), for example, suggested that part of searching for meaning was the making of various control attributions. These include causal attributions ('what caused this?'), selective incidence attributions ('why me?'), and attributions of responsibility ('am I responsible for this?'). Taylor (1995) confirmed this for cancer patients, suggesting that when a cancer patient questions the meaning of having this illness the first response is typically to query what might have caused it. Causal explanations have usually ranged between God's will, chance, carcinogens and various lifestyle factors such as diet and smoking (Taylor et al., 1984; Gotay, 1985; Berckman & Austin, 1993). The discovery or creation of meaning is an underlying process that can be

seen as providing a framework for explaining an individual's response (attributions) to an event such as a cancer diagnosis. When a person derives or discovers meaning in an event or in their life, they are attributing reasons, causes or responsibility to their own actions, or those of another.

Lewis (1987) argued that control is a complex and multidimensional concept made up of a number of types or categories of control. One of these is existential control, which Lewis (1987) defined as the individual's attribution of meaning and purpose to an event to reduce its perceived threat. Lewis (1987) went on to acknowledge Antonovsky's (1980) sense of coherence concept as an expansion of existential control in which the individual experiences the world as being under control, although not necessarily under their own control. A further extension of existential control referred to by Lewis (1987) was Frankl's (1958, 1962) will to meaning concept wherein the search for meaning and purpose extends to meaning and purpose in life itself. In this approach also, meaning is conceptualised as part of the construct of control.

In the present study the view was taken that meaning, both in life's events and in life itself is sufficiently fundamental as a construct, albeit with strong underlying links to the control construct, to be categorised and explored independently. While in general researchers have theorised, conceptualised and researched meaning without reference to the concept of control (see for example, Reker & Chamberlain, 2000a), there has been specific recognition, in an empirical context, of the relatedness of meaning and control. This has been, however, where the conceptualisation of meaning has recognised Frankl's (1975) notion of "ultimate meaning" and its association with religiousness (e.g., Jackson & Coursey, 1988), as was the case in the present study.

## Meaning

### *Meaning as a construct in health behaviour research*

As Coward (2000) commented, some people with serious illness perceive their situation as being devoid of personal meaning while others in the same situation do perceive meaning in their lives. This does not necessarily mean, however, that both groups have not undertaken a search for meaning. The present study was interested in what constitutes a search for meaning, and indeed, what constitutes meaning itself, and where it is found. On this basis it was posited that for those facing life-threatening situations the search for meaning, however undertaken, will likely assume some importance, and the outcome of this search may influence their health-related behaviour.

In the last two decades or so meaning in life and life's events has emerged as an increasingly important construct in health psychology. This is a somewhat belated development since people have been concerned with elusive questions relating to life's meaning for centuries. Throughout the 20<sup>th</sup> century theorists such as Tillich, Sartre, Jung, Frankl, Koestenbaum, Maddi, Yalom, and others have written extensively on the subject, acknowledging it as a central aspect of human existence. A number of eminent authors have written specifically on psychological theories relating to problems of the meaning in life, including Adler, Fromm, Freud, Jung, Frankl and others.

The importance of meaning and its relation to organic illness has been signalled within the medical profession. For example, Cassell (1982) considered that "Personal meaning is a fundamental dimension of personhood, and there can be no understanding of human illness or suffering without taking it into account" (p. 641). For cancer patients specifically, the first 100 days after diagnosis has been described as a time of existential searching when the patient becomes very concerned with the meaning of life, death and illness (Weisman & Worden, 1976). As Koestenbaum (1976) has pointed out, confronting one's own death is one way of gaining a meaningful conception of life, and

Frankl (1962) made a similar observation. He considered that in confronting one's own death one gains a feeling of meaning, substance and worth.

For health psychology, concern about life's meaning is particularly germane among those facing a serious threat to their health. Research in various areas has demonstrated this. One area is emotional crisis resulting from serious illness (e.g., Cantor, 1978; Simonton, Matthews-Simonton, & Creighton, 1978; Siegel, 1990). The role of meaning in stress and coping with serious illness has also been explored (e.g., Fife, 1994; Fife, 1995; Taylor, et al., 1984), as has the role of meaning in adaptation to serious illness (e.g., O'Connor et al., 1990). In a review of recent studies that examined the relation of meaning in life to mental health Zika and Chamberlain (1992) found a consistent relationship between meaning in life and positive mental health outcomes.

There is room, however, for considerably more research into the role of meaning in health-related behaviour. One justification for this is simply the relative paucity of research into such a "fundamental and essential human process", to use the words of Reker and Chamberlain (2000b). Another arises from the potential for an approach to meaning, as adopted in the present study, which appears not to have been embraced by theorists or researchers in the context of health behaviour. This approach acknowledges that meaning may also be approached from an extrinsic philosophical perspective not just from an intrinsic perspective as has typically been the case.

That there are two quite different theoretical approaches to the concept of meaning has been recognised at a philosophical level (e.g., Yalom, 1980), but researchers appear, in general, to have avoided the distinction between these perspectives. The claim has been that philosophical issues about meaning should be avoided because they inevitably lead to the question "what is the meaning of life?" It is agreed that this is a question that eludes empirical investigation. The research question, however, should never be concerned with which philosophical orientation best explains the meaning of life. What it may be concerned with, is whether people's philosophical orientation influences their behaviour, such as decisions they make regarding their health. The

question then becomes whether different behaviours are associated with different philosophical orientations with respect to life's meaning. It is posited that since these orientations are fundamentally opposed, producing highly divergent conceptualisations and operationalisations of meaning for different people, it is likely that behaviour associated with them, such as crucial health-related behaviour, will also be differentially influenced.

The approach that has mostly been adopted as the framework within which to explore the role of meaning in physical and psychological well-being and in associated behaviours has been the existential view of life and its meaning, in the present study, referred to as intrinsic meaning. This approach has variously been referred to as internal meaning, terrestrial meaning (Yalom, 1980) and derived meaning (Lewis, 1989). It is an approach in which the individual finds, or at least searches for meaning within herself or himself. It is meaning that the individual creates for himself or herself (Tillich, 1952). It encapsulates the belief that we are only what we make ourselves (Sartre, 1956).

The alternative approach sees the individual looking beyond herself or himself to find meaning that exists independently. Meaning of this nature has been described as ultimate (Frankl, 1967), external and cosmic (Yalom, 1980). In this approach life's meaning is seen as pre-existent. Frankl (1962) considered that this meaning is 'out there' to be discovered. He held that meaning must not coincide with being, it must be ahead of being. He said that "man's struggle for his self and his identity is doomed to failure unless it is enacted as dedication and devotion to something beyond his self, to something above his self" (Frankl, 1967, p.82). Frankl's approach was predicated on the notion that life has an ultimate goal, an ultimate meaning. He saw this as transcending the individual to a meaning that is not created *by* the individual but created *for* the individual, and discovered by the individual. Implicit in Frankl's (1967) view that there is a "right" and "true" meaning for every individual that exists apart from the individual's own "closed system", is a religious or spiritual quality. In the present study this orientation is labelled 'extrinsic meaning'.

The fundamental essence of the underlying concept of extrinsic meaning, which, it is suggested, underlies Frankl's self-transcendence and ultimate meaning approach, is difficult to express clearly. One of the issues that Singer (1992) considers as he addresses the question of meaning is the perennial philosophical question about nothingness, or why there is something rather than nothing. He likens this to the problem physicists face when they say that everything began with the 'big bang' but feel compelled to ask what preceded it. Singer (1992) observes that asking what there was before there was anything is a truly meaningless question, yet is a question that affects us powerfully – hovering at the periphery of consciousness. He also comments that "in *some* sense we do understand it" (p.77). The notion of nothingness as a precursor to all at least earthly life and existence, creates a sense of meaninglessness (which conflicts with a sense of knowing that something did exist, at least in a cosmic sense) and produces what Singer (1992) refers to as "ontological anxiety". Frankl would refer to this as "existential vacuum". The concept of extrinsic meaning, it is suggested, concerns this fundamental 'knowing' about ultimate and external ontological 'truth'.

The extrinsic approach in the present study was based on a particular interpretation of the Frankl concept of self-transcendence. Typically, however, Frankl has been interpreted within the boundaries of the intrinsic approach. This has interpreted the discovery of meaning as being from within the parameters of the individual and her or his life experiences. The interpretation of Frankl's discovered meaning adopted in the present study was that meaning exists independently of the individual and her or his life and its experiences. This concurs with Debats' (2000) description of Frankl's concept as meanings being not human creations but as possessing an objective reality of their own, with each situation having one meaning only, which is its true meaning. The potential for difference in interpretation is also exemplified by the language that is typically used. For example, Reker (2000) said that for Frankl, meaning stems from what a person derives from experiences, and from reflecting on negatives such as pain and suffering. These are couched in terms of primary sources of meaning. Debats (2000) on the other hand, described meaning as being "attained through" these activities. This allows these



activities to be viewed more in terms of triggers or the conduits through which meaning flows from another, maybe external, primary source.

In a sense, this is stepping back to a recognition of the fundamental philosophical positions that underlie the distinction between these approaches to meaning. Here, the contrast is between psychologism, which is the view that meanings are mental constructions imposed on the world, and realism, which proposes that meanings are determined by the nature of the world and are independent from the way in which the mind works (Johnson-Laird, 1983). Realism concerns objective ultimate truth and equates with a belief system based extrinsic approach to meaning, while psychologism, which subsumes cognitivism, is a subjective intrinsic approach. Assagioli (1974) uses the terms 'universal self' and 'universal reality' to describe similar concepts.

To avoid confusion, a cautionary note is added concerning terminology. In the present study the terms 'intrinsic' and 'extrinsic' are used as explained above, which is in a similar vein to the use of the terms 'internal' and 'external' in relation to control, but the same terms have been used somewhat differently by various authors. McFadden (2000), for example, with reference to religious orientation, defined extrinsic as self-oriented and intrinsic as self-transcendent. Allport (1966) (referred to below) focused on the utility of religion for the individual and referred to the intrinsic value of faith compared to the 'use' of religion for the self, which he labelled as an extrinsic approach.

### ***Spirituality and religion in the intrinsic/extrinsic paradigm***

In the proposed conceptualisation of meaning, intrinsic orientation equates with the more self-sufficient existential approach to life, while the extrinsic approach equates with an external higher power approach that commonly has a religious basis. There is, however, a danger of over-simplification in this approach. Firstly, both orientations concern spirituality since it is the spiritual component of being that deals with existential questions. Secondly, it is important not to treat extrinsic orientation as entirely

synonymous with religiousness and particularly with Christianity. This is because some with an extrinsic orientation may not acknowledge or conceptualise the higher power as God, and also because within religious belief systems there are differing conceptualisations of the role of God in the individual's life.

In fundamental Christianity, for example, the injunction is to worship and glorify a superior God. Implicit in this is to deglorify the self. In Western society another conceptualisation of God and the individual has arisen, however, sometimes referred to as New Age. Beginnings of the thinking of this movement are recognisable in humanistic psychology and the contributions to this of Abraham Maslow. At the higher level of Maslow's (1954) hierarchy of human needs is his concept of self-actualisation, which culminates in his "peak experience" – an experience of oneness, wholeness and unity with the cosmos. For Maslow, this is a transcendent spiritual experience, the object of which is to achieve a cosmic or divine life force within the self, a concept embraced by many Eastern religious belief systems. This demonstrates that an intrinsic orientation can exist within religious belief systems. Religion per se, therefore, does not necessarily equate with an extrinsic orientation.

Some confusion remains, however, as to what the terms spirituality and religion or religiousness respectively encompass. Mytko and Knight (1999) described religion as participation in religious institutions and adherence to guidelines for belief and behaviour. Jenkins and Pargament (1995) suggested that spirituality, while encompassing religion, includes many beliefs and practices from outside the religious sphere. Potts (1996) defined spirituality as "the awareness and acceptance of a higher power, a causal force beyond the material or rational, that operates in all aspects of existence. Spirit is the higher aspect or essence of the person that links one with God. Spirituality has to do with the search for meaning and purpose in life, for life's ultimate significance" (p.2). He went on to observe that religion provides a framework for the expression of spirituality but acknowledged that spirituality is "more basic than, prior to, and different from traditional expressions of religiosity" (p.2).

Haddon (1997) suggested that spirituality is a more fundamental and enduring component of life than religion is and the two should not be confused. This sees religion more in terms of something that is learned or as resulting from the socialisation process and which may or may not endure as a meaningful element of the individual's life as the learning process progresses, and understanding and views develop. Spirituality, on the other hand, relates more to the essence of being. The fundamental and enduring aspects of spirituality characterise what Bellingham, Cohen, Jones, and Spaniol (1989) described as a feeling of connectedness with the self, the community, nature, and the meaning or purpose of life. Such existential concerns encompass a range of fundamental concepts that do not rely on involvement in organised religion (Mytko & Knight, 1999). In a brief review of literature that has dealt with the relationship between spirituality and religion, McFadden (2000) concluded that spirituality incorporates an element of the divine but does not have the connection with religious beliefs and practices. Of interest is research that has found that those who move away from religion tend to elevate the self instead (Bellah, Madsen, Sullivan, Swidler, & Tipton, 1985, cited by McFadden, 2000).

On the other hand, religion or religious belief is often a major component of spirituality, particularly in the West where Christianity is commonly a major form of expression of spirituality. Ellison (1983) considered that spirituality comprises two interrelated yet distinct aspects - religious and existential well-being. They are interrelated in the sense that religion often arises out of the attempt to deal with existential questions (Batson, Schoenrade, & Ventis, 1993), and religious concerns and experiences often affect central perceptions about oneself, who one is and whether one's life has any ultimate meaning and purpose (Batson et al., 1993).

In considering the role of spirituality and religiousness in the context of the present study, a number of researchers have found that religious concepts tend to enter into many peoples' thinking in serious illness situations and when it comes to questions about death. Newman and Pargament (1990) found, among an undergraduate sample, that the issues most frequently linked to religion involved the death, illness or injury of a family member. Social psychologists have also noted a widespread use of religious

attributions for events such as illness (e.g., Gorsuch & Smith, 1993; Pargament & Hahn, 1986), and Furnham (1994) found that religious beliefs are one of the most powerful predictors of health related behaviours. At a theoretical level, Jung (1938) commented that “religion is incontestably one of the earliest and most universal activities of the human mind” (p.1). This is probably still true for the present day. For example in North American society 95% report believing in God or a Universal Spirit, 87% report that they pray to God, 69% feel that God has guided them in making decisions (Gallup, 1985, 1995; Hoge, 1996), 80% of American adults feel at least “somewhat close” to God most of the time (Davis & Smith, 1986), and 93% identify with a religious group (Kosmin & Lachman, 1993).

***The literature has focussed on an intrinsic approach***

Measures developed to assess life meaning, and studies investigating the construct, tend to favour the intrinsic approach. This is not a criticism of these measures because, as is generally acknowledged, they are measures of existential intrinsically derived meaning. Notwithstanding this, however, one of the commonest measures is Crumbaugh and Maholick’s (1964) Purpose in Life Test (PIL), which the authors suggested was developed to assess life meaning as conceptualised by Frankl (1955, 1958). The implication in the test items, however, is that the more one sees oneself as responsible and in control of one’s life, the greater the degree of positive life regard. This suggests that the PIL may not assess the Frankl concept, which stresses self-transcendence and looking beyond oneself. Furthermore, it measures the degree to which an individual experiences purpose in life, making it a measure of depth or strength of purpose rather than source. It has also been argued, quite cogently, that purpose in life, which the measure actually assesses, is a conceptually different concept from meaning in life (e.g., Yalom, 1980; Battista & Almond, 1973).

The Life Attitude Profile (LAP) (Reker & Peacock, 1981) and particularly the revised version (LAP-R) (Reker, 1992), represent a more recent approach to assessing

life meaning. Despite words used by the authors, which are consistent with an extrinsic approach, it is, arguably, a measure of intrinsic meaning only. Reker and Wong's (1988) view was that people interpret their experiences in life and develop understanding and belief. They said their view is a combination of Frankl's [extrinsic] and Maddi's [intrinsic] conceptualisation of meaning fused with Kelly's (1955) personal construct approach. While Reker and Wong (1988) acknowledged that ultimate meaning can be discovered, they saw this as being discovered in individual experiences, religious and philosophical insights, and possibly a different level of consciousness. This is still an approach in which meaning is derived from within one's own life and being.

Battista and Almond's (1973) conceptualisation of life meaning has frequently been adopted by researchers. They proposed that philosophical models should be avoided, proposing the relativity model, which suggests that commitment to a belief system provides the framework for an individual to develop life meaning, rather than the nature of the belief system. Battista and Almond (1973) developed the Life Regard Index, consisting of two subscales. The 'framework' subscale is concerned with life-view and life-goals or purpose in life, while the 'fulfilment' subscale assesses the degree to which life goals are being fulfilled. This approach also concentrates on individual's experiences rather than on their beliefs. It has been carried through to illness meaning research as well. For example, Fife (1994) conceptualised illness meaning as existing within the field of one's experience and being understood in terms of one's response to those experiences.

Approaches such as the guided autobiography (Birren & Hedlund, 1987) and the life-drawing technique (Whitbourne, 1985) are becoming popular for investigating the development of personal meaning in life. In the former, a personal account is obtained of how a person perceives the course of her or his life, providing information on how the individual interprets and attaches meaning to the experiences of their life. This approach is also focused mainly on the individual's experience of life rather than on a belief system. In the life-drawing technique the way the individual integrates the past, present and future can be profiled, also drawing on experience to formulate meaning. Both

measures, however, can be subject to the researcher's personal approach or orientation and interpretation influenced accordingly.

A personal document approach was used by De Vogler and Ebersole (1980) and Ebersole and DeVogler-Ebersole (1985) to assess types and depth of meaning in life. The personal document provided by the respondent is content-analysed for sources of meaning, but again this is subject to interpretation by the researcher who may not detect or objectively interpret belief systems with which they are unfamiliar. Furthermore, one of the difficulties is that the authors do not provide a conceptual definition of meaning in life, nor is their approach guided by theory (Reker & Wong, 1988).

Reker (1996) developed the Sources of Meaning Profile-Revised (SOMP-R) to measure specific domains of an individual's life from which meaning is derived. Development of the instrument was based on an identification in the literature of the most commonly cited sources of meaning. Conceptually, it was based on the premise that individuals create meaning through the choices they make, the actions they take and the relationships they enter (Reker, 2000). This approach positions the instrument in the intrinsic self-created meaning category, although some qualification of this assertion is necessary. A principal components factor analysis of the SOMP-R items yielded four meaning factors. One of these Reker (2000) refers to as "self-transcendence .. sources that transcend the self, that go beyond self-boundaries to encompass cosmic or ultimate meaning" (p.50). This is a reference to the Frankl approach and suggests an extrinsic approach. It is suggested, however, that this is symptomatic of the differences in interpretation of Frankl's self-transcendence concept as discussed above. Even though Reker (2000) refers to "ultimate meaning", the suggestion is that this is not the conceptualisation of ultimate meaning that forms the basis of the extrinsic orientation in the present study.

O'Connor (1991) and O'Connor and Chamberlain (1996) made a comparison of reported sources of meaning across various studies and summarised them into five categories. These categories were: Relationships with people, creativity, personal

development, religious and spiritual, and social and political. A sixth source, relationship with nature, was added based on the authors' own research. Studies have typically asked participants to report domains of life they experience as meaningful or to rate given domains (O'Connor & Chamberlain, 1996). This intentionally encourages people to focus only on their experiences in life, which may be different from what they believe about life's meaning at a philosophical level. It is suggested that the reason O'Connor and Chamberlain (1996) found assessment of depth of meaning to be problematic among the studies reviewed may have been because this begs the difficult and searching philosophical questions. It is beginning to cross the boundary between what Koestenbaum (1976) referred to as a difference between meaning *in* life and meaning *of* life. Meaning *in* life addresses the individual realm of subjective experience which equates with the existentialist intrinsic orientation. Meaning *of* life requires an objective appraisal of human life and being which necessarily evokes philosophical and spiritual queries. Frequently this approach acknowledges and allows for an external cosmic view of the world. In the studies reviewed by O'Connor and Chamberlain (1996) researchers have typically applied only the more intrinsically oriented life experience approach to the assessment of life's meaning.

### ***Justification for a philosophical approach***

It was noted earlier that, traditionally, there has been a reticence on the part of science to delve into philosophical beliefs, especially religious/spiritual beliefs, on the basis that the nature and context of these belief systems is not the preserve of science. This section provides some justification and some explanations for the interest taken in the present study in the substantive content of differing philosophical orientations to life's meaning.

There are a number of justifications of both a structural and conceptual nature. The first is that the study focused on the distinction between two belief systems. Distinctions between belief systems can be empirically investigated by categorising people according to the nature of their belief system (e.g., intrinsic or extrinsic orientation) and observing

any behavioural differences. This is not assessing the merits of a given belief system or making a comparison of the merits of different beliefs. Neither is it attempting to answer philosophical questions raised by the substance of the belief. The study was not, therefore, interested in the answer to the question 'what is the meaning of life?'

A second justification is that to base an investigation of the question 'what is the nature of an individual's experience of life as meaningful' on the presumption that there is no externally focused and no ultimate meaning of life and its events because these cannot be empirically defined, is potentially placing a restriction on the research process. It has the effect of excluding the potential influence of a reasonably common alternative belief system which many people live by, and which likely influences their behaviour.

Thirdly, there is an appropriate theoretical and conceptual basis upon which the influence of an extrinsic orientation may be investigated. This is found in Frankl's (1958) insistence that meaning in life represents a basic human motivating force best described as spiritual. Frankl (1954) stated that "Man lives in three dimensions: the somatic, the mental and the spiritual. The spiritual dimension cannot be ignored, for it is what makes us human" (p.xvi). The suggested fundamental nature of the belief based spiritual dimension in itself justifies its inclusion in an exploration of meaning in life.

Many theorists and researchers have unquestioningly adopted the intrinsic existentialist perspective on life meaning. Others have sidestepped the investigation of alternative sources of meaning, possibly to avoid the philosophical issues. Both of these strategies, it could be argued, amount to avoiding recognition of the extrinsic orientation. It has also been suggested that these strategies are attempts to avoid the substantive philosophical questions getting in the way of empirical research (e.g., Debats, Drost, & Hansen, 1995). They may also be a reflection of a personal belief system, on the part of the researchers, resulting in a bias against the non-existential extrinsic approach. This bias is possibly fuelled by a reticence to acknowledge and delve into matters spiritual, notwithstanding that, as Frankl (1958) pointed out, this is the domain of life into which the fundamental search for meaning fits. Spirituality, therefore, seems to have been



sidelined as a potentially important component in the understanding of health-related behaviour.

The apparent aversion to questions of spirituality by researchers in medicine and psychology may be due to a perception that spirituality equates with religion. This may have contributed to what Jenkins and Pargament (1995) described as “ tensions between the religious and spiritual world and the worlds of psychological research and practice” (p.53). Making matters worse is that those who work in fields such as psychology evidence a noticeably secular background (Larson et al., 1986; Sarason, 1993) which will also likely increase sensitivity in this area. In a survey of APA membership, for example, 43% believed in God (Larson et al., 1986) compared to 95% of the American general public (Gallup, 1995).

An inevitable associating of extrinsic meaning with religion may be unfortunate in the sense that this has probably contributed to the avoidance by researchers of this approach to meaning. This is demonstrated and perpetuated by writers such as Baird (1985). He acknowledged that meaning can be viewed in an ultimate context but saw this as a “theological challenge” as if it was not relevant to psychology. Being a so-called theological concept does not invalidate its relevance to the human condition, nor should it justify its being segregated in some way from main stream psychology.

It is suggested that spiritual and religious beliefs should be recognised as beliefs that are frequently a pervasive and major influence in many lives, and that disagreement with peoples’ belief systems does not justify ignoring that component of their lives as a potential determinant of their behaviour. Potts (1998) has drawn together some reasons why psychology should address these issues. They are: The importance of religious and spiritual issues in the lives of people generally (Bergin & Jensen, 1990) and medical patients particularly (Saudia, Kinney, Brown, & Young-Ward, 1991); the findings of research demonstrating the beneficial effects of religion and spirituality on the emotional well-being of patients (Harris et al., 1995); and the beneficial impact of religious practices on medical outcome (Matthews, Larson, & Barry, 1995, cited by Potts, 1998).

Studies that have investigated the influence of religion have tended to avoid a critical component – the fact that religion is a belief based construct. It has typically been approached as a set of observable religious activities with the claim that this is the only way it can be empirically investigated. One is religious if one regularly attends church for example, instead of a religious person being one who holds certain beliefs about God. Content of belief may, however, be usefully investigated empirically by exploring whether and how different belief systems are associated with different behaviours. This is not to inquire into the appropriateness or the rightness or wrongness of any belief system, but it is a departure from the view that only an exploration of the process of belief rather than its content is possible in an empirical context. Most psychologists of religion agree that religiousness does in fact involve a combination of cognition, emotion, and action, although typically one or another of these elements is emphasised (Wulff, 1995), frequently the latter. It is suggested that the cognitive element should be the one emphasised. It is this element that encompasses knowledge and understanding, faith, religious experience, and religious attitude and belief. What individuals believe about the role in their life of God or some other universal higher power, rather than how they demonstrate that belief system, is more likely to influence their understanding of life's meaning and their behaviour in relation to that. Interestingly, it is the cognitive aspect of belief that defines the orientation in terms of intrinsicness or extrinsicness. For example, Sampson (1981) criticises cognitivism for its taking a relativistic approach in denying a reality or an ultimate truth, giving precedence instead to the individual's subjective knowledge and to subjective determinants of behaviour.

Allport's (1966) concepts of intrinsicness and extrinsicness have perhaps had a greater impact on the empirical study of the psychology of religion than any other approach to religiousness (Donahue, 1985) and have provided the impetus and basis for many subsequent studies. For this reason they are briefly reviewed. Allport recognised a distinction between these orientations, but saw them as ways of describing the use or object of religion for the individual. In his intrinsic approach faith is regarded as a supreme value in its own right. Extrinsic orientation, which Allport (1966) considered

predominates among churchgoers, suggests a utilitarian type of religion which is useful for the self, providing social standing, comfort, security and endorsement of one's chosen way of life. There are two problems with this approach nowadays, however. One is that religion is less likely to be approached or viewed by its adherents in an activity based behavioural sense. It is more generally accepted for what it is in essence, namely a cognitive, belief based construct that should be assessed in a cognitive rather than a behavioural frame. The second problem is that nowadays religion is less likely to be viewed as a self-serving end. Appearance at church, for example, no longer enhances social standing.

Clearly, in the present study the intrinsic and extrinsic terminology is used in a different sense. Allport (1966) did acknowledge, however, a distinction between a self-focused orientation in life and an approach which "strives to transcend self-centred needs", and observed that this latter type of religious sentiment "floods the whole life with motivation and meaning" (p.455). These seem to be observations that do not find their way into his formal conceptualisation of intrinsic and extrinsic orientations, however.

Finally, a problem is that for psychologists to undertake research in the spiritual area has long been perceived as inviting 'professional death', particularly when religious aspects arise. This is no longer the case, however (Levin, 1994). As Schiller and Levin (1988) point out, researchers should recognise that there have been hundreds of empirical studies with religious type variables in epidemiology, health services research, gerontology, biomedicine and behavioural science. Furthermore, key figures such as James, Freud, Jung, Maslow and Allport, among others, have all referred to religion as a force influencing health and well-being, and deserving of careful scrutiny (Vanderpool & Levin, 1990). It has also been suggested that failure by health professionals to consider and respect patients' religious and spiritual beliefs might be unethical or even negligent (Post, cited by Marwick, 1995).

Just as many in medicine have acknowledged the need to move away from Cartesian dualism towards a biopsychosocial approach as expounded by Engel (1977), so too, it is suggested, should a spiritual component be recognised. As McKee and Zenan (1994) have observed: “The reductionist view of the traditional biomedical model has come up sorely lacking and the medical profession is pleading for a broader, more encompassing model of health care to include a biopsychosocial-spiritual model” (p.570). In the same way that health psychology has embraced the biopsychosocial model, so too, it is suggested, should it embrace the biopsychosocial-spiritual model. This must necessarily be accompanied by a recognition of the integral part religious belief plays for many people within the wider concept of spirituality.

### ***Meaning and treatment choice***

The postulated relationship between meaning and treatment choice also centres around the distinction between intrinsic and extrinsic meaning. Essentially, the expectation was that an intrinsic approach to meaning in life and life’s events would be associated with the use of non-conventional medicine as part of the treatment approach, and an extrinsic approach would be associated with a preference for conventional medicine.

The theoretical basis for the relationship between intrinsic orientation and non-conventional use relates mainly to the congruence between intrinsicness and the philosophical and methodological bases of non-conventional medicine. An intrinsic orientation, being an inward focused approach, sees a person look within themselves for meanings. As they do this they see themselves as part of the natural world, and it is in this context that they view causes and remedies and their own role, where blame is linked to causes and responsibility is linked to remedying the problem. Helman (1992), in a medical anthropology context, identified this process when he said “Many patients have an unfulfilled sense of wanting to be connected ..... to locate their suffering in a wider framework – even to somehow contain *within themselves* the many cycles of nature”

(p.12) (emphasis added). Herein lies the philosophical congruence with non-conventional medicine, which is perceived to be fundamentally aligned with the natural world and as championing the notion that the body contains within itself the ability to ward off and cure disease.

The methodology and delivery methods of non-conventional medicine facilitate these connections. Helman (1992) went on to say that “Complementary practitioners often help people “make sense” of their situation in a more meaningful way than does medicine, often utilizing more traditional models of dealing with human misfortune ..... to explain to the patient why they have been affected by that particular illness at that particular time” (p.12). An important aspect of the approach usually adopted by non-conventional medicine is the partnership approach wherein the patient feels an integral part and in control of the treatment process. These feelings are engendered by the provision of explanations of the aetiology of the disease, its effect on the body, and treatment mechanisms, often provided within an unrushed and empathetic environment. In the world of conventional medicine, on the other hand, time is short and expensive. Information about the disease and its treatment in the biomedical context is complex and not easily understood by the lay person, and the approach adopted by the health professionals is often perceived to be one of taking away control and involvement from the patient, other than as a recipient of procedures imposed and performed on them.

The theoretical underpinnings of the notion that an extrinsic orientation is likely to be associated with a preference for conventional medicine are derived from the essentially religious or spiritual nature of this approach. Those who have a religious belief system are familiar with the concept of placing their faith in another and for many this is done unquestioningly. This may amount to a preparedness to relinquish control to a powerful other which, arguably, is what is required by conventional medicine, at least in the context of treating a complex and life-threatening illness. Research has provided some understanding of the psychological mechanisms underlying this relationship between extrinsicness and the tendency to require less personal control. (e.g., Pargament, Sullivan, Tyler, & Steele, 1982).

For those whose approach to life is comprised within a religious frame, the perception will often be that God is somehow involved in, if not responsible for the individual's plight. On the face of it this is an external attribution. This is often linked back, however, to self-responsibility via feelings of guilt and punishment for something the person has done (Cella, Mahon, & Donovan, 1990). The attribution is an external one, but the underlying reasoning may be internally oriented. One explanation for this may be, as Jenkins and Pargament (1988) found, that people submit to an external force in order to gain a sense of control. In this sense, the fact of control, that is that someone or some agency is in control, is what is important rather than the locus of that control.

## CHAPTER FIVE

### A COGNITIVE APPROACH TO UNDERSTANDING TREATMENT CHOICE

Studies that have explored the question of who uses non-conventional medicine and why, from a socio-demographic standpoint, were briefly reviewed in chapter two. In chapter three a cognitive approach to understanding health behaviour in general was defended, but it was suggested that existing social cognition models are somewhat restrictive as bases from which to explore some of the cognitions that cancer patients are likely to experience. Chapter four explained the theoretical basis of the cognitive approach adopted in this study, in contrast to the typical social cognition model approach. The present chapter introduces treatment choice and the cognitive constructs and variables of interest in the study. In conjunction with this it reviews studies that have specifically investigated cognitive influences on treatment choice, with particular emphasis on those that have included cognitive variables similar to those investigated in the present study. It also places the approach to treatment choice adopted in this study in context with treatment choice conceptualisations in previous research.

#### **The beginnings of a cognitive approach to understanding treatment choice**

Some previous studies have been essentially socio-demographic in nature but have contained cognitive elements as well. In some of these, cognitive influences have emerged unsolicited among self-reported reasons for treatment decisions. These responses have generally centred around treatment efficacy and delivery issues (e.g., Moore et al., 1985; Sharma, 1990; Bernstein & Shuval, 1997; Himmel et al., 1993). Other studies have specifically addressed these issues. For example, Sutherland and Verhoef (1994) investigated, inter alia, scepticism toward medicine and satisfaction with health care among patients attending a gastroenterology clinic. Verhoef et al. (1999)

found that delivery issues, specifically the wish for patient-focused treatment, were a common motivation for the use of non-conventional treatments among malignant brain tumour patients. Murray and Shepherd (1993) interviewed 20 patients from a general practice to explore reasons for using non-conventional treatments. Their findings centred around treatment efficacy, negative perceptions of conventional medicine and delivery issues in terms of time and attention given to the patient. Patients perceiving themselves as unconventional, and lack of confidence in conventional treatments were found by McGregor and Peay (1996) to be the variables that best distinguished users of non-conventional from users of conventional treatment. Kelvinson and Payne (1993) found that patients attending a non-conventional clinic had less favourable attitudes to conventional medicine and its practitioners than those attending a conventional pain clinic. Neither group felt that treatment was effective however.

Vincent and Furnham (1996) took a slightly different approach. In that study only users of non-conventional treatments (acupuncture, osteopathy and homoeopathy) were surveyed on a range of descriptive and cognitive variables. The most strongly endorsed reasons concerned the holistic approach of non-conventional medicine, the relative effectiveness of the two modalities, and the ability to be actively involved in maintaining one's own health, the latter being of interest in the present study. While the study was able to rate 20 potential reasons for seeking non-conventional treatment among users of the three treatments, it was not comparing users of non-conventional with users of conventional treatment.

Studies like the above have taken essentially descriptive variables and given them a cognitive content by exploring the way people think about and evaluate them. Other studies, however, have explored variables that are cognitions in themselves. These studies, or at least the cognitive components of them, are relevant to the present study and are reviewed below.



## **Cognitions as treatment choice determinants**

The question of choice of treatment between conventional and non-conventional has only recently been explored in terms of cognitive determinants, and there remains a surprising paucity of studies in this area (Furnham & Forey, 1994). Of the studies that have been undertaken, many have been conducted by Adrian Furnham and colleagues. The social cognition model approach has been common among studies exploring the influence of cognitions on health behaviours, but appears not to have been employed as the basis in research exploring the cognitive determinants of treatment choice. Treatment choice studies have tended to explore various collections of potentially influencing variables usually without providing any underlying theoretical framework as a template for further research. Yates et al. (1993), for example, explored beliefs about cancer and its treatment, need for control over treatment decisions, will to live, and encouragement to use non-conventional treatments. Furnham and Smith (1988) included health locus of control, beliefs about susceptibility to illness, resistance to disease, and efficacy of treatment. Furnham and Bhagrath (1993) added health consciousness, perceived health risks, and general health beliefs. Furnham and Forey (1994) included beliefs on the role of the mind and the body and general health knowledge, and Furnham (1994) looked at individual's perceptions of health and recovery from illness. Astin (1998) investigated the influence of treatment satisfaction, need for personal control, and philosophical congruence and Kelvinson and Payne (1993) included health locus of control, the value placed on health, and comparison of frequency and severity of illness with others.

The present study similarly explored a collection of variables postulated to be influential in the treatment decisions of cancer patients. The constructs explored were knowledge and understanding of cancer, approach to health, attributions of control, responsibility and blame, and meaning. The rationale underlying the choice of constructs and their component variables, explored in this study, included two aspects. The first concerned how being the "victim" of a life-threatening illness evokes certain responses, many of a cognitive nature. Responses that have been found, or explored on the assumption of being associated with the diagnosis of such an illness, include knowledge seeking and

accumulation (Sutherland et al., 1989; Loehrer, 1993); taking an interest in and seeking involvement in one's health (e.g., Furnham & Bhagrath, 1993; Furnham & Forey, 1994; Vincent & Furnham, 1996; Furnham & Kirkcaldy, 1996); the taking or giving up of control over one's life or situation (Coward, 2000); and the perception that one's life and life's situation is either meaningful or devoid of meaning (Coward, 2000).

Coward (2000), however, like the present study, was specifically interested in life-threatening illness and the human responses to this crisis situation. While her research programme was reported after the present study was undertaken, it nevertheless provides some theoretical and empirical support for the particular set of constructs explored in the present study. It demonstrates also the way in which these constructs may be expected, and have been found to combine conceptually as a way of understanding and explaining the "cognitive restructuring processes" experienced by those facing life-threatening illness.

Coward (2000) identified three potential crisis points of the serious illness experience. In one sense, in the present study all three crisis points (diagnosis, completion of active treatment, and recurrence of disease) are represented across the sample. In another sense, however, the post diagnosis phase pervades the whole experience and it is this phase that is common across the sample. In a temporal sense also, treatment decisions typically are made as a response to diagnosis. Coward (2000) identified the post diagnosis phase responses as firstly, an affective response of feeling alone and isolated, followed by a desire to reach out for support and information (knowledge) in the form of a need to educate oneself about one's disease and treatment options. This, according to Coward (2000), is associated with the next response – a feeling of having lost control, the regaining of which may be assisted by assigning an attribution for why one has this illness. The suggestion is that assigning an attribution may help people believe they are able to do something about their illness. Coward (2000) also suggests that for most a fear of dying is present to some degree after diagnosis. She suggests that "pivotal life events, such as the diagnosis, treatment, and progression of life-threatening disease, may lead to cognitive restructuring processes within the individual" (p.160), part of this being that

during these crisis periods meanings are discovered or intentionally created. In the present study the question of death similarly is embedded and addressed within the concept of meaning.

The second aspect of the rationale concerned the response to having a life-threatening illness in health-related behaviour terms and, in particular, in terms of making a choice about treatment. In this context, the four constructs explored in the present study were seen as a set of cognitions, which potentially for some, had conceptual links with the philosophical basis of non-conventional medicine and its attractiveness. The expectation was that this potential relationship between certain cognitive responses and the use of non-conventional medicine may discriminate between users of conventional and non-conventional medicine in terms of these cognitions.

An important aspect of non-conventional medicine is the role of the self, operationalised as the patient wanting and being encouraged to be actively rather than passively involved in the treatment process. Because it mostly operates outside the traditional point of contact with the world of medicine, involvement with non-conventional medicine requires a purposeful effort and commitment to engage with it.

Arguably, this engagement process would necessarily include the accumulation of knowledge about cancer and its treatment. Even in a more general sense, as Kolbe et al (1981) pointed out, knowledge is a predisposing factor that influences a person's health behaviour. Of interest in the present study was whether the need to reach out for knowledge, identified by Coward (2000), is associated with type of treatment chosen. As Coward (2000) pointed out, decisions are made through obtaining information about the disease and treatments.

The expectation that an active and committed personal involvement characterises the use of non-conventional medicine use to a greater extent than conventional medicine underlies the approach to health construct. Conceptually it is linked to the accumulation of knowledge through health interest and motivation to be involved. It is also linked to

the control construct as a component of the concept of personal autonomy in the treatment process. Taking an interest and being personally involved in one's health is potentially a practical outworking of one's own belief system and understanding of medical things as well as that of non-conventional health practitioners. Non-professionally qualified people's everyday theories in medicine have been shown to differ considerably from theories taught in conventional medicine (Herzlich, 1979; Helman, 1984). An individual's approach to health that sees them seeking a degree of personal involvement, autonomy, and freedom to follow their own beliefs and theories about medicine may result in their being attracted to the world of non-conventional medicine.

It is arguable that making the conscious decision to vest control in another, such as a doctor, amounts to the same as deciding to retain control oneself. In a sense both situations amount to having control. At the behavioural response level, however, the positive step of actively retaining or regaining control may differentiate people in terms of their health related behaviour from those who take the negative, albeit conscious, step of giving control away. Choosing to use non-conventional medicine as a behavioural response to a life-threatening illness represents a relatively achievable means of maintaining some control over their care. While the conventional medical profession is increasingly facilitating patient involvement in decision making, arguably there lingers a perception among health consumers of control by the medical profession. Both the nature of non-conventional medicine and the way it is promoted by practitioners and proponents facilitates the retention of personal control over one's health and therefore one's life. Furthermore, at the disease level, the underlying philosophy and the methodology of non-conventional medicine is not so much about controlling symptoms in a coercive way but about addressing the underlying problem(s) causing the symptoms (Furnham & Smith, 1988). This in itself would tend to involve the individual and return some control to them as they address the likes of their own lifestyle and other health-related behaviours.

The rationale for including the meaning construct in the set of constructs was addressed in the previous chapter (see "Meaning and treatment choice"). Similarly, the relationship between the meaning and control constructs and their respective roles in the

combination of constructs was addressed in that chapter (see "Control and meaning as separate but related constructs").

The studies reviewed in the remainder of this chapter are organised around the constructs referred to above. Firstly, however, the conceptualisation of treatment choice in the present study, compared to previous research, is addressed.

### *Treatment choice*

There are two elements involved in the conceptualisation of the treatment choice variable. One concerns treatment, namely, what comprised conventional treatment compared to what was categorised as non-conventional treatment. The other element concerns choice – what constitutes making a choice.

With reference first to treatment, this was classified as conventional if it consisted of surgery, radiation therapy or chemotherapy. All other treatments or therapies were classified as non-conventional. This is a reasonably common approach to categorising conventional and non-conventional medicine in research exploring the use of the two modalities. It is recognising the traditional boundary as promulgated by biomedicine. For example, Eisenberg et al.'s (1993) rationale for this approach to classification was that non-conventional represents interventions that are neither taught widely in US medical schools nor generally available in US hospitals. Vincent and Furnham (1996) commented that such a classification system captures 'treatments' such as exercise and relaxation techniques which are "hardly unconventional" although, by definition, they can be labelled 'non-conventional'.

While the traditional classification of treatments, as outlined above, was accepted, participants were not simply divided into two groups – one of conventional users and another of non-conventional users, an approach that some previous studies have taken. There is a methodological weakness inherent in this approach, namely that, in reality, few tend to abandon conventional medicine totally (Thomas et al., 1991; Eisenberg et al.,

1993). Furthermore, selecting participants from conventional and non-conventional clinics and hospitals, as some researchers have done, and classifying them as conventional and non-conventional users respectively, is unlikely to produce independent groups (Furnham & Beard, 1995). Attendance at a non-conventional clinic or usage of non-conventional treatment does not evidence exclusive use of that modality even for a particular illness.

Another aspect of the conceptualisation of treatment in the present study was that non-conventional treatments were further classified according to how non-conventional, or how far removed from conventional they were. This enabled the arbitrary dichotomy between conventional and non-conventional medicine, which has characterised previous research, to be conceptualised in terms of a continuum.

On one hand, therefore, this approach to treatment classification enabled analysis in terms of the traditional split between conventional and non-conventional treatments as previous research has done. On the other hand, however, avoiding a dichotomy between conventional and non-conventional medicine along traditional lines may more accurately reflect the patient's perspective. It is likely that patients' classifications of what is conventional and what is not may differ from the traditional view. The dividing line may in fact be blurred. For example, chiropractic and acupuncture are now viewed by many (including many in the conventional medicine world) as conventional and as Astin (1998) suggested, certain non-conventional treatments may be deemed not to be non-conventional when used to treat particular problems on the basis that they are practices that are already part of standard medical care and recommendations. Conceptually at least, this view of non-conventional medicine as spanning a spectrum from least to most non-conventional has been recognised in the literature (e.g., Eisenberg et al., 1998; Owens, Taylor, & Degood, 1999).

The theoretical basis of the categorising of non-conventional treatments was centred around a distinction between physical and natural types of treatment on one hand and those that have a psychological or particularly a metaphysical element on the other

hand. Fuller (1989) suggested that those who use what is generally characterised as non-conventional medicine are not just those who are so desperate they will try anything or those who are educationally disenfranchised from scientific knowledge. He contended that the popularity of non-conventional medicine is just as attributable to the “articulation of a religiously significant way of viewing the world” (p.7). The separation of religion and medicine, which followed the rise of scientific medicine, meant that a major spiritual aspect of life, which had always found its outworking in the health arena, was relegated to the fringes of medicine. Caught up in this, however, were healing methods that were not necessarily of spiritual origin or basis. These were various physical and natural methods that, like scientific medicine, act in a physical way on basic metabolic processes. Others do, however, involve what Fuller (1989) referred to as supernaturalistic beliefs and methods and extrasomatic energies. These may well be appropriately characterised as clearly being beyond conventional medicine.

The treatment grouping approach in the present study recognised the potential for a ranking type of approach to classification. This resulted in physical and natural types of non-conventional medicine being characterised as less non-conventional, in the context of cancer treatment, than psychological and metaphysical types. This is not to make a judgement about these methods but rather it is suggesting that both biomedicine practitioners and lay people tend to see physical and natural therapies as less removed from conventional medicine than psychological (with the exception of hypnosis) and particularly metaphysical approaches (Furnham, 1993; Bernstein & Shuval, 1997; Wharton & Lewith, 1986; Furnham, 2000; Claravino & Yates, 1996)

A further aspect of the conceptualisation of treatment in the present study was that non-conventional treatment potentially included any non-conventional treatment. By contrast, previous research in this area has often effectively limited the operationalisation of non-conventional treatment to one treatment, or a small subset only (e.g., Furnham & Bhagrath, 1993; Furnham & Smith, 1988; Furnham & Beard, 1995; McGregor & Peay, 1996). For some this is likely a consequence of selecting study participants from among attendees at a particular hospital or clinic where a limited range of therapies is practiced.

In the present study, participants were volunteers from the general population of cancer patients who were then asked to disclose which non-conventional treatments they had or were using. Participant selection procedures, therefore, did not place any restrictions on respondents in terms of treatment type. This potential for variability in terms of treatments used was important to the study, as the study explored whether different cognitions were associated with different non-conventional treatments or groups of treatments

A brief overview, with some explanation, as follows, of the way in which treatment classification and grouping was operationalised, will complement the foregoing description of the conceptualisation of treatment. Previous authors have grouped or classified non-conventional treatments in diverse ways, suggesting that there is no standardised approach to their classification. For example, Murray and Shepherd's (1993) four categories (physical, herbal and natural, talking, and self-improvement methods) were treatment focused. Claravino and Yates (1996) noted, on the other hand, that they are sometimes classified according to the source they are derived from which include ethnic and folk traditions, religious or semi-religious cults, philosophical and metaphysical movements, or as a competitive response to conventional medicine.

Participants in the present study were asked to indicate from a list which treatment(s) they had used or were using for their cancer. The list included three conventional and fifty non-conventional treatments to which participants were able to add. Two classification schemes were implemented. One classified participants into two groups - one as those who used only conventional treatments and the other as those who used non-conventional medicine either in addition to or instead of conventional medicine. The other scheme avoided this traditional dichotomy between conventional and non-conventional, and created four groupings of treatment. The first was conventional treatment and the second was conventional treatment with the addition of prayer. The third grouping comprised physical, and natural and nutritional non-conventional treatments. The fourth incorporated psychological and psychic and metaphysical non-conventional treatments. The third and fourth groupings respectively were considered to



be progressively more removed from conventional treatments according to their conceptual and philosophical bases.

On the face of it the second grouping appears not dissimilar from the first. The rationale for a grouping which differed only by the inclusion of prayer, however, was that prayer was not classified as a non-conventional treatment, but it is a strategy often used by seriously ill individuals as part of their treatment approach. As Bearon and Koenig (1990) suggest, prayer may be used in a complementary role to medical care. Another reason for the separate grouping based on prayer was to provide for a potential difference between religious and spiritual approaches. Perhaps prayer would be associated with a religious approach but not a spiritual approach. There was a suspicion that, even though religion is an expression of spirituality, the difference between spirituality with and without religiousness may differentiate between conventional and non-conventional medicine use.

Conceptualisation of choice, as the second element of the treatment choice variable, fundamentally concerns the question of what constitutes a choice. A number of considerations arise in relation to this. Firstly, a traditional assumption has been that those with distressing symptoms at least, will automatically turn to conventional medicine. This assumption has been challenged, however, on the basis that choice of treatment is often influenced by the particular complaint that is suffered from as much as the patient's health-related belief system (Furnham & Bhagrath, 1993). For cancer patients, however, it is suggested that the choice about treatment will likely have more to do with the context in which actual diagnosis is made, which is usually within the conventional medicine system. A formal diagnosis of cancer is unlikely to be made within the non-conventional medicine system, and non-conventional practitioners are unlikely to initiate treatment exclusively. Therefore, treatment is likely to be initiated within conventional medicine. This means that the choice to use non-conventional medicine is likely to be a choice about whether to add non-conventional medicine to an existing conventional regimen. This was recognised in the present study with choice of treatment being conceptualised in terms of using either just conventional or conventional

plus non-conventional, although provision was made for any who may have reported using only non-conventional.

A second consideration concerned the point at which a choice was deemed to have been made. This was operationalised as respondents having used a named non-conventional treatment(s) for their cancer as distinct from simply acknowledging its efficacy, investigating and condoning it, or even having made a decision to use it at some future time. Having acted on the decision to use non-conventional medicine was considered important, an issue which previous research has typically addressed by recruiting participants from clinics or practitioners of non-conventional medicine.

Thirdly, choice of non-conventional was not defined in terms of the number of non-conventional treatments used or the frequency of their use. The cognitions of interest in the present study are relevant in the context of an executed decision to use non-conventional medicine. Number of therapies used and frequency of use raise different questions that were not under investigation in the present study. For example, frequency of use may indicate strength of the decision, but would also likely be a function of other influences such as continued availability of a given therapy, economic factors, disease progression and perceived efficacy. Also, there was potential in the present study for a wide variety of non-conventional treatment types some of which would require ongoing use while others may not. Furthermore, a decision to discontinue a non-conventional treatment regimen at a particular, albeit early point, would not in some way invalidate the original choice or detract from its meaningfulness.

Another element considered in the conceptualisation of choice was the possibility that non-conventional medicine is chosen when all else has failed. That is, that it is not so much a rational choice about whether or not to include this treatment modality, but rather a form of automatic progression to the next phase of dealing with the disease. This may be the route taken for some, but it introduces a modified research question and some measurement issues. For example, a standardised operational definition of the point at

which all else had failed may be elusive and there would likely be ethical issues associated with such an enquiry.

### ***Knowledge and understanding of cancer***

Knowledge has not commonly featured in illness cognition or health belief models, but Becker and Rosenstock (1984) did add 'knowledge of the disease' as a supplementary factor in the HBM. Nevertheless, knowledge has been included in research investigating the cognitive determinants of various health related behaviours (e.g., Champion, 1987; Loehrer, 1993). In the present study knowledge was assessed on two dimensions. One was objective information based knowledge. People know about health matters because of the increased availability of health information (some valid, some dubious) in the everyday media and through interaction with others as members of a health conscious society. The media has served to demystify many health issues including some about medicine and its practitioners. The level of knowledge disseminated in the community, both commercially driven and acquired through media attention to health matters, has meant that knowledge and understanding of cancer is no longer necessarily linked to the subjective experience of the disease.

Some knowledge would be accumulated through the experience of the disease, however, and the second knowledge variable acknowledges this. This is a more subjective understanding of 'my cancer'. It is a form of knowledge that could be described as beliefs about the effect on the individual's life of having cancer. There are no right or wrong beliefs, but they can be expressed either positively or negatively.

The precise nature of the relationship between cancer knowledge and health-related behaviour appears to be unknown (Stone & Siegel, 1986), although, there is evidence to suggest a link (Stone & Siegel, 1986; Vaeth, 1993; Loehrer, 1993). Since no theory as to the mechanisms or processes involved in the influence of knowledge on health behaviour decisions has been tested or offered, the expectation that knowledge has

a role in treatment choice decision making is essentially at an intuitive level. Intuitively, knowledge of the domain is an important ingredient in any decision-making. More specifically, knowledge about the body, and a given disease, would mould the thoughts a person has about their disease, what it is doing to their body, and what the future is likely to hold. There is ample evidence that knowledge of the domain is beneficial to sound decision-making, and specifically in the area of health-related decision making (e.g., Haug & Lavin, 1981).

In the area of health-related decision-making there are two possibilities. One is that knowledge itself can contribute to the anxiety and other emotive aspects of having a serious illness, so it is not pursued or wanted. The other is that knowledge does not necessarily contribute to the “right” decision because what is the right decision may be subjective and is often elusive. Decisions about treatment are still made, however, against the backdrop of varying levels and accuracy of knowledge. The expectation in this study was that actual level and accuracy of knowledge and whether knowledge was negatively or positively framed, would be associated with the type of treatment sought. Some ways in which knowledge may influence the decision are addressed below in relation to various research approaches.

As Northouse and Northouse (1987) noted, few studies have investigated the relationship between cancer knowledge and care seeking behaviour generally. In a study among socio-economically disadvantaged cancer patients Loehrer (1993) concluded that knowledge deficits and improper beliefs about cancer and its treatment are likely to lead to inappropriate decisions in the area of health care behaviour. The author gave as examples of this a patient with operable cancer refusing surgery because of the belief that exposure to air spreads the cancer, and another patient discarding proven conventional treatment in favour of non-conventional treatment. Loehrer (1993) did not, however, offer an explanation of the link between knowledge and behaviour other than to say that inappropriate decisions are a logical consequence of inaccurate knowledge.

In prevention research, however, knowledge about cancer has been shown to be an important variable. Champion (1987), for example, found that knowledge was related to frequency of breast self-examination. This suggests a somewhat direct link wherein these perceptions may motivate women to acquire more knowledge and act on that knowledge to carry out the preventative behaviour. Craun and Deffenbacher (1987), on the other hand, found no relationship between knowledge of breast cancer and the practice of breast self-examination, suggesting that findings in this area are equivocal, and indicating the need for further research.

Knowledge has also been found to be positively associated with seeking clinical breast examination (McCance, Mooney, Smith, & Field, 1990). Nemcek (1989), on the other hand, among a sample of 95 black women, found no association between knowledge and frequency of breast self-examination. She did find uniformly low breast cancer knowledge scores, however, indicating that sample characteristics, such as the relatively small sample size and a general lack of knowledge (e.g., about breast self-examination) may have accounted for the finding.

The role of knowledge in treatment choice between conventional and non-conventional has received little attention from researchers. Furnham and Forey (1994) however, tested the hypothesis that a greater biological and physiological knowledge is more likely among those who use non-conventional treatments. They suggested that greater knowledge is likely because of the form of the non-conventional practitioner consultation. Their findings supported the hypothesis, although with the caution that a reported higher level of education among non-conventional medicine users may have accounted for this.

One of the difficulties, which remains unresolved in cross-sectional research, is the inability to distinguish between knowledge accumulated prior to the making of treatment decisions, and knowledge derived as a result of the treatment decision, which would appear to be the case in the Furnham and Forey (1994) study. Sharma (1992), for example, suggested that practitioners of non-conventional medicine see education of the

patient as an important part of their role. Numerous studies have noted patients' reports of the considerable time practitioners of non-conventional medicine spend explaining physiology, disease and its treatment to their patients. This may account for increased knowledge and understanding among users of non-conventional treatments, at least where a practitioner has been consulted.

For cancer patients, however, it is arguable that a more detailed and accurate biological knowledge about a complex condition is unlikely to be obtained through the non-conventional consultation process. It is more likely that this knowledge is attained through a greater personal interest and motivation to seek out information. On the other hand, it is arguable that the effect of vesting control over one's health in one's doctor may override the effect of a lack of knowledge. Where all decisions are left to the doctor, knowledge may become unimportant and unnecessary. The conscious decision to rely on the doctor appears not to be related necessarily to the level and accuracy of knowledge. Siminoff and Fetting (1991), for example, found that more knowledge provided by the doctor about the benefits of treatment was associated with less reliance on the doctor's advice about treatment. These aspects of knowledge acquisition appear not to have been addressed, possibly because less complex medical conditions have usually been investigated in the research.

### ***Approach to health***

Approach to health is the label given to a construct operationalised by three component variables each of which, it is postulated, contributes to understanding the way in which a cancer patient might approach, not just their specific illness, but the concept of health generally, and how this might influence decisions they make about such things as treatment. In its simplest terms, while most would have an interest in their health and the preservation of their life, differences in the level of this interest and the motivation to know about and be involved in health matters, have been found to be related to various

health-related behaviours. This relationship is reviewed in this section and its specific application to treatment choice behaviour is addressed.

### Health interest and motivation

In general terms this concerns the tendency for an individual to be sufficiently interested in and motivated about health matters to engage in health-related behaviours. Unlike many other health-related cognitions that relate to beliefs about behaviours, health interest and motivation is concerned directly with behaviours (Kim, Horan, Gendler, & Patel, 1991). In the present study health interest and motivation was operationalised by two variables. The first was an objective measure of the level of interest, awareness and motivation about health matters. This was assessed firstly in terms of knowledge about environmental, dietary and lifestyle concomitants of cancer, and secondly in terms of self-rated importance of health matters, information seeking behaviour and participation in health matters.

The second variable was a more subjective measure of the beliefs that underlie the value placed on, and level of interest in health matters. They represent the category of general motivation toward health matters that was added to the HBM by Becker and Mairman (1975) in a reformulation of that model to meet a demonstrated need for the inclusion of such beliefs (Cockburn, Fahey, & Sanson-Fisher, 1987). These beliefs are indicators of not only the level of interest and motivation regarding one's health, but also to what extent one is prepared to take action, both of a preventative and treatment nature.

There were a number of reasons for including the health interest and motivation component in the present study. The first was simply the recognition that motivation is a complex phenomenon that strongly influences the decisions people make about what they do (Sandelowski, 1981), and has long been recognised as important in the context of health behaviour. Motivation to act was one of the personal readiness factors in Suchman's (1967) model of preventive health behaviour.

The second was to reflect one of the characteristics of the present decade regarding health, namely, the surge in interest in health matters at the individual level. The instinctive drive to prolong life has been exploited by constant media attention that urges the use of various preparations and strategies to extend life, prevent disease, and look and feel better. Some of the mystery surrounding the medical profession has started to break down, and at least some in that profession have recognised the need to acknowledge the "personhood" of the patient (e.g., Cassell, 1982; Aldridge, 1991). This lay interest and motivation about health matters has been paralleled by an increased interest by health psychologists in the way individuals think about health and illness, how they conceptualise and/or represent their health and threats to it, and the type of health-related behaviour that emanates from this. Behaviours that have interested researchers have included preventative health behaviour, help seeking behaviour, utilisation of medical services, adherence to treatment regimens, adjustment to and coping with illness and treatment, the patient-practitioner relationship, and to a limited extent, treatment choice decision-making.

Thirdly, with the exception of Furnham and colleagues, few researchers have explored this dimension, particularly in the context of treatment choice behaviour. Those who have, have recognised its potential importance. General interest and motivation to be involved in one's own health care had its genesis as a concept for research in studies that explored information seeking and participation behaviours. For example, Cassileth, Zupkis, Sutton-Smith, and March (1980) found, particularly among younger patients, that health-related beliefs reflected the trend towards being well informed and having an active involvement in their treatment (Sutherland et al., 1989; Hack, Degner, & Dyck, 1994). Among cancer patients it has been found that many actively seek information and that this is associated with participation in decision making about their health care. Cassileth et al. (1984) found that almost all cancer patients who used non-conventional treatments believed that patients should take an active role in their own health care compared to 74% of those who used conventional treatment. This finding points not only



to the importance of the variable but also to its potential to discriminate between conventional and non-conventional treatment use.

Furnham and colleagues specifically applied the concept of health interest and motivation to the question of choice of treatment between conventional and non-conventional. Furnham and Bhagrath (1993) referred to this as health consciousness, hypothesising that patients visiting a homoeopath would have greater health consciousness than those visiting a GP. The variable was operationalised in terms of the extent to which people sought out and paid attention to health information. It was measured, however, with three questions that may have been interpreted differently by conventional and non-conventional users. For example, the question 'do you put a lot of effort into staying healthy?' could have been interpreted by GP patients as referring to frequency of GP visits and adherence to treatment regimens, but by homoeopathic patients as seeking information, although no significant difference was found between the groups on this item. The question that did yield a significant result asked whether much notice was taken of television and radio health care recommendations. Presumably the researchers expected homoeopathic patients to take notice of these as part of their health consciousness, but the opposite was found. It was presumed that this was because the advertisement favoured orthodox medicine. Furnham and Bhagrath's (1993) finding may also reflect a limitation of the study to differences between conventional treatment users and homoeopathic treatment users, not non-conventional users in general. Homoeopathy is a specific treatment regimen with a rigorously defended philosophy and method, which to a large extent is based on opposition to allopathic medicine.

Furnham and Forey (1994) operationalised health interest and motivation ("health consciousness and general awareness") in terms of a self and ecologically aware lifestyle and taking an interest in the body, the environment, food and natural products. It was hypothesised that these would characterise users of non-conventional therapies. The findings demonstrated a consistently higher health consciousness and awareness among users of non-conventional therapies. The operational definition of 'alternative practitioner' was considerably widened in Furnham and Forey (1994) to encompass 32 different types

of practitioner. This provided a more representative sample of users of non-conventional medicine than in Furnham and Bhagrath (1993).

Furnham and Kirkcaldy (1996) was essentially a cross-cultural replication of the Furnham and Forey (1994) study with a German population. The findings were similar with respect to health consciousness and awareness. Furnham and Kirkcaldy (1996) acknowledged that it was not clear from their research whether the increased health consciousness of non-conventional users was a result of the experience of non-conventional treatments. This possibility was also acknowledged in Furnham and Forey (1994), but those authors suggested that people use non-conventional therapies because their methods and approaches conflict less with other beliefs.

Health interest and motivation has been approached in various ways in previous studies, as reviewed above. The theme seems consistent, however, with findings suggesting that greater interest in, and motivation to be involved in health matters is associated with the use of non-conventional medicine (e.g., Furnham & Bhagrath, 1993; Furnham & Forey, 1994; Vincent & Furnham, 1996; Furnham & Kirkcaldy, 1996). For certain health behaviours, such as preventative and adherence behaviours, the link is reasonably direct, and a clear relationship between interest and motivation about health matters and demonstration of behaviours such as these is accepted in the literature (e.g., Becker & Maiman, 1975; Cockburn et al., 1987).

In terms of the connection between health interest and motivation and treatment choice, one possibility is that the availability of information emanating from the non-conventional medicine system, and its presentation in an understandable way, may create interest and motivation to become more personally involved (e.g., Furnham & Kirkcaldy, 1996; Furnham & Forey, 1994). Being enlightened about things that were previously a mystery often results in a desire to know more and be more involved. The way non-conventional medicine is delivered, and seen to be delivered, often in a supportive and positive frame and as encouraging involvement and responsibility, would likely give rise to increased interest which may appeal to those whose approach to life is one of seeking

personal control and self responsibility over their life and its events. The suggested mechanism through which this may translate into a particular treatment choice is as follows. The realisation of having a serious illness such as cancer is likely to bring into focus views and beliefs about the illness and its treatment. Those whose beliefs about, and approach to such matters, are cast in a personal involvement and personal control and responsibility frame will likely find a certain congruence with the philosophies and the approach of non-conventional medicine (e.g., Astin, 1998; Furnham & Forey, 1994) which support and encourage this approach. Treatment choices involving non-conventional medicine thus become likely.

On the other hand it is arguable that, traditionally, conventional medicine has been perceived as discouraging personal involvement in treatment issues, other than in terms of compliance, and also as maintaining control over the situation. For those who do not desire personal involvement, allowing another to take responsibility and be in control of the treatment process is likely to be preferred.

#### Biomedical versus biopsychosocial orientation

Furnham and Forey (1994) classified this type of variable as a “general belief about medicine”. Specifically, it assessed the level of acceptance of the holistic approach to physical health. It was included, in a sense, as a check variable designed to assess how people classified themselves in terms of a biomedical or a more holistic biopsychosocial orientation. Brom (1995) described holistic medicine as “not so much a way of treating ill people but rather a philosophical approach to the study of man in health and the process towards disease . . . . . It sees not only the disease but the person that is ill. It sees not only the person that is ill but the environment in which he lives. It recognises not only the outer environment but also an inner, spiritual environment or space.” (p.14). Pietroni (1984) suggested that holistic medicine brings together a number of different developments in medicine, some of which precede modern medicine and some of which reflect changes in our culture and society. He suggested that it encompasses the use of

orthodox approaches, whole person therapies and self-help skills, as well as alternative or complementary methods.

McKee (1988) described holism as the 'systems approach'. This is based on the belief that all parts of the system, the body, mind, spirit and environment, interact to produce a balance within the system. Illness does not result from external agents but from a violation of the natural laws of life, and cure is based on recognition of the existence of curative powers within the body (McKee, 1988).

While there are various specific philosophies attached to particular non-conventional treatments, a general principle is summed up by the British Homoeopathic Association (cited by Furnham & Smith, 1998): Homoeopathy "does not seek to control the individual's symptoms by coercion but to remove the underlying disturbance causing the symptom." In non-conventional medicine generally, removing the "underlying disturbance" includes taking into account the physical, mental and social well-being of the individual. This is aligned with Lowenberg and Davis' (1994) description of the holistic approach: "Holistic health presumes to enlarge the traditional sphere of medical (read 'allopathic') concerns from a narrow, largely technical focus on symptomatology and disease to a broadened domain including such health salient foci as nutrition, psychological and spiritual well-being, interpersonal relations and influences emanating from the environment" (p.581).

Of particular importance in the context of the present study is the fact that holism places considerable emphasis on people assuming responsibility for their own health and well-being (Lowenberg & Davis, 1994). This is where the individual diagnosed with the likes of cancer is able to regain a measure of control and responsibility over their body and their life if that is important to them.

Furnham and Smith (1988) incorporated holistic concepts in their study exploring the opinions, beliefs and behaviour intentions of homoeopathic patients compared to GP patients in the context of treatment choice. They found that homoeopathic patients

displayed a more holistic biopsychosocial approach to their health than GP patients, expressed in terms of belief that their body could help heal itself and that treatment of the 'whole' person is important. The findings of that study, however, may be limited to homoeopathy users, particularly since the two questions comprising the variable relate to some of the principles behind homoeopathy.

Furnham and Bhagrath (1993) also found that homoeopathy patients displayed a more holistic approach expressed in terms of faith in the healing power of their own bodies. Furnham and Forey (1994), whose study was not limited to one type of non-conventional treatment, asked participants about their beliefs on the role of the mind and the body with respect to illness. They also found that users of non-conventional treatment evidenced the more holistic whole person approach. Vincent & Furnham (1996) found that users of non-conventional treatment (acupuncture, homoeopathy and osteopathy) strongly valued the emphasis placed on treating the whole person. No explanation or theoretical basis for their findings was offered, however. This was possibly because, as the authors acknowledged, the study was exploratory,

Astin (1998) found that belief in the importance of body, mind and spirit in treating health problems predicted the use of non-conventional medicine. The suggested explanation for this was that users of non-conventional medicine are part of a particular cultural group who tend to be "at the leading edge of cultural change and innovation, coming up with the most new ideas in society". The intimation was that their 'holistic philosophical orientation to health', which was congruent with the philosophical basis of non-conventional medicine, reflected the "cultural creative", rather than a scientific innovative aspect of the modality. As Astin (1998) noted, this concerns such things as commitment to environmentalism, involvement with esoteric forms of spirituality and the love of the foreign and exotic.

## Optimism

The dispositionally optimistic individual's orientation towards life involves an assumption that good things will happen. Scheier and Carver (1992) see the underlying process in dispositional optimism/pessimism as the idea that people's behaviour is greatly influenced by their expectations about the consequences of that behaviour. Scheier and Carver's (1985) model of behavioural self-regulation suggests that those who expect successful outcomes are more persistent and effective in their goal-directed behaviours. It is probable that such an orientation would influence the approach a cancer patient takes towards their illness, ergo, their treatment.

Dispositional optimism is a cognitive personality variable. Optimism, in terms of optimistic beliefs and outlook, however, has been described as a cognition, and particularly as a health-related cognition (e.g., Schwarzer, 1994; 1995; 1999). It has also been considered to be an important component in certain cognitive theories. For example, in behavioural self-regulation theory optimism links the belief that one is capable of achieving a goal with persistent striving to reach it (Friedman, Nelson, Webb, Hoffman, & Baer, 1994). In a general sense optimism has consistently been found to be related to health behaviour (Schwarzer, 1999; Aspinwall & Brunhart, 1996).

Optimism has been incorporated in the present study mainly to control for its potential to influence the treatment choice decision-making process particularly in the context of life-threatening illness. For example, optimism has been found to be a key component in cognitively focused models of coping with serious illness. These have included problem-focused coping strategies such as advice seeking and deciding where to seek care. Lauver and Tak (1995), for example, found that optimism was associated with less delay and anxiety in care seeking among those with breast cancer symptoms. This was in the context of coping strategies, but their finding that higher optimism is associated with problem-focused coping outcomes as well as emotion-focused strategies, suggests that decision making in general about treatment is influenced or explained by levels of optimism.

Lauver and Tak's (1995) findings confirmed the findings of Friedman et al. (1992) that optimism is positively related to active-behavioural coping with cancer and negatively related to avoidance coping. Active responses that are oriented toward dealing with the problem are problem-focused responses that would be expected to have motivational and proactive internally oriented components. This assumption has some empirical support. Taylor et al. (1992), for example, found that HIV seropositive gay men who were optimistic reported greater efforts to maintain their health through diet and exercise.

In the context of the present study this "assumption" could be represented by an expectation that cancer patients who were more optimistic would be likely to display increased motivation to deal with their health situation proactively by seeking out additional treatment options, most likely non-conventional. Peterson, Colvin, and Lin (cited in Lin & Peterson, 1990), for example, found that optimistic individuals were more likely to take active steps in response to an illness episode than pessimistic individuals. Similarly, Lin and Peterson (1990) found that optimists who feel ill were more likely to take active steps than were pessimists.

Dispositional optimism and pessimism are also conceptually related to the explanatory style approach, which has connections with the attributional basis of the present study. For example, according to Peterson, Seligman, and Vaillant (1988), pessimistic people are those who explain bad events with stable, global and internal causes while those who are not pessimistic attribute negative events to unstable, specific and external causes. Peterson and Bossio (1991), after reviewing studies about learned helplessness, concluded that the way a person explained the causes of an uncontrollable event determined the level of subsequent helplessness in relation to that event. They considered that causal explanations leading to helplessness "are the ones we describe as internal, stable, and global, in other words, pessimistic ones. The opposite types of explanation, invoking external, unstable, and specific causes, are not so apt to produce helplessness, and these are thus optimistic ones" (p.94). Explanatory style (optimistic and

external or pessimistic and internal) therefore, determines the way a person behaves in the wake of uncontrollable events, helplessly or vigorously (Peterson & Bossio, 1991).

Schwarzer (1994), however, has identified various problems with optimistic explanatory style in relation to health. He also has some doubts as to how it would fit as an integral part of a health behaviour theory, although this relates particularly to the preventive behaviour and behaviour change aspects which are not important in the context of the present study. Nevertheless, the measurement issues raised by Schwarzer (1994) are relevant and have influenced the decision in the present study to adopt a dispositional optimism rather than an optimistic explanatory style approach.

As indicated above, in the present study optimism was conceptualised and assessed as a dispositional quality rather than purely as a response to a diagnosis of cancer. A stable tendency to believe that one will generally experience favourable outcomes corresponds with the attributional basis of the study and the meaning construct, which were also conceptualised in a pre-existent and dispositional frame. Furthermore, there is considerable evidence that dispositional optimism is associated with the health-related behaviours of cancer patients. For example, Friedman et al. (1992) found that, among cancer patients, dispositional optimism was significantly and positively associated with the use of active-behavioural coping strategies. Carver et al. (1993) found among breast cancer patients that dispositional optimism was associated with improved coping behaviours in relation to taking steps to deal with the situation.

#### ***Attributions of control, responsibility and blame.***

The concept of control is still commonly conceptualised in terms of locus of control and measured in terms of the Wallston model encapsulated in the MHLC scale. For example, it has been used recently in studies exploring the role of health locus of control beliefs in psychological health (e.g., Raja, Williams, & McGee, 1994), and specifically the psychological health of cancer patients (e.g., Newsom, Knapp, & Schulz,



1996; Jenkins & Burish, 1995). The MHLC approach has also been used in studies exploring behavioural responses to cancer (e.g., Hallal (1982) who investigated the relationship of health locus of control to the practice of breast self-examination). Kelvinson and Payne (1993) utilised the MHLC scale to test their hypothesis that patients who seek non-conventional therapy for pain relief would score higher on internal locus of control than conventionally treated patients. Their results supported this hypothesis, leading to the conclusion that these patients may take more responsibility for their own state of health, whereas conventional patients are more likely to see their health as being controlled by powerful others such as health professionals.

A number of studies (e.g., Furnham & Smith, 1988; Yates et al., 1993; Furnham & Bhagrath, 1993; Furnham & Forey, 1994; Furnham, 1994; Furnham & Beard, 1995; Furnham & Kirkcaldy, 1996; Astin, 1998; Kelvinson & Payne, 1993) have recognised the importance of the concept of control as an underlying factor in explaining treatment choice decisions. Research in this area has often utilised Lau and Ware's (1981) Health Locus of Control Scale, however (e.g., Furnham & Smith, 1988; Furnham & Bhagrath, 1993; Furnham & Forey, 1994; Furnham & Kirkcaldy, 1996). This scale measures beliefs as to who has control over one's health and the extent of that control. It contains four subscales including self-control over health, provider control over health, chance health outcomes, and general health threat. Studies using this scale have consistently reported a significantly lower score on the 'provider control' subscale among users of non-conventional treatment (Furnham & Smith, 1988; Furnham & Bhagrath, 1993; Furnham & Forey, 1994; Furnham & Kirkcaldy, 1996). This shows that across a range of non-conventional treatment users and illnesses (including cancer), non-conventional treatment users preferred less than conventional patients to leave their health in the hands of others. This suggests a preference for personal control over health. None of these studies, however, reported a significant finding for 'personal control', although differences were reported on items making up this subscale (e.g., Furnham & Kirkcaldy, 1996). It is possible, however, that the provider control scores reflected a scepticism of conventional medicine rather than a disclosure about control.

It would also appear that the Lau and Ware (1981) measure, like the MHLC scale, comprises a restrictive pre-determined conceptualisation of external control. Provider control and chance health outcomes do not permit of the broader conceptualisation of externality to incorporate concepts such as spirituality that the present study proposes. Also like the MHLC, it is arguable that the scale is more suitable for those who are healthy or have an acute rather than a chronic illness because of the inclusion of items that relate to the potential for illness. The distinction between control over treatment outcomes and control in the context of treatment decisions, as identified by Degner and Russell (1988), is also not made in the Lau and Ware (1981) approach to control. The above mentioned studies that have utilised that measure may, therefore, have assessed an aspect of control that is focused on outcome control rather than tapping a more generic conceptualisation of control relevant in the decision making phase.

The Degner and Russell (1988) approach also has limitations. While it accounts for control in the treatment decision-making context, it is essentially a consumerist approach. In that sense it is also not tapping a generic concept of the attribution of control and responsibility. The consumerist approach has, however, identified an important practical finding from locus of control studies. The conclusion from a number of studies (e.g., Vertinsky, Thompson & Uyeno, 1974; Cassileth et al., 1980; Haug & Lavin, 1981; Degner & Russell, 1988) has been that many people, including cancer patients, prefer to share decision making among themselves, family, and health professionals. This suggests that in terms of this particular health behaviour, conceptualising locus of control as a dichotomy comprising internal and external styles as mutually exclusive, which tends to be the basis of a number of locus of control scales, may be inappropriate. As Furnham and Beard (1995) suggested, people can be a mixture of the two.

There has been some research that has approached the investigation of the role of control in treatment choice decisions outside the MHLC type of framework. Yates et al. (1993), for example, simply used two items to examine cancer patients' attitudes to having control over the decisions made about their cancer and its treatment. The items were: 'I leave it up to my doctor to decide what is best for my cancer' and 'I need to have

control over the decisions made about the treatment for my cancer'. The authors acknowledged the potential lack of reliability of a two-item scale but did report a Kendall's Tau B correlation of  $-.31$  for the two items. One of the stated aims of Yates et al.'s (1993) study was to determine the beliefs and attitudes of those who chose to use non-conventional medicine in the treatment of their cancer. Since the intention was not to offer an explanation, it is perhaps understandable that no theorising of the role of control was offered. Nevertheless, the study found that those who report a strong desire for control are about six times more likely to use non-conventional treatments for their cancer than those reporting a moderate or weak desire for control.

Subject to the question of the reliability of a two-item scale, the finding is reasonably straight-forward and conclusive. Arguably, however, a stated desire for control over treatment decisions may be a somewhat different concept to the attributions of control, responsibility and blame construct as explored in the present study. The former may be a simplistic consumerist approach compared to the latter, which explores the cognitive structures and processes underlying the attribution of control and responsibility.

Astin (1998) also investigated the need for personal control in the context of the decision to use non-conventional medicine. The participants in the large sample (1035) were suffering from a range of illnesses. The study found that although there was a trend towards the use of non-conventional medicine among those who wished to retain control, this variable was not a significant predictor of non-conventional use. It was found, however, that among those who chose to rely primarily on non-conventional medicine (which was 4.4% of the sample,  $n = 45$ ) there was a desire to keep control in their own hands.

In the present study a questionnaire developed by Stainton Rogers (1991) was utilised specifically to avoid some of the limitations inherent in existing locus of control scales, and to accommodate the attributional theoretical basis of the control construct. There appears to be two reported studies that have employed the Stainton Rogers (1991)

measure in a treatment choice context. These are Furnham (1994) and Furnham and Beard (1995).

Furnham (1994) found, among a sample of 338 users of non-conventional medicine, that the more they believed in non-conventional medicine, the more they believed in controllable and internal causes of health, illness and recovery. Similarly, belief in non-conventional medicine was negatively correlated with external health beliefs. Furnham and Beard (1995) reported that non-conventional treatment users place emphasis on positive attitudes and general happiness as factors influencing future health and believe more strongly that state of mind and emotions have an important role in health and illness in terms of current state of health. Previous models tended not to distinguish between attributions for current and future state of health and effectiveness of recovery in the way the Stainton Rogers (1991) approach does. They were, therefore, less sensitive or less finely grained in their assessment of internal and external control attributions.

Furnham and Beard (1995) also found, however, that non-conventional users believed more strongly than conventional users that environmental factors, which are at least partly controlled by external forces, have a role in future health. This demonstrates another of the criticisms Furnham (1994) and Furnham and Beard (1995) have of health locus of control scales. That is, that people's explanations for health and illness are not based solely on either internal or external attributions but may be a mixture of the two.

### ***Meaning***

Researchers who have been interested in the role of meaning in health behaviour have tended to explore either illness meaning or meaning in life. In the present study both were investigated. In the previous chapter the theoretical basis of the meaning construct was addressed in terms of both its philosophical base and its proposed relationship with treatment choice decisions and the other constructs of interest in the present study. In the

present chapter research that has addressed the role of meaning, as conceptualised in this study, in relation to treatment choice behaviour, is reviewed.

### Meaning in illness

The search for illness meaning is a significant part of the cancer experience (Fife & Taylor, 1995; Taylor, 1995) and determines the patient's affective, cognitive and behavioural responses to it (Lipowski, 1970). In the present study illness meaning was defined as a cognitive phenomenon that refers to the individual's understanding of the implications their illness has for their identity and their future (Fife, 1995). Kleinman (1986) would describe this in terms of the personal and cultural (including spiritual) significance of the illness experience.

Intrinsic illness meaning is meaning that the individual constructs in response to her or his life-threatening illness. Because it is self-constructed it is not based on assigning a purpose and/or cause to the situation, which would involve the individual looking beyond self or the situation. Accordingly, as Fife (1995) explained, it refers to the individual's perception of their ability, notwithstanding their illness, to accomplish goals, maintain relationships and sustain a sense of personal vitality, competence and power. Meaning derived from the situation and 'created' by the individual as a response or a coping mechanism is intrinsically oriented illness meaning.

There appears to be no reported research into the influence of this conceptualisation of illness meaning on illness behaviour. While Fife (1994) acknowledged the potential for relating meaning to adaptation and behaviour, and the possibility of taking meaning into account in the treatment process, she was concerned mainly with the process of the construction of meaning of illness by the cancer patient. She also noted that there have been few attempts to explore these possibilities.

Extrinsic illness meaning in the present study refers to personal meaning of the illness that the patient discovers beyond the self and the circumstances. Lipowski's (1970)

extrinsic dimensions include illness as enemy, illness as punishment, and illness as weakness (i.e., no individual control). These dimensions and related sub-dimensions embody the notion of the involvement of an external agent in the individual's illness situation. Few researchers have explored Lipowski's dimensions. Other than Pritchard, who conducted a number of studies in the 1970s, it appears that only Keltikangas-Jarvinen (1986) and Schussler (1992) have reported studies using these dimensions.

Fife (1994, 1995) acknowledged alternative philosophical conceptualisations of meaning, but did not incorporate them in her illness meaning measure. Various other researchers have defined illness meaning in extrinsically oriented terms (e.g., O'Connor, Wicker, & Germino, 1990; Thompson & Jannigan, 1988; Reed, 1991; Taylor, 1983; Mechanic, 1977), but it appears that the Response to Illness Questionnaire (Pritchard, 1974a) is the only measure that enables the assessment of a distinctly extrinsic approach. Illness meaning, however conceptualised, appears to have had very little attention from researchers in the context of treatment choice, although Astin (1998) theorised that one of the reasons patients seek non-conventional treatments is because they are more compatible with their beliefs regarding the nature and meaning of health and illness. He did not report any findings specifically on this issue, however.

Keltikangas-Jarvinen (1986) explored the influence of the Lipowski (1970) dimensions (except disease as weakness) on another health-related behaviour, namely treatment compliance among patients with intermittent claudication. Three of the dimensions, disease as loss, disease as challenge and disease as gain were found to be significantly associated with treatment compliance. Those whose illness was expressed as a loss showed high compliance, but those for whom it meant a challenge expressed high treatment motivation but actual compliance was very poor. Disease experienced as gain was found to be related to personality pathology and resulted in total lack of treatment motivation and no compliance. It could be argued that these particular dimensions are conceptually less externally focused than the other Lipowski (1970) dimensions such as illness as enemy, as punishment and as weakness. Nevertheless the Keltikangas-Jarvinen

(1986) study does demonstrate that Lipowski's (1970) illness concept approach does constitute a set of cognitions that may influence health-related behaviour.

Schussler (1992) also recognised the value of Lipowski's (1970) illness concepts, particularly when supplemented with control attribution theory. Schussler (1992) found, in relation to coping with chronic illness as a health behaviour, that Lipowski's hypothesis as to the positive relationship between the illness concepts and coping could be "globally proven". Furthermore, Schussler (1992) found that the hypothesis that controllability leads to active coping strategies could also be confirmed.

### Meaning in life

Life meaning deals with the more fundamental life and death issues. Reker and Wong (1988) define life meaning as "...the cognizance of order, coherence, and purpose in one's existence, the pursuit and attainment of worthwhile goals, and an accompanying sense of fulfilment." (p.221). Definitions of this nature have commonly provided the basis for meaning research. This, however, is a definition of meaningful life experience. As such it is able to use "purpose" and "meaning" interchangeably. The essence of this problem of definition is simply that researchers often acknowledge the "cosmic" (extrinsic) approach to meaning but include only the "terrestrial" (intrinsic) approach in their operational definitions of meaning. The extrinsic approach to life's meaning is represented by the concept of ultimate meaning, which often finds its foundation in a religious or spiritual context. It is represented by Frankl's (1984) concept of meaning that is discovered beyond the self, meaning that transcends the self. In the present study, life meaning was approached on the basis that participants were provided with the opportunity to disclose either an existential self-constructivist (intrinsic) or a Frankl type discovery process (extrinsic) approach to meaning, or a combination of both.

For meaning in life, there also appears to be little reported research that has explored the influence of this construct on treatment choice decisions. In one study,

however, Furnham and Beard (1995) explored the relationship between just world beliefs and use of non-conventional medicine among a sample of hospital and clinic patients suffering from various undisclosed illnesses. The just world beliefs variable was conceptualised in a way that is compatible with life meaning as conceptualised in the present study. That is, people who believe in a just world see illness as a consequence of behaviour and as such as a punishment for wrong-doing, rather than resulting from luck, fate or choice (Furnham & Beard, 1995). This variable was seen as addressing the question as to whether there are fundamental differences in patient's wider belief systems as well as specific differences in health beliefs. The difference found between conventional and non-conventional users in terms of their just world beliefs was non-significant, although the difference was in the expected direction with conventional medicine users being more likely to see their illness as being punishment. This equates with an extrinsic approach to life meaning in the present study.



## CHAPTER SIX

### OBJECTIVES AND EXPECTATIONS

#### Objectives

The primary objective of this study was to investigate the influence of the cognitions described above on the choices that cancer patients make about treatment modality between conventional and non-conventional medicine. This objective generated the hypotheses listed at the end of this chapter.

A further objective was to explore whether these health-related cognitions discriminated between conventional and non-conventional users differently when the division between the two modalities was altered. Put another way, were there any differences in health-related cognitions between conventional and non-conventional users when conventional and non-conventional were defined differently?

An underlying objective was to explore and apply the particular conceptualisation of the meaning construct proposed in this study. This included both the influence of meaning on treatment choice, and its relationship with the other constructs of interest, particularly attributions of control, responsibility and blame. This generated a number of expectations that go to the conceptual basis of the set of cognitions explored in the study.

Part of the process of investigating the applicability of meaning as conceptualised, and its influence in conjunction with the remaining constructs, included comparing the approach taken in this study with commonly employed health belief and social cognition models, in the context of those already diagnosed with a life-threatening illness. Meaning as a construct, appears not to have been incorporated in models used to explain health-related behaviour. Where meaning has been explored in health behaviour research that

has not followed existing models, it seems to have been conceptualised in an existential frame only.

Another underlying objective of the study was to explore treatment choice decision-making from an attributional theoretical basis rather than from a decision-making theory perspective. It was suggested that this approach provided a conceptual link between the concepts of meaning and control. In a sense, the notion of control, explored in the broader attributional context rather than the more common locus of control frame, was a pivotal component of the present study.

### **Expected relationships among the constructs and their components**

The proposed set of constructs and their associated variables (discriminating variables) were hypothesised to influence the behavioural response to a life-threatening illness assessed in terms of decisions about choice of treatment. The main analytic strategy in the study was a multivariate strategy designed to explore whether scores on the component constructs, in combination, would show significant differences between conventional and non-conventional users for the different treatment groupings. As a preliminary to this, bivariate relationships between the variables comprising the constructs and between individual variables and treatment modality were explored.

### ***Relationships among discriminating variables***

In terms of expected relationships among the constructs, and among the variables within the constructs, the attributions of control, responsibility and blame construct was expected to display conceptual links with many of the variables in the study. This section is organised around this construct to avoid a cumbersome layout and repetition.

The expected relationship between control and knowledge of cancer was that those who desire an element of control over their health situation would also seek information and knowledge about their illness and its treatment. This was seen as a reciprocal relationship in that as knowledge and understanding increases, it is likely that the patient would want to use that knowledge to take more responsibility and control over their health. Confidence to do this would also likely increase.

Control was also expected to influence the relationship between information based knowledge and treatment choice decision making. For example, in the conventional medical setting choices are often presented in a frame where explanation is brief and where knowledge and understanding is discouraged or hindered by technical terms and scientific jargon. This would have the effect of control being retained by the practitioner or the system, while at the same time permitting the meeting of the ethical and legal requirements of informed consent. Other choices, however, frequently those in the non-conventional sector, are presented with explanations (albeit possibly simplistic) of the disease and treatment. These are generally presented in a supportive frame where knowledge is freely available and encouraged, fostering the maintenance of personal control and self-responsibility.

Similarly, health interest and motivation has conceptual links with the concept of control. While this construct concerns the desire to influence one's health and to complement treatment regimens, it may also be associated with and perhaps generate the wish to exercise some control over one's medical care, or at least to reduce the control of external agencies. This aspect was operationalised as wanting information about one's health and wanting to participate in decisions about medical care.

Meaning is also conceptually interrelated with the control based framework of the present study. The link may be explained by Antonovsky's (1980) argument that controlling the situation is not important, but experiencing one's world as meaningful and purposeful is. In other words, the question of control is not always whether things are within one's own control, but that they are in control, and this brings meaning to life. A

central argument in the present study was that the source of meaning in a person's life determines the nature of that meaning. The source of meaning was conceptualised in terms of internally derived or externally discovered meaning. The outworking of each of these orientations is essentially in terms of to whom control is attributed. For example, one of the factors that Fife (1994) identified as influencing the formulation of illness meaning for the individual was the extent to which an individual perceives he or she is able to control the situation. Intrinsic meaning, in control terms, suggests that a cancer patient who derives illness meaning in this way will see his illness, its treatment, and his recovery, as being somewhat within his own control. Intrinsic illness meaning, therefore, was expected to be associated with attributions of control to self. Extrinsic illness meaning, on the other hand, was expected to be associated with a preference for externally focused control.

Summarised, the expected relationship between control and meaning is as follows. An aversive event (e.g., a cancer diagnosis) attacks beliefs in the existence of a controllable and meaningful world and also attacks assumptions that one is in control of one's fate (Weary et al., 1989). Research suggests that following a traumatic event people attempt to regain a sense that their situation is under control and thus restore their belief in a meaningful world. Often the strategies people use to achieve this are attributional strategies designed to assign causality, responsibility or blame (Weary et al., 1989). The focus of these attributions would be influenced by the individual's orientation to life and its meaning, in terms of an intrinsic or extrinsic approach.

Other expected relationships among discriminating variables, within and between constructs, include a relationship between cancer knowledge and health motivation such that those who are sufficiently interested and motivated about health matters will be those who seek information and knowledge about their illness and its treatment (Cassileth et al., 1980). This was expected to be a reciprocal relationship. Also in relation to knowledge, a relationship was expected between the personal cancer beliefs dimension and meaning, such that less positive beliefs would be associated with extrinsic meaning. This was because the positive beliefs about cancer dimension essentially concerned the

potential for successful treatment. It was posited that those who were extrinsically oriented, most likely derived within a religious frame, would have attributed their cancer to, say God, as His punishment for some wrong doing on their part. Therefore, they would not demonstrate confidence in a successful treatment outcome. It was also expected that more positive beliefs about cancer would be associated with higher dispositional optimism. A positive belief system about an otherwise negative situation shares a certain congruence with the concept of an optimistic outlook on life in general.

Motivation and interest in health matters was expected to be associated with higher levels of optimism and a more intrinsically oriented approach to meaning in illness and life. Those whose outlook on life generally is optimistic are likely to demonstrate the energy and enthusiasm that would characterise those who are eager to learn and participate. Similarly, interest and personal involvement in ones health is likely to find a certain congruence in the concept of self-responsibility and self-help that characterises an intrinsic approach to life and its meaning. Optimism was also expected to be related to a more intrinsic approach to life's meaning. This was based on the expectation that an intrinsically oriented individual would likely have confidence in their ability or their potential to influence their situation. This contrasts with the view of the extrinsically oriented individual for whom God's hand of punishment and God's sovereignty over their life would tend to engender a sense of resignation to the situation. The holistic approach to health was expected to be associated with greater health interest and motivation and an intrinsic approach to meaning. Studies that have included the likes of the holistic approach to health variable, in general, have found that those who subscribe to this approach take an interested and proactive role in health matters and tend to be those who assume responsibility both in a causal and treatment and outcome sense.

Within the meaning construct intrinsic illness meaning was expected to be associated with intrinsic life meaning and the same for extrinsic meaning. This is because the conceptualisation of meaning (as intrinsic or extrinsic) was expected to have a similar influence on both illness meaning and life meaning.

*Bivariate relationships between discriminating variables and treatment choice*

Knowledge and understanding of cancer was expected to be associated with treatment choice as follows. Since non-conventional therapy tends to be more self-participatory, more readily understood, and information about it is often made more available to the patient than conventional medicine information, it was expected that those who chose the former would be those who evidence higher levels of knowledge and understanding. Knowledge about 'my cancer' expressed in terms of a positive belief system was also expected to be associated with the choice of non-conventional treatment. A negative belief system was expected to be associated with less general knowledge and a more conventional approach to treatment. A similar pattern was expected in relation to dispositional negativity and positivity assessed in terms of optimism and pessimism.

Levels of interest and motivation and the extent to which people wish to be involved and to bring their own criteria and ideas to the treatment process were expected to influence the treatment modality decision. Those with higher levels of interest and motivation were expected to be more proactive, wanting more self-involvement in their treatment, and this was expected to be associated with greater utilisation of the often self-prescribed and self-administered non-conventional medicine. It is suggested that the accessibility of non-conventional remedies in terms of ease of use, availability, and cost, means that those who are motivated to participate in their treatment in an active way, as opposed to the more passive mode of compliance with the doctor's treatment regimen, have that opportunity in the world of non-conventional medicine.

Also at the sub-component level, the holistic biopsychosocial approach to illness causation and treatment was expected to be associated with non-conventional treatment use because of the emphasis that holism places on self-responsibility, being in control of one's own body (Lowenberg & Davis, 1994), the body's inherent healing abilities, and the 'whole person' approach in general (Furnham & Bhagrath, 1993; Furnham & Forey, 1994; Furnham & Smith, 1988; Vincent & Furnham, 1996; Astin, 1998). Conversely, the

belief that physiological and medical factors are the main causes of disease, a typical biomedical approach, is likely to be associated with more conventional forms of treatment.

Attributions of control and responsibility were expected to be directly associated with the type of treatment chosen. Control exercised over the treatment process would likely be represented by a preference for a treatment approach which permitted personal involvement, a sense of assuming responsibility and some control over the decision making process. This describes the methodology of non-conventional medicine. Those who attribute control externally, however, would be expected to accept the doctor taking control, the corollary of which is less personal involvement in the decision making and treatment administration processes.

The control concept may also help to explain the influence of meaning on treatment choice, particularly among those who display an intrinsically oriented meaning in their illness and their life. This was because, while control is not conceptualised in terms of locus of control, the intrinsic orientation is effectively an attribution of control to self. The search for meaning in the event and in one's life, now threatened by the event, will, in the intrinsically oriented individual, take place within the self. This search within the self is posited to have its parallel in a self-motivated, self-generated and self-responsible approach to treatment. Non-conventional medicine permits of and facilitates this treatment methodology.

Conversely, those who are extrinsically oriented will likely be familiar with the notion of placing faith in a powerful other, particularly in relation to issues that are serious enough to require "supernatural" or at least specialised input. Furthermore, those whose extrinsicness is religiously derived are thought to view the medical profession as one of God's healing instruments. For patients in this category taking an active part themselves, as in being involved with non-conventional treatments, may be seen as wresting control back again, rather than trusting God.

## **Research questions and hypotheses**

The broad research question addressed empirically by the present study was: What are the differences in the health related cognitions between those who choose conventional medicine only and those who include non-conventional remedies in the treatment of a life-threatening condition such as cancer? The question was also addressed in terms of differences in health-related cognitions according to the category of non-conventional treatment chosen when the division between conventional and non-conventional was altered.

The hypotheses, one relating to each construct, were:

- 1) Those who utilise non-conventional treatments will demonstrate a higher level of knowledge about cancer and have a more positive belief system about their cancer.
- 2) Those who utilise non-conventional treatments will be more positively motivated about and be more interested in health matters. They will also be more holistic in their approach to health matters and be more optimistic in their outlook on life.
- 3) Those who utilise non-conventional treatments will desire more personal control and assume more responsibility for their health and its treatment.
- 4) Those who utilise non-conventional treatments will be more intrinsically oriented in terms of meaning in illness and meaning in life.

The converse was hypothesised in each case for those who utilise only conventional treatments as defined in each grouping.

An hypothesis associated with the configuration of treatment groupings was:

- 5) That the differences between conventional and non-conventional users in terms of knowledge, health interest and motivation, attribution of control, responsibility and blame, and meaning, will vary among the configurations of treatment grouping. As the groupings alter to incorporate prayer and more non-conventional



treatments in the conventional category, the hypothesised effects will become more marked.

## CHAPTER SEVEN

### METHOD

#### **Design and chapter overview**

The present study was conducted by postal survey using a single self-administered 260-item questionnaire. (See Appendix A). A cross-sectional design was used to explore the health related cognitions and treatment choices of those already diagnosed with cancer. Details of eligibility requirements, how participants were located, demographic details of participants, research procedure, and questionnaire content are presented in the following sections. Psychometric data are reported where available for existing measures, as well as being calculated directly from the collected data.

#### **Participants**

People were eligible to take part in the study if they were between the ages of 18 and 85 inclusive. A lower limit of 18 years of age was imposed to ensure an adult sample. A fundamental aspect of the study was the relationship between patients health related cognitions and their treatment choices. It would be reasonably probable that for many cancer patients under the age of 18, treatment decisions would be made or largely influenced by parents. The upper limit was imposed to avoid any difficulties with the completion of a lengthy questionnaire caused by age related impairment or disability.

The second eligibility criterion was that participants must have been diagnosed as having had any form of cancer at any time in their life, provided that diagnosis had not been made within the last 3 months. The 3 months requirement was to ensure that for those recently diagnosed, the question of treatment would have been addressed and also to ensure participants were not responding during the immediate adjustment period. Self-

report of cancer diagnosis was relied on without any other confirmation. It was expected that reference to a 'diagnosis of cancer' would capture only those who had been formally diagnosed. While a second opinion is often sought, cancer diagnosis is a reasonably definitive process. Cancer is rarely misdiagnosed in the sense that a diagnosis of cancer is made erroneously. Furthermore, people are unlikely to be self-diagnosed only, and be prepared to classify themselves as cancer patients.

Participants were located through an advertisement in the local newspaper and by the placing of a flier in pharmacies, health shops, hospitals, doctors' rooms, non-conventional health practitioners' rooms, and practising psychologists' offices, where permission was forthcoming. The flier was delivered personally to pharmacies and health shops in the cities and many of the towns in the regions surveyed. Copies were mailed to various hospitals, medical practitioners, non-conventional therapy practitioners, psychologists, and cancer support groups in the same areas, with a request that they be displayed on notice boards or brought to patients' and clients' attention as appropriate. The flier contained a brief outline of the research and encouraged cancer patients to telephone the researcher on a toll free number to request participation documents. The wording of the newspaper advertisement was similar. 236 sets of consent forms and information sheets were mailed to respondents. Of those who requested consent forms 13 failed to return them and of those to whom questionnaires were sent 11 failed to complete them. A total of 212 completed questionnaires were received. This represented a response rate of 90% of those who responded to the advertising.

Participants were substantially those who resided in those areas of New Zealand served by the then Northern and Central Regional Health Authorities. These included the major population bases of the North Island, including the major metropolitan areas of Auckland and Wellington, and Northern, Central and Southern North Island provincial cities, smaller towns, and rural areas. It is estimated that these areas include 1/2 of the New Zealand population, and adequately represent the ethnic and socio-economic spread of the population. The unrepresentative ethnic content of the sample (3.3% Maori, when Maori account for approximately 12.8% of the New Zealand population and have a

higher cancer morbidity rate (New Zealand Health Information Service, 1997)) is not a function of the geographic area sampled. In demographic terms, with the exception of ethnic spread, the sample appears to be reasonably heterogeneous. (See Table 1).

Subject to the unrepresentative ethnicity aspect of the sample, the method of participant selection provided the opportunity to participate in the research to a reasonably wide cross-section of cancer patients in the community. Any self-selecting procedure will capture only those who are sufficiently motivated and willing to talk about and disclose details of their situation. A strength of the procedure used in the present study, however, was the placing of promotional material in essentially public places, rather than accessing people attending a particular clinic or belonging to a specialised group such as the Cancer Society.

Prior to data collection, an estimate of the required number of participants for the planned multivariate analyses was obtained by the commonly applied rule that there be a minimum of participants equal to 10 times the number of variables. As the study involved 14 discriminating variables, excluding demographic variables, 212 participants was considered sufficient.

### *Demographic details of participants*

This information is presented in detail in Table 1. Questionnaire items that elicited demographic information are found in section I of the questionnaire. Of the 212 participants, 145 (68.4%) were female and 67 (31.6%) were male. This is not comparable with national cancer statistics, which show that incidence among males is higher than among females. For example, in 1993 there were 6579 cases of male cancer registered and 6185 female cases (New Zealand Health Information Service, 1997). In the present sample, the gender imbalance is reflected in the relatively high number reporting cancer that is peculiar to women (101 instances representing 47.9%) and only 22 instances, representing 10.3%, of cancer peculiar to men. (See Table 2). Participants ranged in age

**Table 1.****Gender, ethnicity, marital status, educational level, occupational status, time since diagnosis, and age for the sample (N=212)**

|   | N        | % of total      |
|---|----------|-----------------|
| <b>Gender</b>                           |          |                 |
| Male                                    | 67       | 31.6            |
| Female                                  | 145      | 68.4            |
| <b>Ethnicity</b>                        |          |                 |
| European                                | 205      | 96.7            |
| Maori                                   | 7        | 3.3             |
| <b>Marital status</b>                   |          |                 |
| Married                                 | 149      | 70.3            |
| Widowed                                 | 13       | 6.1             |
| Separated / divorced                    | 36       | 17.0            |
| Never married                           | 14       | 6.6             |
| <b>Educational level</b>                |          |                 |
| Some primary school                     | 2        | .9              |
| Completed primary school                | 7        | 3.3             |
| Some high school                        | 28       | 13.2            |
| Completed 3 years high school           | 16       | 7.5             |
| Completed more than 3 years high school | 27       | 12.7            |
| Technical training beyond high school   | 49       | 23.1            |
| Some university                         | 33       | 15.6            |
| Graduated from university               | 50       | 23.6            |
| <b>Occupational status</b>              |          |                 |
| Employed full time                      | 54       | 25.5            |
| Employed part time                      | 46       | 21.7            |
| Taking care of a home                   | 31       | 14.6            |
| Looking for work                        | 2        | .9              |
| Retired                                 | 70       | 32.9            |
| Student                                 | 5        | 2.3             |
| Unable to work                          | 7        | 1.9             |
| <b>Time since diagnosis</b>             |          |                 |
|   | 209      |                 |
| Mean                                    |          | 8.7 years       |
| SD                                      |          | 9.6 years       |
| Range                                   |          | .25 to 48 years |
| Median                                  |          | 5.1 years       |
| <b>Age</b>                              |          |                 |
|   | Range    | 20 to 83 years  |
|   | Mean age | 55.6 years      |
|   | SD       | 13.2            |

from 20 to 83 years (mean = 55.6 years). Most participants were married (70.4%). This included de facto marriages.

The participants comprised a reasonably well-educated sample. 39.4% had received some university education and a further 23% had received some other tertiary education, the majority of which was teacher training and nursing. This was detected from the "other (please specify)" category in the questionnaire. Only 4.2% had not attended high school. Almost half of the participants (47.2%) were in full-time or part-time employment. Given the median age of 55 years, a reasonable number in the retired category would be expected. As the questionnaire did not include an "unable to work" category, it is probable that of the 32.9% classifying themselves as retired, some of these "retirements" may have been due to the illness. The "taking care of a home" category yielded a 14.6% response. The category "other (please specify)" revealed 5 students, 4 classifying themselves as unable to work, and 2 looking for work.

Although time since diagnosis is not a demographic characteristic, it is important descriptive information about the sample. The median time of 5.1 years is the most representative because the mean is influenced by 3 participants whose cancer had been diagnosed over 40 years before.

Consideration was given to various issues that arise in relation to the length of time that had elapsed since patients had been diagnosed with cancer and their participation in this study. One of these issues was the question of accuracy of memory for relevant details, given the median of 5.1 years since diagnosis and for many, considerably longer. It was considered that being diagnosed and then living with cancer is a major event in a person's life, and how treatment was dealt with would be unlikely to be readily forgotten. In any event, a list of 3 conventional and 50 non-conventional treatments was supplied as memory prompts for participants to choose from. In addition, some indication of generally accurate recall was the 24 additional treatments added by participants.

Consideration was also given to whether the episode of cancer should be defined on the basis that participants may have used different treatments for different types of cancer, at different disease stages, or for different episodes of their cancer. With respect to questions about the use of different treatments for different cancer types, it was considered that this had more to do with treatment efficacy issues, which the study avoided. The question of choosing to use non-conventional treatments at a particular disease stage (e.g., in the late stages) was also not provided for because this would likely have generated additional variables for exploration (e.g., affective aspects such as desperation). This may be a limitation of the study which could be addressed in future research but in the context of the present study it was not seen as necessarily obstructing the exploration of cognitive determinants. Differentiating between treatment types for different cancer episodes was also not considered important. While biologically cancer can be episodic, psychologically it is more perennial in its effect.

Cancer type is also an important descriptive variable. Participants were requested to mark on a list of 18 cancer types which type or types they had ever been diagnosed with. Participants were given the opportunity of adding any types that did not appear on the list. This information is presented in detail in Table 2. The list in the questionnaire included gallbladder cancer, of which there was no instance. The "other" category revealed basal cell and peritoneal cavity cancers. 126 participants reported 1 type of cancer, 68 reported 2 types, 12 reported 3 types, 5 reported 4 types and 1 participant each reported 5 and 6 types. The 212 participants reported 297 separate sites.

Before finalising, the questionnaire was pilot tested to ensure that instructions and questions were understandable and that there was nothing in the questionnaire that was likely to cause distress. Pilot testing was limited to these aspects and was undertaken by one person only who was a cancer patient. Instructions in relation to two of the measures were amended as a result.

**Table 2.****Cancer types reported.**

| Cancer Type       | No. of participants reporting each type of cancer | Percentage of participants reporting each cancer type | Percentage of occurrence of each cancer type |
|-------------------|---|---|--|
| Neurological      | 6   | 2.82  | 2.01   |
| Blood             | 8   | 3.76  | 2.68   |
| Lymph             | 28  | 13.15   | 9.40   |
| Head & Neck       | 10  | 4.69  | 3.36   |
| Respiratory       | 11  | 5.16  | 3.69   |
| Oesophagus        | 4   | 1.88  | 1.34   |
| Stomach           | 4   | 1.88  | 1.34   |
| Breast            | 76  | 36.15   | 25.84  |
| Endocrine System  | 5   | 2.35  | 1.68   |
| Bone              | 16  | 7.51  | 5.37   |
| Urinary System    | 5   | 2.35  | 1.68   |
| Liver             | 5   | 2.35  | 1.68   |
| Melanoma          | 35  | 16.43   | 11.74  |
| Pancreas          | 2   | 0.94  | 0.67   |
| Gynaecologic      | 25  | 11.74   | 8.34   |
| Intestinal        | 26  | 12.21   | 8.72   |
| Male Genital      | 22  | 10.33   | 7.38   |
| Basal Cell        | 7   | 3.29  | 2.35   |
| Peritoneal Cavity | 2   | 0.94  | 0.67   |

**Procedure**

Approximately 90% of participants responded by contacting the researcher after seeing the flier. The balance were referred by hospital staff, cancer support group co-ordinators, psychologists and other respondents. Of those responding to the flier, approximately 65% had seen it in a pharmacy. The rest had seen it in doctors' and non-conventional therapists' rooms, hospitals and health shops. Many respondents had had their attention drawn to the flier by those displaying them.

Respondents were mailed an Information Sheet and Consent Form together with a covering letter requesting them to complete and return the Consent Form in a prepaid



envelope supplied. Two versions of Information Sheets and Consent Forms were necessary because two of the Ethics Committees of the Regional Health Authorities had slightly different requirements. Both versions of each appear in Appendix B. Upon receipt of the completed Consent Form a questionnaire was mailed with a prepaid return addressed envelope. Reminder letters were mailed to respondents who had not returned their completed Consent Forms within 21 days and similarly for those who had not returned their completed questionnaire after 30 days. Reminder letters reiterated the respondent's right to seek further information.

Finally, participants were sent a summary of the findings. This was written simply, avoiding the use of technical language or complex detail. The summary was also sent to those who assisted with participant recruitment and had requested a report of the findings.

## **Questionnaire**

The independent measures included in the questionnaire were selected from measures used in previous research with modification in some instances. These measures are described below in their four construct groupings. The dependent measure comprises the fifth construct. Table 3 contains a summary of the constructs and associated measures linked to the questionnaire.

### **1. Knowledge and understanding of cancer**

This construct was assessed on two dimensions. The first concerned declarative information based knowledge, and was assessed using two measures. One of these was derived from Stone and Siegel (1986). The questions tapped respondents' cancer knowledge in three areas. These were knowledge about the causes of cancer, cure rates for particular cancer sites, and preventative behaviour. Stone & Siegel's (1986) scale was

modified by reducing the number of items from 23 to 19, and combining the items into two sections from the authors' original three sections. The modifications were primarily to maintain relevance to the New Zealand situation and to minimise the number of items by reducing repetition. The items omitted for relevance were exposure to smog and exposure to radiation as possible factors increasing the chance of getting cancer. In the geographical area surveyed smog was not seen as a concerning factor and it was considered that a reference to radiation may have been interpreted differently by different people. Some may consider New Zealand to be radiation-free because of the country's nuclear-free status, while others may be conscious of general low-level radiation that, it is claimed, emanates from electrical installations and appliances. The other two were omitted because they were repetitive or potentially repetitive. Stone and Siegel (1986) included 'smoking' as a factor affecting the chance of getting cancer and 'avoiding smoking' as a factor in reducing the chances of getting cancer. Similarly for 'food additives' and 'artificial sweeteners'.

Stone and Siegel (1986) reported moderate internal consistency among the items in their scale (Cronbach's  $\alpha = .50$ ). They suggested that this was explained by the fact that some aspects of cancer were known by virtually all of the respondents, whereas others were known by relatively few, a common problem in knowledge indices. The present study yielded an even lower Cronbach's  $\alpha$  of .33. Arguably however, inter-item consistency or split-half measures have limited applicability for scales in which each item stands alone. Stone and Siegel (1986) did not comment on validity issues. However, they relied on the American Cancer Society, and a review by an epidemiologist, for correct answers to their items. Their scoring schedule was used in the present study. A certain amount of content validity may be assumed from this process.

Participants were required to select what they considered to be the correct response on a 4-point scale (*not at all, not much, to some extent, to a great extent*), for causes and behaviours contributing to getting cancer. Similarly, response was required on a 4-point scale (*poor, fair, good, and excellent*) for the chances of curing certain types of cancer. Each item was scored with either 2, 1, or 0. 0 was given for a wrong answer and 2

for a correct answer. 1 was given if the answer was in the correct direction. For example, where *to some extent* was checked, when a correct answer was *to a great extent*, a 1 was scored. Missing values were treated as "don't know", therefore as wrong answers.

**Table 3**  
**Summary of constructs and associated measures**

| Construct   | Questionnaire Location | Measures  | Questionnaire Location                    |
|---|------------------------|---|---|
| Knowledge and understanding of cancer             | Section A              | Information based knowledge   | Items 5 – 39<br>pages 1 & 2               |
|   |                        | Belief based knowledge  | Items 40 – 48<br>page 3                   |
| Approach to health                                | Sections D & E         | Health interest and motivation  | Items 39 – 49<br>page 6                   |
|   |                        | Motivation beliefs  | Items 50 – 52<br>& 54 page 7              |
|   |                        | Biomedical vs biopsychosocial orientation                                 | Items 53 & 55<br>page 7                   |
|   |                        | Optimism (Life Orientation Test)  | Items 56 – 67<br>page 7                   |
| Attributions of control, responsibility and blame | Section C              | Influences on Health and Illness Scale                                    | Page 5 & 6<br>Items 27 – 38               |
| Meaning   | Sections B, F & G      | Intrinsic Illness meaning (Constructed Meaning Scale)                     | Items 49 – 56<br>page 3                   |
|   |                        | Extrinsic / intrinsic illness meaning (Response to Illness Questionnaire) | Items 1 – 26<br>page 4                    |
|   |                        | Intrinsic life meaning (LAP-R)  | Items 1 – 48<br>Pages 8 - 10              |
|   |                        | Extrinsic life meaning (Royal Free Interview)                             | Items 49 – 76<br>& 1 – 5<br>pages 10 - 15 |
|   |                        | Treatment   | Section H                                 |
| Demographic Information                           | Section I              |   | pages 17 & 18                             |

The second knowledge measure was a composite measure derived from Dent and Goulston (1982), Vaeth (1993) and Weinrich and Weinrich (1986), adapted for the New Zealand situation by substituting 'New Zealand' for 'Australia' where necessary. This scale was included because it tapped different aspects of knowledge and therefore complemented the scale derived from Stone and Siegel (1986). The scale was a composite one for the following reasons. Dent and Goulston's (1982) scale was a brief (10 item) scale of general cancer knowledge. 6 of these items were used which did not overlap with items from the previous scales. 3 of the 4 items omitted from the scale referred to bowel cancer, which, in the context of the present study was considered to be an over-representation of that particular form of cancer. The fourth omitted item referred to breast cancer, which was covered in the Vaeth (1993) sourced items. Vaeth's (1993) scale assessed breast cancer knowledge only. Three breast cancer items were selected from that instrument because of its specialist nature. Weinrich and Weinrich's (1986) scale concentrated on knowledge of warning signals and myths about cancer and a selection of these was used, avoiding any repetition within Section A of the questionnaire. The resultant composite scale contained 16 items.

On both measures participants were required to mark whether they agreed or disagreed with each statement. *Agree* was scored as '0' and *disagree* as '1'. Scores on the 4 items for which *agree* was the correct answer, were reversed. Scores from the two composite measures were combined to produce a general cancer knowledge score.

Dent and Goulston (1982) reported a test-retest coefficient of .79 for their scale, and inferred content validity from the method of selection of the item pool. Internal consistency of the Vaeth (1993) scale items was demonstrated by item – subscale correlations for the items used ranging from .60 to .70, although in the present study they were used out of this context. Content validity was established by four oncology experts. The two Weinrich and Weinrich (1986) subscales evidenced internal consistency of .36 and .72 respectively as measured by the Kuder Richardson Formula 20. Content validity was confirmed by independent experts. Internal consistency of the composite scale as

used in the present study was reasonably low, however (Cronbach's  $\alpha = .31$ ), although would increase to .38 with the deletion of the item "bowel cancer is difficult to detect". This item may require a greater level of clinical knowledge than the other items.

The second dimension of the knowledge construct concerned knowledge that contains an element of belief generated by the experience of cancer. This could not be objectively assessed as right or wrong, but was assessed in terms of a positive versus negative belief system about cancer. While the items in the scale were drawn from previously developed measures, they were utilised to meet a specific conceptual requirement of the present study. The 9 items in the scale were derived from Champion's (1984) seriousness subscale (4 items), Murray and McMillan's (1993) health belief scale (3 items) and Weinrich and Weinrich's (1986) myths about cancer (2 items). Each item was chosen because it tapped a personal belief which may have been generated from personal experience (e.g., "Having cancer changes one's whole life"), or may represent a belief that is appropriate but is not an absolute (e.g., "If cancer is detected early it can be successfully treated"). Each item, however, indicated either a positive or negative belief system about one's cancer and one's future in treatment terms.

Participants were required to indicate whether they agreed or disagreed with the statements. 7 of the items were phrased negatively. The remaining 2 were phrased positively and were reverse scored. The possible score range was from 0 to 9. The higher the score, the more positive was the belief system.

Champion (1984) reported internal consistency reliability for her seriousness subscale of .78 and test-retest reliability of .76. She also reported satisfactory construct validity. The only psychometric data reported by Murray and McMillan (1993), for their health belief scale, was reliability of the coding scheme used, assessed by independent judge, yielding inter-judge agreement of 93%. Weinrich and Weinrich (1986) reported internal consistency reliability of .36 for their myths about cancer subscale, as measured by the Kuder Richardson Formula 20, but if the scale had triple the number of items (18) reliability would increase to .77. Satisfactory content validity was also reported. Internal

consistency reliability was assessed for the combined scale utilised in the present study using the Kuder Richardson Formula 20, yielding a KR-20 coefficient of .54. This may have been the effect of the relatively small number of items. Using the Spearman-Brown prophecy formula to assess this showed that if the scale had double the number of items reliability would be increased to .76, provided additional items were equivalent.

## **2. Approach to health**

### ***Health interest and motivation***

This construct was assessed with two measures located in Section D of the questionnaire. The first measure operationalised the construct in terms of self rated importance of health matters, information seeking behaviour, and participation in health matters. It comprised 11 positively framed items. 4 were derived from Champion's (1984) 8-item motivation subscale. The rest were derived from Furnham and Bhagrath (1993) (3 items), Berkanovic, Telesky, and Reeder (1981) (2 items) and the Information Styles Questionnaire (Cassileth et al., 1980) (2 items).

Champion's (1984) objective was to develop valid and reliable scales to test the Health Belief Model of which health motivation is one of the dimensions. Both the conceptual basis of the HBM motivation dimension, and Champion's (1984) measurement of it, parallels the conceptualisation and operationalisation of the construct in the present study. The 4 items selected (items 3, 4, 5, & 6) were those that were relevant for a sample of already diagnosed cancer patients. The 3 items derived from Furnham & Bhagrath (1993) (items 7, 8, & 9) added specific behaviours to the scale. For example, a Champion (1984) item was: "I do things to improve my health". A more specific Furnham & Bhagrath (1993) item was: "I read about health matters in newspapers, magazines, books etc.", potentially indicating a greater level of health motivation. The Furnham and Bhagrath (1993) items were changed from interrogatives to statements. The Berkanovic et al. (1981) items (items 1 and 2) add a more cognitive

component (e.g., "I think about my health"). The Cassileth et al. (1980) items (items 10 & 11) introduce the concept of information seeking and involvement in decision making as a component of health interest and motivation.

Participants were required to respond to a 4-point scale ranging from 0 (*not at all*) to 3 (*to a great extent*) indicating the extent to which each statement was true for them. The higher the score, the higher the level of health motivation was. Score possibilities ranged from 0 to 33.

With respect to psychometric properties, Champion's (1984) subscale demonstrated satisfactory reliability (Cronbach's alpha = .60; test-retest,  $r = .81$ ). Content validity was reported as having been judged prior to data collection. Construct validity was tested by factor analysis and all items on the health motivation factor were from the same construct. A multiple regression analysis was also computed to test the constructs with the health-behaviour. For health motivation this yielded a multiple R of .50 ( $p < .001$ ). Furnham and Bhagrath (1993) provided only reliability data (Cronbach's alpha = .81 for the health consciousness subscale). The Berkanovic et al (1981) motivation subscale demonstrated acceptable reliability and construct validity (Bates, Fitzgerald, & Wolinsky, 1994) (Cronbach's alpha for motivation = .65). No psychometric data were provided by the authors for the Information Styles Questionnaire. For the composite scale used in the present study reliability was assessed in terms of inter-item consistency yielding a Cronbach's alpha of .80. Content and construct validity was inferred to the extent that these were present in the underlying scales.

The second health interest and motivation measure comprised 4 items, which were items 1 to 3 and item 5 of the second scale in Section D of the questionnaire. The items were drawn from Furnham and Forey's (1994) general beliefs about illness subscale (2 items), Furnham and Kirkcaldy's (1996) general beliefs subscale (1 item), and Murray and McMillan (1993) (1 item). This measure was used to assess beliefs that underlie the value placed on, and the level of interest in health matters.

Respondents were required to indicate agreement or disagreement with 2 positively framed and 2 negatively framed statements. The latter were reverse scored. The items were scored in the same direction as the previous measure so that a higher score evidenced beliefs that were expected to accompany a higher level of health motivation. The scores on the two measures produced an assessment of the construct in terms of both behaviours and beliefs about health consciousness.

No psychometric data were offered by the authors for the scales from which these items were drawn. Inter-item consistency was assessed in the present study using the Kuder-Richardson Formula 20, yielding a coefficient of .10. Correction for the small number of items would be unlikely to demonstrate acceptable reliability and in the absence of any validity data from the scales from which the items were drawn, it is accepted that validity is seriously attenuated.

### ***Biomedical versus biopsychosocial orientation***

This general belief about how health matters should be approached was measured with two items derived from Furnham and Smith's (1988) belief in efficacy of treatment subscale. The items were "the body has built in mechanisms for healing itself" and "treatment should concentrate on the physical symptoms rather than on psychological and emotion aspects". They were positioned in the previously described measure (second measure, Section D) to avoid particular attention being drawn to them. This measure enabled assessment of the holistic approach to health (as a characteristic of non-conventional medicine use) compared to the conventional biomedical approach. It was included specifically for the testing of the hypothesis that those who believe that physiological and biomedical factors are the main factors in disease causation and treatment, are more likely to use conventional medicine and those who have a holistic approach are more likely to seek non-conventional treatment.



Respondents were required to indicate whether they agreed or disagreed with the statements. The items were separately scored as they each characterised a particular orientation. Furnham and Smith (1988) offered no psychometric information for the scale from which these items were drawn. Psychometric evaluation of this subscale was not undertaken in the present study either. Internal consistency procedures were inappropriate given that it was a two-item scale and retest methods were not available in the design of the study.

### ***Optimism***

The Life Orientation Test (LOT) (Scheier & Carver, 1985) was included to assess levels of dispositional optimism and pessimism. The scale consists of 12 items, 4 phrased optimistically, 4 phrased pessimistically, and 4 filler items. The scale was designed to be scored by reversing scores on the pessimism items and summing to produce an overall score, with a higher score indicating greater optimism. Marshall, Wortman, Kusulas, Hervig, and Vickers (1992) considered that optimism and pessimism are empirically differentiable, however, and confirmed this with a factor analysis of the structure of the LOT. In the present study the LOT was scored both unidimensionally and bidimensionally, the latter producing separate optimism and pessimism scores. It was considered that this approach was appropriate with cancer patients, for whom pessimism is potentially more than the absence of optimism. Participants indicated the extent of their agreement with each item on a 5-point Likert scale ranging from *strongly agree*, through *neutral* to *strongly disagree*.

Scheier and Carver (1985) reported acceptable internal consistency ( $\alpha = .76$ ) and satisfactory test-retest reliability over a 4-week interval ( $r = .79$ ). They also demonstrated adequate convergent and discriminant validity for the measure. The psychometric qualities of the LOT as a bidimensional scale require further examination. It would be reasonable however, to expect reliability and validity to be approximately equivalent.

In the present study internal consistency of the LOT was assessed both as a bidimensional and unidimensional instrument. For optimism alone Cronbach's alpha was .23 and for pessimism alpha was .77. The low alpha for optimism appeared to be attributable to the first item. By deleting item 1, alpha reliability increased to .83. This item refers to expecting the best in uncertain times. For many cancer patients life is likely to be generally uncertain, which could cause inconsistencies in the interpretation and response to this item. Zika (1996) used the LOT with multiple sclerosis sufferers, and also found that deletion of the first item increased the alpha reliability of the scale for similar reasons. Item 1 was retained in the analyses in the present study, however, to avoid any difficulties in the unidimensional application of the instrument. With the knowledge that item 1 was responsible for the low reliability in the optimism subscale, the findings for optimism may still be viewed with some confidence. Assessment of split-half reliability of the LOT as a unidimensional measure using the Spearman-Brown formula yielded a coefficient of .60 and inter-item consistency yielded an alpha of .34 (both computations excluding item 1 from the optimism scale).

### **3. Attributions of control, responsibility and blame**

This construct was assessed using Stainton Roger's (1991) Influences on Health and Illness Scale (IHI) modified as described below. The measure comprises Section C of the questionnaire. Stainton Rogers (1991) identified 4 factors in her IHI scales. The first two factors, comprising state of mind and actions items, expressed internality. The state of mind factor covered positive attitudes that are important for improving health in the future, and negative aspects that are conducive of illness. The action factor concerned a belief in one's capacity to control one's health by one's actions. Factors 3 and 4, comprising chance and powerful-other items respectively, expressed externality. Stainton Rogers (1991) found that in the chance dimension high salience was attributed to uncontrollable agents like infectious organisms, age and other people's actions, not in the sense of some malevolent fate awaiting, but more to do with the unpredictability of

factors outside the individual's control. In the 'powerful others' factor Stainton Rogers (1991) found a strong focus on religious, cultural and kinship aspects of life. This was in contrast to previous health locus of control scales (e.g., Wallston & Wallston, 1981).

The conceptual basis and the dimensions of the IHI made it particularly suitable for use in the present study. As Furnham (1994) pointed out, most of the research in the health beliefs area has concentrated on lay peoples' perceived causes of illness. Fewer studies have considered perceptions of current and future health and factors involved in the recovery from illness. The IHI provides the opportunity to explore such beliefs (Furnham, 1994) from an attributional perspective. It was out of her interest in these wider concepts of attribution of responsibility and blame, as well as control in health and illness, and her dissatisfaction with existing health locus of control scales, that Stainton Rogers (1991) developed the IHI Scale.

The IHI was modified firstly, by deleting a subscale that assessed participants' perceptions of whether they will become ill or not. This was irrelevant because the participants were already ill. Item numbers in the remaining 3 subscales were reduced from 27 to 16, 31 to 17, and 35 to 21 respectively. Some of these deletions were related to substantive relevance. For example, in the context of cancer, 'weather' is unlikely to be seen as a cause. Some were made where very similar behaviours were tapping the same factor. For example, 'my home environment' was included but not 'circumstances of my home life' and being exposed to certain substances' was included but not 'being exposed to infectious organisms'. Some were combined because conceptually they overlapped. For example, 'my home environment' and 'my working environment' were combined into an and/or possibility. Furnham (1994) also noted that there was some similarity among the items. Care was taken, however, to retain sufficient items that loaded on each of the 4 factors that Stainton Rogers (1991) had identified in the IHI (state of mind internality, action internality, chance externality, powerful others externality).

In addition, the wording of some items was modified for appropriateness to the present study. For example, because participants' health status was defined in terms of

already having cancer, the defining statement in the first subscale had to be altered from "my current state of health is due to ..." to "I consider that my cancer was due to ...". Consequently, certain items had to be given directionality. For example, "my body's natural defences" required the words "not working efficiently" added, and "taking good care of myself" became "not taking good care of myself".

Participants rated the extent to which each statement was true for them on a 7-point scale ranging from 1 (*strongly agree*) through *undecided* to 7 (*strongly disagree*). To maintain continuity in the questionnaire, directionality of each Likert scale was the same. This necessitated reverse scoring in some instances. The IHI scale was scored so that a high score on each factor (2 internality factors and 2 externality factors) represented a high level of that type of control. During analysis the items that loaded on each of these factors were identified (following Stainton Rogers, 1991) and coded accordingly.

No specific psychometric information was offered by the author of the IHI Scale. Furnham (1994), however, has confirmed the validity of the four factors comprised in the IHI by a factor analysis designed to reveal the underlying structure of the scale. Reliability of the modified IHI, as used in the present study, was assessed by measuring inter-item consistency. This revealed Cronbach's alphas of .76 and .67 respectively for the state of mind and action internality dimensions and .69 and .73 respectively for luck and powerful others externality. These represent acceptable reliability, particularly when viewed dichotomously in terms of internality and externality.

#### **4. Meaning**

The meaning construct comprised the sub-constructs of illness meaning and life meaning. Each of these was measured in terms of intrinsic and extrinsic meaning. Separate measures were necessary because intrinsicness and extrinsicness were not conceptualised as opposite ends of a continuum. If a high score on a measure of

extrinsicness disclosed high extrinsicness, a low score would not necessarily equate with high intrinsicness. Furthermore, the scale measuring an extrinsic approach to life meaning needed to include a religious component in terms of the conceptualisation of life meaning adopted in the present study, but conceptually, religiousness was not a relevant component in intrinsic meaning.

### *Intrinsic illness meaning*

This was measured with the 8-item Constructed Meaning Scale (Fife, 1995). It is the first measure in Section B of the questionnaire. This scale was designed as a measure of the meaning that is formulated by those adapting to a life-threatening illness (Fife, 1995). The measure focuses on a self constructed type of meaning that refers to the individual's perceptions of his or her ability to accomplish goals, maintain relationships, and sustain a sense of personal vitality, competence and power (Fife, 1995). It is suitable as a measure of intrinsic meaning in the present study because Fife's (1994, 1995) conceptualisation of meaning parallels the conceptualisation of intrinsic meaning in the present study. In addition, unlike previous meaning measures, the scale was specifically designed to assess meaning in illness among cancer patients.

Participants were required to respond on a 4-point scale (*strongly agree, agree, disagree, strongly disagree*). Items 1, 3, and 8 being negatively phrased, were reverse scored. The response scale was also reversed to return it to its original orientation. A higher score (on a range of 8 to 32) indicated a higher level of positive intrinsically oriented meaning.

The psychometric qualities of the Constructed Meaning Scale confirm its appropriateness for use with the present sample. Reliability and validity were assessed by Fife (1995) with a sample of 422 cancer patients representing a wide range of cancer types. They included individuals at various disease stages with an age range of 18 to 80 years. The mean age was 52.3 years. The ratio of men to women was 158/264, with 9%

being black and the balance Caucasian. Item-total correlations ranged from .50 to .73, significant at  $p < .01$ , suggesting strong homogeneity within the scale. A Cronbach's alpha reliability of .81 was also acceptable (Fife, 1995). Internal consistency computed from the data in the present study also demonstrated acceptable reliability (Cronbach's alpha = .72).

Content validity was claimed from a close association between scale items and meaning theory, supported by data obtained from interviews with cancer patients (Fife, 1995, 1994). The author also went to considerable lengths to empirically evaluate and demonstrate construct validity. Firstly it was demonstrated that the scale was able to differentiate between those newly diagnosed with non-metastatic cancer, those with the first recurrence of cancer, and those with metastatic disease. It was also able to distinguish between those having a first remission and those having recurrence or with metastatic disease. Secondly, the scale disclosed a bi-directional relationship between constructed meaning and emotional response in accordance with theory, and thirdly, it demonstrated a relationship between meaning and social support, coping strategies, personal control, body image, and psychological adjustment.

Intrinsic illness meaning was also able to be assessed with the extrinsic illness meaning scale (Pritchard, 1974a) (described below) by separately scoring from the 26 item scale, 14 items judged by this author to relate to an intrinsic approach to illness meaning. These were items 2, 3, 9, 13-17, 19, 21-23, 25 and 26, selected as intrinsic because of their internally focused orientation compared to the externally oriented approach of the remaining items. An example of the intrinsically motivated approach is the item "It is something I must overcome myself" compared to "There is nothing I can do myself about it" which is an extrinsic item in which motivation (e.g., for doing something about it) does not necessarily come from within. Another example is the intrinsically oriented item "I am ashamed of it" compared to an extrinsic item, "It is like an enemy". One item (item 26), which is concerned with thinking about one's illness, appeared to be ambiguous in terms of intrinsicness and extrinsicness. This was confirmed

to some extent by the observation that had it been deleted alpha reliability for this subscale would have increased to .59 from .51.

### *Extrinsic illness meaning*

The Response to Illness Questionnaire (RIQ) (Pritchard, 1974a, 1974b) was utilised to assess extrinsic illness meaning (see second measure, Section B of the questionnaire). Pritchard (1974a) considered that a patient is aware of his or her illness at two levels. One is the physical level that includes the experience of symptoms. The other, which the RIQ concentrates on, is an informational level at which he or she observes and evaluates the illness. Here, the primary concern is with its meaning to the patient, which influences the way he or she responds to the illness. The RIQ was selected for use in the present study because of its high correspondence to Lipowski's (1970) meanings of illness, as demonstrated by Pritchard (1974b). On the basis of clinical experience, Lipowski (1970) described eight "illness concepts" of patients. The importance to the present study of Lipowski's (1970) conceptualisation of illness meaning, is that it acknowledges an external and/or higher power belief system. The RIQ incorporates this conceptualisation.

The original RIQ (Pritchard, 1974a) contained 50 questions relating to a set of 31 inter-related variables which the author considered were relevant psychological factors in the way an individual behaves when ill. In a modified version the number of variables was reduced to 22 and the number of questions to 36 (Pritchard, 1974b). In the present study, of the 26 questions, 22 were drawn from Pritchard (1974b). The remaining 4 were drawn from the other 4 variables comprised in the Pritchard (1974a) version. The revised version (Pritchard, 1974b) incorporated 7 "causal variables" each of which comprised at least 2 sub-components (totalling 22) represented by at least 1 item. In the scale derived for the present study each sub-component was represented by 1 item only. This seemed an appropriate structure and also avoided repetition. For example, Pritchard (1974b) included 2 items for one sub-component – "I feel depressed about it" and "I feel

miserable about it". Only the latter was used in the present study. The 4 items added from the original RIQ (Pritchard 1974a) represented sub-components considered to be important in terms of the conceptualisation of meaning in the present study. They included 'just punishment' (as opposed to 'unjust punishment'), 'self-weakness', 'concealment of illness' and 'shame'.

Participants were required to indicate the extent of their agreement to the statements on a 4-point scale (*not at all, mildly, moderately, extremely*). The higher the score (on a range of 0-36), the higher was the level of extrinsic illness meaning. Because the RIQ taps both the intrinsic and extrinsic conceptualisations of meaning, the researcher was able to classify the items according to which orientation they assessed. 12 items were classified as evidencing extrinsicness and 14 as pointing to intrinsicness, as described above. The measure was then scored bidimensionally, yielding a measure of extrinsic illness meaning and another measure of intrinsic illness meaning. This had two advantages. One was to create a second measure of intrinsic illness meaning to compare with scores on the Constructed Meaning Scale (Fife, 1995). The other was as a means of confirming the construct validity of the scale as a measure of intrinsicness and extrinsicness in illness meaning.

The RIQ has been shown to have substantial test-retest reliability over a 4-week interval. This was in terms of both the whole questionnaire for each participant, and the consistency of participants' scores on each item over the two occasions. Of 27 items assessed, 4 achieved weighted Kappas greater than .81 ('almost perfect' agreement), 12 were between .61 and .80 ('substantial' agreement), 6 had 'moderate' agreement, and 5 displayed 'fair' agreement (Pritchard, 1981). Furthermore the RIQ has been tested with cardiac patients to assess its utility among those with a different illness. (It had been developed among haemodialysis patients). Pritchard (1979) found similar dimensions of illness behaviour, as measured by the RIQ, in both groups of patients, suggesting that these dimensions may be of general applicability to chronic illness. Pritchard (1974a) suggested that the questionnaire is validated by the way most of the items are related to



each other in ways that are understandable, when compared with the descriptions of other authors.

Assessment of the reliability of the instrument as used in the present study yielded a Cronbach's alpha of .62 for the extrinsic subscale and .51 for the intrinsic subscale. Alpha reliabilities of .62 and .51 suggest the need for some caution when interpreting the findings in relation to this measure. The seemingly hard and fast rule in relation to alpha coefficients in internal consistency of measures has been questioned, however. Schmitt (1996) has suggested that when a measure has other desirable qualities, such as meaningful content coverage of the domain and reasonable unidimensionality, low reliability, even in the vicinity of .50, may not be a major impediment to the use of the measure. It is suggested that these additional 'desirable qualities' are present in the use to which the two subscales of the RIQ were put in the present study.

### *Intrinsic life meaning*

The Life Attitude Profile-Revised (LAP-R) (Reker, 1992) was utilised to assess intrinsic life meaning, notwithstanding that it was designed as a general measure of life meaning. The LAP-R is a 48-item instrument which comprises and is scored on 6 dimensions (purpose, coherence, life control, death acceptance, existential vacuum, and goal seeking) combined in different ways to create 2 composite scales (Personal Meaning Index or Life Attitude Balance Index). The LAP-R comprises Section F of the questionnaire.

The authors of the LAP-R (Reker, 1992) and its predecessor, the Life Attitude Profile (Reker & Peacock, 1981), indicated that these scales measure Frankl's concepts of discovered meaning and purpose in life. It is suggested, however, that the LAP-R items may not tap Frankl's concept that an ultimate meaning and purpose already exists in the world. The items suggest, instead, that Reker's (1992) interpretation of Frankl's discovered meaning concept is that people are free to create meaning for their own lives.

Reker (1992) tends to use the terms 'discovered' meaning and 'created' meaning interchangeably. In the present study self-created meaning represents the existential intrinsic approach. This is not Frankl's discovered meaning approach, which, it is suggested, is extrinsic in nature. Furthermore, a study conducted by Reker and Wong (1988) utilising the LAP, evidenced no reported source of meaning that was pre-existent and extrinsic. The LAP and LAP-R do not account for this possibility.

An examination of the LAP-R items comprising each dimension revealed that some items could be interpreted in an extrinsic frame (e.g., items in the coherence dimension). Interpretation in this way would be entirely subjective however, and responses would not disclose that interpretation. They would simply appear as a low life purpose score. The majority of the items, however, were clearly intrinsic in orientation. For example, all items in the life control dimension were worded intrinsically. The author acknowledges that the LAP-R is an index of "the degree to which a person perceives to have personal agency in directing his/her life" (Reker, 1992, p.16). This suggests an intrinsic conceptualisation of life meaning.

In the present study the Life Attitude Balance Index (LABI) form of the LAP-R was used as a measure of intrinsicness. The LABI is derived by summing scores on purpose, coherence, life control, and death acceptance, and subtracting the scores on existential vacuum and goal seeking. Reker (1992) states that the LABI is a "measure of attitudes towards life that takes into account both the degree to which meaning and purpose has been discovered, and the motivation to find meaning and purpose" (p.20). Bearing in mind the previous suggestion that by the term "discovered", the author was actually referring to "created", in terms of Frankl's conceptualisation of meaning, the LABI provides a suitable measure of intrinsicness. A separate measure (described below) was used to assess extrinsic life meaning.

Participants were required to read each statement carefully and indicate the extent of their agreement on a 7-point Likert scale ranging from 1, *strongly agree* to 7, *strongly disagree*. For continuity in the questionnaire, the numbering was reversed from the

original with the effect that a low score on the LAP-R evidenced a high level of intrinsic meaning and purpose in life.

Reker (1992) reported highly satisfactory reliability for the LAP-R. Internal consistency coefficients across age groups and gender for each of the dimensions and for the composite scales (including the LABI) ranged from .77 to .91. For the LABI separately, internal consistency coefficients ranged between .88 and .91. Test re-test coefficients over a 4-6 week interval (N=200) ranged from .77 to .90. The present study provided further evidence of the reliability of the LAP-R with a Cronbach's alpha of .86 for the LABI form. Reker (1992) also reported satisfactory construct, concurrent, and discriminant validity for the LAP-R. Construct validity was assessed by correlating scores on the dimensions of the Sources of Meaning Profile, the Values Survey and the LAP-R, with findings supporting the construct validity of the LAP-R (Reker, 1992). Concurrent validity was assessed and confirmed in a series of 8 studies involving 18 scales as criterion variables. Discriminant validity is evidenced by low correlations with the appropriate dimensions of various scales (e.g., dispositional optimism, physical health) (Reker, 1992).

### *Extrinsic life meaning*

To assess extrinsic life meaning as conceptualised in the present study, an appropriate measure was section C of the Royal Free Interview for Religious and Spiritual Beliefs (King et al., 1995), adapted in this study for use as a self-administered questionnaire (Section G of the questionnaire). The Royal Free Interview included showing the interviewee a 10-point visual analogue scale for most questions. Adaptation as a self-administered scale required little structural change as the same rating scales were incorporated in the written questionnaire. The main content change was that in the original interview those choosing a religious approach were also asked the questions relating to the spiritual approach. That is, the religious and spiritual approaches were, to some extent, combined. In the present study, however separate religious and spiritual

approaches were given as options so it was necessary to reproduce the spiritual approach items, with appropriate wording changes, in the religious approach subscale. This was to avoid any confusion, so that a participant was required to complete a set of questions that related only to the approach chosen. Religious approach and spiritual approach were provided as separate options to accommodate those for whom spirituality, in the form of a higher power belief system for example, was important, but who did not subscribe to a religious church based approach.

The only other changes made to the wording of items were to change some of them from interrogatives to statements, which was considered more appropriate for a self-administered version. Care was taken to ensure clarity of written instructions, particularly as participants were required to answer only one of three subscales depending on their answer to a question about their approach to life.

The Royal Free Interview measure produced various data. In the first instance, participants were given a description of what was meant by religious, spiritual, and philosophical approaches to life and asked to choose how they classified their approach or whether they had "no particular understanding". They then completed a subscale relevant to the choice they made. In the religious understanding subscale, participants provided demographic type information such as religion observed, denomination if Christian, and form and frequency of participation. The spiritual approach subscale was for those who chose not to express their spiritual beliefs in a religious form. The philosophical approach subscale asked participants to classify their philosophy from a list provided. All three subscales asked about the connection between their belief system and events in their life and their world. In a final section, all participants were asked questions about the links between their current illness and their belief system.

Each of the three subscales comprised a 10-point analogue scale where 0 represented none of the quality asked about, through a neutral response (5) to 10, which represented a high level of the particular quality. Note that on the questionnaire only single boxes for coding the analogue scale scores were provided. This was rectified at the

time of coding. Scoring produced, in the first instance, a life approach classification, which was able to be used as a separate variable in the correlational and multivariate analyses. Participants classified themselves as either religious, spiritual, philosophical, or of no particular understanding. During analysis the latter two were combined producing three categories from which two dummy variables were created using ordinal coding and labelled 'life a' and 'life b'. Life a represented the difference between a spiritual approach on one hand and a religious or philosophical approach on the other, and life b represented the difference between a philosophical approach on one hand and religious or spiritual approach on the other.

Finally, a set of three scales was derived from the measure, unlike from the interview version, where only two scales resulted. The three-scale set comprised religious understanding, spiritual understanding (without a religious component) and philosophical understanding. Within each scale the item scores were summed as follows. Religious understanding only: Items 12, 13, 14 and 15; Spiritual understanding: All items; Philosophical understanding: Items 6, 7, and 8.

The data resulting from the "all participants to complete" items were not incorporated in the above scales either by King et al. (1995) or in the present study. In this study these items, with the exception of item 4, were treated as a separate subscale for the assessment of extrinsic meaning and inclusion in the multivariate analyses. There were two reasons for this. One was that the items are conceptually suitable for distinguishing between an intrinsic and extrinsic approach to meaning, a higher score indicating a more extrinsic approach. The other reason was that all participants completed this subscale. This meant that unlike the religious and spiritual subscales where participants were deemed to be extrinsically oriented by choosing to complete either of these subscales, the 'all participants' subscale differentiated among all participants in terms of an intrinsic or extrinsic orientation by their scores on the subscale. Participants were required to complete similar 10-point analogue scales as for the three earlier subscales.

King et al. (1995) reported an alpha coefficient for internal reliability of .81 for the spiritual scale and .60 for the philosophical scale. Test-retest reliability coefficients were .95 for the spiritual scale and .91 for the philosophical scale over a one week interval and Kappa coefficients were high for the categorical variables. Lower internal consistency for the philosophical scale was not a concern since, in the present study, the religious and spiritual scales are of primary concern as a measure of extrinsic life meaning. In the present study alpha coefficients for internal reliability were .90 for the religious approach subscale, .90 for the spiritual approach subscale, and .56 for philosophical approach. The additional extrinsic meaning scale (the 'all participants' subscale) yielded an alpha of .78. The authors undertook no concurrent validity assessment but did undertake two measures of criterion validity. The association between spiritual belief and reported religious observance yielded a Pearson correlation coefficient of .41 ( $p < .0005$ ). Secondly, scores on the spiritual scale for the third group of participants known to have strong religious associations were significantly higher than in the GP and hospital populations.

## **5. Treatment.**

Type of treatment(s) used was assessed by requesting participants to select, from a list of 53 treatments, which one or ones they had used at any time since diagnosis of cancer, or were currently using for their cancer. (Questionnaire Section H). The first 3 items on the list were conventional medicine treatments (chemotherapy, radiation therapy and surgery). To enable participants to recognise that these were conventional treatments a space was left between these 3 items and the beginning of the list of non-conventional remedies. The 50 non-conventional remedies were listed in alphabetical order. They represented 50 of the most common remedies used in New Zealand (Cooper, 1993). Provision was made for participants to add to the list and a further 21 therapies were added. Table 4 contains all treatments used, and the number of participants who used each.

**Table 4**  
**Therapies used as reported by participants**

| Therapy                               | No. of participants | Therapy                 | No. of participants |
|---------------------------------------|---------------------|-------------------------|---------------------|
| Chemotherapy                          | 87                  | Radiation Therapy       | 103                 |
| Surgery                               | 171                 | Acupressure             | 14                  |
| Acupuncture                           | 20                  | Alexander Technique     | 2                   |
| Aroma Therapy                         | 34                  | Ayurveda                | 1                   |
| Bach Flower Remedies                  | 29                  | Bioenergetics           | 3                   |
| Biofeedback Training                  | 3                   | Bowen Techniques        | 6                   |
| Chelation Therapy                     | 3                   | Chiropractic            | 10                  |
| Colour Therapy                        | 15                  | Crystal Therapy         | 14                  |
| Deep Tissue Massage                   | 18                  | Dieting                 | 68                  |
| Faith Healing                         | 17                  | Fasting                 | 9                   |
| Gemstone Therapy                      | 3                   | Gerson Therapy          | 3                   |
| Hellerwork                            | 0                   | Herbal Medicine         | 53                  |
| Homoeobotanical Therapy               | 5                   | Homoeopathy             | 53                  |
| Hoxsey Treatment                      | 13                  | Hydrotherapy            | 1                   |
| Hypnotherapy                          | 8                   | Imagery & Visualisation | 51                  |
| Iridology                             | 16                  | Kinesiology             | 6                   |
| Maori Medicine & Healing Methods      | 3                   | Massage Therapy         | 40                  |
| Meditation                            | 59                  | Naturopathy             | 53                  |
| Neurolinguistic Programming           | 3                   | Osteopathy              | 18                  |
| Ozone Therapy                         | 2                   | Polarity Therapy        | 5                   |
| Prayer                                | 77                  | Pritikin Diet           | 8                   |
| Psychic Surgery                       | 0                   | Rebirthing              | 4                   |
| Reflexology                           | 15                  | Reiki                   | 18                  |
| Rolfing                               | 0                   | Shiatsu                 | 2                   |
| Spiritual Healing                     | 30                  | Therapeutic Touch       | 10                  |
| Vegetarianism                         | 32                  | Vitamin Therapy         | 74                  |
| Yoga                                  | 20                  | Fitness Program         | 6                   |
| Floatation Therapy                    | 1                   | Laughter Therapy        | 5                   |
| Relaxation                            | 2                   | Art Therapy             | 1                   |
| Tai Chi                               | 6                   | Journalling             | 1                   |
| Hakomi                                | 1                   | Spirit Channelling      | 2                   |
| Chinese Medicine                      | 2                   | No Treatment            | 1                   |
| Shark Cartilage                       | 1                   | Quantum Dynamics        | 1                   |
| Electro Acupuncture according to Volt | 1                   | Music Therapy           | 1                   |
| Anthroposophical meditation           | 1                   | Curative Eurythmics     | 1                   |
| Psychotherapy                         | 1                   | Oxygen Therapy          | 1                   |
| Feng Shui                             | 1                   | Immunotherapy           | 1                   |

The treatment choice variable was approached in two ways. The first was where the difference between conventional and non-conventional treatment was dichotomised between the 3 conventional treatments and the 71 non-conventional remedies. This recognised the "traditional" division between conventional and non-conventional medicine. In the alternative approach, treatments were reclassified, a priori, into 4 treatment classes by the researcher. This classification system discarded the traditional arbitrary distinction between so called conventional and non-conventional remedies and classified treatments according to their conceptual approach. It is acknowledged that there is more than one basis upon which such classification could be made. The system used in the present study involved firstly, a consideration of the fundamental nature and methods of each treatment. Consideration was then given to the common understanding of the basis of each treatment and a decision made as to which category it should fall into having regard to both aspects. The reason for taking both aspects into account was to ensure that treatments were classified as nearly as possible in accordance with users' likely understanding of them. For example, some treatments have a strong basis in the metaphysical and psychic realm, yet are perceived and used as a physical or nutritional type of treatment. Such a treatment would have been classified according to its common usage. Others may have an obvious physical component, but are generally recognised as having, for example, a spiritual or metaphysical basis. Such a treatment was placed in the metaphysical category (e.g., yoga).

The first category was physical treatments. This included the conventional treatments and those from the non-conventional list that were essentially physical in their method (e.g., chiropractic). The second category included nutritional and dietary approaches to treatment. Arguably, treatments in this category should not be differentiated from the first category if chemotherapy and radiation treatment were to remain in that category. To test for this, analyses were also performed with these categories collapsed into one. The third category included psychologically based treatments. The fourth category comprised those treatments best described as psychic and metaphysical. Table 5 shows the classification of treatments actually used by participants. It is reiterated that this is describing the alternative approach to classifying treatments.



During analysis the traditional dichotomy between conventional and non-conventional treatment was also accounted for.

Two further categories were created. The first of these was prayer. This was treated as a separate variable because while it was not seen as a treatment per se, it was expected to be associated with the approach to treatment. As shown in table 4, 77 participants reported using prayer. It should be noted that of these, three are included in the 'no conventional' category shown in table 6. The second additional category was 'no treatment' to account for the one participant who reported this, but it was not included in the analyses as a treatment type.

**Table 5**  
**Classification of treatments**

| Physical                                 | Nutrition /<br>Diet Natural | Psychological               | Psychic /<br>metaphysical      |
|--|-----------------------------|-----------------------------|--------------------------------|
| Chemotherapy                             | Chelation Therapy           | Alexander Technique         | Acupuncture                    |
| Radiation Therapy                        | Dieting                     | Faith Healing               | Aromatherapy                   |
| Surgery                                  | Fasting                     | Hypnotherapy                | Ayurveda                       |
| Acupressure                              | Gerson Therapy              | Imagery & Visualisation     | Bach Flower Remedies           |
| Biofeedback Training                     | Herbal Medicine             | Meditation                  | Bioenergetics                  |
| Bowen Techniques                         | Homoeobotanical Therapy     | Rebirthing                  | Colour Therapy                 |
| Chiropractic                             | Homoeopathy                 | Neurolinguistic Programming | Crystal Therapy                |
| Deep Tissue Massage                      | Hoxsey Treatment            | Floatation Therapy          | Gemstone Therapy               |
| Hydrotherapy                             | Maori Medicine              | Laughter Therapy            | Polarity Therapy               |
| Iridology                                | Naturopathy                 | Art Therapy                 | Reiki                          |
| Kinesiology                              | Ozone Therapy               | Journalling                 | Shiatsu                        |
| Massage Therapy                          | Pritikin Diet               | Hakomi                      | Spiritual Healing              |
| Osteopathy                               | Vegetarianism               | Music Therapy               | Therapeutic Touch              |
| Reflexology                              | Vitamin Therapy             | Psychotherapy               | Yoga                           |
| Fitness Program                          | Chinese Medicine            |                             | Tai Chi                        |
| Relaxation                               | Shark Cartilage             |                             | Spirit Channelling             |
| Immunotherapy                            | Oxygen Therapy              |                             | Quantum Dynamics               |
| Electro Acupuncture<br>according to Volt |                             |                             | Anthroposophical<br>Meditation |
|  |                             |                             | Curative Eurythmics            |
|  |                             |                             | Feng Shui                      |

The 6 treatment categories as referred to above, were allocated labels as follows: Conventional; physical; natural; psychological; psychic/metaphysical; prayer; Each treatment type was then allocated to one of 10 different treatment classes as displayed in table 6. The number of participants in each treatment class is also shown in table 6.

**Table 6.**  
**Make up of treatment classes**

| Treatment types                              | Treatment class | <i>N</i> |
|--|-----------------|----------|
| conventional (con)                           | = 1             | 39       |
| con + physical (phy)                         | = 2             | 3        |
| con + phy + natural                          | = 3             | 23       |
| con + phy + nat + psychological (psy)        | = 4             | 13       |
| con + phy + nat + psy + psychic/metaphysical | = 5             | 50       |
| No treatment                                 | = 6             | 1        |
| con + prayer                                 | = 7             | 18       |
| con + phy + nat + prayer                     | = 8             | 18       |
| con + psy + psychic/metaphysical + prayer    | = 9             | 38       |
| No conventional                              | = 10            | 9        |

To enable the study to investigate firstly, distinctions between the traditional conceptualisation of conventional and non-conventional treatment, and secondly, the effect of altering the definition of conventional and non-conventional, it was necessary to create treatment groupings in which the conventional group (of treatments) and the non-conventional group were defined differently between the groupings. In other words, the difference between each treatment grouping was the positioning of the dividing line between conventional and non-conventional treatments. The configuration of each treatment grouping is shown in table 7.

**Table 7**  
**Configuration of the 4 treatment groupings**

| Treatment Grouping | Configuration of Treatment Grouping by Treatment class |
|--------------------|--|
| 1                  | = 1 vs 2, 3, 4, 5, 8, 9, 10                            |
| 2                  | = 1 + 7 vs 2, 3, 4, 5, 8, 9, 10                        |
| 3                  | = 1 + 2 + 3 + 7 + 8 vs 4, 5, 9, 10                     |
| 4                  | = 1 + 2 + 3 + 4 + 7 + 8 vs 5, 9, 10                    |

### Data Analysis

Data analysis was carried out using the SPSS standard statistical package, version 6. The strategies employed to meet the objectives of the study and examine the research questions were mainly correlational and a series of four two group standard discriminant function analyses. Preliminary correlational analyses used two-tailed tests of significance with an alpha level of  $<.05$ . Discriminant analysis is used when groups of individuals are defined a priori and the purpose of the analysis is to distinguish the groups from one another on the basis of the observed scores on the set of independent variables (Nunnally, 1978). It is generally recognised that discriminant analysis has two main uses. One is where it is used for establishing the probability of cases falling into a particular group. The other is its use in maximising the discrimination among groups by combining the variables in some manner (Nunnally, 1978). This includes an explanatory function of identifying the relative contributions of a single variable or a group of variables to the discrimination between the groups. In the present study discriminant analysis was used for examining and understanding group differences rather than for predicting group membership.

The direct-entry discriminant analysis procedure, where all variables are entered simultaneously, was used in the present study because there was no theoretical basis for entering discriminating variables individually or in any specified priority order as in stepwise discriminant analysis.

## **Ethics**

Ethical approval for the research was obtained in the first instance from the Massey University Human Ethics Committee. Because the research was being conducted among patients, many of whom would be currently undergoing treatment in the health system, it was necessary to obtain additional approval from the Ethics Committees of the relevant Regional Health Authorities (RHA's), as they were then named. Ethical approval was sought and obtained from the Manawatu-Whanganui Ethics Committee of the Central RHA, the Wellington Ethics Committee of the Central RHA, and the Ethics Committee of the Northern RHA.

Resulting from this, two forms of Consent and Information Sheet were required. The main differences in requirements were that the Northern RHA Committee required a reference in the Consent Form to the availability of an interpreter in four Pacific Island languages in addition to New Zealand Maori. In the Information Sheet, a reference to and contact telephone number for the Auckland Health Advocates Trust, was also required by the Northern RHA Committee. Copies of both forms of Consent Form and Information Sheet appear in Appendix B.

The content of the Consent Forms, Information Sheets and covering letter to prospective participants stressed the following important ethical matters: Details of what would be required of participants in completing the questionnaire; the opportunity to ask any questions; the right to withdraw from the study at any time and to decline to answer any question. Confidentiality was assured and it was stressed that the researcher would have no contact with the participants' health professionals, nor would the researcher have anything to do with the clinical aspects of participants' health or treatments. Participants were also advised that support contacts would be available if needed. In construction of the questionnaire care was exercised to avoid any questions of an aversive or emotionally disturbing nature, particularly having regard to the frequently fearful and generally stressful nature of life with cancer. A summary of the findings of the study was sent to participants.

## CHAPTER EIGHT

### THE HEALTH-RELATED COGNITIONS OF CANCER PATIENTS

In this chapter and the following chapter the results of the study are presented. The format of presentation in this chapter is as follows. Firstly, a picture of the sample as a whole is presented. This is in terms of their knowledge and understanding of cancer, their approach to health, their attributions of control, responsibility and blame, and the meaning they see in their illness and their life. Demographic details of the sample, including types of cancer and treatments used, were presented in the previous chapter. Bivariate analyses follow, with an examination of the intercorrelations among discriminating variables, firstly to identify any patterns or trends among variables, and secondly to confirm the theoretical and conceptual basis of the study at both a construct and subconstruct level.

#### **Univariate characteristics of the sample**

The theoretical basis of the study comprised the four constructs referred to above operationalised mostly by two or more variables. In summarising the univariate data arising from these variables, this section points out tendencies and patterns that emerge and provides an overall picture of this sample of cancer patients.

#### ***Knowledge and understanding of cancer***

On the causes and curability subscale respondents achieved a mean percentage correct of 55.34 (N =212). A mean percentage correct of 70.25 (N =212) was achieved on the more general cancer knowledge measure. This suggests that in terms of information based knowledge, participants displayed a reasonable level of understanding.

The belief system dimension of cancer knowledge yielded a mean score of 6.45 (SD = 1.56) (N = 198) on a score range of 0-9, where the higher the score the more positive the belief about one's life and future with cancer. This demonstrates, overall, a reasonably positive belief system given the nature of the respondents' health situations.

### ***Approach to health***

Participants also displayed a reasonable level of interest and motivation about involvement in their health. Results were normally distributed with a mean of 24.4 (SD = 4.58) (N = 211) from a possible 33. In terms of beliefs that underlie health interest and motivation, less positive motivation was indicated with a mean score of 1.85 (SD = .38) (N = 206) on a score range of 0-4. This variable was assessed, however, with a less sensitive 'agree' or 'disagree' scale.

In terms of holistic versus biomedical approach to illness 76.9% of patients classified themselves as embracing a holistic orientation, while only 1.9% demonstrated a purely biomedical approach. The 21.2% who were unable to be classified either way suggest that, as a forced choice 'agree' 'disagree' dichotomy, the measure may have been insensitive. At least 21% were a bit of both. Measurement on a continuous scale may have provided a more accurate picture. While the findings on this variable may be seen as confirmatory of a trend towards interest and personal involvement in health matters, it was considered insufficiently distinctive, in a methodological sense, to be included in further analyses. This was justified in a conceptual sense also in that this variable overlapped the health interest and motivation variable.

Overall mean optimism scores depict the present sample as reasonably optimistic given their health situation. Scored conventionally, the LOT yielded a mean optimism score of 22.5 (SD = 2.8), which is comparable to the scores in a normative sample of undergraduate men and women (M = 21.03, SD = 4.56 and M = 21.41, SD = 5.22,

respectively) (Scheier & Carver, 1985). The mean score was also comparable to that obtained by Friedman et al. (1992) among a sample of cancer patients ( $M = 21.9$ ,  $SD = 4.7$ ). Bidimensional scoring of the LOT produced proportionately higher mean optimism ( $M = 15.0$ ,  $SD = 3.1$ ) with a mean pessimism score of 14.0 ( $SD = 1.95$ ). Examination of item frequencies showed that some participants had maximum scores on optimism while others had maximum pessimism scores, indicating that there were both highly optimistic and highly pessimistic participants.

### ***Attributions of control, responsibility and blame***

Overall, participants evidenced more internally oriented attributions of control and responsibility. Mean scores were similar ( $M = 110.9$ ,  $SD = 16.16$ ,  $N = 208$  for internality and  $M = 114.1$ ,  $SD = 18.56$ ,  $N = 200$  for externality), however, possible score ranges were 22 to 154 and 32 to 224 respectively. Actual scores ranged from 50 to 149 for internality, whereas for externality scores ranged between 76 and 166. This suggests that those who made internal attributions were more definite or stronger in their orientation than those who made external attributions.

### ***Meaning***

In terms of meaning in illness the present sample of cancer patients demonstrated a more intrinsic than extrinsic orientation. On the primary measure of intrinsic illness meaning (Constructed Meaning Scale (Fife, 1995)) (CMS) the mean score was 24.9 ( $SD = 4.01$ ,  $N = 211$ ) from a possible score of 32. Extrinsic illness meaning (RIQ (Pritchard, 1974a, 1974b)) yielded a mean score of 11.1 ( $SD = 4.91$ ,  $N = 206$ ) from a possible maximum of 36. This trend was confirmed by results from the intrinsically oriented items of the extrinsic illness meaning scale. This mean was 25.6 ( $SD = 4.67$ ,  $N = 204$ ) from a possible maximum of 42.

The trend towards intrinsic orientation was also evident for life meaning. The standard scoring procedure for the LABI index of the LAP-R (Reker, 1992) is to sum the purpose, coherence, life control and death acceptance dimensions, and subtract scores on the existential vacuum and goal seeking dimensions. The former assess a positive life approach while the latter are framed in terms of uncertainty and dissatisfaction with life. This may not be a very sensitive measure of intrinsic life meaning, however, because the 'uncertainty' score has the effect of reducing the level of intrinsic meaning rather than acknowledging uncertainty as a separate dimension. To get a picture of life meaning approach for this sample it is helpful to examine the two LABI subscales separately. The mean score on the four positively framed dimensions was 161.53 (SD = 26.03) from a possible 224 with a range of 92 to 224. The mean score on the two uncertainty dimensions was 62.00 (SD = 13.88) from a possible 105. This demonstrates a noticeably intrinsic approach to life's meaning accompanied by some uncertainty and dissatisfaction.

Further indication of the intrinsic versus extrinsic approach to life's meaning is provided by the Royal Free Interview for Religious and Spiritual Beliefs data. In the first instance participants were required to classify themselves from four alternative approaches to life. The first two ('religious' and 'spiritual') were conceptualised as representing an extrinsic approach and the latter two ('philosophical' and 'no particular understanding') as representing an intrinsic approach. 37.7% classified themselves as religious, 32.1% as spiritual, 24.1% as philosophical and 6.1% had no particular understanding (N = 212). On this basis 69.8% were broadly self-classified as favouring an extrinsic approach.

Examination of variable levels within these categories was necessary to gauge the levels of involvement of religious and spiritual aspects in the lives of these respondents. Mean scores across the four items that assessed level of involvement of religious and spiritual beliefs (e.g., their influence on life's events, influence on coping, help with understanding the world, and their help with illness) were 29.02 (SD = 9.26) and 26.47 (SD = 9.56) (on a score range of 0 - 40) for religious approach and spiritual approach



respectively. Both had a modal score of 40. This suggests that for the 69.8% of the sample who reported an extrinsic higher power approach to life, the level of involvement of their beliefs in their lives is reasonably high.

Examination of those items that were concerned with the more activity based expression of a religious approach to life also disclosed a reasonably highly motivated sample ( $N = 80$ ). For example, the mean score on importance to the respondent of the practice of their faith was 7.86 ( $SD = 2.34$ ) with a modal score of 10 (on a scale of 0-10). Similarly 82.5% of respondents reported engaging in private prayer, with 78.75% attending worship services. These compare with activities such as contact with a religious leader and religious rituals engaged in by 37.5% and 21.25% respectively.

Viewing the sample as a whole revealed that participants were generally reluctant to blame God or a higher power for their situation. Mean scores out of 10 were 1.11 ( $SD = 2.4$ ) for illness as punishment, 2.81 ( $SD = 2.97$ ) for illness as predetermined, 3.13 ( $SD = 3.43$ ) for illness as a test, and 3.16 ( $SD = 3.32$ ) for illness as linked to approach to life. Overall mean was 10.21 ( $SD = 8.52$ ), on a score range of 0-40, with a modal score of 0. On the other hand, the mean score (out of 10) for illness as a consequence of lifestyle was 6.38 ( $SD = 2.4$ ). This reflects a more self-responsible attributional component, and signals that an extrinsic orientation in terms of meaning may not precisely reflect an externally focused attributional style.

The scores of those who reported a philosophical approach were also reasonably definitive suggesting that the measure discriminated between the different approaches to life's meaning. The mean score across the four items that assessed level of involvement of philosophical beliefs was 18.13 ( $SD = 5.86$ ) on a score range of 0 - 30. In terms of specific type of philosophical approach 66.7% of these participants reported a humanistic approach, which was specifically defined as belief in human effort rather than religion. Only 13.7%, however, reported an atheistic approach. 39.2% also reported an approach labelled "existential" in the questionnaire, defined as man being free and responsible for his own acts.

Summarised, the univariate characteristics of the sample indicate that cancer patients are reasonably knowledgeable about cancer and reasonably positive in their beliefs about their future with cancer. Similarly, they were reasonably interested in and motivated to be personally involved in their health care and tended to be holistic in their approach to illness. Overall, they maintained a reasonably optimistic outlook on life. They were also more internally oriented in terms of control and responsibility, and similarly in terms of meaning. On one measure, a more intrinsic approach was evident for both meaning in illness and in life. On a second measure, however, the majority self-classified as more extrinsically oriented. This may have been a function of the measurement process, however, and is addressed below in relation to subsequent analyses. Both the intrinsically and extrinsically oriented groups demonstrated commitment to their respective orientations.

### **Relationships among discriminating variables**

Correlations among discriminating variables were examined, firstly to consider the interrelation of the variables within each of the major constructs in the study. The variables comprised in each construct and the measures associated with them were intended to represent the conceptual basis of the construct. Accordingly, within constructs a certain level of association was expected among most of the component variables as they added to the operationalisation of the construct. Secondly, correlations among discriminating variables were examined to obtain a preliminary picture of the association among the constructs prior to multivariate analysis. Similarly, a certain amount of association among discriminating variables would be expected in an additive structure such as in this study. They should not display strong associations, however, otherwise one or other of the correlated variables is superfluous (Tacq, 1997). The expectation was that use of non-conventional medicine would be associated with a particular combination of these constructs. That combination was foreshadowed in figure 1 (Chapter 1) and set out in the hypotheses (listed in Chapter 6).

### ***Relationships within constructs***

As expected, the two knowledge dimensions were not associated. They were intended to capture different aspects of knowledge about cancer. The first dimension, objective information based knowledge, was not seen as conceptually related to the second dimension which captured more subjective personal beliefs about having cancer, for which there were not right or wrong answers.

Similarly, the approach to health construct comprised variables that essentially captured separate facets of the approach to health. This is demonstrated in Table 8 with the relationships of note being mainly between optimism and pessimism. As expected, bidimensional scoring of the LOT disclosed a moderate inverse relationship between pessimism and total optimism (scored unidimensionally) ( $r = -.49, p < .001$ ) and a weak but positive relationship between optimism and total optimism ( $r = .17, p < .05$ ). Unexpectedly, however, pessimism and optimism (scored separately) were positively correlated ( $r = .37, p < .001$ ). Perhaps cancer patients are not prepared to speak in terms of being exclusively pessimistic or optimistic as the bidimensional scoring approach assumes, but are more inclined to see optimism and pessimism as being on a continuum in the way in which the LOT was originally conceived. The latter approach may take into account the temporal fluctuations in optimistic or pessimistic feelings, which are most likely characteristic of the cancer experience. Marshall et al. (1992) also found that when optimism and pessimism were scored separately on the LOT they tended to co-vary, which appears to violate common sense. They noted, however, that certain optimistic and pessimistic thoughts represented in the items may not be inherently incompatible. The two health interest and motivation variables evidenced a weak association with each other, which was appropriate. While a positive relationship with optimism was expected, motivation beliefs being associated with lower pessimism was, nevertheless, appropriate (see Table 8). The holistic versus biomedical approach variable was not associated with any of the others within the health approach construct.

**Table 8.****Intercorrelations among approach to health variables (N = 205)**

|                    | Motivation<br>beliefs | Optimism | Pessimism | Total<br>Optimism | Holistic vs<br>biomedical |
|--------------------|-----------------------|----------|-----------|-------------------|---------------------------|
| Motivation         | .14*                  | .10      | .10       | .01               | .02                       |
| Motivation Beliefs |                       | -.09     | -.14*     | .04               | -.06                      |
| Optimism           |                       |          | .37**     | .17*              | .06                       |
| Pessimism          |                       |          |           | -.49**            | .14                       |
| Total Optimism     |                       |          |           |                   | .05                       |

\*  $p < .05$ , \*\*  $p < .001$

Associations among the components of the attributions of control, responsibility and blame construct provide mainly construct validity information about the utility of the IHI as a measure of health locus of control. The intercorrelations among the four variables comprising the components of the construct (state of mind internality, action internality, luck externality, powerful others externality), as well as two combining variables (internality and externality), are shown in Table 9. As expected, the two internality components were reasonably strongly associated ( $r = .69$ ,  $p < .001$ ), but this indicates that there is some difference in the content of internality tapped by each. Unexpected associations were found, however, between the two internality components and powerful others externality ( $r = .39$ ,  $p < .001$ , and  $r = .38$ ,  $p < .001$ ). The combined variables (internality and externality) were also unexpectedly associated ( $r = .34$ ,  $p < .001$ ), but correlations among these and the component variables were in the appropriate directions. Internality was strongly associated with each of the internality components ( $r = .92$ ,  $p < .001$  for both) but not with the externality components ( $r = .14$ ,  $p < .01$  and  $r = .41$ ,  $p < .001$ ). Similarly, externality was strongly associated with the externality components ( $r = .84$ ,  $p < .001$  and  $r = .68$ ,  $p < .001$ ) but not with the internality dimensions ( $r = .26$ ,  $p < .001$  and  $r = .38$ ,  $p < .001$ ). That there is some relationship evidenced, however, may reflect the potential for internality and externality to be mixed rather than being mutually exclusive categories. Furthermore, the experience of cancer may encourage a mixture of internality and externality at different stages of the disease process, for example.

**Table 9****Intercorrelations among components of attributions of control, responsibility and blame construct.**

|                 | Action<br>internality | Luck<br>externality | Powerful others<br>externality | Internality | Externality |
|-----------------|-----------------------|---------------------|--------------------------------|-------------|-------------|
| State of mind   | .69***                | .06                 | .39***                         | .92***      | .26***      |
| Internality     |                       |                     |                                |             |             |
| Action          | —                     | .22**               | .38***                         | .92***      | .38***      |
| Internality     |                       |                     |                                |             |             |
| Luck            |                       | —                   | .18*                           | .14*        | .84***      |
| Externality     |                       |                     |                                |             |             |
| Powerful others |                       |                     | —                              | .41***      | .68***      |
| Externality     |                       |                     |                                |             |             |
| Internality     |                       |                     |                                | —           | .34***      |

\*  $p < .05$ , \*\*  $p < .01$ , \*\*\*  $p < .001$

As demonstrated in table 10, relationships among life meaning and illness meaning variables were inconsistent with conceptual expectations. For example, intrinsic life meaning (LABI index) was negatively associated with intrinsic illness meaning on both measures ( $r = -.23$ ,  $p < .001$  and  $r = -.26$ ,  $p < .001$ ) but positively related to extrinsic illness meaning ( $r = .31$ ,  $p < .001$ ). Intrinsic life meaning as represented by the purpose, coherence, life control and death acceptance (“pucolcda”) subscale of the LABI, however, which was, as expected, highly correlated with the LABI ( $r = .90$ ,  $p < .001$ ), was associated with illness meaning in the opposite directions to those for the LABI variable. These findings were unexpected particularly since illness meaning was conceptualised and measured in terms of intrinsic and extrinsic meaning in the same way life meaning was conceptualised. The expectation was that intrinsic illness meaning would be associated with intrinsic life meaning and similarly for extrinsic meaning, with the corresponding inverse relationships.

**Table 10****Intercorrelations among life and illness meaning variables**

|                      | Pucolcda<br>N = 208 | Evgs<br>N =208 | Ext. life<br>mean<br>N =208 | Phil.<br>mean<br>N =51 | Rel.<br>mean.<br>N =79 | Spi.<br>mean.<br>N =63 | Int. ill<br>mean<br>(RIQ)<br>N =200 | Ext. ill<br>mean.<br>(RIQ)<br>N =201 | Int. ill<br>mean.<br>(CMS)<br>N =203 |
|----------------------|---------------------|----------------|-----------------------------|------------------------|------------------------|------------------------|-------------------------------------|--------------------------------------|--------------------------------------|
| Int. life mean. +    | .90***              | -.57***        | .03                         | -.14                   | -.15                   | -.22                   | -.23***                             | .31***                               | -.26***                              |
| Pucolcda             |                     | -.16*          | .13                         | .17                    | .14                    | .30*                   | .12                                 | -.18**                               | .27***                               |
| Evgs                 |                     |                | .26***                      | -.03                   | -.07                   | .08                    | -.25***                             | .31***                               | -.05                                 |
| Ext. life mean. ++   |                     |                |                             | .14                    | .16                    | .44***                 | -.21**                              | .12                                  | -.15*                                |
| Phil. Mean +++       |                     |                |                             |                        | -                      | -                      | -.19                                | -.10                                 | .17                                  |
| Rel. mean +++        |                     |                |                             |                        |                        | -                      | -.03                                | .14                                  | -.04                                 |
| Spi. Mean +++        |                     |                |                             |                        |                        |                        | .09                                 | -.11                                 | .09                                  |
| Int. ill. mean (RIQ) |                     |                |                             |                        |                        |                        |                                     | -.55***                              | .28***                               |
| Ext. ill. mean (RIQ) |                     |                |                             |                        |                        |                        |                                     |                                      | -.35***                              |

\*  $p < .05$ , \*\*  $p < .01$ , \*\*\*  $p < .001$ .

*Note* Pucolcda – purpose, coherence, life control, death acceptance dimensions of LABI

Evgs – existential vacuum, goal seeking dimensions of LABI

RIQ – Response to Illness Questionnaire

CMS – Constructed Meaning Scale

+ LABI Index (pucolcda-evgs) (Intrinsic life meaning)

++ Royal Free Interview Subscale completed by all participants.

+++ Royal Free Interview Subscales (Philosophical meaning, Religious meaning spiritual meaning)

In a sense, the relationships among the life meaning and illness meaning variables were inconsistent with the relationships among the illness meaning variables themselves. The latter tended to confirm the intrinsic / extrinsic conceptualisation as relevant to illness meaning. The two subscales generated from the RIQ (Pritchard, 1974a, 1974b) appear to tap the separate components (intrinsic and extrinsic) of illness meaning. The CMS (Fife, 1995), judged by this author as measuring intrinsic illness meaning, also appears to tap that approach to illness meaning. The relationship between that instrument and the RIQ components was not strong but they were significant and directionality was appropriate.

In relation to life meaning, the suggestion made earlier in this chapter that using only the purpose, coherence, life control and death acceptance dimensions (pucolcda) of the LABI without subtracting scores on the existential vacuum and goal seeking (evgs)

dimensions was appropriate in the present study context, appeared to have some foundation. The LABI index (pucolcda-evgs) was strongly associated with the intrinsic (pucolcda) dimensions ( $r = .90, p < .001$ ) and negatively associated with the uncertainty (evgs) dimensions ( $r = -.57, p < .001$ ).

An unexpected finding was the relationship between intrinsic life meaning (pucolcda) and spiritually derived meaning (conceptualised as extrinsic meaning) ( $r = .30, p < .05$ ). An inverse relationship was expected between intrinsic life meaning and both religiously and spiritually derived meaning. The present finding, however, may have been affected by the relatively small sample sizes of these subsets, although it is worth noting that there was, as expected, a moderate relationship between spiritually derived meaning and the overall extrinsic life meaning variable ( $r = .44, p < .001$ ). This was not, however, repeated for religiously derived meaning, which was unexpected.

The correlations displayed in Table 10 also indicate that the variable 'extrinsic life meaning', which comprised those items from the Royal Free Interview measure which were completed by all participants, may not be suitable as an overall measure of extrinsicness. Only spiritually derived meaning was associated with this variable. This raises two questions. One relates to the construct validity of this measure. Given that there is theoretical justification for the conceptualisation of religious and spiritual meaning as extrinsic meaning variables, the expectation was that both would be reasonably strongly associated with the overall extrinsic meaning variable. Similarly, it was expected that philosophical meaning, as an intrinsically based variable, would be negatively correlated with the extrinsic variable, which was not found. Another possibility is that there is less conceptual similarity between spiritually and religiously derived meaning than anticipated. This possibility is explored further in later chapters.

In summary, relationships among variables within constructs were found to be as expected in relation to the knowledge and understanding of cancer and approach to health constructs. In relation to attributions of control, responsibility and blame, a suspicion that internality and externality were not entirely dichotomous was confirmed, but a greater

relationship than expected was found between powerful others as a component of externality and the components of internality. In terms of meaning, some unexpected relationships were also found. Illness meaning did not parallel life meaning in terms of the conceptualisation of meaning as intrinsically or extrinsically focused, although the intrinsic/extrinsic conceptualisation was supported within the illness meaning variables. In the context of life meaning, unexpected relationships suggested that religiously and spiritually derived meaning may not contribute jointly to the concept of extrinsic meaning, as expected. There is also the possibility that the construct validity of the Royal Free Interview as a measure of extrinsic meaning is questionable.

### *Relationships between constructs*

The relationship of the knowledge construct with the other constructs is displayed in Table 11. Information based knowledge about cancer was associated only with the optimism component of the approach to health construct. The relationship indicated that increased knowledge was associated with lower optimism on bidimensional scoring of optimism and pessimism ( $r = -.19, p < .01$ ), but was more marked when optimism was scored unidimensionally with pessimism ( $r = -.28, p < .001$ ). In terms of the attributions of control, responsibility and blame construct, information based knowledge was mildly associated with the two internal control dimensions only ( $r = .22, p < .001$ ).

In relation to meaning in life, extrinsically oriented meaning was associated with less knowledge than intrinsically oriented meaning. An unexpected aspect of this, however, was an apparent difference between religiously and spiritually derived extrinsic meaning. That is, lower information based knowledge was associated with spiritually derived meaning ( $r = -.24, p < .05$ ) but not with religiously derived meaning. Illness meaning evidenced no association with information based knowledge about cancer.

The belief based dimension of cancer knowledge was weakly associated with both optimism and pessimism when scored bidimensionally ( $r = .17, p < .05$  and  $r = .19,$



$p < .01$  respectively). A more positive belief system about cancer was associated positively with both optimism and pessimism separately but not with optimism and pessimism as opposite ends of a continuum. This could be explained either as a function of the bidimensional approach to optimism and pessimism or because the sample comprised those who were either highly optimistic or highly pessimistic in outlook on life but whose understanding of cancer acknowledged positive factors about it.

**Table 11**

**Intercorrelations between knowledge and approach to health (N=194), attributions of control, responsibility and blame (N=189) life meaning, and illness meaning (N=192).**

|                        | Info. based<br>knowledge | Belief based<br>Knowledge |
|------------------------|--------------------------|---------------------------|
| Motivation             | .07                      | -.12                      |
| Motivation beliefs     | .10                      | .09                       |
| Optimism               | -.19**                   | .17*                      |
| Pessimism              | .03                      | .19**                     |
| Total Optimism         | -.28**                   | -.07                      |
| Internality            | .22***                   | -.13                      |
| Externality            | .01                      | -.01                      |
| Rel.mean (N= 80, 72)   | .06                      | -.04                      |
| Spi.mean (N= 70, 64)   | -.24*                    | -.32**                    |
| Phil.mean (N= 52, 50)  | -.01                     | -.06                      |
| Ext.mean (N= 211, 198) | -.02                     | -.21**                    |
| Int.mean (N= 206, 193) | -.08                     | .15*                      |
| Int. ill mean (CMS)    | -.07                     | .31***                    |
| Int. ill meaning (RIQ) | -.04                     | .31***                    |
| Ext. ill meaning (RIQ) | .09                      | -.38***                   |

\*  $p < .05$ , \*\*  $p < .01$ , \*\*\*  $p < .001$

*Note* Ext.mean. – extrinsic meaning (all participants section of Royal Free Interview).

Int.mean. –intrinsic meaning (pucolcda subscale of LABI)

In relation to life meaning, an extrinsic orientation was associated with a less positive belief system about cancer. This again was when extrinsicness was derived in a

spiritual rather than a religious frame ( $r = -.32, p < .01$ ). A weak relationship between intrinsicness and positive beliefs was evidenced, however, by the alternative intrinsic life meaning measure (LAP-R, pucolcda) ( $r = .15, p < .05$ ). This was reflected in the context of illness meaning where positively framed cancer beliefs were associated with intrinsic meaning on both the CMS ( $r = .31, p < .001$ ) and the RIQ ( $r = .31, p < .001$ ), and with a less extrinsic approach on the RIQ ( $r = -.38, p < .001$ ).

The components of the health approach construct, in the main, demonstrated the expected relationships with control and meaning. These are shown in Table 12. The level of interest and motivation about health variable was associated with both internal control components ( $r = .22, p < .001$  and  $r = .36, p < .001$  for state of mind internality and action internality respectively) but not with external control. The expectation was that those demonstrating the most interest in involvement with their health and its treatment would also prefer more self control and accept more self responsibility over their health.

**Table 12**

**Intercorrelations between health approach variables and control and meaning.**

|                             | Motivation | Motivation<br>beliefs | Optimism | Pessimism | Total<br>Optimism |
|-----------------------------|------------|-----------------------|----------|-----------|-------------------|
| Internality (N=203)         | .36 ***    | .13                   | .11      | -.09      | -.04              |
| Externality (N=199)         | .13        | .03                   | -.01     | -.19**    | .11               |
| Rel.mean (N=77)             | .02        | -.15                  | -.03     | -.27*     | .08               |
| Spi.mean (N=69)             | .16        | -.30*                 | .34**    | .22       | -.19              |
| Phil.mean (N=50)            | .43***     | -.06                  | .26      | .19       | -.09              |
| Ext.mean (N=203)            | .04        | -.16*                 | .01      | -.22**    | .17*              |
| Int.mean (pucolcda) (N=203) | .25***     | .01                   | .56***   | .27***    | .05               |
| Int. ill mean (CMS N=205)   | .05        | .06                   | .35***   | .23***    | -.11              |
| Int. ill mean (RIQ N=199)   | -.07       | -.10                  | .06      | .16*      | -.11              |
| Ext. ill mean (RIQ N=205)   | .11        | .13                   | -.11     | -.27***   | .17*              |

\*  $p < .05$ , \*\*  $p < .01$ , \*\*\*  $p < .001$

*Note.* Internality combines state of mind internality and action internality.

Externality combines luck externality and powerful others externality.

Similarly for meaning in life, as expected, interest and motivation in health was associated with intrinsic meaning, both in terms of philosophically derived intrinsic meaning ( $r = .43, p < .001$ ) and the LABI (pucolcda) measure of intrinsicness ( $r = .25, p < .001$ ), but was not associated with extrinsically derived meaning. No relationship was found between motivation and meaning in illness. Similarly, no consistent relationships were evidenced between the motivation beliefs variable and control and meaning.

The optimism / pessimism component displayed some associations with both illness and life meaning. Meaning derived spiritually, but not religiously, was associated with higher optimism ( $r = .34, p < .01$ ). While the other extrinsic meaning variables were not associated with higher optimism, they were associated with lower pessimism ( $r = -.27, p < .05$  for religious meaning and  $r = -.22, p < .05$  for Royal Free Interview extrinsic meaning). When life meaning was measured with the “pucolcda” subscale of the LABI a more intrinsic approach was moderately associated with higher optimism ( $r = .56, p < .001$ ), although intrinsicness was also associated with pessimism to a lesser degree ( $r = .27, p < .001$ ). This suggests that there is some variability with respect to optimism and pessimism among intrinsically motivated cancer patients, supporting the possibility that differences are attributable to whether orientation is derived through religious, spiritual or philosophical frames. It may also support the notion that optimism and pessimism are separate constructs and not opposite ends of a continuum.

Optimism was associated with intrinsic illness meaning assessed on the CMS only ( $r = .35, p < .001$ ). Pessimism, however, was mildly associated with intrinsic meaning on both scales ( $r = .16, p < .05$  and  $r = .23, p < .001$ ). This is similar to the situation with life meaning reported above. The inverse relationship with extrinsic illness meaning ( $r = -.27, p < .001$ ) suggests that patients who are intrinsically motivated in terms of the meaning of their illness demonstrate more pessimism than extrinsically motivated patients.

Similarly, the only relationship found for attributions of control, responsibility and blame was a mild inverse relationship between pessimism and powerful others

externality ( $r = -.19, p < .01$ ). This parallels the trend found for life meaning. Neither externality nor internality appears to be associated with optimism, but externality is associated with lower pessimism. Externally focused cancer patients may not feel optimistic but are not necessarily pessimistic either.

Attributions of control, responsibility and blame displayed some unexpected associations with illness meaning. As table 13 shows, intrinsic illness meaning was inversely related to internal control when the former was measured with the RIQ. The opposite was found, however, when intrinsic illness meaning was measured with the CMS. This inconsistency could indicate that the RIQ is best suited as a measure of extrinsic illness meaning only. It also supports the suggestion made earlier that the concepts of intrinsicness and extrinsicness may not be relevant in the context of illness meaning.

In terms of meaning in life, when the data from each of the four dimensions of the IHI were combined to generate an internality factor and an externality factor, the findings were unexpected. No significant associations were found between religiously or spiritually derived extrinsic meaning, and externality. In fact, religiously derived meaning was associated with internality, as was spiritually derived meaning, but not philosophically based meaning (see Table 13). A different picture emerged, however, when relationships between the separate components of the IHI and the intrinsic and extrinsic meaning dimensions were examined. On this basis 'powerful others externality' was associated with each of the religious and spiritually derived dimensions of extrinsic meaning ( $r = .41, p < .001$  and  $r = .44, p < .001$  respectively) (see Table 13). This was as expected indicating that luck externality and powerful others externality (which formed the combining externality variable) are not conceptually similar or complementary concepts. This is supported by the inverse relationship between the religious and spiritual components of extrinsic meaning and luck externality compared to the moderate positive relationships with powerful others externality.

Similarly, powerful others externality was moderately associated with extrinsic meaning ( $r = .48, p < .001$ ) but there was no association between luck externality and extrinsic meaning, suggesting again that luck externality and powerful others externality are not complementary concepts, and that externality may best be conceptualised in terms of powerful others only. In terms of the overall intrinsic meaning measure, the association between this and state of mind internality was as expected ( $r = .26, p < .001$ ) but the association with powerful others, albeit milder and less significant, was nevertheless, unexpected ( $r = .20, p < .01$ ).

**Table 13****Intercorrelations between intrinsicness/ extrinsicness components and control.**

|  | State of<br>Mind<br>Internality | Action<br>Internality | Luck<br>Externality | Powerful<br>others<br>Externality | Internality | Externality |
|--|---------------------------------|-----------------------|---------------------|-----------------------------------|-------------|-------------|
| Int.ill. mean.(CMS) (N=203)            | .09                             | .17*                  | -.05                | -.02                              | .15*        | -.05        |
| Int.ill. mean.(RIQ) (N=194)            | -.19**                          | -.16*                 | .03                 | -.06                              | -.19**      | -.01        |
| Ext.ill. mean.(RIQ) (N=194)            | .09                             | .10                   | .13                 | .13                               | .10         | .17*        |
| Rel.meaning (N = 74)                   | .23*                            | .19                   | -.11                | .41***                            | .23*        | .06         |
| Spi.meaning (N = 64)                   | .40***                          | .13                   | -.26*               | .44***                            | .30*        | .05         |
| Phil.meaning (N = 51)                  | .12                             | .04                   | .01                 | .14                               | .09         | .11         |
| Ext.life meaning (N = 203)             | .32***                          | .23***                | .06                 | .48***                            | .29***      | .33***      |
| Int.life meaning (Pucolcda)<br>(N=205) | .26***                          | .13                   | -.01                | .20**                             | .22**       | .09         |

\*  $p < .05$ , \*\*  $p < .01$ , \*\*\*  $p < .001$ 

Of the demographic variables, it was considered that there was a potential for education, age and gender to be associated with either the discriminating variables or

treatment choice. In the case of education, previous research has found an association between level of education and non-conventional medicine use. Furthermore, the sample demonstrated considerable variability in education level, providing the potential for detectable relationships. The same was true for age and possibly for gender. Marital status, however, demonstrated little variability with less than 7% of the sample having never been married and over 70% being currently married. Any meaningfulness in relation to the 23% who were divorced or widowed was lost somewhat, given the expansive time frame that the study covered. Even though the study was cross-sectional, participants were reporting on behaviours that spanned up to 48 years. Similarly, any variability in employment status was not considered important in a conceptual sense. There was no meaningful way of associating employment status with the point at which a treatment decision was made and there are no theoretical bases for associating employment status with any of the constructs.

Relationships between control variables (education level, age and gender) and discriminating variables are shown in table 1 in Appendix C. Older cancer patients tended to score lower on information based knowledge but evidenced a more positive belief based understanding of cancer. Older patients were also inclined to less personal control, being more likely to acknowledge the role of luck. Interestingly, they evidenced no relationship with powerful others external control. Unexpectedly, given the inverse relationship with internal control, advancing age was associated with a lower level of extrinsic meaning, particularly where this was derived in a religious frame. Advancing age was not, however, associated with intrinsic meaning. This suggests, perhaps, that older patients' experience in life has shown them that while they are ineffective in controlling life and its events, neither is anyone else in control of their situation. They may take the somewhat fatalistic view that luck or fate is the most likely determinant of life's course. It should also be noted that extrinsic meaning, while it contains religious elements, is a somewhat different concept to religiousness and religiosity. The religious component of extrinsic meaning is concerned with God's role in the illness situation. It may be that older people tend to separate religious beliefs and practices from events in their lives.

Gender was weakly related to knowledge and motivation, with women tending to display greater information based knowledge and greater health interest and motivation. Women also tended to be more interested in personal control and the acceptance of responsibility.

Education 1-4 were dummy variables which are described in the following chapter. For the present purposes, it can be stated that as level of education increased there was, not unexpectedly, an increase in the level of information based knowledge about cancer. There was also an indication that a lower level of education was associated with more pessimism, although level of education did not seem to affect an overall lack of optimism. Internal attributions of control and responsibility were not associated with level of education but higher education was associated with less powerful other externality. Higher education was also noticeably associated with less religiously derived meaning which is understandable given the inverse relationship with powerful others externality. Unexpectedly, however, philosophically derived meaning was associated with lower levels of education. Intercorrelations among these control variables disclosed no relationships apart from a lower level of education being associated with advancing age ( $r = -.25, p < .001$ ).

### **Overall summary**

Relationships within and between constructs, reported above, establish the cognitive framework and conceptual basis of the study. At a within construct level, except for meaning, the constructs demonstrated the appropriate relationships. The knowledge and understanding of cancer construct comprised two unrelated dimensions, which captured conceptually different aspects of cancer knowledge and understanding. Similarly, the approach to health construct was made up of separate sub-constructs which stand alone, but which each represent an element in the approach to health. Within the attributions of control, responsibility and blame construct, however, relations among the

components of the construct suggest that internality and externality are not necessarily mutually exclusive categories for cancer patients as was expected. Relationships within the meaning construct suggest that the concept of intrinsic and extrinsic orientation may be a relevant approach for life meaning but not for illness meaning. On the other hand, however, there were indications that this may be a measurement related issue rather than a conceptual issue. Within the life meaning sub-construct, the relationships among intrinsic and extrinsic variables supported the distinction made between these concepts. The conceptualisation of religiously and spiritually derived meaning, as representing an extrinsic approach, with philosophically derived meaning representing an intrinsic approach, may need further consideration.

At a between constructs level the constructs generally demonstrated the expected relationships, supporting the overall conceptual basis of the study. Knowledge, particularly information based knowledge, displayed fewer associations between constructs than did the others. Apart from an expected relationship with health interest and motivation, this was not unexpected, however, because accumulation of knowledge is influenced by various factors other than motivation, attributions of control and responsibility, and orientation in meaning. Other relevant factors would likely include access to knowledge, ability to understand and retain it, time elapsed since diagnosis, and various personality and psychopathological variables. The relationships with optimism, internality and meaning that were evidenced were appropriate conceptually, demonstrating that both dimensions of knowledge potentially contribute to an understanding of the decision process.

The approach to health construct, comprising the health interest and motivation and optimism variables, demonstrated associations with control attributions and meaning orientation that were appropriate both in terms of strength and direction, confirming the potentially meaningful role of this construct in explaining treatment decisions.

Relationships between the attributions of control, responsibility and blame and the meaning constructs confirmed earlier indications that the conceptualisation of religiously



and spiritually derived meaning, as representing the extrinsic orientation, may not be supported by the findings, particularly in relation to spiritually derived meaning. The relationships confirm the suggestion that internality and externality are not necessarily mutually exclusive categories, but the indications are that internality is associated with a more intrinsic approach to life's meaning, while externality is related to a more extrinsic orientation. A similar pattern did not emerge for illness meaning, supporting the suggestion that illness meaning may not be appropriately conceptualised in terms of intrinsicness and extrinsicness. While an alternative explanation would be that the construct validity of the measures used is questionable, a conceptual difference is considered the most likely explanation.

## CHAPTER NINE

### COGNITIONS AND TREATMENT CHOICE

The reader will recall that treatment choice was not conceptualised only in terms of the traditional dichotomy between conventional and non-conventional treatment. It was postulated that consumers of treatments may have differing conceptualisations of what is conventional and non-conventional, and that this would likely be associated with cognitions that influence treatment choice, some of which were explored in this study. For analysis purposes this was achieved by creating four different classification schemes (referred to as treatment groupings), each of which represented an altered dividing line between conventional and non-conventional. The first treatment grouping represented the traditional approach wherein conventional includes surgery, chemotherapy and radiation therapy, with all other treatments being classified as non-conventional. The second treatment grouping was the same as the first except that the use of prayer was added to conventional treatment. In the third grouping physical and natural treatments have been shifted from the non-conventional list to being included in the definition of conventional treatment. In the fourth treatment grouping only psychic and metaphysical type treatments remain in the non-conventional group, all other treatments being classified as conventional.

The chapter commences with an examination, at a bivariate level, of the influence of the discriminating variables, including demographic variables, on treatment choice in each treatment grouping. This provides a preliminary picture of relationships between each of the constructs and treatment choice. This is followed by the results of a series of four two group discriminant analyses that explored, at a multivariate level, how well the combination of discriminating variables discriminated between the choice of conventional and non-conventional treatment as defined in each of the four treatment groupings.

### **A preliminary picture of the cognitive determinants of treatment choice.**

In this section the influence of each construct (and its associated variables) on treatment choice, as defined by each of the four treatment groupings, is examined at a bivariate level. The section is organised by construct rather than by treatment grouping. This avoids repetition in the presentation of the relationships between each variable and treatment choice for each treatment grouping. It also allows for a comparison to be made more easily, construct by construct, between the treatment groupings because all treatment groupings are dealt with together in relation to each construct. In the following section, however, the reverse approach is taken. The multivariate results must be organised by treatment grouping because these analyses examine the effect of the discriminating variables (the constructs), in combination, on treatment choice as defined by each of the treatment groupings.

#### ***Knowledge and understanding of cancer***

In terms of information based knowledge significant differences were evident between users of conventional and non-conventional medicine in treatment grouping 3 ( $F = 4.33, p < .05$ ). On the belief based dimension of cancer knowledge a difference was found on treatment grouping 3 also ( $F = 6.63, p < .05$ ). As table 14 shows, even though differences were not significant across all configurations of treatment group, a trend is evident from the consistency of the mean scores. Conventionals scored lower on information based knowledge than non-conventionals, but higher on the belief system dimension, indicating a more positive belief system.

These findings suggest that there is some support for the hypothesis that those who include non-conventional treatments for their cancer will display a greater level of knowledge and understanding of cancer than those who use only conventional medicine, but unexpectedly, they may have a less positive belief system in relation to their health situation. That the difference is more marked in the 3<sup>rd</sup> and 4<sup>th</sup> configurations of treatment

grouping is also some support for the view that the traditional division between conventional and non-conventional does not necessarily reflect the way patients perceive the distinction between modalities.

**Table 14**

**Means and F levels between conventional and non-conventional groups for each treatment grouping on knowledge and understanding of cancer.**

|                          | Treatment<br>Grouping 1<br>N= 166 | Treatment<br>Grouping 2<br>N= 180 | Treatment<br>Grouping 3<br>N= 180 | Treatment<br>Grouping 4<br>N= 180 |
|--------------------------|-----------------------------------|-----------------------------------|-----------------------------------|-----------------------------------|
| <u>Knowledge</u>         |                                   |                                   |                                   |                                   |
| Conventional             | 31.89<br>(4.31)                   | 31.90<br>(4.39)                   | 32.07<br>(4.37)                   | 32.21<br>(4.38)                   |
| Non-conventional         | 33.12<br>(4.66)                   | 33.12<br>(4.66)                   | 33.48<br>(4.75)                   | 33.52<br>(4.81)                   |
| F                        | 2.04                              | 2.57                              | 4.33*                             | 3.64 (p = .06)                    |
| <u>Knowledge Beliefs</u> |                                   |                                   |                                   |                                   |
| Conventional             | 6.78<br>(1.57)                    | 6.72<br>(1.65)                    | 6.73<br>(1.56)                    | 6.62<br>(1.65)                    |
| Non-conventional         | 6.32<br>(1.51)                    | 6.32<br>(1.51)                    | 6.14<br>(1.50)                    | 6.19<br>(1.40)                    |
| F                        | 2.52                              | 2.37                              | 6.63*                             | 3.50 (p = .06)                    |

\* p < .05

Degrees of freedom for Grouping 1 = 1 and 164

Degrees of freedom for Groupings 2, 3, & 4 = 1 and 178

Parentheses contain standard deviations

### ***Approach to health***

Health interest and motivation was the basis of this construct, represented in the main, by the first of two motivation variables. The mean scores on this variable were

significantly different between the two groups in each of the four configurations of treatment grouping (see Table 15). This suggests that cancer patients who include non-conventional medicine in the treatment of their cancer are more interested in and motivated about their health situation than are those who rely only on conventional treatment. Furthermore, when the boundary between conventional and non-conventional was shifted (as in treatment groupings 3 and 4), those who opted for the more non-conventional treatments were still those who evidenced a higher level of interest and motivation in health matters.

There were no significant differences in the mean scores between conventional users in any of the four treatment groupings on the second health interest and motivation variable (motivation beliefs) or on optimism and pessimism.

#### *Attributions of control, responsibility and blame*

This construct comprised one variable on which participants were assessed on four types of control, responsibility and blame attributions across the four configurations of treatment grouping. As table 16 shows, there were significant differences between the means for three of the four types of control in each of the treatment groupings except one, where two of the control types displayed significantly different means (treatment grouping 2).

It is particularly noticeable that no significant difference was found between conventional and non-conventional users on luck externality (control 3) whereas differences were found on each of the other forms of control for virtually all treatment groupings. Given that the majority of externally motivated participants expressed their externality in either religious or spiritual terms, they would likely be equivocal towards attributions that were neither to a powerful other nor to self. A neutral approach to such attributions would likely also characterise those who are internally motivated. The higher

**Table 15.****Means and F levels between conventional and non-conventional groups for each treatment grouping on health approach variables**

|                           | Treatment<br>grouping 1<br>N= 166 | Treatment<br>grouping 2<br>N= 180 | Treatment<br>grouping 3<br>N= 180 | Treatment<br>grouping 4<br>N= 180 |
|---------------------------|-----------------------------------|-----------------------------------|-----------------------------------|-----------------------------------|
| <u>Motivation</u>         |                                   |                                   |                                   |                                   |
| Conventional              | 23.33<br>(4.58)                   | 22.34<br>(4.71)                   | 23.62<br>(4.68)                   | 23.73<br>(4.70)                   |
| Non-Conventional          | 25.25<br>(4.14)                   | 25.25<br>(4.14)                   | 25.25<br>(4.17)                   | 25.35<br>(4.05)                   |
| F                         | 5.79*                             | 16.53**                           | 6.13*                             | 5.94*                             |
| <u>Motivation beliefs</u> |                                   |                                   |                                   |                                   |
| Conventional              | 1.86<br>(.35)                     | 1.88<br>(.33)                     | 1.87<br>(.33)                     | 1.88<br>(.33)                     |
| Non-conventional          | 1.84<br>(.41)                     | 1.84<br>(.41)                     | 1.82<br>(.44)                     | 1.81<br>(.46)                     |
| F                         | .10                               | .38                               | .71                               | 1.37                              |
| <u>Optimism</u>           |                                   |                                   |                                   |                                   |
| Conventional              | 14.81<br>(2.74)                   | 14.70<br>(2.98)                   | 14.66<br>(3.22)                   | 14.78<br>(3.22)                   |
| Non-conventional          | 15.08<br>(3.22)                   | 15.08<br>(3.22)                   | 15.29<br>(3.06)                   | 15.23<br>(3.06)                   |
| F                         | .23                               | .54                               | 1.77                              | .89                               |
| <u>Pessimism</u>          |                                   |                                   |                                   |                                   |
| Conventional              | 14.47<br>(1.70)                   | 14.22<br>(1.93)                   | 14.17<br>(1.99)                   | 14.20<br>(1.92)                   |
| Non-conventional          | 14.12<br>(1.83)                   | 14.12<br>(1.83)                   | 14.13<br>(1.73)                   | 14.09<br>(1.78)                   |
| F                         | 1.05                              | .10                               | .02                               | .15                               |

\* p &lt; .05, \*\* p &lt; .001

Degrees of freedom for Grouping 1 = 1 and 164

Degrees of freedom for Groupings 2, 3, &amp; 4 = 1 and 178

Parentheses contain standard deviations

**Table 16.**

**Means and F levels between conventional and non-conventional groups for each treatment grouping on attributions of control, responsibility and blame.**

|                  | Treatment<br>Grouping 1<br>N= 166 | Treatment<br>Grouping 2<br>N= 180 | Treatment<br>Grouping 3<br>N= 180 | Treatment<br>Grouping 4<br>N= 180 |
|------------------|-----------------------------------|-----------------------------------|-----------------------------------|-----------------------------------|
| <u>Control 1</u> |                                   |                                   |                                   |                                   |
| Conventional     | 46.11<br>(8.75)                   | 44.86<br>(7.87)                   | 46.30<br>(8.31)                   | 46.43<br>(8.54)                   |
| Non-conventional | 51.71<br>(8.67)                   | 51.71<br>(8.68)                   | 53.23<br>(8.31)                   | 54.13<br>(7.60)                   |
| F                | 11.69***                          | 23.65***                          | 31.30***                          | 39.62***                          |
| <u>Control 2</u> |                                   |                                   |                                   |                                   |
| Conventional     | 56.58<br>(8.93)                   | 55.72<br>(8.34)                   | 58.53<br>(8.14)                   | 58.74<br>(8.14)                   |
| Non-conventional | 63.87<br>(7.92)                   | 62.87<br>(7.92)                   | 63.19<br>(8.53)                   | 63.62<br>(8.52)                   |
| F                | 16.78***                          | 28.55***                          | 14.04***                          | 15.26***                          |
| <u>Control 3</u> |                                   |                                   |                                   |                                   |
| Conventional     | 80.61<br>(11.76)                  | 78.30<br>(12.05)                  | 78.93<br>(13.25)                  | 78.49<br>(13.42)                  |
| Non-conventional | 77.28<br>(14.92)                  | 77.28<br>(14.92)                  | 76.23<br>(14.94)                  | 76.39<br>(15.05)                  |
| F                | 1.52                              | .18                               | 1.64                              | .97                               |
| <u>Control 4</u> |                                   |                                   |                                   |                                   |
| Conventional     | 32.69<br>(9.78)                   | 34.44<br>(9.08)                   | 34.66<br>(9.72)                   | 34.68<br>(9.69)                   |
| Non-conventional | 37.18<br>(10.20)                  | 37.18<br>(10.20)                  | 38.14<br>(9.93)                   | 38.65<br>(9.90)                   |
| F                | 5.56*                             | 2.77                              | 5.64*                             | 7.27**                            |

\*  $p < .05$ , \*\*  $p < .01$ , \*\*\*  $p < .001$

*Note.* Control 1 – State of mind internality; Control 2 – Action internality;

Control 3 – Luck externality; Control 4 – Powerful others externality.

Degrees of freedom for Grouping 1 = 1 and 164

Degrees of freedom for Grouping 2, 3 & 4 = 1 and 178

Parentheses contain standard deviations

scores on control 3 should be ignored. This subscale comprised more items and consequently, a higher possible score (126 compared to either 84 or 63 on the other 3 subscales).

It is also noticeable that non-conventionals scored generally higher on attributions of control, responsibility and blame to a powerful other. This was unexpected given their consistently higher scores on the internal control dimensions, although the differences were not as marked or as consistent as they were on the latter. It was also the opposite of the initial expectation that conventionals would be more likely than non-conventionals to make attributions to powerful others. A possible explanation for this is that it may be that control in terms of the future with cancer should be isolated from attributions of responsibility and blame for past events in relation to the disease. For example, perhaps those who are externally motivated in terms of say God, are prepared to look to Him to help cure them, but are not prepared to blame Him for causing the disease or for past treatment 'failures'. To explore this it was necessary to isolate the powerful others contained in the "I consider my cancer was due to" subscale (which assessed attribution of blame) and compare the mean scores for the conventional and non-conventional groups on this component. However, this analysis produced no significant F ratios between conventionals and non-conventionals in terms of blame. It is observed, however, that mean scores were very low, evidencing an aversion to blaming a powerful other. These findings support the explanation offered above in that conventionals were not prepared to blame a powerful other. Understandably, non-conventionals would also disagree with the concept of blaming a powerful other simply because, as more internally motivated people, the concept of powerful other is not so relevant to them.

These findings were further explored by an informal within group comparison to assess whether there was any difference in response to the negatively framed blaming items and the more positively framed attributions of responsibility and control items among conventional users. The positively framed items were the 'powerful others' items contained in the "my capacity to become healthier or maintain good health in the future" and "how quickly and effectively I recover or have recovered from my illness is due to"



subscales. The mean scores across the blaming items were 2.06 compared to 3.55 across the responsibility and control items. This tends to support the suggestion that conventionals are more prepared to attribute positive outcomes to a powerful other than negative causes and outcomes. The observation is also made that the very low scores on blaming items has probably contributed to the overall lower scores on powerful others control (control 4). It appears otherwise that conventionals have scored higher on internal type control than they have on external control.

### *Meaning*

The suggestion was made in the previous chapter that meaning in relation to illness may be a different concept to meaning in relation to life and that the conceptualisation of meaning in terms of intrinsic and extrinsic orientation may be inappropriate in relation to illness meaning. Adding further weight to this suggestion, no significant F's were found for any treatment grouping on extrinsic or intrinsic illness meaning. Furthermore, intrinsic illness meaning was assessed with two instruments, neither of which displayed a significant difference between conventional and non-conventional users. In addition, both instruments produced similar results in terms of magnitude and direction, suggesting that there may be problems with the conceptualisation of illness meaning rather than its measurement. The illness meaning measured may, therefore, be different conceptually to the concept of meaning the study proposed and is based on. On this basis the illness meaning sub-construct was omitted from further analyses.

For meaning in life, however, significant differences were found between users of conventional treatments and users of non-conventional treatments. A low score on intrinsic life meaning indicated low intrinsicness, not necessarily the alternative extrinsic orientation, although it was expected that those who displayed low intrinsicness would be those who evidenced an extrinsic approach. Table 17 demonstrates the consistent difference between conventionals and non-conventionals across all treatment groupings

for intrinsicness, with non-conventionals displaying significantly higher mean levels of intrinsicness than conventionals.

Extrinsicness was measured with a separate instrument (Royal Free Hospital Interview, all participants subscale). Table 17 shows the difference on extrinsicness between conventional and non-conventional treatment users across each of the treatment groupings. The expectation was that conventionals would score more highly on extrinsic life meaning than non-conventionals. The opposite was found, however, and some possible explanations for this are offered in the following chapter.

An alternative approach to assessing both extrinsicness and intrinsicness involved the self-classification of participants into either a religious, spiritual or philosophical approach to life's meaning. The measure included a "no particular understanding" category (6.1% of participants) that, for analysis purposes, was collapsed into the philosophical category. The rationale for this related to the concept of classifying participants as either extrinsically or intrinsically oriented. This necessitated the assigning of the "no particular understanding" category to either an extrinsic or intrinsic orientation. It was considered that a religious or spiritual approach to life was likely to result from a reasonably focused or well-differentiated belief system and was less likely than the philosophical approach to embrace an element of vagueness. In future administrations of this measure, for this particular purpose, it may be preferable, however, to omit the "no particular understanding" option thereby forcing a choice.

A chi-square analysis was performed for each treatment grouping. A significant difference between the conventional and non-conventional treatment groups in terms of life meaning was found on three of the four treatment groupings. Significant values of chi-square were found for treatment grouping 1 ( $\chi^2 = (2, N= 193) = 7.13, p < .05$ ), treatment grouping 3 ( $\chi^2 = (2, N= 211) = 16.48, p < .001$ ), and treatment grouping 4 ( $\chi^2 (2, N= 211) = 12.41, p < .01$ ). When prayer was included in the definition of conventional treatment (treatment grouping 2) there was no significant relationship between meaning in life and treatment choice.

**Table 17****Means and F levels between conventional and non-conventional groups for each treatment grouping on intrinsic and extrinsic life meaning**

|                               | Treatment<br>Grouping 1<br>N= 166 | Treatment<br>Grouping 2<br>N= 180 | Treatment<br>Grouping 3<br>N= 180 | Treatment<br>Grouping 4<br>N= 180 |
|-------------------------------|-----------------------------------|-----------------------------------|-----------------------------------|-----------------------------------|
| <u>Intrinsic life Meaning</u> |                                   |                                   |                                   |                                   |
| (pucolcda)                    |                                   |                                   |                                   |                                   |
| Conventional                  | 153.42<br>(27.59)                 | 152.14<br>(28.80)                 | 154.18<br>(27.26)                 | 155.82<br>(27.19)                 |
| Non-conventional              | 164.27<br>(24.99)                 | 164.27<br>(24.99)                 | 167.47<br>(24.30)                 | 167.39<br>(24.45)                 |
| F                             | 5.08*                             | 7.80**                            | 11.94***                          | 8.76**                            |
| <u>Extrinsic Life meaning</u> |                                   |                                   |                                   |                                   |
| (Royal Free Interview)        |                                   |                                   |                                   |                                   |
| Conventional                  | 7.36<br>(6.98)                    | 7.60<br>(6.84)                    | 9.07<br>(7.35)                    | 9.05<br>(7.30)                    |
| Non-conventional              | 11.26<br>(8.72)                   | 11.26<br>(8.72)                   | 11.41<br>(9.18)                   | 11.77<br>(9.42)                   |
| F                             | 6.11*                             | 7.12**                            | 3.59 (p=.06)                      | 4.77*                             |

\* p < .05, \*\* p < .01, \*\*\* p < .001

Note Pucolcda – purpose, coherence, life control, death acceptance dimensions of LABI

Royal Free Interview – All participants subscale

Degrees of freedom for Grouping 1 = 1 and 164

Degrees of freedom for Groupings 2, 3, & 4 = 1 and 178

Parentheses contain standard deviations

On a traditional division between conventional and non-conventional (treatment grouping 1) there appears to be less difference among the three approaches to life meaning in terms of treatment choice than there is for the alternative conceptualisations of conventional and non-conventional (treatment groupings 3 and 4). In treatment grouping 1, using non-conventional was preferred by the majority in each meaning classification (religious, spiritual and philosophical classifications reported 80.6%, 88.9% and 69.8% respectively). This was unexpected for religious and spiritual meaning given

their conceptualisation as extrinsic and the expectation that they were more likely to embrace conventional medicine. For treatment grouping 3, however, 60% of those whose meaning was religiously derived, and 54% of those who expressed meaning in a philosophical frame, preferred conventional treatments as defined in that grouping. This was reversed, however, for those whose meaning was spiritually derived (72.1% preferred non-conventional). In treatment grouping 4 conventionals comprised 60% and 65% respectively of those whose meaning was religiously and philosophically derived, and a lower 36.8% of those whose meaning was spiritually derived preferred conventional as conceptualised in that grouping. The apparent congruence between religiously and philosophically based meaning and the incongruence between religiously and spiritually derived meaning, both of which were unexpected, is discussed in the following chapter.

### ***Demographic aspects***

If the groups differed on a demographic variable, any cognitive differences between the groups could be attributed to the demographic differences. It was important, therefore, to check the influence of potentially important demographic variables on group membership so that any variables displaying significant differences could be controlled for in the multivariate analyses.

Given the demographic profile of the present sample and taking into account previous findings, the only variable that was expected to have any influence was level of education. Appropriate analyses were carried out, however, for all demographic variables except ethnicity (96% of participants were European). Analyses of variance were computed for age, gender and time since diagnosis between the groups in each of the treatment groupings. No significant F levels were found for time since diagnosis. For age and gender, however, significant F levels were found on most of the treatment groupings.

Significant differences between mean ages for conventional and non-conventional users were found for treatment grouping 1 ( $M = 58.67$  for conventionals and  $M = 53.82$  for non-conventionals,  $F = 3.87$ ,  $p < .05$ ); treatment grouping 2 ( $M = 60.04$  for conventionals and  $M = 53.82$  for non-conventionals,  $F = 8.26$ ,  $p < .01$ ); treatment grouping 3 ( $M = 58.25$  for conventionals and  $M = 52.91$  for non-conventionals,  $F = 7.55$ ,  $p < .01$ ); and treatment grouping 4 ( $M = 58.03$  for conventionals and  $M = 52.38$  for non-conventionals,  $F = 8.38$ ,  $p < .01$ ). Across all treatment groupings a younger age was associated with the use of non-conventional treatment. For gender, significant differences were found for all treatment groupings to the effect that men were less likely to use non-conventional medicine. Gender and age were controlled for by being included as discriminating variables in the subsequent analyses.

Chi square statistics were computed for employment status, marital status and education level. Employment status categories were collapsed from the original 7 into 5 to avoid expected cell frequencies of less than 5. "Looking for work", "student", and "unable to work" were collapsed into one category. Between them these categories accounted for 5% of the sample. On this basis, one cell out of 10, in two of the treatment groupings, had an expected frequency of less than 5, which does not breach the 20% rule. No significant chi squares were found for any of the treatment groupings for employment status.

Marital status categories were recoded to collapse the original four categories into three by combining "Never married" and "widowed". This category of 'not currently married' does not create any conceptual difficulties in the context of the present study. This resulted in one cell out of six, in one of the treatment groupings, having an expected frequency of less than 5, also not breaching the 20% rule. For marital status also no significant chi square was found for any treatment grouping.

Education level categories were collapsed from the original eight into five. "Some primary school", "completed primary school" and "some high school" were combined, as were "completed 3 years high school" and "completed more than 3 years high school".

This resulted in there being no expected cell frequencies of less than 5. On level of education, only treatment grouping 3 displayed a significant value of chi square ( $\chi^2(4, N=211) = 9.83, p < .05$ ). While only one of the four treatment groupings showed a significant difference for level of education, it was considered important to control for this variable in the subsequent multivariate analyses particularly since previous studies (e.g., Murray & Shepherd, 1993; Bernstein & Shuval, 1997) have found that level of education influences treatment choice decisions between conventional and non-conventional medicine. Accordingly, level of education was recoded as four dummy variables using ordinal coding and included in the discriminant analyses.

The indication that level of education is associated with treatment choice, not so much in terms of the traditional split between conventional and non-conventional treatment, but in terms of a reconstituted division between modalities, also suggests a closer look is called for. This was done by examining frequencies for each level of education by treatment grouping. As figure 2 shows, people who are more educated tend to use non-conventional medicine for treatment groupings 1 and 2, which represent the traditional split between conventional and non-conventional. As the groupings alter to shift the dividing line, the influence of education tends to alter. This suggests that education embraces non-conventional use, in a general sense, but when education levels are explored in terms of the type of non-conventional use, it appears that as treatment moves further away from traditional approaches, the influence of education diminishes.

### ***Summary***

Bivariate analyses generally confirmed a meaningful association between the major elements of the cognitive constructs and treatment choice. In addition, for the composite constructs (attributions of control, responsibility and blame, and meaning) the bivariate analyses have provided a preliminary picture of the relationship between treatment choice and these constructs at a sub-construct level.

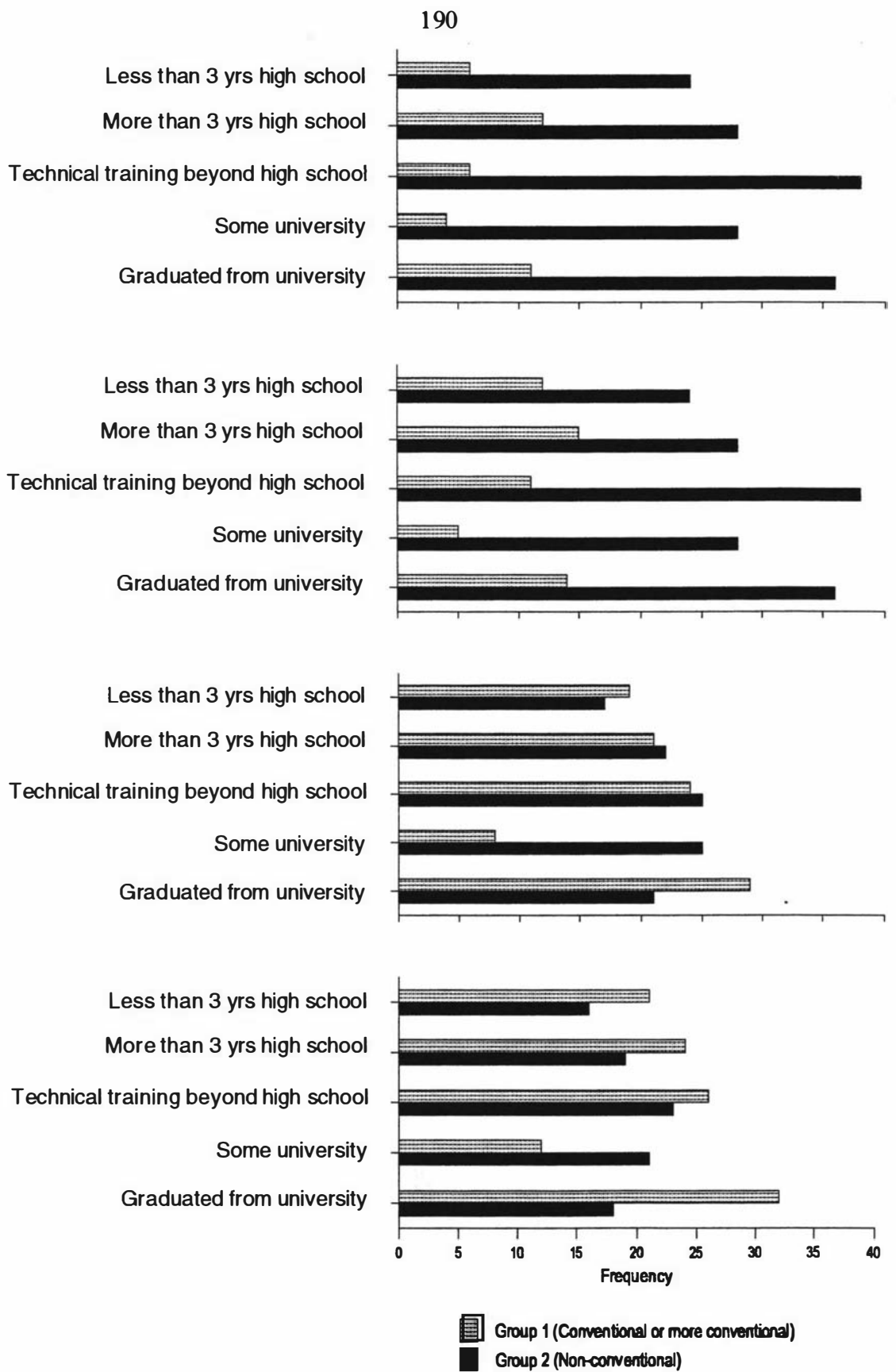


Figure 2 Education level by treatment grouping

These analyses indicate that those who choose to incorporate treatments that are more non-conventional, as defined by treatment grouping 3 (and possibly 4) are likely to be more knowledgeable about cancer in terms of information based knowledge, but less positive in their belief based understanding of cancer.

Health interest and motivation, as the primary element in the approach to health construct, was also associated with treatment choice. In all treatment groupings non-conventional treatment users demonstrated greater health interest and motivation, but no association was found between optimism or pessimism and treatment choice.

In terms of the attributions of control, responsibility and blame construct, the bivariate analyses pointed not only to an expected distinction between conventional and non-conventional treatment users in terms of internal and external attributions, but also to an unexpected association between the powerful others externality sub-construct and choice of non-conventional treatment. This confirmed that analysis at a sub-construct level was appropriate for this construct.

No relationship was found between illness meaning and treatment choice. For life meaning, however, a finding similar to that for the control, responsibility and blame construct emerged. Intrinsic life meaning was associated with non-conventional treatment use across all treatment groupings, but extrinsic life meaning was also, unexpectedly, associated with non-conventional use. At a sub-construct level, however, there were both expected and unexpected relationships with treatment choice. These findings suggest that the proposed conceptualisation of life meaning, particularly extrinsic meaning, may be somewhat simplistic, a notion that is explored in the following chapter.

Finally, there were significant differences in terms of age, gender and education between conventional treatment and non-conventional treatment users. Accordingly, these variables were controlled for in the subsequent multivariate analyses.



## **The influence on treatment choice of the set of health-related cognitions**

### *Analytic strategy and preliminary steps*

So far this chapter has reported on the contributions of individual variables to discrimination between the groups in the various configurations of treatment grouping. This part of the chapter reports the extent to which the two groups can be discriminated on some combination of the discriminating variables, across the four configurations of treatment grouping. Results are reported for each configuration of treatment grouping.

A series of four two group direct discriminant function analyses was performed using the following discriminating variables (grouped by construct) in each: Knowledge and understanding of cancer, beliefs about cancer (knowledge construct); health interest and motivation, beliefs underlying interest in health, optimism, pessimism (approach to health construct); state of mind internality, action internality, luck externality, powerful others externality (attributions of control, responsibility and blame construct); intrinsic life meaning, extrinsic life meaning, approach to life, (as 'Life a' and 'Life b' dummy variables) (meaning construct). The following demographic variables were also included: Age, gender, and level of education (as dummy variables education 1 to education 4). In the first discriminant analysis, groups were those who used only conventional medicine for the treatment of their cancer and those who incorporated non-conventional treatments. In the second and subsequent discriminant analyses treatment groupings were as defined in chapter 7 (see Tables 6 and 7).

Prior to conducting the discriminant function analyses various checks were made. Missing data were checked and were found to be distributed over variables making deletion of these cases appropriate. Checks were also made for outliers. Examination of the descriptive statistics revealed no univariate outliers. Multivariate outliers were checked for by performing a multiple regression analysis and inspecting residuals, with

no outliers being found. This was confirmed by the Box's M analyses reported below which indicated multivariate normality.

Normality was tested by examining skewness. One of the health interest and motivation variables (health interest and motivation beliefs) was found to be highly skewed. Since no significant F levels were found for this variable on any of the treatment groupings (see Table 15), there were grounds for deleting it from the multivariate analyses. Mild skew was found among various other continuous variables but these were not considered to be serious infringements of the normality assumption. Applying square root or log transformations was considered unnecessary, particularly since discriminant analysis is robust to violations of normality that are caused by skewness (Tabachnick & Fidell, 1983; Sharma, 1996). Univariate normality does not guarantee multivariate normality (Tabachnick & Fidell, 1983), but in the absence of any reason to believe that the multivariate normality assumption is being violated, univariate normality lends weight to an assumption of normality.

The data were also checked to evaluate how well they met the assumptions of discriminant function analysis. First, a check was made to ensure that any discriminating variables that may have been non-linear with respect to the other variables as originally coded, had been re-coded into dummy variables to satisfy the assumption of linearity. Gender was retained in its original form because in the case of dichotomous variables the linear discriminant function usually performs reasonably well. Reference has already been made to the recoding of level of education as dummy variables, and the recoding of self-classified approach to life as dummy variables is described below.

A check was also made for violation of the equality of covariance matrices assumption. Box's M statistics computed on each treatment grouping produced  $F(210, 13245.9) = 1.00, p > .05$  for Box's M for treatment grouping 1;  $F(210, 28703.8) = 1.04, p > .05$  for Box's M for treatment grouping 2;  $F(210, 96735.2) = 1.05, p > .05$  for Box's M for treatment grouping 3;  $F(210, 86016.8) = 1.12, p > .05$  for Box's M for treatment grouping 4. The finding of no statistically significant Box's M's indicated that the

covariance matrices were equal in all treatment groupings, thus satisfying the assumption of homogeneity within variance and covariance matrices. Furthermore, since tests for assessing equality of covariance matrices are sensitive to non-normality (Sharma, 1996), confirmation of equality of covariance matrices confirms the non-violation of the normality assumption.

Inspection of bivariate correlations and the resultant non-inclusion of two variables (externality and internality) in the multivariate analyses protected against multicollinearity and singularity. As noted in chapter 8, externality and internality were highly correlated with the corresponding individual control variables. They were also each simply linear combinations of two of the control variables, which is a singularity problem. The tolerance level used in the analyses was the default value of .001, with all variables included in the analyses passing the tolerance test.

Finally, for the multivariate analyses it was necessary to convert the approach to life variable to dummy variables to avoid subsets of participants. On this measure participants were classified as either religious, spiritual, or philosophical, in terms of their approach to life. "Life a" and "Life b" were dummy variables created, using ordinal coding, from the three categories. "Life a" contrasts 'spiritual' with 'not spiritual'. It represents therefore, the difference between a spiritual approach on one hand, and a religious or philosophical approach on the other. "Life b" contrasts 'philosophical' with 'not philosophical' and represents, therefore, the difference between a philosophical approach on one hand, and a religious or spiritual approach on the other. Given that religious and spiritual approaches are conceptualised in the present study as representing an extrinsic approach and philosophical as representing intrinsicness, the "Life b" variable was expected to display the hypothesised difference between the two orientations.

The remainder of this chapter reports the results of the discriminant analyses, organised by treatment grouping. Because discriminant analysis was employed in this study in an explanatory context, rather than in the context of predicting group

membership, group centroids and classification results were not reported. The explanatory context meant that examining the relative magnitude of the standardised canonical discriminant function coefficients and the structure matrices was more appropriate.

### Treatment grouping 1

This grouping reflects the traditional division between conventional and non-conventional medicine where conventional includes only surgery, chemotherapy and radiation therapy and all other treatments are seen as non-conventional. Of the original 212 cases, 46 were excluded because of missing data. The data for 14 of these pertained to the prayer choice, which was incorporated in the second treatment grouping.

The actual discriminant scores in the groups provide an indication of the statistical significance of the discriminant function. The eigenvalue was low (.3390), but there was some variability between groups when compared to within groups, as demonstrated by a Wilks' lambda of .746326, which transforms to a chi-square value of 45.059 with a significance level of .001. This suggests that the analysis produced a discriminant function with significant discriminating power and supports a finding that these groups (defined according to the traditional division between conventional and non-conventional) differ significantly as regards a combination of the values of the discriminating variables.

In terms of the practical significance of the discriminant function, the canonical correlation of .5037 provided some support for the effectiveness of the discriminant function. The squared canonical correlation shows the amount of variation between the groups that is explained by the discriminating variables. In this treatment grouping 25.37% of the variation between the conventional and non-conventional groups was explained.

The relative importance of the various discriminating variables forming the discriminant function is usually assessed using the standardised canonical discriminant function coefficients. While the greater the standardised coefficient the greater the relative importance of the variable in question, the emphasis is on the relative importance of the variable rather than on the absolute value of the coefficient. Table 18 sets out the standardised coefficients in descending order of magnitude to show the relative importance of the discriminators in separating the two groups. The standardised coefficients suggest that education 2, which captures the difference between having a tertiary education and not reaching that level, was the primary discriminator followed by action internality (control 2). Intrinsic life meaning also made some contribution to discrimination between conventional and non-conventional treatment users.

**Table 18****Standardised canonical discriminant function coefficients for treatment grouping 1**

| Discriminating Variable                 | Discriminant Function |
|---|-----------------------|
| Education 2                             | .73593                |
| Action internality (control 2)          | .71402                |
| Intrinsic life meaning                  | .38106                |
| Life a                                  | .35789                |
| Luck externality (control 3)            | -.35618               |
| Gender                                  | .32328                |
| State of mind internality (control 1)   | -.29735               |
| Education 1                             | -.27161               |
| Extrinsic life meaning                  | .22251                |
| Pessimism                               | -.20221               |
| Health interest & motivation            | .18692                |
| Education 3                             | -.16262               |
| Knowledge beliefs                       | -.15749               |
| Optimism                                | -.14080               |
| Education 4                             | -.09085               |
| Knowledge                               | .08520                |
| Life b                                  | .07224                |
| Age                                     | .06484                |
| Powerful others externality (control 4) | .04365                |

The effectiveness of this method of determining the relative contributions of discriminating variables is limited, however, where there are correlations among the variables. The effect of two correlated variables may be shared by both variables leading to interpretation difficulties (Dillon & Goldstein, 1984; Norusis, 1985; Sharma, 1996). Some indication of this possibility is given when the correlations between the values of the discriminant function and the values of the variables, as set out in the structure matrix contained in table 19, are examined. Structure coefficients are helpful in interpreting the relative contribution of each variable to the formation of the discriminant function when variables are correlated among themselves, albeit to a lesser extent than would constitute a multicollinearity problem. A limitation of the loading matrix approach, however, is that the loadings do not necessarily indicate which variables are the most important discriminators after adjustment for the remaining variables.

To some extent the standardised coefficients and the structure coefficients are complementary. The main difference was the inclusion of level of education as a meaningful discriminator when the effect of the other variables included in the function was taken into account and the exclusion of health interest and motivation (standardised coefficients) and vice versa when the relationships between the values of the function and the values of the variables (structure coefficients) were considered.

The apparent difference in the importance of certain variables (between the standardised and structure coefficients), particularly education 2, but also extrinsic meaning and powerful others externality, suggests the possibility of correlation among discriminating variables. This is confirmed by the bivariate correlations, which evidenced associations among the education, control and life meaning variables (see Table 1, Appendix C). It is arguable, however, that since the education dummy variables were essentially correlated only among themselves, which would be expected, this would not necessarily suggest that interpretation of the standardised coefficient for education 2 was ambiguous. This variable captured the difference between having a tertiary level education and an education below that level. As figure 2 shows, the trend in treatment

groupings 1 and 2 is for a higher level of education to be associated with non-conventional rather than conventional treatment use.

**Table 19**

**Pooled within-groups correlations between discriminating variables and the canonical discriminant function (structure matrix) for treatment grouping 1**

| Discriminating Variable                 | Discriminant Function |
|---|-----------------------|
| Action internality (control 2)          | . 54865               |
| State of mind internality (control 1)   | . 45790               |
| Extrinsic meaning                       | . 33114               |
| Gender                                  | . 32937               |
| Health interest & motivation            | . 32222               |
| Powerful others externality (control 4) | . 31559               |
| Intrinsic meaning                       | . 30193               |
| Life a                                  | . 29996               |
| Life b                                  | - . 28914             |
| Age                                     | - . 26351             |
| Education 2                             | . 24480               |
| Knowledge beliefs                       | - . 21281             |
| Knowledge                               | . 19121               |
| Luck externality (control 3)            | - . 16536             |
| Pessimism                               | - . 13747             |
| Education 3                             | . 08177               |
| Optimism                                | . 06354               |
| Education 1                             | . 04055               |
| Education 4                             | - . 03862             |

When the structure coefficients are considered, following the convention that typically those structure correlations that exceed .30 should be considered (Tabachnick & Fidell, 1983), it is evident that of the constructs explored in the study, only knowledge and understanding of cancer did not make a meaningful contribution to the separation of the groups. The remaining constructs were represented by at least one variable each, which were mostly the variables expected to best represent the constructs as conceptualised. The structure matrix suggests that on a traditional division between

conventional and non-conventional use, action internality (control 2) and state of mind internality (control 1) moderately contributed towards distinguishing between conventional and non-conventional users. This suggested that those who incorporated non-conventional treatments in their cancer treatment regimen were more internally motivated in terms of control. Powerful others externality (control 4) also contributed meaningfully to discrimination between the groups, but unexpectedly, this was associated with non-conventional medicine use. This may have been a function of the conceptualisation of the non-conventional group as including those who also used conventional treatments. Explanation of a conceptual nature, however, is offered in the following chapter. Similarly, both intrinsic and extrinsic meaning, contributed to discrimination between the groups, except that extrinsic meaning was not expected to be associated with non-conventional use. Health interest and motivation was also a meaningful contributor to discrimination in the expected direction. Subject to the comments above with respect to education, gender was the only demographic variable contributing to separation, with means suggesting that women were more likely than men to be users of non-conventional treatments.

In terms of the study's hypotheses, the findings in relation to the first treatment grouping may be summarised as follows. No support was found for the first hypothesis that users of non-conventional treatment will be distinguishable from conventional users by their higher level of knowledge about cancer and by a more positive belief system about their cancer. One element of the second hypothesis (that more interest and more positive motivations about health matters will characterise users of non-conventional medicine) received some, albeit limited support. When the effect of all variables was taken into account, health interest and motivation did not rank as one of the more important variables (see Table 18). It did, however, make a meaningful, albeit mild contribution to discrimination between conventional and non-conventional users, (see Table 19). The third hypothesis (that users of non-conventional treatments will seek more personal control and assume more responsibility for their health and its treatment) was supported. In terms of the relative importance of discriminators, internal control, in the sense of taking action, ranked highly among discriminators (see Table 18) and



demonstrated moderate strength in terms of its contribution to discrimination (see Table 19). External control, in the form of powerful others control, also made some contribution to discrimination (Table 19), although unexpectedly, was also associated with use of non-conventional medicine. The findings for meaning in life tended to mirror those for control with extrinsic as well as intrinsic meaning being associated with non-conventional use, suggesting that the fourth hypothesis was only partially supported in this treatment grouping.

### Treatment grouping 2

This configuration of treatment grouping is identical to the first configuration except that those who incorporated prayer in their treatment approach, but no other non-conventional treatments, have been added into the analysis as part of the conventional group. In this grouping 32 cases were excluded for missing data leaving an N of 180. The discriminant function for this treatment grouping also demonstrated reasonable statistical significance. Eigenvalue (.4239) was still low but Wilk's lambda was .702277 with a highly significant chi-square (59.376,  $p < .001$ ).

In terms of the practical significance of the discriminant function, the canonical correlation coefficient (.5456) indicates that almost 30% of the variance between the two groups was accounted for by the discriminating variables. This, together with the statistical significance of the discriminant function scores, indicates that the function has significant discriminating power and that the groups differed significantly in terms of a combination of the values of the constructs hypothesised to influence treatment choice, with the exception of cancer knowledge and understanding.

The relative contributions of the discriminating variables to the discriminant function, assessed using the standardised coefficients (see Table 20), reveal that action internality (control 2) was the primary discriminator in this treatment grouping with education 2 being the second most important. These positions are the reverse of those in

treatment grouping 1. Similarly the third and fourth positions have been reversed and health interest and motivation now makes a meaningful contribution. The two changes to this treatment grouping have been the inclusion in the conventional group of those who use prayer and the consequent increase in sample size by 14. These relatively minor changes in the configuration of the treatment grouping were associated with comparatively larger and seemingly non-commensurate changes in the relative importance of the discriminating variables. Given the minor alteration to the treatment grouping and the reasonable discriminating power of the discriminant function, the explanation may again lie with ambiguity created by correlation among discriminating variables. This may account for the variation in magnitude of the coefficients and the relative importance of the discriminators.

**Table 20****Standardised canonical discriminant function coefficients for treatment grouping 2.**

| Discriminating Variable                 | Discriminant Function |
|---|-----------------------|
| Action internality (control 2)          | .67014                |
| Education 2                             | .53448                |
| Life a                                  | .36572                |
| Intrinsic life meaning                  | .35136                |
| Health interest & motivation            | .32523                |
| Life b                                  | .27119                |
| Extrinsic life meaning                  | .25830                |
| Luck externality (control 3)            | -.22082               |
| Gender                                  | .21014                |
| Education 1                             | -.17108               |
| Optimism                                | -.15281               |
| Pessimism                               | -.15038               |
| Education 4                             | -.13077               |
| Knowledge beliefs                       | -.08856               |
| State of mind internality (control 1)   | -.06499               |
| Powerful others externality (control 4) | -.06387               |
| Education 3                             | .03495                |
| Age                                     | -.02538               |
| Knowledge                               | -.01982               |

It is also noticeable that in this treatment grouping the relative importance of the discriminators, as depicted by the standardised coefficients, shows a greater similarity with the structure coefficients than in the previous grouping, with three of the four constructs represented as meaningful contributors. The knowledge and understanding of cancer construct is consistently not represented.

Table 21 comprises the structure matrix. In this method of assessing the magnitude and relative importance of the discriminating variables in discriminating between the two groups, as in the first grouping, knowledge is the only construct not represented as making a meaningful contribution to the separation between the groups, while the strongest discriminators were again the two internal control variables. Somewhat unexpectedly, the addition of prayerful participants tended to reduce the relative influence of powerful others control in discrimination between the groups. This is possibly accounted for by the fact that the majority of the 77 participants who use prayer were allocated to the non-conventional group because they used at least one other non-conventional treatment. Only 14 were added to the conventional group. The preference, in terms of attributions of control, of prayer users who were in the non-conventional group, likely remained with an internal form of control. Examination of the means between the groups for powerful others externality (control 4), across both treatment groupings, confirms a slightly higher mean score for conventionals in grouping 2, but an identical mean for non-conventionals in both treatment groupings (see Table 16).

A variation from the first treatment grouping is that health interest and motivation moves up to being the 3<sup>rd</sup> most influential variable. The effect of adding those who use prayer into the conventional group then, was to increase the relative importance of health interest and motivation as a discriminator between conventional and non-conventional use. This suggests, in conjunction with the differing means (shown in Table 15), that users of conventional medicine only, when those who use prayer are included, are noticeably less self-motivated as a group than both conventional users who don't use

prayer and users of both conventional and non-conventional (including non-conventionals who use prayer).

**Table 21**

**Pooled within-groups correlations between discriminating variables and the canonical discriminant function (structure matrix) for treatment grouping 2**

| Discriminating Variable                 | Discriminant Function |
|---|-----------------------|
| Action internality (control 2)          | .61505                |
| State of mind internality (control 1)   | .55981                |
| Health interest & motivation            | .46801                |
| Age                                     | -.33094               |
| Intrinsic Meaning                       | .32159                |
| Extrinsic Meaning                       | .30727                |
| Life a                                  | .27401                |
| Gender                                  | .25956                |
| Education 2                             | .23026                |
| Powerful others externality (control 4) | .19172                |
| Cancer knowledge                        | .18437                |
| Cancer knowledge beliefs                | -.17738               |
| Education 3                             | .14881                |
| Optimism                                | .08436                |
| Life b                                  | -.07709               |
| Education 1                             | .06430                |
| Luck externality (control 3)            | -.04950               |
| Pessimism                               | -.03602               |
| Education 4                             | .02200                |

It is also noted that as prayer users were added to the conventional only group, intrinsic meaning means reduced among that group and the relative importance of that variable as a discriminator increased. It is also noticeable that when the prayer group was added to the conventional only users mean age increased from 58.67 to 60.04. This compares to a mean age among non-conventionals of 53.82 years.

In summary, again knowledge and understanding of cancer did not contribute to discrimination between users of conventional and non-conventional medicine, providing no support for hypothesis 1. The second hypothesis was more strongly supported for this treatment grouping both in terms of the relative importance and the strength of health interest and motivation as a discriminator. As in the first treatment grouping, action internality was the strongest discriminator between the conventional and non-conventional groups. Indeed, the discriminant function for the second treatment grouping is largely made up of internal control, providing reasonable support for the hypothesis, particularly since externality did not make any meaningful contribution to discrimination in this treatment grouping. In relation to the fourth hypothesis, however, while intrinsic meaning made some contribution to discrimination as hypothesised, extrinsic meaning was also associated with non-conventional medicine use, which was unexpected. Age also contributed to discrimination and was negatively correlated with the discriminant function. This indicates that younger age was associated with non-conventional medicine use.

### Treatment grouping 3

In this grouping, conventional included conventional, prayer, physical and natural treatments (see Table 5 for a definition of physical and natural treatments). The non-conventional group comprised those who, in addition to conventional medicine, utilised the remaining two categories of non-conventional treatment, as well as the participants who used no conventional as traditionally defined. After excluding 32 cases for missing data, 180 were used in the analysis.

Examination of the canonical discriminant function scores suggests that this configuration of treatment grouping resulted in the greatest separation between the groups. The highest eigenvalue (.5074), the highest canonical correlation (.5802), the lowest Wilk's lambda (.663382) and a highly significant chi-square (68.948,  $p < .001$ ) suggested that in terms of the combination of health-related cognitions explored in this

study, the greatest separation between conventional and non-conventional users occurs when physical and natural types of treatment are treated as conventional along with prayer and traditional conventional medicine.

Furthermore, as a measure of the practical significance of the discriminant function, 33.6% of the variance between the two groups was accounted for by the discriminating variables. This compares reasonably well with other research in this area. Furnham and Beard (1995), for example, found that 38.7% of the variance was accounted for by health beliefs variables. Calnan and Rutter (1986), in exploring the links between health beliefs and behaviours, reported variance of between 3% and 16%. They also suggested that studies using the Health Belief Model never report variances higher than 25%.

In assessing the relative rankings of the various discriminating variables, the standardised coefficients, set out in Table 22, suggest that 'life a' (which represents the difference between a spiritual approach to life's meaning on one hand and a religious or philosophical approach on the other) was the primary discriminator. This was followed by 'life b' (which captures the difference between a philosophical approach on one hand and a religious or spiritual approach on the other) as the second contributor to discrimination. The positions of education 4 and education 3 should be treated with caution, however, given that, in terms of magnitude, neither variable made a meaningful contribution to discrimination (see Table 23). Intrinsic life meaning remained a consistent contributor, as did the control construct, although represented by powerful others external control rather than internally oriented control as had been the case in the first two treatment groupings.

Internal control has consistently been the primary discriminator based on structural coefficients as shown in Table 23. In this case, however, control was represented by state of mind internality, which is a change from treatment groupings 1 and 2 where action internality was the primary discriminator. Internal control remained as the most important, but this would indicate a change in the type of internal control that

differentiates the groups when the division between conventional and non-conventional is altered. This suggests that users of physical and natural treatments have a more pragmatic 'action' approach to treatment than users of the psychological and psychic and metaphysical approaches who subscribe more to a 'state of mind' type of approach. Group means (shown in Table 16) confirm this.

**Table 22****Standardised canonical discriminant function coefficients for treatment grouping 3**

| Discriminating Variable                 | Discriminant Function |
|---|-----------------------|
| Life a                                  | .62858                |
| Life b                                  | .47599                |
| Education 4                             | -.43835               |
| Intrinsic life meaning                  | .39892                |
| Powerful others externality (control 4) | .39403                |
| Education 3                             | .36278                |
| Education 2                             | .30555                |
| Knowledge beliefs                       | -.30345               |
| Gender                                  | .24489                |
| Luck externality (control 3)            | -.23970               |
| State of mind internality (control 1)   | .22919                |
| Action internality (control 2)          | .16961                |
| Extrinsic life meaning                  | -.15462               |
| Pessimism                               | -.11137               |
| Knowledge                               | .10868                |
| Health interest & motivation            | .10064                |
| Education 1                             | -.08332               |
| Optimism                                | -.03601               |
| Age                                     | -.00032               |

Also contributing to discrimination between the groups, according to structure coefficients, was approach to life's meaning as represented by the 'life a' variable. This confirms the importance of this variable as identified by the standardised coefficients. As noted above, this variable captures the difference between spiritually derived meaning on one hand and religiously or philosophically derived meaning on the other. This suggests,

somewhat unexpectedly, that the difference between spiritually and religiously derived meaning discriminated between the groups (as well as the difference between spiritually and philosophically derived meaning). The expectation however, was that the 'life b' variable, which contrasted philosophically derived meaning with religiously and spiritually derived meaning, would discriminate between conventional and non-conventional users.

**Table 23**

**Pooled within-groups correlations between discriminating variables and discriminant function (structure matrix) for treatment grouping 3**

| Discriminating Variables                | Discriminant Function |
|---|-----------------------|
| State of mind internality (control 1)   | .58868                |
| Life a                                  | .44888                |
| Action internality (control 2)          | .39431                |
| Intrinsic life meaning                  | .36357                |
| Age                                     | -.28920               |
| Gender                                  | .28123                |
| Cancer knowledge beliefs                | -.27101               |
| Health interest & motivation            | .26064                |
| Powerful others externality (control 4) | .24999                |
| Cancer knowledge                        | .21886                |
| Extrinsic life meaning                  | .19932                |
| Optimism                                | .13985                |
| Luck externality (control 3)            | -.13493               |
| Education 3                             | .12975                |
| Education 2                             | .12773                |
| Life b                                  | -.11124               |
| Education 4                             | -.09931               |
| Education 1                             | .04977                |
| Pessimism                               | -.01390               |

As with the first and second treatment groupings, level of intrinsic meaning continued to contribute to discrimination, with those utilising the more non-conventional treatments demonstrating a greater level of intrinsic meaning. The contribution of health



interest and motivation, however, appears to diminish in grouping 3. This does not necessarily imply that motivation is unimportant as a discriminator between users of conventional and non-conventional medicine, but it does imply that when the dividing line between conventional and non-conventional is shifted, the discriminating effect of motivation reduces, presumably because it is more sensitive to the traditional division. That is, the use of physical and natural treatments (now defined as conventional) is likely associated with motivation as much as use of psychological and psychic and metaphysical types of treatments.

The influence of the configuration of treatment grouping 3 on the hypothesised discriminatory power of the study's constructs may be summarised as follows. Hypothesis 1 remains unsupported, although the strength of the correlations between cancer knowledge and cancer beliefs with the discriminant function has moved closer to the .30 cut off point (Table 23). Similarly, health interest and motivation (hypothesis 2) appears not to make a meaningful contribution to discrimination, but this may be the effect of the treatment grouping configuration. When the division between conventional and non-conventional medicine reflected the more traditional approach, as in treatment groupings 1 and 2, health interest and motivation was a meaningful contributor (see Tables 19 and 21). In treatment grouping 3, where physical and natural treatments have been reclassified as conventional, however, the health interest and motivation associated with those who use those forms of 'non-conventional' medicine, has likely been transferred to the conventional group. This would cloud the distinction between the groups on this variable. This also suggests that, in relation to this variable, the fifth hypothesis (that discrimination between conventional and non-conventional use will become more marked as the non-conventional treatment grouping becomes 'more non-conventional') was not supported.

The third hypothesis continues to be supported with internal forms of control and responsibility correlating with the discriminant function, indicating that internal attributions of control and responsibility continue to predominate among users of non-conventional medicine. The slight reduction in the magnitude of the correlations (from

treatment grouping 2 to this treatment grouping) may be accounted for by the reclassification of physical and natural treatments as conventional. It also suggests that the fifth hypothesis is unsupported for this construct, at least in relation to the altered division between conventional and non-conventional proposed by treatment grouping 3.

The fourth hypothesis was also supported in relation to treatment grouping 3. Intrinsic life meaning made a meaningful contribution to discrimination with intrinsic meaning being associated with non-conventional use. Given the relative importance of the 'life a' variable, compared to the 'life b' variable, the indications are, however, that spirituality may be associated with intrinsicness rather than the expected extrinsicness. Furthermore, this may add weight to the possibility that spirituality and religiousness are not complementary concepts as they were expected to be.

#### Treatment grouping 4

In this configuration of treatment groups the non-conventional group comprises those who use psychic or metaphysical types of therapies (as well as other types of non-conventional), and the conventional group comprises those who use all types of treatment except psychic and metaphysical types. 180 cases were included in the analysis, 32 having been excluded for missing data.

Overall, the discriminant scores for this treatment grouping indicate a significant discriminant function. Wilks lambda was .709739 with an equivalent chi square value of 57.600,  $p < .001$ . In practical terms a canonical correlation of .5388 meant that the discriminating variables accounted for 29% of the variance between the two groups.

Table 24 displays the standardised coefficients in descending order of importance. The consistency of internal control, in this case represented by state of mind internality, as the primary discriminator continued. Correlation between the two internal control variables may have accounted for action internality appearing to be comparatively

unimportant in the discriminant function, whereas in the structure matrix this variable was the second most important variable after state of mind internality (see Table 25). Again a high level of education appears to be an important discriminator but, as in treatment grouping 3, having a university degree (education 4) was associated with conventional treatment use rather than non-conventional use, as it was for treatment groupings 1 and 2. These findings confirm the univariate results displayed in figure 2 although should be interpreted with caution given that the structure matrix (Table 25) did not indicate such an important role for education. Similarly, 'life a' continues to be a consistently important discriminator as assessed by both standardised and structure coefficients.

**Table 24****Standardised canonical discriminant function coefficients for treatment grouping 4**

| Discriminating Variable                 | Discriminant Function |
|---|-----------------------|
| State of mind internality (control 1)   | .50761                |
| Education 4                             | - .42894              |
| Life a                                  | .41029                |
| Education 2                             | .36451                |
| Education 3                             | .26638                |
| Intrinsic life meaning                  | .25053                |
| Powerful others externality (control 4) | .22131                |
| Luck externality (control 3)            | - .19984              |
| Knowledge beliefs                       | - .18626              |
| Health interest & motivation            | .17260                |
| Gender                                  | .16391                |
| Education 1                             | - .12443              |
| Life b                                  | .12072                |
| Optimism                                | - .10971              |
| Cancer Knowledge                        | .08556                |
| Extrinsic life meaning                  | - .08262              |
| Pessimism                               | - .06849              |
| Age                                     | - .06653              |
| Action internality (control 2)          | .02964                |

In terms of structure coefficients, as a means of assessing the meaningfulness of the discriminant function and the relative contributions of the discriminating variables, the pattern of variables contributing to separation between the groups continued. The structure matrix (shown in Table 25) confirms state of mind internality as contributing strongly to discrimination followed by action internality. Approach to life's meaning (represented by 'life a') and level of intrinsic meaning also contributed to discrimination in a similar way to treatment grouping 3. In grouping 4, however, age appears to make a greater contribution. Not unexpectedly perhaps, younger participants were more likely to be interested in psychic and metaphysical forms of treatment.

**Table 25**

**Pooled within-groups correlations between discriminating variables and discriminant function (structure matrix) for treatment grouping 4**

| Discriminating Variable                 | Discriminant Function |
|---|-----------------------|
| State of mind internality (control 1)   | .73776                |
| Action internality (control 2)          | .45788                |
| Life a                                  | .44940                |
| Intrinsic life meaning                  | .34696                |
| Age                                     | -.33937               |
| Powerful others externality (control 4) | .31610                |
| Health interest & motivation            | .28537                |
| Gender                                  | .27655                |
| Extrinsic life meaning                  | .25610                |
| Life b                                  | -.24476               |
| Cancer knowledge                        | .22360                |
| Cancer knowledge beliefs                | -.21941               |
| Education 2                             | .14587                |
| Luck externality (control 3)            | -.11533               |
| Education 4                             | -.11146               |
| Optimism                                | .11038                |
| Education 3                             | .10975                |
| Pessimism                               | -.04588               |
| Education 1                             | .01395                |

Powerful others control also made a greater contribution to discrimination in this treatment grouping than in the others, with the non-conventional group scoring higher on this form of control than the more conventional group. This was an unexpected finding, particularly since this non-conventional group also scored more highly on both forms of internal control than the reconstituted conventional group.

In summary, the trend among the findings in relation to the study's hypotheses continued for treatment grouping 4. Knowledge and understanding of cancer was not confirmed as a discriminator. Health interest and motivation was only marginal in its discriminatory effect, although the shifting of the dividing line between conventional and non-conventional may have affected the discriminatory power of this variable in this treatment grouping, as suggested for the third grouping.

Again, the discriminant function was largely made up of the control and meaning constructs, with internal control and intrinsic life meaning characterising users of non-conventional treatments. Powerful others externality also made a meaningful contribution, but also in association with the use of non-conventional treatments. An explanation for the increased relative importance of the control 4 variable in this configuration of treatment groups may be that the non-conventional group includes those who have a greater spiritual awareness in a broad sense rather than in a narrow religious sense. It could also be accounted for by non-conventional users who use the psychic and metaphysical types of treatments having a different conceptualisation of 'powerful other'. The instrument provided for a supernatural power (other than God) to be identified as a 'powerful other'.

### **Significant discriminator subset analyses**

A further series of discriminant analyses was performed on the subset of discriminating variables that appeared to include those variables making a significant contribution to separation between the conventional and non-conventional user groups.

Education variables were not included in these analyses because they did not demonstrate significant Wilks' lambdas and univariate F-ratios. Neither did they feature in the structure matrices in the previous analyses above the .30 cut-off point for any of the treatment groupings.

In these subset analyses, as would be expected, each treatment grouping displayed a highly significant discriminant function ( $p < .001$  in each case). As a measure of the effectiveness of the subset of discriminating variables, a comparison was made of the variances (in the groups for each treatment grouping) between the all in analyses and the subset analyses. For treatment grouping 1, when all discriminating variables were included in the analysis, 25.4% of the variance was accounted for by these variables but on the subset analysis this was reduced to 15%. For the remaining treatment groupings the difference was less marked. For the second grouping variance reduced from 29.8% to 23%. For treatment grouping 3 the explained variance reduced from 33.7% to 26% and for treatment grouping 4 the reduction was from 29% to 24%. The differences in the variances between the two analyses represent the variance attributable to those variables included in the all in analyses but not the subset analyses.

This suggests that the three constructs represented (health interest and motivation, attributions of control, responsibility and blame, and life meaning) have been shown to be reasonably effective in discriminating between conventional and non-conventional treatment use, particularly when the dividing line between the modalities is moved away from the traditional division. Furthermore, a number of the variables not included in the subset analyses also represent these constructs. At a construct level there may, therefore, be less difference between the variances accounted for in the two analyses.

Tables 1 to 8 in Appendix D show the standardised coefficients and structure coefficients for each treatment grouping. A comparison of the standardised coefficients for these subset analyses and the previous all in analyses shows, essentially, a similar picture of the relative contributions of discriminators to the discriminant functions, excluding education variables. Similarly for the structure coefficients, relative importance

of discriminators remained the same with a general elevation of magnitude of coefficients. This confirms the overall stability of the structure matrix in so far as these variables are concerned, and provides some support for the appropriateness of the combination of discriminator variables.

## CHAPTER TEN

### DISCUSSION

Discussion of the results of the study is presented in four sections, broadly structured around the format in which the results in the previous two chapters were presented. The first section comprises a summary of the overall findings of the study. The second section contains a discussion of the conceptual basis of the set of constructs explored in the study as a meaningful approach to understanding some of the cognitions expected to influence treatment choice decisions. In the third section the findings in terms of the specific hypotheses of the study are discussed. Integrated with this is discussion of the merits of the conceptualisation and measurement of the key constructs of attributions of control, responsibility and blame, and meaning. The fourth section addresses limitations of the study, future research possibilities, and contains some suggestions about applications of the findings.

#### **Summary of findings**

The influence of demographic variables and of each of the constructs separately, and in combination, on the treatment choice decision, may be summarised as follows: Overall, the younger age group (25-50) was associated with the use of non-conventional treatment, and more women than men tended to use non-conventional medicine. There was also some evidence to suggest that a higher education is associated with the use of certain forms (the more traditional) of non-conventional medicine.

The expectation that greater knowledge and understanding of cancer would be associated with the use of non-conventional medicine was only partially supported, although a general trend supporting it was evident. When those who used physical and natural types of non-conventional medicine were added to those who use only



conventional medicine, this group demonstrated significantly less knowledge than those who used the less traditional non-conventional treatments.

The expectation that those who took more interest in health matters and who showed more motivation to be involved would be more likely to use non-conventional medicine was supported. This component of the approach to treatment construct was reasonably robust as a discriminator relative to the other discriminating variables, when the division between conventional and non-conventional treatment was along traditional lines. Whether a person had an optimistic or a pessimistic outlook on life, another approach to health component, did not have a direct effect on the type of treatment chosen. It was, however, related to how meaning in life was derived.

The hypothesis that users of non-conventional medicine would be those who desire more personal control over their health and are prepared to attribute responsibility to themselves, was consistently supported. The results demonstrated, however, that control is a complex concept with non-conventional users embracing powerful others externality as well as an overall internal approach to control. Overall, the attribution of control and responsibility, particularly when attributed to self, was an important discriminator between users of conventional and non-conventional medicine.

Whether meaning in illness was derived intrinsically or extrinsically appeared to make no difference to treatment choice. For meaning in life, however, as expected, those whose approach to life was intrinsically oriented were more likely to use non-conventional medicine. As to whether those who derived meaning in their life from an external source were more likely to use conventional medicine, it was found that religiously derived extrinsic meaning was associated with conventional use but not meaning derived in the broader spiritual frame. Overall, the way in which meaning in life is derived (either intrinsically or extrinsically) was found to be an important discriminator between the use of conventional and non-conventional medicine.

### **The conceptual integrity of the constructs comprised in the study**

Relationships among variables at both a within and between constructs level provide information about the conceptual basis and measurement of the set of constructs comprised in the study. These are discussed construct by construct in this section.

#### ***Knowledge and understanding of cancer***

No consistent pattern emerged among the constructs in relation to information based knowledge. One expectation was that the accumulation of knowledge about cancer would be associated with health motivation and interest and with attributions of control. The overall reasonable level of knowledge was not related to levels of interest and motivation, however, although the expected relationship between higher levels of knowledge and control attributed to self was found. The relationship may have been in either direction, however. A preference for personal control and the taking of some responsibility over health matters could lead to the accumulation of knowledge. On the other hand, more knowledge about cancer aetiology and particularly its treatment, may encourage a cancer patient to assume more personal involvement in the decision making and treatment process. As Eliopoulos (1999) pointed out, understanding the disease is necessary if an individual is to effectively manage it, but she also suggested that knowledge means little if the patient is insufficiently motivated to engage in the necessary health-related behaviours.

Another expectation was that if higher levels of knowledge were related to more internal attributions of control, which they were, they would also be positively related to intrinsically oriented meaning. The finding was, however, that those who derived meaning in a spiritual frame demonstrated noticeably less knowledge about cancer than those whose meaning was derived in religious or philosophical frames. This was expressed mainly in terms of how their spirituality helped them cope with life, indicating

that where spirituality helped in the coping process, knowledge was less important. The same effect was expected, but not found, for those whose meaning was derived in a religious frame. The noticeable effect of a spiritually derived orientation compared to religiously and philosophically derived orientations (see Table 11) must be interpreted with some caution, however, because of the reduced sample size (70) on the orientation variables. Nevertheless, this was an early indication that a spiritual orientation may be distinctive in some way.

Research into the correlates of cancer knowledge has generally found that it is participant characteristics that have mostly explained knowledge, particularly knowledge acquisition (Stone & Siegel, 1986). In the present study, while it was expected that those who were interested and motivated about health matters could for that reason have acquired a cancer knowledge, it was participant characteristics such as education, gender and age that were significant correlates of knowledge levels. Interestingly, however, time since diagnosis was negatively correlated with level of knowledge ( $r = -.20, p < .01$ ). Intuitively it would be expected that the longer a person lived with cancer the greater the knowledge they would accumulate. The opposite findings could be a function of age, however, since knowledge decreases with increasing age ( $r = -.26, p < .001$ ). It may also reflect the effect of involvement mainly with conventional practitioners, which was also found to be a characteristic of increasing age. Older patients may not seek or want information from their doctor, which is a characteristic of the doctor/patient relationship than older people are likely to be familiar with.

The findings in the present study tended to confirm that participant characteristics are more likely to influence the level of knowledge than are cognitive concomitants. This calls into question the usefulness of the cancer knowledge variable as a contributive element of the cognitive approach to understanding treatment choice decisions. With a number of participant characteristic correlates of cancer knowledge, it is difficult to conclude that high levels of knowledge have something to do with high motivation about health matters, or wanting to take personal control or responsibility. It may simply be that those who were diagnosed and treated for cancer earlier, when the medical profession

perhaps were less forthcoming with information, may have been given less information. It may also be that older patients have poorer information retention or recall ability, or that education contributes to knowledge acquisition, understanding or retention.

Findings on the personal beliefs about cancer dimension of knowledge were also largely unexpected, in that, apart from some association with optimism and pessimism, only the meaning construct appeared to be related. Those for whom meaning in their illness and their life was intrinsically derived consistently evidenced a more positive belief system about cancer, with an extrinsic approach being associated with a more negative belief system. It was expected, however, that an extrinsic orientation would bring a level of positiveness or "hope". An extrinsic orientation was conceptualised as one where existential questions are answered with reference to an external powerful other. In a Western culture this would usually be God, however conceptualised by the individual. The "hope" therefore, would emanate from belief and faith in one's God to intervene in some way. The contrary finding could be explained by the aversive nature of a cancer diagnosis, or the often inexorable progress of the disease eroding trust in one's God to the point where the loss is compounded. Not only would there be a loss of health status, but also a sense of loss of the security previously enjoyed through the faith relationship.

### ***Approach to health***

Health interest and motivation was the key variable in the approach to health construct. The relationship between this variable and internally focused control provided support for the suggested theoretical link between these concepts. This could be interpreted as the more a person attributed responsibility for events and control to themselves, the more motivation they would need to maintain the focus on self. Alternatively, interest and motivation about health matters would likely perpetuate a desire for personal control, encouraged by the urge to be getting on and doing something about the situation. Hack et al. (1994) suggested that two important ways by which

cancer patients may gain a sense of control over their illness include acquiring information about their illness and its treatment (which links the concepts of control and knowledge) and playing a more active role in treatment decision making (which links control and motivation to be involved).

The other variables that health interest and motivation was associated with were the two intrinsic life meaning variables (see Table 12). This confirmed the expectation that intrinsically derived meaning in life would be associated with both the motivation to be involved with one's health and to be in control and assume responsibility. It also indicated that health interest and motivation, control and responsibility attributed to self, and a self focused approach to life's meaning are complementary concepts.

The relationship between the motivation beliefs variable and the other constructs was found to be inconsistent. As noted earlier, this is a variable that had been added to the Health Belief Model tapping the value a person places on taking an interest in and being personally involved in their health. The overall inconsistency of results on this variable support the suggestion now made that, in the context of this study, the variable was superfluous. Arguably, the value placed on motivational aspects is implicit in the scores on the health interest and motivation variable itself.

The dispositional optimism component of the approach to health construct indicated that there were some potentially complex aspects associated with levels of optimism and pessimism. On one hand there were some confusing findings, but on the other, there was a certain consistency. For example, intrinsic life meaning and intrinsic illness meaning were associated with both more optimism and more pessimism (see Table 12), although the effect was more pronounced with optimism. When the measure was scored unidimensionally, however, as the authors intended it to be, optimism was mildly associated with extrinsic life meaning and extrinsic illness meaning, as was expected. As suggested in Chapter 8, treating the Life Orientation Test (Scheier & Carver, 1985) as a bidimensional measure of optimism and pessimism may not be appropriate for the likes of cancer patients.

The consistency referred to above, however, was that less pessimism was consistently expressed by those who attributed control externally and for whom meaning in illness and life was derived extrinsically, including religiously derived meaning. It is suggested that it is not inconsistent for people living with cancer to express low pessimism without a corresponding expression of optimism. An external focus would appear to moderate pessimistic outlook without necessarily offsetting the perceived “reality” of cancer. It is notable however, that spiritually derived meaning, like intrinsically oriented meaning, was associated with higher levels of optimism. A consistent trend seemed to be developing that spiritually derived meaning should not be conceptualised similarly to religiously derived meaning as an extrinsically oriented form of meaning.

#### *Attributions of control, responsibility and blame*

The theoretical basis underlying the influence of this construct in the present study may be briefly summarised as follows. As Lowenberg and Davis (1994) pointed out, throughout the non-conventional health movement considerable emphasis is placed on returning the responsibility for health, illness and cure to the individual. The attribution of this responsibility to self therefore, is congruent with the non-conventional medicine model, while the concept of external control, as conceptualised in the present study, is congruent with the concept of causality (and responsibility) in the allopathic model. This approach includes the notion of responsibility and blame but in the context of attributing it to a powerful other.

A major consideration in the use of the Influences on Health and Illness Scale (IHI) (Stainton Rogers, 1991) to measure attributions of control, responsibility and blame was to avoid the strict dichotomous nature of other health locus of control scales. As Furnham and Beard (1995) observed, internal and external attributions are not necessarily mutually exclusive dispositional traits. Similar to Furnham and Beard’s (1995) findings,

the results of the present study support Stainton Roger's (1991) criticism of health locus of control scales. By applying a more finely grained definition, assessment and analysis approach (i.e., conceptualising internality and externality with two separately assessed variables for each), a more detailed and insightful picture of internality and externality was gained (see Table 9).

The IHI scale is also able to tap the complexities of the concept of control in more depth than previous locus of control scales had permitted. For example, conceptualising control within an attributional framework encouraged the inclusion of the notions of responsibility and blame, which have themselves tended to differentiate among health-related behaviours in a way that the locus of control concept overlooks. While in the literature there is an overlap between the locus of control and the attribution approach, there is a major difference between them (Furnham & Steele, 1993). In the attribution literature a distinction has been made between attributions of cause and attributions of responsibility, whereas locus of control is usually concerned with perceived cause but not with responsibility (Furnham & Steele, 1993). Furthermore, as Christensen et al. (1999) found when exploring the role of behavioural self-blame in the assessment of future health-related behaviour of cancer patients, expectancies individuals hold about future health-related outcomes influence their ongoing health-related behaviour. This was acknowledgement that it is not only causal attributions that influence the behavioural response to life-threatening illness, as the locus of control concept would support.

Another advantage of the IHI scale is that the items comprising the powerful others subscale allow for a religious or spiritual interpretation of 'powerful other'. Other health locus of control scales tend to steer the respondent towards powerful others as representing health professionals and the like. The importance of the broader view of 'powerful other' appears to have been confirmed in the present study. Powerful others externality was clearly associated with religiously and spiritually derived meaning (and extrinsic meaning) but not with philosophically derived meaning (see Table 13). This was further supported by the finding that luck externality may be irrelevant, or at least ambiguous, as a dimension of externality.

In conceptual terms, a relationship between attributions of control, responsibility and blame and the concept of meaning seems reasonably clear when powerful others externality is cast in a religious or spiritual frame, or at least given that potential. This is particularly important in the context of critical life events such as cancer. As Fosterling (1992) pointed out, the person experiencing these events will search for an attribution for the events by asking why they have happened. The 'why' questions link attributional concepts and existential issues of meaning. It is suggested that the "linking" questions are as follows: "Why have I got this illness (which will most likely reduce the quality and length of my life)?" The answer to this question is likely to be of an attributional nature. The follow-on question would be something like: "What does my life mean if this can happen?" This is an existential question.

When intrinsic and extrinsic approaches to meaning were compared with attributions of control, responsibility and blame, the expectation was that religious and spiritual meaning would be positively associated with externality, while philosophical meaning would be associated with internality. Religious and spiritual meaning were equally significantly associated with powerful others externality, as expected. Unexpectedly however, there was some internality among the religious meaning group, but a noticeably more pronounced level of internality among the spiritual meaning group (see Table 13), suggesting that a spiritual approach has more in common with the internal and intrinsic orientation than does the religious approach.

Within the constructs of attributions of control, responsibility and blame and meaning there was a clear separation between the internal/external and intrinsic/extrinsic approaches respectively (see Tables 9 and 10). The expectation that there would be a certain congruence between internality and intrinsicness and between externality and extrinsicness was supported to some extent. The results (as set out in Table 13) suggest, however, that these relationships are not as well defined as was expected in terms of the conceptualisation of these variables in previous chapters. The results have shown that



some modification is necessary in the way aspects of intrinsic and extrinsic meaning are defined and measured. These are addressed below in relation to the meaning construct.

### *Meaning*

The conceptualisation of illness meaning in terms of intrinsicness and extrinsicness may be fundamentally flawed even though the measurement instruments used permit of this conceptualisation. If illness meaning could be conceptualised in this way some association between illness meaning and life meaning would be expected. That is, those who evidenced an intrinsic approach to life meaning would tend towards an intrinsic approach to illness meaning, and similarly for extrinsic meaning. No relationships were found so it can be concluded that either the meaning of meaning is not the same for both, or the measurement instruments used for illness meaning were psychometrically inadequate. Both are possibilities.

The psychometric qualities of the illness meaning scales were inferior in comparison to those found for the life meaning scales. As reported in chapter 7, reliability for the Constructed Meaning Scale (Fife, 1995) was only just acceptable ( $\alpha = .72$ ) and at best marginal (alphas were .60 or below) for the intrinsic and extrinsic subscales of the Response to Illness Questionnaire (Pritchard, 1974a, 1974b). Construct validity may also be in doubt since neither of the above scales was developed to assess meaning conceptualised as intrinsic or extrinsic. This was to some extent confirmed by the low to moderate relationships found among the scales measuring intrinsic and extrinsic illness meaning (see Table 10). While Schmitt (1996) has suggested that alpha reliabilities in the vicinity of .50 may still be acceptable when domain coverage is meaningful and unidimensionality is reasonable, in the present instance potential validity problems, arising from using the instruments in a conceptual context for which they were not designed, still signals psychometric problems.

Support for the view that measurement rather than conceptual issues account for there being little relationship between illness meaning and life meaning comes from the fact that in the literature it appears that the two have been approached as interwoven concepts. For example, the transpersonal philosopher Wilber (cited by Millenson, 1995) has identified some of the major types of meaning given to illness by various religions and philosophies. For example, the Christian fundamentalist approach sees illness as a punishment from God for some sin. New Age characterises illness as a lesson, in which one gives oneself the disease because there is something that must be learnt from it. In Eastern religions illness has resulted from non-virtuous past actions reappearing in the form of disease, which represents the purification process. The holistic approach sees illness as a product of physical, emotional, mental and spiritual factors, and the existential approach sees illness as like life itself, without meaning, so it can take on any personal meaning the individual may care to give it. These are all mixtures of life meaning concepts with illness meaning. Freund and McGuire (1999) went a step further with their assertion that religious meaning is connected with illness explanations when arguing for the importance of theodices.

The view that measurement rather than conceptual issues account for the difficulties with illness meaning is also supported by examination of the correlations contained in Table 10. These suggest that within the context of illness meaning, the concepts of intrinsicness and extrinsicness are appropriate. On each measure intrinsicness was negatively correlated with extrinsicness. It is possible, however, that, rather than illness meaning and life meaning being subconstructs of the same concept (i.e., meaning), meaning in illness may be something quite different from meaning in life. In any event, these problems, it is suggested, justified the decision to remove illness meaning as a discriminating variable on the basis that either it may not be compatible with the collective conceptual basis of the group of constructs, or it was psychometrically unsound.

The conceptualisation of life meaning in terms of intrinsicness and extrinsicness appears to have been justified in a general sense by the findings in this study. As has

already been signalled, an unexpected distinction was found, however, between religiously derived life meaning and life meaning derived in a spiritual frame. In the original conceptualisation they were expected to be equivalent measures of an extrinsic orientation with the latter simply catering for those who do not identify with a church based or religious practice based approach.

A possible explanation for the difference observed between religious and spiritual approaches is that the latter is something of a mixture of extrinsicness and intrinsicness. While it was conceptualised essentially as a religious approach without the formal religious observation component, it may be more accurately described in terms of the New Age approach to religion. This incorporates some of the self-focused aspects of Eastern religion in which God is not necessarily conceptualised in an external sense. A possibility is that the conceptualisation of the spiritual approach to meaning in this study was too simplistic. The distinction would appear to go deeper than simply a religious minus the religious ritual and observation component, suggesting that in both research and applied situations, religious type variables should be approached in a broad frame to capture the varied conceptualisations and practices of "religion".

It may be that extrinsicness and intrinsicness are not mutually exclusive orientations that individuals choose or can be classified by, but are approaches that they can be a mixture of. As this study shows, people are prepared, when required, to classify themselves as one or the other, and no doubt this accurately reflects their belief system. When, however, they are presented with detailed propositions (such as those contained in specific questionnaire items) that represent these approaches, the distinction between the two approaches appears to be less than dichotomous.

Another explanation lies in the difference between assigning meaning and searching for meaning. Those who make some form of religious commitment, in a sense, have completed their search for meaning. They could be said to have found what they are looking for. They are therefore able to assign meaning (which they have discovered) to their life and its (negative) events, and proceed with the task of dealing with the illness.

Those whose approach to life is not religious, but spiritual and intrinsically oriented, may still be searching within their environment, themselves and their life for meaning. This approach to religion and spirituality is at odds, however, with the suggestion of Zinnbauer et al. (1997) that religion and spirituality should not be split and that researchers should adopt a “broadband” approach to the study of religion. In the context of the present study, however, it is suggested that the splitting is justified.

This has implications for the Royal Free Interview measure. King et al. (1995), in developing the measure, recognised that the narrow use of the term ‘religious’ has led to a presumption that if a person does not profess a recognised religious faith, they do not have spiritual discernment or need (Speck, 1988, cited in King et al., 1995). They used questions, therefore, which could be answered by those who consider themselves to be spiritual but not religious. As mentioned in chapter 7, only two scales were derived by the authors from the interview, a spiritual scale and a philosophical scale. They assumed that interviewees who considered themselves religious would be happy to answer the spiritual belief questions having previously answered questions about their religious practice, and those who considered themselves to be spiritual would not have to answer questions that referred to religion. The effect of this approach, however, was to preclude the possibility of detecting any difference between those who classified themselves as religious and those who classified themselves as spiritual. It was the provision of separate subscales to those classifying themselves as religious or spiritual that resulted in the detection of the considerable conceptual distinction between religiousness and spirituality

Empirical support for the conceptualisation of life meaning as intrinsic or extrinsic, and for the distinction between religiously and spiritually derived meaning was found to some extent in the associations among the life meaning variables (see Table 10). The use of the “pucolcda” subscale of the LABI (LAP-R) (Reker, 1992) in isolation (i.e., without subtracting “evgs” items) was also confirmed as appropriate to tap intrinsic meaning as defined in this study. The relationships between the intrinsic and extrinsic meaning variables and philosophical, religious and spiritual meaning should be treated

with caution, however, because of the effect of the reduced sample size in the latter three variables.

As signalled in Chapters 8 and 9, the extrinsic life meaning variable, derived from the Royal Free Interview subscale completed by all participants, should be treated with caution. Examination of the items in the subscale suggests that there may be some conceptual problems with this variable. For example, for the first item (“illness is a punishment for wrong doing”) those subscribing to a religious or spiritual approach appear reluctant to blame God or a higher power for their ill health. The notion of blame may not be appropriate as a measure of extrinsic orientation. The second item, “illness as predetermined / due to fate” was possibly ambiguous. Some participants may have interpreted “predetermined” as extrinsicness because it connoted a powerful other’s involvement, but “due to fate” may have been seen as luck, which participants in this study have not embraced as a component of the related concept of externality. Those with an intrinsic orientation may have seen this as the opposite of predetermined and agreed with it. For the item “illness is sent to test / try us”, both extrinsically and intrinsically oriented participants may have related to this. Extrinsic individuals could have interpreted this literally as “sent by God” who must be satisfied, and intrinsic people may have interpreted it more figuratively as a challenge sent by life which one must satisfy oneself on.

### ***Summary***

If the constructs as a group in combination were to have a role in explaining treatment choice decisions, the expectation was that there would be some association among the constructs at a bivariate level. These analyses suggested that knowledge and understanding of cancer, particularly in terms of information based knowledge, was associated more with various participant characteristics than it was with the other discriminating variables. The remaining constructs, including to some extent, the belief based dimension of knowledge, evidenced meaningful associations. This provided, in a

preliminary sense, some indication of their conceptual integrity. There was an indication, however, that the illness meaning component presented some conceptual difficulties, but the conceptualisation of meaning in terms of intrinsic and extrinsic orientation was supported. This was on the basis, however, that there appeared to be a conceptual difference between religiousness and spirituality in the context of the intrinsic/extrinsic paradigm. Further indication of the performance of the constructs in combination, at both a sub-construct and construct level, was obtained from examining their relationship with treatment choice behaviour. Discussion of this follows.

### **Choosing whether to use non-conventional treatment for cancer**

This section discusses the findings in relation to the main research question – the influence of the cognitions of interest on the treatment choice decision. It is organised as follows. First, the influence of demographic variables on treatment choice is addressed. Discussion of the findings in relation to each of the hypotheses follows. Hypotheses one to four were concerned with the relationship of each of the constructs separately with treatment choice. It was important to examine these bivariate relationships to detect any unexpected associations between individual discriminating variables and treatment choice prior to assessing the multivariate combination. The discussion in relation to each hypothesis, therefore, addresses firstly the relationship between the particular construct and treatment choice in a bivariate sense. Secondly, the relative contribution of the construct to discrimination between conventional and non-conventional use, when assessed in combination with the other constructs is discussed.

Any distinctions arising between treatment grouping configurations are also discussed in relation to each construct. This is a comparison across the four two-group discriminant analyses performed in relation to each treatment grouping. Following this, the findings relating to treatment grouping are addressed in an overall sense. The fifth hypothesis related to where the division between conventional and non-conventional medicine was perceived to be. The hypothesis was that differences between users of

conventional and non-conventional treatment, in terms of the combination of cognitions, would vary according to where the division between modalities was set on four different configurations. (See Chapter 7 and Tables 6 and 7 for an explanation of the composition of each treatment grouping). This hypothesis was central to the main analytic strategy, which comprised a set of four standard two-group discriminant analyses, one for each of the four configurations of treatment grouping. The expectation was that scores on the variables comprising the set of constructs, in combination, would permit discrimination between users of conventional treatment only and those who included non-conventional treatments in their treatment regimen.

### *Demographic influences on treatment choice*

Age was not specifically hypothesised to differentiate between the treatment groups in the present study. Previous research (e.g., Eisenberg et al., 1993; Fulder & Munro, 1985; Thomas et al., 1991), however, has found age to be a factor, with those opting for non-conventional medicine typically being in the younger age group (25 – 50). In the present study bivariate analyses found that across all configurations of treatment groupings mean age was significantly higher for conventional users compared to non-conventional users.

In the multivariate analyses, however, when the relative importance of age as a discriminating variable was assessed using the structure matrix approach, it became a relatively important discriminator in treatment groupings 2 and 4 (see Table 21). Subject to the caveat that caution is necessary in interpreting these loadings because they are not adjusted for the remaining variables in the analysis, there is a possible explanation for the finding that the addition of prayer (as in treatment grouping 2) resulted in meaningful discrimination and that prayer was associated with decreasing age. The way in which prayer was used is of interest. An assumption that older people more than younger people value and utilise prayer as a form of “treatment” for their cancer may be simplistic. Examination of the responses to the religious demographics subscale indicates that older

people tend to place less reliance on their faith but practice their religion more. This coincides with Brown's (1965) finding that faith in the "direct material efficiency" of prayer as compared to the non-specific result of prayer, reduces with age. He found that older people avoid making direct requests, preferring to make more general or conditional requests. In the present study it was found that older people were more likely to use conventional medicine, but the majority of those who said they used prayer as a treatment joined the generally younger non-conventional users. Older people may include prayer as part of their religious practice, but younger people, and those who use more non-conventional treatments may use prayer for its "direct material efficiency" as a treatment. This may also point to a distinction between the conservative approach to religion in which God is seen as sovereign and will do what He wants, and a more contemporary approach, which recognises the importance of the individual and the individual's "right" to good health, for example.

In terms of gender, women were more likely to utilise non-conventional medicine across all configurations of treatment grouping, which is consistent with previous findings (e.g., MacLennan et al., 1996; Bernstein & Shuval, 1997). In terms of discriminatory power, however, relative to other discriminators gender had very little effect.

The only other demographic variable on which any difference was evident between conventional and non-conventional users was level of education. This was the case in only one (treatment grouping 3) of the four treatment groupings, however. In the multivariate analyses, where the focus was on the difference between each level of education, in each treatment grouping one or other of the education dummy variables appeared as the first, second, or third ranking discriminator relative to the other discriminating variables. The structure coefficients, however, which describe the contribution of a given variable to the formation of the discriminant function, indicated that none of the education variables in any treatment grouping made a meaningful contribution to discrimination. In the context of the present study what the discriminant



score represents is more important and more useful than the rankings between discriminating variables.

Nevertheless, this variable was investigated a little further, mainly because it has consistently been found to be influential in previous research and because there was some indication that treatment grouping differences may have had an effect. When the effect of education was examined across the four treatment groupings a pattern did emerge that merits reporting. The pattern that figure 2 (Chapter 9) seems to disclose is that, consistent with previous findings, more education was associated with use of non-conventional medicine when non-conventional medicine was traditionally defined (as in treatment groupings 1 and 2). As the dividing line was shifted to incorporate, in the conventional classification, treatments that are traditionally non-conventional but are seen by many as being reasonably closely related to conventional medicine, so the difference in level of education between users of conventional versus non-conventional dissipated (as in treatment grouping 3). When non-conventional was defined as comprising those treatments that could be said to be the furthest from traditional approaches, level of education tended to have the reverse effect, so that more education was associated with the more conventional approach to treatment.

The influence of participant characteristics on treatment choice could be summarised as follows. For age, the trend evidenced in previous research that non-conventional medicine use was associated with a younger age tended to be confirmed. In two of the treatment groupings, age made a meaningful contribution to discrimination. In the other two groupings, while the structure coefficient was below the cut-off point of .30, directionality was consistently appropriate. In relation to gender, previous findings that women are more likely to utilise non-conventional medicine were supported, but gender was not an important discriminator. For level of education there was some indication that higher education may be associated with the use of non-conventional medicine but only when the division between the modalities was in traditional terms, suggesting that higher education is associated with the use of those non-conventional treatments that could be described as closest to the traditional concept of medicine.

### ***Knowledge and understanding of cancer***

The findings in this study provided only mild and partial support for the first hypothesis, with the only significant difference between conventionals and non-conventionals being found on treatment grouping 3. This was the case on both dimensions of cancer knowledge. The trend was for non-conventionals to be more knowledgeable in terms of information based knowledge, as hypothesised, but the trend was towards conventionals displaying a more positive belief system about their life with cancer, which is contrary to the second leg of the hypothesis (see Table 14).

The finding in relation to treatment grouping 3 and the overall trend towards more knowledge being associated with non-conventional medicine use may have resulted from the interaction effect of factors other than knowledge level itself influencing treatment choice. For example, a younger age was found to be associated with a higher knowledge level (see Table 1, Appendix C) and with the use of non-conventional medicine. A higher level of education was also associated with higher level of knowledge. Furthermore, a number of authors have suggested that knowledge about one's health is often gained from non-conventional health practitioners who devote considerable time and effort to explaining their patients' conditions to them. This would suggest that knowledge is accumulated through the use of non-conventional treatments rather than the use of these treatments being the result of increased knowledge. Cancer, however, is very complex and imparting a clear understanding of the disease and how treatment works is difficult and requires considerable scientific knowledge. This may account for a lack of knowledge among conventional users. Either they have difficulty understanding complex explanations, or explanations are not offered by conventional practitioners because of the complexity that is necessary.

In relation to the knowledge beliefs findings, these evidenced little more than a trend. Furthermore, when viewed in context with the mediocre psychometric qualities of the subscale little importance should be attached to the findings.

In terms of treatment grouping configurations, the finding of a significant difference for treatment grouping 3, and close to significance for treatment grouping 4, on both knowledge dimensions, lends some support to the notion that the positioning of the dividing line between conventional and non-conventional is potentially important.

When the position of this construct within the set of constructs was assessed, it was clear that neither component of the construct ranked as an important or meaningful contributor, relative to the other constructs, in discriminating between conventional and non-conventional use across any of the configurations of treatment groupings. Overall, these findings tend to support the findings of previous research. For example, investigation of the effect of knowledge has been common in research into preventative health behaviours such as breast self-examination (for a review of this literature see McCance et al., 1990) where it clearly can have an important direct applied function. Research aimed at understanding the relationship between cancer knowledge and health behaviour generally, however, seems to be inconclusive.

### ***Approach to health***

Central to this construct was the health interest and motivation variable. The first leg of hypothesis 2, that those who utilise more non-conventional treatments will be more interested in and motivated about health matters, was supported by the results. Non-conventional users were significantly more motivated and interested about health matters and about being involved in them across all configurations of treatment grouping. This finding was in line with those of previous studies.

Health interest and motivation itself embodied some distinctive features that have been identified and explored in previous research. Each component appeared to contribute to the overall robust nature of the health interest and motivation variable in differentiating between conventional and non-conventional users. One of these components was general health consciousness and awareness. Furnham and Forey (1994) and Furnham and Kirkcaldy (1996) had also found that this characterised non-conventional users to a significantly greater degree than conventional users. In those studies, participants were not suffering from a specific life-threatening disease, however. They suffered from the likes of angina, backache and insomnia. It may have been expected, however, that all cancer patients would have a high level of awareness and consciousness about their health simply by virtue of the nature of their illness. The findings suggested that this was not the case, however.

Another component concerned the extent to which people seek out and take notice of health information, on which Furnham and Bhagrath (1993) had found that having information and participating in health care decisions also characterised non-conventional users. The findings in the present study appeared to support those findings as well. Taylor's (1983) theoretical basis for understanding psychological adjustment to a life-threatening situation is a useful basis for understanding the information needs and decision making involvement of cancer patients (Hack et al., 1994). Two of the three aspects of Taylor's (1983) theory in fact are central to the theoretical basis of the present study. These are the patient's desire to extract meaning out of the situation and the need to maintain a sense of mastery or control. Acquiring information about their illness and its treatment and playing an active role in treatment decision making are two important ways of gaining a sense of control (Hack et al., 1994) and of helping to make some sense out of the situation.

Previous findings that the majority of cancer patients desire information and prefer to be actively involved in decision making regarding treatment (e.g., Blanchard, Labrecque, Ruckdeschel, & Blanchard, 1988; Hack et al., 1994) may have been too sweeping in their generalisations, however. The indications from the present study were

that motivation to acquire information and be actively involved was related to type of treatment preferred. That is, motivation characterised those who included non-conventional treatments significantly more than it was a characteristic of purely conventional users.

The mechanisms underlying the relationship between health interest and motivation and treatment choice may be reasonably complex and worthy of further research. For example, the motivation to collect information and use it may be related to the level of knowledge about cancer. It may not be the influence that the substantive knowledge itself may have on the decision-making process, but having knowledge may encourage an individual to seek more information and personal involvement and may also be associated with the ability to source appropriate information and to understand it.

Another example of the potential complexity of the relationship between health interest and motivation and treatment choice is demonstrated by the possibility that if a patient's needs for these are being met, their feelings of control over the situation would be enhanced. This may be a reflection of the use of non-conventional medicine, wherein these attributes are encouraged. On the other hand, feelings of control would likely decrease for a patient whose need for information and involvement was not being met, as is sometimes the case in a conventional medicine setting. Those who do want information, involvement and control, but are not being satisfied, may well seek this in a non-conventional setting. It should be recognised, however, that a lack of information and involvement is not necessarily a function of using only conventional medicine. It is possible that conventional medicine users may simply be those for whom information and personal involvement is not as important or is not even wanted.

A further example of the potential for the health interest and motivation variable to embrace or subsume other concepts is the way, arguably, it subsumes perceived effectiveness, a variable which has frequently been used to explain the choice of non-conventional medicine. The argument is that as Furnham and Beard (1995) pointed out, if patients choose non-conventional medicine because of its perceived effectiveness, that

suggests that they “hold different explanatory beliefs systems about health and illness, which consequently makes them more intrinsically inclined to know about health care, the limitations of orthodox medicine and the benefits of complementary medicine” (p.1426).

In terms of its relative importance as a discriminator between conventional and non-conventional users, health interest and motivation made a meaningful contribution in the first two treatment groupings, both of which represented the traditional division between the modalities. In a sense this demonstrated the robust qualities of health interest and motivation as a variable. When considered in combination with the other constructs it goes clearly to the most fundamental form of the distinction between conventional and non-conventional medicine.

Of the other component variables comprised in the approach to health construct, holistic versus biomedical approach was not included in analyses beyond correlations among the variables for the reasons outlined earlier. The second leg of hypothesis 2 was therefore not tested.

On optimism and pessimism a consistent pattern was observed to the effect that across all treatment groupings, those who used non-conventional treatment demonstrated slightly higher levels of optimism and fractionally lower levels of pessimism. This was a tentative indication of support for the third leg of the second hypothesis but the differences were not statistically significant (see Table 15). These relationships were not sufficient to see it as a variable making a meaningful contribution to discrimination. In a sense, however, the trend evidenced by optimism tended to provide support conceptually, within the approach to health construct, of the generally positive and hopeful approach to health matters that would appear to characterise non-conventional users.

An explanation for this trend, referred to above, could be that being more optimistic in outlook on life leads to the use of non-conventional treatments in that an optimistic person may be motivated by a belief that their disease is beatable and so will

search for all the possibilities that might help achieve this goal. An optimistic individual is also likely to be less sceptical about claims made by non-conventional medicine as they look for the most favourable outcome to their situation. Alternatively, optimistic outlook may be a function of the non-conventional system itself. Downer et al. (1994) found that optimism and hope tend to result from non-conventional treatment use. Involvement with non-conventional medicine would usually include taking an interest in media and advertising coverage, mixing with like-minded individuals, perhaps the recognition of some signs interpreted as encouraging after using non-conventional therapy, and possibly, the influence of optimistic non-conventional practitioners.

### *Attributions of control, responsibility and blame*

The third hypothesis was that those who use non-conventional medicine will exercise more personal control over and take more responsibility for their health and treatment matters. The results of the study supported this hypothesis. The consistent significant difference between conventional and non-conventional use across all treatment groupings (see Table 16), for both forms of internal control attributions, confirmed the view that control is a pivotal concept in understanding and explaining this particular health-related behaviour. The results also supported the view that the concept of control is a complex one. This was demonstrated by the unexpected finding that the significant difference between conventionals and non-conventionals, in terms of external powerful others control, was in the same direction as for internal forms of control (i.e., that non-conventional users also tended to embrace powerful others externality). While the differences were not as significant, on the face of it, this appears inconsistent.

One explanation for the finding that non-conventional users scored higher on powerful others (external) control than did conventional users was mentioned in the previous chapter. It was that for externally focused individuals, attributing responsibility and blame in a causal sense may differ from the attribution of control for treatment matters in the present and future. This means that they may have acknowledged, say,

God's involvement in a causal sense but not made Him responsible. Actual responsibility may still have been reserved for themselves in the sense that they stepped outside of God's protection in some way through their behaviour or their lifestyle. In terms of cure, however, God may still be looked to and relied on. The results of additional analyses reported in the previous chapter tended to confirm the suggestion that users of conventional medicine were prepared to attribute positive outcomes, and the expectancy of positive outcomes to a powerful other, but were not so likely to attribute the more negative causal factors directly to their powerful other. This goes some way towards explaining the inconsistent findings without detracting from the fundamentally external orientation of conventional medicine users.

Of particular interest is the finding (shown in Table 16) that luck externality played no part in separating the conventional and non-conventional user groups within any of the treatment groupings. This suggests that luck should not be equated with powerful others as a measure of externality, although a caveat should be added to this conclusion. It is possible that, for cancer patients, most of whom will have been involved in an intense, scientifically sophisticated diagnostic and treatment programme, a notion such as luck will have been discouraged. Subject to this caveat, given that the majority of externally motivated participants expressed their externality in either religious or spiritual terms, they would likely be equivocal towards attributions that were neither to a powerful other nor to self. A neutral approach to such attributions would likely also characterise those who are internally motivated.

Another explanation for the equivocal nature of the luck dimension is the observation of Pepitone (1995) that luck may be attributed to a "vaguely identified external agent", but it may also refer to an extraordinary sense of power within the individual. This is something which individuals claim in an internal sense. This supports the suggestion made above that luck may be differentially perceived as being external for some and an internal quality for others.



Results of the multivariate analyses demonstrated that, overall, attributions of control, responsibility and blame was consistently the most important construct, relative to the other cognitions or demographic factors, in discriminating between the conventional and non-conventional groups. Across all treatment groupings one or other form of internal control attribution was the most important discriminator in terms of either standardised coefficients or structure coefficients (see Tables 18-25). Because there was some intercorrelation among the attribution of control variables (see Table 9), and among the attribution of control variables and various other variables, particularly meaning variables, interpreting the relative contributions of these variables using the structure coefficients rather than the standardised coefficients may be more appropriate. This approach further strengthened the consistent relative importance of this construct.

Unexpectedly, powerful others control was not a meaningful discriminator in treatment grouping 2, which was where prayer users were added in. An explanation for this could be that prayer is a more universal activity than expected, particularly among those who perceive their life to be threatened. (A North American poll disclosed that 82% believed in the healing power of personal prayer; 73% believed their illnesses could be cured or helped by the prayers of others; 77% believed that God sometimes intervenes to cure people of serious illness; and 64% believed that health care professionals should join patients in prayer if requested (Kaplan, 1996)). For this reason, and also because non-conventional medicine use by definition included conventional medicine use, many of the prayer users were added to the non-conventional group. Powerful others externality did, however, make a meaningful contribution to discrimination in treatment groupings 1 (see Table 19), 3 (see Table 22) and 4 (see Table 25). In any event, given that internality was conceptualised as an opposing concept to externality, of which there was some evidence, it was sufficient that one of the opposing types of control attribution made a substantial contribution to discrimination. Furthermore, the strength of this variable as a discriminator may have been compromised by the differentiation within the variable between causal responsibility and outcome control referred to above.

The doubts expressed above about the conceptual relevance of luck externality as a discriminator were confirmed in the multivariate analyses. Relative to the other discriminating variables, luck externality made no meaningful contribution to discrimination in any of the treatment groupings.

The finding that action internality made the greatest contribution to discrimination in treatment groupings 1 and 2, but that state of mind internality was the most important contributor in treatment groupings 3 and 4, suggests that when the division is along traditional lines (as in groupings 1 and 2), the assuming of personal control by non-conventionals is more action oriented. That is, it is based more on pragmatic physical aspects such as lifestyle, environment and treatments. This is a demonstration of the 'fine grained' approach of the IHI scale as referred to above. It is a particularly helpful distinction in the context of the present study in that it helps to explain the link between health-related beliefs and behaviours. The behaviours (treatments) that are based on or associated with the psychological and/or metaphysical concepts and philosophies (treatment grouping 3 and particularly 4) are associated with a more attitudinal and philosophically oriented approach to control issues. This is compatible with the holistic aspect of non-conventional medicine, which is based on a belief system as much as a treatment regimen. Those who choose treatments from the more 'physical' methodologies (treatment groupings 1 and 2), tend to approach the concept of control in a more taking of action 'hands on' oriented way.

To summarise the main points made above, while users of non-conventional medicine clearly attributed control internally, they also indicated a certain level of powerful other external attribution. This may be explained, however, by a difference between attributing responsibility and blame in a causal context and the attributing of control over outcomes. Relative to the other discriminating variables, internal control and responsibility attributions was an important discriminator with non-conventional users evidencing this form of control. Within those displaying an internal orientation, a distinction was evident in terms of how non-conventional a treatment was. This provided some support for the suggestion that the question of how far removed from conventional

a non-conventional treatment is, is a relevant consideration. It also supported the view that there is a certain congruence between the philosophical basis of non-conventional medicine and the concept of internal control and responsibility attributions.

### *Meaning*

As already mentioned in the two previous chapters, the conceptualisation of meaning in the present study appeared to be inappropriate in the context of illness meaning. Since this was omitted from the treatment choice analyses, discussion about hypothesis 4 relates only to meaning in life. On this basis, the hypothesis was at least partially supported, subject to some modification to the conceptualisation of extrinsic meaning as outlined below.

Measurement of the concepts of intrinsic and extrinsic life meaning was in itself an exploratory undertaking. This was because existing instruments available for the measurement of life meaning measured this in intrinsic terms only. Since intrinsic and extrinsic meaning, as conceptualised in the present study, were separate concepts, the same instrument could not be used to measure both as if they were opposite ends of a continuum. The LAP-R (Reker, 1992) seemed to be an appropriate measure for assessing intrinsic meaning and its impressive psychometric qualities were confirmed in the present study. For the measurement of extrinsic meaning the Royal Free Interview (King et al., 1995) modified to a questionnaire format was an existing measure (designed as a measure of spiritual, religious and philosophical beliefs for use in medical, psychological or social settings) utilised for the specific purposes of the present study.

Findings in relation to intrinsic life meaning were as hypothesised. Across all configurations of treatment grouping non-conventional treatment users displayed a significantly higher level of intrinsic meaning (see Table 17). It was unexpected, however, that non-conventional users would score higher than conventionals on extrinsic life meaning. The difference was significant although not as marked as it was for intrinsic

meaning. This mirrors the finding for internal and external control attributions. It is suggested that in this case, it is largely explained by the conceptualisation of extrinsic meaning as incorporating both religiously and spiritually derived meaning. That is, the finding that non-conventional use rather than conventional use was associated with extrinsic meaning tends to confirm the suggestion that spiritually derived meaning should not be treated as evidencing an extrinsic orientation. Overall, however, the conceptualisation of meaning in terms of intrinsic and extrinsic orientation was supported.

In addition, there may have been some ambiguity within the measurement instrument itself, which may also have influenced the relationship observed between orientation and treatment choice. At the risk of being repetitious, this is reiterated as follows. It is arguable that an individual could score highly on the extrinsic meaning subscale while having interpreted the items quite differently to another individual. For example, "illness as punishment", "illness as predetermined", and "illness as a test" might be interpreted by one participant as punishment or a test emanating from a powerful other, such as God, which was the expected interpretation. Another may have interpreted the reference to punishment or a test as emanating from their own behaviour or lifestyle, which, in the context of the present study would have been an intrinsic interpretation, but resulting in an extrinsic score. Furthermore, the subscale did not account for differing conceptualisations of the role of God as a powerful other. Many extrinsically oriented individuals may not cast God in the role of punisher or as predetermining good and bad outcomes in their lives.

The approach taken in the present study recognised the potential for a difference between religiousness and spirituality, although such a profound effect was not envisaged. This was the rationale for adjusting the Royal Free Interview measure to enable separate assessment of spirituality and religiousness. The thesis was that religiousness is an expression of spirituality, coinciding with Fry and Tan's (1996) description of religiousness as having a formal set of beliefs about God and using religious practices as a way of expressing spirituality. The expectation was that the

difference between religiously and spiritually derived meaning would represent the difference between a religious (particularly a Christian) expression, and a non-Christian expression of a powerful other approach. It was unexpected, however, that the distinction would be sufficient for the two approaches to be associated with different treatment choices. This suggests that spiritually derived meaning may be associated with an intrinsic orientation rather than an external or powerful other extrinsic orientation. The following offers some explanation for this.

As McFadden (2000) has noted, there is substantial diversity among the definitions scholars have given to religiousness and spirituality. Perhaps at the hub of this is what McFadden (2000) (citing Wulff, 1997) described as one of the greatest points of disagreement – “Whether spirituality includes a transcendent object outside the self ... and if it does, whether that automatically puts it in the camp of religion ....” (p. 173). Of particular interest in the context of the present study is the point made by McFadden (2000) that for many, spirituality has retained an element of the divine, but without religious traditions, structures and practices, this abandoning of organised religion has resulted in spirituality being “privatized”, leading to a “radical individualism” in which the self is elevated. In the present study this is referred to as an intrinsic orientation to meaning in life and its events. This serves to emphasise the difficulties definitions pose and why, in the present study, it was seen as important to explore underlying belief systems. It also explains the conceptual relatedness of the concepts of religiousness and spirituality as well as providing some understanding as to why, within the conceptualisation of meaning adopted in the present study, a rather profound difference was found, in which spirituality equated with intrinsicness while religiousness equated with an extrinsic approach.

The multivariate analyses showed that across all treatment groupings the ‘life a’ dummy variable was consistently a more important discriminator than the ‘life b’ dummy variable. In terms of original expectations this was unexpected but reflects the finding that the difference is between a spiritual approach on the one hand and a religious or even philosophical approach on the other hand. This points, however, to an unexpected

congruence between religious and philosophical approaches. An explanation for this may be that the choice of conventional treatment by those whose approach to life's meaning is philosophical, may have nothing to do with an intrinsic or extrinsic orientation. It may instead have been a reflection of a so-called rational approach to life. While rationalists tend to take an existentialist and intrinsic view of life, in this case, their use of conventional medicine may have resulted from taking a rational approach directly to the question of treatment. This would have included weighing up the scientific evidence, which is almost entirely conducted within and supports conventional medicine, and making a decision for conventional medicine accordingly.

When the relative importance of life meaning orientation as a discriminator between conventional and non-conventional use was explored in the multivariate analyses, the validity of the Royal Free Interview extrinsic life meaning variable again came into question. Apart from being the third most important variable in treatment grouping 1 based on the structure matrix, overall extrinsic life meaning was a relatively minor contributor to discrimination. This is somewhat in contrast to the role of the 'life a' variable, which, as mentioned above, was consistently a reasonably important discriminator relative to the others. Unlike the extrinsic meaning variable, this variable effectively accounted for the distinction found between religious and spiritual approaches to life meaning. This suggests that extrinsic meaning, when appropriately conceptualised and assessed, is potentially a relatively important discriminator.

Intrinsic life meaning overall was consistently shown to be a relatively important contributor to discrimination across all treatment groupings (see Tables 18-25). It is arguable that notwithstanding the methodological shortcomings of the extrinsic meaning variable, and the demonstrated need to reconceptualise aspects of extrinsic meaning, the reasonably strong and consistent discriminating power of intrinsic meaning in itself supports the concept of a meaningful distinction between intrinsic and extrinsic meaning. This is strengthened by the performance of the 'life a' variable which also consistently demonstrated a meaningful contribution to discrimination across all treatment groupings ( $F = 5.02$ ,  $p < .05$  for treatment grouping 1;  $F = 5.67$ ,  $p < .05$  for treatment grouping 2;

$F = 18.20, p < .001$  for treatment grouping 3;  $F = 14.70, p < .01$  for treatment grouping 4). Directionality was appropriate as well, confirming that preference for conventional medicine was associated with the religious (and philosophical) approach to life meaning, with the majority of those whose meaning was derived in a spiritual frame choosing conventional treatment as defined in the respective treatment groupings.

So far this section has discussed the specific findings of the study. In the remainder of this section an attempt is made to position the findings in relation to meaning within the theoretical and conceptual framework of the study.

In the context of treatment choice research, Furnham and Beard (1995) acknowledged that a question to be answered is whether there are fundamental differences in patients' wider belief systems as well as specific differences in their health beliefs. The present study was predicated on the notion that a person's worldview, their wider belief system, comprises important potential determinants of their health related behaviour.

A foundational premise of the present study, therefore, was that meaning in life and its events underlies much of the cognitive approach to living with a life-threatening illness such as cancer. The assertion was made that there are two fundamentally opposed philosophical approaches to meaning in life and that these underlie various other cognitions and that they influence various health-related behaviours. Taylor (1995) suggested that a loss, a change, or a negative important life event precipitates a search for meaning and observed that numerous studies have found that the search for meaning is a significant part of the cancer experience.

The relationship between meaning and treatment choice was based on the notion that those who evidenced or classified themselves as being of an extrinsic orientation to meaning in life and its events, would have derived their meaning in a religious or spiritual frame. The theoretical basis of the extrinsic orientation, found to be associated with meaning derived in a religious but not a broader spiritual frame, was an orientation in

which meaning and purpose in life is discovered beyond the self. This, it was suggested, is a Frankl concept. Frankl's 'beyond the self' or 'self transcendence' approach is usually not cast in a religious or spiritual frame, however, although Yalom (1980) and Pargament (1997) recognised the theory as fundamentally religious given that it suggests that there is an absolute 'right' and 'true' meaning to be discovered. The relationship between an extrinsic orientation and treatment choice was proposed to lead to conventional medicine use because of the inclination and preparedness to trust a powerful other, which characterises a religious belief system. The doctor either becomes a powerful other, the one perceived to have the power and authority to treat and cure, the one to be revered and not questioned, or possibly the one provided and equipped by God to carry out this function of understanding and dealing with the complexity of the human body as His creation. This has the doctor in a type of 'God's agent' role. Another aspect of this is that the doctor and the conventional medicine system represent the status quo and the time-honoured establishment that has official validation from those in authority. These are concepts that have a certain synergy with a religious belief system.

The relationship between an intrinsic orientation and treatment choice was posited to be associated with non-conventional medicine use because of a certain congruence between these approaches. Eliopoulos (1999) considered that when people have a positive and harmonious relationship with God or a higher power they feel a sense of spiritual wellbeing characterised by feelings, *inter alia*, of connectedness with other people, nature, and the environment. It is suggested, however, that this describes the spiritual approach rather than a religious approach. Spiritual approaches tend to be 'tuned in' to nature and the environment, and self, as the embodiment of some higher power, divine or otherwise. This is unlike Christianity, which relies on the personification of God in Jesus Christ. This 'tuning in' to nature, the environment and self in the spiritual approach reflects in the holistic and 'natural' approach of non-conventional medicine.

Easthope (1999) considered that in the search for meaning in illness, suffering and death (which amounts to an explanation of the meaning in life and in the universe) cosmologies are developed. He suggested that the non-conventional medicine cosmology



explains these things in terms of spiritual forces, the balance of elements in the body, or the development of life force. These are concepts that are embodied in holism and many non-conventional medicine treatments. Easthope (1999) also suggested that conventional medicine operates under an outmoded germ theory cosmology, which provides no reliable explanation for personal misfortune, such as why a given individual contracts a particular illness but another does not. Freund and McGuire (1999) also observed that conventional medicine has difficulty dealing with sufferers' problems of meaning. They suggested that Western illness aetiologies that deal with causes such as germs, viruses and genetic defects "are not adequate explanations for many people, because questions of meaning frequently beg for ultimate causes" (p. 135).

One of the ways in which meaning is addressed is through causal attributions (Taylor, 1983). Questions relating to attributions of control, responsibility and blame are particularly salient in the experience of cancer (Royak-Schaler, Stanton, & Danoff-Burg, 1997; Lowenberg & Davis, 1994; Easthope, 1999). Attributing control and responsibility is a parallel process to the ascribing of meaning, and the concept of internal and external attributions has a parallel in the concepts of intrinsic and extrinsic meaning. As Easthope (1999) has pointed out, in a society where much of life is outside the control of the individual, people search for areas of control. One thing that the individual feels they can control is the self, something non-conventional medicine permits – "Healers give people the ability to manage their own disease by giving them the ability to reconstruct themselves" (p. 274).

Lowenberg and Davis (1994) explained the practical implications of attributions of control and responsibility. Holistic health, they said, places great emphasis on individuals assuming responsibility for their own health. They saw the demonstration of this through health information seeking, diet and behaviour modification, spiritual exploration, and generally taking a more activist stance towards one's health. The reference Easthope (1999) made (above) to "healers" points to another aspect of the controllability inherent within non-conventional medicine. Conventional medicine focuses on curing, a process which may well need the scientific expertise of allopathic

medicine. Non-conventional medicine, however, focuses on healing. As Coward (2000) has pointed out, healing comes from within the person while a cure comes from an external source acting upon the person. In the context of a life-threatening illness healing can occur in the absence of a biomedical cure (Coward, 2000). Both approaches may be “successful”, therefore. This begs the question, of course, as to whether healing may include curing. Proponents of non-conventional medicine would answer in the affirmative.

### *What is conventional and what is non-conventional - the treatment groupings*

Furnham and Smith (1988) suggested that future research perhaps should identify the “motive-pattern” for the category of non-conventional users as a whole and then specify different paths within that. They seemed to have in mind categorising consumers of non-conventional medicine into groups based on consumer characteristics. In the present study the category as a whole was divided into groups based on treatment characteristics and consumers allocated to those groups accordingly. This approach has at least two advantages. One is that it enables investigation into the cognitive concomitants of treatment approaches in terms of how non-conventional a treatment or remedy is. The other is that the use of a wide range of non-conventional treatments was able to be explored. This has taken account of the possibility mentioned by Furnham and Smith (1988) that different kinds of people, with different beliefs and experiences, seek out different forms of non-conventional medicine.

Some non-conventional treatments are more non-conventional than others. Hypothesis 5 was predicated on the notion that regardless of where the traditional division between conventional and non-conventional is, people will have their own attitudes towards what is for them a normal approach to treatment. For example, many cancer patients would see a diet regimen, even a specific diet such as the Pritikin diet, as part of a conventional treatment approach. The same individual may not see psychic surgery as a conventional approach to treatment, however. In seeking to understand the

influences on the choice between conventional and non-conventional medicine, what is perceived to be conventional and non-conventional is important. The cognitions of interest were expected to explain what the individual perceives to be conventional or non-conventional, not what is deemed to be so by the world of medicine.

Broadly, the results supported the hypothesis that the differences between conventional and non-conventional users, in terms of the cognitions of interest, will vary as the boundary between conventional and non-conventional alters. This is not to say that the judgement made by this author as to which category a particular treatment should fall into was necessarily accurate. It did, however, serve to give a reasonably clear indication that there is a difference in the cognitions of those choosing treatments as those choices move to the more non-conventional end of the spectrum. At the least it can be said that as the choice of non-conventional treatment changes from one category (e.g., physical and natural) to another (e.g., psychic and spiritual) so there is a change in associated cognitions.

More specifically, the results demonstrated that the greatest separation between conventionals and non-conventionals appeared on treatment grouping 3 and the greatest change appeared between treatment groupings 2 and 3. In relation to knowledge and understanding, for example, treatment grouping 3 displayed the only significant differences between conventionals and non-conventionals. On the health interest and motivation, attributions of control, and life meaning constructs, the greatest difference in the variability between conventionals and non-conventionals was evident on treatment grouping 3 and between groupings 2 and 3. Little variability was expected between treatment groupings 1 and 2 since the only difference between them was the addition of those who pray. The difference between groupings 2 and 3, however, represented the shift in the boundary from its traditional location to include as conventional some of the more closely allied non-conventional remedies.

The results did not, however, confirm the usefulness of a treatment grouping (treatment grouping 2) in which the addition of prayer was the only distinguishing factor.

The rationale for its inclusion in this way was primarily because the use of prayer as a treatment was expected to be a differentiating factor between those who were religiously motivated and those who were spiritually oriented. The results showed, however, that this distinction was more fundamental than could be displayed by the use of prayer or not.

Various other conceptual aspects also tended to obscure any effect. For example, as Owens et al. (1999) have suggested, prayer is more complementary than alternative, so that it may not have been a particularly definitive factor. This is supported by the view of Kuhn (1988) that prayer belongs to the spiritual domain and is essentially an attitude more than an activity. In the context of the present study, prayer was not necessarily an activity of the religiously oriented only. As Eliopoulos (1999) has noted, most people believe that prayer has a role in healing. Furthermore, prayer may have been conceptualised differently by different participants. For some it may have included being prayed for, not necessarily something they do themselves.

In terms of its construction, treatment grouping 4 of itself is of less importance to the study. The findings in relation to it, however, serve to reinforce the indication that there is a relationship between the cognitions of interest and the type of treatment modality a cancer patient will be interested in. The concomitants of the use of treatments included in treatment grouping 4 compared to grouping 3 are of interest in this regard. As tables 24 and 25 show, state of mind internality was an especially strong discriminator relative to the others followed by all the other internally and intrinsically oriented cognitions. The trend tends to have received some confirmation in the intersection of clear internality and intrinsicness with more non-conventional treatment approaches. It is also notable that decreasing age was a meaningful discriminator in this grouping as well. Spirituality as opposed to religiousness also characterised this grouping, suggesting perhaps, an acceptance of a New Age approach to things spiritual among those using treatments in the psychic and metaphysical category.

### *The combined influence of the constructs summarised*

The cognitive determinants of treatment choice among those facing a life-threatening illness are complex and multi-faceted. In recognising this the present study was interested in the influence of a group of cognitions in combination, some of which have been explored in previous research of a similar nature and some of which have not, at least as conceptualised in this study. Of the four constructs of interest two were of fundamental importance to the investigation. One of these was the construct referred to as attributions of control, responsibility and blame which provided a theoretical basis utilised to explain some of the psychological processes and mechanisms involved in making choices about treatment. The other was meaning, the conceptualisation of which (as intrinsic or extrinsic orientations), in a sense provided an underlying conceptual foundation for the study.

The results of the study essentially supported the conceptualisation of these two constructs and demonstrated that both in combination with each other and with the other constructs, they made a meaningful contribution to an explanation of the treatment choice process. Similarly, the approach to health construct, and specifically the health interest and motivation component, was a meaningful part of this combination of cognitions. The fourth construct, knowledge and understanding of cancer, did not appear to be an important contributor relative to the other three.

In the main analyses, in which all components of each construct were included (with the exception of illness meaning and motivation beliefs), as well as demographic type control variables, the variance explained by the discriminating variables in combination, particularly for treatment grouping 3 (33.6%), provided a measure of support for the contribution of this group of cognitions to differentiation between conventional and non-conventional users. Furthermore, the magnitudes of discriminant function coefficients and structure loadings generally indicated that aspects of control attributions and meaning orientation were major contributors. When a subset analysis was performed including only discriminating variables that individually had made a

significant contribution to discrimination between conventional and non-conventional use, the relative importance of the contribution of the control attributions and meaning constructs was confirmed.

### **Limitations, directions for future research and applications**

The research question in the present study was not asking the broad question ‘why do people choose to use non-conventional medicine?’ It was limited to the question ‘what are the differences in health-related beliefs of those cancer patients choosing to include non-conventional treatments and those who do not?’ Furthermore, the study was hypothesis driven to the extent that a particular set of cognitive constructs was selected that it was considered were likely to be important in the context of life-threatening illness. Some of the variables previous research has signalled are important and need more exploration, and others appear not to have been researched in this context.

Clearly, cognitive factors will comprise only a subset of the potential determinants of treatment choice, and only a subset of potential cognitive determinants was explored in this study. There will also be cognitive variables that were not accounted for which may influence treatment choice decision making, either directly, or in mediating or moderating roles with the cognitions explored in this study.

Furthermore, the cognitions explored in the present study could themselves be expanded and explored further. For example, the concept of intrinsic and extrinsic meaning needs further investigation, particularly in the area of conceptualisation and measurement of the extrinsic approach. This would include exploring in more depth the cognitions and behaviours associated with religious approaches compared to spiritual approaches. While in the present study a potential difference was suspected and accounted for in the measurement process, no provision was made to empirically examine any differential effect of these approaches.

In addition, the relationship between life meaning and illness meaning was shown to be insufficiently theorised in this study. A question remains as to whether meaning in life is a separate construct to meaning in life's events. Clarification of this at both theoretical and empirical levels is needed as well.

More specific attention to the relationship between meaning in life and its events and attributions of control, responsibility, and particularly blame, would also likely contribute further to understanding the relationship between the individual and the health professional and their respective roles in the health care process. The attribution of blame was not specifically addressed as a separate sub-construct. It was treated as closely associated with the attribution of responsibility, but research indicates that self-blame is a concept worthy of investigation in its own right in relation to health-related behaviour among cancer patients (e.g., Christensen et al., 1999).

In a general sense in relation to the cognitions explored in the present study, an inherent limitation was an inability to fully respond to McGregor and Peay's (1996) challenge that it is time to move away from exploratory approaches to more explanatory approaches. While the study endeavoured not so much to maximise explained variance as to provide some explanations for relationships found among cognitions and behaviours, because the particular conceptualisation of meaning, and its relationship with control and responsibility attributions, underpinned the theoretical basis of the study, the study did necessarily have a strong exploratory element.

McGregor and Peay (1996) also made the suggestion that studies with patients suffering from a chronic disorder such as cancer (among others) are not very informative about the range of factors which may influence the choice of non-conventional treatment. They claimed that this is because these conditions generally receive no cure and often limited help from conventional medicine, so for that reason it is not surprising that many of these patients look elsewhere for help. Cancer patients do look elsewhere, but not necessarily for the reasons suggested by McGregor and Peay (1996). There is increasing potential for, and evidence of a cure for many cancers, at least within conventional

medicine. It is suggested that because cancer is representative of life-threatening illness it brings into focus some of the important existential and spiritual issues about life and these issues in themselves may lead patients to seek healing, if not a cure, outside of conventional medicine.

Notwithstanding the room for more theorising of some of the study's constructs and sub-constructs, it is suggested that the study went some way towards overcoming a frequent limitation inherent in research aimed at investigating cognitions, namely, their complexity and multidimensional nature. An individual is likely not to have a single overall attitude to a complex issue (in this case, whether to use non-conventional medicine) but may favour it in some circumstances and reject it in others (Conner & Waterman, 1996). As pointed out by those authors, these complexities make it important to have a clear theoretical basis for the cognitions. In the present study the theoretical basis incorporated in the intrinsic and extrinsic approaches to meaning in the conceptualisation of attributions of control, responsibility and blame was reasonably definitive.

Limitations of a methodological nature included the study's cross sectional design which precluded the drawing of any cause and effect conclusions. For example, it is unclear whether orientation in terms of intrinsic meaning in life, and congruence with the philosophical basis of non-conventional medicine has led to its use, or whether use of the therapies and exposure to those who propound its philosophy and extol its virtues, has influenced the way individuals view health and illness and life itself in the context of serious illness. Nevertheless, in the exploratory and explanatory context of the present study, these issues do not necessarily detract from the study's findings. Whether those who use non-conventional medicine do so because of some previous contact or experience with it, or whether they do so because of the way they see the world and their role in it, is not critical. This is particularly so if, as is likely for those in a life threatening situation, exposure to the non-conventional world and its philosophies has influenced their belief systems and perpetuated the use of non-conventional medicine, rather than simply being convinced by anecdotal evidence of treatment efficacy. As Astin (1998)



found, users of non-conventional medicine are more likely to report having changed their view of the world, which supported their hypothesis that involvement with non-conventional medicine reflects shifting beliefs about the nature of life, spirituality and the world in general. This supports Charlton's (1993) suggestion that some may be attracted to non-conventional medicine because of its acknowledgement of the importance of spirituality and life meaning in the context of illness.

The study also had some limitations in relation to the psychometric qualities of some of the instruments used. In some instances these were generated by using existing measures but for the specific conceptualisation of a construct required by this study. This may have raised construct validity issues. Overall, however, care was taken to acknowledge this, as well as any reliability shortcomings, both as already reported for instruments and specifically as to their application in this study. The possibility also of measurement error associated with some variables was signalled when it was recognised that participants may have interpreted some items differently depending on their worldview or their religious viewpoint. This was the case particularly in relation to the extrinsic meaning variables. Psychometric data for each measure indicated no major departures from previously reported administrations of the same instrument or the instrument from which the present study's version was drawn.

Typically, there are potential limitations resulting from the use of self-report measures. This is particularly likely when this method is used in the assessment of complex belief systems. Common problems involve the faking of beliefs and attitudes to be deliberately destructive of the research process, to express disapproval of some aspect of the project, or for the respondent to somehow convey a better picture of themselves. Response biases are also a common problem in self-report measures. This is particularly so where items are complex, sometimes resulting in either a systematic type of responding or simply a random response pattern. The data were checked, however, for any systematic response bias or omission and none was found.

The potential for these limitations in the present study is acknowledged, however since complex matters such as belief systems and attitudes are not exhibited behaviourally, assessment options are limited. There were some mitigating factors, however. Perhaps of primary importance was the gravity of the subject matter of the research. It is suggested that few would take the time to respond if they were either ineligible or not intimately interested in the subject matter. The questionnaire was lengthy and would hold no interest for someone who was not a cancer patient genuinely concerned about their and others situation. Furthermore, an effort was made to ensure items were understandable in isolation, but the questionnaire was designed and structured to minimise the possibility of respondents developing some expectation of what was to follow. It is suggested that those factors combine to reduce the likelihood of there having been a noticeable level of response artefacts.

A further potential limitation concerns the relatively small amount of pilot testing that was undertaken. The questionnaire was administered to one cancer patient as a pilot mainly to ensure that questionnaire items were understandable, response requirements were not confusing, and that the structure of the questionnaire posed no problems. This resulted in two minor amendments. Since the questionnaire consisted of existing instruments, generally with acceptable psychometric qualities, albeit in some cases shortened for the present study, it was considered that pilot testing for psychometric purposes was not critical.

There were also some inherent limitations in terms of representativeness and generalisability. For example, while the sample was reasonably representative in terms of both general population and cancer population demographics, there was a greater proportion of women than men than is reflected in general cancer statistics. This was possibly due to a greater willingness by women to talk about health matters and to take the time to be involved in a research project about health. Another possibility was that since participants responded to advertisements to take part in the study, it is unlikely that those who cope with their cancer through denial strategies would have responded, so in terms of motivation and interest, there may have been some sampling bias with those

who are more motivated about health matters being more eager to participate in a research project.

In addition to the various suggestions for future research made above, future research could also explore the influence of this group of cognitions on other health behaviours, such as help seeking behaviour and adherence issues. Arguably, cognitions that help explain treatment choice decisions would be sufficiently consequential to be of use in understanding other treatment focussed health behaviours.

Perhaps one of the most important areas where more research is needed in terms of the influence of patient cognitions, is in the area of the patient/practitioner relationship. As Millenson (1995) has commented, "The patient/practitioner relationship is actually itself a very powerful 'drug' but one whose pharmacology, side effects and dosage remain virtually unexplored" (p. 237). Understanding the patient's cognitive response to their illness would potentially improve this relationship. Not only could it help the patient understand some of the non-clinical aspects of the aetiology of their illness, but could enable the health professional to deal with their patient more holistically.

Finally, in future research more attention is needed to the conceptualisation of non-conventional medicine including the question of what is non-conventional and what is conventional medicine. Research specifically aimed at eliciting people's perceptions of where the division should be, and exploring the conceptual basis of the division would be useful. In the present study the researcher made an essentially arbitrary decision based on the researcher's understanding of the basis and methodology of non-conventional therapies. The advantages of classifying non-conventional treatments into meaningful groupings for the purposes of research, has been signalled before (e.g., Wardwell, 1994) but the suggestion has been acted on to a very limited extent. In addition, in the present study the philosophy underlying non-conventional medicine was offered as one explanation for the relationship between certain cognitions and treatment choices, but the study did not specifically explore the philosophical basis of holism and other non-conventional approaches in terms of their relationship with treatment choice.

In terms of potential applications of the findings the study made some contribution to the understanding of non-conventional medicine use. In a broad sense the findings provide information that would be useful to health professionals, particularly conventional practitioners, about the health and illness related beliefs of their seriously ill patients. More specifically, the results give an indication of the existential concerns that accompany serious illness and how these may influence decisions about treatment choice.

The findings also show how patients will have different approaches to the question of the measure of control the patient should maintain compared to the health professional. The results indicate that those who approach life in an intrinsic frame will likely present as self-motivated, interested in knowing about and being involved in decisions about their health, accepting some responsibility for their health and demonstrating a desire to maintain some control over the treatment process. Patients who demonstrate these qualities are likely to be involved in or become involved in non-conventional medicine. Furthermore, the propensity of patients to attribute a measure of control to themselves will be represented by a desire for information and involvement which if satisfied is likely to enhance the doctor/patient relationship and the patient's commitment to the treatment programme. Conversely, failure to recognise this would likely lead to a decrease in commitment to the treatment programme and the involvement of non-conventional treatments.

Another practical clinical application of the finding that many patients are interested in a measure of control is the suggestion of a shared treatment decision-making process. Charles, Redko, Whelan, Gafni, and Reyno (1998), who made a similar recommendation in relation to breast cancer patients, suggested that the important implication of this for clinical practice concerns the question of blame for a bad decision. They also suggested that participation in treatment decision-making is linked to better health outcomes.

The finding that patients view conventional and non-conventional medicine on a continuum rather than as a clearly defined dichotomy suggests that a rethink by the biomedical establishment is called for as to where the boundary between conventional and non-conventional should be placed. At least, perhaps, there should be room for flexibility on a case by case basis. At a practitioner and at a medical student level there is evidence of so called non-conventional medicine being viewed as having considerable merit (e.g., Furnham, 1993; Bernstein & Shuval, 1997; Verhoef & Sutherland, 1995; Perkin, Percy, & Fraser, 1994; Fisher & Ward, 1994; Marshal et al., 1990).

The patient/practitioner relationship, referred to above, is a particularly important consideration in terms of the application of the findings of this study. The findings have confirmed the suggestion made by Charlton (1993) when he stated that "The current vogue for 'alternative' therapies may be taken as evidence that there is a hunger among at least some of the public for a more broadly spiritual dimension to medicine – a 'holistic' (or whole-istic) approach which relates therapy to the patient's overall purpose in life. But equally some other patients prefer to view doctors as primarily technical experts, who will 'fix' just that thing which has gone wrong and not meddle with other personal and private aspects of life". (p. 125). One of the doctor's roles is to detect which approach a given patient prefers. In speaking of the demand for a spiritual dimension to the consultation, Charlton (1993) went on to say that "If nothing else, it [i.e., the doctors' responding to the demand] would mean that patients who want something 'extra' will not be compelled to consult fringe practitioners in order to find it." (p. 126).

In a sense, the latter comment contradicts Charlton's earlier suggestion that of the two alternatives facing conventional medicine (i.e., to expand conventional medicine to include the unconventional or to expand the scientific integrity of conventional medicine to demarcate it more clearly from the fringe) he prefers the latter (Charlton, 1992). It is suggested that the first alternative is workable without necessarily detracting from the integrity of conventional medicine. The suggestion is not that practitioners of these non-conventional therapies be 'elevated' to conventional medicine status, but that the training

of conventional practitioners incorporates these approaches, supported of course, by the appropriate research.

An important part of the role of the health professional is to support patients in making informed, safe and appropriate choices (Astin, 1998). Ultimately, however, included in the decision making process will be powerful cognitions which may not be modified or overruled by the evidence, knowledge, and logic of the conventional practitioner's approach. It is, therefore, critical that health professionals understand the robustness and power of cognitions such as those explored in this study. It is important too that they understand that for many, the use of non-conventional medicine is part of a broader value orientation and set of beliefs that often finds some congruence in a holistic, spiritual approach to life (Astin, 1998). As Millenson (1995), Kuhn (1988) and others have observed, inherent in human nature is the need to seek meaning out of the chaos of events. They usually need assistance with this and look to their health professional as one of those equipped to help.

If the biomedical world has the treatments and the evidence to back them up, is prepared to factor in side effects and quality of life issues, and is prepared to relate with empathy and time to patients as individuals with diverse needs and priorities, and who have a right to be informed and involved, then it will experience less difficulty in setting up a treatment regimen to which the patient is committed and which will be less likely to be jeopardised or undermined by alternatives.

Surely a cure for cancer is the goal, but a cure that subsumes healing. As Cassileth (1989) profoundly stated, "when we find a cure for cancer, questionable cancer therapies will disappear. There are no unproven treatments for universally curable diseases" (p. 1250). Where a universal cure is to be found is the issue, rather than by whom. For decades calls have been made for more cooperation and less polarising between conventional and non-conventional medicine. Perhaps a step towards working in concert to find a cure is simply to adjust the dividing line between the modalities so that the psychological approach for both practitioners and patients results in less divisiveness, less

secrecy, and less, or preferably no detriment. Many people want to understand, to be involved, to have some control, and to know what having this illness and their now endangered life means. They want all of this psychosocial-spiritual input along with a biological cure.

As most commentators acknowledge, non-conventional medicine is here to stay. In a system where there can be no argument with the notion that what is best for the patient must be the only concern, there can be no room for polarising scenarios like those identified by Alper (1984) where conventional practitioners feel threatened by talk of dissatisfied patients and non-conventional practitioners avoid references to their credentials and to their success as being anecdotal.

Plato called medicine ‘the science that pertains to the love of the body’. The health practitioner must be a unique combination of high levels of scientific knowledge, empathetic and caring concern, and an understanding of the cognitive dimension of illness. Understanding why a patient wants to learn about what is happening to them, why they want to be involved and maintain some sense of control, what their illness means and why they have it, and ultimately what meaning their life has, will combine with scientific knowledge in the health practitioner to give him or her the ability to meet the challenge of both curing and healing. This is a biopsychosocial-spiritual approach for which there is considerable evidence of “success” as a treatment approach.

As Sloan, Bagiella and Powell (1999) acknowledged, health outcomes may be viewed in terms of health-related behaviours as well as medical outcomes. It is in this area that it will be important for the medical practitioner to have an understanding of the patient’s approach to spiritual and religious matters. Understanding the patient’s approach to the existential questions of life will equip her or him with potentially important information about the patient’s approach to treatment and other health-related behaviours.

A particularly important application of the findings of this study may be for the world of conventional medicine to acknowledge the importance for their patients of the spiritual response to illness. Lerner's (1994) comments sum this up - "A spiritual response is undoubtedly one of the most common human reactions to cancer. The fact that spiritual support in the treatment and care of people with cancer is considered *unconventional* today, or at best the marginal province of the hospital chaplain, is a testament to how alienated from core human needs the conventional medical system has become". (p. 98).

### **A concluding comment**

Muzzin, Anderson, Figueredo and Gudelis (1994) made the statement that "Faced with the intolerable incompatibility of life and death, persons with cancer ..... make various attempts to attain control over their lives. Emotions appear to be compartmentalized or 'postponed', so that the person can function in everyday life (Lewis, Haberman & Wallhagen, 1986)." (p. 1201). Freund and McGuire (1999) said that "Illness is also upsetting because it raises the questions of meaning: Why is this happening to me? Why now? How could God allow this to happen? ..... Western medicine is having difficulty dealing with sufferers' problems of meaning ..... Illness etiologies in Western medicine typically deal with such proximate causes as germs, viruses, and genetic defects, but these notions are not adequate explanations for many people, because questions of meaning frequently beg for ultimate causes" (pp. 134-135).

These comments essentially sum up the conceptual basis of this study. They demonstrate that the cognitive response to cancer is intense, challenging and represents very fundamental aspects of life. The study endeavoured to assess these cognitions, along with some additional complementary cognitions, among a sample of cancer patients and to explore their influence on the making of a potentially critical decision about treatment. The conclusion was that a person's approach to life and its deepest existential questions



will be helpful in explaining their behaviour in relation to their illness, a concept that health professionals may do well to take into account.

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**APPENDIX A: QUESTIONNAIRE**

## Psychological Aspects of Cancer Questionnaire

Please read the following instructions and those throughout the questionnaire and follow them carefully.

Remember that all the information you provide remains confidential and will be used only for the purpose of our research. Remember also that you have the right to withdraw from the study at any time and you may refuse to answer any particular question.

We expect that this questionnaire will take you between 1 and 1½ hours to complete. Please do this as soon as is convenient.

It is important that you give your own answers. We therefore ask that you do not discuss this questionnaire with others. Please answer as honestly and as accurately as you can.

For most of the questions there is no right or wrong answer. An answer is correct if it is true for you. Try not to spend very long on each question. Your initial response to a question is most likely to be the best for you.

Please try to answer all the questions, and be careful not to miss any pages.

When you have finished please return the questionnaire in the enclosed envelope. No stamp is required.

## Questionnaire

### Section A

*This section is about general knowledge of cancer. For the first two parts please write opposite each statement, the number of the option which you consider to be the correct answer. For example, if you consider smoking affects the chances of getting cancer to a great extent you write a 3. Please answer these questions from your own knowledge.*

|  |  |
|--|--|
|  |  |
|  |  |

0 not at all                      1 not much                      2 to some extent                      3 to a great extent

**How much do the following increase one's chances of getting cancer?**

- Smoking \_\_\_\_\_
- Birth control pills \_\_\_\_\_
- Family history \_\_\_\_\_
- Food additives \_\_\_\_\_
- Sun exposure \_\_\_\_\_
- Cosmetics use \_\_\_\_\_
- Industrial fumes \_\_\_\_\_
- Blow to breast \_\_\_\_\_
- Eating a low fibre diet \_\_\_\_\_
- Drinking milk \_\_\_\_\_
- Being over weight \_\_\_\_\_
- Drinking alcohol \_\_\_\_\_
- Eating red meat \_\_\_\_\_

17

**What are the chances of curing the following cancers if detected early?**

0 Poor                      1 Fair                      2 Good                      3 Excellent

- Breast \_\_\_\_\_
- Colon-rectal \_\_\_\_\_
- Larynx \_\_\_\_\_
- Skin \_\_\_\_\_
- Lung \_\_\_\_\_
- Bladder \_\_\_\_\_

23

**For the following statements please circle whether you Agree or Disagree**

|  |       |          |
|--|-------|----------|
| In New Zealand lung cancer is more common in men than it is among women  | Agree | Disagree |
| Bowel cancer is difficult to detect  | Agree | Disagree |
| Cancer can be caught from contact with a person who has cancer   | Agree | Disagree |
| In New Zealand more people die of cancer than of any other single disease.   | Agree | Disagree |
| In New Zealand lung cancer is more common among women than breast cancer   | Agree | Disagree |
| Exercise makes cancer spread faster  | Agree | Disagree |
| The more extensive the breast cancer surgery the better are a woman's chances for a cure   | Agree | Disagree |
| One out of five women will get breast cancer some time in her life   | Agree | Disagree |
| Women who have their first child before age 30 are less likely to get cancer than women who have their first child after the age of 30 | Agree | Disagree |
| Men get bowel cancer more often than women   | Agree | Disagree |
| Blood in your bowel movement means you have cancer for sure  | Agree | Disagree |
| Age is not related to a person's chances of getting cancer   | Agree | Disagree |
| Cancer can be successfully treated only by surgery   | Agree | Disagree |
| Pain is the first symptom of cancer  | Agree | Disagree |
| A sore that does not heal can be a cancer warning signal   | Agree | Disagree |
| A persistent cough can be a cancer warning signal  | Agree | Disagree |

24

39



**Please circle whether you Agree or Disagree with the following statements**

|  |       |          |
|--|-------|----------|
| Having cancer changes one's whole life   | Agree | Disagree |
| One feels negative about oneself when one has cancer   | Agree | Disagree |
| Thinking about cancer scares me  | Agree | Disagree |
| Cancer is a hopeless disease   | Agree | Disagree |
| If cancer is detected early it can be successfully treated   | Agree | Disagree |
| The medical profession has made considerable progress in the treatment of cancer in the last ten years | Agree | Disagree |
| It doesn't matter what treatment you get, once you get cancer you can't get rid of it                  | Agree | Disagree |
| Surgery spreads cancer   | Agree | Disagree |
| Cancer treatments can be worse than the cancer   | Agree | Disagree |

**Section B**

**The following 8 statements relate to your opinions and feelings about having cancer. Read each statement carefully and indicate the extent to which you agree or disagree by writing the appropriate number in the space provided.**

|                   |       |          |                      |
|-------------------|-------|----------|----------------------|
| 1                 | 2     | 3        | 4                    |
| strongly<br>agree | agree | disagree | strongly<br>disagree |

- I feel cancer is something I will never recover from \_\_\_\_\_
- I feel cancer is serious, but I will be able to return to life as it was before my illness \_\_\_\_\_
- I feel cancer has changed my life permanently so it will never be as good again \_\_\_\_\_
- I feel I have made, or will make, a complete recovery from my illness \_\_\_\_\_
- I feel that I am the same person I was before my illness \_\_\_\_\_
- I feel that my relationships with other people have not been negatively affected by my illness \_\_\_\_\_
- I feel that my experience with cancer has made me a better person \_\_\_\_\_
- I feel that having cancer has interfered with my achievement of the most important goals I have set for myself \_\_\_\_\_

**The following are some statements concerning feelings you may have about your illness. Please indicate how much, if at all, you agree with the statements. To do this please write the appropriate number alongside the statement from the following key.**

|            |        |            |           |
|------------|--------|------------|-----------|
| 0          | 1      | 2          | 3         |
| not at all | mildly | moderately | extremely |

- It is like an enemy \_\_\_\_\_
- I am ashamed of it \_\_\_\_\_
- I must fight it \_\_\_\_\_
- In some ways I gained from it (e.g., illness improves us people in some way) \_\_\_\_\_
- It is a punishment for something I have done \_\_\_\_\_
- I am defenceless against it \_\_\_\_\_
- I appreciate the help and sympathy it has brought me \_\_\_\_\_
- I cannot think of any reason to do with me why I should have it \_\_\_\_\_
- I want to escape from it \_\_\_\_\_
- I feel miserable about it \_\_\_\_\_
- It is a punishment which I do not deserve \_\_\_\_\_
- I have to give in to it \_\_\_\_\_
- I am worried that because of it I am not meeting my responsibilities as I should \_\_\_\_\_
- I feel it indicates that I am inferior \_\_\_\_\_
- I will never be the same again because of it \_\_\_\_\_
- I feel anxious about it \_\_\_\_\_
- I think of it as a problem to be tackled \_\_\_\_\_
- There is nothing I can do myself about it \_\_\_\_\_
- I am not told enough about it \_\_\_\_\_
- I feel angry about it \_\_\_\_\_
- I put the thought of it out of my mind \_\_\_\_\_
- I resent the way it makes me dependent on others \_\_\_\_\_
- It is something I must overcome myself \_\_\_\_\_
- It is worse than others realise \_\_\_\_\_
- I want to find out all I can about it \_\_\_\_\_
- I think a good deal about it \_\_\_\_\_

2/1-6  
1

**Section C**

**Section C is concerned with your beliefs about your health. Please write opposite each statement the number of the option which is true for you. There are no right or wrong answers.**

- |                |       |                  |           |                     |          |                   |
|----------------|-------|------------------|-----------|---------------------|----------|-------------------|
| 1              | 2     | 3                | 4         | 5                   | 6        | 7                 |
| strongly agree | agree | moderately agree | undecided | moderately disagree | disagree | strongly disagree |

**I consider that my cancer was due to:**

- The constitution with which I was born \_\_\_\_\_
- My body's natural defences not working efficiently \_\_\_\_\_
- My emotions \_\_\_\_\_
- My overall lifestyle \_\_\_\_\_
- Not taking good care of myself \_\_\_\_\_
- Bad luck \_\_\_\_\_
- Simple probability \_\_\_\_\_
- The society in which we live in New Zealand \_\_\_\_\_
- The culture within which I live \_\_\_\_\_
- Somebody 'ill wishing' me or placing a curse on me \_\_\_\_\_
- My relationships with family and friends \_\_\_\_\_
- Treatment by medical professionals \_\_\_\_\_
- God or some other supernatural power \_\_\_\_\_
- My home and /or work environment \_\_\_\_\_
- Being exposed to certain substances (e.g., food additives) \_\_\_\_\_
- My age \_\_\_\_\_

27

42

- |                |       |                  |           |                     |          |                   |
|----------------|-------|------------------|-----------|---------------------|----------|-------------------|
| 1              | 2     | 3                | 4         | 5                   | 6        | 7                 |
| strongly agree | agree | moderately agree | undecided | moderately disagree | disagree | strongly disagree |

**My capacity to become healthier or maintain good health in the future is due to:**

- The constitution with which I was born \_\_\_\_\_
- My current state of health \_\_\_\_\_
- Marshalling my body's own strengths \_\_\_\_\_
- Promoting a positive attitude \_\_\_\_\_
- Taking charge of, and responsibility for, my own life \_\_\_\_\_
- Actively changing to a more healthy lifestyle \_\_\_\_\_
- Giving up unhealthy habits \_\_\_\_\_
- Good or bad luck \_\_\_\_\_
- Simple probability \_\_\_\_\_
- Getting advice from books, magazines, TV or radio \_\_\_\_\_
- Getting advice/ treatment from my doctor \_\_\_\_\_
- Getting advice/ treatment from practitioners of alternative therapies \_\_\_\_\_
- God's power or influence \_\_\_\_\_
- Any other supernatural influence \_\_\_\_\_
- Improvements in my home and /or work environment \_\_\_\_\_
- My age \_\_\_\_\_
- Taking vitamins or a tonic \_\_\_\_\_

3/1-6

1

17

|                |       |                  |           |                     |          |                   |
|----------------|-------|------------------|-----------|---------------------|----------|-------------------|
| 1              | 2     | 3                | 4         | 5                   | 6        | 7                 |
| strongly agree | agree | moderately agree | undecided | moderately disagree | disagree | strongly disagree |

**How quickly and effectively I recover or have recovered from my illness is due to:**

- Finding ways to resolve any inner conflicts \_\_\_\_\_
- Taking responsibility for myself and doing all I can to get better \_\_\_\_\_
- Actively taking steps to make my lifestyle more healthy \_\_\_\_\_
- Good or bad luck \_\_\_\_\_
- Simple probability \_\_\_\_\_
- The care I get from my family and friends \_\_\_\_\_
- The quality of any alternative therapy or remedy I use \_\_\_\_\_
- The sympathy and understanding of my health care provider \_\_\_\_\_
- The quality of any conventional medical treatment I receive \_\_\_\_\_
- Taking drugs or having treatments that are effective \_\_\_\_\_
- Prayers said for me \_\_\_\_\_
- God's will \_\_\_\_\_
- Some other supernatural power \_\_\_\_\_
- The virulence of the disease itself \_\_\_\_\_
- An environment or circumstances which are conducive to recovery \_\_\_\_\_
- My body's own natural defences \_\_\_\_\_
- A curse or ill wishing \_\_\_\_\_
- The constitution with which I was born \_\_\_\_\_
- Following 'doctors orders' - complying properly with treatment I am given \_\_\_\_\_
- Thinking positively and seeing the illness as a challenge \_\_\_\_\_
- Letting nature take its course \_\_\_\_\_

18

38

**Section D**

***For the following statements please write the number of the option which is true for you.***

|            |          |                |                   |
|------------|----------|----------------|-------------------|
| 0          | 1        | 2              | 3                 |
| not at all | not much | to some extent | to a great extent |

- My health has always been an important consideration in my life \_\_\_\_\_
- I think about my health \_\_\_\_\_
- I do things to improve my health \_\_\_\_\_
- I search for new information about health matters \_\_\_\_\_
- I eat a well balanced diet \_\_\_\_\_
- I follow medical advice because I believe it will benefit my health \_\_\_\_\_
- I read about health matters in newspapers, magazines, books, etc.. \_\_\_\_\_
- I take notice of health care recommendations from TV, radio, magazines etc.. \_\_\_\_\_
- I put effort into my health \_\_\_\_\_
- I like to have information about my health, good or bad \_\_\_\_\_
- I like to participate in decisions about my medical care \_\_\_\_\_

39

49

**For the following statements please circle whether you agree or disagree**

|  |       |          |    |
|--|-------|----------|----|
| Regular check-ups are essential if good health is to be maintained                                       | Agree | Disagree | 50 |
| Good health depends on putting effort into trying to stay healthy  | Agree | Disagree |    |
| Medical examinations, tests, and procedures are likely to be painful and embarrassing                    | Agree | Disagree |    |
| The body has built-in mechanisms for healing itself  | Agree | Disagree |    |
| You only need medical advice when you are ill  | Agree | Disagree |    |
| Treatment should concentrate on the physical symptoms rather than on psychological and emotional aspects | Agree | Disagree | 55 |

**Section E**

***This section is not specifically about illness but about your life in general. Please be as accurate and honest as you can. Try not to let your answer to one question influence your answer to other questions. There are no right or wrong answers.***

***Write opposite each statement the number that best indicates the extent to which you agree with the statement***

|                   |       |         |          |                      |
|-------------------|-------|---------|----------|----------------------|
| 1                 | 2     | 3       | 4        | 5                    |
| strongly<br>agree | agree | neutral | disagree | strongly<br>disagree |

|   |       |    |
|---|-------|----|
| In uncertain times I usually expect the best                      | _____ | 56 |
| It's easy for me to relax   | _____ |    |
| If something can go wrong for me, it will                         | _____ |    |
| I always look on the bright side of things                        | _____ |    |
| I'm always optimistic about my future                             | _____ |    |
| I enjoy my friends a lot  | _____ |    |
| It's important for me to keep busy                                | _____ |    |
| I hardly ever expect things to go my way                          | _____ |    |
| Things never work out the way I want them to                      | _____ |    |
| I don't get upset too easily                                      | _____ |    |
| I'm a believer in the idea that "every cloud has a silver lining" | _____ |    |
| I rarely count on good things happening to me                     | _____ | 67 |

**Section F**

**The following are a number of statements related to opinions and feelings about yourself and life in general. Read each statement carefully, then indicate the extent to which you agree or disagree by writing a number opposite the statement. For example, if you strongly disagree write 7 following the statement. If you are undecided write 4. Try to use the undecided category as little as possible.**

|                   |       |                     |           |                        |          |                      |
|-------------------|-------|---------------------|-----------|------------------------|----------|----------------------|
| 1                 | 2     | 3                   | 4         | 5                      | 6        | 7                    |
| strongly<br>agree | agree | moderately<br>agree | undecided | moderately<br>disagree | disagree | strongly<br>disagree |

- My past achievements have given my life meaning and purpose \_\_\_\_\_
- In my life I have very clear goals and aims \_\_\_\_\_
- I regard the opportunity to direct my life as very important \_\_\_\_\_
- I seem to change my main objectives in life \_\_\_\_\_
- I have discovered a satisfying life purpose \_\_\_\_\_
- I feel that some element which I can't quite define is missing from my life \_\_\_\_\_
- The meaning of life is evident in the world around us \_\_\_\_\_
- I think I am generally much less concerned about death than those around me \_\_\_\_\_
- I feel the lack of, and a need to find a real meaning and purpose in my life \_\_\_\_\_
- New and different things appeal to me \_\_\_\_\_
- My accomplishments in life are largely determined by my own efforts \_\_\_\_\_
- I have been aware of an all powerful and consuming purpose towards which my life has been directed \_\_\_\_\_
- I try new activities or areas of interest and then these soon lose their attractiveness \_\_\_\_\_
- I would enjoy breaking loose from the routine of life \_\_\_\_\_
- Death makes little difference to me one way or the other \_\_\_\_\_
- I have a philosophy of life that gives my existence significance \_\_\_\_\_
- I determine what happens in my life \_\_\_\_\_
- Basically, I am living the kind of life I want to live \_\_\_\_\_
- Concerning my freedom to make my choice, I believe I am absolutely free to make all life choices \_\_\_\_\_

4/1-6  
1

|                   |       |                     |           |                        |          |                      |
|-------------------|-------|---------------------|-----------|------------------------|----------|----------------------|
| 1                 | 2     | 3                   | 4         | 5                      | 6        | 7                    |
| strongly<br>agree | agree | moderately<br>agree | undecided | moderately<br>disagree | disagree | strongly<br>disagree |

I have experienced the feeling that while I am destined to accomplish something important, I cannot put my finger on just what it is

I am restless

Even though death awaits me, I am not concerned about it

It is possible for me to live my life in terms of what I want to do

I feel the need for adventure and "new worlds to conquer"

I would neither fear death nor welcome it

I know where my life is going in the future

In thinking of my life, I see a reason for my being here

Since death is a natural aspect of life, there is no sense worrying about it

I have a framework that allows me to understand or make sense of my life

My life is in my hands and I am in control of it

In achieving life's goals, I have felt completely fulfilled

Some people are very frightened of death, but I am not

I daydream of finding a new place for my life and a new identity

A new challenge in my life would appeal to me now

I have the sense that parts of my life fit together in a unified pattern

I hope for something exciting in the future

I have a mission in life that gives me a sense of direction

I have a clear understanding of the ultimate meaning in life

When it comes to important life matters, I make my own decisions

I find myself withdrawing from life with an "I don't care" attitude

I am eager to get more out of life than I have so far

Life seems to be boring and uneventful

I am determined to achieve new goals in the future

20

43

1 strongly agree    2 agree    3 moderately agree    4 undecided    5 moderately disagree    6 disagree    7 strongly disagree

The thought of death seldom enters my mind \_\_\_\_\_ 44

I accept personal responsibility for the choices I have made in my life \_\_\_\_\_

My personal existence is orderly and coherent \_\_\_\_\_

I accept death as another life experience \_\_\_\_\_

My life is running over with exciting good things \_\_\_\_\_ 48

**Section G**

***We are now going to ask you to classify yourself as to whether you have a religious, a spiritual, or a philosophical approach in life. The questions are designed to help us understand whether a person's beliefs affect what happens to them.***

***In using the word religion, we are meaning the belief in and practice of a religious faith.***

***Some people don't follow a specific religion but do have spiritual beliefs, (for example, they believe that there is some other power or force outside themselves which might influence their life. This could be God or some other power).***

***Some people make sense of what happens to them in life without a belief in God or any outside power. They see themselves as self-sufficient. This could be called their philosophy of life.***

In the way just described, would you say your understanding of your life is primarily:  
(Circle the appropriate option)

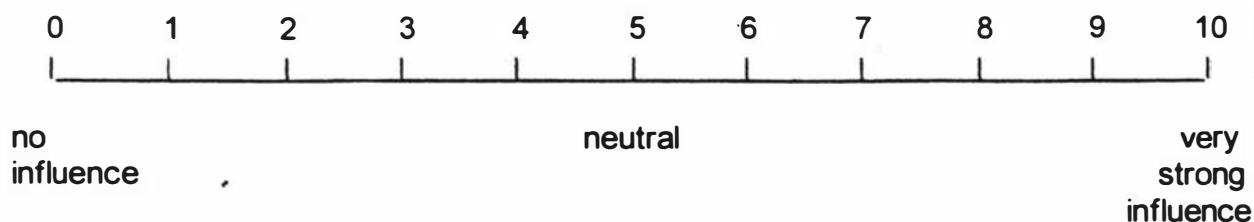
- Religious (now go to page 11)
- or Spiritual (now go to page 13)
- or Philosophical (now go to page 14)
- or No particular understanding (now go to page 15)





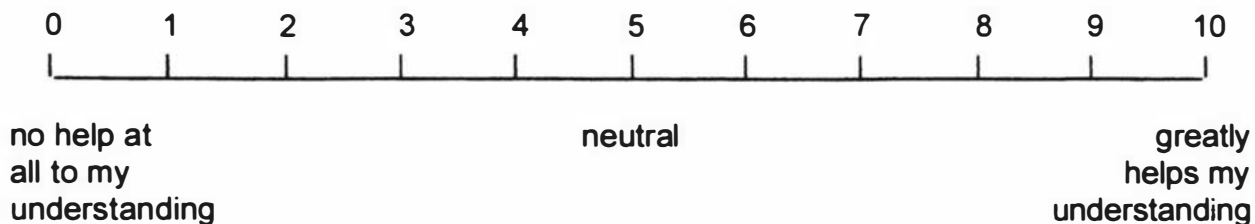
**Religious Understanding: continued**

How much does your religious faith affect how you respond to things that happen to you? (i.e., How much does it help you cope when you are affected personally by change or other events in your life?) Circle a number on the scale below:

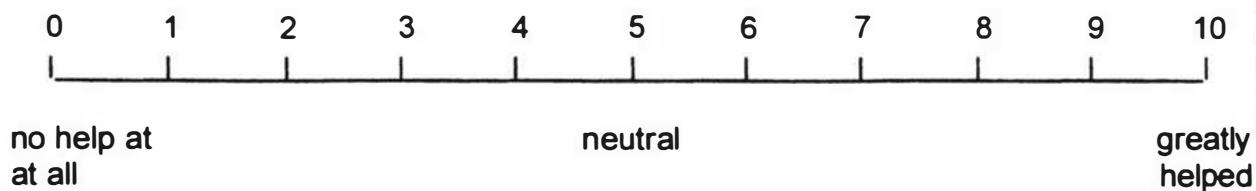


62

How much does your religious faith help you to understand why things happen in the world, outside of your day to day activities? (e.g., Political events, wars, accidents, natural disasters). Circle a number on the scale below:



How much have your beliefs helped you during this illness? Circle a number on the scale below:

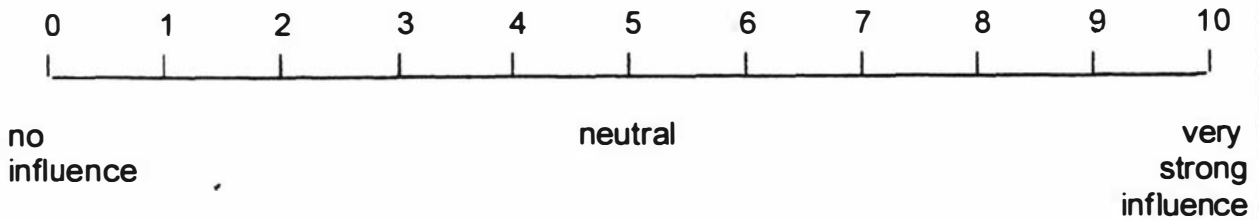


64

**Now Go to Page 15 Please**

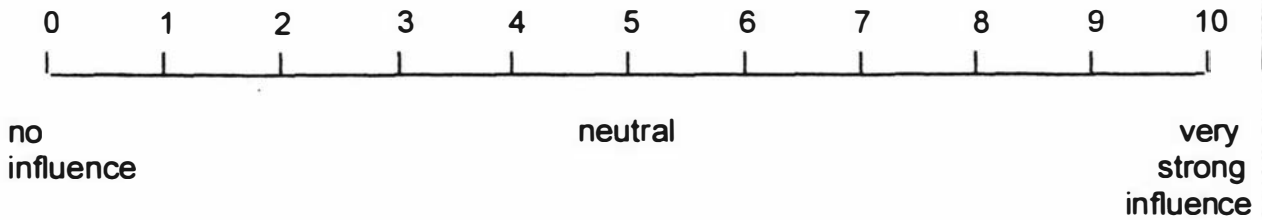
**Spiritual Understanding**

You said that you believe in a power or force outside of yourself. How much does this influence what happens to you in your life? (i.e., Can this affect your day to day life, e.g., chance meetings, accidents, illness, unexpected opportunities?) Circle a number on the scale below:

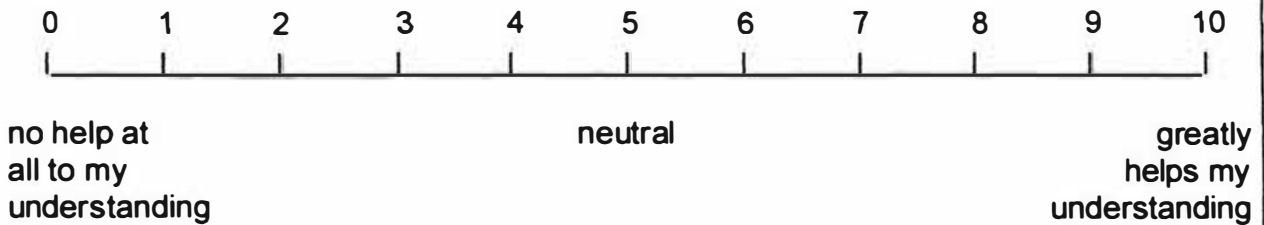


65

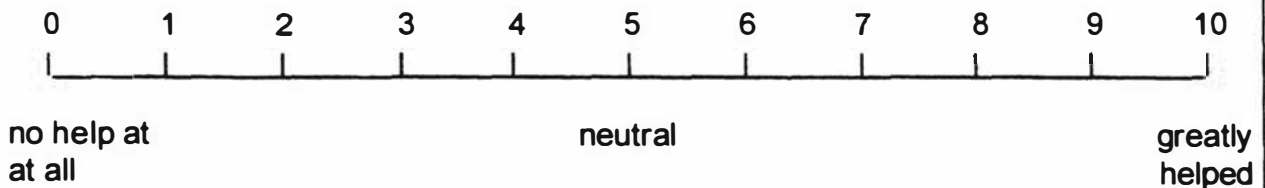
How much does this power affect how you respond to things that happen to you? (i.e., How much does it help you cope when you are affected personally by change or other events in your life?) Circle a number on the scale below:




How much does this power help you to understand why things happen in the world, outside of your day to day activities? (e.g., Political events, wars, accidents, natural disasters). Circle a number on the scale below:




How much have your beliefs helped you during this illness? Circle a number on the scale below:



68

**Now Go to Page 15 Please**

**Philosophical Understanding**

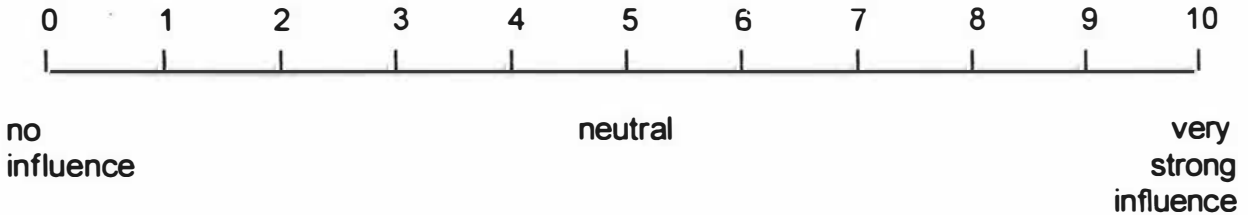
Does your philosophical approach to life have a specific name or names?  
Please indicate with a tick(s):

- Existentialism (man is free and responsible for his own acts) \_\_\_\_\_
- Atheism (belief that there is no God) \_\_\_\_\_
- Humanism (belief in human effort rather than religion) \_\_\_\_\_
- Free Thinker (Skeptic who forms his/ her own opinion) \_\_\_\_\_
- Other (please specify) \_\_\_\_\_

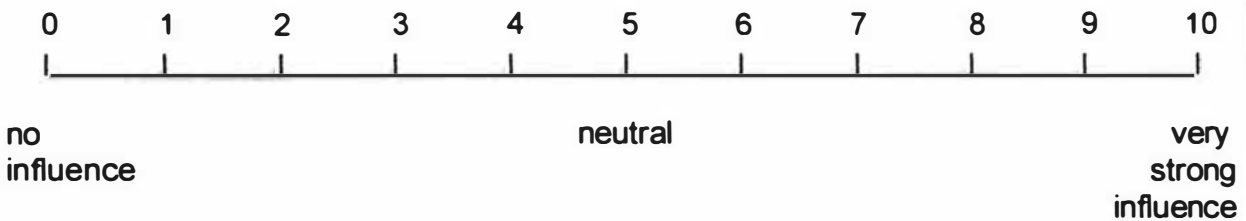
69

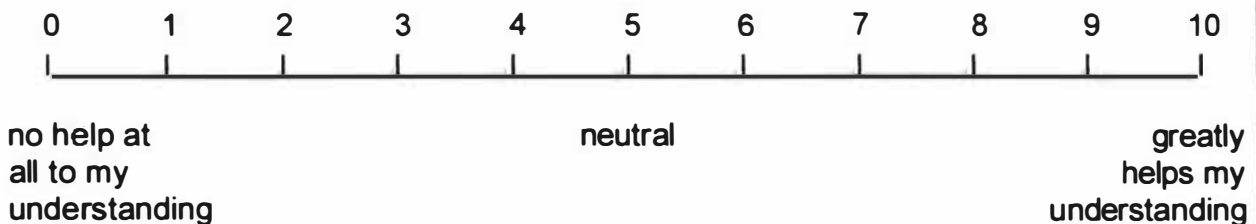

You said that you had a particular philosophical approach to life. How much does this influence what happens to you in your life? (i.e., Can this affect your day to day life, e.g., chance meetings, accidents, illness, unexpected opportunities?) Circle a number on the scale below:



How much does this philosophy affect how you respond to things that happen to you? (i.e., How much does it help you cope when you are affected personally by change or other events in your life?) Circle a number on the scale below:




How much does this philosophy help you to understand why things happen in the world, outside of your day to day activities? (e.g., Political events, wars, accidents, natural disasters). Circle a number on the scale below:



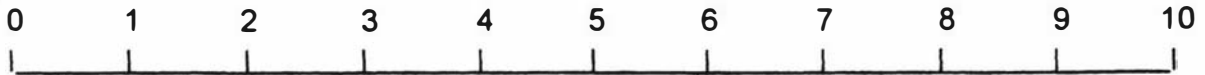
76

**Now Continue on Page 15 Please**

**All Participants to complete**

**What do you think about the following views people sometimes express about illness? Please indicate on the scale for each statement.**

Illness is a punishment for wrongdoing



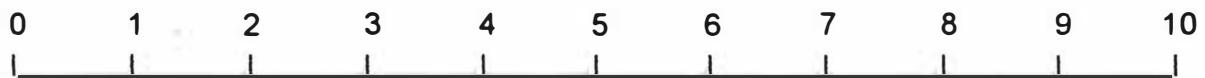
strongly disagree

neutral

strongly agree

1

Illness is predetermined /due to fate



strongly disagree

neutral

strongly agree

Illness is sent to test/ try us

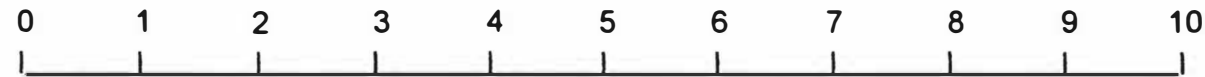


strongly disagree

neutral

strongly agree

Illness is a consequence of lifestyle (e.g., smoking, drinking, sex)



strongly disagree

neutral

strongly agree

With these thoughts in mind, would you think there is any link/ association between **your** illness and **your** religious/ spiritual/ philosophical approach to life ?



convinced there is no link

neutral

convinced there is a link

5

**Section H**

***This section concerns your own treatment situation. Please carefully read through the list below and tick as you go, as many of the treatments or activities you have used or are using in connection with your cancer.***

***Please be sure:***

- 1. That you tick ones that you have used in the past or are presently using***
- 2. That you only tick them if you are sure that you have definitely used them***

Chemotherapy  
Radiation Therapy  
Surgery

Acupressure  
Acupuncture  
Alexander Technique  
Aromatherapy  
Ayurveda  
Bach Flower Remedies  
Bioenergetics  
Biofeedback Training  
Bowen Techniques  
Chelation Therapy  
Chiropractic  
Colour Therapy  
Crystal Therapy  
Deep Tissue Massage  
Dieting  
Faith Healing  
Fasting  
Gemstone Therapy  
Gerson Therapy  
Hellerwork  
Herbal Medicine  
Homeobotanical Therapy  
Homeopathy  
Hoxsey Treatment  
Hydrotherapy  
Hypnotherapy  
Imagery & Visualisation  
Iridology  
Kinesiology

Maori Medicine & Healing Methods  
Massage Therapy  
Meditation  
Naturopathy  
Neurolinguistic Programming (NLP)  
Osteopathy  
Ozone Therapy  
Polarity Therapy  
Prayer  
Pritikin Diet  
Psychic Surgery  
Rebirthing  
Reflexology  
Reiki  
Rolfing  
Shiatsu  
Spiritual Healing  
Therapeutic Touch  
Vegetarianism  
Vitamin Therapy  
Yoga  
Other or Others (please specify)

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***Please read through the list a second time to ensure that you have not missed any***

**Section I**

**The following are some questions about yourself and your medical history**

Are you male or female ?  male  female

1

In what year were you born? 19\_\_\_\_\_

3

What is your current marital status? (circle one number)

- Married (including de facto)..... 1
- Widowed..... 2
- Separated / divorced..... 3
- Never married..... 4

4

To which ethnic group do you consider yourself to belong?

- European / Pakeha..... 1
- Maori..... 2
- Pacific Island..... 3
- Other (please specify)\_\_\_\_\_ 4

Please indicate the highest level of formal education you have reached (circle one)

- Some primary school..... 1
- Completed primary school..... 2
- Some high school..... 3
- Completed 3 years high school..... 4
- Completed more than 3 years high school..... 5
- Technical training beyond high school..... 6
- Some university..... 7
- Graduated from university..... 8
- Other (please specify)\_\_\_\_\_ 9

Would you classify yourself as primarily (circle one):

- Employed full-time..... 1
- Employed part-time..... 2
- Taking care of a home..... 3
- Looking for work..... 4
- Retired..... 5
- Other (please specify)\_\_\_\_\_ 6

7

To the best of your recollection, what month and year were you first diagnosed as having cancer?

19

8

|  |  |
|--|--|
|  |  |
|  |  |

**From the following list of cancer types, please circle the number or numbers corresponding to the type(s) of cancer you have been diagnosed as having at any time in your life**

- Neurological (e.g., brain & spinal cord)..... 1
- Blood (e.g., Leukaemia)..... 2
- Lymph System (e.g, Hodgkin's disease, non Hodgkin's lymphoma)..... 3
- Head & Neck (e.g., Larynx)..... 4
- Respiratory (e.g., lung)..... 5
- Oesophagus..... 6
- Stomach..... 7
- Breast..... 8
- Endocrine system (e.g., thyroid)..... 9
- Bone..... 10
- Urinary system (e.g., Bladder, Kidney)..... 11
- Liver..... 12
- Melanoma..... 13
- Pancreas..... 14
- Gynecologic (e.g., uterus, ovaries)..... 15
- Intestinal (e.g., colon, rectum)..... 16
- Male Genital System (e.g., prostate, testis)..... 17
- Gallbladder..... 18
- Other(s) (Please specify)..... 19

11

29

**Finally, are there any comments you would like to make about things which may have influenced your choice of treatments which you feel the questionnaire has not covered? Please use the space below.**

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**Thank you.**

**We appreciate the time you have taken to complete this questionnaire. Please return it to us in the envelope provided. No stamp is required.**



**APPENDIX B: PARTICIPANT LETTER,  
INFORMATION SHEETS  
AND CONSENT FORMS**

Letter to participants

Information sheet for participants in northern region

Consent forms for participants in northern region

Information sheet for participants in central region

Consent forms for participants in central region



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**FACULTY OF  
SOCIAL SCIENCES**



DEPARTMENT OF  
PSYCHOLOGY

Dear Sir/Madam

As part of my doctoral studies in psychology at Massey University I am conducting some research into the way people diagnosed with cancer think about health and illness and how they make decisions about treatment.

Thankyou for requesting further information about this research. I am hoping that you will be willing to assist by filling out a questionnaire. I would like to think that you would find involvement in this exercise to be worthwhile, both for yourself and other people in your situation. I recognise that you may find involvement to be stressful, which may leave you deciding not to take part in this project. I will respect that decision.

You will find enclosed an Information Sheet describing the research and what your participation would involve, and a Consent Form for you to complete and sign if you are willing to take part. Also enclosed is a prepaid envelope for you to return the Consent Form.

I look forward to receiving your consent shortly. If, however, you do not wish to participate, thankyou for taking the time to read the enclosed material.

Yours sincerely

Glen Haddon



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**FACULTY OF  
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PSYCHOLOGY**

## INFORMATION SHEET

### RESEARCH INTO TREATMENT CHOICES BY PEOPLE DIAGNOSED WITH CANCER

#### What the research is about:

In the 1990's we generally have more understanding about health matters, and we are encouraged to take more responsibility in the treatment of our illness than once was the case. We are also confronted with more treatment choices. The aim of this research is to explore how people diagnosed with cancer think about their illness and about their health in general, and how these thoughts influence the decisions they make about treatment. The type of thoughts we are interested in include the way we define health and illness, our interest in health matters, how much we think we should be involved in our health care, what we think about our particular illness and our life with it, and what our illness and our life means for us. We believe that research which will improve our understanding of those diagnosed with cancer and the decisions they make is extremely valuable. The research is being conducted by Glen Haddon as part of doctoral research under the supervision of Mr. Kerry Chamberlain and Dr. John Spicer of the Department of Psychology, Massey University. If you have any questions at all about this study please call Glen Haddon collect at Massey University, (06) 3505955 or John Spicer on (06) 3504137.

#### Eligibility to take part:

You are eligible to take part if you are 18 years of age or over, and not older than 85, and have been diagnosed as having cancer at any time in your life except if your diagnosis has been made in the last three months.

#### What you will be asked to do:

If you are willing to help with this research you will be asked to fill out a questionnaire which will be mailed to you. In general the questionnaire is straight forward comprising mainly the marking of choices, although you may find that some questions require more thought than others. It will take you in the vicinity of 1 to 1 1/2 hours to complete, at a time convenient to you. You will be given a prepaid, addressed envelope to return the questionnaire in.

#### If you agree to participate:

1. Your name and the information you provide will be confidential at all times to the researchers. Your questionnaire will be seen only by the researchers and you will be identified only by code number. It will not be possible to identify individuals in any reports of the research.
2. You have the right to refuse to answer any particular question, and to withdraw from the study at any time.
3. You have the right to ask any further questions at any time.
4. You will be informed of the results of the study in a written summary if you wish.

It is important that you understand that participation in this research has nothing to do with any treatment you are receiving. We have no contact with your doctor(s). The research is of a psychological nature and the researchers will not be commenting on or offering any advice about your health or treatments. We do not expect you would find filling out the questionnaire distressing in any way, however, support contacts will be available should you feel that you need some support.

If you have any queries or concerns regarding your rights as a participant in this research you may contact the Health Advocates Trust, phone 6389638.



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## CONSENT FORM

**Title of Project:** Cognitive determinants of treatment choice among cancer patients.

**Principal Investigator:** Glen Haddon.

**Name of Subject:** ..... **Age** .....years.

|             |  |     |      |
|-------------|--|-----|------|
| English     | I wish to have an interpreter                                | Yes | No   |
| Maori       | E hiahia ana ahau ki tetahi tangata hei korero Maori ki ahau | Ae  | Kao  |
| Samoan      | Oute mana'o e iai se fa'amatala upu                          | Ioe | Leai |
| Tongan      | 'Oku fiema'u ha fakatonulea                                  | Io  | Ikai |
| Cook Island | Ka inangaro au i tetai tangata uri reo                       | Ae  | Kae  |
| Niuean      | Fia manako au ke fakaaoga e tagata fakahokohoko vagahau      | E   | Nka  |

I have been given and I have read and understood a written explanation of the research project I have been invited to take part in, and what is asked of me. I have had an opportunity to ask questions and to have them answered. I understand that I may withdraw from the project at any time and that, if I do, my medical care will not be affected in any way.

I consent to take part as a subject in this research.

Signed: ..... subject

In my opinion consent was given freely and with understanding

.....  
Witness name (please print)

.....  
Witness signature

.....  
Date

Consent obtained by: .....  
Name Signature



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## INFORMATION SHEET

### RESEARCH INTO TREATMENT CHOICES BY PEOPLE DIAGNOSED WITH CANCER

#### **What the research is about:**

In the 1990's we generally have more understanding about health matters, and we are encouraged to take more responsibility in the treatment of our illness than once was the case. We are also confronted with more treatment choices. The aim of this research is to explore how people diagnosed with cancer think about their illness and about their health in general, and how these thoughts influence the decisions they make about treatment. The type of thoughts we are interested in include the way we define health and illness, our interest in health matters, how much we think we should be involved in our health care, what we think about our particular illness and our life with it, and what our illness and our life means for us. We believe that research which will improve our understanding of those diagnosed with cancer and the decisions they make is extremely valuable. The research is being conducted by Glen Haddon as part of doctoral research under the supervision of Mr. Kerry Chamberlain and Dr. John Spicer of the Department of Psychology, Massey University. If you have any questions at all about this study please call Glen Haddon collect at Massey University, (06) 3505955 or John Spicer on (06) 3504137.

#### **Eligibility to take part:**

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#### **What you will be asked to do:**

If you are willing to help with this research you will be asked to fill out a questionnaire which will be mailed to you. In general the questionnaire is straight forward comprising mainly the marking of choices, although you may find that some questions require more thought than others. It will take you in the vicinity of 1 to 1 1/2 hours to complete, at a time convenient to you. You will be given a prepaid, addressed envelope to return the questionnaire in.

#### **If you agree to participate:**

1. Your name and the information you provide will be confidential at all times to the researchers. Your questionnaire will be seen only by the researchers and you will be identified only by code number. It will not be possible to identify individuals in any reports of the research.
2. You have the right to refuse to answer any particular question, and to withdraw from the study at any time.
3. You have the right to ask any further questions at any time.
4. You will be informed of the results of the study in a written summary if you wish.

It is important that you understand that participation in this research has nothing to do with any treatment you are receiving. We have no contact with your doctor(s). The research is of a psychological nature and the researchers will not be commenting on or offering any advice about your health or treatments. We do not expect you would find filling out the questionnaire distressing in any way, however, support contacts will be available should you feel that you need some support.



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■ ■ ■

DEPARTMENT OF  
PSYCHOLOGY

## CONSENT FORM

**Project Title:** Cognitive determinants of treatment choice among cancer patients.

**Principal Researcher:** Glen Haddon

**Institution:** Massey University (Department of Psychology)

**English:** I wish to have an interpreter Yes/No  
**Maori:** E hiahia ano koe ki tetahi hei korero Maori kia koe Ae/Kao

1. I have read the Information Sheet and have had the details of the study explained to me including what will be required of me.
2. My questions have been answered to my satisfaction and I understand that I may ask further questions at any time.
3. I understand that I am free to withdraw from the study at any time, and that such withdrawal will not adversely affect me in any way.
4. I agree to provide information to the researcher on the understanding that my information will remain confidential and that my identity will not be revealed in any written or verbal reports.
5. I understand that if I have any ethical concerns regarding the study, I may contact the Manawatu-Wanganui Ethics Committee on 06 3567773 and the Massey University Human Ethics Committee on 06 3569099.
6. I agree to participate in this study under the conditions set out in the Information Sheet.

Signed:.....

Name: .....

Date: .....

I would like to receive a summary of the findings Yes / No

**APPENDIX C: CORRELATIONS BETWEEN CONTROL  
VARIABLES AND DISCRIMINATING  
VARIABLES**

**Table 1**  
**Intercorrelations among discriminating variables and control variables**

|                             | Age     | Gender | Ed.1   | Ed.2  | Ed.3   | Ed.4   |
|-----------------------------|---------|--------|--------|-------|--------|--------|
| Knowledge                   | -.26**  | .17*   | .16*   | .16*  | .26*** | .18**  |
| Knowledge beliefs           | .18*    | -.16*  | .01    | .11   | .08    | .07    |
| Motivation                  | -.07    | .17*   | -.01   | -.08  | -.08   | -.03   |
| Motivation beliefs          | .12     | .01    | -.15*  | -.09  | -.02   | .01    |
| Optimism                    | .11     | .05    | -.01   | -.01  | -.11   | -.12   |
| Pessimism                   | .07     | .01    | .20**  | .18** | .13    | .09    |
| Optimism total              | .09     | .06    | -.19** | -.12  | -.21** | -.21** |
| State of mind internality   | -.34*** | .23**  | -.05   | -.02  | .01    | -.01   |
| Action internality          | -.24*** | .20**  | -.05   | -.06  | -.05   | -.09   |
| Luck externality            | .18*    | .01    | -.10   | -.04  | -.02   | .05    |
| Powerful others externality | -.09    | .10    | -.06   | -.14* | -.21** | -.20** |
| Int. ill. meaning (CMS)     | .09     | .07    | -.04   | -.02  | -.04   | -.06   |
| Ext. ill. meaning (RIQ)     | -.15*   | .03    | -.09   | -.09  | -.13   | -.08   |
| Int. ill. meaning (RIQ)     | .18*    | .06    | .07    | .09   | .11    | .07    |
| Rel. meaning (N=80)         | -.22*   | .01    | .11    | .01   | -.07   | -.24*  |
| Spi. Meaning (N=70)         | .08     | .18    | .04    | -.18  | -.15   | -.02   |
| Phil. Meaning (N=52)        | -.12    | .03    | .30*   | .25   | .01    | .04    |
| Int. Life meaning +         | .03     | -.03   | -.02   | .01   | -.02   | -.09   |
| Ext. Life meaning ++        | -.24*** | .14*   | -.06   | -.05  | -.07   | -.05   |

\*  $p < .05$ , \*\*  $p < .01$ , \*\*\*  $p < .001$

+ Pucolcda subscale of LABI

++ All participants section of Royal Free Interview



**APPENDIX D: STANDARDISED COEFFICIENTS AND  
STRUCTURE MATRICES FOR SUBSET  
ANALYSES**

(Tables 1 – 8)