COMPARING APPROACHES TO EVALUATE GROUP MIND/BODY PROGRAMS FOR INDIVIDUALS LIVING WITH CHRONIC ILLNESS: CONSIDERATIONS OF THEORY AND METHODS

by

ALISON SANDRA ANNE POPE

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Department of HEALTH CARE & EPIDEMIOLOGY

The University of British Columbia
Vancouver, Canada

Date OCT 9, 2002.

Abstract

Objective: To explore what can be known about the relationship between mind/body in the processes of health and wellness using the positivistic tradition of Western medical research, and to compare this to what can be known by utilizing research methods with a non-positivistic, qualitative epistemology. An evaluation of a group mind/body program provided a case example by comparing findings gained using standardized health outcome measures with in-depth qualitative interviews to assess participant experiences.

Methods: A clinical trial was undertaken as a feasibility study. Forty clients of the Tzu Chi Institute were assigned to the intervention or control group on a first-come-first-served basis. All participants were receiving individualized care with practitioners at the Tzu Chi Institute clinic. Participants in the intervention group also experienced an 8 week, 50 hour meditation-based Mind/Body Program. Questionnaires were administered at 3 and 6 months post-program and included measures of health status, quality of well-being and social support. Thirteen in-depth qualitative interviews were conducted with participants of the Mind/Body Program.

Findings: The social functioning scale of the SF-36 Health Status Survey was the only significant change found using a repeated measures analysis of variance. On the other hand, the qualitative analysis revealed these individuals engaged in a process of personal growth that led to improved well-being. The theme of these findings entitled 'A Process

of Transforming Well-Being' captured the way participants moved through several stages of personal growth.

Conclusion and Implications: Efforts at understanding the benefits of mind/body interventions have not paid sufficient attention to the important subjective experiences of participants related to working through their 'inner process' and self-discovery. Traditional assumptions regarding the nature of 'positive' change, the assumption that positive change is necessarily linear, and the reliance on changes in short-term physical and psychological symptoms as indicators of the value of a successful intervention of this nature are questioned. Further, it was demonstrated that physical symptoms may not have the direct relationship to well-being that the questionnaires assume. The need to begin to understand the 'process' of a healing experience as opposed to emphasizing the assessment of health 'outcome' was noted.

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Chapter 1: Introduction

1.1 Background

In Western medical research, the study of human healing has been given relatively little consideration compared to the study of specific therapeutic interventions to improve health outcomes. The reductionist, mechanistic approach of Western medical science, based on the Cartesian duality of mind and body, has greatly contributed to ignoring a holistic approach to understanding health, and instead, focusing on an intervention and symptom specific orientation to treatment. Challenges to mind/body duality have been put forth within the conventional medical system, evident in the study of the placebo response and the emerging field of psychoneuroimmunology developed to study the relationship between the psyche and the nervous, immune and endocrine systems. Further, various traditionally non-Western practices designed to influence the mind/body relationship such as meditation and yoga have been given increasing attention in research, as their potential efficacy on improving health status is being evaluated in Western medical contexts. Outside of the health conventional system, numerous non-Western systems of health care acknowledge the connection between mind and body as central to their practice, such as Traditional Chinese Medicine and Ayurvedic Medicine. However, even with the increased awareness of the potential of the mind to affect the experiences of health, this learning has yet to significantly shift the approach to mainstream health care delivery to a more holistic orientation. In fact, it is not uncommon for the realm of mind/body medicine and the use of mind/body techniques to be primarily positioned within the domain of 'alternative' or 'complementary' therapies, relegating it outside mainstream medical practice in spite of clear scientific evidence of its value. An examination of the philosophical underpinnings of

Western science and the resulting understanding of the nature of mind/body may be useful in understanding this phenomenon.

While medical research has provided undeniable evidence of the interconnectedness of mind and body, what is known about this interconnectedness has been largely determined by the questions asked and by the approach taken to find answers to such questions. Does the mind affect the process of healing? Is a particular mind/body intervention efficacious? These questions make assumptions about the nature of mind and healing, thus they cannot truly be answered without considering additional questions such as: What is the nature of mind? What is healing, or what constitutes an improvement in wellness? Do people who choose to use mind/body interventions do so with the same expectations or assessment of a positive outcome as they do for a drug or surgical intervention? To date, Western medical science's evaluation of interventions designed to influence the mind/body relationship has focused on the evaluation of standardized health outcomes representing 'external' states of health and wellness and conventionally defined notions of health, health status and quality of life used to assess therapeutic interventions. This is occurring even though many of the techniques being studied are derived from Eastern traditions whose explanation of the nature of mind, the process of healing, and assessment of a 'positive' outcome differ markedly from a traditional Western medical perspective.

1.1.1 Objective

The objective of this dissertation is to explore what can be known about the influence of the relationship between mind and body on the processes of health and wellness by comparing the research of the positivistic tradition of Western medical research to what can be known

by utilizing research methods with a non-positivistic, qualitative epistemology. An evaluation of an 8 week, 50 hour group mind/body program provides a case example. Findings obtained using standardized quantitative health outcome measures are compared with in-depth qualitative interviews to assess participant experiences over a 6 month follow-up period.

1.2 The Nature of Mind/Body

What are mind and consciousness? What is the nature of the mind/body connection? The belief that mind and body are not separate entities, but one entity in a state of mutual communication, is not a new concept, but part of many ancient health beliefs which were dismissed or ignored with the introduction of scientific medicine. The historical roots of this dismissal can be traced to René Descarte (1596-1650), acknowledged with the commonly used term 'Cartesian Dualism'. His conception of mind and body working as separate entities became a basic assumption of what came to be called 'scientific', 'positivist' or 'Western' medicine as follows: the body operates mechanistically wherein the physical and mental aspects of health are separate. As a result, the study of illness has been focused exclusively on the physical body, amenable to study using a reductionist scientific method.

There is little dispute today that dualism is an insufficient paradigm to understanding health, healing and the mind/body connection. However, what has emerged within Western medical science is not the dismissal of dualism, but rather a new type of dualism where a 'correlative relationship'[1] between mind and body is acknowledged, a 'revised dualist view' if you will. From this perspective, mind and body are still considered separate

entities, but it is acknowledged that a causal link exists between the two. In other words, the mind is still dualistically isolated from the body and is treated as if it were doing something 'to' the body. Even the term 'mind/body' focuses attention on the dualistic image this modification was meant to dissolve. According to this modified perspective mind and body still exist as separate entities, however, they can interact.

From a non-dualist perspective, a mind/body approach to health focuses on the interrelated nature of the mind/body. From this perspective, mind and body are but reflections of the same whole. In other words, thoughts or feelings do not just influence physiological processes, the mind exists within the entire body.

The nature of mind and its relationship to the body cannot be understood without consideration of the nature of consciousness. Perhaps the most important point in which Western and Eastern perspectives diverge is regarding the nature of consciousness. According to the standard view of Western neuroscience, consciousness is an emergent property of the physical brain. From this perspective, even though consciousness is yet to be scientifically mapped out, understanding conscious awareness is only a matter of discovering the correct circuits of neurons. How such a complex circuit of neurons can be aware of itself is yet to be understood, and is an important question to be addressed within Western medical science.

From an Eastern perspective, consciousness is not solely an emergent property of the brain, but has a separate existence[2]. From this view, while there are forms of consciousness associated with brain function, there are also elements of consciousness, such as self

awareness, that are not solely dependent on brain activity. In other words, the understanding of the nature of 'mind' is not simply synonymous with 'brain' function.

1.3 Evaluating the Relationship Between Mind and Body

The approach to evaluating the mind/body relationship has relied on this revised dualist perspective, which assumes a mechanistic biomedical view of the body and illness. As a result, the evaluation of mind/body techniques and therapies has focused on objective quantitative measures of outcomes consistent with a biomedical therapeutic approach. This research on specific mind/body interventions has yielded impressive results of beneficial outcomes, including reduction in negative emotions (i.e. depression and anxiety[3,4]), improvement in physical markers (i.e. pain[5]and improved immune response[6]), a reduction in the subsequent use of health services[7], and increase in length of survival[8,9]. While these outcomes are powerful indicators of therapeutic effects, the process of mind/body interaction, and the inner experiences of the individual during the therapeutic process have not been examined. In other words, the qualitative personal experience of mind/body interaction has been mostly ignored, and the explored range of possible effects of such interaction has been limited to what is amenable to 'objective' analysis.

Many mind/body techniques are useful for directly influencing measurable physiological processes, but often more important from a patient's perspective are the more subtle processes related to increasing awareness, emotional expression and release, and deeper inner psychological processes. While the evaluation of a technique such as biofeedback*

* Where one learns to monitor their physiological changes during different emotional states (for example, galvanic skin response) in order to learn how to initiate the desired physiological state.

may be quite appropriately accomplished with traditionally objective measures of physiological change, other methods such as meditation and breathing techniques that are aimed at influencing these deeper inner processes may be difficult to meaningfully evaluate when only objective outcomes are considered. The outcome measures used to date have not looked at the subjective inner experiences of individuals or attempted to look at the processes and outcomes of psychological/personal growth and self-awareness. What is considered a 'positive' outcome of personal growth? How is personal growth related to changes in one's experience of health? How do you measure self-awareness? Without this understanding, the appropriate and full range of assessable impacts cannot be known.

1.4 Rationale for an Alternative Approach to the Evaluation

This problem makes apparent the need to explore new forms of scientific inquiry. It was clear at the outset that the focus was not solely to measure or look for causal relationships, but rather to understand and find meaning in a human experience. Understanding or uncovering the meaning of a phenomenon or intervention for research participants is not what traditional scientific methods under positivistic assumptions are intended, or able, to address. A careful 'unpacking' of assumptions, experience, and basic philosophical belief systems regarding ontology, epistemology and methodology was necessary.

1.4.1 Paradigms of Inquiry

Positivism, a paradigm of understanding describing the philosophical roots of the scientific method, is only one of a number of research paradigms each of which offer a different vision of reality, and with it, a set of different guidelines for conducting research. More

specifically, because these paradigms differ in the way they explain reality and 'truth', there are differences in what each paradigm defines as legitimate and feasible areas of study, the way these areas should be studied, as well as the role that the researcher and the researched assume in this process. They define what knowledge is, what knowing is, how we come to know, and what is worth knowing. Rather than assuming the researcher is engaging in his/her research with an 'objective' point of view, it is important to frame and make explicit the lenses the researcher uses to view the world.

The important philosophical questions are [10]: First, the *ontological question*: What can be known? Or, what is the nature of reality? Second, the *epistemological question*: What is the relationship of the knower to what is to be known? Or, how do we know what we know? Third, the *methodological question*: How can the inquirer go about finding out whatever s/he believes can be known? It is only when these questions are answered that one can choose an appropriate method. In other words, a method must be matched to a predetermined methodology, and this methodology is determined based on the ontological and epistemological underpinnings of the paradigm.

From a positivist ontological perspective, there exists one 'true' reality. It is the aim of scientific inquiry to capture this reality. In other words, there is a true and measurable reality for all participants resulting from an experience with a mind/body intervention. The matching epistemological orientation assumes it is possible and desirable for subject and researcher to remain separate and independent, without one influencing the other. Other world views, such as interpretivism, deny the existence of only one 'true' reality everyone can agree upon, and insist on the existence of multiple realities. Reality, from this

perspective, is what one perceives it to be, and the goal is to understand an experience from the point of view of those who are experiencing it. Evaluating a mind/body intervention from this perspective would focus on the subjective reality of the participant as the most important piece of information. This involves understanding the perception of meaning from the experience for the participant, and is therefore not well suited to predetermined, quantitative standardized measures of outcomes. Instead, more in-depth, interactive and qualitative approaches to inquiry are favoured.

1.5 Dissertation Focus

The aim of this dissertation is to explore meaningful ways of evaluating the mind/body connection and its relationship with health and well-being by exploring two different methodological orientations. In order to do this, the dissertation links with an evaluation of a comprehensive mind/body program run by the Tzu Chi Institute of Complementary and Alternative Medicine in Vancouver . All participants in the program were experiencing a chronic state of illness. The contribution of the dissertation is to add a qualitative assessment to the quantitative evaluation designed by the Institute, as well as to provide a comparison of methodological approaches. More specifically, the two different epistemological and methodological approaches used to guide the evaluation and provide a basis for comparison include; 1) quantitative outcome measures designed to measure health status, quality of life and social support, and 2) in-depth one-on-one qualitative interviews designed to measure the subjective experiences of the participants. The Mind/Body Program offered by the Tzu Chi Institute is a replication of a well established and widely used program often referred to as The Mindfulness-Based Stress Reduction Program founded by Jon Kabat-Zinn at the University of Massachusetts Medical Center[11].

1.5.1 Research questions

1) How does participation in a mind/body group program influence the experience of health and well-being for participants living with a chronic state of illness?
2) How do the participants' experiences, as told in their own words, compare to the assessment of the experience using quantitative measures of health status, quality of well-being, and social support?

1.6 Significance

It is evident from this introductory discussion of the mind/body relationship that the historical distinction between soma and psyche has become blurry. Attempting to heal this Cartesian split begs answers to some of the most basic questions of human existence, questions that are normally reserved for the realm of philosophy or religion. But, these questions can no longer remain outside of medical discourse or research endeavours given: 1) our conception of health and healing has expanded, challenging the simplistic dualist perspective on mind/body; 2) greater numbers of health consumers are choosing to use health practices aimed at influencing their state of health and well-being through mind/body pathways, many of which are informed by an Eastern, non-dualistic perspective on mind/body; 3) increasing social and economic pressures to provide integrative or more holistic approaches to health care delivery; and 4) the need for evidence to guide this process. This dissertation aims to contribute to this understanding, and offer a methodological contribution to assist with future evaluation of the effects of mind/body interactions on health and well-being.

1.7 Dissertation Layout

Chapter 2 of this dissertation provides a literature review of what is known about the effectiveness of mind/body programs to positively influence the well-being of individuals living with illness. Gaps in the current understanding of the effectiveness of mind/body programs in the medical literature, and an alternative approach to evaluate such programs are discussed. **Chapter 3** provides an explanation and theoretical basis of the mind/body program intervention involved in this study, including objectives, program format, techniques and activities. **Chapter 4** covers the methodological journey of the project. **Chapter 5** outlines the findings from the quantitative component of the project. **Chapter 6** gives an overview of the thematic findings from the qualitative component of the project. **Chapter 7** provides a discussion of the study findings, including details of the comparison between the qualitative and quantitative approaches to the evaluation. Implications of the project outcomes and suggestions for directions of continued study are discussed in **Chapter 8**.

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Chapter 2: Literature Review and Theoretical Perspectives

2.1 Background

2.1.1 A Biopsychosocial Perspective

The need for a new Western medical model which expands understanding to include the important interrelationships of biological, psychological and social influences in health and illness, often referred to as a 'biopsychosocial' approach, has been acknowledged[1]. From the perspective of this new paradigm, maintaining health is not a matter of solely striving for a new technological medical advance (pharmaceuticals etc.), rather it is a matter of balancing the interaction amongst genetic endowment, environmental inputs (bacteria, pollutants, etc.), psychological factors (stress, lifestyle, behaviours, attitudes), and social issues (social support, economic well-being, access to health care services, family and community relations).* Within this context, a growing interest and acceptance of evaluating behavioural or psychosocial influences and interventions on various health outcomes has emerged.

There is increasing documentation in the literature that personal qualities, lifestyle, and emotional responses influence the development and prognosis of chronic illness[2]. It is also well documented that a significant proportion of patients diagnosed with chronic illness experience difficulty adjusting to their illness, and may have severe psychological disruption throughout their illness[3]. The need to assist patients in dealing with these psychological dimensions to improve adjustment to illness, coping, and quality of life has

* The issue of balance is central to the ancient concept of health related to the balance of the humours in Greek medicine (maintained through the middle ages), to the physiologically based concept of homeostasis developed in the 19th century by Claude Bernard.

been well recognized and is being more widely studied. Further, the important influence of the healing context on health outcomes has been acknowledged[4]. This context includes: the belief and expectancy on the part of the patient; the belief and expectancy on the part of the caregiver; and the belief and expectancies generated by a relationship between the patient and the caregiver. Research documenting the influence of belief and expectations on health outcomes has resulted in a conceptual shift that acknowledges the importance of one's personal beliefs and expectancies on health outcomes, rather than dismissing these influences as *just* the placebo effect[5]. There is empirical evidence that our beliefs about our own health are the most accurate predictors of both health outcomes and use of the medical care system.[6]

2.1.2 Mind/Body Medicine

From the increased understanding of the psychosocial properties that have a marked influence not only on subjective psychological indictors[7], but also on immune function and general physiology[8], the field of mind/body medicine has emerged. A mind/body approach to health focuses on the relationship between mind and body, where the two are not considered as separate entities, but as parts of a whole. Mind/body medicine focuses on how thoughts and feelings influence the body via communication between the mind and the body through the nervous, endocrine, immune and circulatory systems.

The idea that the mind influences physiological processes is not new as is demonstrated by the fact that positivist researchers conducting drug studies have been attempting to control for the so-called 'placebo effect' for many years. What is more recent is the dramatic rise

in popular acceptance of therapies which support the mind/body connection, demonstrated by both their increased use and the growing interest of 'mainstream' clinicians and institutions. The increasing rate of chronic illness, and rising interest in exploring traditional or ancient healing practices have fueled growth in the area of mind/body medicine[9]. The term 'mind/body' is used widely to describe the influence of the context of the healing environment. This includes any influence of the mind on physiological processes. The term 'mind/body therapies' is used as a description for any of a number of specific techniques or therapies aimed at influencing the connection of mind and body including: meditation, progressive relaxation, mental imagery, visualization, biofeedback, breathing techniques, hypnosis, yoga, music therapy, art therapy, dance therapy, prayer and mental healing, tai chi, qigong, and spiritual/energy healing.

Mind/body relationships are known to influence the development of illness, in addition to playing a role in mediating both the process and outcomes of illness. Mind/body influences have been shown on a wide range of physiological outcomes as well as emotional, psychological, behavioural, cognitive, mental health, physical functioning, health status, and quality of life outcomes[10]. The field of mind/body medicine incorporates many areas of study including stress reduction, the placebo response, personality and emotional factors and their relationship to illness, the role of active coping mechanisms and social support to mediate experiences of illness, and the influence of many different interventions aimed at influencing the mind/body connection including group programs.

The growing field of psychoneuroimmunology, which focuses on the relationships between the body's integrative systems - nervous, immune and endocrine - has resulted in improved understanding of the physiological mechanisms of the mind/body relationship, and the subsequent health effects of the mind/body interaction. This has served to legitimize and provide the basis for further evaluation of potential benefits of interventions that influence mind/body communication.

In addition to substantial psychological and physiological benefits, mind/body therapies have also been shown to reduce health care costs due to reduced utilization of other, more expensive, in- and outpatient health care services. There are numerous examples of cost-effectiveness of comprehensive mind/body programs[11], as well as particular mind/body techniques such as meditation[12], the relaxation response[13], and biofeedback[14]. For example, a meta analysis of 191 different studies in which individuals undergoing surgery were taught various mind/body techniques showed an average reduction in length of hospital stay of 1.5 days (12%)[15]. Results showed that these individuals recover faster from surgery, experience fewer complications, and have reduced levels of post-surgical pain.

2.2 Relevant Literature

2.2.1 Focus of the Literature Review

While there is an immense literature that describes and evaluates a wide variety of mind/body interventions, this review focuses on the literature most relevant to the mind/body program studied in this project. This includes what is known in the medical literature about the impact of group programs aimed at influencing the mind/body

relationship (variously termed psychoeducational, stress reduction, behavioural etc.) for individuals living with illness, and the various individual components and techniques involved in the program including meditation, relaxation, biofeedback, movement, breathing techniques, and emotional expression. This summary is followed by a discussion of the gaps in knowledge and methodological challenges when researching mind/body programs. Suggestions for addressing both methodological issues and gaps in knowledge, in addition to limitations of the 'medical' healing paradigm[16] that has framed most of the evaluation of mind/body programs, are discussed.

Literature exists in a number of fields that reflects on the issue of the mind/body relationship and issues of healing including various branches of psychology (i.e. Freudian, Jungian), anthropology, religion, and philosophy. A conscious choice was made to limit this review to the medical literature designed to measure the impact of mind/body interventions on health status indicators. This was based on the desire to outline the literature that has been the focus of and has directed the evaluation of the mind/body relationship in the medical and health sciences. This literature includes the previous work that has been carried out to evaluate the prototype program of the Mind/Body Program under study, specifically, assessing the program impact using conventional assessments of health indicators (i.e. changes in psychological and physical symptoms).

2.2.2 Group Mind/Body and Stress Reduction Interventions

Many different types and varieties of group programs have been used to aid with various psychosocial and quality of life issues for people living with illness. The primary

objectives of group programs have been described as fitting into one or more of the following categories[17]: providing information; emotional support; behavioural training in coping skills; psychotherapy (aimed at fundamental psychological change); and spiritual/existential therapy.

The group format is well supported by the many studies that provide empirical evidence for the relationship between health and social support. It is now known that the number of social relationships one has is not the most important predictor of health, but instead the quality of these relationships[18] and the 'feeling cared for' dimension[19]. Increasing evidence is developing which has demonstrated the positive physiological benefits on immune function of self-disclosure in the presence of others[20]. The group experience allows for patients to form bonds with each other, also referred to as the experience of 'connectedness'[21], which is believed to be an important component in well-being. The following summary will outline the most relevant and methodologically sound studies of group programs for people living with illness.

2.2.2.1 Mindfulness Meditation Based Stress Reduction Programs

The Stress Reduction Clinic at the University of Massachusetts Medical Center offers a Stress Reduction and Relaxation Program , an 8 week outpatient behavioural medicine program seen as a complement to conventional medical treatments[22]. This program was the basis of the program offered at the Tzu Chi Insitute. This program involves intensive training in mindfulness meditation, and is one of few programs that have been replicated in a number of different settings across a range of study populations. This program has

undergone continual evaluation with sound methodology and has demonstrated its effectiveness for improving a variety of conditions including depression and anxiety[23], psoriasis[24-25], and chronic pain[26-27]. Effectiveness has been found to continue several years after the end of the intervention[28-29]. Research on the program has also documented increased melatonin levels in individuals with breast and prostate cancer[30].

The mindfulness meditation-based stress reduction program has been replicated in other settings and been found to decrease symptoms and use of health care services in individuals experiencing a number of additional health care concerns. For example, after program participation, self-esteem and medical and psychological symptoms were improved in individuals experiencing a variety of chronic health conditions[31]. Another study that replicated the program in a group of people living with HIV/AIDS at various stages of immunodeficiency found an improved sense of well-being and reduced depression and anxiety[32]. A further study documented the usefulness of the program for reducing the symptoms of fibromyalgia[33], however, given the lack of control group in this study, the findings need be interpreted with caution.

A recent study (2002)[34] suggests that mindfulness-based stress reduction reduced health care utilization by 'inner-city' patients. Because most studies of this program have involved middle-class and working class populations, this study focused on an inner-city, mainly Spanish speaking, population of lower socioeconomic status than participants in other similar studies. The program was conducted in Spanish. These are preliminary findings, and methodological limitations including small sample size and lack of a control

group make them somewhat tentative. However, these findings are evidence of continued interest on researching the benefits of mindfulness-based stress reduction programs, and the potential benefits to another segment of the population that deserves further exploration.

2.2.2.2 Group Programs In A Variety of Populations

The influence of a group mind/body program has also been evaluated in a primary care setting. In this example, two different mind/body/behavioral programs aimed at stress management were compared with a group program focused exclusively on providing information. The participating individuals were a group of primary care patients experiencing psychosomatic complaints (i.e. individuals felt psychosocial factors played an important role in their symptoms). Three-quarters of participants reported a physical complaint, most commonly, cardiovascular symptoms, gastrointestinal disorders, and headaches. More than half (55%) reported tension, stress or anxiety as a complaint, 12% reported depression. Significantly greater reductions in discomfort from physical and psychological symptoms and visits to the health maintenance organization were found for those receiving both the mind/body groups[35] compared to the 'information only' group. This study provides support for using experiential educational group sessions for stress management in preference to participants receiving group informational sessions.

Individuals living with HIV/AIDS are known to have substantial quality of life challenges, and much evaluation has been focused on the use of psychosocial intervention aimed at this population. A recent meta-analysis of 40 studies involving 1500 participants summarized the benefits of individual and group-based training programs for people living with

HIV/AIDS. The results of the analysis suggested that programs which combine basic training in relaxation techniques, active coping strategies, emotional support and enhancing healthy lifestyle choices are likely to be most effective in improving well-being and reducing stress, depression and anxiety. Several of the studies also showed a physiological benefit in the form of either improvement in or delayed decline of immune status indicators[36].

2.2.2.3 Group Therapies for Cancer Patients

While there is an abundance of evidence demonstrating various improvements in quality of life for cancer participants experiencing group therapy and support programs, some programs have also been shown to increase the length of survival in cancer patients, although the evidence is currently somewhat uncertain. In a ground breaking randomized controlled trial by Spiegel and colleagues (1989)[37] which looked at the effect of a one-year intervention for women with metastatic breast cancer, consisting of weekly supportive group therapy, a significant difference in survival at a 10-year follow-up was found. Women in the intervention group survived twice as long as women in the control group. Further, a study by Fawzy et al.[38], which used a six-week structured group psychotherapeutic intervention, was shown to have beneficial effects on survival of people with malignant melanoma. Participants were followed up five to six years after the intervention.

More recent studies attempting to replicate the findings of the Spiegel study have not found the same influence on survival[39,40,41]. Additional research by Cunningham and colleagues

has attempted to expand our understanding of the relationship between psychological interventions and survival in cancer patients. A study utilizing a mixed qualitative/quantitative design assessed the relationship between psychological work and duration of survival in metastatic cancer patients. Findings indicated five particular themes of psychological work to be related to length of survival; ability to act and change; willingness to initiate change; application of self-help work; relationships with others; and quality of experience[42]. An additional exploratory study found degree of involvement in psychological work to be associated with enhanced survival in patients with a variety of metastatic cancers[43]. These studies indicate that the influence of psychological interventions needs to be understood in terms of degree and nature of involvement in the work rather than solely attendance at the sessions. It has been suggested that future efforts focus on identifying individuals who are most likely to need and most likely to respond to emotionally supportive interventions[44].

Evaluation has also been initiated which addresses the issue of program format (i.e. weekly sessions vs. a weekend intensive) in which it was found the two formats produced similar results in terms of benefits in both mood and quality of life for cancer patients.[45] Another study assessed the differences in outcomes for a large classroom oriented group approach to a small group format and did not find there to be substantial differences in the improvements seen in cancer patients and family members[46]. Further, research aimed at addressing the question of which patients benefit the most from a group intervention indicated there were no differences in benefits based on the following sub-groups: gender, martial status, religious orientation, education level, or previous experience with self-help

techniques in cancer patients[47]. However, it was found patients under fifty showed greater improvement by the end of the program than older patients, but this difference was no longer evident at the 3-month follow-up. Further, those with recurrent disease showed less positive change in quality of life than those with primary cancer.

2.2.3 Mind/Body Techniques

A number of reviews exist which have analyzed the benefits of individual mind/body techniques and therapies for particular illness groups including cancer[48], HIV/AIDS[49], cardiovascular[50] and musculoskeletal disorders[51] providing evidence of positive benefits on both psychological and physical endpoints. The need for continued evaluation particularly around appropriate 'dosage' and understanding the mechanisms at work has been highlighted[52]. The following summary provides brief highlights of what is known about each technique used in the Mind/Body Program at the Tzu Chi Institute.

2.2.3.1 Relaxation Training

Relaxation training is the most widely studied mind/body technique with hundreds of studies documenting beneficial psychological and physiological effects[53]. Herbert Benson of the Mind/Body Medical Institute at Harvard Medical School is known for his work on what he calls "the relaxation response", a collection of psychological and physiological effects that are common to a number of practices including: meditation, prayer, progressive relaxation, and autogenic training. Benson and colleagues have developed a large body of research over a 25 year period demonstrating the 'relaxation response' to have a wide range of effects on physiological functions including: oxygen consumption, carbon dioxide and

lactate production, adrenocorticotropic hormone excretion, blood elements such as platelets and lymphocytes, cell membranes, norepinephrine receptors, and brain wave activity.

2.2.3.2 Meditation

Frequently meditation is divided into two types: concentration and mindfulness practices. Concentration meditation involves placing the mind's attention on a single object. This 'object' can be anything from a candle flame, one's breath or a mantra. When the mind's attention begins to wander, the meditator directs his/her attention back to the object. As concentration begins to deepen the meditator often experiences states of relaxation and calm. Mindfulness meditation[54] involves focusing on present moment experience. A state of 'mindfulness' describes an effort to pay attention to present-moment experience, without judgment, and to sustain this attention over time[55]. Mindfulness is thought of less as a technique than as a way of 'being'. Mindfulness meditation training involves a formal meditative practice, but the ultimate intention is to learn to live a more 'present moment focused' life outside of the formal 'sitting'. While relaxation is a frequent outcome of meditation practice, it has been shown using electroencephalographic (EEG) recordings that that both concentration and mindfulness meditation are unique forms of consciousness, not simply degrees of relaxation[56].

Transcendental meditation (TM), a concentration meditation, has led the way in mind/body research. There are over 500 published articles in 108 scientific journals, written by authors representing 211 different institutions and universities in 23 countries[57]. TM is associated with: increased longevity and quality of life; reduction of chronic pain; reduced

anxiety; reduction of high blood pressure; reduction of serum cholesterol levels; reduction in substance abuse; longitudinal increase in intelligence-related measures; blood pressure reduction in African-Americans; and lowered levels of stress-induced blood cortisol levels.

Mindfulness meditation, popularized in Western medical settings by Jon Kabat-Zinn of the Stress Reduction Clinic, University of Massachusetts Medical Center, has now undergone quite extensive evaluation, demonstrating its effectiveness in reducing physical and psychological discomfort[58,59,60,61,62,63].

2.2.3.3 Breathing Techniques

Breathing techniques can be used to stimulate pain relief, and reduce tension and anxiety. Slow, deep, regular, diaphragmatic-abdominal respiration has been found to be associated with stress reduction[64]. Fuller breathing is believed to give the body a greater supply of energy, which can be used for healing processes such as the body's self repair mechanisms, including the immune system. In addition, a breathing technique, called evocative breath therapy, is utilized to stimulate emotions and enhance emotional release. Evidence in support of this therapy is still preliminary, but one study evaluating the salivary immunoglobulin A (S-IgA) in a group of adult cancer patients undergoing a group therapy program showed a 46% increase in S-IgA levels at the completion of an hour long evocative breathing session[65]. Other approaches, such as Sudarshan Kriya also called the Healing Breath Technique, a yoga-based breathing technique, have been shown to have significant anti-depressive effects[66,67,68,69,70,71] in addition to reducing anxiety[72] and cortisol levels [73], and improving sleep[74-75].

2.2.3.4 Emotional Expression and Management

The influence of various emotions on illness, including the suppression of emotions, has been linked to various health outcomes and the prognosis of disease. For example, a great deal of attention has been given in the literature to what is called a 'Type A' personality and its links with coronary artery disease[76]. Type A behaviour is characterized by constant hurriedness, competitiveness and hostility. More recently, a Type C pattern of behaviour has been identified as the exact opposite of Type A and is characterized by non-expression of anger, fear, sadness, unassertiveness, and a preoccupation with meeting the needs of others[77]. This pattern of non-expressiveness has been linked to the risk of developing cancer and impaired recovery from this disease. A third behavioural pattern, called Type B, is demonstrated in people who are capable of the appropriate expression of anger and other emotions, have a relaxed and comfortable sense of self, and are able to meet their own needs while responding to others. People who cope in this more balanced way are at a decreased risk for serious illness[78]. Given this knowledge, techniques or activities emphasizing the management and expression of emotions are often a key component of mind/body interventions.

2.2.3.5 Biofeedback

The technique of biofeedback involves the use of a monitoring instrument to give physiological information to patients. This gives individuals the opportunity to monitor their own physiological changes in response to varying stimuli. Substantial research has documented the effectiveness of biofeedback to address a number of conditions including:

bronchial asthma, drug and alcohol abuse, anxiety, tension and migraine headaches, cardiac arrhythmias, essential hypertension, Raynaud's disease/syndrome, fecal and urinary incontinence, irritable bowel syndrome, muscle reeducation, hyperactivity and attention deficit disorder, epilepsy, menopausal hot flashes, chronic pain syndromes, and anticipatory nausea and vomiting associated with chemotherapy.

2.2.3.6 Movement

There is considerable evidence of the benefits of movement of many forms on health and well-being ranging from exercise training involving aerobic exercise to creative movement and dance. Creative movement or dance is thought to be a direct expression of the mind through the body. Dance or movement therapy has been shown to be clinically effective in many areas including: developing body image; improving self-concept; increasing self-esteem; decreasing depression; fear; bodily tension and anxiety; expressing anger; reducing isolation; improving communication skills; decreasing chronic pain; enhancing circulatory and respiratory functions; reducing suicidal ideas; and improving feelings of well-being[79].

2.3 Methodological Considerations

2.3.1 Gaps and Challenges

There are a number of challenges when reviewing the medical literature on group interventions, perhaps the biggest one being the lack of standardization amongst interventions. Comparing one program to another when they each involve a number of differing objectives and components is difficult. The mindfulness meditation-based stress reduction program from the University of Massachusetts provides one of very few

examples where a program has been replicated and is comparable across studies and illness populations. More examples are needed to improve comparability. Further, the differing outcome measurements; the range of study populations (i.e. primary care, disease specific); the differing intensity, duration, quality of instruction and format of the interventions; the differing length of follow-up; and varying types and quality of methodology to guide the evaluations make it challenging to assess the state of research in this area. A recent review (1998)[80] of group psychosocial interventions (excluding those involving individuals with cancer or HIV) to investigate the strength of evidence that these programs improved quality of life provides a good example. The review provided some support that these interventions are beneficial, but the evidence was found to be inconclusive. A particular limitation cited in the review is the high degree of variability of the interventions, the sample populations, and the outcome measures employed.

Having said this, what is known? It is known there is a range of potential benefits, particularly in the area of quality of life, across illness populations, and some indication that survival may be influenced. The benefits measured are mainly studied using clinical trial methodology and are aimed at measuring impacts that are short term and symptom specific[81]. Which types of group interventions are most useful has been given limited consideration, and deserves attention. For whom these programs are most suitable, the mechanisms by which the effects are mediated, and the range of potential impacts beyond short-term changes in symptoms need further attention.

Aside from the challenges in assessing the state of the literature in this area, and the gaps mentioned, it would seem fair that the quality and significance of the information obtained be assessed by asking a number of additional questions: How relevant are the outcomes being measured to clinicians and to participants? Have all of the relevant changes been measured? How well have they been measured? What do we know about the mechanisms by which changes occur? What is the relationship between a change in symptoms and perception of well-being? These questions are not easily answered with traditional experimental methods. Anecdotes and preliminary data indicate that the complexity of the mind/body interaction may not be adequately revealed using a positivistic approach that generally assesses short-term, symptom specific changes. A number of considerations help to illuminate this situation.

2.3.2 The Role of Unconscious Emotions

An example of the limitation of conventional methods to capture the complexity of mind/body processes is well illustrated in a recent review (2000) of the mind/body link in hypertension[82]. Evidence is presented which critiques the conventional idea that perceived emotional stress raises blood pressure and eventually leads to sustained hypertension. The author provides evidence that the more important indicator of sustained hypertension is unconsciously held emotions, those emotions of which the patient is not aware and are therefore ignored by patients, physicians and researchers. Quantitative measurement of psychological states relies on self-report measures that are limited to measuring perceived emotional distress an individual is consciously aware of. They cannot measure emotional distress that is kept from conscious awareness. From this perspective, therapeutic

interventions aimed at mind/body processes must address the issue of accessing repressed emotions, and further research on understanding the mind/body link must find ways of assessing the role of unconscious emotional processes. Qualitative approaches to research therefore may offer insights not detected with quantitative methods.

2.3.3 Ignoring Context

Many mind/body interventions come from ancient healing traditions with theoretical understandings and implications that are largely ignored in Western clinical and research settings. The benefits of mindfulness meditation practices for example are assessed outside of the Buddhist context from which they are derived.[83] The 'outcome' oriented approach ignores the processes involved in initiating a meditation practice. The ultimate aim of participating in meditation from a Buddhist perspective is not to learn a new 'technique' per se, but to use meditation as an opportunity for insight, personal growth, and to adopt a new way of 'being'. The aim is to be 'mindful' in everyday life. The assessment of short-term physical and psychological change is not unimportant, but it is only one piece of a much larger picture.

It has been documented that meditation can initiate a process of tapping into repressed trauma[84] which highlights again the complexity underlying the mind/body link, and the limitations of using short term outcomes as indicators of intervention effectiveness. If repressed emotions are linked to illness, as the hypertension example indicates, interventions that allow individuals to access these emotions would be desirable, provided there is appropriate informed consent for participants, and adequate support and guidance

are in place to facilitate the experiences. The evaluation of resulting benefits for participants would then need to be sensitive to understanding how increased emotional distress as a result of the meditative experience, for example, may be seen as a positive outcome of the intervention, and find ways to better understand this process.

2.3.4 Therapy Versus Education

A further limitation of the traditional experimental analytic approach to evaluating a group intervention is that it does not easily allow for understanding the interaction of a vast number of meditating variables that may influence the outcomes of these programs. For example, these interventions are experiential educational experiences as much as or more than one-time 'therapeutic' encounters. How participants respond to, practice, and generally bring the experiences and/or techniques into their everyday lives may have a significant influence on the benefits experienced. Quantitative measurement may be able to document these additional processes, but there is also a need for more in-depth, qualitative analysis to explore the range of influential factors.

2.3.5 Remaining True to A Mind/Body Philosophy

Ironically, the true implications of understanding mind and body to be inseparable states of the same whole, preclude the use of a mechanistic approach to evaluation, the basis of the medical scientific approach. Outcomes from this conventional medical perspective are measured to reflect either a state of mind (i.e. emotional state) or body (i.e. physical symptoms) exactly reflecting the Cartesian duality. Measures that reflect a more holistic orientation of mind/body states are rarely examined. In other words, the '*outcome*' oriented

approach in general may be vastly oversimplifying the *process* of mind/body interactions, and it is the process that may be more critical than the outcome.

2.4 Towards a New Approach

It has been argued that investigating healing interventions within medical or clinical frameworks, such as the randomized controlled trial, can frame both the questions and subsequent research methods too narrowly[85]. This approach serves to move attention away from an understanding of interventions as having both process and outcome components, each of which deserve attention. The so-called 'medicalized' view of healing[86] and its associated quantitative research methods do not allow for adequate consideration of potentially important contextual influences. Qualitative approaches to research, which value the patient experience and place an emphasis on contextual influences, can be of great assistance to understanding process issues related to therapeutic encounters. These methods allow the findings to move beyond description to offer explanation. A brief overview of the philosophical underpinnings of an interpretive, qualitative approach in contrast to a positivistic, quantitative approach helps illuminate this point.

2.4.1 An Interpretive Tradition

Qualitative research, informed by an interpretive philosophical tradition, provides an opportunity to focus on the wholeness of an experience, rather than focusing on components, parts or predetermined outcomes. It allows the researcher to search for meanings of experiences rather than simply explanations or measurements. It provides a means of eliciting the emic, or insider view, from the participants involved, as well as a

richness of understanding that is not possible through more quantitative means. An interpretivist research tradition was born out of the need to adopt a research method for the human and social sciences as opposed to the natural sciences. While positivism looks for universal laws of science in order to provide explanation and prediction, interpretivism, on the other hand, "looks for culturally derived and historically situated interpretations of the social life-world"[87].

The goal of this paradigm is to understand the world from the point of view of those who are experiencing it.[88] Interpretivists believe that to understand the world you have to interpret it, and continually re-interpret it. According to this paradigm there does not exist a 'real-world' that is independent of human thought and symbolic language. Knowledge cannot be found, but instead, it is constructed. In other words, what is 'real' is a construction in the mind of an individual that does not exist outside of the person who has created it. Constructions are essentially a person's attempt to interpret experiences and develop a coherent sense or understanding of them.

This ontology is best described as 'relativist'. From the perspective of this paradigm, there are multiple realities that are the product of human intellect which change as their constructors learn and adapt to new information. 'Truth' is assigned to the "best-informed and most sophisticated construction in which there is consensus at a given time."[89] This contrasts with a positivist perspective in which it is believed there is one objective, externally existing and empirically definable, and importantly, verifiable reality. This

reality is believed to be true for, and apply to, everyone. In this view there is no room for differing realities.

2.4.2 A Positivistic Tradition

Positivism, the foundation of Western scientific research, is based on the premise that there is an external 'truth' to be discovered. Discovering this 'truth' is a matter of finding the right measurement tools, making the right measurements, and replicating the findings. Critically, this 'truth' is viewed as independent of the researcher, the researched, and the social institutions in which they both are situated. The ontological descriptor often used is 'realism'.

This empirical-analytic perspective sees its purpose as describing the world as it is, and ultimately being able to predict and control it. Through proper control and manipulation of the phenomena of interest, whether these are data on objects or human behaviour, the complexities and truths can be revealed. Events and objects in the world are sorted into dependent and independent variables of study, where the relationship between them is hypothesized and then tested through observation. Observations accumulate to lead to theories, which are considered universal and context-independent. It is possible to assign causality when certain stringent criteria are met, and this is seen as a critical goal of research. Positivism provides a rigorous method of capturing the complex natures of this world into predictable, explainable, controllable, law-like relationships, as in physics.

An assumption of this paradigm is reductionism, where complexities can be reduced to

simpler measurable phenomena. It is legitimate to break down a complex phenomena into smaller parts to be studied and understood, and when these data are taken together it should explain the larger phenomena of interest (i.e. the human body). In other words, you can study phenomena independently of the system or the context in which it exists, which will lead to a better understanding of the system as a whole.

2.4.3 The Contribution of Qualitative Methods to an Intervention Study

While these two philosophical perspectives seem irreconcilable, when they are used in combination, they have the potential of sharing an important relationship in research. Specifically, the benefit of using qualitative research in combination with an intervention study utilizing a quantitative, experimental methodology lies in the ability of the qualitative piece to enhance the meaningfulness of the study by bringing in a 'real world' understanding. It provides a means to understand how the participants experience the intervention in real time and in real life[90]. The ability to examine the quality and experiential reality of a phenomenon under study can be critical in helping guide the interpretation of findings and the evolution of quantitative measurement. In particular, it assists with understanding two important questions; are the measures capturing the complex array of changes that are occurring, and if so, how meaningful is such measured change to the participants in the study?

Without qualitative forms of data collection it may not be known whether the chosen measurement instruments are sensitive enough to measure the change actually occurring. The qualitative perspective can be of assistance in assessing the degree of sensitivity to

change. If it can be established that the chosen measures are capturing this change, the meaningfulness of this change from a clinical perspective, and from the participants' perspective, can be evaluated. Specifically, combining quantitative and qualitative research allows us to begin to address the following questions: Is a statistically significant change meaningful in a clinical context? Would clinicians agree that a particular outcome has real-world significance for a patient? Further, if the measurable change has clinical significance, is it also meaningful and desirable for the participants in the research - do they see this as 'positive' change? What constitutes a 'good' outcome in an intervention study is a matter of individual perception[91], and clinical significance is a value judgment based on one's idea of what is a meaningful and desirable change[92]. Measurement instruments have a particular conceptualization of what optimal or positive functioning is. Without the associated qualitative assessment, it is not possible to know how closely this conceptualization fits with the ideas of the individuals undergoing the intervention. Enhancing clinical significance is also related to understanding the relevance of the findings to the participants in the study. Moreover, qualitative assessment capturing differing responses to the intervention can bring to light important and clinically relevant individual variations in response to the intervention of interest. This can provide valuable information related to between- and within-person differences on outcomes that may not be adequately detected statistically[93-94], and can provide information on the generalizability of the statistical findings both outside and within (relevance to individuals in study) the study group.

2.4.4 Contribution of the Dissertation

Reviewing the philosophical tradition of positivism highlights the limitations of this approach to capture important subjective, experiential realities of participants involved in group mind/body interventions. These experiential realities are needed to understand mind/body processes as well as outcomes. Preliminary evidence exists that conventional quantitative measurement may not be adequate for capturing these experiences, and the need to begin using qualitative approaches has been documented[95]. Conflicting results of the impacts of group programs on survival of cancer patients, as an example, illustrate the need to investigate the intricacies of the mind/body processes of individuals doing this work more closely. There is an additional need to understand the reason participants are increasingly drawn to mind/body interventions and what constitutes the meaningful impacts of the intervention. This dissertation aims to portray patient experiences to address the process and contextual issues. These qualitative experiences are then evaluated alongside quantitative outcome measures to help illuminate the impact of The Mind/Body Program at the Tzu Chi Institute. At the same time, differing methodological approaches for evaluating programs of this nature are explored.

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Chapter 3: The Mind/Body Program Intervention

3.1 Background

The Tzu Chi Institute's Mind/Body Program is modeled after the Stress Reduction and Relaxation Program (SR&RP) run at the Stress Reduction Clinic at the University of Massachusetts Medical Center. A detailed description of the program is available[1]. The SR&RP is a well-established meditation-based program, in operation for over 15 years and that has served more than 6000 physician-referred patients with a wide array of medical and psychiatric problems including chronic pain, cancer, hypertension, psoriasis, gastrointestinal problems and anxiety. It is estimated that more than 200 programs modeled on the SR&RP are currently offered in health care settings throughout the United States and Canada. This program has been described and analyzed extensively in the literature. A description of the documented benefits of the program on both physical and psychological symptoms across a range of illness conditions is outlined in Chapter 2.

The SR&RP is a systematic training program in mindfulness[2], a form of meditation originally developed by the Buddhist tradition. Mindfulness is thought of as the "heart of Buddhist meditation".[3] In most simple terms, mindfulness is moment-to-moment awareness. A state of mindfulness is induced by purposefully paying attention to things to which we normally would not give a moment's thought. The framework is educational and experiential rather than psychotherapeutic[4]. The program philosophy is based on the belief that mental and emotional factors have a significant influence on physical health, and on

one's ability to manage and recover from illness and injury. It is meant as a complement to medical treatment.

3.2 The Tzu Chi Institute's Mind/Body Program

The sessions of the Tzu Chi Institute's Mind/Body Program involve individual and group experiential sessions, guided practice of various mind/body techniques, group discussions, and didactic lectures. The program is 50 hours long spread over an 8 week period, with one full day per week. Between sessions participants are expected to practice skills, including a daily 45 minute meditation practice. The program experience involves learning about, and experiencing, the mind/body connection.

3.2.1 Program Objective

The objective of the program is for participants to develop skills to self-regulate health. The program aims to guide participants to work with their own stress, pain and illness more effectively; assist participants to mobilize their own inner resources of mind and body for improved coping and to move to greater levels of health and well-being; and assist participants to take charge of their life in new ways.

3.2.2 Core Program Experiences

Each session begins with a 'check-in' for each participant. The 'check-in' is an opportunity for each person to share anything they choose with the group. They may choose to share what they are feeling on that week, that day, or in that moment. This sometimes includes their feelings about the group, issues related to living with and/or managing their illness, or

integrating their experiences of the program into their lives. It is a chance to share with each other, and bring the energy of the group together, and serves to develop connectedness within the group. After the check-in, the day involves a collection of exercises and practice of mind/body techniques (outlined below). The facilitators follow a program guide, but still allow themselves to remain open to moving with the group energy. They work with issues, emotions and discussions as they present themselves. Facilitators may utilize various art supplies (i.e. drawing materials) and music to enhance the exercises.

Program participants sit in a large circle on the floor. Cushioned chairs without legs are provided to participants for comfort and back support. Regular chairs are also provided for those individuals who are physically restricted from sitting on the floor. Pillows and blankets are available, and are often used by the participants. Boxes of Kleenex are placed within the circle. Participants are asked to wear very comfortable non-restrictive clothing, and they usually choose to remove their shoes while sitting in the circle. During the meditations, mats are placed on the floor and the lights are dimmed to comfort participants while they are lying down.

The program incorporates opportunities for participants to engage in three core experiences: mindfulness (awareness), release (of stored energy and emotion), and connectedness.

3.2.2.1 Mindfulness

One of the main program objectives is to encourage participants to enhance their 'mindfulness'. The term 'mindfulness' is synonymous with awareness. A state of 'mindfulness' describes an effort to pay attention to present-moment experience, without judgment, and to sustain this attention over time. Normally, one's mind is kept occupied with either past memories or thoughts of the future, and is rarely in the present moment experience. Mindfulness means maintaining moment-to-moment awareness by paying attention and tuning into each moment as one lives through it.

Techniques to assist with learning to maintain a state of mindfulness include meditation and breathing exercises. When participants begin to maintain this state of present moment experience, they become more deeply connected to their bodies. Connecting to their bodies allows them to become in touch with bodily sensations and feelings.

3.2.2.2 Release

When participants access sensations and emotions they have held within themselves, they are asked to acknowledge and maintain awareness of these. These occurrences are believed to be a source of important insight into repressed energy and emotional 'blockages'. Participants are encouraged to work towards releasing these energy blocks if they feel comfortable doing so. Many of the mind/body practices and exercises encourage and facilitate this release. For example, breathing exercises may facilitate the release of emotions such as sadness through tears. Reminiscent of an old Yiddish saying: 'When the

heart is full, the eyes run over and it relieves the pressure.' Other forms of release may involve physical movement or verbal expression.

3.2.2.3 Connectedness

The experience of working in a group setting and relating to others provides the experience of connectedness. The program involves group discussions and activities where practical tools and principles are taught to enhance self-awareness, and to cope with daily life stressors and negative emotions. These focus on various points including managing emotions, commitment to participation in personal health, illness and the mind/body connection, and strategies to maintain wellness. When participants share emotional experiences within the group, it can allow other group members to resonate with this emotion. In other words, being present with an individual who is expressing and sharing an emotional experience can allow participants to tap into the emotion held within themselves.

3.3 Mind/Body Practices

The following techniques and experiences are taught and practiced in the Mind/Body Program to facilitate the experiences of mindfulness, release and connectedness.

3.3.1 Techniques of Mindfulness Meditation

3.3.1.1 The Body Scan

The body scan is a meditation technique designed to assist participants to reestablish connection with their own bodies. Program participants are asked to lie down on their backs, if they are physically able to do so. They are asked to bring their awareness to their

breathing, starting at the belly. They are then asked to move their awareness into the toes of the left foot. Once they bring their attention to this spot, they are asked to connect it with their breathing. When they breathe in, they are asked to start at the nose and, in their minds, follow the breath down into the toes, and then back up again. As they breathe out, they are asked to let go of any tension in that region of the body. If they feel any sensations, they are asked to focus on them, and breathe with these sensations. This process of bringing awareness into a region of the body, and then connecting to this region with the breath continues gradually through the entire body. The complete experience takes forty-five minutes. In each moment they are noticing and letting go, noticing and letting go, over and over throughout the exercise.

3.3.1.2 Sitting Meditation

The sitting meditation essentially involves mindful sitting. The instructions are very simple, they involve watching the breath move in and out. If a participant's attention begins to wander, they are asked to simply bring it back to the breath. Participants are asked to expand their awareness to the entire body, not scanning this time, but becoming aware of the body as a whole. They may find a significant sensation of pain, or stored emotional pain, in a particular region of their body. They can choose to focus on that if they wish. If they do not find a strong sensation in any one region, they are asked to focus on the experience of the body as a whole.

3.3.2 Movement

Participants are asked to engage in a collection of movement-oriented activities including simple yoga stretches, creative movement and exercises that do not require any previous training or any particular level of fitness, strength or flexibility. These experiences prepare the body for the breathing and meditation techniques and keep the energy moving through the body. Creative or authentic movement experiences are also included where participants are asked to bring their awareness into their body and let their body move in any way it feels drawn to while listening to a piece of music. They are encouraged to let go of intentionally moving in certain ways, but to literally let their bodies move them. In this way, the mind/emotion/self can be expressed through the body, awareness of body sensations can occur, and emotional blocks may be released.

3.3.3 Biofeedback

Participants are given an opportunity to experience biofeedback. Each individual is given a digital thermometer to measure galvanic skin temperature. The skin temperature reading is taken on a finger and used as an indicator of their level of stress and anxiety. Participants are encouraged to use the thermometers to monitor their levels of stress during the techniques taught in the program, and while doing various life activities after class.

3.3.4 Breathing Techniques

Maintaining conscious awareness of the breath is a critical component to understanding the mind/body connection. Participants are taught a variety of techniques where they are asked to more consciously focus on their pattern of breathing. Skilled use of breath can result in

optimum utilization of the respiratory system to raise the level of energy, promote deep relaxation, reduce one's reaction to stress, and facilitate the release of emotion. Patterns of breath are linked to emotional states. For example, shallow breathing is a natural reaction to stress. The use of conscious breathing techniques can assist with managing and becoming aware of stress, and releasing emotions.

3.3.5 Effective Communication

A communication model is introduced to participants to assist them with using more authentic and responsible ways of communicating. Participants are encouraged to practice using this model with other participants in the group. This exercise is intended to help participants to develop awareness about their patterns of communicating. Verbal communication can be another form of release, where participants can experiment with expressing themselves in ways they normally would not. Participants can 'find their voice' so to speak, where they can learn to voice the issues in their life that need expressing.

3.3.6 Genograms

Participants are asked to complete charts or family trees, also called genograms, to track family patterns around illness, relationships and other psychological and emotional issues. The purpose of becoming aware of this history is to give participants an opportunity to see themselves and the patterns in their own life within the context of their family histories. Each participant is given the opportunity to discuss their genogram with other members of the group including one of the facilitators.

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Chapter 4: Methodology

4.1 Background to Dissertation

4.1.1 The Mind/Body Program Feasibility Study

The Tzu Chi Institute for Complementary and Alternative Medicine conducted a feasibility study in the spring of 1998 anticipating a larger study to be developed and implemented when funding was obtained. The larger study was designed as a randomized clinical trial assessing the effectiveness, dose-response and cost-utility of a Mind/Body Program on a general sample of Lower Mainland residents with a variety of presenting complaints. The mind/body intervention in this trial was to be provided as an adjunct to individualized complementary care also delivered at the Institute. The feasibility study provided an opportunity to test clinical services, establish administrative support and data management systems, pilot the Mind/Body Program, explore methodological choices, and obtain some preliminary results regarding program outcomes.

4.1.2 Contribution of the Dissertation to the Feasibility Study

This dissertation is linked to the Mind/Body Program feasibility study. It was designed to test the appropriateness and contribution of differing methodological choices to the evaluation of the Mind/Body Program experience. Specifically, the dissertation contributes a qualitative assessment to this study in order to understand the experience of participating in the Mind/Body Program and reveal the range of affects of this experience on health and wellness for the program participants. It also provides a comparison of these findings to the quantitative data obtained using standardized health status and quality of well-being questionnaires. An emphasis is placed on analyzing the philosophical

assumptions that drive these methodological perspectives and the subsequent methods of data collection. Thus, the dissertation contributes to directing future work in this area.

4.1.3 Overview of the Feasibility Study

In the feasibility study, all participants, control and intervention, received a maximum of eleven hours of individual complementary therapy in the Tzu Chi Clinic. An individualized complementary care program was agreed upon by the participant, and a team of clinic practitioners including the integrative physician (an MD), the lead Mind/Body Program facilitator, and a number of fully accredited complementary practitioners. The program included one or more of the following: naturopathic care, chiropractic care, massage therapy, and acupuncture. The intervention group also received the eight-week fifty-hour Mind/Body Program, followed by three-hour 'refresher' sessions at 3 and 6 months. Standardized outcome measurements were made at 0, 3, and 6 months to assess health status, quality of life, social support. The control group was offered the Mind/Body Program after the 6 month follow-up was complete.

The initial study protocol anticipated a follow-up period of one year. The agreement with the participants in the control group was that they would be given the opportunity to participate in the Mind/Body Program after the follow-up period of the study was complete. However, due to the numerous requests and concerns expressed by the participants in the control group, given their belief that the Mind/Body Program was beneficial to the intervention group*, it was therefore considered unethical to deny them the opportunity

* Such a belief raises issues of expectancy that are discussed more fully in Chapter 7.

until the end of one year, thus the follow-up period was shortened to 6 months. This situation likely developed because both intervention and control group participants were seeing the individual practitioners in the clinic where they had opportunities to meet and discuss their experiences during their clinic visits (i.e. waiting room conversations).

4.1.3.1 Recruitment and Participants

The participants were composed of a consecutive sample of individuals who responded to an advertisement about the study in local newspapers. All of the individuals were screened during an interview according to explicit eligibility criteria, and made the choice to pursue the mind/body intervention in conjunction with individualized complementary care to be received at the Tzu Chi Clinic, or agreed to receiving only individualized complementary care, with the option of pursuing the mind/body intervention at the end of the follow-up period. Forty participants were recruited. It was decided that a maximum of 26 people (the intervention group) could participate in the Mind/Body Program, and the remaining 14 would receive the individualized therapy only (the control group). See Section 4.1.2.5. Methodological Challenges.

The inclusion criteria required the participants to be 19 years or older, able to schedule Mind/Body Program attendance, and able to identify their primary care physician. The exclusion criteria included those requiring primary care for acute mental or physical illness, those currently experiencing substance addiction problems (i.e. drugs or alcohol), those with insufficient English comprehension to complete study measures, and those physically unable to tolerate the weekly six-hour session of the intervention.

The participating individuals presented with a wide range of chronic health care conditions including HIV/AIDS, cancer, rheumatoid arthritis, hepatitis C, fibromyalgia, chronic fatigue syndrome, multiple chemical sensitivities, multiple sclerosis, ALS, advanced cardiovascular disease, asthma, depression, and chronic pain.

4.1.3.2 Intake Interviews

Candidates were first interviewed for one hour by the lead facilitator of the Mind/Body Program. In this meeting candidates discussed their suitability to be involved in the Mind/Body Program, including basic eligibility criteria, emotional stability, physical tolerance, social support, expectations of participation and the commitment required to be in the program. If they were considered eligible after this meeting, they then met with the study research nurse, who administered the informed consent, took a detailed health history, and gave the participant the first set of research questionnaires to be returned on their first visit back to the Institute. Following this, the participant's chart was reviewed by the team of multi-disciplinary practitioners and treatment recommendations were made. Each participant then met with the institute's complementary/integrative physician to assess whether they were capable of undertaking the demands of the program, and to participate in the planning of an individualized therapy program plan, based on the recommendations of the clinical team.

4.1.3.3 Withdrawals

One individual in each group withdrew from the program leaving 25 mind/body participants and 13 individualized care only participants.

4.1.3.4 Data Collection

Standardized outcomes were measured before the intervention at one of the participant orientation interviews, and again at 3 and 6 month follow-up data points. The official start date of the study was February 26, 1998, the first day of the Mind/Body Program. The questionnaires for the 3 month data point were given to the patients at the last Mind/Body Program session, and were returned on May 25, 1998 when they met for their 3 month 'refresher session'. The refresher session consisted of three hours of the Mind/Body Program to review the main components of the program. The 6 month measures were mailed to the participants and brought to the 6 month refresher session. Those who did not attend the refresher sessions mailed in their completed questionnaires.

4.1.3.5 Methodological Challenges

At the outset of the project, randomization of study participants was anticipated. However, due to the strong opposition of study participants to being randomized, it was decided study subjects would be allocated into the mind/body intervention group until the maximum group size was achieved on a first-come-first-served basis. The remaining participants were then assigned to the control group, with the option of participating in the Mind/Body Program intervention once the follow-up period was complete. There were also some instances where participants were assigned to the control group before the intervention

group was full because they had a scheduling conflict with the days or times the program would be run. There were no other determining factors for study group allocation. No major differences were found between study groups on demographic characteristics or on the baseline measures for any of the three questionnaires.

The study group sizes were not equal, as was originally planned. Given the demand to participate in the program, instead of cutting off the group size at 20 participants, as originally planned, staff at the Tzu Chi Institute enlarged the group size to 26. Given this was a feasibility trial, it was decided that some flexibility in study procedures was acceptable. This population of participants tended to be very ill, very anxious for help, and rather outspoken about their rights and privileges of participating in research. The study also tended to attract individuals who were inclined to complementary therapies, had exhausted what they believed were other viable options, and were not anxious to be part of a control group. It is possible that those who were involved in the intervention group were somewhat more anxious to receive the program experience for a variety of reasons.

There were further political issues that influenced some of the changes in study procedures. In particular, there had been a long waiting list of individuals wanting to be part of the research programs at the Tzu Chi Institute. This was the first research project initiated at the Institute, and given the long time period between the opening of the Institute and the first study (because of the need to establish a research agenda, gain ethical approval, and get the clinic's clinical programs up and running) many individuals on the waiting lists

were becoming impatient and distraught at the length of time they had been waiting for the opportunity to participate.

4.1.3.6 The Questionnaires

Three outcome measures were chosen by the Tzu Chi Institute researchers to be used in the study to measure health status, quality of life and social support.

The **SF-36**[1] measure was used to measure health status. This measure is a short form from the Rand Corporation's Medical Outcome Study, and is designed as a generic indicator of health status suitable for use as an outcome measure in clinical practice and research[2]. It is known to be applicable to a range of health and illness conditions, and useful for comparisons among individuals with differing illness conditions[3]. This measure involves eight dimensions of health status: physical functioning, role limitations due to physical problems, bodily pain, social functioning, general mental health, role limitations due to emotional problems, vitality, energy, or fatigue, and general health perceptions. It also includes a single item that provides an indication of perceived change in health (health transition). Reliability studies demonstrate median alpha coefficients over 0.80 for all scales except social functioning (0.76)[4-5]. Criterion validation shows good discrimination, and outcome studies show good sensitivity to change[6].

Quality of Well-Being Scale (QWB) is used to compute Quality Adjusted Life Years, or quality of life. The QWB scale is a health index that summarizes current symptoms and disability in a single number that serves to represent the social undesirability of the

problem, expressed in terms of quality-adjusted life years[8-9]. This scale can be used with individuals experiencing any type of disease. The Quality of Well-Being Scale is based on a three component model of assessment: 1) an assessment of the current functional status based on performance is made, 2) a value is given to this state to reflect the relative desirability (or undesirability) associated with this state, and 3) an estimation of the future need for health care services is made. Subscales include: acute and chronic symptoms, self care and mobility, physical activity, self care and usual activity, daily quality of well-being, and average QWB score. Normative research has attached preference weights to each level of functioning. A complex scoring procedure links preferences to functional status in estimating Quality Adjusted Life Years. Inter-rater reliability is 0.90 or greater[10]. The QWB has been shown to be capable of showing significant treatment effects across a range of conditions and treatments[11].

Social Support is measured using The Medical Outcomes Study (MOS) Social Support Survey[12]. The measurement of social support is included to explore its potential impact as a predictor or mediating variable in the outcome of the Mind/Body Program. This measure looks at overall social support, in addition to four major types of social support: tangible support; affectionate; positive social interaction; and emotional/informational support. Internal consistency for the overall scale is high (α=0.97) and values range for the different sub-scales from 0.91 to 0.96[13]. One year test-retest in the absence of an intervention suggested excellent stability (0.78). Construct validity of the scales has also been demonstrated.[14]

4.1.3.7 Timeline

The individual therapies with the clinic practitioners took place between February and May, 1998. The Mind/Body Program ran over an 8 week period from February 26th to April 14th, 1998. A second Mind/Body Program was run for the control group from October 15th to December 8th, 1998 after the 6 month data were collected from both groups. See Table 4.1.

4.1.4 The Individualized Care Program

All participants received up to 11 hours of individualized complementary care during the study period. A program of treatment was negotiated with the integrative physician (a medical doctor) based on the advice of a multi-disciplinary team of complementary practitioners, and included a combination of massage therapy, acupuncture, naturopathy, and chiropractic care. All practitioners were from accredited professions and had the appropriate training and credentials.

4.1.4.1 Integrative Team Meetings

Twelve practitioners team meetings took place between February 17th and May 29, 1998. All practitioners, along with the head facilitator of the Mind/Body Program and the research nurse met to review progress and form recommendations for each participant.

4.1.4.2 Exit Interview

At the end of the program each participant had a final interview with the clinic's integrative physician. A personal assessment and plan were discussed.

Table 4.1 Timeline for Data Collection: Questionnaires and Interviews

DATE	TIME-POINT	INTERVENTION	TYPE OF ASSESSMENT	STUDY GROUP
January 1998	**Baseline**		**Questionnaires** (SF-36, QWB, MOS)	Mind/Body Group and Control Group
February 1998 (8 Weeks)	**Time 0**	**MIND/BODY PROGRAM**		
May 1998	**3 Months**		**Questionnaires** (SF-36, QWB, MOS)	Mind/Body Group and Control Group
August 1998	**6 Months**		**Questionnaires** (SF-36, QWB, MOS)	Mind/Body Group and Control Group
September 1998 to February 1999	**7 to 12 Months**		**Qualitative Interviews** (M/B = 8; Control = 4)	Mind/Body Group and Control Group*
October 1998 (8 Weeks)	**Time 0**	**MIND/BODY PROGRAM II for Control Group**		
February 1999 to April 1999	**4 to 6 Months**		**Qualitative Interviews** (5**)	Control Group

*Interviews with control group participants were all completed in September/98 prior to their participation in the Mind/Body Program.

** Of these five, three had been interviewed prior to their participation in the Mind/Body Program.

4.1.5 The Mind/Body Program Intervention

See Chapter 3 for the complete program description. Two separate programs were run, one for the intervention group, and a second one for the participants in the control group of the study, once the last follow-up questionnaires were completed (at 6 months). There were 26 participants in the first program and 10 in the second. The first program was organized and run by four facilitators, and the second program involved 10 participants, and required two facilitators. All facilitators were trained counselors with significant experience facilitating group programs. The lead program facilitator has a nursing background and a history of training and experience facilitating group programs for individuals living with illness. All facilitators are prepared and experienced to deal with emotionally sensitive issues with participants. Both the programs were run in rental space located in the YWCA Hotel/Residence in downtown Vancouver.

All mind/body participants had a one-hour follow-up interview with the lead facilitator after the program finished. This meeting served to provide written feedback from the facilitator, discuss progress, and develop a plan for the future. Three hour 'refresher' sessions were held for the mind/body participants at the 3 and 6 month follow-up dates May 25th and September 15th, 1998 for the participants in the intervention group. The purpose of the refresher sessions was to review main components of the program and give the participants an opportunity to discuss their experiences since the completion of the program.

4.1.6 Hypotheses and Statistical Data Analysis

The primary hypothesis of the quantitative assessment was that the Mind/Body Program, in addition to individualized complementary care, would improve self-reported health status and quality of well-being in comparison to receiving individualized complementary care only. To look at short-term impacts of the program, paired t-tests were conducted to assess change between baseline (0 months) and the 3 month data point in both control and the intervention groups. In addition, t-tests were conducted to assess differences between the control and intervention groups at 3 months for each measure. A repeated measures analysis of variance was also employed to assess for significant differential changes in the intervention group scores versus the control group scores for the duration of the follow-up period (up to 6 months). The primary outcomes of interest were the health status survey (SF-36) and the Quality of Well-Being Scale. The secondary outcome was differential pre-post changes on the MOS Social Support Survey.

4.1.7 Power

With a sample size of 40 participants there would be 80% power to detect changes with a large effect size. Because the study groups were not of equal size as originally planned, the power was a little less than this. A large effect size correlates with a difference between two means of a magnitude of two-thirds (0.67) a standard deviation[15]. This is considered a clinically observable and relevant change. Power to detect changes of a medium effects size (0.5 of a standard deviation) will be lower. Approximately 60-65 participants would have been needed to have 80% power to detect changes of a medium effect size.

4.2 THE DISSERTATION

4.2.1 Introduction

This dissertation contributed to the evaluation of the Mind/Body Program intervention within the context of the feasibility study by including an assessment of the experience from an interpretive epistemological stance utilizing a qualitative research technique. This allowed for a comparison between a positivist (quantitative) and an interpretive (qualitative) methodological approach to obtain a broader understanding of both the nature and the potential therapeutic impact of the experience for the participants.

As distinct from the Tzu Chi Insitute study hypothesis, the hypothesis which directed the inclusion of the qualitative assessment was that individualized complementary care in addition to the Mind/Body would improve the experience of health and well-being for participants, but these changes may not be adequately captured, or may even be missing, in the quantitative questionnaires being utilized in the study.

4.2.1.1 A Methodology for Clinical Applications

The field of qualitative health research is characterized by a large number of theoretical, epistemological, methodological and methods options. While some respected and well known 'schools' of research within the interpretive tradition (i.e. phenomenology, grounded theory, ethnography), there are many branches of methods within each of these, and many variations in their application. In this environment of increasing complexity within the field, researchers have been discouraged from methodological variation from the main schools of qualitative research, and any such deviations have been criticized with such

descriptions as "method slurring"[16]. As a consequence, even if the fit is not exactly right, a researcher may choose from one of the traditional methods in order to claim methodological integrity for his/her work. In this instance, ironically, either the lack of an appropriate fit ends up compromising their work, or they stray from the 'true' use of the methodological orientation, in effect "posturing"[17] for a true phenomenological or ethnographic account for example.

A more pragmatic approach put forth by the field of nursing acknowledges the need to depart from traditional qualitative approaches in order to respect the nature of clinical research within the health field[18]. The description and interpretation of an experience of health or illness from the perspective of those who are living it is an important task in nursing and health sciences that may not neatly fit within one of the traditional domains[19]. The traditions of ethnography, phenomenology and grounded theory have evolved from the disciplines of anthropology, philosophy and sociology respectively. It has been recognized that a method of inquiry is needed which responds well to the interdisciplinarity of nursing and health sciences in general, and is, importantly, also responsive to the clinical nature of the research. Two methodological alternatives have been developed to respond to this need; *basic or fundamental qualitative description*[20] and *interpretive description*[21]. While they share many philosophical and methodological roots, they differ in their degree of interpretation. As the name implies, interpretive description emphasizes a greater degree of interpretation.

4.2.1.2 Criteria for Choosing a Qualitative Method

The aim of this study was to understand the experience of the Mind/Body Program for the participants, and how the experience affected their experiences of health and well-being. Given this objective, a research approach was needed which aimed at capturing how participants feel, respond and give meaning to their experiences. It required an approach not dissimilar to the methods of phenomenology[22], or grounded theory[23] for example, but is distinct in that it aims to describe and interpret an experience, rather than generating theoretical constructs to explain a social process, important to grounded theory, or focusing on describing the essential essences of an experience important to phenomenology. While generating a rich phenomenological description of the program experience was appealing, there was a need to move one step further to generate findings that would be of more clinical relevance by including an understanding of the impact of the experience over time on health and well-being. The presentation of the resulting findings also needed to be in a form that was more readily comparable to the quantitative measurements.

4.2.1.3 Methodological Orientation: Interpretive Description

The methodological orientation that guided this inquiry is interpretive description developed by Thorne and colleagues[24]. Interpretive description is an approach to qualitative inquiry based in an interpretive epistemological foundation that responds to the need for generating clinically relevant knowledge. Its intent is to describe a phenomenon of interest, that is, it summarizes the "facts" of the responses or experiences collected or observed. Description of the researched phenomena addresses the question of: 'What is

happening here?'[25] The data to inform this can be observations by the researcher or observations given to the researcher by the research participants.

Interpretation addresses the question of meaning. It involves a summary of the new meanings researchers derive from working with the data[26], and addresses the question of 'how do we understand this?'[27]. Interpretive description departs from some of the traditional schools of qualitative research in that it is not as highly interpretive in terms of re-presenting data in a particular conceptual or philosophical form such as a theoretical framework, used in grounded theory, or in lifeworld existentials, used in phenomenology[†28]. Instead, when using interpretive description, the researcher stays closer to the words of participants, and presents the data in everyday language.

Researchers aim for *descriptive validity*, that is, an accurate description of the phenomenon that most people (including both researchers and participants) observing the same phenomenon would agree is accurate, and *interpretive validity*, where the researcher accurately captures the meanings participants themselves attribute to their experience of the phenomenon[29]. Even though it draws upon some of the more traditional schools of qualitative research, interpretive description is not simply comprised of a random assortment of epistemological and methodological orientations, but instead, has evolved into a distinct method of qualitative research. It offers a formalized method of qualitative

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[†] Four existentials are often used to reflect upon and frame the analysis of phenomenological data including lived space (spatiality), lived body (corporeality), lived time (temporality), and lived human relations (relationality or communality) as outlined by Max van Manen[†]. The lifeworld refers to the lived world of experience in everyday situations. Grounded theory aims to frame findings into a theoretical framework involving defined categories; their properties; and the types, circumstances, and conditions of these properties[†].

inquiry useful for understanding the complexities of individual health and illness experiences, at the same time allowing for understanding of shared experiences[30];

> [interpretive description] is grounded in an interpretive orientation that acknowledges the constructed and contextual nature of much of the health-illness experience, yet also allows for shared realities. As such, it differs from eclectic approaches that "slur" methods without regard for the coherence of their epistemological foundations.

The method of interpretive description suggests that a new inquiry be located within a critical analysis of the existing knowledge in the area. This criterion separates the method from phenomenology, which encourages a researcher to 'go in blind', or to bracket preconceived ideas about the particular phenomenon in order to look at the world anew[31]. Existing knowledge, in the form of formal research in addition to clinical interpretations, is used to shape and guide the design of the inquiry. Theoretical assumptions and biases are acknowledged at the forefront of the inquiry. Once findings are obtained, linkages are then again made with previous knowledge in the field and can assist in constructing the presentation of findings. Previous findings can be challenged as this process proceeds, new meanings can emerge in the literature, and increasingly complex interpretations are possible.

A theoretical sampling strategy is used in interpretive description. A theoretical sampling method advocates sampling from all known possible variations around the phenomenon of study in order to capture a complete picture[32]. In contrast to probability sampling in quantitative research, theoretical sampling means purposefully selecting particular research participants based on criteria that fit with the known theoretical variations within the

phenomena under study, and that respond to the evolving variations as the inquiry proceeds. This is the most efficient way to achieve saturation of the sample, or in other words, the most efficient way to gain 'data adequacy' where data are collected until no new information is being obtained. There are no easy guidelines to estimate sample size, but instead, the researcher must use judgment and experience in evaluating the adequacy of the data obtained.[33] The researcher must feel comfortable that a theoretical category has been adequately explored which means knowing what is there, and whether the data obtained is sufficient for the intended product.

Interpretive descriptive studies can utilize a combination of techniques of data collection including participant observation and individual interviewing, in addition to the examination of documents (i.e. clinical papers), media information, or clinical case reports.

The *analysis* of qualitative data looks at the relationships amongst the observations; it looks at 'how things work'[34]. It is a systematic description, and identifies the fundamental characteristics of the phenomena of interest. The analysis of the data using interpretive description emphasizes focusing on questions that look at the overall picture such as "what is happening here?" and "what am I learning about this?" which allows for more coherent analytic frameworks than focusing at the outset on sorting large quantities of small segments of data using complex coding systems. The emphasis is on repeated immersion in the data before the processes of coding and classifying begin. A number of analytic procedures can be employed that emphasize processes of synthesizing, theorizing and recontextualizing as opposed to simply coding and sorting[35]. A process of analyzing

individual cases, extracting common themes from these, and producing knowledge that can then be applied back to the individual is the ongoing task of analysis in interpretive description.

4.2.2 Study Methods

The study methods involved in-depth interviews[36] and participant observations of the Mind/Body Program. This involved participants in the intervention group, as well as participants in the control group after they had attended the Mind/Body Program when the 6 month study follow-up period was complete. Individuals in the control were also asked to participate in an interview prior to their participation in the Mind/Body Program in order to understand the experience of participation in the individualized therapy component without the Mind/Body Program experience. The interviews were an interactive process characterized by openness. A set of pre-determined questions guided, but did not limit, the conversation.

4.2.2.1 Participants

All participants in the intervention and control group were invited to participate in a one-on-one interview. A letter of introduction was given to each participant at the 6 month mind/body refresher session. Participants who did not attend the session, and the control group received the letter by mail. All individuals from the control group who participated in the second Mind/Body Program were also invited to be interviewed, and received the same letter of introduction upon completion of the program. Willing participants were asked to phone to set-up an interview time.

4.2.2.2 Interviews

The qualitative piece allowed for an exploration of the experience and meaning of well-being for the participants, as well as some information on the possible range of experiences and meaningful outcomes that resulted from the program. This assessment was designed to address the questions: How do participants believe the program has affected their well-being? Do the participants feel the experience was in any way 'healing' for them? What do they think healing is?

The interviews were semi-structured and open-ended. A loosely structured interview guide was utilized in order to ensure the key issues were addressed, but the interviews were not limited to the questions on the interview guide. All of the interviews took place between September, 1998 and April, 1999 and lasted an average of approximately one hour and fifteen minutes. All interviews took place at the Tzu Chi Institute, except for one interview that took place on a park bench near a participant's home (a special request of this participant). All interviews were audio-taped, with the permission of the participant.

Seventeen interviews were conducted in total. Eight interviews were with participants in the intervention group (3 men and 5 women), and 4 participants were with individuals in the control group (2 men and 2 women) *before* they had the opportunity to participate in the Mind/Body Program. Five additional interviews were undertaken (2 men and 3 women) with participants from the control group after their experience in the Mind/Body Program. Three of these individuals were the same participants interviewed before they had the Mind/Body Program. In other words, three participants from the control group were

interviewed twice (once before and once after participation in the Mind/Body Program), which means that while 17 interviews were conducted, they represented 14 different participants. See Table 4.2.

Table 4.2 Interview Participants

	Number of Participants	Number Who Were Interviewed
Mind/Body Group	26	8 (31%)
Control Group	14	4 (29%)*
Mind/Body Program for Controls	10	5 (50%)*

* Three participants are represented in both groups i.e. they were interviewed before and after participating in the Mind/Body Program.

4.2.2.3 Participant Observations

The researcher was a participant in both the Mind/Body Program for the treatment group, and the Mind/Body Program for the control group. Through active participation in the group sessions, observations were made and documented in a research journal. The experience of participating allowed for a greater depth and personal understanding of the program experience, a closer relationship to the study participants, and a feeling for the context in which the responses to the interview questions could better be understood.

4.2.2.4 Research Journal

A detailed research journal[37] was kept from the beginning of the interviewing process throughout the analysis of the research. This provided a place to document insights about the data, make notes on methodological decisions, outline potential limitations in the methods, and reflect on the role and experience of being a researcher. It also provided an

opportunity to reflect on personal assumptions, evolving ideas, thematic issues, literature and personal experiences that illuminate some of the themes of the data, as well as evolving ideas about the process of the research. See Appendix A for reflections on being a participant observer.

4.2.3 Qualitative Data Analysis

4.2.3.1 Transcription and Initial Reading

The audio-taped interviews were transcribed word-for-word and printed and stored on a hard disk drive and a floppy disk. Each interview was read through in its entirety in order to check for errors and get a sense of 'the whole'. The transcription immediately followed the interview. Issues that were unclear, not sufficiently explored, or not fully understood were noted. This helped to guide subsequent interviews with other participants.

Interview transcripts, as complete documents, were then entered into Atlas.ti[38], a qualitative software analysis package. Atlas is designed for working with large bodies of textual data, and offers a systematic approach to data management and model building. Atlas.ti is very useful for facilitating such activities as selecting quotations, coding, commenting and annotating sections of text which gives the researcher a better sense of control over a large qualitative data set. This program is not used to 'automate' the analysis process, but instead, provides a medium for organizing large amount of research materials without taking over any of the necessary intellectual processes of the researcher.

4.2.3.2 Indexing Data (Segmenting)

The data were sorted into broad categories in order to provide a useful 'index' after reading a hard copy of each transcript. This process served to make the data more 'manageable'[39,40]. These categories served the purpose of compartmentalizing data into content areas that included: *'program structure'* (program evaluation issues such as program format, content, physical environment, and schedule); *'program experience'* (participants' experience during the program); *impacts, processes and facilitators* (descriptions of the influences the program experience has had in their lives, how this influence plays out, and facilitators of the impact); and *'measurement issues'* (direct comments participants made related to their views on measuring their experiences). The remaining analysis focused on only three categories, *'program experience'*, *'impacts, processes, and facilitators'* and *'measurement issues'*, as these are the areas of most interest for this project.

4.2.3.3 Establishing Preliminary Codes (Organizing System)

Once the data were sorted, the analysis focused on establishing initial meaning units or codes. This list of codes served as the 'organizing system' for the data[41]. Three transcripts were selected to read through again slowly. These transcripts were chosen to reflect a range of experience, and depth or richness of information. It was noted each time a transition in meaning was perceived. Phrases that illustrate each of these meaning units were highlighted. A meaning unit is defined as, "a segment of text that is comprehensible by itself and contains one idea, episode, or piece of information."[42] Phrases or quotes that represented similar ideas or themes were then grouped together, and preliminary identifiers,

or codes, were chosen. This step served to establish commonalities between the quotes to develop the initial code list.

4.2.3.4 First Level Coding (Sorting Data)

All of the transcripts were coded, focusing on the data sorted to the categories 'program experience', 'impacts, processes and facilitators' and 'measurement issues'. ATLAS.ti's memo and commenting functions were used in order to make notes on particular quotations or codes, to describe relationships between codes, and to document ideas on the process of the analysis overall. ATLAS.ti was used to print hard copies of the textual data assigned to each code, identifiable by interviewee.

4.2.3.5 Restructuring Codes and Re-coding

Once all the transcripts were coded and the hard copies of the quotations attached to each code were reviewed, the appropriateness of the codes chosen was assessed. In some cases it was found that the name of the code needed to change, or in some cases, two codes were combined to form one code that encompassed both ideas, or one code was broken down into two or more codes. This process necessitated recoding of the transcripts, and new printouts of the text associated with each code.

4.2.3.6 Second Level Coding

The hard copies of textual data were then read through line by line and second level codes were attached to each idea by handwriting in the margin. The second level codes served to

generate patterns amongst the concepts, and illuminate the properties that describe each code.

4.2.3.7 Writing

The final stage of analysis occurred during the writing process to illuminate the ideas inherent in each code. Utilizing the memos and comments captured in ATLAS.ti, and working with the various codes, analytic categories and themes began to emerge. Code names were listed and grouped together to look for similarities. Ways the codes relate to each other, the depth of data supporting each code, and the notes from the participant observations were used together to finally create the major theme which was entitled 'A Process of Transforming Well-Being'. The conceptual findings that make up this theme provide an overview of the analytic categories and codes and are presented and "grounded" in the words of the participants.

4.3 Ethical Review

Ethical approval for the feasibility trial was obtained through the Office of Research Services at the University of British Columbia. A separate ethical review and approval was obtained for the dissertation component of the evaluation, also through the Office of Research Services, U.B.C.

Because participants of the Mind/Body Program were engaging in personal and/or psychological work, there were risks to participants associated with the potentially emotionally charged nature of the experience. This issue was clearly outlined in the

application for ethical review that was approved by the university. Safeguards that were in place included the appropriate training and experience of program facilitators to handle difficult emotional reactions of participants. Also, an interview between each participant and the Mind/Body Program lead facilitator prior to the program to review their suitability gave participants adequate information on the potentially difficult emotions that could surface as a result of the experience.

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Chapter 5: Quantitative Findings

5.1 Overview of Statistical Analysis

The statistical analysis assessed changes on two primary outcome measures, The SF-36 Health Status Survey and the Quality of Well-Being Scale, and one secondary outcome, the MOS Social Support Survey. Results reported describe changes within each study group (intervention and control) over time, in addition to changes between groups over time. More specifically, univariate testing was conducted using paired t-tests to compare the results within each study group at the 3 and 6 month time-point to baseline measures. In order to look at the short-term program impacts, comparisons were made between the intervention and control group at the 3 month data follow-up point. In addition, univariate analysis of changes between the 3 and 6 months for each study group were conducted in order to look for sustained changes over time. A repeated measures analysis of variance was employed to assess the pattern of change over time between the two study groups.

The primary outcomes of interest were the health status survey (SF-36) and the Quality of Well-Being Scale. The secondary outcome was differential pre-post changes on the MOS Social Support Survey. A significant difference is based on an alpha of 0.10 ($p < 0.10$) due to the small sample size.

5.1.1 Power

As mentioned in Chapter 4, with a sample size of 40 participants there was 80% power to detect changes with a large effect size. A large effect size correlates with a difference between two means of a magnitude of two-thirds (0.67) a standard deviation[1]. This is

considered a clinically observable and relevant change. A larger sample size was necessary to detect smaller effect sizes.

5.2 Description of the Sample

5.2.1 Demographics

The control group (n=14) had a mean age of 56.0 years with a median of 56.0 years. The intervention group (n=26) had a mean age of 50.0 years with a median of 48.5 years. The control group was composed of 4 males (31%) and 9 females (69%), and the intervention group had 12 males (46%) and 14 females (54%). The differences in age or gender were not statistically significant.

5.2.2 Withdrawals

Forty participants were recruited for the study. Two participants, one from each group, withdrew immediately following recruitment before their baseline questionnaires were completed. One participant withdrew from the intervention group after the Mind/Body Program was underway. One participant from the control group withdrew before the 3 month questionnaire time-point. The resulting sample by the 3 month time-point was 36 participants.

5.3 Baseline Comparisons Between Groups

The intervention and control groups were compared on baseline measures of primary and secondary endpoints. The intervention and control groups display no significant differences on any sub-scales of the three measures. See Tables 5.1 to 5.3.

Table 5.1 Baseline Measures on the SF-36 Health Status Survey by Group

Sub-Scale	Intervention Mean	SD	Control Mean	SD
Physical Functioning	55.7	28.5	62.9	31.5
Role-Physical	22.1	39.6	17.3	29.6
Bodily Pain	51.6	22.7	50.2	31.2
General Health	45.1	19.5	48.7	24.5
Vitality	35.8	20.5	35.4	27.7
Social Functioning	52.5	26.3	47.1	26.1
Role-Emotional	49.3	42.1	30.8	44.0
Mental Health	59.5	19.0	58.5	22.9

Items scored on a 0 to 100 Scale

Table 5.2 Baseline Measures on the Quality of Well-Being Scale by Group

Sub-Scale	Intervention Mean	SD	Control Mean	SD
Day 1* – Acute and Chronic Pain	42.4	8.5	44.5	7.5
Day 2*– Acute and Chronic Pain	40.4	6.9	41.3	9.1
Day 3*– Acute and Chronic Pain	41.7	8.0	40.3	10.1
Day 1 – Self Care and Mobility**	0.5	1.2	0.7	2.5
Day 2 – Self Care and Mobility	0.4	1.0	0.7	2.5
Day 3 – Self Care and Mobility	0.6	1.3	0.0	0.0
Day 1 – Physical Activity	5.9	4.5	5.1	4.9
Day 2 – Physical Activity	6.4	5.5	5.8	5.8
Day 3 – Physical Activity	6.0	5.1	7.8	6.7
Day 1 – Self Care and Usual Activity	3.2	2.7	3.3	2.7
Day 2 – Self Care and Usual Activity	2.6	2.8	2.5	2.8
Day 3 – Self Care and Usual Activity	2.6	2.8	3.3	2.7
Day 1 – Daily Quality of Well-Being	47.9	9.1	46.3	9.2
Day 2 – Daily Quality of Well-Being	50.3	9.8	49.7	10.6
Day 3 – Daily Quality of Well-Being	49.1	11.0	48.6	11.3
Average QWB Score	49.1	9.0	48.2	8.4

Items scored on a 0 to 100 scale where higher scores are more positive.
*Respondents are asked to respond for Day 1 = yesterday, Day 2 = 2 days ago, Day 3 = 3 days ago
**significant difference between groups

Table 5.3 Baseline Measures on the MOS Social Support Survey by Group

Sub-Scale	Intervention Mean	SD	Control Mean	SD
Tangible Support	49.3	33.0	49.5	29.9
Affectionate	62.3	31.5	59.0	30.9
Positive Social Interaction	61.3	24.0	49.5	36.2
Emotional or Informational Support	57.0	26.3	62.0	25.5
Overall Social Support	57.5	25.9	55.0	27.5

Items scored on a 0 to 100 scale where higher scores are more positive.

5.4 Short-term Findings: 3 Month Comparisons

5.4.1 SF-36 Health Status Survey

The health status questionnaire showed no significant changes for the control group between the start of the program and the 3 month follow-up point. The intervention group displayed significant positive changes in health status in the areas of general health ($p=0.0001$), vitality ($p=0.008$), mental health ($p=0.003$), and social functioning ($p=0.026$). The single item that provides an indication of perceived change in health (health transition), also displayed a significant positive change ($p=0.053$). At the 3 month follow-up, a significant difference was found between the control and intervention group in the area of mental health ($p=0.032$), showing a more positive rating in the intervention group.

5.4.2 The Quality of Well-Being Scale

No significant differences were found on this scale for either group, or between study groups. Each question on this scale asked the participants how they were feeling at three different times: yesterday, one day ago, and two days ago. Some significant changes were found on some scales for one of the three days (yesterday, 2 days ago, or 3 days ago) in which the participants were asked to respond, but in this case, the findings are not believed to be stable enough to report.

5.4.3 The MOS Social Support Survey

The social support questionnaire showed no significant changes for the control group between the start of the program and the 3 month data point. The intervention group showed a significant change in tangible support ($p=0.003$), informational ($p=0.025$), and

overall social support (p=0.021) between the beginning of the program and the 3 month data point, indicating a positive improvement. Specifically, significant differences were found for the following questions:

How often is each of the following kinds of support available to you when you need it?

* *Someone to take you to the doctor if you needed it (p=0.006)*
* *Someone to give you information to help you understand a situation (p=0.005)*
* *Someone to confide in or talk to about yourself or your problems (p=0.013)*
* *Someone to help you with daily chores if you were sick (p=0.005)*
* *Someone to share your most private worries and fears with (p=0.007)*
* *Someone to turn to for suggestions about how to deal with a personal problem (p=0.004)*

One significant difference was found between the control and intervention groups in social support at the 3 month data point, where the intervention group showed a significantly higher amount of tangible support (p=0.055).

5.5 Comparisons Over Time

5.5.1 Repeated Measures Analysis of Variance (MANOVAs)

The primary and secondary outcomes measures were analyzed using a multivariate repeated measures analysis of variance. Measures were examined over 3 time periods: baseline, 3 months and 6 months from the start of the program. MANOVA F scores at $p < 0.10$ for each sub-scale were considered significant. This analysis revealed a significant positive improvement in the intervention group on the social functioning sub-scale of the SF-36 Health Status Survey (p=0.067), which univariate analysis indicated was sustained up to the 6 month time point. No significant group by time interactions were detected on any of the sub-scales of the Quality of Well-Being or MOS Social Support Survey.

5.5.2 3 and 6 Month Comparisons

Comparisons were made on all outcome measures for each study group between the 3 and 6 month data-points. No significant changes for either group were noted on the SF-36 or the MOS Social Support Survey. On the Quality of Well-Being Scale, the control group showed a significant decline between 3 and 6 months on the average QWB score ($p=0.031$).

5.5.3 Comparison of Changes in Means

On the SF-36 Health Status Survey, for the intervention group, all sub-scales showed a positive change at the 3 month time point, with role limitations due to physical health, and social functioning showing the greatest change (See Table 5.4). Between 3 and 6 months, further increases were seen, except for a small decline in general health, and no change in social functioning. The increases tended to be much smaller than the baseline to 3 month changes. The control group also showed increases on all sub-scales between baseline and 3 months, except for a decline in the general health scale, and a very small decline in the role limitations due to physical health sub-scale. Of note is the large increase in the mean for the role-emotional sub-scale (role limitations due to emotional problems), indicating positive change. While the control group started the study with a lower score on this scale compared with the intervention group, the control group showed greater change through the study period and ended with a higher score than the intervention group. However, the large standard deviations associated with these changes make it difficult to interpret this pattern of change. The changes between 3 and 6 months for the control group showed

mainly small fluctuations, with an increase in role-emotional sub-scale again being the most noteworthy change. These findings suggest the possibility that the intervention group may have experienced significantly greater improvement than the control group on some of the SF-36 subscales (i.e. physical functioning, role limitations due to physical health, and general health), and the control group may have experienced significantly greater improvement on the role emotional sub-scale had the sample size been greater.

Changes in means of the Quality of Well-Being Scale did not indicate any particular pattern in either group. There were small fluctuations in both directions in both groups across time, indicating there may not be any particular trends in the findings. See Table 5.5.

On the MOS Social Support Survey, the changes in means between baseline and 3 months demonstrate more positive changes in the intervention group. All sub-scales for the intervention group showed positive change, whereas the control group showed decline on three of the five scales (tangible support, affectionate support, and overall social support). By 6 months the intervention group showed some smaller fluctuations (positive and negative), but not any substantial change. The control group, on the other hand, showed greater improvement between 3 and 6 months on all sub-scales. While the intervention group showed a positive change more quickly, the resulting overall changes in social support in each group seem not dissimilar by 6 months. See Table 5.6.

Table 5.4 Comparison of Changes in Means Over Time on the SF-36

Sub-Scale	Baseline to 3 Months	3 Months to 6 Months	Baseline to 3 Months	3 Months to 6 Months
	MIND/BODY		CONTROL	
Physical Functioning	10.7	2.2	1.1	<1.5>
Role-Physical	16.0	6.0	<1.7>	6.3
Bodily Pain	7.0	3.3	11.6	<0.4>
General Health	12.4	<4.2>	<11.6>	2.5
Vitality	13.2	0.2	10.9	<5.6>
Social Functioning ▽	15.4	0.0	1.3	<1.6>
Role-Emotional	3.1	7.9	23.4	12.5
Mental Health	11.4	0.2	4.0	<1.5>

Items scored on a 0 to 100 scale where higher scores are more positive.
▽ Significant group by time-point effect
< > Indicates a decrease in score

Table 5.5 Comparison of Changes in Means Over Time on the Quality of Well-Being Scale

Sub-Scale	Baseline to 3 Months	3 Months to 6 Months	Baseline to 3 Months	3 Months to 6 Months
	MIND/BODY		CONTROL	
1* – Acute and Chronic Symptoms	0.6	<2.7>	<7.0>	7.2
2* – Acute and Chronic Symptoms	<1.0>	0.0	<2.6>	3.6
3* – Acute and Chronic Symptoms	<0.2>	<0.01>	<2.1>	6.3
1 – Self Care and Mobility	<0.3>	0.2	<0.7>	0.4
2 – Self Care and Mobility	<0.1>	0.0	<0.7>	0.4
3 – Self Care and Mobility	<0.3>	0.4	0.4	0.4
1 – Physical Activity	0.1	1.1	<1.5>	5.2
2 – Physical Activity	<2.2>	1.2	<2.2>	2.0
3 – Physical Activity	<0.2>	<0.7>	<2.2>	2.0
1 – Self Care and Usual Activity	<0.2>	<0.5>	<1.3>	1.4
2 – Self Care and Usual Activity	<1.3>	0.3	0.2	<0.7>
3 – Self Care and Usual Activity	<0.3>	0.0	<1.3>	1.4
1 – Daily Quality of Well-Being	0.1	2.0	10.6	<14.1>
2 – Daily Quality of Well-Being	4.5	<1.5>	5.3	<5.3>
3 – Daily Quality of Well-Being	1.1	0.3	5.1	<10.1>
Average QWB Score	1.9	0.2	7.0	<9.8>

Items scored on a 0 to 100 scale where higher scores are more positive.
< > Indicates a decrease in score; *Respondents are asked to respond for Day 1 = yesterday, Day 2 = 2 days ago, Day 3 = 3 days ago

Table 5.6 Comparison of Changes in Means Over Time on the MOS Social Support Survey

Sub-Scale	Baseline to 3 Months	3 Months to 6 Months	Baseline to 3 Months	3 Months to 6 Months
	MIND/BODY		CONTROL	
Tangible Support	9.8	<2.8>	<12.8>	14.1
Affectionate Support	6.5	0.0	<8.0>	3.1
Positive Social Interaction	2.8	<4.1>	4.5	7.0
Emotional or Information Support	7.2	0.3	0.5	5.1
Overall Social Support	6.5	<1.6>	<4.0>	7.3

Items scored on a 0 to 100 scale where higher scores are more positive.
< > Indicates a decrease in score

5.6 Summary of Results

The only significant change seen between study groups across the study period was on the social functioning scale of the SF-36 Health Status Survey. Significant differences were seen at the short-term follow-up point, 3 months, which indicates an improvement in mental health and tangible support for those who participated in the Mind/Body Program. The small sample size limited the power to detect significant changes, and the findings need to be interpreted with caution. Additional significant changes between groups on the questionnaires might have been detected, particularly on the SF-36 Health Status Survey, if the sample size had been greater. However, it is unclear whether the Quality of Well-Being Scale can demonstrate stable changes that could be enhanced with a larger sample. The one exception was a significant decline in the overall Quality of Well-Being sub-scale score for the control group between 3 and 6 months. The repeated measures testing accounts for the problems of multiple testing that the t-testing does not, therefore it is also possible there could be spurious results due to the number of tests which were performed.

[1]Cohen J. Statistical Power for the Behavioural Sciences. Mahwah: Lawrence Erlbaum Associates Inc., 1988.

Chapter 6: Qualitative Findings

6.1 Overview of Findings

An analysis of the interviews with participants in the Mind/Body Program revealed these individuals engaged in a process of personal growth that led to improved well-being. The findings indicated this process of moving towards improved well-being was not just the result of learning and using mind/body techniques, but was also about a willingness to be open to the opportunity they provided for self-discovery. Participants demonstrated this had the potential to alter not only their experience of illness, but of day-to-day life. Findings indicated that a process of integrating the experiences and 'tools' learned in the program into everyday life could lead participants through a process that came to be the theme of these findings: A Process of Transforming Well-Being. Participants journeyed through the following stages in this transformation: 1) Doing the Work, 2) A New Way of Being, and finally, 3) A New Way of Living. This process was continuous, as participants were likely to move back and forth through the various stages. There was no endpoint, per se, but only continued learning and growth that continued to deepen and transform their experience of well-being. The findings indicated a number of influences affected an individual's readiness to engage in this process, and the nature of their involvement in the various stages of transformation.

6.1.1 The Choice of Language and Development of the Theme

The language used to present the findings was carefully considered and deserves some explanation. In the interviews, participants were asked whether or not they believed their experience in the program had been a 'healing' experience for them, and were asked to

describe what healing meant to them. This generated a great deal of data which captured the concept of 'healing', a term often used without a clear explication of the true meaning. Participant responses described 'healing' as not solely or necessarily linked with physical change, but linked to shifts in their experience which deepened one or all of such things as increased awareness, personal insight and expression (understanding and expressing self in a more complete way), connecting to emotion and/or release of this emotion, and/or feelings of connectedness with others. There was no predetermined end point or expectation for such development. This description captured a great deal of information and raised many additional questions. Given this situation, the presentation of remaining findings does not include the word 'healing', but instead, speaks of changes in terms of well-being. The term 'healing' is often described as an endpoint, which implies there is a particular destination desired or anticipated, similar to the word 'curing'. By not using the word 'healing' it is hoped that confusion with commonly held understandings of this word, which may not reflect the descriptions by the participants, will be avoided.

The responses participants gave to the question, "What does healing mean to you?" provided the framework in which the results are presented. What participants described were various stages of change with varying degrees of depth of inner work. It was these degrees of change that came to be stages in the theme of the findings: A Process of Transforming Well-Being. The remaining discussion provides an overview of the analysis of the interviews, which tells a story of how individuals transform their experiences of 'being well', or 'well-being'. While the interviews represent males and females, the

pronoun 'she' is used exclusively in the following discussion for simplicity and anonymity of the participants.

6.1.2 Effect of the Researcher

My participation in the group is worth noting. Because it was critical for group members to find a sense of comfort, I not only observed the group, but was a full participant in the program. I allowed myself to come forward in an authentic and vulnerable way. I believed I would have interfered with the group dynamics it if I did not do this. I believed group members may have felt uncomfortable about expressing themselves because they were being observed by someone who was not herself sharing. I do not know precisely what my influence was on the other participants and the group dynamics, but I believe I was accepted as a participating group member. Some comments made by the participants during the program and during the interviews lend support to this possibility. The following comment from one of the interviews, regarding my presence in the group, provides an example.

> I really liked it when you talked about yourself. And I zeroed in immediately because it was difficult for you. And I zeroed in and thought, she's letting herself be vulnerable even though she's a professional doing a specific job, and yet, she's brave enough and loving enough of herself to do that. I remember you got a little teary. I loved that about you. I thought, wow, a person. (11)

6.2 Stages of Transformation

6.2.1 Introduction to the Stages

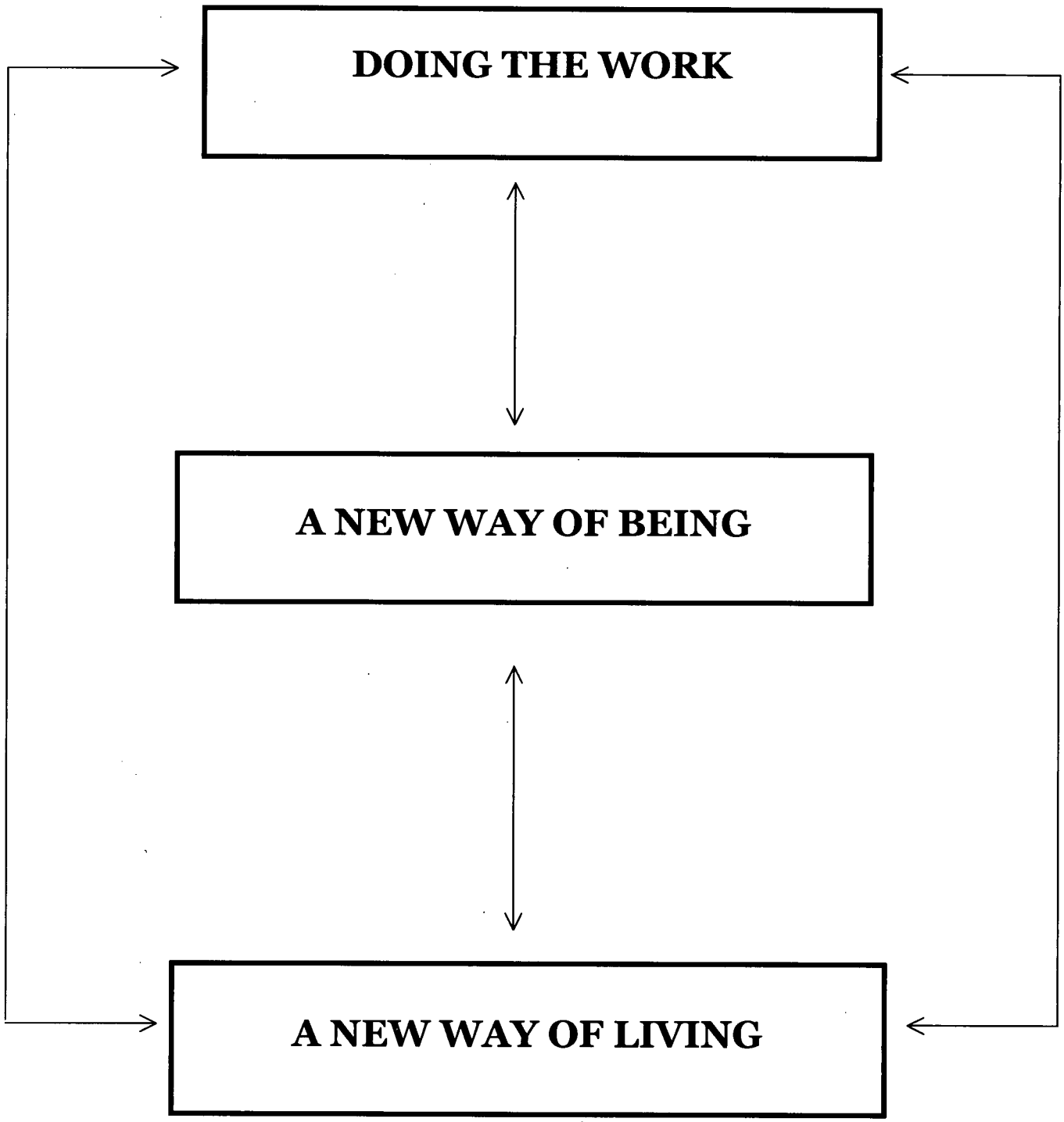
The analysis of the interviews with participants highlighted the importance of understanding experiences of well-being as a process of change, not an outcome. The benefits gained by the participants were not felt only as a result of using mind/body

techniques; a critical component was a participant's willingness to use these techniques for personal growth and transformation thus altering their experience of day-to-day life. The practice of mind/body techniques and the group experience of the program facilitated this process. However, of particular interest for this study, is how these experiences and tools were ultimately used both within and outside the program, which together determined the extent of the impact on participants' experience of well-being.

The analysis indicated the Process of Transforming Well-Being involved three stages of experience (See Figure 6.1). The first stage, entitled 'Doing the Work' described the experience of participants' engagement in the program experiences. Stage two, entitled 'A New Way of Being' described how participants experienced themselves, their inner selves, their 'being' in the world as a result of doing the mind/body work. The final stage, entitled 'A New Way of Living' described how participants took this new way of being one step further and began to live their daily lives differently. Moving from stage to stage involved continued application of the program techniques, and personal transformations which participants sometimes referred to as 'shifts' or 'turning points'. The transformation in well-being gained from this sequence of events became deeper the further along a participant moved through these stages.

Each participant traveled an individual journey. The following explanation of stages and steps in a process of growth and change do not reflect each person's exact experience, but rather an overview of the patterns in their experiences captured by the analysis of the

Figure 6.1
A Process of Transforming Well-Being



interviews. There was overlap of each of the stages, but for simplicity of explanation, they have been outlined separately.

6.2.2 Doing the Work

The stage entitled 'Doing the Work' was created as a description of how participants experienced the Mind/Body Program. Their experience of 'Doing the Work' included both learning the techniques taught in the program, and their experience of working and learning in the group setting. Participating in the program provided an opportunity for participants not only to experience more consciously the mind/body connection, and learn new tools to facilitate this connection, but also to embark on a personal journey where they delved deeper into themselves. This is where they began to do what they sometimes referred to as their 'inner work'. Doing inner work referred to bringing their awareness deeper into their bodies, and into themselves in ways that facilitated a deeper awareness and understanding of their authentic selves, emotions they were carrying, and unresolved pain, trauma or conflict.

As one participant explained, the program allowed people to "really get their problems right to the very core of themselves." The techniques used in the program were designed to assist participants to access body sensations and emotion held deep within, as well as provide opportunities to assist with the release of pent up energy and emotion. This release could be in the form of voicing issues, bodily movement, or emotional expression. The group setting gave participants the opportunity to engage in exploring new ways of communicating and relating to each other. The support of the group provided an

atmosphere that participants found very influential in deepening their experiences of the techniques and program exercises.

'Doing the Work' involves two main aspects that gave breadth to the descriptions participants gave to their experience: shifting awareness, and connecting with others. While these two categories are not mutually exclusive, for clarity of presentation, they are discussed separately.

6.2.2.1 Shifting Awareness

'Shifting Awareness' described the process participants underwent when they learned to become aware of not only their minds, but also their bodies. They learned that mind and body are not separate, and they learned to understand and 'read' the signs, signals and emotions carried deep in body tissue, which, in the past, were not part of their conscious awareness. In essence, they were consciously feeling the mind/body connection. Bringing this awareness into their body was synonymous with bringing their awareness deeper into themselves, as it was here they connected with a deeper sense of their emotional and spiritual selves that provided them with both insight and understanding of their true nature. The group experiences and exercises facilitated and provided opportunities for participants to gain awareness about themselves and the ways in which they relate and communicate with others.

6.2.2.1.1 Becoming Aware of One's Body

The first step of unfolding the process of self-discovery was teaching participants to bring their awareness from their mind into their bodies. Techniques of meditation and breathing were used to guide this process. Shifting their awareness in this way was, for many participants, an experience they were unfamiliar with, and some felt resistance to making this shift. For some, this felt equivalent to letting go of control, "I didn't want to lose control in the class. Even though it was a safe environment, I was tense." (11) Once the experience became more familiar, and they began to understand the significance and benefit of doing so, the fear often began to subside.

> When they said listen to your body, I thought, "Listen to my body? Forget it! I like my mind. I don't want to focus on my body." But, it's such a delight to let go of your mind, and realize that you do have a body. (11)

Once their awareness was focused in their bodies, participants described becoming more in touch with feelings, emotions and memories they were holding from their past. Often these experiences were tied to particular places within the body, and as their attention moved within their body from place to place, certain openings to hidden emotional scars would occur. The insight gained from these experiences was more than an intellectual understanding, but was a 'body awareness'. Participants found the depth of learning and understanding was much greater when a particular emotional issue was accessed on a body level. Accessing on a 'body level' was not an easy sensation to describe verbally, but essentially meant connecting to the essence of a feeling, emotion, or memory of which the participant was previously unaware of. This came about as a result of bringing awareness into the body using such techniques as meditation, creative movement or breathing

exercises. The following participant explained this link between depth of awareness and the physicality of the experience for understanding emotional experiences:

> I think I was in touch with them [feelings about an experience], but I think it was at greater depth. I would say that I was aware of that at an intellectual and somewhat emotional level, but this sort of took it, it went deeper into the iceberg. I likened it to permafrost. And, it was getting through the layers of the permafrost, and so it took the understanding that much deeper and that much more into my body. (2)

Another participant provided a specific example of how the physical body can communicate as she explained how her physical reaction to completing an exercise in the program gave her surprising insight about her emotional connection to some of her childhood experiences:

> There was another exercise where the instruction was to draw your childhood, your childhood family as it was when you were six, or seven or eight years old. That has been the only time I've felt such huge resistance in almost anything I've ever done in my recent recollection. It was just sorrowful, and I was in tears. I was really overwrought with emotion and could feel it in my physical body. I just could not, I mean I finally did do the exercise, but it was an overwhelming feeling of, maybe inertia is the word, resistance and inertia, no energy to draw on to draw. No energy to draw on to draw (laugh). That sort of surprised me. So there was a physical thing going on, but there was this kind of insightful surprise or surprising insight, whichever way. I mean both ways you can look at it, and it was profoundly physical. It took all my effort to do the drawing. And I am a doer, so for me not to be able to, to be rendered almost paralytic was really quite amazing. I've known that time is significant in my life, but I think the significance of it was really magnified through doing that exercise. (2)

Accessing these 'pockets' of emotional history would often bring insight, understanding, and possibly a release of the emotion being held. In order to come to terms with one's 'old haunts', as one participant explained it, there needed to be a full acknowledgment of how the experience affected the individual. One participant called it, 'owning my own experience', which meant she was able to come to truly acknowledge how a particular event or circumstance affected her, without blurring this acknowledgement by how

someone else had interpreted it. This acknowledgement involved coming to terms with the full range of feelings, emotions, and personal reactions. Through authentic acknowledgement this participant was better able to gain personal insight into how she was relating to others and living her life. Specifically, she spoke about the importance of:

> More fully acknowledging the event, or the time frame, but also maybe the variability and the uncertainty. Like if you look at an event, and you say oh, that made me sad or that made me frustrated, you can maybe go to the heart of it and get a specific out of that. With this, it was a recognition that it wasn't just about sadness, it was about a lot of other things. So I think it gave texture or layering to what it looked like. So, instead of simply seeing it, I mean, I had acknowledged it, and even talked about it, but it gave it more fullness and by so doing greater understanding as to why I have behaviours the way I do, or why I'm who I am. (2)

Having the opportunity to access emotional history on a bodily level allowed for what some of the participants called a 'release' of the emotion. Release occurred when a participant felt they had come to terms with a part of their history, experienced the impact it had emotionally on a deep body level, and physically let go of the emotion. The following participant explained an example of such a release:

> There was body meditation, a guided meditation, that one of the facilitators did, a body-scan, where she itemized the different organs. When she got to the spleen there was such profound grief, like the tears, like for me there was just sort of this cleansing tears, and I feel I'm fairly centred. I feel I have a fairly reasonable idea of what is going on, but this was very profound in terms of the spleen. And I could feel it was like a release, a physical release of grief and sadness, but particularly grief. (2)

6.2.2.1.2 Self-Awareness

As participants began accessing feelings that had not been part of their previous conscious awareness, faced issues and acknowledged their past, they gained insight into who they were and how they related to the world in deeper ways. Essentially, they 'got in touch with

themselves'. This learning involved accessing a core sense of self, or a more authentic aspect of their being[1] which was often unacknowledged or unaccepted.

> A lot of the time it felt good to have that space for introspection. It was kind of a forced way of looking into yourself. I'm kind of curious about that anyway. I'm always curious how my mind, brain, body, spirit, everything moves. I mean, what makes me tick. It's always kind of an interesting topic to me. And this was a way of forcing myself to sit down and look into it, which I wouldn't do as much otherwise. (13)

The following participant alluded to the courage it took to move toward this understanding by facing herself honestly, and the need for the,

> willingness to go in there, and to take what makes up [participant's name], and to lay it all out on the table, and to look at each part of me mercilessly.

Awareness for participants of the way they related to others was an important part of this process, and the program experience provided opportunities for participants to gain insight about this.

> And after learning all this mind/body connection, I'm thinking what I portray to myself and to others is not exactly what I want. I just didn't know that that's the only way. That was me. And that's an a-ha. That's a stunner. It can take you back and you think, well, now I have to learn a different way. (11)

Some participants found there was a tangible difference between the beginning and end of the program in terms of their understanding of who they felt they were, and who they wanted to be.

> At the beginning of the program you gave me a piece of paper and told me to draw what I want, how I want to see myself. And then at the end of the program you got me to draw how I wanted to see myself. And that was very good because the original one was quite vague, and then at the end of it, it was quite specific, as how I saw myself. So, that was good. (1)

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[1] It should be noted there is considerable debate in the literature regarding the notion of an essential self. (For example, Fuss D. Essentially Speaking. Routledge. New York, 1989.) The idea of authenticity described in these findings describes each individual's expression of what they regarded as "authentic". It does not imply essentialism in terms of broader categories of gender, race, or culture.

Learning about themselves was a critical part of the journey for participants to begin to express themselves, and to choose to live life in a more authentic manner.

6.2.2.2 Connecting With Others

The group experience was an important part of the learning participants described, and participants felt it often facilitated a deeper inner exploration than could have been achieved otherwise. Relating to others, and resonating with experiences of others could facilitate and intensify a participant's inner work. The program provided an opportunity for individuals to form strong and intimate bonds with other participants given the atmosphere of openness, and the willingness of participants to share on a deep emotional level. An important element that allowed participants to form these bonds, and feel comfortable with interacting with each other, was being open and vulnerable with one another. As one participant explained, "People started to allow themselves to show themselves, and then I felt comfortable." (11)

Some participants called this type of experience 'connecting'. One participant defined connecting in this way:

> Connecting is a non-judgmental thing. It's connecting from one soul to another soul, just totally being present, completely present with that person, at that time, at that moment. (1)

Listening to the stories of others sometimes allowed participants to access similar emotions in themselves, or in other words, resonate, with their feelings or experiences. This experience of resonance was potentially a valuable opportunity for accessing one's own emotion that has been repressed or ignored, and not fully experienced or released.

6.2.2.2.1 Finding Comfort in the Group

A participant's level of comfort working in the group setting greatly influenced their resulting experiences. Feelings of trust and safety were key components of finding a sense of comfort, in addition to a participant's perception that group members and facilitators were both respectful and compassionate of their personal journey throughout the program. Feeling the group was operating in an atmosphere of 'non-judgment', as one participant described, made the group experience feel both beneficial and supportive:

> All the people that were there were there with me doing it with me, and I just felt a great feeling of support that, there was not going to be any judgment of me. If I broke down and started crying there was a great understanding of where I was at, and no judgment which was huge for me. And through the tears and through the non-judgment, released a lot of tension in my body. (1)

While it was the perception of non-judgment that was important, it was evident that an atmosphere of non-judgment was not always possible. The following participant explained her initial tendency to judge others in the group:

> I remember the first day, what I call a go-around. Each person introducing themselves, and making their opening statement. And feeling nervous, and my nervousness expressing itself in a way where I started judging everybody. I don't like this person, I'm not attracted to this person, I'm attracted to this person, and making these judgments which is a form of anxiety for me. When I'm anxious I fall into this kind of behaviour. (7)

But, instead of remaining in this pattern, she was able to step back and observe her behaviour, and with this awareness, make a choice not to continue.

> And, realizing right then that this is a chance for me, this is an opportunity to think about this. I'm here, I'm judging these people, and this is a chance to say, why should I be judging? What else can I do with these people? So, I give myself a huge amount of credit for that awareness. (7)

As closeness developed within the group, there were opportunities for judgments to be expressed and sometimes diffused in an open but respectful manner. This served to provide an atmosphere where the fear of judgment was not paralyzing for many participants.

Maintaining a 'fit' in the group could be challenging when there were differing personalities, situations, needs and processes taking place all at once. Participants sometimes found their feelings of comfort shifting in different situations, and felt uncertainty as to their place within the group. As one individual described:

> In some ways I liked the group part of it, but I was never quite sure where I fit-in in a group like that. Everyone had different needs and at different times of the day or different day of the week, or different week of the program, these needs would change, according to how their moods changed. There were just so many variables flying around the room. And then, me in the centre of it, or side of it, wherever I was, I was never, or not never, but often I was unsure exactly where I was, what my role should be. (13)

Emotions would shift dramatically through the program as the group and individuals processed different aspects of their 'inner work'.

> I went through a lot, a lot of different emotions. There were some times when I was jumping from elation to frustration. Kind of ran the gamut. And that was good, anytime I can, you know, I like experiencing things, I like trying new things, I like meeting people. All of those things were good and positive, and even if they weren't all happy and pleasant and fun, I still think they were good. Valuable, in those ways, they were good for me. (13)

A group setting could also be useful for providing an incentive to participants to commit to the program work. As this participant described, feeling accountability to the group encouraged her to continue practicing the program techniques:

> What the program did for me was it forced me to do the work because I knew I had to go back there the next week and they would ask me, "So, did you do your meditation?" And, if I had been on my own, I probably wouldn't have done it. (1)

6.2.2.2.2 The Experience of Sharing

As one participant described, working with others allowed her to find company in her experiences. Knowing others shared similar experiences and emotions brought comfort and feelings of normalcy to the individual. In a group where participants were encouraged to be authentic in their expression of feelings, and were encouraged to disclose themselves to the group, participants began to see they were not alone in their suffering. They began to see their feelings as a normal reaction to being human:

> I saw what I wouldn't have seen if I was just in one-on-one therapy with acupuncture yada yada, is that everybody has ups and downs, everybody has U-turns, everybody is scared everybody is human, and I'm not alone. And what I'm feeling is no different than what anybody else is feeling. That brings great comfort and peace to me because I know that I am okay. (1)

Not only was it a source of comfort to know that others shared similar feelings and experiences, it sometimes actually helped an individual to work through the feelings. For example, the following participant found greater peace from finding this comfort:

> I have no idea how it happened, but working with the group in a group setting and hearing other people's stories, and sharing my experience in a group setting, which for me is very difficult, changed it. I thought that I was the only one feeling the way that I was feeling, and that there was nobody else feeling these things and everybody else was walking around the world, feeling a lot better than I was and didn't have this craziness going on in their head. Now through the process of seeing everybody else - that they do have this craziness - allowed me to work through *my* craziness. Now it's a lot quieter in my head. (1)

The group setting offered participants hope and inspiration by allowing participants to see other group members doing well. This positive energy would impact the experiences of the group members:

> Just hearing other people's journeys, their struggles, how they deal with things, was healing. You know, really, what to me was even more healing was when someone made a break-through or when they started feeling better and they shared that with the group. I could feel the energy of the group just rise, you know, just success

> stories, you know, little success, you know where we learn, we got to know each other, we knew where we were and then you would hear these little success stories, it just, something inside also started healing, I believe. There's real power in that. (4)

6.2.3 A New Way of Being

'A New Way of Being' described the impact the program experience had on how participants felt within themselves, about themselves, and the experience of their day to day lives. In contrast to 'New Ways of Living', described in the next section, 'A New Way of Being' was a description of a state of mind/body, and the feelings participants had as they went through their daily lives, rather than the impacts of their everyday 'doing'. In other words, it was about how an individual 'is' in the world, not what this individual 'does'. It was a description of their 'inner experience' as they moved through their lives. The experience of living with illness became changed as a result of this new way of being. The major identifying aspects of this new way of being included: experiencing inner calm, expressing a deeper sense of self, surrender/giving up control, and acquainting oneself with the power of choice.

6.2.3.1 Experiencing Inner Calm

Becoming more aware of the relationship of mind/body, and learning tools which can be used to influence this relationship, gave participants the ability to consciously alter their mind/body state. Participants described their experience of feeling a greater state of inner calm as a result of their influence over this relationship. Inner calm was described as feeling centred or grounded. Feeling grounded referred to a feeling of having your feet

firmly planted on the ground and feeling connected to the earth. It is an integral part of being centred. One participant described the feeling of being 'grounded' in this way:

> Feeling your bum in the chair. Feeling your own presence. Feeling like nobody, like you couldn't get knocked over. However, like with the base of a tree, at the same time, you are, like a willow, bendable without snapping. Like an Oak, still very solid to the ground, very connected to the ground and to yourself. (1)

Feeling centred included, but moved past, feeling grounded and described a place of inner peace and tranquility. In this space, participants described feeling focused and connected to themselves. They sometimes experienced a quieting, stilling or silencing of the usual chatter in their mind. This space was often a very rewarding place for participants.

> I don't know if I can express the, just the calm and centredness that I feel into a machine [the tape recorder], it's here, and within me where I am now, and I think the program is very valuable for bringing that to people. (4)

Experiencing a state of centredness could bring improved mental clarity. This clarity assisted in decision-making and concentration. In other words, a participant was much more able to focus and felt less scattered.

> I function a lot better, more organized. My mind is a lot clearer. I like being able to make decisions quickly. There was a long period of time I didn't and that got me back on track. I feel it gets better all the time. (3)

When participants became less distracted, more at peace, and more focused, it became easier to have perspective on their life. Rather than placing thought, worry and attention randomly and rather thoughtlessly, it was possible to more consciously place energy on what was most important.

> It really allows a lot clearer thought getting back into my own mind the important things, and taking it is just, clear thought, anything I've got out of this the most is just clearer thought. And, what's important and what's not. (3)

> It's very subtle, but it's very powerful and it just changes...slows you down enough so that you can think clearly. I get much more pleasure out of the little things, the smaller things in life now than I used to. (1)

A component of finding inner calm was either releasing or managing emotional weights. When an individual was caught up in emotional turmoil, finding a calm place within themselves, and maintaining focus on thoughts or tasks of importance could be nearly impossible. As one participant pointed out, the opportunity in the program to release her anger had a huge influence on her ability to focus and gain an improved attention span:

> For me the mind body program was wonderful because, as I said, just to take the anger out of me, that was a big, big thing. I would not be able to sit down and talk to you here before that. I mean, you would see that, it doesn't matter how much I'm interested in that, I had an attention span, I think, like a 2-year-old, maybe. Seriously. (5)

6.2.3.2 Feeling More Connected to Oneself

An important aspect of this 'new way of being' was related to the process of self-discovery and expression of this awareness that occurred for participants. The program experiences provided an opportunity for participants to explore themselves in ways in which they would not normally be able to do. They learned about how others see them, and had opportunities to become more aware of how they relate to others. Gaining a greater understanding of themselves offered them the opportunity to express themselves in a more authentic way. This could literally mean they felt more comfortable in their own skin as this participant explains:

> Actually, it's come a long way (laugh). I mean I spend a lot of time by myself, and I feel a lot more comfortable by myself. I mean I don't have to have music on anymore. There was a long period of time, 5-6 years that I needed constant noise around me, people or everything. So, that changed, it's back into where I feel good about myself and I can deal with that. I'm a happier person. (3)

> So it actually allowed, I think, a better person than I was before. And I thought I was a pretty smart guy and able to deal with things, but maybe not. So, there was things in there that kind of helped to scratch away at things that held me back, so I appreciate what they were. (3)

6.2.3.3 Balancing Surrender and Choice

Another 'new way of being' the participants spoke about was understanding the fine line between letting go of what is out of their control and choosing to take charge of what is within their control. It seems ironic that on one hand, participants were learning how to take responsibility to care for themselves and manage their illness, while on the other hand, they spoke of learning to let go of trying to control it. The distinction was between learning to better manage aspects of their illness that are manageable, at the same time learning to acknowledge the uncontrollable by accepting limitations of their present condition. In this way, by relinquishing control, they gained more control. The following description illuminates the choice of one participant to surrender to the uncontrollable:

> I've always wanted to be in control and if I surrender what the hell have I got left? Right? It was too scary for me to surrender, to surrender to the illness in a sense. I was going to, when my heart valve started closing up and I mean there was one time when I collapsed, cause my heart couldn't, I was just pushing it too much and it couldn't pump the blood out, so it went into spasms and I couldn't breathe. I was gonna, damn it, I was gonna overcome this, because I have overcome everything in my life. I'm in control here, nobody else is. Well, it's taken me awhile, but I've learned to surrender to it. If this is what my heart is doing, then I'm gonna let it do it. I'm gonna let go of controlling it, right? And as I let go of controlling it, the body always goes back to homeostasis right? It always does, it has to get back into balance, so when you just let it go it will do it, but I don't just mean physically, I mean here. Here between the temples, that space there, that's where I do my controlling. (4)

Another participant described her decision to understand and manage the experience of chronic pain by working with it, rather than feeling antagonized and fearful of its influence.

She had thought of the pain as a huge scary monster, but began to see it more as a 'gentle giant'.

> It wasn't this big snarley thing, it was just in pain and it wanted to be comforted. It wanted comfort, and so it turned into this big, it was still big, but it was like this gentle giant that had a thorn in its toe and it wanted to be held and paid attention to. So, I started paying attention to it and looking at it, looking at my pain as a gift. It was trying to tell me something, and it was trying to teach me something, and if I didn't pay attention to it then it would just scream louder just like a little baby right? I wasn't scared of it [the pain] anymore, and I was much more gentle towards it. And if I would hold my pain, I started to learn to hold my pain, very gently and let it do whatever it would want to do, and sure enough it would change and transform into, into this, you know, big old gentle giant. Or, sometimes it would just go to sleep or whatever. (1)

Once she learned to work with the pain, to accept when it was present, and manage it as best as possible, the negative impacts of the experience of pain began to diminish. In fact, the experience of the pain began to lessen when she became gentler with the pain, and more gentle with herself when it appeared.

While sometimes it is necessary to surrender to circumstances out of one's control, in contrast, participants also became more in touch with their ability to have control over other elements in their lives. They learned to use the 'power of choice'. Learning mind/body techniques taught some participants important tools that could be used to manage their experience of illness giving them more confidence in their own ability to manage.

> The mind/body seemed to do more for me because what it did was give me confidence in myself to be healthier, to kind of get past the illnesses. (3)

> I see results in the way I felt once I started using some of the tools - the breathing techniques, the meditation, the mind/body. Feeling positive results for myself, now it has given me the confidence and reassurance that there is something to the fact that if you think and believe in yourself you have the ability to make a change. And that's what the whole thing is I think, bringing into yourself the ability to control what goes on in your body. It wasn't instantaneous, but within a short period of time I thought hey, okay, this does work. I went in open-minded, but not willing to

> accept anything for face value, waiting to make a judgment myself. It has given me the confidence, and the confidence is my ability to aid myself in my own well-being. So that's the confidence. (3)

As these quotations illustrate, through first hand experience, participants gained confidence that they do have the potential to manage aspects of their own illness.

6.2.4 A New Way of Living

When a participant took this new way of being and began to outwardly create a life that reflected this, they moved into the stage entitled 'A New Way of Living'. This stage occurred when participants' entire life shifted because of the expression of growth in the active engagement of their life. The day-to-day living with illness shifted because the way they understood, managed and accepted the illness had changed. They were no longer forced to just endure illness, but instead, they learned how to live with it. Their illness was less able to undermine their sense of well-being and vitality. The way participants engaged in life, related to others, and managed life's challenges, became a reflection of a larger learning process that had taken place and was continuing to take place within the individual. In essence, they were living a more authentic life. The following participant alluded to the shift in her day-to-day life that can result after the program experience:

> It changed everything. It changed every aspect of my life. It changed my relationship, and everything in a positive way. Because I'm more grounded, I'm more centered, I'm calmer, my head doesn't feel as busy, and that affects a big part of your life. (1)

While many aspects of 'a new way of living' are very closely related to those described in 'a new way of being', the latter reflects taking the awareness gained in the first two steps and putting it into action. It is one thing to become more connected to themselves, to learn

about their true nature, and it is another to actively engage in a life that allows this true nature to be expressed and experienced. Ways of being and ways of living are dependent on one another, and it is essentially impossible to affect one without the other. Having said this, the distinction between the two is important because a 'new way of living' described a deeper degree of integration of new awareness or experience.

6.2.4.1 Living With Illness

During the first two stages, 'Doing the Work' and 'A New Way of Being', participants had the opportunity to reflect on and question their relationship with their illness. A component of a new way of being for some participants was relating to their illness differently. Understanding their illness differently, finding a greater level of acceptance, discovering a greater sense of meaning behind their body's signs and symptoms, could allow them to begin to live with illness differently. The day-to-day way of life could then be altered to manage the experience of illness. The following participant explained her awareness that a particular way of living was no longer possible with the bodily pain she was experiencing:

> How I had always accomplished everything in my life was by strength. Which okay, yeah, I am a strong person. If I wanted to get to the top of that mountain, or whatever, I'd just climb to the top of the mountain. If I wanted to get from point A to point B then I would. And if there was a wall in my way, I would hit that wall, and then I'd take two steps back and I'd hit it harder, and I'd take two steps back and I'd hit it harder, until I broke through that wall and got to the other side to where I wanted to be. Now that's fine and dandy, and that will get you far in a lot of different situations, but when it comes to pain, you hit that wall, and its pain 'OUCH'. You take two steps back, hit that wall again, and the pain is just gonna keep on getting worse and worse and worse because you can't, you can't go through pain that way. So, what I learnt was a way around the wall. And I learned that through the processes that I got at the Tzu Chi. (1)

The next example illustrated a method of managing the illness, of working with the 'ebb and flow' of the illness. This allowed her to experience less emotional distress due to the confidence of knowing what to do and what to expect. She explained the important transition from a stage of 'crisis' to a place where she was able to effectively manage it.

> So, what's happened for me is I've said, I'm not my disease, but I've actually sort of made friends with the disease. So, I'm not my disease, but I have it. I know that it is there. I know the ebb and flow of it. I know that I have moved, what I would say, from sort of the crisis part of what it is, what it is doing now part of living with it. To kind of managing it. So, part of it is a mind-set that has come out of managing it. If I get to a place where I'm moving to, oh my God, I've got this pain I've got to contend with, then I go back to, okay, what can I do to assuage that, that apprehension, that fear. (2)

Being ill can mean an individual must adjust to changes in lifestyle that can lead them to feel like an outsider, as though they do not fit in as they once did. As they began to experience 'a new way of being', including becoming more connected with themselves and more confident in their ability to manage living with their illness, this feeling of confidence would begin to grow.

> It also, what it did, also with not feeling physical ills of the disease that I thought I felt before, it also brought more confidence in myself and in the thinking I have in dealing with myself with society. It's like I fit in better now. I always felt a little out of place because I don't drink anymore and stuff like that. And just feelings, because they are all related to illness in the first place, I only had those feelings once I got sick. So now, it doesn't bother me anymore. It does well not only for handling disease, it does well for handling yourself, period, everyday type of stuff. (3)

6.2.4.2 Engaging In Life Differently

Another part of a 'new way of living' participants spoke about was beginning to live more fully and more consciously – they began to engage in life differently. They could become more open to do things, and allowed themselves to pursue things they would not have

pursued before. For some it was stepping forward into a life they had hid from due to circumstances and experiences of their illness.

> I think it would give me opportunity to come back to life. I think it was the part that, I don't know if you remember, we had to make a picture at the beginning, who am I? And I was kind of a lion or a tiger in the woods, and I really didn't want to get out of and I really felt like going to live in the woods, but there are too many bears there (laugh), and not to see anyone. And after that [the program], I felt almost ready to come into the society. (5)

In a 'new way of being' participants described recognizing the power of choice, and in a 'new way of living' they begin using it. They recognized and acted on their ability to choose how they wanted to live. For some participants with a poor prognosis that had reduced their interest in truly engaging in life, they experienced a renewed interest in living fully regardless of their expected length of life. As one participant explained, she re-engaged in learning and taking courses.

> They say, "Oh gee, you don't look like you are going to hang around too much longer," kind of idea because it's that bad. So, something clicks in a person, maybe it's the woe is me, and everything else and life doesn't feel important. You just feel sorry for yourself, and you don't function well doing what you do or even hope to do, like going to school. I always took courses or whatever, but there was a period of 6, 7 years I didn't do anything because you just kind of give up in that kind of way. And then taking it [the program], it all came back again and that's what happened, it all came back. (3)

Another participant moved forward with travel plans which otherwise may have seemed too daunting.

> I was able to travel this year. We had a large trip planned at the end of the summer, and I also wanted to see my brother and family. I had things I wanted to do, so I kind of pushed myself to get out there and do that. So I think part of that probably came from the program. That resolve. (2)

Not only did participants engage more actively in their lives, they gained more clarity about how they wanted to live their lives. They were better able to make decisions and act on

them. When their awareness became more present, they had greater focus, and became more concerned with living life for today. They had the ability and the desire to make choices for today that were fulfilling.

> I can, and any person can, make themselves feel better, and I do because of this [the program]. I just feel more mentally capable of doing things. I do a lot more fun things now...I know now it doesn't matter whether the virus, they don't have a cure or anything like that, and whether it's eating away at the liver, it doesn't matter. Today is today and that's great and that's good. (3)

As this participant explained, her experience of engaging was also shifted due to an improved experience of feeling more centred:

> I mean I was taking courses prior to going into the Mind/Body Program, and while on drugs, but I wasn't doing very well at all. But now I'm doing exceptionally well, and I do attribute it partly to the program and what that's done for me. And part of being calmer, being able to concentrate better and stuff like that, so, it's a real big change, I think. (3)

In some cases, engaging in life differently meant slowing down the pace of their lives as opposed to engaging more. As one participant explained, her learning was related to understanding that the way she engaged in life in such a fast-paced manner, was not serving her well. Running at such a fast pace meant she missed being able to truly appreciate life as it was passing by.

> I'm on a different track now. I feel like before I was on the fast track, you know, blinders on, full speed ahead. This is, you know, not looking right or left, this is the way, this is the path to success, this is the path to where I want to be. And now, I'm on a completely different track. I'm on a slower track, which is not necessarily a bad thing - at all, at all in fact. It's just a different track. And now I'm looking around me, taking in the scenery. Seeing something over there that I wouldn't have seen before which was a wonderful opportunity, which I would never have seen had I been on that other track. And what that has brought me has been, it's brought me great joy, it's brought me peace. I feel like the universe has just opened up to me. (1)

This slower pace of life could give her the opportunity to be more present – it provided the opportunity to experience a new way of being. It could provide the chance to fully experience each moment, moments that would have passed without conscious awareness. Gaining this awareness was an empowering experience. Having more knowledge brought a new level of control that enabled her to make more conscious decisions as this example illustrated.

6.2.4.3 New Ways of Relating to Others

An element of engaging in life differently is how participants engaged in relationships. How they related to others could become shifted from this process of personal growth, as they gained awareness of their patterns of relating to others. As participants learned new ways of being in the world, they needed to adopt ways of relating to others that reflected this learning, and enhanced their ability to maintain the connection to their true self. In this light, relationships provided a challenging opportunity to put their new awareness into practice. The following participant explained her attempt at trying to use new awareness to relate in new ways:

> Before, I would stand up, I would defend myself, I would argue. I would do everything else that I'd do dealing with my mom. And now, whether it's right or wrong, I'm choosing not to go closer with my intimate thoughts. I'm choosing with certain people not to be close to them. Now I know there's skill involved. How you be close, don't do that, you won't be close. So it's all left to us. We're still left with what we're going to do, ultimately. So, I always thought, it's a matter of personal efficiency to figure it all out. Now I know it's a matter of self-preservation to walk away from things, and not figure it out. (11)

Participants also spoke about their willingness and need to make changes in relationships, or to eliminate some relationships from their lives if they were not serving them well.

Participants indicated they could become unwilling to accept relationships that do not reflect authenticity and support. The following participant described this experience:

> I also find that what I got out of the program was that, and this was really sad for me, was that I thought that I had more support in my life than I did. I found out that I was, that I am very self-sacrificing, that I am willing to, you know, give up my own needs before others, and it just comes so it just came so naturally to me that I didn't even realize that I was doing it. So, then during the program and after the program I was testing my relationships with my friends and family as to how supportive are they of me, and you know what, a lot of them weren't and that was really sad so I lost some friends during the process as well, but really, were they real friends? (1)

Learning to engage in more authentic relationships was a theme of learning to relate to others in new ways. Communication tended to become clearer and more open. Authenticity meant being honest with others even when it was difficult or hurtful to do so.

> You know, to the issues in my life that need the voicing, so I have been able to go one-on-one with the people that I have the need to do the one-on-one with. (2)

Truly connecting with others meant being truly open and fully present with others. It was this experience that enhanced relationships for participants.

> The friends who I am moved and touched by are the ones who can relate to me no matter what's going on. However, the better I can express what's going on, and I've learned to do that more through this program, and other stuff I've done, the more empathetic they are. Defining who I am in a way that they understand. Say hey, this is a part of me you know, I'm not okay, you're not okay but that's okay, you know, being fully who one is. And I think the program, the Tzu Chi program, better allowed that than any other. (6)

Connecting with others authentically meant being more vulnerable, which was not always easy, but some participants noted its benefit in their lives.

> My relationship with my husband is better, they [relationships] are different because I am expressing. They are just so different I'm really, I'm really getting to know people now as opposed to, I'm really connecting with people now which I had never done before which is such a wonderful thing. I had no idea that you could have these types of relationships with people, I would never express my, you know I was always the strong silent type. So, I would never express my hurt or my

> vulnerabilities to anybody before and now I do, and my goodness (laugh), it's a good thing you know and it just makes you human. (1)

Authenticity also meant learning to communicate more responsibly. This meant expressing feelings the moment the feelings are present, and in a way that does not blame. One participant described it in this way:

> First of all I'm more aware of my internal conflict. I pay more attention to what's going on, the tension I feel, and I'm more willing to express that in a way that is not blaming. I find the more I can key into it, deal with it, right now, in the here and now, than let it build up and explode or implode, the better I work, the better things function. (6)

Participants also spoke about their need to learn to set boundaries with others, in order protect their own needs. Many participants described their challenges with saying 'No' when they wanted to, as this participant explains:

> Well, it helps me to say, 'No' to people. If I feel I can't do anything, instead of stewing and letting it bother me, I will phone and say, "I'm sorry, I can't do that." The way we went, "No! No! No!" That was excellent. It helped us a lot. It really did. That really stands out in my mind because I couldn't say, 'No' before. So, I find I'm doing that more now. (10)

6.3 Mediating Factors

There are a number of mediating variables that influenced participants' experience in the program, and the resulting impact. These included their willingness to engage in the program experience, and their commitment to integrate the awareness gained and the mind/body techniques learned in the program into everyday life. For example, it is one thing to expand awareness, but for participants to use that awareness in how they live their lives was quite another step. As this participant explained, the value of the program experience rested on what they chose to do with the program experience:

> You see, you're given a gift, and you open it, but unless you use it in the way it was intended, it's only another happening. (11)

This could be dependent on their readiness for this type of experience. Each person was on an individual journey and came to the program with differing past experiences, expectations and openness to the experience.

6.3.1 Readiness for the Experience

Participants were at varying degrees of openness and willingness, and in large part, 'readiness' for the program experience. Being open to the experience included being open-minded about learning something new and willing to engage actively in the experience. The program invited participants to become aware of their mental and emotional patterns, judgments and assumptions, as well as their interpersonal responses, reactions and behaviours. Participants were at varying comfort levels with each of these tasks, which had a profound impact on their willingness to participate fully. As the following participant explained, "You know, maybe one has to be ready for it or something." (9) The following participant explained:

> I started thinking this might be a little bit more psychological than I am interested in. If this is the kind of thing that they are focusing on and serious about, and I'm not as serious about those kinds of things, or just not as interested in, maybe I'm not going to do well here, or I'm not going to see eye to eye on some things here. (14)

Participants who were less willing to fully embrace the program experience were less likely to be committed to the practices after the program experience, and may have struggled to a greater degree with integrating the experiences into their lives. The same individual as above described the challenges of integration in this way:

> Even though while I was doing the skills in the program, at times, I was really pleased with how well some of them worked, the breathing, the mind/body ones,

moving the energy around. I was really thrilled sometimes. Yeah, this works I can feel the energy moving. I feel better now then I did before and that's good, and now I can go and do this and I think this is great. I'm going to do this everyday. And, I don't do them. Not everyday, not any days most times. So, the only solace I can give myself is I think now that I know these things and I will do them soon. One of these days I'm gonna get back on the program. (14)

6.3.1.1 Familiarity

An influencing factor in participants' response to and readiness for the program appeared to be their familiarity with the nature of the experience and the techniques involved. A number of participants had participated in somewhat similar programs or activities which appeared to enhance their ability to 'go deeper' into the experience. For those beginning on this journey, the growing pains sometimes felt much greater. To truly understand the extent and nature of the impact of the program experiences for an individual, an understanding of their past experiences and where they were at in their personal journey seemed critical. Without this information, assessing the benefits becomes much more complicated.

The reaction to some feedback the following participant received helps to illustrate this point. One participant explained that she felt 'wounded' by an insight given to her by a program facilitator. The wounded feeling was a reaction to feeling surprised and overwhelmed by the new information, or a new way of understanding circumstances in her life. The context of the rest of the interview confirmed this feeling was not necessarily a negative experience for the individual in the long run, but an important piece of the growth and learning. Nevertheless, it was a piece of learning that was difficult and did not feel 'good' in that moment.

> It's amazing how people come into your life, don't know you, and two or three things occur, and then you have to re- assess what you thought. You thought you were doing okay, but in reality, you were misguided. Actually, I had a lot of things explode when I came here. I really thought, indeed I had a very good family, a very supportive healthy family. I mean my mom, and my sister and all my relations. I don't mean my husband and son. Although with my husband, maybe, I found out some things as well. And, I walked out less healed, in a way. I walked out more wounded. (11)

Many participants did not view the program as an isolated intervention of sorts, but saw it as another 'stepping stone' in their journey, as this participant explained, "A lot of steps have taken me along the way, I've done work before the Tzu Chi." (1) In this light, the benefits need to be understood in the context of their journey, what they experienced, and what they will do next.

> What I see with the program is it served as yet again another stepping stone to do other work. So, it in and of itself is very helpful. It also created, call it curiosity, call it areas in which I saw as needing more work, and I thought, gee, I'd like to explore that more. It's been ongoing from there so if you take the program in and of it itself as a finite thing, it had a certain benefit, and then the benefit from there gets maybe a little more amorphous because of where I think it led me. (2)

Participants spoke about similar programs they had participated in.

> Now, I came to it having done other work around sort of healing, either in a retreat form or just my own exploration, whether its yoga and a variety of things. So, I came to it with a fairly good base of knowledge. So, some things were familiar to me and other things were fine-tuned. (1)

As the following quotation illustrates, their depth of experience can increase the more they are engaged in this type of work. This can include choosing to integrate the experiences more into everyday life.

> I went to the XXX, they have a similar type program, well, mind/body like, you know. They believe the same thing. We did movement there, we did connection, and meditation there. So, I sort of learnt something about it there and then applied

it a lot more at the Tzu Chi. So, after the program I just started integrating it more into my life. (1)

6.3.3 The Major Shifts and Transformations

Another mediating factor appeared to be a 'threshold' of awareness, readiness, or learning that needed to be reached before a participant was inclined to move further in the process of transforming well-being. Participants spoke about major transitions or shifts in their awareness, ways of understanding themselves or their illness, or deep personal insights that appeared to be related to their experience of profound change. While the steps outlined above indicated a fluid process of change, the 'shifts' described turning points in which the change moved abruptly in their journey. These 'shifts' did not describe a particular stage per se, but a way of moving between and within stages. Words or phrases participants used to describe this included, "I finally got it", "I had this major shift", or, as in the following quote, "It gelled".

> All of the things that I have done up to now have helped me to be where I am now and to help me to be gelled. (4)

An example of such a 'shift' was when participants adopted the belief that their experience of illness was in fact a gift in their lives. They felt it was a gift because it moved them to grow and change in a way they would not have without it. In this scenario, they were able to see illness as the catalyst to personal growth.

> So, I finally got it. And, that's what I believe. I believe that it's a gift. It was a gift for me really because I was moving so quickly and I was so disconnected from the world. Without a doubt, I would never have re-connected without my pain. I would have never reconnected to the world. (1)

> This heart problem that happened four years ago to me was a gift. It was gift for me to myself because if this hadn't occurred at the time in my life that it did, I probably

> would have died. Or, I would have just continued pushing myself to achieve certain goals and I would have been, well, either miserable or dead. (4)

Another such shift, related to this, was increased acceptance of their illness experience. It was a letting go of having complete control over the illness experience, including the prognosis.

> Am I always gonna be in pain? I don't know. I don't know. Nobody seems to be able to give me that answer. The ligaments don't heal, so I don't know. I don't look at it as a bad thing at all and that was a huge shift for me, getting over the anger and the anger of, of you know, this happening to me. (1)

The following quotation provided an example of a shift that took place for a participant following the program. As she indicated, the shift was likely a result of the program experience, as well as her continued journey upon program completion. The 'shift' described a new way of being in the world that she was experiencing which was leading to a new way of living life. It illustrated a depth of inner change that seemed to transform her experience of herself, and her relationship to the world to be more authentic and more satisfying.

> I have had this major shift. I can't say that it happened while the workshop was going on, or as a result of the workshop specifically, but the workshop helped me, plus the other things that I was doing. Helped me to move into this shift that happened this summer for myself, where I am so much more centred, much more within myself, and much more accepting. I feel as if all, all the blocks, all the coverings that have been over my heart, and I don't mean just physically, I'm talking metaphorically and well, spiritually, all these coverings have dissolved or shifted. Moved, so that my heart, my heart chakra, my energy, my centre, my love, is much more open now, much more allowed to express itself again. I've given myself permission to express my own love, I think that's it. (4)

6.4 Summary of Findings

The Process of Transforming Well-Being for the participants described a process of deepening participants' connection to and expression of their true being. Participants described opportunities to access and release emotional blocks, body pain and other symptoms they held within themselves. These experiences of accessing and release brought insight about emotional issues they were previously unaware of, and opportunities to let go of energy blocks which were detrimental to their overall well-being. They acknowledged and re-connected with their true nature in a deeper and more profound way then they had previously been. Bringing their awareness to the present moment facilitated this re-connection with their bodies, with themselves, and insights about ways they were living their lives that were not serving them well.

Becoming well was not distinct from, but was also not reliant on removing physical complaints. Instead, the experience of illness became a background to a larger process of personal growth. Participants described experiences that were captured in three stages of transformation: Doing the Work, A New Way of Being, and A New Way of Living. Participants described various ways they moved through these stages including 'turning points' where they moved more deeply and quickly towards an integrated expression of awareness. As participants moved through the stages beginning with Doing the Work and moving toward A New Way of Living, they displayed a deeper level of integration of the awareness and the use of techniques into their lives. Numerous factors influenced their willingness to engage in the process of transforming well-being, and their journey through

these stages including past experience. A number of insights from these journeys are worth particular mention.

6.4.1 The Nature of the Mind/Body Experience

While participants experienced relaxation and a sense of inner calm that these mind/body therapies have been shown to generate, they also demonstrated that becoming more deeply and consciously aware of the mind/body relationship allowed them to work on deep emotional issues. They gained insight and awareness they did not previously possess. As participants began this process they began to see that their self was not separate from their illness. In order to understand the true value of the experience for the participants, this journey into self and the transforming experience of gaining new awareness, must be acknowledged.

Further, the interviews with participants illustrated that evaluating the value of the program was not so much the study of a one-time 'intervention', per se. The program offered an experience and taught participants various tools that could be used and integrated into daily life, continuing to affect the experience of well-being. The resulting effect in a participant's life was a complex interaction of such things as the impact of using the techniques, degree of integration into daily life, past experiences, and readiness to engage in personal work. From this perspective, understanding mind/body influences needed to involve not only understanding what happened immediately following the intense period of the intervention, but what results if a participant brought the experience and principles into everyday life.

6.4.2 Transformation

The mind/body experience was shown to be related to shifting awareness that had the potential to not only *change,* but to *transform* a participant's relationship to illness, to herself, to others, and to the world. When participants began to 'see' differently, their way of being changed, and their resulting experiences were therefore transformed. These transformations that occurred were much deeper than a change in physical or psychological symptoms, but could have an effect on symptoms. A transformation appeared to have involved a major shift in awareness or understanding that shifted the individual into not only a new way of being, but further into a new way of living.

6.4.3 The Individual and The Group Journey

The findings describe a process involving three stages of experience. Each individual moved through these stages in different ways. The benefits appeared to be related to a complex array of influences that contributed to the stage of the journey for each participant. For some, the program was the beginning of a new journey, and for others, the program was another step of a journey they began long before beginning this program. Patterns in the data allowed for the creation of the three stages that outline and provide an overview of the Process of Transforming Well-Being. While the participants shared common elements in their journey, the ways they traveled, the distance, and the ease of the journey was distinct for each one. Like any experience of travel to a foreign place, each person can see the same sites, walk the same paths, fly the same airways, but each is affected in their own distinct way. Analyzing every step and every decision along the way in order to replicate

the 'trip' would still not guarantee that one who followed the steps would experience the same journey. Those who have done more traveling may find the trip easier, as some of the challenges will not feel so unfamiliar, but it is still a unique experience.

Similarly, how individuals reacted to new awareness was an individual decision. Learning more deeply about oneself did not always feel good. While it enhanced their potential to live more consciously, it also required them to face issues and characteristics they may feel more comfortable repressing. Working with and integrating new self-awareness was a task that took patience, practice and courage. Because participants were at varying degrees of comfort, and varying degrees of integration with the new awareness when the program ended, some participants felt as though they wanted the ongoing support of the program to continue on this path.

> I felt it was really really good, but I felt like I needed more. You've had them [problems] for, say 58 years or maybe 50, who knows? But I feel that's not enough to, you know, to help you. I mean it very much gets you on your way, but I felt like I could have more. (10)

Further, accessing emotion that has been repressed can be particularly uncomfortable, and participants can feel a resistance to doing so. The willingness of a participant to engage in accessing and releasing emotion and an honest self-discovery affected the experience of their journey through the program, and continued to influence the process of integrating this learning into everyday life.

6.5 Interviews with Control Group Participants

An analysis of the interviews with members of the control group before they had the opportunity to experience the Mind/Body Program was undertaken and deserves mention. While there were only four interviews completed with this group, and individuals were not able to speak to the experience of the Mind/Body Program yet, they were able to speak about their experiences in the individualized care component of their care at the Institute. It is recognized that a comprehensive summary of the range of experiences from the individualized experience was not likely accomplished with only the four interviews. It was also evident that participants were aware that they had missed the experience of the Mind/Body Program that the intervention group had received. Moreover, they were anxious to have this opportunity. Given this, they may have been more likely to feel more critical or disappointed in their experiences; indeed, all four of the interview participants mentioned their positive anticipation of the program. However, some of the preliminary themes are worth noting.

A theme that emerged from this analysis was the lack of a truly holistic experience for the participants. While benefits were discussed from their interactions with the individual practitioners (including a medical doctor, an acupuncturist, chiropractors, a naturopath, and massage therapists), there was some disappointment about the ability of these therapies to address the emotional and spiritual aspects of healing in addition to their emphasis on the physical experience.

> The holistic, the whole body, everything, the systematic approach, I like that stuff. It all sounds good to me, and sounds like it should work. And that's what I was hoping to get more of here, which I didn't really get. I got some good massage, some neck cracks, and some acupuncture. (14)

The individualized therapies involved a more 'hands-on' approach by the practitioners (i.e. something was done to them) rather than actively involving the participants as the Mind/Body Program did. Rather than learning tools to aid in their own healing, participants were more reliant on the practitioners for the intervention. The quality of the personal relationships with the individual practitioners was a critical element of the experience for the participants. One participant described supportive relationships with practitioners that gave her a new sense of hope:

> Well, you have a feeling of confidence, you have a feeling that somebody's there to help you. You have a hope, there's something at the end of it. (17)

Another participant greatly struggled with her interactions with practitioners as she felt she was not 'heard'. Given this feeling, and her disappointment that the team approach was not working, she found herself experiencing great depths of despair.

> I found I was not being heard a lot of the time. Because they, I think people are trying to put it like it's all in my head. I was going into very deep depths of suicidal tendencies, and it was getting worse rather than getting better. I was just finding that I was feeling, here I was with a team now, my ideal. I was having a team here, but the team wasn't, nothing was changing for me. (16)

While the multidisciplinary team approach was generally considered by participants to be a worthwhile concept, and the practitioners were believed to be committed individuals, some participants believed they had experienced little real healing, "I don't feel that I had any experience of healing when I was with these people." (14) The lack of emphasis on emotional issues was noted in these interviews. There was discussion of the desire to work on deeper emotional issues, as it was believed by some that this is the key to the healing process. As one participant explained,

> I wanna look at my core. I want to do my core work. I've done a lot of work over the years, but I think I want to tap into that part. (16)

Testing out the Process of Transforming Well-Being theme illustrated the participants in the control group who were interviewed prior to having the opportunity to participate in the Mind/Body Program did not appear to move through the stages in the same manner or to the same degree as those who had the Mind/Body Program experience. The experience of 'Doing the Work' of the individualized therapies appeared to involve less emphasis on exploring their inner processes which then resulted in few changes in their ways of being and living.

Chapter 7: Discussion

7.1 Overview

The intention of this study was to assess the effectiveness of the Tzu Chi Institute's Mind/Body Program to positively impact the health and well-being of individuals living with chronic illness. More specifically, the aim was to examine how the program influences standardized measures of health status, quality of well-being, and social support, in addition to how participants would describe the influences on their well-being using their own words. Overall, the combination of quantitative and qualitative sources of data provided evidence of positive impacts on well-being for participants. However, the quantitative component did not appear to capture the extent or nature of changes in well-being participants described in the interviews. The combined findings illustrate complexity in understanding how program impacts are experienced and sustained over time.

7.1.1 Quantitative Findings

Three months from the start of the 8 week Mind/Body Program, participants demonstrated significant improvements on two subscales of the outcome measures indicating an improvement in well-being. In particular, on the SF-36 health status measure, the mental health subscale, which measures psychological distress and well-being, showed a significant difference between the intervention and control groups, indicating a more positive change in the intervention group. In addition, the tangible support scale of the MOS Social Support Survey indicated a more positive rating between study groups; the intervention group experienced a more positive change compared to the controls.

The repeated measures analysis of variance, which looked at changes between study groups across the follow-up period, demonstrated only one significant finding, the social functioning scale of the SF-36 Health Status Survey, which showed a more positive improvement in the intervention group. Univariate analysis indicated this difference was sustained up to the 6 month time point. The social functioning scale measures the degree to which physical and emotional problems interfere with one's social activities.

7.1.2 Qualitative Findings

While the analysis of changes between groups over time (up to 6 months) showed only one significant difference between groups, the qualitative findings indicate there were profound changes in the intervention group. When participants were asked about their experience of the program and the resulting impacts 3 to 6 months post-program, the major theme that emerged was entitled: A Process of Transforming Well-Being. This three stage process of personal growth captured the patterns in the participants' experiences as they moved toward improved well-being. The various stages were entitled Doing the Work, A New Way of Being, and A New Way of Living.

The first stage, 'Doing the Work', was developed to describe the experiences of participating in the 8 week program, as well as integrating these experiences and mind/body techniques into their everyday lives. The second stage, 'A New Way of Being', was developed to describe how the participants experienced themselves differently as a result of the program and using the mind/body techniques in their life. This encompassed

their experience of inner calm, feeling more connected to themselves, and learning to use the power of choice in their lives when appropriate, and when to surrender to things out of their control. The third stage, 'A New Way of Living', involved a further transformation of bringing their new experience of 'being' into the way they live their day to day lives. Elements of a new way of living include new ways of living with illness, engaging in life and relating to others.

This process of transforming well-being is a continuous one, without an endpoint; well-being becomes increasingly improved as one deepens one's journey through these stages. Not all participants moved through all the stages, nor did they move through them at the same pace. It was very much an individual journey. This model of transformation is intended to show how the movement flows, not to imply that each and every participant experienced the model in the same way.

7.2 Understanding the Findings

The quantitative findings display few significant differences between the study groups, and yet the interviews describe some profoundly positive changes in well-being for those who participated in the Mind/Body Program. Given these somewhat contradictory findings, why there were few significant impacts detected statistically, deserves closer examination. A couple of possibilities exist: 1) changes exist between groups, but the statistical power is insufficient to detect this change, 2) changes detectable by the outcome measures utilized are not able to capture the nature of the impact participants are describing in the interviews.

This could mean, essentially, that the questionnaires and interviews are measuring different things. Each of these scenarios will be discussed.

7.2.1 Statistical Considerations

Given that this was a feasibility study, the sample size was small. The small size of this group along with the poor response rate in the control group for the 3 and 6 month questionnaires reduced statistical power to detect differences between the groups. Even with the smaller sample size and the poor return rates of questionnaires in the control group, the effect size was sufficiently large to detect some changes, but a larger sample size would have been necessary to detect other changes where the effect size may not have been as large. No further differential statistical tests were conducted as it was decided, in consultation with biostatisticians, that the risks associated with multiple testing with small numbers (i.e. falsely significant results) made such an endeavour inappropriate. Moreover, correlations evaluating contrasts between quantitative and qualitative assessments were not considered appropriate due to the small sample, although it would have been interesting to undertake if a sufficient sample size had been available.

Because participants were not randomly assigned to the study groups it is possible they are not comparable groups. However, baseline comparisons of the questionnaire data do not show any significant differences between the groups, suggesting that the two groups do not vary on variables of interest in this project. It is not known why some participants chose not to return questionnaires, or how their experiences compared to those who chose to return them. Those who were in poorer health may have been less likely to return the

questionnaires. If this was the case, given that the response rate was poorer in the control group, the measurement of well-being in the control group would have been over-estimated, decreasing the apparent effect of the program. Additionally, given that all participants, those in the control and intervention groups, received individual treatments from the practitioners at the Tzu Chi Clinic, the effects of the Mind/Body Program were likely less pronounced from what might have been seen if the control group was not receiving any complementary care.

7.2.2 Interpreting the Qualitative Findings

While the qualitative research clearly indicates changes exist, for a variety of reasons, they do not seem to be detected by the questionnaire responses. Given this, it is important to consider who within the study group the interviews represent. For example, is it possible the interviews represent only those with a more positive experience (this may also be true of the questionnaires)? However, participants in the interviews discussed both positive and negative experiences in the program, which means that not all people who agreed to be interviewed had only positive experiences. Some of the participants who did not agree to be interviewed indicated reasons including being in the midst of moving and the distance needed to travel for the interview. Still, it remains unknown what all of the experiences are of those who did not participate in an interview. It is possible that some who had negative experiences were not willing to share these.

Another important point is that the interviews involved participants from both the intervention group (8 participants), and from participants from the control group once they

had the opportunity to experience the second Mind/Body Program offered to them (5 participants). In this way, the statistical results and the interview findings are not comparing the exact same group of people. There is no reason to believe that the experience of those in the control group who experienced the Mind/Body Program would be different from those who experienced the original program. The second Mind/Body Program session for the control group involved a smaller group, but involved the same program content and facilitators.

During the program, it appeared that while some participants did react negatively to some aspects of the program, it did not necessarily mean it was not an important and valuable aspect of the program. An exercise that encourages participants to release anger in front of the group is an example. Not all participants found this comfortable, and some found it extremely uncomfortable. It is possible, and this was the belief of the program facilitators, that negative reactions to this particular aspect of the program were sometimes an indicator of the type of work one most needs to do. In other words, one can resist that which they need the most because this can be the most difficult for them to face. This then brings up the question: Does a 'negative' experience necessarily generalize to a negative comment on the program overall? Having said this, there is an important difference between not enjoying and feeling harmed or traumatized by an experience, and this balance always needs to be carefully considered.

In further studies it would be worth more carefully determining the reasons some participants chose not to be interviewed. Ethically, it did not feel appropriate to phone and

inquire in detail regarding this issue with participants, but perhaps a very brief non-respondent questionnaire could have been mailed to participants to assist with understanding this issue. Because I participated in the program and had a closer relationship to each person, I believed it would be uncomfortable if I phoned and inquired about the reasons for not participating. I believe they would have felt pressured to participate. This was the reasoning for giving each participant a letter of invitation to participate, and asking them to approach me for an interview time.

After considering the sample of people the interviews represent, the next question then becomes, how valid or credible is the data for the people they do represent? The conventional notions of validity and reliability from quantitative research are not used in qualitative research, and are replaced with the concepts of credibility and dependability as criteria to evaluate the quality of findings[2-3]. Specifically, dependability matches most closely with the concept of reliability, and credibility with internal validity. The credibility and dependability are strengthened in this project in a number of ways. First, not only did the researcher have repeated immersion in the data, but the analysis of data was assisted by the thesis committee allowing for sharing and exploring the data and verifying findings. Second, because the researcher was a participant and observer in the program, additional context was understood and documented to assist with the interpretation of interview data (See Appendix A Reflections of Being a Participant Observer). Further, the author conducted a similar study during the same time period that demonstrated similar results (See Section 7.4.2 The Art of Living with HIV Study).

7.2.3 Determining and Measuring the Nature of Change

Statistical considerations may account for some of the discrepancies between the qualitative and quantitative data, but it is also worth considering whether the questionnaires are capable of measuring meaningful changes even if there had been sufficient statistical power to detect changes that were occurring. In other words, do they cover the right domains, or do they even capture the nature of change that is actually occurring?

The experiential data in the interviews provided the framework for the major theme of the qualitative findings, 'A Process of Transforming Well-Being'. Participants described positive changes in their personal growth that translated into changes in their ways of being, and for some, eventually changed how they began living their day-to-day lives. On the other hand, the questionnaires measured standardized, conventional benchmarks of well-being emphasizing the importance of particular emotional, mental, physical and behavioural states. These benchmarks are included, either implicitly or explicitly, in the stages inherent in the themes that emerged. However, how they are experienced, and whether the participants attribute positive or negative associations to various experiences in one of these stages is more complex than the way these concepts are presented in the questionnaires. In other words, the theme of transforming well-being provided a number of insights which challenge some of the assumptions about health and well-being which guided the development of the questionnaires. Some of these insights include: 1) Changes in physical health may not be as directly related to well-being as the questionnaires assume, 2) Positive changes may not always feel positive, and they may not necessarily be linear

across time; and finally, 3) The difference between 'transformations' and 'changes'. Each of these items will be explained further.

7.2.3.1 Relationship Between Well-Being and Physical Change

It was found that physical symptoms may not have the direct relationship to well-being that is assumed in the questionnaires used in this study. For example, the experience of pain and its relationship to one's well-being is a complex situation including one's understanding of pain, ability to manage pain, and acceptance of pain. The standardized measurement instruments do not account for these additional factors. Knowing the amount of one's pain may not be adequate to evaluate its impact on one's well-being. The following participant illustrated this point when she indicated the amount of pain may not have changed, but the impact in her life was much different:

> So, to look at it [the questionnaire results], it would be like wow, you know, she really didn't, she didn't experience anything great about this program. But in fact, if there was a section in the questionnaire about how are you feeling emotionally, I think you would see a significant difference in there. (1)

Participants indicated that feeling well or healthy does not mean that one must be free from cancer, HIV or any other illness. The following participant illustrates that assumptions of the questionnaires, reflecting the notion that having illness means you are not 'well', may be inappropriate:

> They [the questionnaires] are dippy. (Laughter) Well, it says how is your health? Well, I think my health is pretty good, but I've got cancer. Fourth stage, probably, lymphoma. I mean, what kind of a question is that? How is my health? Well, eventually this is going to kill me, so they say. It may not be this year, maybe five years, maybe 10 years. So, how is my health? How do I answer that question? I feel better than I have ever felt in my frigging life, and yet, by the standard of measurement that we use, I'm not well. So, define health. (2)

This strongly illustrates that measuring changes in health and well-being needs to move past an illness/health dichotomy to include many states of wellness within a continuum of having illness and being without illness.

7.2.3.2 What is Positive Change?

It has been found that positive change might not always initially feel 'positive'. For example, is feeling more depressed immediately following the program experience necessarily a 'negative' impact for the participant? The depressed feelings may be an important part of experiencing new awareness, or an improved ability to access emotions. Participants spoke about the benefits of learning about themselves in deeper ways, but this did not mean their emotional reaction to this awareness was always positive. Participants were accessing and experiencing emotion in greater depth. They were learning to 'feel' everything, pleasant and unpleasant, with greater intensity. The greater self-awareness experienced by the participants may have included greater awareness of change and stress in life, physical pain and discomfort, and social issues. Instead of turning away or refusing to face the problems, the participants accepted and embraced the experiences. This ultimately could be seen as a very positive outcome, although not a completely comfortable one.

Participants described a process of personal growth which they felt moved them towards a greater state of well-being, but conventional 'indicators' of well-being (i.e. changes in physical or psychological symptoms) do not always display positive, linear change over time. The interviews illustrate the important issue is not short-term end-points, but rather

the change in terms of growth in their own personal process. Someone feeling more depressed after the program for example illustrates this point. A well known phrase states: Success is the journey and not the destination. The same could be said for the process of transforming well-being. Essentially, the process is the only outcome. There is no completion, only continued growth. The following participant explains the role of process:

> Did I experience healing? I feel it's a process, so I can't say yes I experienced healing at this time, or at this moment or on this week. I believe that the healing has been an ongoing process, and that this workshop helped to refocus my energy and my thoughts, my focus, refocus my focus, into my own, into areas that I needed to explore, to facilitate the healing (4).

The control group displayed greater improvements in the role-emotional sub-scale, indicating they had a greater improvement in role limitations due to emotional problems. It is possible that the intervention group was experiencing greater amounts of discomfort due to emotional issues because they were accessing their emotions more deeply. This finding is tentative due to the large standard deviations associated with the changes in means, but is suggestive of a change that should be further investigated. This demonstrates, again, the findings themselves need to be interpreted carefully.

7.2.3.3 Transformation vs. Change

The Mind/Body Program has been shown to shift awareness in the participants. The question then becomes, what happens when awareness shifts? When someone learns about him/herself more deeply, how does this affect their resulting attitudes and perspective, and therefore, their experience of living with illness? The experience of changing awareness has been shown to not only change, but transform one's experience. The Random House Dictionary[4] defines transformation as, "change in form or structure; to change in condition,

nature or character". When speaking of personal transformation it has been said, "ancient traditions describe transformation as new *seeing*. Their metaphors are of light and clarity. They speak of insight, vision."[5] It is this shift in insight and vision that captures the type of changes seen for participants. They are not merely 'changes', but transformations because the resulting effect is somehow different in form or perspective. The metaphor of a caterpillar transforming into a butterfly provides a perfect example.

Transformation can occur in many realms of experience and is discussed in the physical and mathematical sciences as well.

> A transformation is, literally, a forming over, a restructuring. Mathematical transforms, for example, convert a problem into new terms so that it can be solved. In the physical sciences, a transformed substance has taken on a different nature or character, as when water becomes ice or steam[6].

When talking about transformation in people the discussion has specifically focused on the transformation of consciousness.

> In this context consciousness does not mean simple waking consciousness. Here it refers to the state of being conscious of one's consciousness. You are keenly aware that you have awareness. In effect, this is a new perspective that sees other perspectives – a paradigm shift. This awareness of awareness is another dimension[7].

And it has been said that,

> The beginning of personal transformation is absurdly easy. We only have to pay attention to the flow of attention itself. Immediately we have added a new perspective. Mind can then observe its many moods, its body tensions, the flux of attention, its choices and impasses, hurting and wishing, tasting and touching[8].

It was possible that a participant could undergo a transformation, but not necessarily be seen to 'change' on a particular factor of interest. An example from the data is one individual's explanation that the absolute amount of her chronic pain had not necessarily

changed, but her awareness around the pain had changed. This meant her experience of the pain and the resulting impact in her life was greatly shifted – it was transformed. She gained insight related to the reason she was experiencing pain and learned to manage it more effectively. She no longer had an antagonistic relationship with it, but learned to surrender to it when necessary. This example illustrates the need to consider how transformation can affect the participants' responses to the items on the questionnaires, and whether the responses before the transformation are comparable to the ones after.

7.2.3.4 The Questionnaires

Looking at each of the questionnaires used in this study helps to illuminate the points being made above. Both the content of the questionnaires and their lack of ability to address the process components of change are highlighted.

7.2.3.4.1 The SF-36 Health Status Survey

The SF-36 Health Status Survey conceptualizes health status using nine domains or subscales: physical functioning, role limitations due to physical problems, bodily pain, social functioning, general mental health, role limitations due to emotional problems, vitality, energy or fatigue, general health perceptions, and health transition (perceived overall change in their health status). While this scale measures changes in physical and some psychological symptoms, the qualitative findings illustrate that the measurement of short-term symptomology fails as a direct measure of one's well-being. Changes in physical and psychological symptoms can become secondary to the process of personal growth that is taking place. Asking about health issues in terms of how their experience of

their health/illness impacts their day to day living appears to be more relevant. This was confirmed by the findings that the social functioning subscale (measuring interference with social activities as a result of physical and emotional problems), was the only item on any scale that showed significant changes between the study groups across the study period (up to the 6 month time point). This scale is made up of two questions which respondents are asked to respond to using a five-point scale where the responses range from 'not at all' to 'extremely':

> During the past four weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?
>
> During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives etc.)?

The social functioning scale items do not tap into the actual experience of a physical or emotional state, but the external effect of this experience in the way one is living one's day to day life. A participant confirmed this need to understand the impact of illness in one's life by indicating the most important issue to measure is how much the illness 'consumes' one:

> Does your disease consume you? I mean, is it something that you can set aside and say, gee, I can do this much, I can do these activities, and I can be involved. Or, does it debilitate you in such a way emotionally and mentally that you can't do any of that? (2)

7.2.3.4.2 The Quality of Well-Being Scale

While the qualitative interviews indicated profound change in well-being, the Quality of Well-Being Scale did not detect changes in well-being. The Quality of Well-Being Scale purports to provide an index that summarizes a person's current symptoms and disability in

a single number that represents a judgment of the social undesirability of the problem and expresses it in terms of quality-adjusted life years. It is intended to be used as an outcome indicator that estimates both the present and future need for health care services. It is based on a three component model: 1) the assessment of health starts with an objective appraisal of one's present functional status, based on performance, 2) a value is attributed which reflects the relative desirability or utility that is associated with the functional level assigned, 3) health implies a consideration of both one's present state in addition to the future prognosis for any illness the individual is experiencing.

The qualitative findings question three main assumptions of this scale including its heavy physical orientation, the collective assumption of the relative desirability of particular physical and functional states, and the assumption that a person's attitudes toward the constructs remain constant. First, the interviews clearly indicate that quality of life is much broader in scope than the QWB acknowledges. Quality of life or well-being is a combination of one's experience of physical, emotional, social and spiritual health. This questionnaire does not adequately measure social, emotional or spiritual aspects of health, therefore making it more a measure of physical health than quality of life. Participants clearly demonstrated their ability to separate their experience of well-being from their illness experience. As their experience of illness became a background to their process of self-discovery, their quality of life became more closely tied to their process of growth, rather than to the physical experiences of illness. The QWB cannot assess experiences of well-being that are separate from illness.

Further, a quality of life measure needs some flexibility to reflect unique perceptions and values of the individual, as the findings indicate symptoms, in and of themselves, do not necessarily reflect the amount of suffering these symptoms create for an individual. The utility of their state of health in the QWB is not judged directly by the respondents or people like them, but is previously determined by a sample from the normal population. In this way, those who have permanent physical impairments are judged a priori to have a worse quality of life than those who do not. Again, the findings demonstrate that quality of life is not necessarily highly correlated with physical limitations. The QWB's ability to summarize current symptoms and disability in a single number seems to oversimplify the complex nature of the concept of quality of life.

Finally, when using quality of life measures, there is an assumption that the point of reference does not move, or in other words, a participant's feelings towards a particular construct remain stable. Attitudes are not always stable, but can vary with time and experience, as well as with psychological changes such as adaptation, coping, expectancy, optimism, self-control and self-concept[9]. With an intervention such as the Mind/Body Program, that has the potential to induce a number of deep psychological changes, the 'reference point' is likely to shift as well.

7.2.3.4.3 The MOS Social Support Survey

The MOS Social Support Survey is designed to cover the functional aspects of social support, or in other words, not just the size of one's social network (structural support), but one's perception of support (perceived availability if needed). This scale is made up of

four subscales: tangible support; affectionate; positive social interaction; and emotional or information support. This measure was included in the assessment in order to understand the potential mediating factor of social support to the outcomes of the Mind/Body Program. The qualitative findings demonstrate that social support is a critical factor in the experience of the program. However, it is the quality of this interaction that is most important, and it is questionable whether the scales that make up this measure are sensitive enough to capture the complexity of the social interactions that are most relevant.

What appears to be most relevant for participants is the degree of connectedness in their lives. The MOS Social Support Survey does not appear to adequately measure the quality of relating to others such as authenticity, vulnerability, and responsible and honest communication. As an example, this scale does not differentiate between informational and emotional support. The interviews described changes in participants' relationships that reflected their personal growth. Participants explained the number of support people in their lives may still be the same as before the program, but because they were communicating and expressing themselves more openly and authentically, the nature of their social interactions shifted.

> Social support was the same pretty much before as after, but the nature of it probably changed because I had changed. So, I don't think the questionnaire really allows for kind of, the nuances, of what's changed. I still have the same sort of support people. I'm not one who would call my mother and say oh golly gee whiz or cry on her shoulder, I wouldn't. I would be more open with her now than I would a year ago. I would be less angry, less sort of ticked off because I'm communicating clearer when things come up, so that's what's changed. The person is still there, there's still one before and one after, but the context in which you are interacting is very different. (2)

If social relationships become closer, more open-hearted, more communicative and authentic, it is likely that one's perception of social support changes, generally becoming more positive.

> So maybe there is something about whether you are more open with your support people. And, are they more open with you? Have you noticed change in your willingness to be more open? Maybe it's around quality and willingness and need, and opening your heart? (2)

The benefits of this kind of support in one's life are likely to be greater. In this way, it is more than just the number of people that is important. Participants also described eliminating some relationships from their lives if these were not serving them well. The conventional measurement of social supports assumes that a greater number of relationships is better, but the participants explain that authenticity of relationships is critical, even if it means reducing the number of people in one's social network. Authenticity, as a state and a process, is not tapped in this scale.

7.2.3.5 Self Reported Experiences

The quality of the data collected from the questionnaires relies on self-reported answers. While it is the participant's perception of experience that is of interest, there needs to be some consideration for the validity of these responses. As one participant explained, when she became frustrated with the types of questions that were being asked, and felt that her experiences were not well represented in the questionnaires (i.e. SF-36), her effort and attention to responding began to diminish.

> I don't remember specifically much of the questions, but I remember more my reaction to them that these are kind of dumb. Who asked this question? Why are they asking this one? And, the answers could go so many ways depending on how I interpret this question. How can they possibly hope to get anything from me on this

> one? And once I had that reaction then the whole thing, my reaction to it is kind of skewed because I would just think well this isn't going to work, so does it really matter what I put down here now? They are not going to capture anything with this one. I kind of lost confidence in them I think. And once I lost confidence, then I'm sure it must have had some effect on how I put down the rest of the answers. And at some point, I think I remember thinking, well I just gotta get through this, and go on with my day (laugh). This isn't really going to help me, and its probably not going to help the person who is going to read these as well. (13)

This response questions the quality of some of the quantitative data being used to represent participant experiences.

7.2.4 The Relationship Between Well-Being and Healing

What is the relationship between transforming well-being and healing? As previously explained, the discussion of the findings from the interviews did not use the word healing in order to avoid confusion with common associations with this word. According to Kleinman[10], healing is a process by which one manages illness rather than specifically treats a disease. From this perspective, as Glik[11] (1986) points out, "If we take Kleinman's view that healing is associated with the alleviation of psychosocial distress rather than the cure of overt pathology, the logical extension is that healing is also associated with the enhancement of feelings or states of wellness." From this perspective, it appears that the process of transforming well-being can also be viewed as a description of a healing process.

Because the results were presented as the framework around the responses participants gave to the question, "What does healing mean to you?" they do also represent a process of healing. It is also evident that the responses given correlate with the some recent definitions of healing in the literature, developed from other qualitative work, such as:

> Healing is an experiential, energy-requiring process in which space is created through a caring relationship in a process of expanding consciousness and results in

> a sense of wholeness, integration, balance and transformation and which can never be fully known.[12]

Further study of mind/body interventions should address outcomes more closely representing the broader concepts inherent in 'healing' as explored in various fields of study outside of the health and medical sciences. These understandings, which move beyond a biomedical framework, appear to be more similar to the types of meaningful experiences described by the study participants.

7.2.5 Areas in Need of Further Exploration

While the qualitative findings provide a fair depth of information on the experience and impact of the program, there are a number of areas that are not yet clear and deserve further study. Such examples include: understanding the role of expectations; the influence of spirituality; and for whom the program is most beneficial. It is clear, and of great interest, that a number of factors influence one's depth of engagement and commitment to the program experiences.

7.2.5.1 The Role of Expectations

The role that expectations play in the participants' reaction to the program is an interesting and likely, complex issue. While it was hoped that participants would not come to the program with rigid expectations, but instead, that they would stay focused on moment-to-moment awareness and look deeply into themselves during the program, it is clear that expectations did play a role. What is not clear though is how expectations affect one's perception of program benefit. While the role of expectations cannot be comprehensively understood from the interviews, it can be said, tentatively, that it appears that those who

came to the program with a specific expectation, namely, wanting to 'fix' their particular physical ailment, were the most disappointed.

> Ultimately that is what I want to get out of all of this is, and not just the Tzu Chi, but any other of the medical things that I am doing - I'd like to be able to get my heart beating on a regular rhythm and have that be finished and then get on with the rest of my problems in life. And the physical part [individualized therapies], some good, some not so good effects. Ultimately, they didn't do anything for my heart rhythm so, ultimately, my estimation of it was not so great. It didn't do what I wanted it to do. So, I didn't have the high marks for it, and the same with the mind/body. At the end of the day, I'm still pumping along the same way I was before, so I kind of had the same reaction. (13)

On the other hand, those who saw this experience as a journey of their own personal process, and saw their particular physical ailment as solely one part of this process, appeared to be most pleased with their experience, and described themselves as being most positively affected. This is solely a hypothesis at this time. Further study would need to be initiated to substantiate this. One participant noted this possibility in this way:

> I know not everybody found what they thought they were looking for. I know there were people who came to the program that were looking for goals, that were looking to be healed of their problem, to have the problem go away. For me, I have just been learning, and through the program I have been learning to not look at the problem as a goal, but as a process in my own living. That's what's been valuable for me. (4)

It is possible, for many participants, if they are willing to leave their specific goals and expectations at the door, they will find something much different and much deeper than they ever could have expected.

As the above example illustrates, it is possible that those with high and/or very specific expectations may be more dissatisfied with the experience than those with lower expectations. It is also possible that those who were more optimistic about potential benefits may have been more open and willing to engage in the program experience,

therefore improving the possibility of potential benefits. These differing scenarios imply that the resulting influence of expectations on the participants' assessment of value could be altered in either a more or less positive direction. It is important to note that the role expectations do play in the assessment of the experience is likely to affect not only the interview data, but also the questionnaire responses.

7.2.5.2 The Role of Spirituality

The qualitative findings allude to the importance of spirituality in one's journey to improved well-being, but its exact role is not clear from these findings. Some participants speak of experiencing a new way of being and living that includes using inner guidance and connecting to a universal life force. The ways in which participants describe and understand spirituality in their lives was not asked about specifically, and was only sometimes mentioned by the participants, but it is clear that it can play an important role in the personal growth of many. What is difficult in understanding this role is the implicit nature of spirituality in many of the stories. Participants themselves made references to concepts that implied connecting to a greater purpose, or universal connection, but it was not discussed by the participants in enough depth to have made a meaningful analysis possible. This is an important area in need of further study.

7.2.5.3 Mediators of Program Effects

As mentioned in Chapter 6, section 6.3, there are certain mediating factors that influence how one engages in the program, and the process of integrating new experiences and techniques into everyday life. The program is not a passive 'therapy' where one just needs to show up, but the impact of the program is greatly influenced by one's engagement in the

program. Knowing that one attended the sessions in not necessarily a sufficient indicator of one's 'exposure' to the intervention. One of the most important mediators is one's 'readiness' for the experience that is related to a number of factors including willingness to take responsibility for one's own well-being, and commitment to integrating the learning into everyday life. In this light, it is important to not only ask, does the program work, but for whom does it work? When, and under what conditions? Further study needs to address these additional questions.

Findings also allude to important shifts in one's experiences that seem to solidify or deepen one's learning. These 'turning points' appear to be important in understanding the ultimate impacts of the experience, and the way one moves through the stages of transforming well-being. Further understanding of these experiences may be critical to understanding why some experience greater levels of well-being than others. Because the measurement of well-being will be influenced by the effects of integrating new awareness and personal growth into everyday reality, factors which influence or inhibit this process need to be better understood. Jon Kabat-Zinn, the founder of the mindfulness based stress reduction program at the University of Massachusetts, described the importance of integration as follows:

> No matter how skillful you become in mindfulness and in developing calmness and stillness and relaxation, if it does not spill over into daily life, there's no wisdom. It's no use sitting like a Buddha for one hour if the rest of the time you're out of control like a bull. You can get very deluded that you are a great meditator without any awareness of serious problems with your work or family. We believe that mindfulness in daily life is extremely important to the essence of meditation training.[13]

7.2.6 Ethical Considerations

Of special note is the issue regarding the potential for the experience of the Mind/Body Program to be emotionally charged and potentially harmful if not appropriately facilitated. Tapping into repressed emotion, and gaining increased self-awareness are activities that can be distressing and even harmful for participants if there is not appropriate respect within the group, as well as skillful and compassionate guidance from the program facilitators. While there were not any reports to indicate that participants felt particularly harmed by the experience, they do allude to the discomfort that can result as they learn to integrate new awareness or emotion within themselves. My experience involving similar research has shown that it is essential for participants to be clearly informed of the potential for the experience to bring up emotions and repressed issues. This needs to be a part of the informed consent process. The Tzu Chi Institute Mind/Body Program addressed this issue by choosing well qualified facilitators, as well as setting up one-on-one sessions between the lead program facilitator and the participant both pre- and post-program. These sessions served initially to fully inform and assess the participant's suitability to participate, and post-program, to debrief these experiences.

The issues around potentially harmful or discomforting affects from the intervention are not unique to this program in particular, or to many health care interventions in general. It is often the case that interventions can cause some physical or emotional distress (i.e. psychotherapy, surgery, chemotherapy etc.) in order to eventually produce potential therapeutic benefits.

7.2.7 Limitations and Methodological Considerations

While a number of limitations have already been outlined including small sample size and the lack of information on why some individuals chose not to participate, it is also worth noting the limitations due to the alterations in the study design that evolved during the study. Specifically, a number of circumstances occurred during the implementation of the study design that required it be adapted from its original conception including deciding not to randomize participants, poor response rate, particularly at the 3 month point for the control group, and reducing the length of the follow-up period. These so-called 'real world' factors highlight the difficulties conducting randomized clinical trials in this setting. While these changes in study design were not helpful in terms of adding to the statistical power, or assisting with understanding the impacts of the program over a longer period of time, they provide very important insights into the reality of doing research in the real world. There is a growing acknowledgment and trend for research designs to be more fluid in order to address issues such as the ones outlined here[14]. Perhaps studying interventions of this nature demands this flexibility. Many individuals who are drawn to this type of work tend to seek out opportunities for more empowered health care choices and interventions that emphasize this. Research designs may need to better respond to this desire.

7.3 Generalizability of Findings

7.3.1 Statistical Generalizability

The participants represent a group of people experiencing a variety of chronic illnesses, who are motivated to try complementary and self care approaches to managing their illness.

A discussion of statistical generalizability is not of too much relevance given the lack of statistically significant findings, although, because the program was a replicate of the Mindfulness Based Stress Reduction and Relaxation Program of Jon Kabat-Zinn, they can be compared to a growing literature looking at the effectiveness of that program.

7.3.2 Analytic Generalizability

While it is often believed that qualitative results cannot be generalized to settings other than the ones in which they were developed, it has been argued that analytic generalization, as opposed to sample-to-population generalization, is both useful and legitimate.[15] In other words, it can be legitimate to generalize to a theory rather than to a population. The theme developed from interviews describes how participants use the mind/body techniques and experiences to enhance well-being. It is likely this type of process occurs with participants from other programs and non-programmatic experiences of this nature. There may be important ways this theme and the components within it can be generalized to more broadly assist with understanding the impacts of similar programs, and the techniques used within them. The elements that make-up the Process of Transforming Well-Being, including the three stage process, the importance of transformation, self-discovery and mindful awareness, likely have important contributions to make toward the understanding of healing.

7.4 Comparison with Existing Literature

7.4.1 The Findings in Context

The study findings did not show the same degree of quantitative change on physical and psychological symptoms shown by other studies of group mindfulness based stress reduction programs modeled after the Stress Reduction and Relaxation Program, originally developed by Jon Kabat-Zinn of the University of Massachusetts[16,17,18,19,20,21]. Different questionnaires were used from the Kabat-Zinn studies that may account for the difference, and it is very possible at least some of this difference is due to the small sample size in the present study. The Kabat-Zinn studies have focused on short-term and long-term changes particularly in depression, anxiety and chronic pain, rather than more global measures of health status and quality of life.

The findings of this dissertation expand on previous work which has assessed the effects of group mind/body programs for individuals living with illness by adding an in-depth look at the experiences of participants undergoing this type of work, and documenting their perceptions of the meaningful impacts in their lives. One particular finding is that measuring short-term changes in symptoms is not sufficient to understand the process of transforming well-being the participants experience. The contribution of this study includes highlighting the limitation of some conventional standardized measurements of physical and psychological changes and their relationship to well-being, and the need to understand the inner process work the participants undergo. This study involved only three of many potential outcome measures, but it is evident that much of the critique may apply to many of the currently available measures due to their common underlying assumptions related to

health and well-being. In addition, some clues as to the mediators of program effects, and some of the reasons why some participants have a more positive experience than others are assessed. Why some participants choose to integrate the experiences back into their everyday lives, and the barriers of doing so are also explored. A complete understanding of the program's value must recognize both the immediate influences from the program work, as well as the influences post-program as participants integrate the experiences and awareness into their lives.

Some of the findings of this dissertation are unique within the Western medical literature in terms of considering and discussing self-discovery and personal growth as outcomes of programs of this nature, the importance of uncovering unconscious emotions in the process of improved well-being, and critiquing the notion that well-being is heavily tied to physical change. However, these ideas do exist and have been quite extensively discussed in the sphere of complementary, alternative, and non-Western approaches to understanding of health and healing. The following quotation by a B.C. physician, who mainly works with chronic pain patients, and has written quite extensively on the journey of becoming well provides an example:

> I have repeatedly seen that lasting solutions to chronic problems invariably involve a profound transformation of mind and spirit. It is as if these engrossing riddles of irremediable pain and illness present themselves most importantly as invitations to a greater understanding of ourselves and only secondarily as physical phenomena. This seems to be the philosophical explanation of the remarkable journeys of healing I have witnessed. Until a profound shift in an individual's understanding occurs – a shift often necessitating a descent into the chaos of unresolved traumas, an examination of emotional "baggage", and a confrontation with previously unexamined cultural assumptions – no real healing occurs.[22]

While little rigorous scientific evidence exists to illuminate these ideas, there are numerous descriptions involving anecdote and case studies.

Some existing literature supports the findings that it is possible to feel 'well' despite having an illness, questioning the present dichotomy between health and illness. 'Health within illness'[23] is a concept just beginning to gain recognition in the academic literature. One qualitative study indicated that feeling healthy while living with illness involved the themes of honouring the self, seeking and connecting with others, creating opportunities, celebrating life, transcending the self, and acquiring a state of grace[24]. These six themes are highly correlated with the Process of Transforming Well-Being explained here as they deal with improved connection with self, connectedness with others, and finding new ways of living and re-engaging in life.

Consideration of the degree of involvement in a group mind/body program has rarely been acknowledged. One exception is the work by Cunningham and colleagues[25]. While the influence of group therapy on survival of cancer patients is somewhat uncertain due to conflicting results in various studies, Cunningham's work indicated the degree of involvement in psychological work seemed to be related to survival in cancer patients, offering an understanding of a potentially important mediating factor. An implication of the theme of The Process of Transforming Well-Being is that the deeper one goes into the experience, and hence, the deeper the psychological work that takes place, the deeper the healing experience. More work exploring this issue could help illuminate more carefully the complex array of influences in the lives of participants post-program. It is becoming

clear that the 'exposure' to an intervention of this nature, measured more accurately than simply attendance at the sessions, could assist with better understanding program impacts.

7.4.2 The Art of Living with HIV Study

The author was involved in conducting a concurrent study while working on the dissertation that is worth mention. This project was conducted to assess the effectiveness of another mind/body program, the Art of Living with HIV Program, aimed at improving well-being of individuals living with HIV/AIDS. The Art of Living with HIV program is designed to teach people living with HIV/AIDS breathing, movement and meditation techniques in a group setting. The Art of Living with HIV program is somewhat similar to the Mind/Body Program at the Tzu Chi Institute in content (breathing, movement, meditation, group process), but the format is different as it involves a 15 day in-residence program in addition to twelve, once-per-week follow-up sessions. This study was also mixed-method utilizing a randomized controlled trial methodology with standardized outcome measures, as well as in-depth qualitative interviews to measure program impacts. The three questionnaires used to assess general well-being were the Mental Health Index, the MOS-HIV Health Survey, and the Daily Stress Inventory. Sixty participants were enrolled in the study, thirty in each study group.

7.4.2.1 Overview of Art of Living with HIV Study Findings

Upon return from the fifteen-day residential component of the program, participants demonstrated significant improvements on a number of scales on the outcome measures that indicate an improvement in well-being. In particular, the Mental Health Index showed improvements in the overall mental health index summary score, as well as the subscales

positive affect (feeling happy, calm and peaceful), and psychological well-being, but significant differences between groups were not maintained over time. The MOS-HIV Health Status Survey showed significant improvements immediately after the residential program in general health, social function (which measured interference with social activities as a result of physical and emotional problems), and cognitive function (which measured interference with concentration, decision making, and memory) subscales, but again, these were not sustained for the duration of the study period. The Daily Stress Inventory, on the other hand, did not show any significant changes between groups immediately after the residential program, but showed differences at 6 and 12 weeks post residential program. In this case, the amount of personal stress and average amount of stress associated with daily events was greater for those in the treatment group.

While the quantitative findings did not detect significant changes in well-being between groups at the 6 and 12 week data points, the qualitative findings provided a different picture. When treatment group participants were asked to describe their experience of well-being four to six weeks after returning from the residential program, the major theme that emerged described positive and profound changes in their experience of day to day living. The changes in how individuals are living their lives, in large part, were attributed to four main skills and experiences gained in the program: developing a greater awareness of themselves; learning to live in the moment; developing a greater level of acceptance for themselves, others and circumstances of their lives; and learning techniques to calm their mind/body.

The changes experienced in day-to-day living were described by the theme that was developed and entitled: A New Way of Living. This theme illustrated profound shifts in the lives of the respondents that included beginning to engage in life in new ways. Participants began to live their lives more fully, which included engaging more socially, striving to reach personal goals and trying new activities. Essentially, they began to actively create the life they wanted to live. A New Way of Living also includes a new sense of comfort and acceptance for uncertainty in their lives. Participants gained a faith that regardless of the outcome of situations outside of their control, they will be 'okay'. Living moment by moment allowed them to let go of worry, and focus on their present situation instead of becoming overwhelmed with concerns of past and future. Finally, participants gained skills to manage the physical and emotional issues related to their HIV status in more positive ways.

Positive changes in well-being, captured by the quantitative measures, peak immediately following the residential portion of the training program. While statistically significant changes in well-being are not maintained at the six and twelve week data points, it may not be accurate to simply assume the positive changes in well-being are not sustained, but instead, a more complex process is taking place.

7.4.2.2 Implications of the Art of Living Study for the Dissertation

Complexity in measuring program impacts is illustrated again in the HIV study. For example, the quantitative findings document an increase in the number of stressors and the impact of these stressors in the lives of those in the treatment group. These results appear to

be at variance with components of the qualitative theme that described increased feelings of 'being okay', including an improved ability to manage everyday stressors. Again, the complexity of attempting to measure 'positive' changes is inherent in this contradiction. This study provides additional support that understanding the benefits of mind/body programs is difficult to sufficiently measure using some currently available quantitative measures.

The qualitative findings from the Art of Living with HIV study helped inform the development of the qualitative theme of the dissertation: 'A Process of Transforming Well-Being'. The ideas developed in the 'A New Way of Living' theme in the HIV project were developed further and the three-stage process was developed in this dissertation. While there were differences in some of the program experiences, it appeared the inner process work that occurred for the participants demonstrated very similar properties. The nature of one's illness did not appear to influence the fundamental aspects of the journey of self-discovery and personal growth that these programs initiate.

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Chapter 8: Conclusions and Implications

8.1 Overview

The objective of this dissertation was to explore what can be known about the influence of the relationship of mind/body on the processes of health and wellness. Comparing research methods utilizing the positivistic tradition of Western medical research to research methods utilizing a non-positivistic, qualitative epistemology highlighted some interesting and important differences. Findings from the qualitative interviews illustrated a valuable process of change that was not easily correlated with short-term changes in symptoms captured in the questionnaires. For example, while the interviews describe profound changes in the lives of participants related to improved well-being, the Quality of Well-Being Scale did not reflect these changes. Because the quantitative results in this study had limitations due to lack of randomization and sample size, the quantitative results are not strong enough for a thorough comparison of specific results. However, the qualitative findings indicate the nature of the quantitative measurement undertaken may not ever demonstrate sufficiently meaningful changes regardless of the statistical power and quality of the methodological execution. Instead, results call for a renewed look at methodological appropriateness, and the need to assess further some of changes captured in the theme of the qualitative findings: A Process of Transforming Well-Being. Traditional, collective assumptions regarding the nature of 'positive' change, the assumption that positive change is necessarily linear, and the reliance on changes in short-term physical and psychological symptoms as indicators of the value of a successful intervention of this nature are questioned.

The nature of the experience of the program for participants indicates our efforts at understanding the benefits of mind/body interventions have not paid sufficient attention to the important subjective experiences of participants related to working through their 'inner process' and self-discovery. While it is known that in addition to the physiological changes due to increased relaxation produced by mind/body therapies, they can influence deep psychological processes, but these changes are rarely assessed or even acknowledged when mind/body programs are evaluated. For example, the ability of mindfulness meditation (also referred to as 'insight meditation') to assist individuals to become aware of issues they have long held unconscious is recognized, but rarely examined in a rigorous scientific evaluation. It is understandable that assessing cost effectiveness and changes in symptoms may be a first priority because it appeals readily to a medical audience, and reflects the health administrators' concern with cost containment. However, until we move past this limited evaluation approach, the true impact and potential of some of these therapies will never be fully and appropriately documented in a rigorous manner.

8.2 Healing: Moving to A More Holistic Approach

It is worth considering the implications of these findings related to the way we conceptualize health and healing and the ways health interventions are assessed which will then direct the ways in which health care is delivered. Specifically, these findings raise a number of questions that deserve further consideration such as: How can we move forward with a new understanding of health and well-being? How can clinical effectiveness as well as value and meaning be assessed when evaluating health care interventions? How can we continue to undertake research on the mind/body/spirit relationship to facilitate this new

understanding of health and well-being? Each of these questions will be considered briefly.

1. **How can we move forward with a new understanding of health and well-being?**

A rigid dichotomy between health and illness is questioned. The participants in this project demonstrated that feeling well does not necessarily mean getting rid of physical symptoms or overt pathology. Moving past this dichotomy means acknowledging that feeling well and healthy can co-exist with the experience of illness or disease. Thus a paradigm of healing suggests that healing rather than solely treatment or cure may be a legitimate ultimate objective. Healing aims to address issues from a holistic, mind/body/spirit approach:

> The reason we need to clarify the difference between healing and curing is quite simple: Effective therapy – whatever its outer form – initiates, facilitates, and supports the patient's self healing efforts, whereas the "curing" process is one that provides a more temporary and perhaps only palliative effect. Although "curing" may remove the symptoms of disease from the outside, so to speak, it usually leaves the underlying causes of symptoms untouched.[1]

When the participants were asked what healing meant to them they expressed the idea that healing was linked to increased awareness, personal insight and expression (understanding and expressing self in a more complete way), connecting to emotion and/or release of this emotion, and/or feelings of connectedness with others as opposed to simply a reduction or disappearance of symptoms. Further, healing was about a journey, a process, whereby some individuals could actually see how their illness facilitated both an important personal journey, and the experience of the journey itself was a healing phenomenon.

The mind/body relationship clearly holds the key to shifting a treatment oriented approach to a healing oriented approach. Thus an emphasis on exploring more about the nature of mind/body and it's relationship to healing is needed to truly understanding the complex and holistic qualities that encompass healing. Until such time, shifting mainstream health care delivery to reflect a holistic orientation is unlikely to occur to any significant degree.

2. How can clinical effectiveness as well as value and meaning be assessed when evaluating health care interventions?

Moving from a 'treatment' orientation to a paradigm of healing would mean that the value of health interventions be assessed not only for clinical effectiveness (i.e. change in symptomology), but also on how closely they reflect the values of those choosing to use them. If healing means addressing issues of self awareness, personal growth, and transformation, then healing interventions should be evaluated for their ability to address these processes. If patients are looking to be 'heard', and for a holistic approach to care, these elements of an intervention need to be assessed.

In an era of increasing chronic illness, there is an increasing trend for those experiencing chronic illness to choose to use complementary therapies (those offered outside of the conventional system) including therapies aimed at influencing mind/body pathways. Individuals appear to be choosing these therapeutic modalities in order to achieve outcomes they value, values not generally addressed by conventional care. It is known that patients value such things as a sense of being in control, being an active participant in treatment, and developing a caring and trusting relationship with their practitioner. From a healing perspective, 'feeling better' is as important as 'getting better'. As patient preferences and

values shift, so should the criteria in which interventions are judged to be successful. Research protocols will need to be designed to be sensitive to these new criteria.

3. **How can research methodologies be adapted and further research be conducted to investigate the mind/body/spirit relationship to reflect this new understanding of health and well-being?**

The findings suggest research methodologies need to be adapted to respond to the challenges highlighted. A 'qualitative add-on' to a study designed with a positivistic epistemology is not sufficient. The foundation on which studies are designed must respect the non-dualist reality of participants. With increasing evidence that healing shares a close relationship to self-awareness, it becomes important to consider how self-awareness can be appropriately understood and measured. Further, a more thorough understanding of the experience of transformation needs to be obtained. The measurement of these aspects of healing will require additional qualitative exploration in order to assess their true complexities, the breadth of individual experience, and the process-oriented nature of the journey. There is a study currently being designed and will be undertaken by the Tzu Chi Institute to do just this. The project 'Exploring cancer patients' transformation experience in integrative health care' is anticipated to commence in the Fall of 2002. The objective of this study is to describe the essential features of the transformation experience among people living with cancer using one-on-one qualitative interviewing. Barriers as well as facilitators of transformation will be explored.

While quantification likely oversimplifies the changes taking place, once a deeper, more experiential understanding of mind/body influences and the process of healing is

documented and understood, it may be possible that quantitative measures could be developed which would better capture these experiences. Issues around appropriate instrument design, as well as appropriate interpretation of the data will have to be addressed. These measures would need to capture within-subject changes, and assess the *process* nature of healing. To capture within-subject changes more individualized questionnaires are likely to be useful. While completely individualized questionnaires may not be possible because of the need for adequate between-subject assessment, at least partially individualized ones may be feasible. For example, including a generalized impact assessment along with the measurement of an individual's symptoms to understand not only the impact of symptoms in one's life, but the relationship between this impact and the journey associated with healing. Individualized items and/or individualized weights for items may assist with this. In this case, the focus remains more on change rather than absolute values, and allows for the assessment of *subjective* experiences of health and well-being.

When interpreting these data, considerations about the timing of data collection, the number of repeated measures, and the length of the follow-up period need to be carefully considered. In particular, it may be appropriate to rely more on long-term assessments for evaluating interventions that encourage participants to work on deeper psychological issues. Short-term outcomes may not reflect change in this context and need to be interpreted with caution. Because depth of psychological work experienced during the program is likely related to the nature of the outcome, there is a need to find ways of assessing the degree of involvement in psychological growth in order to more accurately

interpret outcomes. Judgments regarding what are seen as positive and negative outcomes will have to be carefully considered as it is the subjective feelings towards a particular 'state of being', and the role this state has in one's overall healing journey that may be most relevant.

In addition to challenges around outcome measurement this study also illuminated some of the challenges using randomized clinical trial methodology for studying an intervention of this nature. The clinical trial, also called an explanatory trial, is meant to replicate a controlled laboratory environment, and as such, is methodologically challenged by everyday variations and individual differences for complex interventions of this nature. The core value of this methodology is control through random assignment, blinding of researchers and participants to the study group assignment, and the expectation of a standard 'exposure' of the intervention for each participant in the treatment group. The execution of the evaluation of the Mind/body Program struggled with each of these elements. Specifically, participants resisted randomization, it was impossible for blinding to occur, and the degree of 'exposure' to the intervention was dependent on a number of complex factors related to the individual participant. Further, withholding the treatment from the control group was difficult, and the follow-up period was reduced due to pressures from the control group to have the opportunity to experience the intervention. In contrast, a 'pragmatic trial'[2] that values carrying out a comparison under everyday conditions may provide an improvement to some of the challenges listed. The aim of this trial is to assist more directly with clinical decision-making as it reflects the actual nature of day-to-day clinical encounters. In a pragmatic trial, as long as the criteria are clearly and reliably

predetermined it is possible to tailor the treatment to the individual patient. For interventions that emphasize a 'holistic' approach and choice for participants, this is a very important consideration. It does not necessarily require the patient or therapist to be 'blind' to the treatment being given, and is designed to take patient preference into account.

An example of a pragmatic trial about to be initiated is a joint project between the BC Cancer Agency and a complementary cancer care center in Vancouver, The Centre for Integrated Healing. The study is being conducted to evaluate the effectiveness of participation in the holistic cancer care program offered at the Centre for Integrated Healing to improve quality of life, survival and assess costs to the health care system for patients diagnosed with cancer believed to be incurable by conventional means. The treatment group will be given the opportunity to participate in the holistic cancer care program at the Centre involving an introductory workshop as well as a collection of experiences the participants can choose from, including private consultations with physicians, consultations with associate practitioners, and opportunities to attend a number of ongoing classes. Both groups will be offered standard conventional palliative care. This project will use an integrated mixed method protocol utilizing a randomized trial methodology in which the qualitative assessment is not an 'add-on', but is used to guide the methodological direction and work closely to direct and illuminate the quantitative measurement. Individualized assessments will be included with the quantitative questionnaires where possible.

8.4 In Conclusion

Continued exploration of the mind/body relationship using methods that extend beyond a reductionist, positivistic epistemology is critical to advance the area of mind/body medicine, and to appropriately direct the subsequent delivery of care. A truly holistic approach means acknowledging not only that a causal relationship exists between mind/body, but also dismissing the conceptual dualism that is still widely prevalent. This dismissal of dualism must occur not only in the use of language, but in the ways research protocols are operationalized, ways in which the value of such mind/body interventions are assessed, the way health is conceptualized, and the way in which health care is delivered. Three themes of a holistic approach to health, which are common threads in the literature, include self-awareness, transformation, and wholeness[3]. These concepts are not easily or appropriately understood with objective, quantitative measurement, and assessments do not always comfortably fit within a traditional randomized clinical trial methodology. In this dissertation, even accounting for potential statistical limitations, the implications suggest the need to rethink the basis of an evaluation of an intervention of this nature. This does not suggest the need for the abandonment of quantitative methods, but instead, puts forth a challenge for the quantification of the value of programs and individual experience to be more intimately tied to the true experiential realities of participants. It is important to consider whether the objective is to understand 'outcome', or to understand 'healing'. It may be that specific 'outcomes' in and of themselves, particularly in the form of short-term changes in symptoms, may not tell us very much about the process of healing.

[1] Upledger, J. Self-discovery and self-healing. Carlson R, Shield B, editors. Healers on healing. New York: G.P. Putnam's Sons; 1989. p. 68.

[2] Walker LG, Anderson J. Testing complementary and alternative therapies within a research protocol. European Journal of Cancer 1999; 35(11):1614-1618.

[3] Ballentine R. Radical healing and the rebirth of science. Townsend Letter for Doctors & Patients 2001; Feb/March: 28-36.

Appendix A

Reflections on Being a Participant Observer

The Mind/Body Program

My role as a participant and an observer in this research is worth a special note. I participated in both of the Mind/Body Programs that were conducted (the second program for participants in the control after the study follow-up period had ended), and through this, I gained immense experience and understanding. This kind of understanding would not have been possible by any other means. Witnessing the journeys of the participants gave me an understanding of the context within which to interpret the interview data. This produced a higher quality of data, and a richness of description of the findings not otherwise possible. After having this experience, I believe this type of participant observation should be considered as an integral aspect of the assessment of interventions of this nature in the future. Having said this, it also feels important to reflect on some of the challenges I experienced using this method of data collection.

While the experience of participating provided me with the opportunity for profound learning, and at various times, it also brought profound uncomfortableness. Finding a balance between being a researcher and a participant was not always easy. It was a place where I felt boundaries were too rigid and too loose all at once. They were too rigid because I longed for everyone in the room to see me as truly 'one of them', and yet, they knew, and I knew, I was there trying to understand their experiences for my research. That made me different. And sometimes they were too loose because there were moments where I found myself with intense emotion, caught up in my 'own stuff' so to speak, and I

worried I would miss something that was happening for someone else while immersed in my own process. I had to make choices in some moments between allowing myself to completely become immersed in an experience, and pulling myself out of the experience to remain an observer. I allowed myself to do both at different times. If I had only observed, I would not have fully *known* the experience, and if I had only experienced, I would have lost the opportunity to fully witness what was happening for others around me.

One question of relevance to this project is whether the participants ever really saw me as 'one of them', and whether they were able to experience the program freely with me there. I feel confident that they were able to do this to a large extent. I will never fully know my influence, but I consciously tried to behave the way others participants behaved in the program. I spoke when it was my turn, expressed emotion when it came up, and engaged in the activities with curiousity and wonder. I chose not to take any notes in the presence of participants. So, while my presence was known, I was part of the group. The comments, the questions, and conversations I had with participants lend support to this.

The Research Interviews

Conducting the research interviews was another source of challenge for me. It was difficult to find a balance between being a researcher, an information gatherer, and a more active participant, or a friend. This discomfort was enhanced because of my previous relationship with interviewees during the Mind/Body Program. While my long-standing training in positivist methods told me to detach, an interpretivist tradition allows for and embraces the importance of interaction. But, what does interaction look like? An example of this struggle is represented in a quote from my research journal on September 18, 1998:

> I felt today more issues around what my place is as a researcher. Specifically how much do I engage in the discussion and the dialogue? I found I could relate to so much that she [the interviewee] was talking about, and it's very difficult for me to know when and if to share my experiences as part of the interview. Is it appropriate, misleading, or biasing? There was one point when she said to me, "Does any of this make sense to you?" And it did make absolute sense to me. I had experienced the same things and I said so. I think she needed confirmation that I could relate to her, that I could understand her. It wasn't enough to just listen, she wanted to be understood. We share an understanding.

It took time and experience to learn to find a place of comfort in the interviews. What I learned was a balance between making sure I did not create an environment which one participant responded to by saying; ' I feel as though I am on stage here,' and giving myself permission to engage in the conversation. I learned that I could share a piece of myself with someone and still collect the data that I am looking for. I learned that when I bring myself forward, even in a small way, I become human, and the level of comfort for the participant can shift dramatically. From here, a deeper, richer, more open conversation can often occur. I realised the question of bias is significant at any level of engagement with a participant. The bias created from a participant feeling discomfort due to my detachment in the interview process is as important a bias to consider and address as the potential bias from the interviewer actively engaging.

Appendix B

Means and Standard Deviations for all Scales by Group and Time-Point

Means and (Standard Deviations) for SF-36 Health Status Survey by Group and Time-Point

All scales are scored between 0 and 100 with higher numbers indicating more positive change.

Physical Functioning			
	Baseline	3 Months	6 Months
control	62.9 (31.5) **N=13**	64.0 (32.9) **N=8**	62.5 (33.6) **N=8**
mind/body	55.7 (28.5) **N=26**	66.4 (25.8) **N=25**	68.6 (28.2) **N=21**
Role - Physical			
	Baseline	3 Months	6 Months
control	17.3 (29.6)	15.6 (35.2)	21.8 (36.4)
mind/body	22.1 (39.6)	38.1 (42.3)	44.0 (44.0)
Bodily Pain			
	Baseline	3 Months	6 Months
control	50.2 (31.2)	61.8 (31.1)	61.4 (29.4)
mind/body	51.6 (22.7)	58.6 (22.3)	61.9 (26.4)
General Health			
	Baseline	3 Months	6 Months
control	48.7 (24.5)	37.1 (22.5)	39.6 (30.2)
mind/body	45.1 (19.5)	57.5 (19.3)	53.3 (23.9)
Vitality			
	Baseline	3 Months	6 Months
control	35.4 (27.7)	46.3 (23.9)	40.6 (31.6)
mind/body	35.8 (20.5)	49.0 (20.7)	49.3 (20.2)
Social Functioning			
	Baseline	3 Months	6 Months
control	47.1 (26.1)	48.4 (37.5)	46.9 (30.4)
mind/body	52.5 (26.3)	67.9 (27.3)	67.9 (26.1)
Role-Emotional			
	Baseline	3 Months	6 Months
control	30.8 (44.0)	54.2 (43.4)	66.7 (39.8)
mind/body	49.3 (42.1)	52.4 (44.2)	60.3 (45.5)
Mental Health			
	Baseline	3 Months	6 Months
control	58.5 (22.9)	62.5 (24.0)	61.0 (20.9)
mind/body	59.5 (19.0)	70.9 (19.6)	71.0 (17.5)
Health Transition*			
	Baseline	3 Months	6 Months
control	3.2 (1.1)	3.1 (0.8)	2.8 (0.9)
mind/body	3.1 (1.1)	2.4 (1.0)	2.6 (1.0)

*A single item that provides an indication of perceived change in health. Scored on a 5-point scale where lower numbers indicate more positive change.

Means and (Standard Deviations) for Quality of Well-Being Scale by Group and Time-Point

All scales are scored between 0 and 100 with higher numbers indicating more positive change.

Acute and Chronic Pain	Baseline	**N=13 N=26**		Three Months	**N=8 N=25**		Six Months	**N=8 N=21**	
	Day 1	Day 2	Day 3	Day 1	Day 2	Day 3	Day 1	Day 2	Day 3
control	44.5 (7.5)	41.3 (9.1)	40.3 (10.1)	37.5 (13.7)	38.7 (14.6)	38.2 (13.5)	44.6 (10.2)	42.2 (9.3)	44.5 (6.3)
mind/body	42.4 (8.5)	40.4 (6.9)	41.7 (8.0)	43.0 (9.1)	39.4 (8.8)	41.5 (9.5)	40.2 (12.6)	39.4 (12.3)	41.4 (13.1)
Self Care and Mobility	Baseline			Three Months			Six Months		
	Day 1	Day 2	Day 3	Day 1	Day 2	Day 3	Day 1	Day 2	Day 3
control	0.7 (2.5)	0.7 (2.5)	0.0 (0.0)	0.0 (0.0)	0.0 (0.0)	0.4 (1.1)	0.4 (1.1)	0.4 (1.1)	0.8 (1.4)
mind/body	0.5 (1.2)	0.4 (1.0)	0.6 (1.3)	0.2 (0.7)	0.3 (0.9)	0.3 (0.9)	0.3 (0.9)	0.3 (0.9)	0.7 (2.1)
Physical Activity	Baseline			Three Months			Six Months		
	Day 1	Day 2	Day 3	Day 1	Day 2	Day 3	Day 1	Day 2	Day 3
control	5.1 (4.9)	5.8 (5.8)	7.8 (6.7)	3.6 (3.8)	3.6 (3.8)	5.6 (5.6)	8.8 (6.9)	5.6 (5.6)	7.7 (6.2)
mind/body	5.9 (4.5)	6.4 (5.5)	6.0 (5.1)	6.0 (4.7)	4.2 (4.5)	5.8 (5.6)	7.1 (6.7)	5.4 (5.7)	5.1 (5.8)
Self Care and Usual Activity	Baseline			Three Months			Six Months		
	Day 1	Day 2	Day 3	Day 1	Day 2	Day 3	Day 1	Day 2	Day 3
control	3.3 (2.7)	2.5 (2.8)	3.3 (2.7)	2.0 (2.8)	2.7 (2.9)	2.0 (2.8)	3.4 (2.8)	2.0 (2.8)	3.4 (2.8)
mind/body	3.2 (2.7)	2.6 (2.8)	2.6 (2.8)	3.0 (3.4)	1.3 (2.4)	2.3 (3.1)	2.5 (3.1)	1.5 (2.5)	2.3 (2.7)
Daily Quality of Well-Being	Baseline			Three Months			Six Months		
	Day 1	Day 2	Day 3	Day 1	Day 2	Day 3	Day 1	Day 2	Day 3
control	46.3 (9.2)	49.7 (10.6)	48.6 (11.3)	56.9 (17.8)	55.0 (19.6)	53.7 (19.0)	42.8 (15.4)	49.7 (15.2)	43.6 (12.0)
mind/body	47.9 (9.1)	50.3 (9.8)	49.1 (11.0)	48.0 (12.6)	54.8 (12.8)	50.2 (15.2)	49.9 (16.2)	53.3 (14.6)	50.5 (15.3)
Average QWB Score	Baseline			Three Months			Six Months		
control	48.2 (8.4)			55.2 (18.6)			45.4 (12.9)		
mind/body	49.1 (9.0)			51.0 (11.8)			51.2 (14.4)		

Means and (Standard Deviations) for the MOS Social Support Survey by Group and Time-Point

All scales are scored between 0 and 100 with higher numbers indicating more positive change.

Tangible Support			
	Baseline	3 Months	6 Months
control	49.5 (29.9) **N=13**	36.7 (27.0) **N=8**	50.8 (32.8) **N=8**
mind/body	49.3 (33.0) **N=26**	59.1 (28.1) **N=25**	56.3 (29.0) **N=21**
Affectionate			
	Baseline	3 Months	6 Months
control	59.0 (30.9)	51.0 (38.0)	54.2 (32.4)
mind/body	62.3 (31.5)	68.8 (29.2)	68.8 (30.2)
Positive Social Interaction			
	Baseline	3 Months	6 Months
control	49.5 (36.2)	54.0 (32.2)	60.9 (32.5)
mind/body	61.3 (24.0)	64.1 (23.2)	60.0 (22.3)
Emotional or Informational Support			
	Baseline	3 Months	6 Months
control	62.0 (25.5)	62.5 (31.3)	67.6 (27.6)
mind/body	57.0 (26.3)	64.2 (26.4)	64.5 (25.9)
Overall Social Support			
	Baseline	3 Months	6 Months
control	55.0 (27.5)	51.0 (28.6)	58.4 (29.0)
mind/body	57.5 (25.9)	64.0 (24.2)	62.4 (24.1)