HEALTH AND THE SPIRITUAL SELF:

Development and Application of a Theory and Measure of the Process of Healthy Change

A thesis

submitted in fulfilment of

the requirements for the Degree

of

Doctor of Philosophy

at the

University of Waikato

By

KIEREN FAULL

University of Waikato

2006

Abstract

Introduction

The overall goal of the thesis was to investigate the nature of the healthy human self and the process of achieving health. This was undertaken by reviewing established self-theory and presenting a summary of each theory and its position with regard to self-composition, self-agency and the nature of the healthy self. An inclusive self-theory was then developed, congruent with reviewed literature, which positioned spirituality as the essential core of self. From the foundational Spiritual Theory of Self and the findings of the first study in this thesis, the Health Change Process Theory was developed to explain and predict how people achieve sustainable health. Three subsequent studies resulted in the construction and testing of a quantitative measure which enabled scientific investigation of the nature of the healthy self and the process of achieving health.

Method

The methodology of the four studies in this thesis was based on the instrumental approach which posits that, while there are procedural differences between qualitative and quantitative methodologies, philosophically speaking, there is no fundamental difference as they are both equally applicable and valuable. Consequently, the methodology judged to be the most appropriate instrument to investigate each study's topic of inquiry was chosen rather than allegiance to either qualitative or quantitative methodology.

The first study was qualitative, as it investigated the definition of health and the process by which it was achieved from the perspective of 30 people with chronic musculoskeletal impairments. The findings from this study provided the theoretical basis for the three subsequent questionnaire development and validation studies. The second study used qualitative methodology with 59 participants to identify participant-generated items used in a new quantitative holistic health questionnaire and then employed quantitative methods to perform preliminary tests of the reliability and validity of this measure. The third study used quantitative methods with 233 participants to evaluate more robustly the reliability, content and concurrent validity of the original developmental measure and another, behaviourally-orientated assessment instrument, which used the identical item content but re-framed in the past tense. The fourth study employed

qualitative and quantitative methods with 205 participants to evaluate the clinical validity of the scale found to possess reliability and validity in the previous investigation.

Results

The critical review of self-theory concluded with the development of the Spiritual Theory of Self. The initial study supported this theory as a robust explanation and predictor of the determinants of a healthy self. Furthermore, the findings of this study and a review of relevant literature concluded with the development of a Health Change Process Theory, which was based on the Spiritual Theory of Self. The Health Change Process Theory explains and predicts the process by which a healthy self develops. The subsequent questionnaire development and validation studies sought to provide a quantitative holistic assessment tool, congruent with the Health Change Process Theory, and found the 28-item QE Health Scale (QEHS) to be a reliable and valid measure of holistic health. These results also demonstrated that the Health Change Process Theory and the underpinning Spiritual Theory of Self were robust. With regard to clinical application, the QEHS was found to aid assessment, therapeutic intervention, a client-centred holistic approach to healthcare and evidenced-based practice. The Patient Profile, derived from QEHS responses, provided a tool that enabled theory to be applied to practice by identifying the key indicator personal attributes determining holistic health status.

Conclusion

The research results demonstrated that the Spiritual Theory of Self and the Health Change Process Theory provide valid explanations of the constructs that enable people with musculoskeletal disorders to remain otherwise healthy with such conditions. Furthermore, the relationship between the findings and established self-theories suggest that the Spiritual Theory of Self and the Health Change Process Theory may advance knowledge of the predictors and interventions that enable all people to undertake a health-enhancing process of change when confronted with adversity.

The QEHS and associated Patient Profile were found to be reliable and valid tools that facilitated assessment and enhancement of the holistic health status for people

with musculoskeletal impairments. These tools identified barriers to achievement of holistic health, predicted by the Health Change Process Theory; facilitated the therapeutic process through a focus on issues meaningful to those receiving healthcare; aided treatment decision making; and enabled quantitative evidence-based evaluation of the efficacy of interventions.

Moreover, the overall results have advanced psychological knowledge with implications for all fields of psychology involved in the study of people. The evidence of the research undertaken provides a basis for promoting knowledge and research of chronic healthcare delivery and a spiritually based conception of self and health. The QEHS and associated theories provide a tool and basis for investigations where people are experiencing traumatic, irreversible crises. However, the initial aims of further research should be to refine the QEHS and the associated Patient Profile to enable the use of theory and the QEHS across a diverse range of research populations and to investigate the applicability of these to facilitate the maintenance or achievement of a healthy self.

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The next component of the health psychology programme began in the early 1990s. Things were beginning to work out for the Faull family. They built their home on the Mohakatino farm, which along with the shearing business was quite profitable. Full-time farming was becoming more a reality than a dream. The next module of Kieren's training was then presented to him. He managed to acquire rheumatoid arthritis in 1995 facilitating the development of reflection and problem solving skills. This event ensured he could no longer carry on doing what he enjoyed and had structured his life around.

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PREFACE

Background

The overall goal of this thesis was to explore how people either remain or become healthy through the experience of a change event that results in a personal crisis of the self. In particular, this thesis explores the possibility that to be a healthy human being requires a view of self that encapsulates more than just biopsychosocial aspects. It is proposed that for the material biopsychosocial self to be healthy, meaningful and resilient, there is a need for the individual to acknowledge and increase awareness of the foundational component of self as nonmaterial, that is, possessing properties inconsistent with material entities. Examples of change events that may precipitate a personal crisis of self include natural disasters, war, immigration, loss or change of occupation, loss of significant others and ill-health. In this thesis, the experiences of people with a chronic physical impairment were employed to examine this notion.

The term commonly used in reference to the nonmaterial aspect of self is spirituality. There has been a quantity of qualitative research undertaken to observe and record the characteristics of this phenomenon. There appears to be a consensus that self awareness of the spiritual and highly subjective core of self results in specific types of relationships, connections and self-perspectives. Beyond that, there is no one consensual, clear and precise definition of spirituality evident in the scientific literature.

Moreover, the tendency in much of the literature is to associate spirituality with religion, implying that these concepts are similar, if not identical. Consequently, it is implied that spirituality is not the nonmaterial basis of all life but rather a phenomenon peculiar to humans and defined by particular prescriptive beliefs concerning life. In contrast, others view spirituality and religion as distinctly different, often opposing concepts. Within this perspective spirituality is considered to possess properties that behave in a manner distinctly different from the more observable, material aspects of this world. However, the nonmaterial is assumed to be able to somehow integrate with the material to become an indivisible whole. From this view, the material and nonmaterial are not distinct and separate but somehow complementary and integral components of life.

Hence, spirituality is not seen as solely a part of human composition but rather the basis of all life. This thesis adopts the latter conception of spirituality.

Consequently, in this thesis the concept of spirituality is employed in a specific and particular manner. First, as it appears too early in the process of scientific investigation of this phenomenon for accurate, detailed description of what spirituality is, scientific investigation must rely on description and measurement of the impact of spirituality on the objective world. The literature on spirituality and health indicates that there is uniformity of description of the impact of spirituality on personal relationships, connections, meanings and beliefs. Therefore, these universal descriptors of the characteristics of the impact of spirituality on the biopsychosocial self were employed to provide an operational definition of this phenomenon. For many people, the perception of being fully human involves an experience of interconnection and interrelatedness that also encompasses the objective reality of physical or material separateness.

The term spirituality also emphasises the essential subjectivity of human perception and the present limitations of knowledge in this area. Spirituality is about relationships and connections that enable individuals to resolve seeming contradictions. For example, it enables the individual to perceive the self not only as separate, special and unique but also as a minuscule and integral component of the whole of life. Spirituality is proposed to be the component of life that enables relationships and connections to transcend the separateness of self and of temporal realities and to bind together all that is life, resulting in extension, connections and integration of the biopsychosocial being with self and the world.

Moreover, the concept of spirituality was employed to emphasise the essentially subjective nature of the human experience and to distinguish it from culturally specific behaviours and beliefs (religion) that do not necessarily include spirituality. While acknowledging that all people possess strong beliefs, the exact nature of these is idiosyncratic. Moreover, from the spiritual perspective, a person is viewed as an integral, unique but miniscule component of the whole. Therefore, individual beliefs are perceived as, at best, partial knowledge rather than absolute knowledge. While people may have an inner surety that their partial knowledge is ‘right’ they cannot claim that it is complete. Consequently,

from the spiritual perspective, beliefs are seen as tentative and constantly changing and developing. Hence, beliefs should be constantly evolving and for this reason are believed not to be amenable to scientific investigation of universal commonalities. Within the context of the thesis research, that is healthcare delivery, it is considered that investigation of the health benefits of particular belief systems is not scientifically credible.

Consequently, this thesis aimed to begin quantitative investigation of the relationships between the concepts of spirituality, health and self by developing a theory of personal change, based on a spiritual conception of self, and to construct a measurement tool to assess the effects of such spiritual awareness on the biopsychosocial components of self as individuals experienced change events that instigated a crisis of self. The experience of chronic physical impairment was employed as an accessible sample representing a change event likely to cause a personal crisis of self.

The thesis was based on the following assumptions regarding the state of spiritual theory and measurement of self and health:

1. At this point in time, science is limited by its degree of technological sophistication to not being able to directly observe or measure 'spirituality'. Nevertheless, science can develop quantitative tools to measure the predicted effects of this phenomenon on the biopsychosocial self. Constructing instruments to measure effects rather than the entity itself is an accepted scientific method of investigation of subjective concepts (e.g., wind and temperature).
2. However, measurement of self and health typically assumes that multifaceted measurement of objective function and dysfunction will identify the individual's health status. In essence such measurement requires momentarily freezing the object of measurement as separate and distinct from other objects. By doing so, the dynamic, fluid, interconnected and holistic nature of life is not measured. Quantum physics appears to be at the forefront of those attempting to address this problem.
3. Conceptions of self reinforce the division of the material from the nonmaterial in healthcare and can be classified according to the

philosophical reasoning that underpins psychology. That is, historically it has been assumed that the composition of people can be reasoned to be material or nonmaterial but not both.

4. The central issue that has lead to the conclusion of distinctness, incompatibility and separateness of material and nonmaterial entities is the assumption that these entities possess opposing and mutually exclusive properties. Much of this rationale is based on knowledge of the material world as represented by classical physics.
5. There is a need to address this fundamental issue of the separateness of the material and nonmaterial in self-theory in order to construct a view of each self theory as a coherent part of the whole. To do so, this thesis reviews self-theory from the material – nonmaterial viewpoint and seeks to construct a rudimentary holistic theory of self from existing evidence. In essence the aim is to attempt to explore established evidence from a different perspective and construct a measure from this perspective.

The specific questions addressed in this thesis are:

1. When people are healthy, how do they perceive themselves? Specifically, what do they perceive themselves as composed of and what degree of personal control do they perceive they have over their lives?
2. How are healthy people able to remain healthy when confronted by major change events?
3. How can major change events become opportunities to be healthy?

Thesis Aims

The overall goal of the thesis was to investigate the nature of the healthy human self and the process of achieving health. To achieve this goal, the following sequential aims were addressed.

The first aim was to develop a concept of self, based on existing evidence of the nature of the healthy human self, and incorporating spirituality as a fundamental component of self. Chapter One categorises existing self-theories within a material-nonmaterial framework, presenting a synopsis of each theory and an accompanying outline of each theorist's conception of self-composition, self-agency and the healthy self. Chapter Two then critically examines the rationale of

these theories. Chapter Three considers the results of the Chapter Two critical review and related literature, and concludes with a Spiritual Theory of Self.

The second aim, to test and refine the characteristics of the healthy spiritual self, is addressed in Chapter Six. This first study (the HSD Study) sought to investigate the robustness of the Spiritual Theory of Self and asked two questions, "What is health for you" and "How did you achieve this health?" of a sample of people with chronic physical impairment.

Chapter Seven addresses the third thesis aim. This was to develop change theory explaining the process by which people develop a spiritually-based and healthy self. The Spiritual Theory of Self, the conclusions of the HSD Study, and relevant literature were all examined to develop the Health Change Process Theory.

The fourth aim was to use the Health Change Process Theory, developed in Chapter Seven, to derive factors and develop potential measures of these factors in order to discriminate a sustainable healthy self from others. The second study, the SIQS Study (Chapter 8), resulted in the development of two possible measures.

The fifth aim, addressed in the HAS Study (Chapter 9), was to evaluate the reliability and validity of the measures developed in the previous SIQS Study. Reliability was tested statistically, and validity was evaluated predominantly by using the Spiritual Theory of Self to predict differences in health status which the two scales should discriminate, and testing whether they succeeded in doing so.

The sixth aim was to evaluate the clinical applicability of the Health Change Process Theory and the associated measure, validated in the previous HAS Study, for use by health professionals in assisting a person dealing with chronic health issues to establish and maintain a healthy self. The QEHS Study (Chapter 10) applied the theory and measure to a population dealing with physical disability.

Chapter Eleven addresses the overall goal of the thesis, that is, to identify the characteristics of the self and the process of self-development that provides people with the capability to remain healthy when faced with adverse, life-changing events. The relationships between the findings of the four studies, self-theories,

the Spiritual Theory of Self, the Health Change Process Theory and the QEHS scale are discussed. Possible limitations of the research are indicated and future research proposed and, finally, scientific and social implications of the research and resultant theories are examined and the thesis conclusions stated.

Thesis Structure

The thesis explores accepted concepts of self and the processes of acquiring a robust healthy self, with a focus on the relationship of spirituality to self. Analysis and classification of self theory from both a material and a nonmaterial philosophical perspective is not common in psychology. Moreover, research focusing on self theory and its relationship to health typically centres on examination of concepts less abstract than spirituality. Consequently, robust theoretical conceptions of self have been developed on which research designs, procedures and measures have been well established. In contrast, spiritually-based theories of self and health, and methodologies for researching these, including quantitative measurement of holistic health, are not well established. Therefore, a need existed to establish a rational spiritual theory of self, and to develop a theory that explained and predicted how such a spiritually-based healthy self evolves. Having done so, it became necessary to construct a reliable and valid quantitative measure of the spiritually-based self to provide a basis for further research in this area. Consequently, the thesis includes reviews of the literature on self-theory and coping with significant change or adversity, which were used to contribute to the theories developed. The four related studies not only tested such theories but also developed a measure to enable further testing as well as the application of the new theories developed in this thesis. In consequence, a conventional thesis structure was deemed inappropriate.

The thesis has been divided into six parts to clarify the logical and interrelated sequence of the theoretical explorations, the theory development, the overall research methodological approach, the four studies and the final discussion. As the four studies consist of diverse methodologies and aims, each study is presented autonomously, within its own chapter, in conventional research report format of introduction, method, results and discussion sections. However, Chapter Four discusses overall methodological issues relevant to all four studies

and Chapter Five describes the setting and research population from which samples for all four studies were sourced.

Part One, *The Healthy Self*, includes three chapters. Chapter One, *Theories of Self*, reviews established self-theories from both the material and the nonmaterial philosophical perspectives. A synopsis of each theory is presented with an accompanying outline of each theorist's conception of self-composition, self-agency and the healthy self. Chapter Two, *Health and the Critique of Self Theories*, provides the definitions of health and disability employed in this thesis, and critically examines the rationale of the theories reviewed in Chapter One, and the alignment of each to either a material or a nonmaterial perspective of self. Chapter Three, *Towards a Spiritual Theory of Self*, discusses the problem of interaction between the material and nonmaterial properties of self and introduces quantum physics reasoning as a possible explanation of that interaction.

Literature concerning coping with significant self-change is discussed, and the definition of spirituality used in this thesis is presented. The literature discussed in this chapter and the results of the Chapter Two critical review are then used to construct a spiritual theory of self. The chapter concludes by stating the research questions that are addressed in the thesis.

Part Two, *Empirically Investigating Health and Self*, provides an overview of the methodological issues, research population and setting pertaining to the four studies presented in the thesis and includes Chapter Four, *Overall Methodology* and Chapter Five, *The Research Setting and Population*.

Part Three, *Health and the Spiritual Self: Initial Explorations*, begins with a study that explores the definition of health and the process of health attainment from the perspective of those with significant physical impairment. The findings from this study, in Chapter Six, *The Health, Self and Disability Study,* are considered along with a review of relevant literature and the Spiritual Theory of Self to develop a theory of the process of health change in Chapter Seven, *Developing a Spiritually-Based Health Change Process Theory*.

Part Four, *Developing and Testing a Measure of the Spiritual Self,* includes two empirical studies, the *Spiritual Health Questionnaire Development Study* (Chapter 8) and the *Health Attitudes Scale (HAS:2) and QE Health Scale (QEHS) Development Study* (Chapter 9). The goal of the first study was to develop a measure of health congruent with the Spiritual Theory of Self, and to undertake preliminary testing of that scale. This first study resulted in two potential measures, which were evaluated for reliability and validity in the second study (Chapter 9).

Part Five, *Applying and Testing a Holistic Health Measure,* comprises Chapter 10, *Clinical Application and Investigation of the Reliability and Validity of the QE Health Scale (QEHS).* This chapter reports on the investigation of the clinical applicability, reliability and validity of the QEHS, including its relationship to the relevant theory.

Part Six, *Health and the Spiritual Self,* consists of Chapter 11, *Conclusions and Implications,* which draws all of the research findings together, and examines them with respect to the reviewed self theories, the Spiritual Theory of Self, and the Health Change Process Theory. The consequent measure, the QEHS, is presented as a reliable and valid measure to advance knowledge with respect to the role of spirituality in health. Finally, the wider implications of the thesis findings are considered.

PART ONE: THE HEALTHY SELF

CHAPTER 1: THEORIES OF SELF

The terms 'personality' and 'self' need to be discussed at the outset as they are often used interchangeably. Personality is possibly the more correct term but 'self' is the term preferred in this thesis. It is used because personality implies (even if it is not literally defined as such) the specific nature or character of a person, not the complete physical, social, cognitive and spiritual experience that being human entails. Personality is too easily assumed to be a part of self rather than the totality of self.

The Construction of Self Theory

Self-theories aim to identify and explain what we are and how we can live physically, socially and cognitively well. Typically, through working with clients, theorists have developed personal beliefs of the critical components necessary for a person to be healthy. These are then progressively refined by a diverse range of formal and informal data collection procedures that range from reflecting on therapeutic interactions to robust scientific investigations. All aim to advance understanding of what we are, why we exist and how we can remain well in the face of constant change and frequent adversity. Self-theorists are asking 'What does it mean to be human, what is the meaning of our lives and how can we live well?' These questions all address the following central issues:

1. What are people composed of? Are observable body, brain and relationships all that self is? Or are 'mind', 'I' and other subjective phenomenon real - or illusionary - components of self?
2. To what degree are we active or passive agents controlling our lives, determining our destiny and health?
3. What is a healthy person?

Each of these issues arises from the preceding one. The theorist's belief about the fundamental nature of humankind will determine the assumptions of self-agency and both of these will guide the theorist's reasoning as to what are the necessary characteristics of a healthy person.

In essence, self theories attempt to shed light on the fundamental questions of human existence. Such questions began in the literary field of philosophy, from

which psychology emerged. Consequently, philosophical rationale about the nature of self forms the foundational *a priori* assumptions of self theory, and understanding each theory's *a priori* position is essential to fully comprehending the theories.

Philosophical Foundations of Self Theory

The basis of theories of self are abstract rather than the objective physicality of self, that is, metaphysical, focusing on the big questions of life. Typically, data is gathered to support beliefs and interpreted by the theorists with these beliefs. Consequently, the development of self theory is speculative, somewhat circular with subjective beliefs, and also objective data commonly incorporated to support rather than refute a particular belief. Therefore, each theory is attempting to support or refute a specific set of beliefs or *a priori* assumptions about the nature of humankind. These beliefs can be categorised as either the material or nonmaterial views of humankind.

Termed the materialistic philosophical position (Taylor, 1992), the majority of self theorists view humankind as consisting of material, largely visible, objectively discernible organo-chemically based compounds that, by evolution, became a highly complex animal. Moreover, from evolutionary theory they assume species survival and mastery of the environment are the fundamental purposes of existence.

Such theorists view self as consisting of body and brain, comprised of and therefore explainable in terms of genetic makeup, chemical, hormonal, energy and neural activity. The sense of a distinct, autonomous 'I' and such subjective health states as love, hate, anxiety and wellness are believed to be products or epiphenomena of material processes. Therefore, it is assumed that the nature of subjective health states directly result from the nature of function of the material self. Therefore, there are physical properties of the body and brain not yet fully understood, and, for now, identified as abstract concepts that in fact are material. The brain and body affect the state of each other in yet unidentified material processes so that altering the psychological state will alter body state, or vice versa. In both cases, explaining self requires the objectification and reduction of mental states and other nonmaterial phenomena to their material derivatives.

Epiphenomena are regarded as real *only* if the scientist or other such authorities can provide a rational explanation of how such states might arise from the fundamental material basis of humankind. Furthermore, all healthy aspects of human behaviour and thought must be able to be explained in terms of preserving existence and enhancing survivability.

With regard to self-agency, materialists assume our complexity is attributable to chance genetic and environmental interactions. This includes random genetic mutations occurring at environmentally favourable times, so advancing our competitive advantage within a hostile world. Such a view of humanity negates the possibility of the individual self being capable of authentic active agency; free will is simply a perception, an illusion. Nonetheless, although illusionary, it can be suggested that it is a successful motivator aiding survival.

More recently, materialists have argued that we are evolved animals but that self has broken free of its material roots, expanding and discovering the core, nonmaterial self. From philosophical principles (Taylor, 1992), this position is indefensible because, for people to be self-determining, they must be free of what materialists assume the self to be, that is, determined by extrinsic factors.

The only possible way something that is material, and therefore determined, can be self-determining is if there is an actual component of self that does not possess material characteristics, that is, possesses nonmaterial properties. For a materialist such a position is a negation of their core premise that people are material beings. If this nonmaterial component is assumed not actually to exist then any feelings of self-agency must also be illusionary. Theorists who seem unaware of this fundamental contradiction are categorised in the present discussion as transitionalists.

The second philosophical position, the nonmaterial, seeks to solve the problem of a nonmaterial core of self existing in a material body (Taylor, 1992). The essence of self is proposed to be nonmaterial and therefore not restricted by, or subject to material laws. The nonmaterial is seen as the basis of all life, and the physical and social worlds as special cases of the fundamental nonmaterial nature of the universe.

Because the nonmaterial does not conform to the same scientific laws or uniform ways of being, it is often assumed that the nonmaterial is totally free and, therefore, as the core of a person is nonmaterial, people have total free will. But if the nonmaterial is not created from within and by self, how can self freely determine the characteristics of this core? Therefore, the core characteristics of the nonmaterial self are as equally determined (but in a different manner) as the material self. Consequently, active agency is confined to a free choice of the degree to which the inner, nonmaterial self is reflected in outer thought and behaviour. Self-agency is perceived not as personal power or mastery, but as personal expression of a universal, nonmaterial or spiritual force. Accordingly, the purpose of human existence is not to survive, but progressively to align the material with the nonmaterial foundation of life to strengthen self as an integral component related and interconnected to all that is life.

Such a conception of self assumes that there is a realm of existence that is neither material nor objectively observable. Moreover, the 'mind' and soul are seen as products of the interactions of the material self, physical and social worlds with the nonmaterial, spiritual core self. Such a view places primary importance on the mind and deeper still, the spiritual, but acknowledges interaction between the material and nonmaterial. The mind is assumed to be an autonomous entity, with choice as to the characteristics of its existence, and therefore it is assumed that the self is a partially active agent in determining the nature of thought and behaviour.

The third answer to the problem of existence, the idealistic, and antithesis of the material position, dismisses the material as an illusion of the mind and argues that the only reality an individual can be sure of is that known in one's mind (Taylor, 1992). This is a credible philosophical argument; however, psychology is a science, requiring interaction between objective data and abstract concepts to advance knowledge. Therefore, the idealist argument will not be considered here.

Monte's (1991) text, which provides a comprehensive critical review of theories of self, was the core source for self-theory in the following discussion. However, a literature search did not identify any work that categorised these theories according to a material or nonmaterial perspective and therefore the following critical review is possibly a first attempt to do so. In addition, interpretation of

self-composition, self-agency and what constitutes a healthy self, which follows the review of each theory, is the thesis author's interpretation.

The Material Self

The core assumptions of the material theories of self are:

1. The purpose of human existence is to construct an impregnable, competent, independent being to survive and master the environment.
2. All behaviour and thought has a molecular explanation (e.g., DNA, neuronal, hormonal or energy).
3. Self is constructed from inherited genetics, patterns of thought and environment (e.g. family, culture, climate).
4. Self is a passive agent behaving and thinking in the manner dictated by genetic predisposition and physical and social environmental moulding.
5. Human beings are neither good nor bad; they simply are.
6. Individuals do not posses values, they learn laws of survival.

The Psychodynamic Self: the inner being

Sigmund Freud (1923) viewed the self as defined and determined by resolving three potentially conflicting components of the inner person. The first component is the inherited unconscious urges or drives of sex and aggression (*the id*). However, passions cannot impede social acceptance and integration as without interaction the id cannot be satisfied. Therefore, the second component of self, *the superego*, brings reason to the id's passion. The third component of self, *the ego*, is the conscious element of self, the 'I' we are aware of. The ego acts to satisfy id demands within societal constraints. Potentially, the ego may primarily give attention to the demands of either the id or superego creating an inner tension which will be released via dysfunctional, unhealthy behaviours.

Consequently, anxiety is the primary sign of ill health and considered to indicate unsatisfactory ego responses to the dominant id demands, causing an accumulation of psychic energy. Freud (1940) proposed that anxiety resulted from an ego solution that typically focused on satisfying the superego's need for moral, acceptable behaviour while repressing id urges. Such dysfunction may arise at any stage of human development if the needs of the id are not met, causing the individual to be fixated on that stage. Dysfunctional ego decisions fall into

two main categories. Firstly, the ego may employ one or a number of various strategies that repress into unconsciousness the needs of the id but satisfy the superego. Secondly, and less typically, the demands of the id may be addressed without consideration of societal realities, resulting in antisocial behaviour. Therefore self is a passive agent that must accept, confront and resolve the problems of the reality of bodily and societal demands.

Self-Composition

Asserting that instincts or basic traits aid species survival, which are the drivers determining behaviour and thought, fits logically with materialist philosophy and evolutionary theory. Self is a brain and body determined by genetic and environmental factors and the purpose of existence is gratification of self aiding survival of the human species.

Self-Agency

Self is completely determined, a passive agent.

Healthy Self

The healthy self openly acknowledges and accepts id drives as the basis for behaviour but these are countered by the superego need for social and self-acceptance as a good, moral person. The ego finds behavioural solutions, enabling both the id and the superego to be satisfied. In this way a balance between potentially opposing individual desires and societal demands is achieved.

The role or nature of physiological drives and the possibility of at least a partially active agent ego were the issues that those following Freud wrestled with. But first, we will review the behavioural approach, which conceives a self that is the antithesis of the Freudian self.

Behaviourism

Skinner's (1983) behavioural theory was based on the work of Watson (1967) who developed classical conditioning learning theory. The basic idea is that we learn a chain of behaviours because of their ability to satiate a physiological need. Self has inherited sensory-organ associations linking external stimuli and bodily responses which, when satiated, we find pleasurable. For example, experiencing stomach contractions (hunger) we respond by salivating. In time, we learn to associate food with satisfaction of hunger and, eventually, the sight or smell of

cooking food results in salivation. Watson believed that all human behaviour could be reduced and analysed as learnt associations, leading to conditioned, reflexive responses that satisfy our basic biological needs.

In contrast, Skinner (1983) believed Watson's approach only explained the simplest, involuntary learning common to most animals. He contended that behaviours initiated by internal stimuli (thoughts), in which the reward is responding to a thought, were the basis of higher learning in humans. Skinner believed that psychological laws that directly link thinking with behaviour would more accurately reflect human reality. Returning to the example of associations of hunger, salivation and food, Skinner argued that there were a large number of behaviours between food intake and consequent hunger satiation that are unexplained by simple classical conditioning. The growing or capture and the preparation of food are examples. Food intake and hunger satiation are *contingent* on these.

The shaping of human behaviour by such contingency reinforcement culminated in the laws of operant conditioning, addressing voluntary behaviour that *operates* on the environment so that the probability of obtaining a positive reinforcer, or alternatively, avoiding an adverse stimulus (negative reinforcement) or punishment, is increased (Skinner, 1983). Accordingly, the neural-sensory networks that determine behaviour, in interaction with environmental stimuli, determine how the self behaves. Once classical and operant conditioned learning reaches sufficient complexity, the organism then responds to the internalised learnt behaviour as if their thoughts are driving behaviour. Contingent behaviour associations commonly are prerequisites for receiving bodily satiating reinforcement and become reinforcing in it self. Consequently, the self appears to possess active agency through seemingly voluntary behaviour but, in essence, these behaviours are simply complex conditioned responses.

Self-Composition

Skinner viewed self as consisting of a conglomerate of memorised behaviours that through past interaction with the environment has 'taught' the organism how to act to increase the likelihood of gratifying the body. Skinner came to exactly the same conclusion as Freud: the difference is that Skinner views the source of self

as the external behaviours and environment while Freud believes it is an inner, cognitive conscious and unconscious thinking that is self. For both, self is progressively developed through accumulation of memorised data of past behaviours and their consequences.

Self-Agency

We do not shape our environment but rather are shaped by it and we have no inherent self, no self-agency and no personal destiny. The Skinnerian self is a totally passive agent.

Healthy Self

Health is the learning of competent, adaptive behaviours that satisfy biological needs enabling the organism to survive. Consequently, emotions such as anxiety are involuntary, reflexive behaviours caused by the learnt associations of stimuli and responses and are not indicators of the human health status. Anxiety is simply a memory signal to remind the organism of the past consequences of the present behaviour (Skinner, 1983).

Next, psychodynamic theories that increasingly attribute behaviour to a powerful, strong, autonomous and independent ego are discussed.

The Freeing of the Ego: The Egocentric Self

Anna Freud (1969), Hartmann (1958), White (1959) and Erikson (1959) questioned the dynamics of the id/ego relationship, exploring other possible drivers of behaviour. Monte (1991) describes the psychodynamic progression across these theorists as being similar to the degree of control a rider has over a horse. For Freud the id-horse is bolting and the ego-rider can, at best, hang on.

Anna Freud, Hartmann, White and Erikson all conceive of the id as consisting of physiological needs resulting in psychic energy demanding release but unlike Freud, the ego also possesses a degree of power, autonomy and its own drives. Anna Freud (1969) concluded that the ego's goal is to create warm, interpersonal relationships. Similarly, Hartmann (1958) proposed that the ego functions to develop and construct a place for the self alongside and in interaction with others in a way that is meaningful to the ego. White (1959) reviewed research and concluded that reducing tissue need does not explain curiosity, playfulness,

inquisitiveness or even a mouse running on an exercise wheel with no possibility of a drive-reducing reward. He proposed that the ego drives comprise: mastery of one's environment; to explore the world freely; and for the ego to expand and grow. Furthermore, he proposed that, except when survival is threatened, the ego drives dominate the id drives.

Self-Composition

Self is a material being but the brain has dominance over the body as tissue needs can be put to one side to satisfy mental needs. Self has become a purposeful, thinking being primarily concerned with relationships with others and social integration rather than bodily gratification. The self is ego-centric but no longer solely an inner construct; it is an entity, an 'I' that acts to further itself within its social and physical environments. The ego is now the true centre of 'I', of mastery of self in relation to society and even has some say over self-destiny.

Self-Agency

Clearly the relationship between the id horse and ego rider has changed. The horse is now harnessed to the ego's buggy; the ego-rider satiates the id-horse needs only to ensure the id-horse can be used to achieve the ego-rider's goals. In effect, the self is now an active agent in constructing self-identity and a place in the world, striving to master the id and the environment.

Healthy Self

A healthy self is one who has gained mastery over the id and superego to the extent that it can manipulate the environment, curtail physiological drives, create a distinct self and express this through meaningful social integration.

Erikson (1959) exemplifies such a psychodynamic concept of self. Though founded in the psychosexual conceptions proposed by Freud (i.e., the oral, anal, phallic, latency and genital), self is formed by the *psychosocial* experiences of each stage. Each stage is a self-identity crisis challenging self constancy and continuity but also providing an opportunity of developing what Erikson terms psychological virtues. Table 1.1 lists the developmental stage, the corresponding ego or identity crisis; and the virtue.

When young, through interaction with others, the individual learns the core values or virtues of self. However, the ego is not totally dependent on social and other

cultural-environmental influences. The earlier stages of identity crises are a progressive process from an identity embedded in biological needs (id) and parental norms (superego) through to complete freewill and fully active agent ego.

Table 1.1: Erikson's model of identity development

Developmental Stage	**Identity/ego Crisis**	**Virtue**
Infancy - oral stage	Trust versus Mistrust	Hope
Early childhood - anal stage	Autonomy versus shame & doubt	Will
Childhood (play age) – phallic stage	Initiative versus guilt	Purpose
Childhood (school age) – latency	Industry versus inferiority	Competence
Adolescence - early genital	Identity versus role confusion	Fidelity
Young adulthood - genital	Intimacy versus isolation	Love
Mature adulthood	Generativity versus isolation	Care
Old age	Ego integrity versus isolation	Wisdom

Self-Composition

The initial self is dominated by biological drives that motivate interaction with the social environment. In turn, interaction leads the individual to question the nature of self and others. Such identity crises teach the person virtues which are the core of self. Self begins as a completely material being but evolves into an essentially nonmaterial being. Self consists of four characteristics: first, a conscious, distinct identity; second, striving to maintain an experience of self as constant and continuous; third, inner, value centred, self-evaluation processes that, fourth, guide behaviours.

Self-Agency

Self has limited active agency. It does not choose the biological drives or experiences. Erikson stresses that the social environment is pivotal, particularly in the early developmental stages, to the nature of the virtues established. Therefore Erikson implies the self-agency is limited to a free choice to acknowledge and develop (or not) the inner self.

Healthy Self

The extent self is healthy is the personal experience of inner solidarity that is congruent with outward expression and behaviour. The healthy individual aims to achieve mastery over self-identity as opposed to mastery of one's social or physical environment.

The Transitionalists: Material Explanations for the Nonmaterial

Alfred Adler: The Superior Self

The relationships between self-perceptions of superiority and inferiority are a primary focus of Adler's (1973) self-theory. He asserts that the basic human drive is a striving for superiority, in order to compensate for our inadequacies. Inferiority is displayed as fear and helplessness, particularly when facing perceived loss of self or 'I', the greatest of these being powerlessness over the ultimate loss of self: death. He contended that feelings of inferiority are the basis of anxiety, providing the motivation to achieve superiority. Superiority is also a self-perception, a comparison of actual self with idealised self rather than comparison with others. Adler's concept of the idealised self was that it is a set of values, what self *should* be arising from childhood experiences of inferiority. For example, if a child has a physical impairment (as Adler did) with the consequence that it cannot run, play and interact with siblings, the child learns that it is inferior. Subsequently, the individual will feel this is wrong, establishing a value that inequality is wrong and so strive to establish, at least, an equality of interaction with others. To compensate for areas of inferiority, the child will focus on areas where they can match the actual self with the idealised value of equality.

Various childhood experiences of inferiority establish a value system that is integrated and unified by adulthood into a superordinate perception of self with a unified life purpose (Adler, 1973). Adler stressed the outward orientation of life purpose and that a preoccupation with superiority over others and self-centred feelings of inferiority is driven by a need for self-security as opposed to self-growth.

Self-Composition

Consciousness is self and the unconscious is in fact simply conscious memories not presently readily accessible. The id is a falsehood. All people have biological needs, but satisfying these needs does not result in a whole, healthy self. Adler emphasised personal values as the core of a self creatively merged with the social and physical world to form a whole, perfect self.

Self-Agency

He asserted that self is a totally active agent; an autonomous, creative intelligence striving to match behaviours with personal values, successfully adapting to life's circumstances and ensuring survival of self.

Healthy Self

Health can only be achieved when the self perceives itself as whole; that is, mastering self-determined goals. Therefore, the innate, evolved drive of humankind is to compete, grow and strive towards maximising one's inherited potential. A healthy self has transcended its physical self, gaining mastery over it and wholly conscious of and protective of the core personal value system. Hence, it has created a self integrated within the wider physical and social system of life, which enables the wholeness, unique roles and purpose in life of self to be perfected. Such a self is assumed to be the shaper, determiner and controller of their life events.

Albert Bandura: Social cognitive behaviourism

Bandura's (1986) self theory combines classical, operant conditioning and observational learning. Observational learning occurs because personally meaningful goals act as the reinforcer as opposed to tissue need satiation. To be effective, the person must *anticipate* reinforcement, that is, it is achievement of a cognitive ideal or goal that determines behaviour and interactions of the person with their environment. Individual variables determine what behaviours occur, what they aim to achieve and the likelihood of such behaviours being repeated. These variables are the individual's self-regulatory processes or value system consisting of self-observation, judgmental and self-reaction processes (Table 1.2).

Self-observation employs personal values to evaluate actions. Values are the essential meaning of self, providing the reinforcement for acting in a particular way. Judgmental regulatory processes evaluate the congruence and worth of actions. Self-reaction is an emotional evaluative signal of the effect of behaviour on self.

Consequently, self-efficacy is the person's measure of the degree that thoughts and actions align with the essence of self. Accordingly, people require full

awareness of the core nature of self, behaviours and environmental opportunities or restraints to maintain self-efficacy. Anxiety and feelings of helplessness arising from a discrepancy between the core of self and behaviour are caused by unrealistic expectations of self-power or control over the environment. Therefore anxiety is a signal of the degree of synthesis between person, behaviour and the environment. When the cognitive summation of actions and interactions with the environment is incongruent with values, the person concludes that they are not competent and anxiety results. In such instances, the person has learnt that they have little power (self-efficacy) over events, generalising to the individual experiencing a fear of all that life is, and a resigned certainty (learned helplessness) that there is nothing they can do about it.

Table 1.2: Subprocesses involved in the self-regulation of behaviour by internal standards and self incentives (from Bandura, 1986, p. 337).

Self-Observation	**Judgemental**	**Self-Reaction**
Performance dimensions	Personal standards	Evaluative self-reactions
Quality	Challenge	Positive
Rate	Explicitness	Negative
Quantity	Proximity	
Originality	Generality	Tangible self-reactions
Sociability morality		Rewarding
Deviancy	Referential performances	Punishing
Regularity	Standard norms	
Proximity	Social comparison	No self-reaction
Accuracy	Personal comparison	
	Collective comparison	
	Valuation of activity	
	Regarded highly	
	Neutral	
	Devalued	
	Performance attribution	
	Personal locus	
	External locus	

Self-Composition

Self is an active symboliser of experience, converting these into personal meaning and choosing the reinforcers. Self is a biopsychosocial system consisting of a core of values and cognitive-emotional processes interacting through behaviours with the person's social and physical environment. The material self creates the nonmaterial self. Bandura reasons that 'values' are learnt subconscious

underlying assumptions about the personal meaning and therefore expectations of self and life.

Self-Agency

Bandura uses the term reciprocal determinism in recognition that our actions contribute to the nature of our environment and in turn the environment impacts on self, implying that self is an active agent. Self-agency is confined to choosing the degree to which the core self is both expressed and congruent with behaviour, and so results in a cohesive meaningful self.

Healthy Self

The foundation of a healthy self is awareness of personal values and expression of these through behaviour. The unconscious needs to be brought into consciousness so that incongruence between values and behaviour are identified, remedied and anxiety reduced.

Abraham Maslow: Self-actualisation

Maslow (1973) contends that people are at any one of seven levels of existence but that all humans aspire to self-actualise. He believed that people could not move to a higher level of existence unless the needs at the preceding lower level were first met. The lowest level of existence is physiological where needs for such things as food, water, oxygen and rest dominate the individual's life. Once met, the self focuses on security, comfort and freedom from fear to provide a safe existence. Attachment (to love and be loved and have friends) needs follow at the next level, and then esteem issues such as the need to be of value comprise the subsequent level. At the fifth level the person focuses on development of knowledge through curiosity, exploration and understanding of the world. Once satisfied the individual then concentrates their attention on appreciating and achieving such aesthetic needs as harmony, order and beauty. Finally, the individual can self-actualise, which is to fully transcend the physical self, completely comprehending self and life in its entirety by insight gained through peak experiences.

People who have not self-actualised are striving to become their whole self while the self-actualiser is no longer struggling to become but is simply being their full self (Maslow, 1973). The focus of self-actualisers is on being all that they are, ensuring their actions, work and interactions are a pure expression of their being.

Peak experiences (encounters of intimacy with a deeper, mystical and spiritual phenomenon) result in awareness of being a part of something of infinite power and knowledge providing self with insights that expand, radically alter and advance perceptions of self and life. Maslow contended that most people encounter peak experiences but desacralise these, refusing to consider such experiences as real. When the need to know is motivated by a search for absolutes, for certainty rather than a simple enjoyment of adventure and discovery, it is pathological.

Self-Composition

Not all people acknowledge experiences of self-actualisation. Maslow (1973) contended that self was neither whole nor fully human until it is connected with the spiritual as the centre of existence. Therefore, he viewed the essence of the whole self as spiritual but argued that it is necessary for biological and psychological needs to be met before the self is able to acknowledge, connect and fully comprehend self.

Self-Agency

The self has limited active agency. There is a need to master the preceding stages in which environmental factors are not entirely subject to self-control before one can self-actualise and choose whether or not to acknowledge and seek connection, knowledge and guidance from the spiritual realm.

Healthy Self

A healthy self has all their biological and psychological needs met and is in relationship with the spiritual so that it feels complete, of value and is no longer striving to become somebody but simply celebrates being.

Erich Fromm: Self the Productive Contributor

Fromm (1968) emphasised the impact of the social world on the formation of self, focusing on the impact of capitalism and religion as threats to the existence of self He reasoned that personal and social freedom arising from industrialisation threatens the basic human need to be in meaningful relationship with others. To compensate, industrialised Protestant societies created a particular type of god, on which they could depend and never be separated from. This god is perfect, prescriptive, omnipotent and fearful. The imperfection and limited power is self-evident, therefore as self can never be of equal worth to this god, the individual is

continually reminded and confronted by feelings of helplessness and worthlessness. To appease this god, the Protestant work ethic developed, consisting of personal striving to perfect self through hard work and strong will, denying bodily urges, disregarding the emotional and subjective, suppressing unproductive thoughts and actively constructing a 'pure', highly structured society.

To counter helplessness and loneliness, the individual may merge their identity with a powerful other or exchange personal identity for role identity, resulting in the loss of self. Alternatively, the external world may be seen as threatening and as external aggression is not possible, destructiveness may be directed inwardly.

Countering helplessness and loneliness requires focusing on the uniquely human capability to transcend the present self, to reflect on what has been and to contemplate what could be. Aspiring to be what self presently is not results in creative connectedness, independence and uniqueness. Without self-reflection that transcends individuality, responses to the demands of the world ignore the essence of self. The primary needs of self are not biological, but for the self to become a distinct identity expressed through integration and connectedness to others (Fromm, 1968).

Consequently, Fromm perceived self as a productive, proactive, psychosocial being. Through love, self experiences relatedness and unity but is able to transcend present experiences perceiving the core of self as constant and continuing. A clear set of values and beliefs about the grand dilemmas of life, such as the meaning of life and death, creation and the order of the universe, define the core of self, the self-identity. To develop and expand such a self the person requires excitation and stimulation, provided by environmental change and challenges to self. Fromm asserts that concentration on stimuli that excite the biological self will eventually lead to boredom, life without meaning, and either inwardly or outwardly directed violence and aggression. He argues that it is the choice between a focus on these basic bodily desires, or on positive, self-growth and productive social integration, that is our foundational free will choice (Fromm, 1973).

Self-Composition

Fromm queries the existence of the spiritual, specifically a nonmaterial creator of the nonmaterial self. However, his focus on a productive identity, defined by its values, is not congruent with material philosophical assumptions. Explanation of his theory requires acceptance that the core component of self is nonmaterial. While Fromm stresses the importance of a productive self, contributing to society, he reasons that such behaviours are an expression of self rather than being the core self.

Self-Agency

The fundamental choice self has is to either be self or not. Self is not constructed by the individual but can be acknowledged, reflected upon and expanded to know itself as constant and continuous.

Healthy Self

The healthy self has an outward orientation transcending individuality and focusing on integrating and contributing productively to the greater whole of society while maintaining a distinctive, developing identity through awareness, protection and nurturing of the essence of self.

Carl Jung: Inherited Spirituality

Jung (1961) began with the concepts of id, ego and superego but moved beyond a concept of self confined to inner mental states, to a concept of self that transcends individuality and places self within the cosmos as a part of the past, present and future. Accordingly, biological drives (the personal unconscious) are subordinate to the spiritual or transcendent drive (collective unconscious). He identifies contradiction as a key component of self-growth and that transcendence creatively integrates paradoxes. The collective unconscious facilitates reconciliation of opposites enabling identification of personal values, which in turn lead to identification of self and a unique identity. For instance, the meaning to self of conflicting concepts such as life-death or good-evil requires an understanding that crosses the boundaries of time, to access inherited ancestral wisdom.

Jung (1958) identified four ascending levels of consciousness from the surface level of sensing (physical), to thinking (cognitive), which leads to feeling (emotions) and, at the highest level, intuition (spiritual). Intuition provides us with the knowledge to combine information into a meaningful whole and assess

the origins and potential of something. In essence, there is no difference between conscious and unconscious except for levels of personal awareness, openness, acknowledgement and acceptance. Consequently, thoughts, dreams, visions and fantasies are the vehicles by which the collective unconscious passes on understanding of the universe, meaning of self and knowledge of such things as past and future events.

Self-Composition

Jung's self is blatantly nonmaterial: it does not obey material laws, it races across time, it sees, hears and dreams things no one else is aware of; it consists of more than one person, no longer resides in a body or even an individual self, it is interconnected with all life and is essentially spiritual. But Jung maintains that this immaterial self is formed from a material process, the most significant being the inherited collective unconscious.

Self-Agency

Active agency is restricted to one free-will choice, to acknowledge self, actively listening and accepting direction from the collective unconscious or to deny transcendence and growth of self and remain encased in one's body and ego.

Healthy Self

The healthy self has resolved the seemingly conflicting paradoxes of life by tapping into the knowledge available from the collective unconscious. Integration of the collective unconscious within one's sense of 'I' dispels any tension and separation within self, between self and the physical and social worlds, between life and death, past present and future. Paradoxes and ambiguities of this kind are not unhealthy but rather the building blocks on which each person needs to focus and combine into the whole self to be healthy. When the collective unconsciousness in all its forms is acknowledged, these may be integrated with self through such mediums as dreams, visions, mythology, art, story telling and religion, which he viewed as healthy forms of self expression. For Jung, the process culminating in a healthy self consists of the dragging of the subconscious into consciousness, using the collective unconscious to mould all knowledge into a cohesive whole that is self.

Gordon Allport: Self as a Constant and Continuous System

Allport (1961) viewed human development as beginning with perceiving self as a physical being with tissue needs that evolves into a self that is nonmaterial, a distinct and known 'I'. Allport's fully developed self is characterised by the three attributes of self-objectification (viewing self as an object as well as the subject), extension of self (transcendence) and a unifying philosophy on life (core personal values), which provide cohesiveness to the seven developmental stages. The goal is to create a self as the knower of self, consisting of awareness, acceptance and a willing sense of proprietorship of all self is.

The process by which self changes from a material to a nonmaterial being involves repetitive revisiting through various experiences of each developmental stage until what is learnt becomes an unconscious, reflexive way of responding to the world and the underlying values determining worldview and behaviour. Termed functional autonomy, he contends that establishment of self as a system (which he called the 'proprium') rather than a physical entity enables the self to become free to creatively determine the meaning and functioning of self in the world. The central thrust of Allport's concept was propriate functional autonomy or the self as the proprietor and knower of self.

Self-Composition

Though stressing the nonmaterial aspects of self, Allport employs a material explanation for the development of the nonmaterial self. His self-theory with its empirical base in trait theory is often assumed to support the materialistic view of humankind. But, I do not believe this was Allport's intent as indicated by his references to 'the Creator' and his personal belief statement that our basic yearning and need was to transcend and enlarge ourselves and in so doing, bind ourselves to the ultimate knower, the Creator.

Self-Agency

Self can either choose to strive to acknowledge and action a self defined from within that strives to be ego-less or extract resources from the world to construct an ego-centred self.

Healthy Self

He termed the healthy self the *proprium*, being a self-system comprising those aspects of life one willingly claims proprietorship over and that one is custodian

of. The proprium is not to be confused with a collection of possessions belonging exclusively to self but rather things the self *knows* are integral components of self. Health requires perceiving oneself as a sub-system that only has full meaning and value when merged with the wider social system but in such a way that creatively expresses the essence of self.

Core Self as Nonmaterial – Material Self an Expression of the Nonmaterial Self

The theories already discussed explain much of human thought and behaviour. Other theorists have approached the concept of self from the opposite direction. Rather than assuming the basic building blocks of self are material, they propose that the material aspects of self are meaningful to the individual if fitted to the inner, spiritual foundation of self. They assert that spirituality provides the common thread that creates and binds all life into a cohesive holistic system. Moreover, because all life shares a commonality, all life is inherently interwoven and therefore the self system, which includes one's inner and outer worlds, can only be distinguished from the rest of life by the unique core meaning, purpose and place of the individual in the universe.

The core assumptions of the nonmaterial theories are:

1. The purpose of existence is to know infinite self through connection with the nonmaterial source of all things and by doing so, discover roles and the place of self within the universal system that allow the unique spiritual core of self to be fully expressed.
2. Understanding human behaviour and thought requires recognition of the spiritual realm, as well as examination of the congruence between self values and behaviour, and between self and the greater whole.
3. Self is nonmaterial, but in this world is in relationship with a physical body as well as the social and physical worlds – it is a subsystem.
4. The spiritual 'I' is constant and continuous.
5. Human beings tend to seek spiritual union, which requires a focus on other things than ego self. However, they also seek to satisfy ego at the cost of others.

6. The unique spiritual self is created from the spiritual realm, with common properties and characteristics as the basis of all life, providing a commonality, connection and oneness across all life.

Rollo May: Self the Meaning-Maker

May (1961) proposed that the basic human striving is continually to seek increased understanding, awareness and proficiency of knowing and fulfilling one's unique place, purpose, and roles while remaining in harmony with the greater system. He viewed human life as a process of being in the present but with a focus on becoming more fully meaningful in the future. The guiding principle in the formation of self is personally meaningful life encapsulating a balance of the three modes of the world. The three world dimensions are (a) self in the universe (the meaning of the whole system, the cosmos) (b) self with other (the external component of the self-subsystem) (c) the inner self world (the internal component of the self subsystem). The nucleus of the self-system is the value system, from which meaning of the worlds of self is derived. Identity is formed from values, refined by interaction with the physical and social world as well as experiences and interpretations of what the universe is about. Consequently, every human being is unique with particular meanings and subsequent unique goals and purposes in life.

Humans are not only aware that they exist but also that they may cease to exist. Unresolved, this struggle between being and non-being can shatter the self-system and result in the self and its worlds being meaningless. If the self is meaningless, in existential terms, the self is nonexistent. It is the fear of non-being (as opposed to the actuality of non-being) that creates anxiety (May, 1961). The spiritual core provides the nonmaterial element by which self can connect, communicate and harmonise with all life. Comprised of bipolar characteristics, self is inherently neither good nor bad, but through the dynamic process of being and becoming we are able to reconcile such seeming opposites as good/bad, life/death, love/apathy, will/control and hate/love.

Intentionality is the term May (1981) uses for the process of self formation and interaction with the world. Self cannot control or manipulate the present external reality but does interpret the meaning of present experiences. By encompassing

what is meaningful to self while discarding that which is not, we change our world of existence even if not the world. Moreover, as humans can transcend the immediate and envisage a radically different future, the self has the power through intent to determine its future meaning, purpose and consequent behaviours. Not only does intentionality change the world of existence but it also impacts on the external world.

The paradox of freedom and destiny is resolved if the essence of self is considered to be spiritual (May, 1981). The conundrum is that freedom implies that the individual is the designer of self while destiny suggests that the designer is external to self. May reasons that freedom operates within the confines of destiny. Freedom is the ability to choose and act with intentionality, becoming more fully the innate destined potential of self. Self is not able to change destiny but possesses the capacity to choose whether to increasingly exist in harmony with the grand design.

Self-Composition

The self is in essence a spiritual being but, in this life, self is comprised of three personally meaningful worlds (the cosmos; one's particular social and physical world; the inner world) in which the healthy self expresses its spiritual core through its behaviour.

Self-Agency

Self has limited and specific free will either to claim and creatively express the spiritual self through interactions with the world (intentionality) or to deny the essential self and slip towards non-being.

Healthy Self

For health, the individual needs to protect, nurture and express the core self to continue being and becoming the true self.

Carl Rogers: Loving self

Carl Rogers (1961) viewed the essence of self as a resilient core identity. When resilient, the individual's orientation is outward rather than ego-focused and enthusiastically committed to self-growth, openly meeting challenges to self, even if these are personally traumatic. Emotions are indicators of the present state of core self rather than signs of what are good or bad for self. Negative emotions

indicate incongruence between the innate inner core self-identity and outer behaviours, while positive emotions indicate the reverse. Consequently, the resilient self focuses on the now; the experience of being, yet constantly transcending the present seeking to become more fully self. The core of self is a unique, value-based identity and the aim is to ensure this is constant and continuous through all life's fluctuations.

Consequently, uncertainty and unpredictability are viewed as opportunities for self-growth rather than threats to self. Constancy and continuity of the growing self is sustained by sourcing intrinsic knowledge, evaluating what is right by what 'fits', 'feels right' and is synchronous with deeper feelings rather than immediate emotions. The core self is the knower and protector of what is right and self is perceived as inherently interconnected to all things so that self creatively interacts in a manner that encourages a sense of oneness, self-expression, self-ownership and a freedom.

Self-Composition

Self is not progressively formed but created fully formed but unknown, unexpressed and not developed or integrated with the physical and social worlds. It is nonmaterial and the implication is that it has been created from something of like nature, that is, the nonmaterial.

Self-Agency

Rogers advocates a self that is an active agent who, by choice, freely expresses its predetermined self by creatively interacting with the external worlds to expand its self-system.

Healthy Self

The self is healthy when there is harmony between the inner true self and outer behaviours and thoughts, but the expression of self also continually develops and synchronises with the world through expansion of the self-system so that it positively and meaningfully impacts on the external worlds.

Mason Durie: The house of self

Durie (1998) presents an indigenous New Zealand Maori concept of self, whare tapa wha, portraying self as founded on four (wha) interactive elements (tapa) of the house (whare) of self. Each tapa is an essential component of self and is

expressed in the characteristics of the corresponding side or aspect (taha) of the house. Taha wairua represents the spiritual, taha tinana the physical, taha hinengaro the cognitive and taha whanau the social aspects of self. Durie asserts that, for Maori, wairua (spirituality) is the core component of self, the aspect that binds together and determines the nature of the other aspects.

Durie (1998, 2001) contends that the spiritual is the foundational element of all life and the Maori meaning of self can only be comprehended within this context. Consequently, an individual is not independent but is part of the continuing flow of all life. While each individual possesses a separate identity, purpose and life role, self has meaning only if connected to and in relationship with the 'chain' of life of which it is a link. Individual characteristics such as freedom, independence, expertise, preserving and maintaining the physical self are meaningless without reference to fulfilling one's purpose within the greater whole of the present and after life. Cognitively, self-generated knowledge is not considered to be as authentic as spiritual knowledge, particularly if rational, cognitive reasoning contradicts spiritually-derived knowledge. Whatever logic and science might say, a sign or symbol (e.g., a fantail inside the house, a sudden sickness after offending something or someone worthy of respect) are usually assumed to be of greater substance.

Intuition, evaluated by deep feelings (rather than shallow ego emotions) is used to guide and evaluate the worth of knowledge. Knowledge is interpreted by what Jung (1969) termed synchronicity. The greatest significance is given to events related by their simultaneous occurrence, rather than any clear rational, objective cause-and-effect. For instance, if someone wakes up in physical pain at 2.00am and a friend wakes up at the same time feeling anxious, disturbed and cannot get back to sleep, these events have related synchronicity. They are not chance coincidences but are meaning related and accepted as a normal component of communication and, additionally, one of primary importance and significance because of the perceived involvement of the spiritual. Acknowledgement of the superiority of spiritual knowledge and its system over rational cognitive comprehension of life is the basis of such a perspective.

The social aspect of self centres on an awareness that the self lives in a world within the spiritual world. Consequently, the self is not restricted to relationships with people only presently living but also old people now living in the spiritual world, gods, the land, sea, buildings, etc.

Self-Composition

The core self is spiritual, nonmaterial and interconnected with all life.

Self-Agency

Self has the power to be what it is created to be, contributing to the greater whole and in so doing enhancing the value and meaningfulness of self.

Healthy Self

The healthy self acknowledges its formation upon a spiritual foundation, including gods, earth, sky, sea, forests and ancestors and its responsibility and life purpose is to advance and protect the 'chain' of which self is a part.

By contrast, it is worth noting that Pere (1997) posits Te Wheke (the octopus), a concept similar to Durie's, but with greater emphasis on the fluid and dynamic nature of the eternal core of self. Pere stresses the interweaving and eternal nature of connections between self and the universe.

Zohar and Marshall: The neuronal basis of self

Zohar and Marshall (2001) examine the neurological processes determining self-knowledge and meaning. Three types of thought processes are identified, which are serial, associative and unitary neuronal activity.

Serial thinking involves neurons linked serially forming an inherited or learnt neural circuit of rational, logical decision-making rules. The characteristic of the on/off synapse patterning determines the cognitive destination and therefore meaning of each stimulus. Such thinking is usually associated with short-term memory and conscious (ego) problem solving common to the accomplishment of rational, logical, unambiguous tasks.

Subconscious or associative thinking, typical of long-term memory uses neural networks or bundles of interconnected neurones to simultaneously process input in multiple directions. A pattern of connections within a particular network is

either an inherited cognitive structure (e.g., biological responses such as suckling and salivation) or learnt. Through repeated experiences, the interconnections of elements within a network bundle are incrementally modified and strengthened to create personally meaningful symbolic schema. Ambiguity and incomplete data can be assessed for fit against the pattern rather than rejected. Because of the vast array of neuronal networks and the type of biochemical processes involved it takes time to build patterns, test data input against these and alter them if experience contradicts established schemata. Furthermore, as the nature of network structures are learnt, requiring personally meaningful reinforcement (positive or negative emotions) all of us must learn for ourselves resulting in no two brains possessing identical neural networks and subsequently, unique emotional lives.

Serial and associative processes interact so that we can store or retrieve information from unconscious thought to aid conscious problem solving. Emotional associative thinking provides the mechanism enabling learning to be transformed into unconscious reflexive behaviour. This ranges from simple tissue need responses to the recognition of when something 'fits', or is 'right', allowing us to focus on the crux of a problem rather than examining every permutation before using rational thought to arrive at a solution. The interaction of these two processes results in the formation of deeply imbedded habits or laws, often referred to as values.

A self constructed systematically from the incremental collection of knowledge by these two cognitive systems forms laws or neuronal formulae to satiate ego and tissue needs; they are literally laws of self survival, not values.

However, humans exhibit a unique ability to change the rules and break the habits. Human thinking is creative, insightful and intuitive; we are aware of our existence and strive to find the meaning of self and the world. We can choose how we behave; we possess a degree of free will. Self possesses the capacity to transcend the present. The self also possesses conscious awareness of 'I' as it is now, and the capacity to contemplate how it was and perceive how it may be, and then alter thought and behaviour so that self becomes something different than it presently is. This requires unitary or holistic thinking, the ability to grasp the overall

context that links the component parts, interconnecting cognitive knowledge centres. It requires a unitary process that is independent of serial and associative processes, that acts as the overall command centre, the 'I' of self, in which autonomous free will choices are made.
There is no apparent physical interconnection of all neurones and neuronal networks but the research of Zohar and Marshall (2001) indicates that it is brain waves (in the 40 Hz range) oscillating across the entire brain that allow the coordination of serial and associative neural information.

Zohar and Marshall (2001) contend that associative intelligence is comparable to Freud's unconscious id drives and Jung's collective unconscious. Similarly, Adler's (1973), Bandura's (1986), Fromm's (1973) and Allport's (1961) values or virtues result from neural network learning that has become unconscious patterns of thought and behaviour.

Newberg, D'Aquili & Rause: The indestructible self

Neurobiologists Newberg, D'Aquili & Rause (2002) go one step further and contend that these cognitive structures are guided by organising principles they term cognitive operators that work in complex harmony to make our thoughts and emotions whole and uniquely our own.

While Zohar and Marshall (2001) attribute spiritual experiences of oneness, transcendence and access to a greater knowledge as a direct result of the unifying effect of 40Hz wave oscillations, Newberg, D'Aquili & Rause (2002) have looked more closely at the biology of the brain.

When serial and associated processes are either in states of extreme excitement or quiescent (e.g., prolonged repetitive physical activity or deep meditation), unitive thinking has been shown to take on a whole new form. No longer receiving new information from the rest of the brain, it somehow acquires an energy of its own that results in a unitary experience different from simply coordinating the learnt and inherited serial and associative knowledge. The boundaries between the cognitive operators become transparent or fuzzy, resulting in a loss of the sense of self as a separate entity and culminating in an experience of oneness, wholeness, discovery of universal, foundational knowledge and the blurring of time and space

boundaries. Such experiences are congruent with Maslow's peak experiences and Allport, Fromm, Jung and May's transcending self, all of which are spiritual experiences of self. Unitive thinking provides a neurobiological explanation for the unique human ability of spiritual awareness.

It is this often deeply subconscious, unitive, inclusive spiritual self that pierces the boundaries of autonomous ego-centred serial and associative self-knowledge, resulting in a resilient, constant and continuous self that is outward-orientated and an ego-less eternal component of all life. Awareness of this core component of self provides the building blocks to source and integrate conscious and secondary level subconscious self-knowledge into a meaningful cohesive whole self.

Self-Composition

Self is viewed from this neurobiological perspective as essentially a part of a greater whole. On one level, inherited and incremental learning or cognitive associations construct self. But the autonomous, ego-centric and fragmented self is largely meaningless, without awareness of the wider context of existence. By moving the deeper unconscious to consciousness through unitive thinking, self accesses knowledge and insight on such matters as the purpose of self, the nature of the individual and the paradoxes as life-death, good-evil and same-different. Moreover, Newberg, D'Aquili & Rause (2002) contend that as there is no evident internal stimulation causing the process of integrative unitive cognition, the stimulus for this may be external, that is, spiritual. They propose that such reasoning provides the basis for self to act, express and create an expansive self that is interrelated to all life and of value and in harmony with the universal system. The core of self is indestructible as it made up of the same elements as the universe and eternally connected to the spiritual source of all life.

Self-Agency

Similar to other non-materialists, Zohar and Marshall (2001) contend that we have the ability to control the degree to which we acknowledge and become our authentic core selves and express this in our outer layers of being.

Healthy Self

The healthy self is in union with all life but also repetitively sources self knowledge from the universal life source, having a distinct place, purpose and identity which is openly and increasingly expressed through thought and behaviour.

Summary

The theories reviewed above portray self as being healthy in two main ways. Firstly, the goal of existence is perceived as satisfying ego or id-centric physical (tissue) or psychological (ego) needs. Secondly, the reprioritisation of self-centred desires is seen as necessary so that perception of self changes to an ego-less, ongoing part of something greater than self. The expression of the spiritual self through thoughts and subsequent actions is argued to satisfy the central goal of existence; to contribute and be a component of life.

Moreover, the ego-centric perspective assumes that we are material beings and therefore our essential desires and needs are material. The second position assumes we are nonmaterial beings and therefore our fundamental needs are nonmaterial. Furthermore, although material self-theorists may imply that self is not determined, their self is based on either learning theory (where reward or punishment is determined by an external agent) or inherited traits and therefore such a perspective results in a self without free will or active agency. Nonmaterial theorists acknowledge the essence of self is determined and the potentially conflicting physical self is also determined by genetics and environment. The fundamental freedom self possesses is the choice to think and behave in a manner that satisfies ego-centric or ego-less desires.

CHAPTER 2: HEALTH, DISABILITY, AND A CRITIQUE OF SELF THEORY

In this chapter, the World Health Organisation definitions of health and disability are presented and the self-theories, reviewed in Chapter 1, are critiqued.

Health

Health is defined by the World Health Organisation (1997) as not just the absence of disease, but as a state of optimal physical, mental and social well being. Illness can be defined as the subjective experience of dysfunction; the perception of being unwell (Broderick, 2000). Therefore, the opposing concept of health is the experience of meaningful existence resulting in the perception of wellness. In essence, health is a state of overall wellness in which the individual perceives their self as whole and functional, regardless of the level of physical, social or mental functionality observed.

Disability

The original WHO (1980) definition of disability was the 'inability to perform an activity in the manner or within the range considered normal for a human being'. This definition implies that those with disabilities are, in some manner, less than normal and that the standard to judge the degree to which one is normal is the individual's level of independent functioning. WHO acknowledged the inadequacies of this definition and in 1997 redefined disability in terms of activity, participation and impairment. Subsequently, the International Classification of Functioning, Disability and Health (ICF) widened functioning to include not only the body but the person as a whole, as well as the place of the person within society (WHO, 2001). Consequently, disability was defined as resulting from the nature of interaction between environmental and social demands on one hand, and the individual's capacities to satisfy those demands on the other hand.

The research population for the purposes of this thesis comprised people with physical disabilities. Generally speaking, within this population, disability stems from a diagnosed disease or syndrome resulting in a chronic physical impairment. The ability of the individual personally to adapt to change and to maintain and

develop their societal roles, as well as the societal resources and attitudes aiding or hindering wholeness of self, determine the level of disability.

Therefore, disability is the degree to which an individual perceives they are inhibited from being a whole person; a healthy self. Disability creates an illusionary and distinct social category of people when, in reality, all people are confronted with traumatic threats to self (Linton, 1998). Linton contends that disability is only one variation of such an experience. Investigation of how people with functional impairments either achieve or remain healthy, in spite of experiencing ongoing threats to their cognitive, social and/or physical selves, provides an opportunity not only to advance healthcare for those with such impairments but also to increase understanding of the necessary determinants of health for all people.

As Wright, (1983) argues, people with chronic impairments will not be healthy if 'the predominant focus is on disabling aspects of disability' and that 'constructive views of life with a disability, conceptualised within the coping framework, provide an excellent basis for developing positive attitudes' (p. 479). She also asserts that there is a need for the person with the impairment to take responsibility for how they participate in life, to perceive themselves and to be regarded as intrinsically worthy individuals who actively collaborate with others, focusing on their potential to contribute rather than their specific impairment.

Wright (1983) also views disability 'as much a function of physical and social environmental barriers, if not more so, than personal disability' (p. 479). However, the setting of this thesis is within a healthcare organisation and while it is acknowledged that environmental barriers do impact on the individual's wellbeing, it is argued that frequently, both the individual and health professionals are limited in their capacity to alter these limitations. Nonetheless, it is proposed that people with chronic impairments have the right to experience optimal wellbeing irrespective of changing levels of availability of external resources. Much of this can be facilitated through healthcare interactions based on the values identified by Wright (1983). These focus on personal factors that enable the individual to access and control their level of wellbeing and health. This thesis

posits that health is attainable irrespective of the nature of the social environment or physical dysfunction.

The Crucial Components of a Healthy Self

The review of self-theorists in the previous chapter identified a wide range of claims as to what are the necessary individual needs for a person to be healthy. The review focused on each theory's assertions with regard to the composition of self; what determines self (self-agency); and what a healthy self is. Table 2.1 provides a summary of the two underlying philosophical positions of these theories and the assertions with regard to self-composition, agency and health.

The Materialists

Sigmund & Anna Freud, Skinner, Hartmann, White and Erikson unmistakably view self as derived from the physical, that is, material self. Self is composed of inherited and learnt characteristics that either aid or impede the acquisition of the necessary resources for construction of a competent, healthy self. Such a self is perceived as needing to extract from the environment the required biological (e.g., food, shelter, sex, etc.), psychological (e.g., self-esteem, competency, self-identity) or social supports (e.g., love, belonging, cultural identity) to construct an autonomous, independent self. Comparisons are frequently made between self and other higher animals providing explanations for human thought and behaviour. Initially, behaviour is a response to the inherited biological drives that ensures survival of the organism. The extent that learnt social and psychological drives encroach upon tissue need drives is the main point of contention between these theorists. However, all perceive the self as composed of a combination of inherited tissue need and learnt psychosocial drives that aim to enhance survival and competitiveness of the human animal.

Therefore, self is a passive agent determined by external influences. Subsequently, a healthy self is that which satisfies internal drives by extracting the necessary resources from the environment.

Table 2.1: Summary of self-theories based on philosophical assumptions of theorists.

	Materialist	**Non-materialist**
Theorists	Sigmund Freud, Anna Freud, White, Adler, Maslow, Skinner, Hartmann, Erikson, Bandura	Fromm, Allport, Rogers, Zohar & Marshall, Jung, May, Durie
Self-Composition	Inherited physical, social and psychological traits Learnt identity and sense of self	Inherited physical, social and psychological traits provide no meaningful or positively purposeful sense of self unless built upon the unique spiritual core of self derived from the spiritual realm.
Self-Agency	None – self determined by inherited and environmental factors	Limited to the choice of being determined by inherited and environmental influences or accessing spiritual resources enabling self to use intentionality to increasingly align self behaviours and thought with the spiritual self and in so doing control the effect of the environment on self and possibly impact and alter the environment.
Healthy Self	The most competent environmental adapter able to extract the maximum external resources possible to increase longevity, independence, self-control of the environment and self	The self identified as highly principled, possessing strong values will display behaviours that openly indicate that behaviour and thought are based on the same constant and continually repeated unique values. In short, the person has become a set of values as opposed to a set of behaviours or accomplishments

The Pseudo-Non-materialists

A second group of theorists, including Adler, Bandura and Maslow, base their theories on the same materialistic biological assumptions as the materialists. They then assert that the fully developed, healthy self somehow frees itself from its biological origins and is transformed into a psychosocial being. While continuing to view the aim of existence to be the construction of an independent, masterful self, which manipulates and extracts what it needs from the environment, each asserts that the core of self is a nonmaterial value system. They argue that the value system is learnt from interaction between the self and the environment. Self gains knowledge of what behaviours and thoughts are good or bad with regard to their continuing autonomy and mastery. More precisely, these 'values' are personally learnt laws of survival and adaptation.

Bandura has based his self-concept on associative, contingent and observational learning; reasoning that we progressively and systematically accumulate self-knowledge so that we incrementally develop an autonomous sense of 'I'. He acknowledges that social learning theory offers no explanation for such experiences as spontaneous insight; whereby an individual radically changes perception of self, thinking and behaviours; contradictory to past learning (Bandura, 1986).

Maslow contends that self-actualisation, or transcendence of self, leads to experiences of a spiritual connection with nonmaterial aspects of all life. Such connection allows the self to access the essential knowledge of life enabling the self to be whole. Consequently, it is commonly assumed that Maslow is proposing that the essence of self is nonmaterial. However, examination of the process by which he claims self achieves this state of completeness reveals that his theory is based on materialistic assumptions. Maslow's hierarchy of needs asserts that material needs (physical and psychological) must be met before an individual can self-actualise. Furthermore, the implied aim is to construct a self that is independent and able to extract sufficient resources from the environment to perceive oneself as robust and autonomous. Until this is achieved, Maslow argues that the individual is not strong enough to transcend self. Transcendence of self is inferred to be the 'icing on the cake' that ensures that the self can extract even greater resources from the environment. Consequently, the core of self is viewed as physical and material, in relationship with the universe but not inherently integrated and connected with the universe.

Adler, Bandura and Maslow view self as an active agent, striving to construct a sense of 'I' based on 'values' acquired from inherited genetics and learning. However, these processes are deterministic and outside individual ability to control. Therefore they are proposing that a self-determined entity develops out of one that is externally determined. The individual may perceive themselves as making completely independent choices, based on values as opposed to knowledge acquired by learning, but according to learning theory such decisions can only be based on past learning, which is determined. Therefore, 'values' in this context are personally learnt laws of survival, which determine thought and

behaviour, rather than freely acquired and individually unique characteristics. Logically such a self is, in reality, a passive agent with no free will.

Consequently, health for such a self requires that self is able to achieve increasing autonomy, competency and mastery over the environment and, in doing so, extract the resources necessary to satisfy the egocentric needs of belonging, self-worth and efficacy; as well as satisfaction of tissue needs.

The Pseudo-Materialists

A third group of theorists, represented by Fromm, Jung, and Allport appear to propose a similarly material concept of self. The free agent, an independent and self-determined individual, arises from the determined self, highlighting the same contradictions of logic found with Adler, Bandura and Maslow's reasoning. Superficially, similar constructions of self, self-agency and self-health are proposed, but the distinctive theme expounded by these theorists is a transcendent self that results in self as a dependent part of the world, rather than a separate independent entity. These theorists emphasise relationship and interconnection of the individual and the universe; implying that the aim of human existence is the identification and expression (through action) of the unique core of self. There appears to be an assumption that the motivating purpose for healthy existence is to act in a manner that adds value to the whole system of which self is a part. Consequently, the proposed healthy self is fundamentally different from the materialistic view. Rather than achieving health by extracting the necessary resources from the environment, a healthy self is one in which the individual activates and actions their potential or self-resources to add value to the whole system.

Fromm, Jung, and Allport imply that the essence of self consists of the immaterial with the primary purpose of existence being to contribute to the immaterial universal whole; often at the cost of the material self. Fromm contends that a healthy self is one that is a purposeful, productive psychosocial being. Jung asserts that self is not complete unless the four levels of consciousness are accessed, with the intuitive spiritual level guiding thought and behaviour. Allport speaks of propriate strivings, the formation of the proprium or self-system over which the individual acknowledges a proprietorship. Proprietorship infers a sense

of protection, care and promotion of those things within the self-system; the physical and social worlds as well as the spiritual world.

Consequently, Fromm, Jung, and Allport clearly perceive the essence of self as nonmaterial. The core of self is not learnt laws that facilitate personal physical survival but universal values that are individually tailored, providing a place and purpose for self within the whole. These values are accessed from spontaneous knowledge or instantaneous insights, visions, tellings, etc., attributed to the spiritual realm; rather than incremental learning.

The Non-materialists

What Fromm, Jung, and Allport suggest, May and Rogers put more specifically, and Durie, Pere, Zohar & Marshall and Newberg, D'Aquili & Rause openly state and explore. These latter theorists have abandoned the attempt to explain self in terms of the material physical, cognitive and social self. The inner self, the deep unconscious and spiritual self, that Fromm, Jung and Allport assume is the essence of self, and that Adler, Bandura, Maslow and even Erikson seem to imply, is claimed by the non-materialists to be the self. From their perspective, self is brought into existence as a nonmaterial spiritual being and the material aspects of self are only healthy when they are aligned with and an expression of this core self.

They contend that self has the agency to choose the meaning of self and its worlds and that for the self to be healthy, it must be based on the immaterial, the spiritual. By doing so, people can then think and act with intentionality, to be free and capable of applying their own meaning to events, objects and experiences. Consequently, self can possess freewill to choose to act as opposed to react to the world. People have the unique ability to transcend the present reality, perceive the way things could be, but presently are not, and act in a way to alter attitudes and behaviours. As a consequence of altered attitudes and behaviours, and because self is inherently integrated with others and the world, such alterations also change others and the world of self; at least to some degree.

They contend that the individual who chooses to strive to act, interact and foster attitudes that are in line with and are expressions of their core values is living as a

healthy spiritual being. Self has the limited active agency of either choosing to reach towards one's predetermined spiritual potential or be limited by one's learnt physical, cognitive and social realities.

Consequently, the healthy self is characterised by an awareness of the core of self as being spiritual. Subsequently, the purpose of existence is the continued identification and expression of this potential through thought and behaviours that strengthen the individual's ability to contribute to the greater whole of which it is a component. The spiritual self is outwardly focused and recognised by the constancy and clarity of its value-based actions. Such individuals obtain their vitality by immersion in the wider system rather than extracting from it – they are partakers and contributors to life. As the self is perceived as whole only when immersed in the greater whole, the healthy self is ego-less. It does not require a separate, independent and autonomous identity but rather develops its unique identity by being a component, a link within the greater whole.

The Material-Nonmaterial Relationship

The nonmaterial self confronts the same paradoxical problem as the material self. The material self that evolves into a nonmaterial self is illogical as the properties of both are assumed to be distinctly different and incompatible. The materialistic solution to this dilemma is to contend that the nonmaterial does not actually exist. Values, a sense of 'I', possession of freewill and an independent mind are viewed as illusionary perceptions that can be attributed to either inherited responses or incrementally learnt and cognitively stored, associated and unified memories. Such linear laws and reasoning of physical relationships are explained and supported by classical physics research. However, as pointed out by Bandura, such a rationale does not explain the frequent occurrence of radical, spontaneous self-change where the individual's life course, worldview and self-knowledge suddenly and completely alter in a manner not attributable to past learning. Non-materialists explain such spontaneous acquisition of self-knowledge or revelation as the essential spiritual self connecting with the source of all life (the spiritual realm). They claim that for knowledge to be relevant and authentic for self, it must be based on a worldview not learnt through experience of the physical or social world but by being informed from the spiritual world. The individual does not incrementally learn what the self, the world or life is; it receives

enlightenment or insight (as Jung describes) when it acknowledges, and is aware of, and is in connection with, the spiritual world.

Non-materialists would credit Bandura's self-regulation system, particularly the core values-orientated self-observation system, to spiritually sourced knowledge of the essence of self. Consequently, the meaning to self of incrementally acquired knowledge is determined by the nature of this spiritual core of self.

Non-materialists reverse the self-developmental process of the healthy self. Beginning with a core self that is spiritually determined, thoughts and attitudes are established so that they 'fit' this unique individual core. In turn, these cognitive states determine the interpretation of experiences, what are paid attention to, and consequent behaviours. In essence, the material aspects of self are viewed as derived from the nonmaterial.

CHAPTER 3: TOWARDS A SPIRITUAL THEORY OF SELF

The preceding chapter presented definitions of health and disability. A person is healthy when they perceive self to be a meaningful and an integral component of a greater whole. Disability is the antithesis this.

The critique of self theory concluded that there are two dominant views of how self achieves this sense of meaningfulness, interconnection and wholeness. The material perspective conceives self to be a biopsychosocial organism in which nonmaterial aspects, such as thought and perception of a free-will 'I', are incrementally developed through the interaction of genetic predisposition, experience, and cognitions.

Conversely, the nonmaterial perspective posits that the free-will 'I' and higher thought, is derived from the spiritual realm. This perspective acknowledges the biopsychosocial aspects of self as being influenced by genetic and environmental factors. However, it proposes that cognitions, which control perception of meaningfulness, interconnection, and wholeness, and therefore health, are determined by the nature of the interaction between the spiritual core and biopsychosocial aspects of self. Therefore, from this perspective, a healthy self pays attention to, interprets experiences and alters behaviour so that the biopsychosocial aspects of self align with the unique, inborn spiritual essence of self, rather than being formed by the biopsychosocial self.

Both the material and nonmaterial views of self are confronted by the same philosophical problem. How can the nonmaterial state arise from the material state; or vice versa? The properties of these two states are assumed to share nothing in common. Consequently, it is assumed that material and nonmaterial states cannot relate, communicate, or connect to pass stimuli or energy from one state to the other. Quantum physics offers a possible solution to this problem.

The Nonmaterial Basis of the Universe

Until the beginning of the twentieth century, classical physics assumed energy, such as light, behaved like a wave, having a regular, observable and constant form (Jackson, 2004). The assumption was that this wave-like energy consisted of

particles emitted uniformly and continuously. Jackson (2004) outlines how Planck, investigating heat radiation, suggested that energy is emitted in intermittent discrete packets that he termed quanta. Subsequently, Bohr found that subatomic particles did not behave consistently nor were emitted continuously as was assumed by classical physics. At the subatomic or quantum level, the basis of all material forms, matter behaved as if interconnected and in a random state of continual change and movement. Experiments indicate that the classical singular cause and effect, linear physical laws of relativity, and particle autonomy do not apply at the quantum level. Quanta, the basic building blocks of all material things, including humans, do not possess material properties and are, in fact, nonmaterial. At this level, particles become dynamic, indeterminate clouds of energy. Electrons that have been connected act as if they still are; even when entirely separated. They act in a holistic manner. As Jackson (2004) states this '…shows how different the quantum realm is from the classical realm of the senses' (p. 2).

Because of the dynamic, rapid, continual movement and interrelated nature of quanta, it is impossible to accurately and objectively measure, assess and understand any quantum as distinct and autonomous entities. Individual quantum can only be understood as components of a greater whole. At first glance, our objective physical everyday reality, which consists of clearly distinct, separate and autonomous entities (e.g., trees, chairs, tables, and people) conflicts with this quantum reality of interconnection rather than autonomy. In fact, objective linear law-abiding classical physics and holistic quantum physics are complementary.

This seeming contradiction results from the limitations of our senses and the subsequent limitations of objective, sensory-based measurement rather than contradictions in the natural world. As Heisenberg clarifies in his indeterminacy principle, 'The more accurately one determines the position of the dynamic quanta, the less accurately the velocity is fixed; the converse is also true' (Jackson, 2004, p.1). Consequently, in our efforts to understand things, we examine them at a particular point in time, *assuming that the object will remain constant, as it is at time of measurement.* But by examining something *as if* it were fixed in space and time we deny the possibility of measuring the equally probable dynamic, ever changing characteristics of the object. This logic applies

to all matter, including people. Quanta are claimed to be the basis of all life and therefore all life is in a constant state of flux. Our human senses are possibly inadequate and probably not trained to readily recognise and acknowledge this interconnected, dynamic and holistic aspect of nature. It is not that matter does not have some objective, constant, wave-based patterns of behaviour but rather that these are not all that matter is.

For this reason, the material can be seen as derived from the nonmaterial. Dynamic, interrelated systems of energy rather than separate, distinct and solid entities are the basis of our universe. Matter and non-matter are essentially the same; it is our perception or sensing of these that distinguishes one from the other.

The vast majority of the universe is space, potential but unexcited energy possessing no form, no mass; in essence a vast, transparent nothingness. As Zohar and Marshall (2001) state; 'The universe itself can be seen as a still and transparent ocean of energy, and all existing things and beings as waves upon it'. (p. 69). What we sense, as material objects are essentially energy in different states of excitement transposed on a background of identical composition but quiescent energy.

Because of the universality of the energy source and its composition, there is no fundamental separation between things and non-things, between material and nonmaterial, between being and non-being; all things are interconnected. From this energy source, energy fields or entities emerge, of which the self-system is one. At this level, because we consist of all the properties that constitute the universe, we are a separate sub-universe derived from and therefore part of the greater whole. Newberg, D'Aquili & Rause (2002) quote the experience of mystics who have '…shed the limits of self and returned to that original condition of wholeness, the primal state of unity with God, or the cosmos, or the Absolute' (p. 106).

In conclusion, it is proposed that, without acknowledgement of the nonmaterial as the fundamental basis and reality of self and understanding of the biopsychosocial aspects of self as derived from this, self will be perceived and experienced as meaningless and disconnected, particularly when aspects of the biopsychosocial

self are threatened. Therefore, capability to cope healthily with permanent, biological, psychological, or social loss (impairment) is proposed to be determined by the individual's conception of the essential self as either material or nonmaterial.

Coping with Significant Changes to Self

Coping with Adversity: Incremental or Transformational Change?

Breakwell (1983) identified three coping strategies, Inertia, Action and Transformational coping, used when people experience threats to self.

Inertia entails doing nothing, either in the hope that the problem will resolve itself or believing that one is powerless to change anything and giving up all hope.

Action requires activity thereby acknowledging the challenge to self and assuming control of the outcome. For those with disabilities an action strategy may include seeking knowledge of the disease, a focus on a return of physical flexibility and fitness, experimenting with various medications and supplements, the sourcing and use of functional aids, examination and change of attitudes and lifestyles or even prayer. All aim to seek a cure by actively 'fixing' the dysfunction. Pargament (1997) refers to these two options as the Conservation of Ends whereby the individual attempts to preserve who they perceive themselves to be (Inertia) or reconstruct and regain their pre-threat identity (Action).

To varying degrees, disability often denies a complete return to former function, role fulfillment and a previously held concept of self. Incremental adaptation, based on present self-knowledge does not provide knowledge of the unknown potential of self. Loss of previous function, occupational role and lifestyle resulting in the loss of former self is the norm and may be perceived as a threat to meaningful personal existence, that is, non-being. Consequently, a radical change of the meaning of self is the sole positive solution.

Breakwell (1983) terms this third coping strategy Transformation, and Pargament (1997) refers to it as Transformation of Ends, involving transcending the present reality and accessing resources previously unacknowledged. Such radical change is not based on past learning but rather transcendence of the present and past self. It encompasses assessing and changing attitudes about self, others, meanings and purpose in life beyond those previously held, enabling the individual to expand self meaning and subsequent expression of self.

Transformational processes have been identified as essential for health of those recovering from mental ill-health (Lapsley, Nikora & Black, 2002) and trauma caused by natural disasters, war and other similar events (Beardslee, 1989; Tedeschi, Park & Calhoun, 1998). Consequently the ability to recover well-being, irrespective of the cause of trauma, described as resilient self-identity by Tedeschi, Park & Calhoun (1998), depends on an understanding of self as an integral and resilient part of a larger whole.

Strength of Identity

Materialistic self-theory suggests that strength of identity is constructed through a learning process of interaction and identification with others, which is perceived and cognitively processed in an individually unique manner. Thus the self is developed from the interactions of the closed self-system with the external environment.

Evidence and logic partially support such a view, but such a self-concept does not fully encompass the reality of human experience. Non-materialists assert that a strong resilient identity cannot logically be developed by clipping on experiences, social resources and roles if one is not aware of, or does not understand, the innate core of self to which they are to be added. They reason that self does not necessarily become stronger or more whole simply by learning rules of thought and behaviour that enable greater autonomy. They argue for an opposing process of increasing interdependence, relationship and connection with all things in the individual's world, resulting in a strong resilient identity.

Constancy and Continuity of Self

To maintain a strong identity, the individual must perceive their core self as constant and continuing, although the social and physical environment, as well as personal roles, abilities, physique, and relationships, relentlessly change.

Objectively, a continuous self results from awareness of the continuation or connection across time of physical and social aspects of self, such as one's genealogy, surname, ethnic and cultural identity, accomplishments, and eventually estate and memorial. Spiritually, however, a sense of continuity results from a belief that the self is in some way an enduring part of a greater whole that may or may not be similar to the self's present objective form. The self is perceived as eternal, being part of a greater, meaningful, everlasting system. Ultimate power, knowledge and ultimate control of life are perceived as residing outside of the individual, who is a small component of the wider system.

Objectively, a constant self results from perceiving oneself as consistent, in that one's family role, given name, social identity, education and skills, possessions and status are assumed to be unchanging. To varying degrees, the objective aspects of self are outside individual control. Physical, social and even cultural aspects of self may be lost whatever the individual does. A similar fate may also ensue with regard to social roles and identity derived from these roles as well as material possessions. Spiritually, however, constancy is achieved by awareness of the self as a specific part of the greater whole. "I" always has been and always will be a particular element of the wider system.

To achieve a resilient continuity and constancy of self, the individual needs to acknowledge, relate and experience connection with the wider system. The reviewed spiritual concepts of self are evidence that all people have a spiritual core, which provides the resources for strong interconnection, sense of place and purpose. All dimensions of self are perceived as affecting one another but as the other dimensions of the self function they either promote or impede growth of the spiritual core of the self.

In summary, perceiving self as only material implies that incremental modifications of the objective aspects of self will eventually result in health. The

experience of ongoing objective change and loss suggests that such an individual will need to ensure that personally meaningful objective gains outweigh losses if they are to experience a constancy and continuity of self. It also leaves unanswered the ultimate question of life; how does one retain the resilient self, required for health, when adversity causes permanent loss of seemingly essential objective aspects of self? The non-materialist argument adopted in this thesis is that radical transformational change utilising a spiritually orientated concept of self enables the development of a self sufficiently resilient to remain healthy through all life's experiences.

A Definition of Spirituality

Four broad literary themes encapsulate the concept of spirituality (Baldacchino & Draper, 2001; Do Rozario, 1997; Dyson, Cobb & Forman, 1997; Fitzgerald, 1997; Selway & Ashman, 1998; Strang &Strang, 2001; Tedeschi, Park & Calhoun, 1998; Tuck, McCain & Elswick, 2001; Vash, 1981; Walton, 1999; Weaver, Flannelly, Flannelly, Koenig & Larson, 1998). The themes assume that there is a supernatural creative force from which all has been formed. They are:

1. Relationships: The strongest theme is the existence of meaningful relationships within the self, and between the self and others, external spiritual forces and the natural world. In other words, the self is perceived as an inherent part of a greater whole.
2. Connectedness: This theme is intrinsically interwoven with relationships. Not only must a relationship be acknowledged, but its nature must be experienced and acknowledged as an essential component of self. Health is dependent on the degree of connection with self, others, the natural world and external spiritual forces as well as on the level of health of those things to which one is connected.
3. Meaning: The characteristics of the individual's relationships and connections determine individual interpretation of the purpose of life. Included is the concept of hope, which is an assurance that all will work for the betterment of the system, including the individual, even though objective evidence may suggest otherwise. The opposing construct to hope is fear, which is the conviction that there is no certainty that outcomes will be positive for the self.
4. Values/Clarity of Principles: The preceding three themes enable the development of a personal value system that is clear, strong and rigorously

upheld, and which provides a structure for rationalisation of life purpose and experience. The strength of this belief system depends on the clarity of individual values, life meaning and of the concept of 'I'. It is the means by which the individual comprehends, interprets and reacts to experiences.

A Spiritual Theory of Self

Traditional models of self propose that the 'I' is constructed from social, cognitive and physical dimensions. On the other hand, the spiritual model claims that as the 'I' is an intrinsic part of a greater whole, it is constant and continuous, and thus determines how the physical, cognitive and social dimensions of self are constructed.

The common theme of nonmaterial self-theorists is that self is a spiritual being, observable through the objective aspects of self that are an expression of the individual's core values. The individual prioritises protection, promotion and survival of these nonmaterial values over protection, promotion and survival of the material self. Such an individual will risk physical life, job, friendship, family acceptance, etc. rather than risk losing the spiritual essence of self from which values are derived. Cognitions, behaviours, roles and relationships are expressions of this inner core *if* the person is healthy. The theories of May, Rogers, Durie, Zohar and Marshal, Fromm, Jung and Allport, and even Adler, Bandura and Maslow are all indicative of such a spiritual self-theory. Excepting Skinner's behavioural theory, the theories of the materialists can be readily interpreted as components of spiritual theory. They imply that the key determinant of a healthy self is the degree that the inner core is expressed, developed and cognitively and behaviourally integrated within the wider system. The nonmaterial theories stress that self is outwardly focussed and of use for the whole system rather than directly beneficial for the physical, egocentric individual. Conversely, they stress that the individual is responsible for protecting the essential self, ensuring that the integration and contribution to the whole is an authentic expression of the unique self rather than the result of external physical or social influences.

Consequently, the indicators of health are not independence, autonomy and ego-strength but interdependence, awareness and growth of the spiritually-derived,

ego-less identity that is meaningful only when integrated into the wider system. The finiteness and mortal nature of the physical, cognitive and social aspects of self are openly acknowledged and accepted. The individual has total control and choice only over the degree to which the essence of self is acknowledged and present reality is used creatively as an expression of the core self. For those with physical disabilities, radical change and loss of former self-concept, roles, relationships, physical functioning and appearance are constant companions. Ongoing experiences of pain, disease progression, attitudes of others and societal limitations reinforce the boundaries of self-agency for people with disabilities. The constant and continuous nonmaterial spiritual core is the only aspect of self over which they have authentic active agency.

The Spiritual Theory of Self (Figure 3.1) draws together the common themes of the nonmaterial theorists. The physical dimension consists of the physical body and external physical entities such as home, the natural world and other people; the social dimension consists of relationships and roles, and the cognitive dimension is one's view of the world and the self. These aspects of self, often observable to others, are largely outside the realm of individual control and subject to ongoing change. Consequently, they are depicted as fluid, opaque and porous. In contrast, the spiritual core or 'I' of self remains perpetually constant and continuous. Retention and continued growth of self requires that the cognitive, physical and social qualities attributed to the self match or are an expression of the unique and essential characteristics that are the spiritual core. In other words, each of these dimensions must 'fit' or affirm the values that form the spiritual core.

A spiritual concept of the healthy self requires the spiritual core to be perceived as the fundamental component of self which influences the external aspects of self. Consequently, perception of the spiritual core of the self as constant and continuous is necessary for wellbeing; loss of this perception results in spiritual distress. The self as a whole is an open and permeable system in which there is dynamic interchange between its physical, cognitive and social dimensions and the environment.

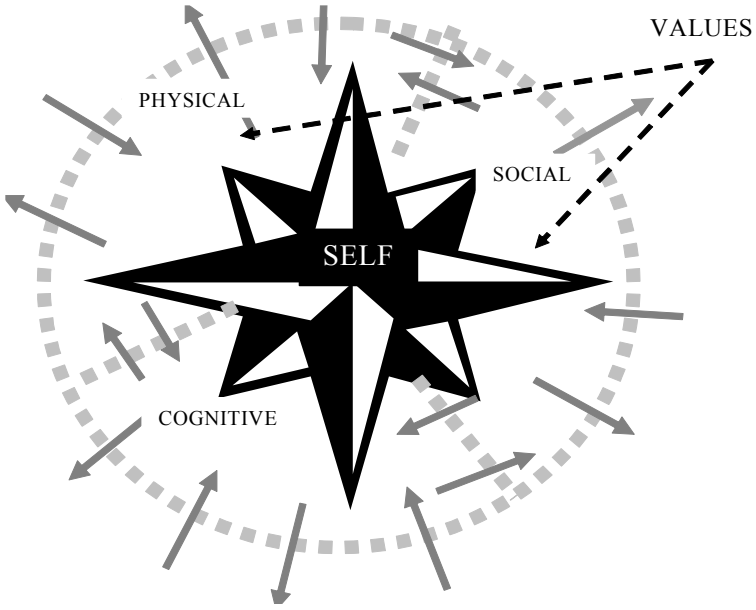
Figure 3.1: The Spiritual Theory of Self

Arrows represent the dynamic interrelationships between the physical, cognitive and social dimensions of self. The dashed lines illustrate that the self-system is open and that there are no impermeable barriers between these dimensions of self or between the self and other selves, nature or the supernatural.
The 'star' represents the spiritual self. It is depicted as solid as it is constant and continuous. It protrudes into all other dimensions. Therefore, when developed, its influence is observable in other dimensions. Individual values determine the 'shape' of the star and therefore what physical, social and cognitive characteristics 'fit' the spiritual self.

The essence of Self is spiritual. It is sourced from and connected to an external spiritual source.

Awareness of the connectedness of the dimensions of the self and of the self and the external world, results in the development of self-understanding. The outcome is clarity of beliefs and life meaning, which is exhibited as personal values.

As values develop and strengthen, social connections, cognitive schemata and physical priorities become increasingly aligned with the spiritual self. Such reconfiguration enables continuity and constancy of identity, which results in a stronger, more resilient self.



Health cannot be achieved without a strong, resilient self-identity, provided by the perception of self as not only unique but also part of a wider system. A spiritually centred identity provides access to coping resources that are essential for achievement of resilience. An open system of self allows access to spiritual resources that widen comprehension of experience, allowing greater self-understanding and transformational change. The person who embraces an open system is able to see their life as a continuum between past, present and future, in contrast with a closed system of self, which encompasses only one time frame (either past, present or future).

Research Questions

People with physical disabilities experience loss of physical, social and cognitive aspects of their self-system. Health is defined as optimal levels of functioning in these aspects of self but commonly such a goal is unachievable for many within this population. Nonetheless, many people with physical disabilities claim to be fully healthy, despite obvious dysfunction. Therefore, the first question is:

1. What is health for those with physical disabilities?

Following from this, there is a need to understand how people become healthy, that is:

2. What are the factors and process that enable people with physical disabilities to be healthy?

The review of theories of self resulted in the conclusion that the critical determinant of health is the perception of self as constant and continuous. People with chronic physical impairments is an ideal group to explore a nonmaterial theory of self as such individuals experience ongoing changes of physical function and appearance; social roles and relationships; and assumptions of power, control, concept of self and meaning. That is, they experience and therefore are aware that material aspects of self are not constant and continuous. Based on the reasoning just discussed, for such people to be healthy it is perception of the nonmaterial aspects as constant and continuous that must be the critical health determinant.

Consequently, to test the validity of this rationale, there was a need to quantitatively assess relationships and perspectives concerning the self, others and the world as objective indicators of the influence and effect of the nonmaterial core self on the biopsychosocial self. Hence, there was a need to develop a quantitative measure in line with spiritual theory of health. To do so, answers to the following question needed to be sought;

3. What are the themes and consequent item content that will capture the holistic, spiritual concept of self and health?

These items then needed to be tested for validity and reliability.

The procedures used by the researcher to meet these needs, followed by their results, are described below.

PART 2: EMPIRICALLY INVESTIGATING HEALTH AND SELF

Chapter 4: Overall Methodology

Chapter 5: The Research Setting and Population

CHAPTER 4: OVERALL METHODOLOGY

Methodological Approach

Assuming humans are material entities and all truth about humans can be obtained by objective measurement of the observable is the view commonly referred to as positivism. It proposes that all reality can be explained by linear, cause and effect, objective relationships. The quantum physics reasoning discussed in Chapter Three does not oppose the positivistic position but proposes that material and nonmaterial are simply different perceptions of the same thing. Indeed, much of reality can be explained as linear cause and effect relationships. It is argued that the positivistic paradigm does address the reality of life but not reality in its entirety. From this perspective there is a need to use both quantitative and qualitative methodologies if the full reality of human experience is to be explored.

Choosing a quantitative or qualitative approach does not automatically assign the researcher to either objective or subjective realities. After all, if both realities are in essence one reality then choice of method will be determined by the nature of the question the specific research study seeks to answer. However, it is the ontological worldview of the researcher that determines the interpretation of objective and subjective realities resulting from either quantitative or qualitative research. For example, qualitative research generally focuses on defining abstract, subjective, multiple perspectives, truths and causes. Nevertheless, if the qualitative researcher assumes that humans are material beings, their inquiry and interpretations will be congruent with known material characteristics, that is, physical Newtonian laws. Freud utilised qualitative methodologies but interpreted his data within a positivistic framework while Bandura used quantitative methods to do likewise. In this thesis, positivistic investigation is considered as a necessary component of scientific inquiry about the self but insufficient alone to fully investigate the reality of self.

Merging the Quantitative and Qualitative Approaches within a Holistic Worldview

Qualitative and quantitative approaches are often seen as incompatible (Murphy, Dingwall, Greatbatch, Parker & Watson, 1998). The four reasons advanced to highlight the disparity are, first, that they stem from fundamentally opposing

ontological and epistemological positions; secondly, each has a different basis of reasoning and interpretation of data; thirdly, they consist of distinct, divergent methods of gathering data and, fourthly, a greater emphasis is placed on description within the qualitative paradigm. These arguments do not reflect the reality of scientific research.

With respect to the first reason, the example cited earlier of Freud and Bandura indicates that quantitative or qualitative research is not limited to a particular ontological or epistemological position (Murphy et al., 1998). Researchers holding similar ontological positions can, and frequently do, employ diverse methodologies even when their views of human nature are similar.

Secondly, interpretation of data and deductive or inductive logical reasoning is not confined to any one paradigm (Murphy, et.al., 1998). For example, those undertaking quantitative investigations frequently infer general conceptual laws and theories that go far beyond the data produced to much the same degree as do qualitative investigators. Similarly, qualitative investigators, like their quantitative colleagues, tend to reduce data to categories and deduce relationships between them using deductive reasoning.

Thirdly, while methods of gathering data are superficially different in each paradigm, quantitative researchers also employ open questioning, discussion and opinions in the interpretation of data (Murphy et al., 1998). Likewise, qualitative researchers may use a more open process of data collection but also use their own interpretations and assumptions to select what data is relevant. Therefore, to a similar degree, both quantitative and qualitative researchers use a combination of subjective and objective judgment to determine what data is relevant. The main difference is whether this takes place pre or post data collection.

Fourthly, while qualitative researchers tend to investigate the subjective meanings forwarded directly by participants, they then reduce, combine and identify common themes or laws from this data. The quantitative researcher also seeks to discover the meaning of, and define, similar subjective phenomena; but uses established meanings and descriptions as the starting point of investigations, which are then tested against the data (Murphy et al., 1998). Consequently, where

meanings and definitions are previously established, clear and comprehensive, quantitative investigation provides a method to test whether or not these are indeed valid, generalisable and supported. However, the intent is still the same; to discover the meaning of abstract concepts, and this is not inherently philosophically different from qualitative aims.

The Instrumental Approach

The methodological approach that utilises both qualitative and quantitative processes is termed an instrumental approach (Murphy et al., 1998). It requires qualitative and quantitative methodologies to be viewed as symbiotic partners rather than opposites. While acknowledging differences between the processes of quantitative and qualitative research, Murphy et al. argue that the difference is simply a matter of choosing which of the two methods is the best instrument to collect the knowledge or data necessary to answer the research inquiry. They challenge the existence of philosophical differences while accepting an instrumental difference.

Quantum physics provides a view of reality which supports the integrated instrumental approach to scientific investigation. While classical physics reinforces a stable, fragmented and autonomous view of all physical objects, including humankind, quantum physics promotes a view of life as integrated, dynamic and holistic. From this perspective, excited quanta are the basis of what we sense as objects but represent only a minute fraction of all quanta, the majority being unexcited quanta; what we perceive as space or nothingness. There are therefore two levels of perceived existence and reality. The more readily observable level of atoms and those objects constructed from atoms, including the material self first level. At this level, Newtonian classical physical laws apply, an objective reality exists and objects can be separated and quantified (Jackson, 2004). Below this, at the subatomic level, is a more holistic, fluid and dynamic reality that defies Newtonian laws.

With regard to the study of people; at one level, the self is separate, measurable and quantifiable as such. But without acknowledgement and incorporation of the deeper level of self (the dynamic, interconnected, inclusive nonmaterial foundation of self) the self cannot be fully understood. Consequently, focusing on

objective attributes of self without acknowledgment that each of these is a particular expression of the dynamic, subjective, nonmaterial core of self denies full understanding of self.

Consequently, the problem in social research is not whether things are viewed in part or in whole, nor whether we perceive linear cause-and-effect or a complex interrelationship of association, nor whether we vow allegiance to numerical or thematic quantification. Each appears to be a constituent of reality. The issue on which to base the credibility of research is whether the researcher acknowledges and takes into account in study design and interpretation both or only one of these realities. The researcher's assumptions about human nature determine what questions are asked, what data is viewed as relevant and how the data is interpreted.

Though science derives its data from the objective, it need not limit the development of data gathering tools by assuming that the objective measurements assess the entire reality. Theory that rationally links the material and nonmaterial, forwarding each as differing forms of the same thing, enables construction of a measure of the objective that indicates the nature of the underlying subjective. Moreover, if the objective (material) is viewed as an *expression* of the subjective (nonmaterial) then explanation and interpretation of objective behaviour and thought will also encompass the greater reality. Rather than assuming we are directly measuring reality, it is equally plausible that we are measuring expressions of a deeper fundamental reality.

In fact most scientific endeavour concerns the exploration of a deeper reality by investigating relationships within the observable reality. Scientific knowledge is founded on the development of abstract concepts, theorising about lawful objective relationships that are possible expressions of these and then objectively testing predicted interrelationships. The data gathered from such inquiries then result in refinement of the abstract concept. In the context of the present thesis, the abstract concepts are self, health and spirituality. What we seek to comprehend is the universal objectified expressions that characterise healthy selves which are constructed from a spiritual core.

In summary, the methodological approach adopted in this thesis was instrumental. The particular research design adopted for each of the four thesis studies was determined by identifying which method would most likely advance rational, valid, yet refutable knowledge that encompasses both material and the underpinning nonmaterial realities.

The philosophical position of the researcher was the critical determinant of the methods employed, results obtained and conclusions drawn. Consequently, the methodological approach aimed to incorporate the researcher's contention that self is essentially nonmaterial and subjective but that this self is expressed materially and objectively. The methodology followed a cyclical pattern. It began with subjective investigation, then tested those findings objectively, followed by revisiting the subjective findings and exploring other possibilities and so on. It reflected a continual oscillation between qualitative and quantitative research methods.

Qualitative Research

Next, qualitative methodological issues pertinent to the research included in this thesis are outlined and the parameters for assessing the validity and generalisability of these are discussed. First, threats to the worth of qualitative research with regard to sample selection, data collection and analysis are reviewed. Then the criteria for assessing validity and relevance are discussed followed by strategies to counter these threats. Finally, the parallel quantitative parameters of validity and reliability are outlined.

Sampling

In this thesis, qualitative sampling was based on the assertion that participant selection should be theory driven (Murphy et al., 1998). That is not to say that the theory was established before sampling but rather that some 'idea', however rudimentary and unformed, guided the researcher and determined what data might clarify that idea. The basis of reliability in such qualitative research is not representativeness of the research population but rather that the sample is a potential source of or exhibits theoretical principles (Murphy et al., 1998). Consequently, selection of participants in the thesis' qualitative research targeted participants who perceived spirituality as an essential component of health.

The predominant method of theoretical sampling was the grounded theory approach (Glaser & Strauss, 1967). In grounded theory, sampling aims to provide data, aiding the emergence of a theory through a progressive cyclical process of data collection, followed by analysis, resulting in rudimentary theory construction, then further data collection and so on until new data no longer adds to theory clarification. The qualitative studies in the thesis (the Health, Self and Disability Study, Chapter 6; and the Spiritual Item Questionnaire Study, Chapter 8) employed this method. Moreover, throughout the series of four studies the emerging concepts and measures were continually reviewed against the new data. Hence a broad grounded theory approach, combining quantitative and qualitative data collection, was adopted as a unifying theme across the entire thesis.

The dominant technique of data collection associated with grounded theory is interviews. The threats to validity of this technique are discussed next.

Interviews versus Observations

Observation is frequently proposed as being of superior validity and reliability to interviews (Murphy et al., 1998). The influence of the interviewer on the interviewee (reflexivity), the effects of group dynamics, and participant construction of stories rather than factual reporting are threats to the validity of interviews. In the context of this thesis, whether or not observation is scientifically superior to interviews was debatable, as the focus of inquiry was nonmaterial and therefore not directly observable.

Only interviewing allows the researcher to access peoples' perceptions and interpretations of experience. Moreover, all people actively construct their worlds, including stories that may not appear to agree with observable 'facts'. This specific human characteristic is the essence of this thesis. Investigations of health, self and spirituality seek to understand how and why people construct their self-system as they do.

The aim was to construct a questionnaire that identified what types of 'stories' about their self and their health people with musculoskeletal disabilities were telling themselves.

Interviews provide a method to generate data that grants authentic insights into individual constructions of perception that are based on their experiences rather than relying on researcher interpretations of these experiences derived from observation.

Unstructured interviews, otherwise known as conversational, open-ended or depth interviews are seen by many as the most appropriate means of achieving such insights (Murphy et al., 1998). Additionally, interviews are particularly suitable for exploratory or hypothesis generating research because they have the capacity of enhancing the generation of ideas and theories. Consequently, they were chosen as the research methodology to uncover the meanings, beliefs, and understandings attributed by participants to the concept of health.

Remaining threats to interview validity are the type of questions asked, distortion of data by the researcher, the researcher assuming there is a shared common perspective, the role of the interviewer in the interview, the transience of the research relationship, status inequalities and constraints incumbent in the interview context (Murphy et al., 1998). Consequently, the validity of interviews can be judged in terms of how carefully the researcher has overcome these potential threats to validity inherent in this method.

In the case of the Health, Self and Disability study (Chapter 6), these threats were countered by using unstructured interviews allowing deeper insights; limiting inquiry to two broad questions; and employing members of the research population as interviewers. In the Spiritual Item Questionnaire study (Chapter 8), strategies used were the underpinning theory of the initial questionnaire used; a large number of participants (in terms of qualitative inquiry); repetitive return to the data source to develop items; and use of statistics to test emerging concepts.

A further strategy to ensure validity is to use interviews but combine these with participant-observer derived data for cross checking (Murphy et al., 1998). In this thesis (particularly in the initial study, Chapter 6), the principal researcher employed others as participant observers while retaining the responsibility for countering participant observer reflexivity and facilitate objectivity.

In quantitative research the procedure used to collect raw data can be readily and explicitly communicated and followed. However, procedures of data reduction arguably pose the greatest threat to validity of qualitative research as they are inherently subjective and resist standardisation (Murphy et al., 1998).

Qualitative Analysis

A distinctive characteristic of qualitative analysis is that collection and analysis is commonly iterative. According to Miles and Hubermann (1994, cited in Murphy, et al., 1998) qualitative analysis consists of three concurrent flows of activity. These are data reduction, data display, and finally, conclusion drawing and verification. These processes always include a significant element of individual interpretation. Consequently, the researcher must have what is called theoretical sensitivity, which is the ability to think conceptually and independently of data and data sources, to rationally amalgamate previous experience and theoretical knowledge in the interpretation of data and theory development. Hence, Miles and Hubermann propose that, while theoretical sensitivity increases through interaction with the data, there is a need to maintain a balance between the researcher's theoretical conceptions and scientifically gathered data in order to produce theory that is valid.

The elements of individuality and uniqueness make a complete standardisation of method in qualitative research impossible. In the thesis, the researcher critically reviewed self theory and developed theory from these theories (Chapters 1, 2 & 3) attempting to encapsulate all the major assertions of each theory, reasoning that each theory provides explanation of some aspect of human thought and behaviour, and then developed a spiritually based model of health and self from these. In doing so, the researcher's theoretical sensitivity was enhanced. Furthermore, the researcher's supervisor ensured that interpretations of data were logically linked to theory by continually requiring the researcher to compare findings to emerging theory to ensure theory was congruent with data. Moreover, the grounded theory approach to data analysis followed in the thesis provided a cyclical method to compare data and theory across all four studies.

Grounded Theory

It is probably more appropriate to view grounded theory as being a set of approaches for generating and advancing theory, rather than as a specific, singular technique (Murphy et al., 1998). However, researchers using the grounded theory method can be expected, at the minimum, to incorporate five main criteria. Firstly, the structure of inquiry will be fundamentally shaped by the aim to discover social and psychological processes. Secondly, data collection and analysis phases occur simultaneously. Thirdly, the aim of analysis is theory discovery and development rather than verification of pre-existing theories. Fourthly, theoretical sampling is used to refine, elaborate and exhaust conceptual categories. Fifthly, the systematic application of the analytic method leads to progressively more abstract categories. These criteria are conventionally addressed through the analytic process of coding.

Two main processes are central to grounded theorising (Glaser and Strauss, 1990). The first is continual comparison between derived categories and concepts to refine relationships and categories within the overall category that is the focus of investigation. In the present context, the overall category was holistic health. The second process is the exploration of concepts by the collection of further data based on those concepts to facilitate elaboration of the emergent theory. These two characteristics of the grounded theory approach provided the predominant methodological theme across all four thesis studies. The coding process was employed only in the first two studies (Chapters 6 & 8)

The Coding Process

Theory development requires that data be reduced to units of common meaning or categories and linking relationships identified. Each category is labelled with a term that conceptually represents the category's meaning. Then the connection between meanings and ideas is explored to discover how the categories interact and contribute to the mega-category (e.g., holistic health). This is termed coding (Strauss & Corbin, 1990) and is the process by which data is broken down, conceptualised and put back together that culminates in a theory. Typically, in grounded theory, coding refers to the whole process of analysing data and theory building.

The three-stage process begins with open coding (Murphy et al., 1998). Data is broken down and grouped into categories containing data with common meanings. The second phase is axial coding in which data is put back together again in new ways to search for additional properties of each category and connections between them. Key questions at this stage are; Is there another way of arranging the data, clustering data or labelling data? Could this data better fit in a new or another already existent category? What are the relationships between categories? This process frequently involves the use of decision trees or flow charts. The final phase of theory development is termed selective coding. This is the process of picking out core categories, systematically relating them to other categories, validating these relationships and filling in categories which need further refinement and development.

Consequently, analysis is a cyclical process of progressive focusing involving the presentation of data without analysis, followed by analysis for accurate description, then development of theory which requires conceptualisation of data. Next, how qualitative research is assessed for scientific merit is outlined.

Criteria for Assessing Qualitative Research

Previously, it was argued that there is no inherent philosophical difference but rather a methodological difference between qualitative and quantitative research. Consequently, while it is acknowledged that qualitative methods are not identical to quantitative; it is argued that they are not completely distinct and incompatible with quantitative criteria of assessment.

Hammersley (1990, cited in Murphy et al., 1998) proposes that the function of qualitative research is 'To produce knowledge that is of public relevance' (p.56) and asserts that there are two criteria against which such research needs to be assessed; validity and relevance. Validity is the extent to which the account accurately represents the phenomena to which it refers. Relevance refers to the capacity of a piece of research to resolve the problems faced by some group of practitioners. While seemingly multiple realities and conflicting truths may emerge from data, it is the inductive solving of such paradoxes by identifying the abstract concept that links these into a cohesive whole that is the basis of valid and

relevant qualitative research. Consequently, the two criteria for assessing the qualitative research in this thesis were validity and relevancy.

Assessing Validity

Five processes are required to assess the validity of qualitative research (Murphy et al., 1998). These are clear explanation of data collection procedure, clear explanation of the process of data analysis, consideration of reflexivity, attention to negative cases, and ensuring fair dealing.

Detailing data collection and analysis

Clear explanation of the data collection procedure facilitates third party judgement of the validity of the method (Murphy et al., 1998). The analytic coding and categorisation processes and conclusions need to make clear the reasoning behind development of concepts and relationships. The relationship of theoretical constructs to representative data quotes must be clear and key concepts need to be defined unambiguously and coherently with the conclusions being justified by the data collected. Other researchers should be able to use the original report as an operating manual by which to replicate the original study.

Inherent in assessing validity of qualitative data collection and analysis is the issue of data trustworthiness. Hammersley (1990, cited in Murphy et al., 1998) suggests that asking some common sense questions will clarify data trustworthiness. These include whether or not the participants are likely to have had access to the events they describe, examination for any possible motives for misleading the researcher and seeking to identify how the researcher's presence contributed to the data obtained. With regard to the written report, there is a need to display enough data to allow the reader to assess whether the interpretations are adequately supported by the data. Also, each major concept must be accompanied by at least some of the empirical cases which led to its development. Finally, trustworthiness is enhanced where the researcher demonstrates that they considered alternative, plausible explanations of their data.

Reflexivity

Judgments of validity with respect to reflexivity requires consideration of the ways the researcher's presence in the research setting may have influenced the

data collected and the possibility that their own *a priori* assumptions may shape data analysis. Validity is enhanced where researchers make explicit in their research report the personal and theoretical biases which they bring to the research (Hammersley, 1992). Since it is possible to provide multiple, true descriptions of any phenomena, we are forced to recognise the role of values and *a priori* assumptions in shaping the research report. Hammersley identifies a further threat to validity as being the risk of the researcher identifying with members' perspectives and hence failing to treat these as problematic.

Research for this thesis was undertaken by a researcher who strongly believes that spirituality is the key determiner of health. Such a viewpoint is only one of several equally valid and scientifically supportable perspectives. All researchers involved in this thesis were members of the research population and the principal researcher utilised his PhD supervisors and professional colleagues at QE Health to counter any potential reflexivity threats.

Negative cases

Attention to negative cases strengthens validity when negative cases are displayed in the report. Likewise, incorporating existing knowledge or being able to explain theoretically seemingly contradictory findings from the emergent theory strengthens validity.

Fair dealing

Fair dealing is interacting even-handedly and respectfully with all those studied, and in doing so, acknowledging other truths or realities. For example, as Dingwall (1992) states;

> Our science will never progress if we simply assume that all those middle-class heterosexuals leading orderly lives represent some sinister force opposed to our underdog heroes or heroines and never acknowledge that they too are human beings making their way in an uncertain world. (p.172)

Thesis data was sourced directly from health consumers rather than health providers. Such an approach had the potential to facilitate a 'them' and 'us' philosophy, advocating for the noble, suppressed disabled and striving to help

them break free from power hungry, tyrannical health professionals. It is essential that the researcher acknowledges the validity of opposing worldviews, and addresses how research concepts and theory explain and incorporate the findings of other research. Science needs to concentrate on the rational exploration and advancement of knowledge; not dogmatic campaigning for support of one's own viewpoint.

In summary, the procedures of qualitative research entwine the researcher and the researched in the research subject matter in a manner distinctly different from the processes of quantitative research. Although each qualitative study has idiosyncratic characteristics, addressing the four threats to validity discussed above will enable the researcher to produce valid results. But no matter how valid findings are, if they are of no practical use or relevance such research is without merit (Hammersley, 1990, cited in Murphy et al., 1998).

Assessing Relevance

The key issue for relevance is transferability or applicability; the extent to which findings can be applied to similar contexts (Murphy et al., 1998).

Qualitative thesis findings were the basis of subsequent theorisation, the development of quantitative measures and quantitative application and testing of theory that formed the later studies in this thesis. Relevance was assessed directly by the degree to which other people with disabilities as well as health professionals found the findings of the initial study (Chapter 6) useful. Indirectly, relevance was judged by the usefulness of thesis theory and the resultant holistic health measure for people with disabilities and clinicians.

An overview of assessment of the validity and reliability of quantitative health measures is presented next.

Quantitative Research

The quantitative component of the thesis focused on testing the reliability and validity of a holistic health scale. The following review is based on that provided by Brooks (1995).

Reliability

Reliability refers to how accurately a measure provides consistent, predictable results. A measure is accurate if it reflects the 'true' state of the attribute being measured as represented by the formula:
Measured Value = True Value + Systematic Error + Random Error (Brooks, 1995, p.46).

The true value of a scale may be hidden because of seemingly random responses. For example, there may be no clearly evident relationship between (a) how people respond from item-to-item and (b) how the scale is answered at two different points in time. Such unsystematic or random error that cannot be predicted or explained is the focus of examination in reliability analysis. However, systematic error is any between or within subject changes that can be explained, including those attributable to diversity of the sample; how items that are not responded to are handled; and changes connected to environmental and personal changes such as health interventions. Consequently, reliability testing examines the degree to which a scale is internally consistent and stable.

Assessment of a scale's internal consistency requires data collected at one point in time and seeks to identify the degree that responses to items systematically vary. The accepted measure of internal consistency is Cronbach's alpha. It measures the degree that the individual responses to each item vary in a manner that is reflected in the total score variance of individuals. If a scale is perfectly reliable, that is if all variance of all responses to all items occur in a systematic manner, then every individual's response to each item will contribute to the variance of the total scores. Consequently, the variance of the total scores will equal the total variance of the items. Therefore, all variation would be consistent and patterned across all participants and Cronbach's alpha would equal one but if the error (variance) was completely random, Cronbach's alpha would equal zero. Obviously, perfection is more of an ideal than a reality and Brooks states that a Cronbach's alpha of 0.85 or above indicates satisfactory internal consistency for health measures.

However, while Cronbach's alpha is a measure of a scale's internal consistency, because it assesses whether variance is systematic or random, it also can be

viewed as a measure of a scale's stability between scale respondents. Consequently, a high Cronbach's alpha demonstrates that a scale is reliable.

A closely associated measure is item-total correlation. While Cronbach's alpha assesses the degree that response variance is systematic, it does not identify the direction of variance. The nature of responses to an item may vary in a systematic manner so that they impact on the total score but Cronbach's alpha does not directly identify the precise nature of the relationships between each item and the total score. The item-total correlation does this by assessing the magnitude and direction of the correlation between the responses to each item and the total score.

A further but somewhat less precise measure of a scale's reliability is test-retest reliability. Inherent in respondents completing a questionnaire at two points of time is the practice effect, which suggests identical scores at test and then re-test are unlikely. However, this test is commonly used as an indicator of a scale's stability or ability to measure systematic change and counter random fluctuations. Brooks (1995) suggests that the minimum correlation of total scores at the two measurement points should be 0.5 for the scale to be deemed stable. He also points out that there is little agreement amongst analysts as to what level of correlation is satisfactory. However, the argument is not solely the size of the correlation but whether or not the correlation obtained predominantly reflects true value plus systematic error or true value plus random error. In this thesis, the QEHS Study (Chapter 10) assessed test-retest reliability and the proportion of each type of error was identified by the degree that the error was explainable and predictable by health status change between pre- and post-intervention and whether or not any changes were also paralleled by changes in established valid measures that were administered concurrently.

Validity

Validity is a multi-dimensional construct and concerns the 'trueness' of a measure to measure what it proclaims to measure. Brooks (1995) sums up the overall intention of validity as testing the 'meaningfulness of a health status measure' (p. 48). Each type of validity can be seen as asking a question about an aspect of meaningfulness. The following review reflects the criterion as set out in Brooks (1995).

Face Validity

Question: Does the measure appear meaningful to respondents and clinicians?

Face validity concerns how credible people subjectively judge an instrument to be. It is viewed as desirable but of somewhat less importance than other forms of validity.

Content Validity

Question: Are the items a true representation of the total meaning of the concept or phenomenon the instrument proclaims to measure?

A measure needs to consist of items that are a thorough measure of what it aims to measure. Content validity is partially assessed by examination of how items were selected and the scale constructed. Brooks (1995) lists four methods of selecting items for health care measures: investigator or clinician judgment; patient judgment; group consensus techniques; statistical technique of data reduction (factor analysis). In this thesis, all four of these methods were used.

The second method of assessing content validity is related to face validity but entails a closer, critical examination of the items and questionnaire format to judge the degree that an instrument possesses the capacity to carry out the task for which it was designed. The question usually addressed is, 'Do the items clearly address separate, distinct components of the targeted concept and also *all* components of that concept.

However, the aim of this thesis was to develop a holistic measure of health. Thesis theory and the subsequent content validity for such a measure were somewhat different to those used to assess conventional health measures.

Although holistic health is commonly viewed as 'adding up' the characteristics of the distinct social, psychological or biological and even the cultural/spiritual dimensions, such an assumption contradicts the meaning of holism from which the holistic concept is derived. Merriman-Webster Online (2004) define *holism* as 'a theory that the universe and especially living nature is correctly seen in terms of

interacting wholes (as living organisms) that are more than the mere sum of elementary particles'. *Holistic* is defined as; '1:of or relating to holism, 2:relating to or concerned with wholes or with complete systems rather than with the analysis of, treatment of, or dissection into parts'.

Hence, holistic health is first a perception that health can only be seen as a whole and that identification and measurement of the 'parts' of self will not provide one with a holistic measure of health. As the whole is greater than the sum of the parts; simply identifying the parts and adding them up will not provide the assessor with a meaningful measure of the whole; that is, the person. One dimension of health is inseparable from another. The nonmaterial, the spiritual, is the unifying, connecting factor and common denominator between people, nature, the world and the universe, which makes the whole greater than the sum of its parts.

Consequently, such a radically divergent view of self and health, in turn, requires altered criteria for judging content validity. Judgement of a holistic health measure's content validity by comparison of item content, format and structure with, for example, that of a measure of physical function is inappropriate. The same rules simply do not apply because the aim of a holistic health measure is to assess multiple, interrelated and interconnected aspects of a singular concept.

Ideally, in a holistic health measure all items should impact on each other and somehow each will address all four dimensions of self and health. For items to do so, it is fair to speculate that such items will contain language that is less precise and probably more abstract than the norm. Moreover, holistic items seek to explore the individual's holistic meaning or response to different scenarios. To do so requires that each item has the capacity to measure individual worldview, that is, be able to be interpreted in terms of a worldview based in the material, nonmaterial or something in between. The aim is to discover the degree that the individual perceives and behaves as part of a whole (nonmaterial worldview) or the whole (material worldview).

In summary, a holistic measure aims to measure the degree that an individual is integrated, interdependent and contributing to the greater whole, enabling the

retention and development of their unique resilient self. The primary focus is on the degree an individual is reaching towards their potential; their strengths, rather than focusing on dysfunction. This does not infer that health change will not occur in other dimensions; it simply implies that holistic health is interrelated and cannot be assessed simply by degree of improvement in objective function.

Criterion Validity

Question: Does the measure really measure what it means to measure?

In the context of the thesis, we wished to know if the instrument measured the holistic health status of individuals within the research population. Criterion validity includes two closely related types of validity; concurrent and predictive validity (Brooks, 1995).

Concurrent validity or testing for significant relationships between established validated health measures and the developmental measure was investigated in the third thesis study (Chapter 9). It is a direct, one point in time examination of the question of whether or not the developmental scale includes key constructs, as measured by established validated scales that it claims to relate to.

In contrast, predictive validity tests the experimental scale's capacity to assess change in a manner predicted from the theoretical basis of the measure and supported (or otherwise) by similar change in established valid and related measures. It involves a test-retest design to investigate relationships at two points in time. The final thesis study (Chapter 10) examined predictive validity.

Construct Validity (convergent validity)

Question: Does the new measure provide meaningful information with respect to the theory from which it was developed?

Brooks (1995) refers to construct validity as '*the* crucial test of validity' (p.51). In some ways, convergent validity seems a more appropriate term. This type of validity is an evaluation of the degree that the previously discussed validity criteria converge or come together to answer the question which was the reason for the development of the measure in the first place. The developed tool needs to

be a meaningful and useful instrument for investigation, application and development of theory. The purpose of health theory is to inform and advance health practice and, in turn health outcomes. Theoretical predictions of factors that are important for health need to be tested to determine the validity of theoretical claims. To do so, requires the collection of clinical data, which necessitates the development of a data collection tool that has satisfactory face, content and criterion validity. Even if such validity has been achieved, many propose that a new instrument remains meaningless to clinicians if it is unable to test theory, inform and advance health practice.

Discriminant Validity

Question: Does the information captured by the developed measure provide a different meaning of the measured concept (health) than other measures; whether these measures are supposedly related or not?

Brooks (1995) emphasises the comparison of the developmental measure to measures of unrelated concepts. If the results are different, as would be expected, then a measure has discriminant validity. But, at least in this thesis, it was necessary to be able to assess whether the new measure was distinguishable from established measures purporting to assess aspects of the same concept, that is, health. Consequently, discriminant validity was evaluated in the thesis by asking the question, 'Does the new measure result in information clearly different from that provided by other health measures?'

Other Criteria for Assessing Worth of a Measure

Four additional factors are frequently included when assessing the value of a measure; these are responsiveness, generalisability, sensibility and practicality, which are discussed next.

Responsiveness

Related to discriminant validity, responsiveness concerns examination of an instrument's clinical ability to be both reliable and valid. 'Does this instrument possess the capability to sensitively capture health change when it does occur?' Responsiveness is tested by comparing the responses to the measure under development with responses to related validated measures at two time points.

Generalisability

For a health measure, it is essential to determine the range of settings (e.g., in-, day- or out-patient), participant group (e.g., old, young, male, female) and other variables such as type of disorder or trauma in which the measure can be used. Generalisability is an overall assessment of the usefulness of an instrument based on summating its usefulness from scientific evidence. Generalisability is largely beyond the scope of this thesis and will be the focus of future studies.

Sensibility

The first priority of a health measure is to be clinically sensible (Brooks, 1995). To a large extent, this is already addressed by exploring criterion, construct and clinical validity. However, some believe that only by examining the specific purpose and clinical setting for which the measure is used can the clinical sense of a measure be evaluated. Arguably, the best test of clinical sensibility is whether an introduced measure is 'owned' and used by clinicians in a particular setting and results in changes to clinical processes and practice. In the thesis, these outcomes were used to assess sensibility.

Practicality

Practicality concerns any issues surrounding the use of the instrument in practice. The issues are setting or context dependent. As the introduction of a measure requires the use of additional resources, practicality concerns the *meaning* and subsequent value of the instrument to the health organisation, clients and funding agencies. Consequently, issues requiring examination are use of patient/client resources (respondent burden), clinical burden and administrative burden. Of interest with regard to the thesis research, is the finding of Mistianen (1992), which Brooks (1995, p.55) cites. A new questionnaire was withdrawn after one week because nursing staff felt some items were inappropriately personal, even though the response rate of 80% indicates a contradictory respondent opinion. Hence, the evaluation of burden cannot be separated from the issues of meaning. Ultimately, the health organisation needs to have a clear rationale for the introduction. Arguably, practicality can be viewed as a context-specific component of construct validity and was so in this thesis.

Criteria used for Evaluating Instrument Worth

Threats to credible evaluation of a measure's worth, resulting from a myopic focus on statistical analyses, at the expense of applicability, can be countered by acknowledgement and consideration of the issues of responsiveness, sensibility and practicality. However, these issues should be a component of validation rather than distinct evaluation criteria. Moreover, generalisability can be viewed as a component of construct and discriminant validity but is commonly discussed as a separate issue. Consequently, the worth of the measure developed for the thesis was evaluated by its reliability and validity. Generalisability will largely be addressed in subsequent studies.

Interpreting Statistical Results

The size of correlations judged to be of importance is largely dependent on the aims of a study. For Pearson's bivariate correlation, Aron and Aron (1999) cite the accepted Cohen convention for a large correlation is 0.50 or above, medium 0.30 and small 0.10. These guidelines were followed when interpreting thesis results. However, Aron and Aron note that research with humans inherently involves multi-causal variables and therefore it is seldom that the correlation exceeds 0.4.

The theory on which a measure is based enables the prediction of the number of major concepts that should be identifiable as the principal components derived from factor analysis. The thesis sought to develop a holistic measure of health and therefore it was predicted that all items would be interrelated and load onto one principal component.

The relative connection of each item to a factor or cluster is called the item's factor loading on that factor. The accepted convention for an item to contribute meaningfully to a factor is a loading above 0.3 or below -0.3 (Aron & Aron, 1999). Hence, factor loadings outside this range were not included in the thesis study results. Once factor analysis had been run and factors identified, the researcher examined each item within a factor to ascertain what were the common theme(s) linking all the items within the cluster. The single most critical step in factor analysis is the naming of the each factor (theme) as this process relies on the researcher's subjective judgement of the unitary meaning of the items within a

cluster. The risk to validity is that factor labels may become accepted as comprehensive descriptors of the items contained within a factor without ongoing re-examination of the congruency between items and factor labels.

CHAPTER 5: THE RESEARCH SETTING AND POPULATION

QE Health: The Research Setting

QE Health, Rotorua, New Zealand, is an accredited private hospital providing rehabilitation services for people with physical disabilities (QE Health website, 2004). Established by the New Zealand War Department in 1942, it aims to address health issues affecting the whole person, not just physical function. Medical interventions are part of the multidisciplinary holistic paradigm.

The founding leader, Dr. W. S. Wallis, advocated that those with physical impairments need to front up to their reality and use reflection to confront personal reality, the need for radical personal change, and to identify a personally meaningful way forward. To do so, he believed such people needed to perceive themselves as of value and whole, despite physical loss, and aim to reintegrate as fully contributing members of their communities (Faull, Kalliath & Smith, 2004). Consequently, two predominant underlying assumptions guide interventions at QE Health. First, people are assumed to have unique potential: to be of value, irrespective of any physical, social or cognitive limitations. Secondly, the person undergoing trauma is assumed to have unique expertise and to be the critical determinant of health outcomes: clinicians facilitate health change, but only the client can achieve change. Therefore, people are expected to take personal responsibility over their lives, including perception of self and health.

The core aim of QE Health interventions is to assess and treat all people individually and holistically. Within the research population, services are provided by an interdisciplinary clinical team comprising a rheumatologist, nurse, physiotherapist, occupational therapist and a counsellor/social worker.

All participants in the thesis research programme had undergone a three-week inpatient intervention consisting of spa-type treatments, education, peer group interaction, and structured time for reflection as well as the conventional forms of rehabilitation such as physiotherapy, occupational therapy, orthotics, medical and counselling treatments.

Interventions aim to enable people with chronic physical impairment to be healthy through radical changes of self-perception, worldview, behaviour, lifestyle and roles (Faull, Kalliath & Smith, 2004). A return to functioning and roles identical to pre-trauma state is often not possible. The theoretical approach guiding intervention stems from the existential approach to health, that is, the assumption that for optimal well-being it is essential that people can make meaning of their lives, perceiving their self as of value. The inference is that people have an innate core potential and that wellbeing is achieved when this is expressed through an individual's attitudes and behaviours. While other health providers often have repaired or strengthened physical aspects of clients' outer self, QE Health aims to continue such improvements while facilitating the development of inner strength and awareness of a resilient, spiritual identity. The aim is to remove disability, that is, any barrier limiting the person's ability to strive towards their potential as fully contributing members of their community.

Prevalence of Musculoskeletal Disabilities

Musculoskeletal disorders are identified by Lidgren (2003) as including more than 150 diseases and syndromes commonly manifested by pain and/or inflammation. The main types are 'rheumatoid arthritis, osteoarthritis, osteoporosis, spinal disorders, major limb trauma, gout, fibromyalgia, sprains and strains' (p. 4). The Orthopaedic Trauma Association (1999) states that accurate musculoskeletal prevalence data is generally not available, limiting determination of the incidence of these disorders in most countries. The New Zealand Health Research Council (2003) likewise identifies a lack of reliable epidemiological data in New Zealand.

There is wide variation, lack of clarity and uniformity of reported prevalence rates. The reported prevalence of musculoskeletal disorders in the general population range from 2 to 65% (Akesson, 2003; Euller-Ziegler, 2003; Nassonov, 2003; Picavet & Haze, 2003). The New Zealand Ministry of Health (1999) define musculoskeletal conditions as either 'arthritis' or 'back problems' and estimate that for people over 45 years of age approximately a third of the population experience such disorders.

Perhaps the most reliable data is that provided by the WHO Technical Report on the Burden of Musculoskeletal Conditions, 2003; cited by Lidgren (2003, p.4). The main points are:

- 40% of people over 70 suffer from osteoarthritis of the knee.
- 80% of patients with osteoarthritis have some degree of limitation of movement, and 25% cannot perform their major daily activities of life.
- Rheumatoid arthritis, within a decade after onset, leads to work disability, defined as a total cessation of employment, in no less than 51% of patients and maybe as high as 59%.
- Low back pain has reached epidemic proportions being reported by about 80% of people at some time in their life.
- In 1990 a worldwide estimate of 1.7 million hip fractures occurred as a result of osteoporosis. This number is expected to exceed 6 million by 2005.
- Traffic injuries cause approximately 1 million deaths and result in more than 30 million severe or disabling injuries costing US$500 billion, annually.

The QE Health Inpatient Rheumatology and Rehabilitation Population

The thesis research population included people who attended QE Health for inpatient Rheumatology or Rehabilitation programmes. The average demographics between June 1998 and June 2004 included 88.13% New Zealand European/Pakeha, 11.1% indigenous Maori and 0.77% other ethnicity while 70.23% were female and the average age of the population was 61.51 years. The majority (67.57%) were either retired (44.3%), homemakers (13.3%) or under 65 beneficiaries (9.97%). A small number were students (1.2%) while 20.31% were working, either as unskilled workers (6.1%), skilled workers (4.67%), professionals (5.57%) or self-employed (3.97%).

The predominant disorder was any of the 100 plus arthritic diseases (58.55%), including osteoarthritis (27.66%), rheumatoid arthritis (17.7%), ankylosing spondylitis (4.13%), psoriatic arthritis (2.43%), gout (2.2%) and other arthritis (4.43%). Non-arthritic disorders included back pain (17.3%), fibromyalgia syndrome (12.57%), unspecified pain (3.43%), osteoporosis (2.4%), post polio syndrome (2.0%) and other miscellaneous conditions (3.77%).

In summary, middle to older age white female New Zealanders and those not in paid employment with disorders of pain impacting on function were the common characteristics across the research population.

PART 3: HEALTH AND THE SPIRITUAL SELF: INITIAL EXPLORATIONS

Chapter 6: The Health, Self and Disability Study.

Chapter 7: Developing a Spiritually-Based Health Change Process Theory

CHAPTER 6: THE HEALTH, SELF AND DISABILITY STUDY

Introduction

This study examined the definition of health held by those with chronic musculoskeletal impairments in order to identify the critical factors they perceived as determining health status. Understanding these people's definition of health was important because accepted health definitions do not provide realistically achievable and sustainable health goals for this population.

The WHO definition of health, adopted by the New Zealand Ministry of Health (Ministry of Health, 1999) defines health as a state that is not determined by the absence of disease but by optimal levels of physical, mental, and social wellbeing. This is frequently interpreted as meaning that wellbeing is achieved primarily through physical mobility, independence and control; a health concept that is not only impossible for those in this population to achieve but may even be a causal factor of ill health.

The common experience of such people is that not only is the ideal of optimal wellbeing unattainable but that some aspects of health intermittently or constantly deteriorate. It was proposed that people experiencing chronic disability can nevertheless, *also and at the same time,* experience wellbeing, and therefore good health (Cwikel, 1999; Frey & Upchurch, 2000; Japlensky, 2000; Joslyn, 1999; Kriegsman & Deeg, 1999). Health goals need to be widened to include personal growth that often results from health challenges (Fuhrer, 1994). Moreover the general health concept must embrace the subjective aspects of wellbeing as well as its more observable objective components (Foote, 2000).

Social health, the strength of intimacy with others, personal and societal value of one's relationships and roles, also relate strongly to physical health (Fratiglioni, Wang, Aericsson, Mayton & Winblad, 2000; Fuhrer, Rintala, Hart, Clearman & Young, 1992). Similarly, cognitive health (i.e., level of self esteem and ability to perceive meaning) relates to physical health (Akkasilpa, Minor, Goldman, Magder & Petri, 2000; Benjamin, Morris, McBeth, Macdarlane & Silman, 2000). The common means by which social and cognitive health improve not only physical health but also health overall is stress reduction (Lazarus & Folkman, 1984; Scheier & Carver, 1988;

Oulette-Kobasa & Pucetti, 1983). For instance stress level and duration relate strongly with prevalence of cancer, cardiovascular diseases, chronic pain and fatigue syndromes, asthma, diabetes and some forms of arthritis (Cohen & Williamson, 1991; Jemmott & Magloire, 1988; Moss, Moss & Peterson, 1989). Consequently, the likelihood of living successfully with dysfunction can be increased by interventions such as strengthening support networks and altering perceptions of experience as well as dealing with physical abnormalities.

Moreover, improved overall health results from learning to live successfully with dysfunction. Enablement or the construction of a healthy self can result from the experience of ill-health (Fuhrer, 2000). A health challenge provides an opportunity for change and growth of self, as one accepts and identifies one's unique potential rather than focussing on loss of objective aspects of self. Evidence for this comes from disability research (Do Rozario, 1997; Vash, 1981), nursing studies (Kazanjian, 1997; Reed, 1992), psychiatry (Ellis & Smith, 1991; Resnick, Harris & Blum, 1993) and general medicine (Ornish, 1998; Pargament, 1997). The common conditions these studies identify as being necessary for enablement to occur are relationships, connections, beliefs and values that develop and strengthen one's intrinsic self or sense of 'I'.

These factors have been identified as the central themes of a fourth dimension of health, the spiritual dimension (Dyson, Cobb, & Forman, 1997; Egan & Delaat, 1994; Weaver, Flannelly, Flannelly, Koenig & Larson, 1998). It was therefore argued that health is derived from accessing and utilising the spiritual dimension; transforming self perception from a largely unchanging concept to a dynamic, developing self, not limited but even enhanced by ongoing physical degradation. Therefore, for those with musculoskeletal disabilities, good health attainment may depend upon positive perceptions of the value, purpose, roles and expectations of self in relationship with others. Moreover, one needs to perceive oneself as part of the past, the present and the future, as well as of the world as a whole (Ballard, 1994; Durie, 1998; Vash, 1981).

Hence the consumer of disability health interventions clearly plays a pivotal role in health attainment. Consequently interventions must primarily address the consumer's health goals and successful health interventions depend on the consumer's definition

of health, including all the dimensions of self and not just the physical (Persson & Lilja, 2001). Thus health is more than the restoration of the physical, social and cognitive resources available to the individual. Growth of the subjective aspects of relationships with self, others, nature and the spiritual world must also be attained, producing resilient beliefs about the self and others (Foote, 2000). A strong sense of self-identity, founded on such relationships and on accepting one's level of understanding of the meaning of experience, is central to the development of a healthy self. This is subjective health, and applies to all including people with chronic disorders and permanent disability.

Consequently, the aims of this study were to define health from the consumers' perspective and to investigate the process by which participants achieved health.

Methodological Approach

Feelings, thoughts, intentions and consequent health perceptions cannot be observed directly. The personal nature, sensitivity and unknown content of the consumer health concept made an interview design appropriate (Hammersley, 1995; Miles & Hubermann, 1994; Wolcott, 1994). However, interviews may encourage socially desirable responses rather than a factual description of individual experience (Dingwall & Miller, 1997, Silverman, 1993). Moreover, interviewing in a group situation can exacerbate this. Nevertheless, data validity can be enhanced by a design that counters social influence effects by incorporating participant-observation data collection within an interview framework; reducing face-to-face interaction; and facilitating reasoned, rather than emotionally based analysis.

Such criteria can be met by employing the Delphi technique (Mead & Moseley, 2001) to achieve a grounded theory approach (Strauss & Corbin, 1990). Furthermore, comparison across multiple groups enhances data validity by identifying consensus (triangulation) and countering reflexivity by identifying contradiction between groups (Denzin & Lincoln, 1998, Hammersley & Atkinson, 1995).

The Delphi technique (Mead & Moseley, 2001) was therefore used to counter the negative influences of group dynamics while still retaining the benefit of input

from multiple perspectives. Typically, this technique commences with selection by the Researcher of an expert panel with respect to the topic being investigated. The Researcher then informs the group of that topic, and requests their opinion on it. A series of cyclical rounds of autonomous data analysis by panel members follows. Each member sends their own analysis to the Researcher, who ensures anonymity and redistributes it to all other panel members. Panel members then reconsider their own analysis in the light of those performed by the other members. Each then returns to the Researcher either the resultant modification of their analysis, or a justification for not altering it. If analyses still differ, the PR then requests reconsideration of points of disagreement by all members. This cyclical process of individual analysis and group feedback is continued until either consensus is achieved or the group agrees to differ. This procedure aims to achieve consensual agreement without direct panel member interaction and was employed in analysis of study data carried out by the co-researchers.

In this study the Delphi expert panel comprised the co-researchers (CRs), using the data they had each sourced from participants they interviewed in focus groups. The data they collected from other participants provided the raw material for Delphi analysis. Furthermore, once consensually agreed common concepts and interrelationships had been identified, the principal researcher worked with an independent researcher (MDH) to develop the models presented in this study. This design was used to counter validity issues, particularly reflexivity.

Method

Participants

Thirty people with chronic musculoskeletal disorders who had been inpatients of the QE Health inpatient rheumatology and rehabilitation services participated in the study. The majority had undergone one admission but remained in contact with QE Health staff and/or fellow patients. Others had experienced ongoing admissions to address continuing health challenges.

The sample consisted of 13 males and 17 females, 2/3 of whom were married, with ages ranging from 36-82 (M = 56.37). Maori comprised 5/30 although English was the first language for all. Most had been admitted to QE Health once, although some more often. Disability types included fibromyalgia syndrome

(26.7%), chronic back pain (20.0%) rheumatoid arthritis (16.7%), osteoarthritis (13.3%), other forms of arthritis (13.3%), post-polio syndrome (6.7%) and an amputee (3.3%).

Materials

Co-researcher Group Facilitation and Data Analysis Training Manual (Appendix 3).
Audio tape recorder with central desk-mounted microphone.
Large sheets of paper and felt tip pens.

Researchers

The PR, employed by QE Health, had been an inpatient and had existing relationships with the co-researchers but with none of the participants (Table 6.1). The CRs had also been QE Health inpatients. They were selected because they were known by the PR; demonstrated an ability to work with others; possessed required communication skills; represented a diversity of disabilities; and had time to undertake the study and associated training. They were recompensed for their time and travel expenses.

Procedure

Potential participants were selected in order of admission date from the QE Health 1999-2000 inpatient database. Criteria for selection included residing within 100km of QE Health, aged over 18, English as first language and no history of major intellectual, psychological or emotional dysfunction. An information sheet was sent to those selected, inviting participation in a study to investigate "how people with disabilities define health" and which involved discussion of personal health stories, individual meanings of health, self and disability (Appendix 1). Of the 109 approached, 30 accepted, 47 declined citing health, transport or employment difficulties, and 32 were not interested.

To enhance data validity the CRs were selected for their potential ability to maximise rapport, trust and empathy with the participants. The PR developed a training manual and conducted two full-day training and practice sessions with the CRs to develop their skills of group facilitation, qualitative data collection, the Delphi process and grounded theory analysis. Eight focus groups of participants,

facilitated by the CRs, were employed to collect the raw data. These groups enabled inter-group data comparisons to identify data distortion and to counter threats to validity related to interview designs. They then formed the expert panel required by the Delphi process to undertake data analysis as well as being the primary data sources in later rounds of grounded theory development.

The CRs each facilitated one focus group at QE Health per day for two separate days, although CR absences reduced the total number of groups from 10 to 8. Their main tasks were to ensure that (a) data was recorded by audiotape, mind maps and notes, (b) all participants had equal opportunity to speak, (c) an environment facilitating openness and story-sharing was promoted, and (d) the research questions remained the focus of discussion.

After a general introduction, participants were randomly assigned to groups. The PR played an external support and supervisory role. Data collection began once rapport had been established and was guided by the question, 'What is health for you?' Once consensus had been reached that no new information was being generated, they discussed a second question: 'What has helped, or would help you achieve this health?' The same recording and facilitation procedures were used. Maximum total time involved per group was five hours.

Table 6.1: Researcher and Co-researcher Demographics

Gender	Age	Years since first consultation	Number of inpatient admissions	Diagnosis*	Ethnicity	Occupation
			Principal Researcher			
Male	46	7	2	RA	European	Researcher
			Co-researchers			
Female	49	3	3	Postpolio	Maori	Graduate student
Female	28	4	3	RA	Maori	Beneficiary
Female	57	3	2	FMS	European	Beneficiary
Male	41	7	3	AS	European	Owner/mgr Gymnasium
Male	45	8	10	Postpolio	European	Beneficiary

* RA: Rheumatoid Arthritis; FMS: Fibromyalgia Syndrome; AS: Ankylosing Spondylosis

Analytic Procedure

The intention was to follow the Delphi process strictly, using the grounded theory analytic approach, with the aim of reaching a consensus based on logical reasoning as opposed to social influence.

Once participants' definitions of health and of means of achieving it had been collected, the initial research question 'What is health for you?' was therefore analysed by the CRs as follows (throughout the process the PR provided methodological guidance and discussed with the CRs the titles to be commonly assigned to each category):

1. Each CR returned to their own home to transcribe their group's audio-recorded data. They were in telephone communication with the PR but not with each other.
2. They reduced the data by identifying and coding categories occurring within the group(s) they had facilitated. Quote and consensus frequency was used to identify category salience to the participants' health concept.
3. Defining quotes were extracted for each category.
4. Each CR's findings were communicated to the other four by the PR in writing.
5. Each CR then compared the findings of the other CRs with their own, identifying commonalities and differences.
6. Commonalities were agreed upon and most differences consensually resolved by all five CRs, in repeated telephone consultation with the PR.
7. However, although CRs transcribed and developed initial categories, they then found it difficult to remove themselves from the detail of the data to advance the conceptualisation process. The PR therefore abandoned the original plan and convened and facilitated a face-to-face group meeting with the five CRs to continue the grounded theory process
8. This group meeting discussed the principles of generalization and trend analysis inherent in the Delphi technique and the grounded theory approach, as well as how they might be applied to specific categories, titles and relevant participant quotes.
9. The CRs then returned to their homes and re-examined the data in light of similar but not identical interpretations of it by the other CRs, aiming to

reconcile aspects of their interpretations with those of other panel members. They remained in telephone communication with the PR but not with each other.

10. When it became apparent that complete consensus was still not going to be achieved, the PR called a second group meeting, at which agreement was finally obtained on category content and titles. The Principal Researcher recorded these and posted a summary to each CR.

Back in their homes, the CRs repeated the above process on the second question: 'What has, or would, help you achieve this health?'

1. In telephone communication with the PR and each other, CRs identified possible relationships between the themes achieved during the first stage.
2. They then identified possible stages of health change, constantly testing these hypotheses against the data.
3. A third meeting discussed the emerging relationships and critical points of health change and developed a rudimentary model of the health concept.
4. Back in their homes again, CRs reflected on the appropriateness of the derived health concept model for their data, discussing it by telephone with other CRs and the PR, and continuing to test its appropriateness as it evolved.
5. A fourth meeting reached consensus on a refined version of the model of health (Figure 6.1).
6. The refined draft was then mailed to all participants and feedback invited and noted. All who responded endorsed the derived model of health.
7. The PR and his thesis supervisor then used the model of health and feedback on it, together with the concepts of critical points of health change which had been derived, as a basis for developing the Self Attributes model presented in Figures 6.2 and 6.3
8. At a fifth and final meeting the CRs unanimously agreed that these models accurately reflected their data.

Results

Question 1: Defining Health. 'What is Health for You?'

Participants and CRs readily identified the Primary Categories: Reflection, Interaction, Strength of Identity and Bearable Pain; but all categories were

interdependent to some degree and offered an expanded explanation of one another (see Figure 6.1).
One participant's approach to health was to deny disability, to treat it as an adversary to be conquered and to aspire to pre-disability roles. This was useful as it provided a contrast to the predominant perception of health.

The primary and associated categories were defined as follows.

A: Primary category: reflection
Reflection involved acknowledgement and incorporation of experiences, reactions, feelings, emotions and behaviours as part of the individual. In addition, the experience of 'being alone, but not alone' resulted in a sense of place and purpose in life as well as positive appreciation of that life.
'I found that by being alone - it just sort of sorted itself. It's about looking at yourself – need to put things in balance - I had to re-evaluate my whole life'.

Reflection included connecting with the natural world; for example, being by the sea, in the bush or a favourite spot in the garden, house or park. Such communion is a type of relationship, interaction or connection. Reflection was also frequently mentioned in association with acceptance, self-responsibility, beliefs, identity and the perception of pain. Reflection included meditation, prayer or simply Time for Self, the strongest associated secondary category.

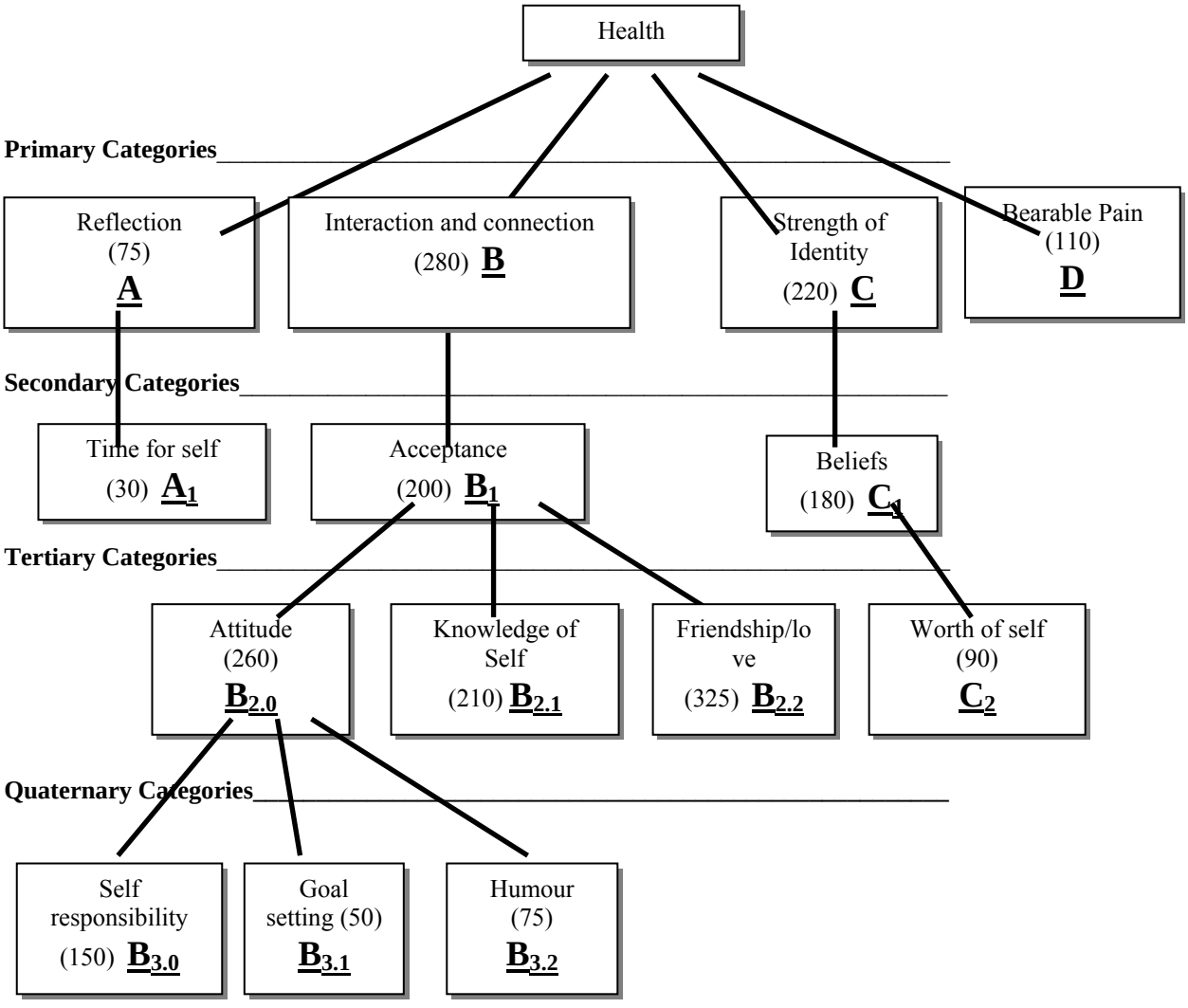
A_1: Time for self
'But now I make sure I have time for myself. You know, a walk along the beach – forest. I dunno; it all makes it right – makes you see how you are part of something bigger and awesome'.

Participants found that they needed to identify and accept Time for Self, in the sense of enabling self-awareness and ownership of the self's experiences, as an essential component of their health practice and take responsibility to ensure this occurred.

B: Primary category: interaction and connection

Interaction with others aroused both positive and negative reactions: *'The love I feel for my family and my dog keeps me carrying on - to go to work - through good days and bad'* or *'Some doctors don't believe you...so often you come out worse than when you went in because you feel guilty - maybe I am loony after all'*. Interaction with people who had had similar experiences allowed participants to perceive themselves as normal. Interaction with the supernatural, others, animals and nature, integrated through Reflection, assisted development of a sense of place and purpose, together with awareness and experience of mutual connection and nurturing. All of this resulted in a greater sense of self worth, improved self-knowledge, general Acceptance and a health-enhancing attitude.

Figure 6.1: Categories found for question 'What is health for you?'



Note: Numbers in parenthesis are the number of quotes identified as referring to each category

B_1: *Acceptance*

The secondary category associated with Interaction and Connection was Acceptance.

The first level of Acceptance was the acknowledgement of disability as an element of ongoing life, with recognition of resultant limitations and of change from the pre-disability self. *'You have to front up to yourself'*.

Acceptance was closely related to the categories of Knowledge of Self, Attitude and Friendship/Love. It was the converse of the view: *'I've never admitted to myself that I've got one arm. It's something I can't do. I'd rather die than do that. I never have and never will. That I have got a disability - I can do anything'.*

On another level, Acceptance meant acknowledging the finiteness and immediacy of human existence: *'You accept you have got what you've got and you can do something about it'. Maybe not physically but you know you can cope because the door has been opened'.*

However that was balanced by focusing on growth of the intrinsic aspects of self: *'Learn to relax, work with myself, not ignore and fight myself – I discovered myself'.*

Finally, Acceptance also included awareness of individual inability to control life events, while realising that one is personally responsible for the way events are perceived and experienced. A cyclical process occurred of Interaction and Connection, requiring Reflection, and eventually producing Acceptance.

$B_{2.0}$: *Attitude*

Closely associated with Acceptance was Attitude, which centred on perception of a health challenge as an opportunity to profit from improved awareness of uncertainties, finiteness and limits of control to live a fully inclusive life. *'I do believe I am as good as all those wobblies who walk around on two legs, and I think everybody should have that attitude'.* The quaternary categories of Self Responsibility, Humour, and Goal Setting further defined Attitude.

$B_{3.0}$: *Self responsibility*

Self-Responsibility involved acceptance that health and the practices that promote individual well-being are primarily the responsibility of the individual. *'I own my own health and only I can take it away...we have a responsibility to ourselves – be our own experts'*. Retrospective stories expressing an unhealthy viewpoint commonly portrayed feelings of anger, frustration and injustice, frequently centred on violation of individual rights. Examples included demands of work, traumatic life experiences, incompetent practitioners, callous funders, societal bigotry or lack of resources.

Significant challenges to such attitudes, commonly by health professionals, resulted in acceptance that even if life experiences such as tragedies, mistakes, different agendas and power inequalities are addressed, health cannot be ensured. The attitudinal focus shifted from attributing blame externally for such events to an internal focus on the responsibility of the self to explore ways through them.

$B_{3.1}$: *Goal setting*

Acceptance led to awareness of the need to live the reality of the present and to control what one has self-responsibility to control. In other words, realising that one has to determine, focus on and implement actions currently necessary to move oneself toward long-term goals. *'My goal ... was to increase my ability to look after myself - so, the first week I worked with the OTs so that I could squeeze my own toothpaste onto my own tooth brush - I did that in a day! I knew then I was going to achieve so much. Small changes – one at a time – big gains'.*

Goal Setting encompassed envisaging relevant, realistic, pragmatic and achievable goals, then prioritising and adopting them. Examples included physical adaptation, planning for career development, and developing appropriate life roles and perspectives of self and their world. Essentially, this concept acknowledged that, while long-term goals might appear vague, uncertain and ultimately outside one's control, they nevertheless provide a direction and purpose for living positively in the present.

$B_{3.2}$: *Humour*

The third category of Attitude was Humour, notably an ability to laugh at oneself and with others about experiences and situations. *It involved a conscious choice to '...see more positives than negatives – look on the good side of life'.*

A dominant characteristic of the humour described was that it was 'in-house' or 'black', and in some way at the expense of the teller. Stories often told of catastrophic experiences which humour was used to make more bearable and acceptable as an aspect of normal life.

One of the few printable examples involved a participant sharing her painful experiences of childhood sexual abuse, followed by marital physical abuse and finally, chronic physical disability. When she finished, there was a lengthy silence. Finally, another participant commented, *'Well, what a greedy old bugger you turned out to be'*. Only those who had had similar experiences would find this funny, and by the level and duration of laughter and the ensuing stream of related jokes, this group obviously did.

Humour such as this was seen to indicate an ability to view oneself from outside and to see oneself in the context of a wider picture. Moreover, it was considered to reflect the New Zealand cultural norm of understatement, together with an awareness of the self as a component of a life that is precious and enjoyable. *'You learn that life is precious, no matter what'.*

$B_{2.1}$: *Knowledge of self*

The Knowledge of Self tertiary category, associated with Acceptance, captured the way in which disability increases awareness and understanding of the inherent individual strengths and weaknesses, developing and clarifying the self-concept. *'When you go through the pain, loss and grieving like we all have – it gives you a wisdom that you can pass onto other people'.* The distress traumatically transformed the self-concept into being perceived as an integral part of a wider system, connected to others, nature and the supernatural, rather than as a closed, autonomous system. *'I didn't realise all those things from so long ago still affected me – it was good to talk about it – somehow talking about it – it wasn't nice – it's still a part of my life but I seem to have dealt with it'.*

$B_{2.2}$: *Friendship/love*

The other tertiary category within Acceptance was Friendship/Love. It explored the characteristics and outcomes of close relationships between people, nature and the supernatural. The dominant outcome cited was that *'when I am contributing in some way I feel valuable, at peace and happy. I'm no longer so alone'*. Participants described such interactions as markedly reducing the stress they identified as a major cause of ill health.

Experiences involved included compassion, caring and nurturing given to or received from others, animals, the supernatural - even themselves, commonly without any expectation of reciprocation. *'As soon as I realised that I could be useful as well, by helping to uplift others, I felt worthwhile'*. A component of this category was the experience of connection felt with others who had also experienced adversity. *'You're relaxed, you're out of your own environment and all the demands and pain and all that...then you go home and you're not amongst people going through similar experiences. You're on your own then. You know, for me, even my own family didn't realise as much as the people here (QEH) did. What I was going through y'know. They can't go through it for you'.*

Another manifestation of such 'unconditional love' was greater acceptance of self, including spiritual connection with the supernatural. *'I don't know – something spiritual if you like – sense that I am loved, wanted, worth something – people do care about me because I am me rather than in spite of me'.* A common element of this category was awareness and acceptance that subjective feelings are important and should be complied with.

In summary, all the categories comprising the primary category of Interaction and Connection described acceptance of the self as part of a greater gestalt. The self became perceived as not alone but part of a greater whole.

C: *Primary category: strength of identity*

Participants developed a new perspective of the self. With surprise and even astonishment, they discovered that despite losing physical functions, occupations and life roles, they themselves not only remained, but could even grow *'because of disability, rather than in spite of it*'. The core of their identity, their 'I', was not as

fragile as they had thought. *'You don't measure anybody's stature physically or financially – it's what's inside that counts'.*

In contrast, one participant's identity focused on his ability to fulfil pre-disability tasks and roles *'I'll tell you what my biggest fault is...my biggest fault is that I am a life failure, obscurity y'know'*. A continued focus on objective aspects of self was causing an identity crisis. This participant also repetitively described health professionals as not respecting him as a person, *'...then I come in here to be told I'm a loser...he didn't even look at me'*.

Nonetheless, most participants described health professionals as influencing identity strength positively. A critical turning point was often when the health professional *'made me feel respected as a person and they really listened and supported me through my uncomfortableness with my physical condition and emotions'*. Consequently, *'I learnt to accept myself as I am'.*

C_1: *Beliefs*

The secondary category associated with Strength of Identity was Beliefs. Change in self-perspective significantly impacted upon participants' beliefs about themselves, others and life in general. *'Success is achievement and by that I mean achievement in every sense of the word - it definitely isn't just material success. Successful relationships, good friends and family - they are an important part of health'*. Facing personal challenges clarified and developed their beliefs about the meaning and purpose of their selves, others, nature and the supernatural. *'I got to the point where I realised that life was very precious - my life is precious!'* All had very definite beliefs about what activities were important for them to remain healthy, describing them as bringing 'peace of mind', and 'clear thinking'. Such activities ranged from walks along the beach or in the bush to helping others, meditating, praying, or being with family. They systematically embraced activities that were congruent with a view of self as a part of a wider life.

C_2: *Worth of self*

The tertiary category of Worth of Self had a common theme that value or worth was not earnt, but something innate. It was closely related to the Time for Self category. Participants spoke of needing time for self to perceive self as of worth

but also the need to perceive self as worthy to ensure they allowed time for self amidst the demands of everyday life. *'But now I make sure I have time for myself. You know, a walk along the beach – forest. I dunno; it all makes it right – makes you see how you are part of something bigger and awesome'.*
'I found out that I was special – not my disability...you know, they made me see that I also was somebody – no matter what my husband and kids think – I am the only one who can help me'.

Commonly, participants spoke of 'release', 'hope' or 'excitement' when they realised that their identity was not only intact, but developing. To find that there were choices of perspective, that one was resilient and whole despite major loss, enabled people to regain control of life direction and health, and to see themselves as of value. *'I own my own health and only I can take it away'*. Again, the individual had a definite place and purpose.

D: Primary category: bearable pain

The degree of pain attributable to physical dysfunction varied. Coping with it required acceptance. People at first fought the uncontrollability of their pain, and feared its variable nature. They desperately sought medications, therapies and strategies in the hope that they 'could be me again'. Eventually, interaction with others with disabilities, as well as with some health professionals, led to acceptance that such pain experiences can be part of 'normal' life and that their unique identity was not only still intact but developing. They also identified previously unresolved painful life events, often unrelated to the physical disability, as models for perceiving and coping with all pain. Their focus then shifted from eliminating pain to managing it as a part of who they were, rather than a determiner, of their lives. *'Pain is part of my life – not my life'*.

Prior to experiencing physical disability, many participants had assumed that they could control and order their lives. One participant had set her day of marriage five years in advance, but conditional on her suitor obtaining his qualifications and the right house. He did so. After some years of marriage, including raising children, they moved to Southeast Asia. Her ordered world became disrupted. *'Armed guards everywhere, no white line down the middle of the road'*. She then was involved in a traffic accident in which she *'wasn't hurt badly but it frightened*

the life out of me and after that I had to have a tranquilizer to put me to bed and one again in the morning'. Eventually, *'I got sick of taking tranquillizers and the terrible mind blowing pains'.* Finally, with the assistance of health professionals, she realised that fear and its resultant stress were increasing the pain. She had attributed the fear to the accident but now realised that it was 'something else that triggered it off...the things I have kept hidden away for 17 years'. Life was not as ordered and controllable as she had believed.

For pain to become bearable thus required a loss of fear and of the associated need to eliminate pain, as well as acceptance of the uncertainty and finiteness of life and of the limits to individual control. The outcome of such a perceptual shift was to be 'at peace', 'relaxed' and have a 'clear mind' - all symptomatic of lowered levels of stress.

The health process model: 'What has helped or would help you achieve this health?'

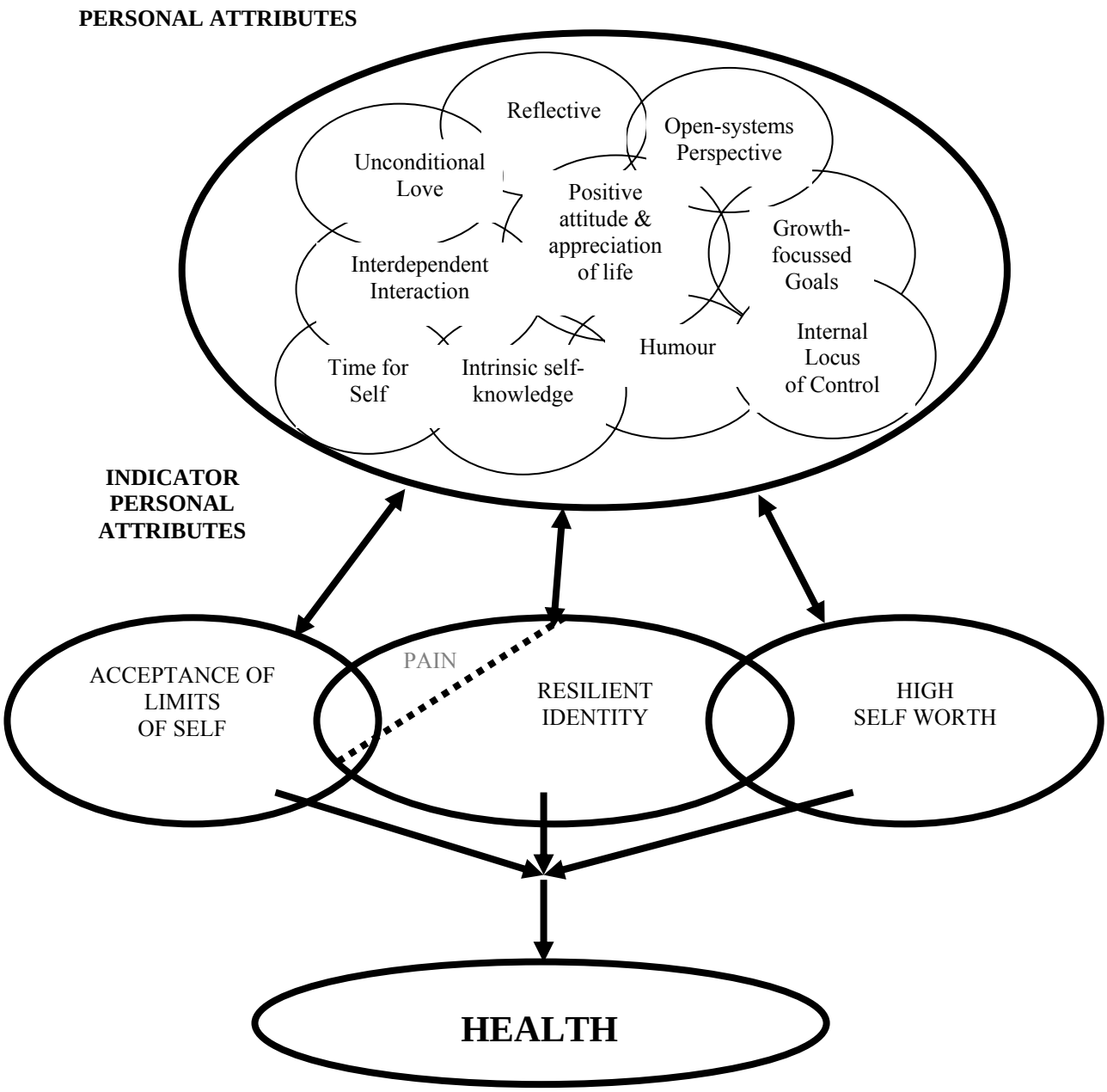
Relationships between the variables

The central question addressed during the second stage of analysis was whether or not participants used a common process to achieve health. This stage of data analysis was inductive, allowing development of a model which was authenticated by continually returning to the data, and in turn allowed generation of hypotheses concerning relationships (see Figures 6.2 & 6.3).

Two clear points emerged from the first stage of analysis and were clarified in this second stage. First, there was a high degree of inter-relationship between categories with no clear linear 'cause and effect' relationship evident. What was common was that change in any category could trigger change in the other categories. Secondly, there were three indicator categories (personal attributes) that had to change if there was to be authentic movement toward health along the health - ill health continuum. These indicator personal attributes were self worth, the identity/pain relationship and acceptance, and were persistently mentioned in answer to the second study question.

Analysis of participants' experiences of movement along the continuum towards health focused on the extremes. Attributes identified for each pole of each personal attribute are summarised in Table 6.2.

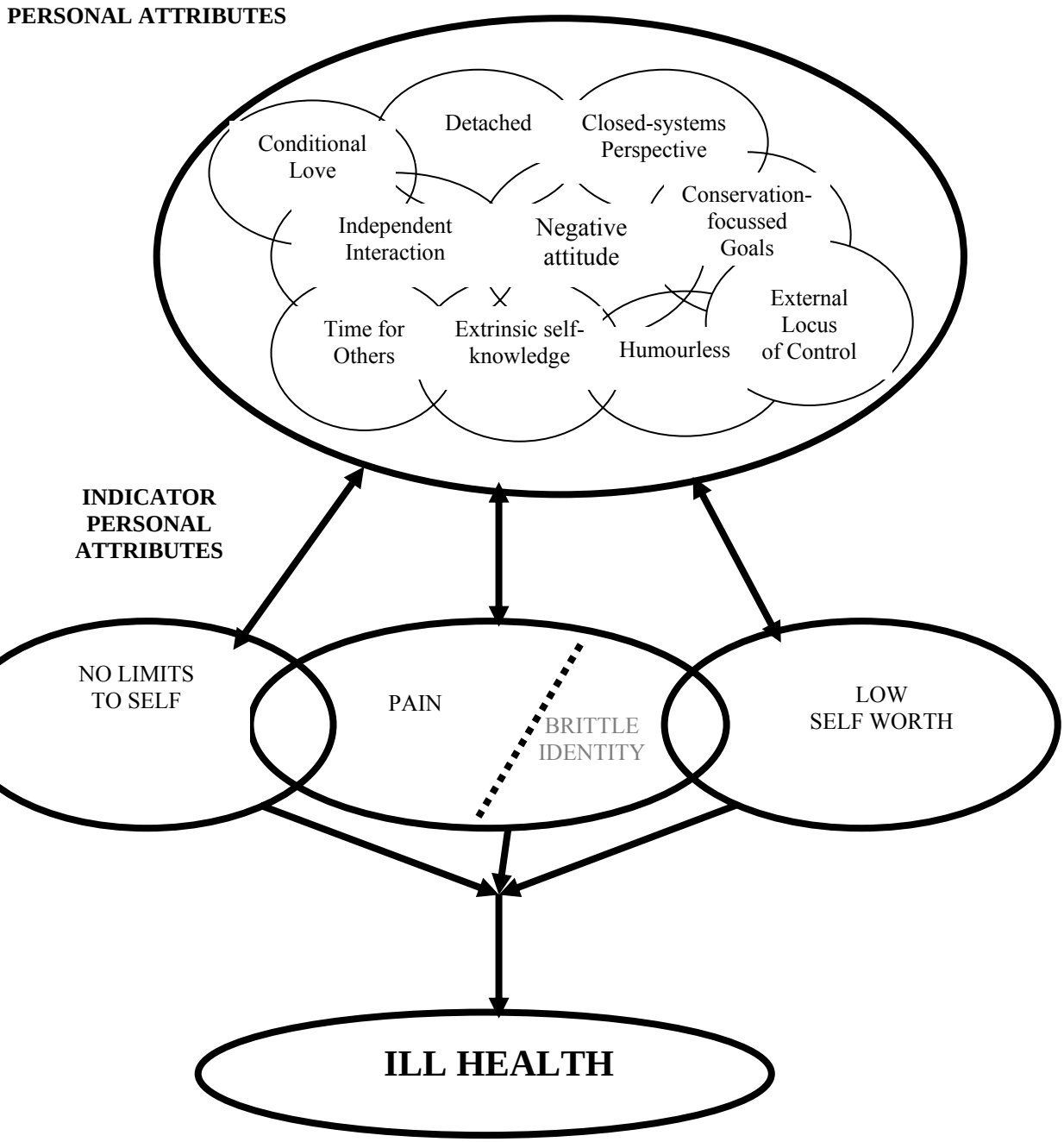
Figure 6.2: Model of Individual Attributes and the Process Resulting in Health



No one of the three indicator attributes was sufficient to achieve health alone – all three had to be achieved. Moreover none of them was necessarily the initiator: Movement could be initiated at any point, among any of the personal attributes –

indicator or other. Nonetheless all three indicator attributes had to be achieved before the goal of health could be reached.

Figure 6.3: Model of Individual Attributes and Process Impeding Health



Examples of movement initiation included experiencing a rehabilitation environment where staff and fellow patients behaved interdependently and exhibited unconditional positive regard, combined with a programme that enforced time for self. Likewise, health professionals sparked attitudinal and self-knowledge change by constantly informing participants there was no cure,

apparently ignoring participants' attempts to focus on pain, and continually asking the question; 'So, what are you going to do now and in the future?' For others, regaining function led to hope that all future health and self change need not be negative, and resulted in radical change of responsibility and attitude. Hence each of these three examples had a ripple effect on all attribute categories – including the indicator attributes.

Participants saw the first of the three indicator attributes required for movement toward health as developing the resilient identity necessary for complete health. Identity resilience and pain interacted dynamically. Their relationship changed from a brittle self dominated by the experience of pain, and requiring pain elimination for identity acceptance, to pain being perceived as an acceptable part of self, and therefore bearable.

A second integral component in the development of a resilient identity was the open system perspective attribute, emerging from the beliefs category (C_1). Participants needed to move from viewing themselves as an autonomous, closed system 'I', to seeing oneself as a part of a wider system. Consequently the individual had to nurture the wellbeing of the wider system, particularly those components vital to sustain self. As the self came to accommodate pain and to see itself as an open system, so the self-percept developed to a resilient, constant and continuous identity, part of a greater whole.

A cyclical reflection-action process was essential for resilient identity development. Nonetheless people needed to see themselves as worthy before they would take time out for reflection. Achievement of high self worth was therefore the second pre-requisite for health achievement. Finally, resilient identity and high self worth cannot be sustained unless one is aware of, and accepts, the limitations of one's self. Resilient identity, self worth and self-acceptance are all intertwined. Consequently, change in all three indicator attributes had to occur in parallel for authentic health change to be achieved.

To sum up: relationships and the experience of connection, wholeness or oneness obtained by interacting with their world, combined with reflective behaviour, resulted in the development of resilient identity, bearable pain, self-worth and

self-acceptance (see Figure 6.2). Although the model might suggest a limited linear process, any of the personal attributes can potentially trigger movement toward health. However, any such movement will be unsustainable unless it includes change in the indicator attributes. Therefore, the indicator attributes are the second step essential to movement toward health. Moreover, health will not be achieved without a third 'stage' of congruence between the three indicator attributes. Thus participants said that if movement among personal attributes (indicator or other) leads to movement in all three indicator attributes, and if these then reach congruence, then movement toward full health will occur. The model shown in Figure 6.2 tries to portray this conception.

Discussion

The study sought to identify the fundamental components of health as defined by people with musculoskeletal disabilities. The relationships between these components were then used to develop a model of the personal attributes associated with health status.

Health is not the absence of disease but rather the perception of overall wellness (World Health Organisation, 1997). Participants in the current study identified themselves as healthy when the primary components of Reflection, Interaction and Connection, Strength of Identity and Bearable Pain were present. Reflection concerns understanding relationships within self as well as between self and the world. Interaction and Connection consists of relationships within self, between self and others and between self and the universe. Strength of Identity is the ability to cope or manage changes in all relationships in a manner that enables the core self to continue and grow. Bearable Pain also concerns relationships; the capacity to perceive pain as a part of self rather than as an external barrier preventing the existence of a meaningful self.

While participants identified pharmaceutical, mobility, work environment and occupational or psychological interventions as important, they considered such interventions effective only if they supported the strengthening of the core self. Interventions may first seek to return lost mobility through mechanical aids; reduce pain; increase strength, flexibility and mobility; or reduce stress through

education. These in turn allow social relationships at home and work to strengthen attitudes, expectations and goals to alter sufficiently to compensate partially for residual loss.

Nonetheless, although participants acknowledged that physical, social and cognitive changes were important, alone they were not sufficient to achieve optimal health. Also necessary were interventions which strengthened the relationships, connections, meanings and values comprising the self. This was expressed as the regaining of 'I'. The degree of wholeness of self was perceived as an indicator of health status.

While physical, social and cognitive wellbeing are not sufficient determinants of health, the results indicated that personal awareness and acceptance of lack of such wellbeing was a prerequisite for the changes to the core of self required for holistic health. 'I'm me and only I can take that away!' was a common participant statement of the importance of this health/self relationship. Such participants claimed that they had gained health *because* rather than in spite of disability but also was a cry of anguished rebellion addressed to all those friends, family members, members of the public and health professionals who could not see past the disability to the complete person.

Consequently, participants attributed much of their experienced pain to a loss of a sense of the complete self, rather than the onset of a physical disorder. This loss of self stemmed from previous personally traumatic experiences such as discrimination, relationship break-down, death of significant others, or abuse (psychological, physical and sexual) from powerful others. Most participants had coped with such trauma by assigning it to the past; 'forgetting' it; or 'just getting on with life. They effectively denied these experiences as being a part of their present self. Initially, participants attempted to cope similarly with the impact and experience of musculoskeletal disorders. However, past trauma stemmed from adverse experiences that were time specific; these experiences were contained within a specific episode without the constant day-to-day reminder that the adversity remained present.

Table 6.2: Personal Attribute States Associated with Health and Ill health

Personal Attribute	Health	Ill health
Reflection	Reflective, willing to critically examine self	Detached from self. Lacks critical self-examination.
Time for self	Ensures time is allotted to be alone	Avoids being alone
Interaction and Connection	Interdependent. Other people, nature & the supernatural seen as a part of self and vice versa.	Independent. Self is autonomous and focuses on 'doing' as opposed to 'being'.
Acceptance	Accepts the continual changing nature of self and the world. Accepts limits on the self's ability to understand, predict and control the wider system.	Fails to accept change in the self and the world. Fails to accept limitations of self
Attitude	Has a positive attitude towards the future and appreciates both past & present	Has a negative, fear-dominated attitude towards the present and future, and appreciates only the past
Responsibility for self	Views self as responsible for self	Views others as responsible for self
Goal setting	Forward, future and growth orientated, seeking maximum potential	Past oriented; aims to regain past functions
Humour	Able to see the humour, smallness or ridiculousness of one's situation, thoughts and behaviours.	Unable to see one's situation as anything but a tragedy
Knowledge of Self	Sourced intrinsically. 'Truth' determined by the subjective 'fit' of available knowledge with self. Internal locus of control.	Bases self-knowledge on external authority and approval of others. External locus of control.
Love	Loves unconditionally. Has a conscious, proactive and pre-determined way of behaving towards others	Loves conditionally, depending upon the behaviour of others
Strength of Identity	Has a resilient identity which develops further when self is challenged by adversity	Has a brittle identity, easily shattered by adversity
Beliefs	Perceives self as an open system, part of a greater whole	Perceives self as a self-contained, closed system
Worth of Self	Views the self independently of others' opinions, as having an innate worth as an integral part of a wider system	Views self-worth as dependent on others' opinions, earnt and developed and potentially valueless
Pain	Perceives pain as a minor component of the self, and therefore bearable	Perceives pain as a dominant and potentially destructive component of the self and thus only bearable if it can be eliminated

Consequently, previous coping strategies that had, at least, been partially successful were found to be unsuccessful when confronted by the ongoing nature of chronic musculoskeletal dysfunction. It was only when the impairment and

issues of anxiety and self-worth, originating as much from past trauma as the present dysfunction, were acknowledged and accepted as essential components of self that participants claimed that they were healthy. Acknowledgment and acceptance of all personal experience as parts of the whole that self is and addressing how these may be integrated as positive components of the whole resulted in a decrease in participants' fear and anxiety and an increase in self-efficacy. Denial of experience was then recognised as denial of integral components of one's identity, culminating in the loss of self-completeness and wellbeing.

Spirituality, love and friendship are concepts not normally associated with health. Although many (Collins, 1998; Do Rozario, 1997; Ellis & Smith, 1991; Fitzgerald, 1997; Frankl, 1992; Gill, 1997; Harris & Blum, 1993; Kazanjian, 1997; Ornish, 1998; Pargament, 1997; Petit, 1988; Reed, 1992; Resnick, Wyatt & Friedman, 1996; Vash, 1981) cite their relevance to health, there is little evidence of this relevance influencing health training or practice. Participants reported health interventions they had previously experienced as focusing on physical and cognitive health. Nonetheless they reported that their health was primarily promoted when interventions also facilitated development of their sense of self. Effective physical, social and cognitive interventions facilitated personally meaningful connection, relationships, beliefs and values. Consequently, such interventions needed to be led by the person rather than by a therapist, as only they had the insight to know what physical, social or cognitive interventions were personally meaningful.

Moreover, development of a fully resilient, healthy self also required reflective processes such as quiet contemplation, meditation and communion with spiritual sources. Good health was regained by interventions meaningful to the recipient, identifying and strengthening sense of self, so making it resilient.

Health for this sample was a subjective experience and centred on relationships and strength of identity. However, rather than health being achieved *despite* disability, participants clearly believed they had achieved health *because* of disability. Therefore health interventions need to enable individuals to experience greater health because of loss rather than in spite of it. Fuhrer (2000) terms such a

process enablement, which is the opportunity for change and growth that enables the individual to construct a more resilient self.

The results demonstrated that for health, intra-self, inter-self and self-natural world relationships merged together, resulting in the self no longer being perceived as separate from non-self, but as part of a wider, complete system. The Personal Attributes Model (Figures 6.2 & 6.3) illustrates the processes identified by participants as necessary for health achievement. The positive and negative extremes of the attributes of health and ill health, which appear in the Personal Attributes Model, are presented in Table 6.2.

When in a state of ill health, cognitive or behavioural changes in any one of the personal attributes can cause dissonance and consequent movement in all other attributes. This applies both to basic Personal Attributes and to Indicator Personal Attributes. However, only when there are observable behavioural changes in the Indicator Personal Attributes will authentic change and positive movement occur along the health continuum.

The Pain/Identity Indicator Attribute is the pivotal point of the health process but it does not change without parallel change in the Self-worth and Acceptance Indicator Attributes. Acceptance of the self as a component of the system requires acceptance of the limits of personal control. Control is then restricted to interpretation of and response to life events, rather than control over what life events are encountered or control of one's environment.

Development of self-worth requires acceptance of the self as being a highly valued part of the system as well as perception of painful events as a component of self rather than a barrier to being self. Doing so enables development of a self-identity that is dependent not on protecting oneself from the external world, often perceived as hostile, nor on conserving an autonomous self, but rather on expanding and transforming self as an active, interdependent and essential component of the wider system.

The personal attributes required for the development of such a resilient identity imply that the individual perceives self as part of something larger than the

objective self. Generally, participants acknowledged that life and health involved the spiritual. Newberg, D'Aquili and Rause (2002) define this as '...a realm of beings and forces beyond the material world' (p.66). Participants identified this larger reality as 'God', 'the universe', 'the old people' or just feeling and being at one with nature, animals and others so that they were a part of a greater whole.

Common to all healthy participants was a perception of health attainment as an internally-driven process centred on an intrinsic personal identity independent of physical form or acquisitions, social or work roles, rational cognitive competence or mastery of life events. Instead health resulted from a personal experience that the essence of self is a constant and continuous 'I'. Furthermore, healthy participants accepted personal responsibility to alternate between engagement with the world and self-reflection. This process enabled identification of the unique role, identity, place and purpose of self. Time alone to reflect on actions and consider the resultant impact of such actions on their inner feeling of wellbeing enabled participants to control their own health status by ensuring actions were congruent with the essence of self.

Participants identified this process as self-transforming and it required transcendence beyond previous experience and knowledge. Movement from experiencing the self as an autonomous system to perceiving oneself as a component of one universal system required parallel changes in identity, thought and behaviour. Carl Jung (1958), among others, has argued that such movement requires acknowledgement that the human experience is essentially spiritual. He proposes that archetypal concepts are the essence of human thought and behaviour, are universally inherited, and are in the depths of every human mind. The common pattern of personal transformation found among participants of this study suggested that for people to be healthy there is a need to perceive self as being of worth, as a part of something greater than self, and as concurrently constant and continuous.

In summary, the essence of self, the 'I' or spiritual dimension, was perceived as inherently intact, constant and continuous so that the individual viewed other dimensions of self as a positive medium for creative expression of 'I' because of rather than in spite of their instability. Participants often spoke of changing from

a fear that the self was being lost to realising that the essence of self could not be lost.

The Self-Attributes Model provides a foundation on which to develop and test hypotheses of possible relationships between categories and the influence of each category on overall health. The importance and interrelationships of a strong and resilient sense of 'I', spiritually based self-worth and acceptance of one's reality have been insufficiently considered in developing health measures. This study found that a spiritually based perception of self, evidenced by the importance of relationships, connection, values and meaning, is the foundation on which health is built. To do so, assessment requires a measure based on the definition of health as identified in this study.

Limitations

The requirement that participants travel up to 200 km at their own expense and the impediments of pain, fatigue and reduced mobility associated with musculoskeletal impairment, together with the time involved, tended to discourage those in poor health, limited finances or those with negative experiences of QE Health from participating. Although this was not considered when the study was designed, the outcome was that the sample comprised those motivated to participate, probably because of a positive experience of intervention at QE Health.

Consequently the sample was a self-selected subset for whom intervention had facilitated good health. The sample may possibly have possessed personal characteristics facilitating health attainment irrespective of any interventions experienced.

Nonetheless, any effect such personal characteristics had on the findings can be seen as strengthening the conclusion that personal characteristics influence health. The results of this study suggest that person-perceived handicaps act as a barrier to health for those with disabilities (Cardol, Brandsma, de Groot & vanden Bos, 1999). However the findings go on to suggest the importance of the relationships between handicap, disability, impairment, quality of life and health. While it may be argued that these concepts should be defined as distinct and separate, those

experiencing these states of being were emphatic that only when they are seen as subjective and inter-related can the resilient identity result which is essential for coping successfully with adversity.

Possibly the major limitation to interpretation and generalisation of the results is the qualitative nature of the study. The results have been presented to a wide audience, including others with musculoskeletal disabilities, people with head injuries, those recovering from mental illness, various rehabilitation professionals and health professionals. All these audiences have found the categories and model both relevant and valid within their work or life experiences. However, the study developed a model using inductive qualitative techniques and, by definition, the resulting model extends beyond simple interpretation of data. Therefore, the relationships proposed within the model can be viewed as a basis for exploration of consumers' health process rather than as definitive.

Nonetheless, the essence of self, a resilient identity founded on a spiritual world-view, appears to be an essential factor affecting health. Participants in this study and others who have been confronted with unpredictable life events and the instability of cognitive, social and physical dimensions of self have nevertheless attained stable, healthy states of being by gaining an awareness and acceptance that the spiritual self remains intact, constant and continuous.

Research that further explores the dynamics of these concepts, the relationships between them, and the processes they undergo would not only advance our understanding of the crucial role of spirituality in the health process but also increase the ability of individuals to achieve health in the face of adversity.

CHAPTER 7: DEVELOPING A SPIRITUALLY-BASED HEALTH CHANGE PROCESS THEORY

Health despite Impairment

In the previous study health was found to be a state of overall wellness in which the individual perceives their self as whole and functional, regardless of the level of observable physical, social or mental functionality. This chapter explores the implications of these findings and related literature to propose a theory of the health change process that is based on the Spiritual Theory of Self (Chapter 3, Figure 3.1).

The previous study identified that health is achieved when an individual perceives the core component of self (their sense of 'I') as constant and continuing to exist. Loss of objective aspects of self was found to be a catalyst for awareness and development of the resilient core self.

Trauma results from the perception that part of the 'I' has been violated or lost. Such trauma is commonly described as a loss of wellbeing, which is the central tenet of the WHO definition of health (World Health Organisation, 1997). Therefore, wellbeing can only be restored when the individual once again perceives the core of self as constant and continuing. Perception of such loss or violation is usually triggered by a bodily, relational or psychological impairment. The degree of observable impairment is only a partial indicator of the level of violation or loss causing diminished wellbeing (Fitzgerald, 1997; Fuhrer, 1994). Consequently, interventions that repair, compensate or stabilise observable impairment deal only partially with the sense of loss or violation of self that is affecting the health those interventions aim to restore.

The human experience is one of continual change, including loss of cognitive, physical and social aspects that were previously perceived as key components of self. Nevertheless, such change provides an opportunity for growth and development of the more intrinsic aspects of self (Fuhrer, 1994). In the HSD study (Chapter 6), for those with chronic physical disorders, definition of health was found to centre on acquiring a resilient self-identity that reflected an open system concept of self. Optimal wellbeing was achieved when self was

experienced as a component of a larger system rather than as an autonomous, self-sustaining closed system. Despite the changing nature of the objective aspects of self, the subjective 'I' has permanence, continuity and potential for growth. Healthy individuals focus on 'being', orientated towards 'becoming', so seeking the inherent potential of the self.

The process of 'being' and 'becoming' involves interaction with others, with nature and with the supernatural (the wider system), which is then integrated into a self-system through contemplative reflection. Such reflection culminates in deeper, more meaningful relationships and an expanded self-knowledge, based on a comprehension of one's identity, place, meaning and purpose in life. Self-understanding is thus achieved by restructuring one's worldview to include attitudes focused on nurturing a wider system, while accepting the limitations of any one individual's control and knowledge.

The Healthy Self

Strength of identity

Materially orientated self theory implies that a strong self-identity is constructed by interactions of our closed system with the external environment to extract the necessary resources to develop an autonomous, independent and competent self. Although interaction with others is essential for learning about self, a strong intrinsic resilient identity cannot logically be developed by clipping on external experiences, social resources and roles if one is not aware of or does not understand the innate core of self to which these are to be added. Such an externally orientated view assumes that the healthy self requires only the right external resources and mastery over events to ensure health-enhancing events are encountered. The implication is that the individual can and should be able to predict and control events encountered, and extract external resources to be healthy. Such assumptions logically mean that, if a person is unhealthy, they are exhibiting a deficit with regard to control and mastery; either they are a personal failure or the external world is failing them.

Strategies for Maintaining Identity Strength

Two coping strategies aim to retain our perception of self as knower and controller. The first, Inertia coping, requires us to do nothing when faced with

challenges to the self, in the belief that the challenge will disappear or resolve itself. The second, Action coping, involves the individual or others doing something to address the challenge to self and regaining control (Breakwell, 1983). For example, a person experiencing a health challenge may seek knowledge of the disease/dysfunction, focus on a return of physical flexibility and fitness, experiment with various medications and supplements, seek and use functional aids, examine and change attitudes and lifestyles, or pray for a cure. Pargament (1997) refers to these two options as the Conservation of Ends whereby the individual attempts to preserve who they perceive themselves to be (Inertia) or reconstruct and regain their pre-threat identity (Action).

While these are credible and usually partially successful strategies for coping with ill-health, they imply that for one to be healthy, it is necessary that the individual focuses solely on returning as closely as possible to the former levels of functioning and control. The reality of many health challenges is that they are traumatic learning experiences, which change one's perceptions of power, control, infallibility and knowing to the extent that a return to the same pre-trauma state is impossible. Indeed, physical, social and cognitive function may be regained but the knowledge gained through the ill-health experience that such aspects of self are not necessarily constant and continuous culminates in self-awareness of the uncertainty, unpredictability and frailness of life, which cannot be removed. Changes to the core self - the "I" – may occur that are not only irreversible, but ongoing. For those with chronic disorders, this experience is magnified as typically even a return to former levels of physical, social and cognitive function is not possible.

The Spiritual theory of Self acknowledges that many life experiences challenge the assumption of self-mastery and resumption of a pre-trauma state. It supports a third view of coping, known as Transformation (Breakwell, 1983; Pargament, 1997). Transformation allows the retention of well-being by acknowledging that health challenges offer an opportunity for self-growth. The model developed by Tedeschi and Calhoun (1995) to depict posttraumatic growth has been adapted for those with disabilities and illustrates the three coping strategies (Figure 7.1). Realising that personal control and individual knowing are always incomplete leads to acceptance of the limits of self. This increased self-understanding in turn

results in a radical change to a worldview in which self is perceived as a subsystem of a larger system. Such identity growth requires not only interaction with others but also time spent alone. Interaction results in experience and knowledge of the commonalities and contrasts between our own and others' realities. Time spent alone enables identification and understanding of both the universality and uniqueness of human existence.

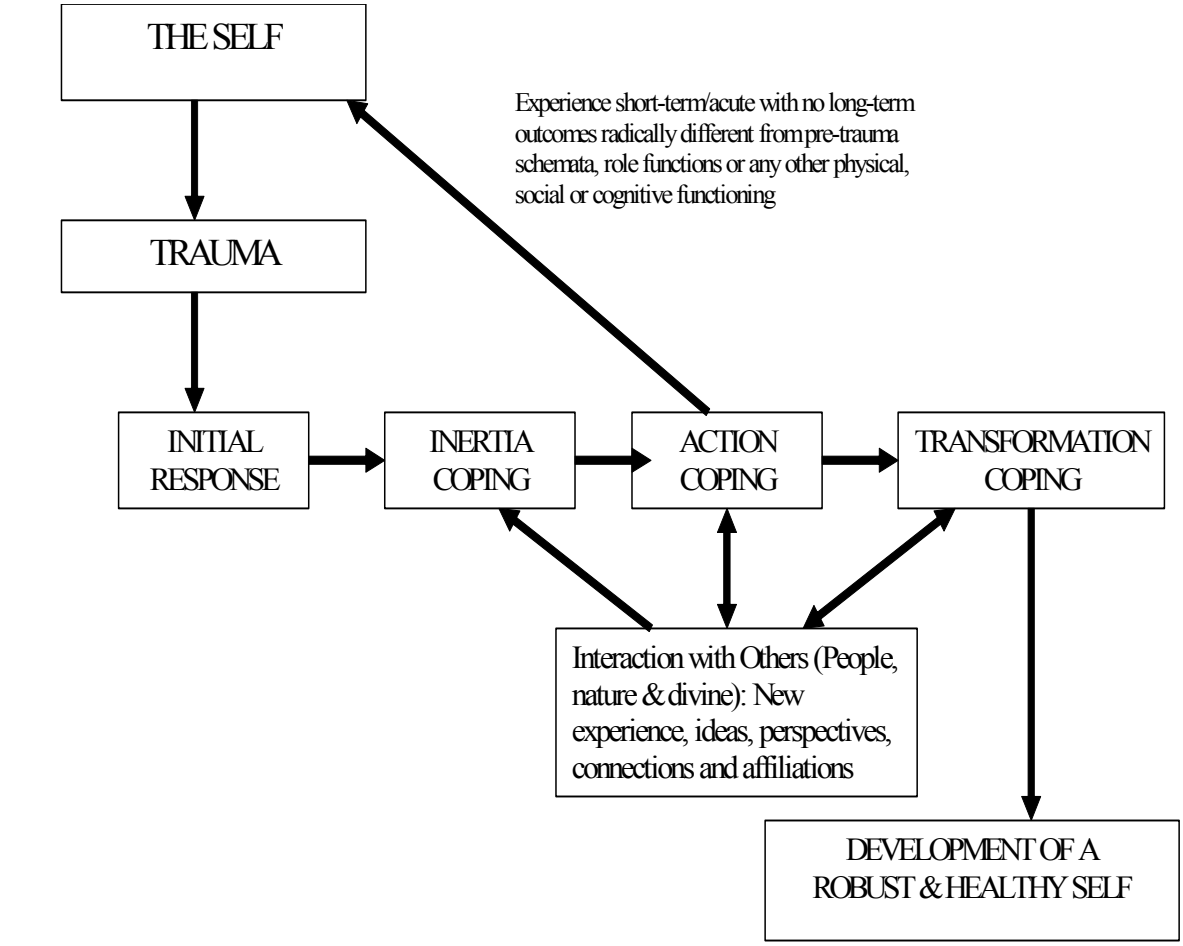
Awareness of the ways in which we are connected with or separate from the world allows understanding of the self as a unique individual within a wider system (Weber, 2000). In summary, understanding of self, meaning of life and consequent successful management of life experiences is central to health. Awareness and understanding of the essence of self as a spiritual being connected to all other life is argued as being essential for the self to reach its full health-giving potential (Faull, 2000; Faull & Kalliath, 2001).

Constancy and Continuity of Self

To maintain a strong identity, the individual must perceive their core self as constant and continuing, although the social and physical environment, as well as personal roles, abilities, physique, and relationships relentlessly change.

Materially, a continuous self is expressed through awareness of the continuation or connection across time of physical and social aspects of self, such as one's genealogy, surname, ethnic and cultural identity, accomplishments, and eventually estate and memorial. Spiritually, however, a sense of continuity results from a belief that the self is in some way an enduring part of a greater whole that may or may not be similar to the self's present objective form. The self is perceived as eternal, being part of a greater, meaningful, everlasting system. Power, knowledge and ultimate control of life are viewed as residing outside of the individual, who is a small but valuable component of the wider system.

Figure 7.1: The Process of Coping with Trauma



State of shock and loss, lack of life manageability – life out of control. Role behaviours and perspectives of self no longer appropriate nor offer adequate explanation of experience	Emotional overload and accompanying stress and fatique. Goal: To return life and self to how it was Method: Personal reflection interspersed by sharing feelings/self-state with others and seeking their support to achieve goal	Perception of control and manageability returns, belief that the individual can regain old self if he/she tries hard enough – hope rekindled Goal: To return life and self to how it was Method: Interaction and schemata challenge with others – two way sharing. Acceptance of need to take responsibility for self and health	Return to old self not possible	Awareness and experience of self as constant and continuous Awareness and experience of the limits and responsibilities for self control and knowledge Goal: To explore and develop towards one's potential Method: Self-reflection combined with interaction with others, nature & the divine

Materially, a constant self is expressed by experiencing oneself as consistent, in that one's family role, given name, social identity, education and skills, possessions and status are assumed to be unchanging. Spiritually, however, constancy is achieved by awareness of the self as a specific part of the greater whole. "I" always has been and always will be a particular element of the wider system.

To achieve a resilient continuity and constancy of self, the individual needs to acknowledge, relate and experience connection with the wider system. Within the disability literature, spiritual models of self propose that all people have a spiritual core to their being that provides people with the resources for strong interconnection, sense of place and purpose (Do Rozario, 1997; Matthews, 2000; Vash, 1981;). All dimensions of self are perceived as affecting one another but as the other dimensions of the self function, they either promote or impede growth of the spiritual core of the self. For many in our individualistic society, this core may be relatively inactive and unacknowledged and therefore access to greater self-understanding is hindered (Do Rozario, 1997; Fitzgerald, 1997). In this case the universal human need for constancy and continuity of self is met by a focus on the material rather than the spiritual self (Weber, 2000).

The material self cannot fully explain how people manage to retain the resilient perception of self required for health when adversity causes permanent loss of objective aspects of self. Only a spiritually orientated concept of self enables the development of a self sufficiently resilient to remain healthy through all life's experiences.

A Spiritual Theory of Self

The Spiritual Theory of Self (Chapter 3, Figure 3.1) proposes that the essential characteristics of the spiritual core or 'I' of self remain constant and continuous. Retention and continued growth of self requires that the cognitive, physical and social qualities attributed to the self match the unique and essential characteristics that are the spiritual core. In other words, each of these dimensions must be an expression of and 'fit' or affirm the values and beliefs that form the spiritual core. A spiritual concept of self means that the spiritual core must be perceived as *the* fundamental component of self which needs to influence other more external

aspects of self if one is to be healthy. Consequently, perception of the spiritual core of the self as constant and continuous is necessary for wellbeing. On the other hand, the self as a whole is an open and permeable system in which there is dynamic interchange between its physical, cognitive and social dimensions and the environment.

To sum up, wellbeing and therefore health cannot be achieved without a strong self-identity; that is, the perception of self as not only unique, but also as part of a wider system. A spiritually centred identity provides access to coping resources that are essential for achievement of a resilient identity. An open system of self provides a belief system that widens comprehension of experience, allowing greater self-understanding. The person who embraces an open system is able to see their life as a continuum between past, present and future, in contrast with a closed system of self, which encompasses only one time frame (either past, present or future).

Self-transformation is the ultimate strategy for coping with significant life change (Breakwell, 1983; Pargament, 1997). Transformation requires that the objective aspects of self radically change while the essence of self remains the same. A closed self-system is defined by its 'doing'; its objective reality and therefore denies an individual access to the Transformation coping strategy. An open self-system facilitates access to it. As outlined above, such an open system requires a spiritually centred identity. Therefore a spiritually centred identity is necessary for healthy coping with significant life-change.

The Health Change Process Theory

To put it another way, an identity whose strength is based on no more than physical, social and cognitive resources is not sustainable when the self-system is challenged significantly. An apparently strong identity that lacks a spiritual worldview of self will result in low resilience and a loss of health when significant challenges are experienced. Resilience implies that the identity is not brittle but can bend, absorb and change. Consequently, transformational coping with major challenges to the self results in growth of a stronger, more resilient identity (Figure 7.2).

The fundamental need is to be able to perceive life experiences as manageable, comprehensible and meaningful (Antonovsky, 1987) and the essential factor for this to occur is the perception of self as constant and continuous. Resilient identity requires self-understanding, which is a product of the schema or perception of self that one has. For those who view self as a closed, autonomous and exclusive state of being, the concept of self-identity will assume that strength is achieved by adding external resources to the individual. In contrast, self-identity for those with a spiritual worldview of self will entail nurturing or contributing to the whole system in a manner that reflects and is congruent with the spiritual core. Doing so allows perception of the self as constant and continuous, despite external assaults on it.

This implies that acknowledgement and development of the spiritual dimension of self is the key to maintaining health in the face of threatening challenge.

Understanding one's self relies on both cognitive awareness and experiential development. For example, awareness and acknowledgement of the concept of love is not the same as understanding love. One has to love and be loved to fully understand it. Similarly, one cannot fully understand the meaning and impact of the spiritual self without experience of externally orientated spiritual relationships and connections. Therefore, the experience of loss of physical, social or cognitive dimensions of self can stimulate understanding of the permanence and resilience of the essence of self, the spiritual core.

Spirituality resulting in acceptance of self as a subsystem that is externally orientated, inclusive, interdependent and predominantly subjective is the resource for accessing a self that is constant and continuous, which will result in a strong, healthy self-identity.

That is: Self-understanding = function (Awareness x Experience)
Health = function (Self-understanding x Spirituality)

A self based on understanding and spirituality can develop a sense of control, knowledge and living in the present (being) but with an optimistic focus on the future (hope). Such a worldview allows appreciation and celebration of present

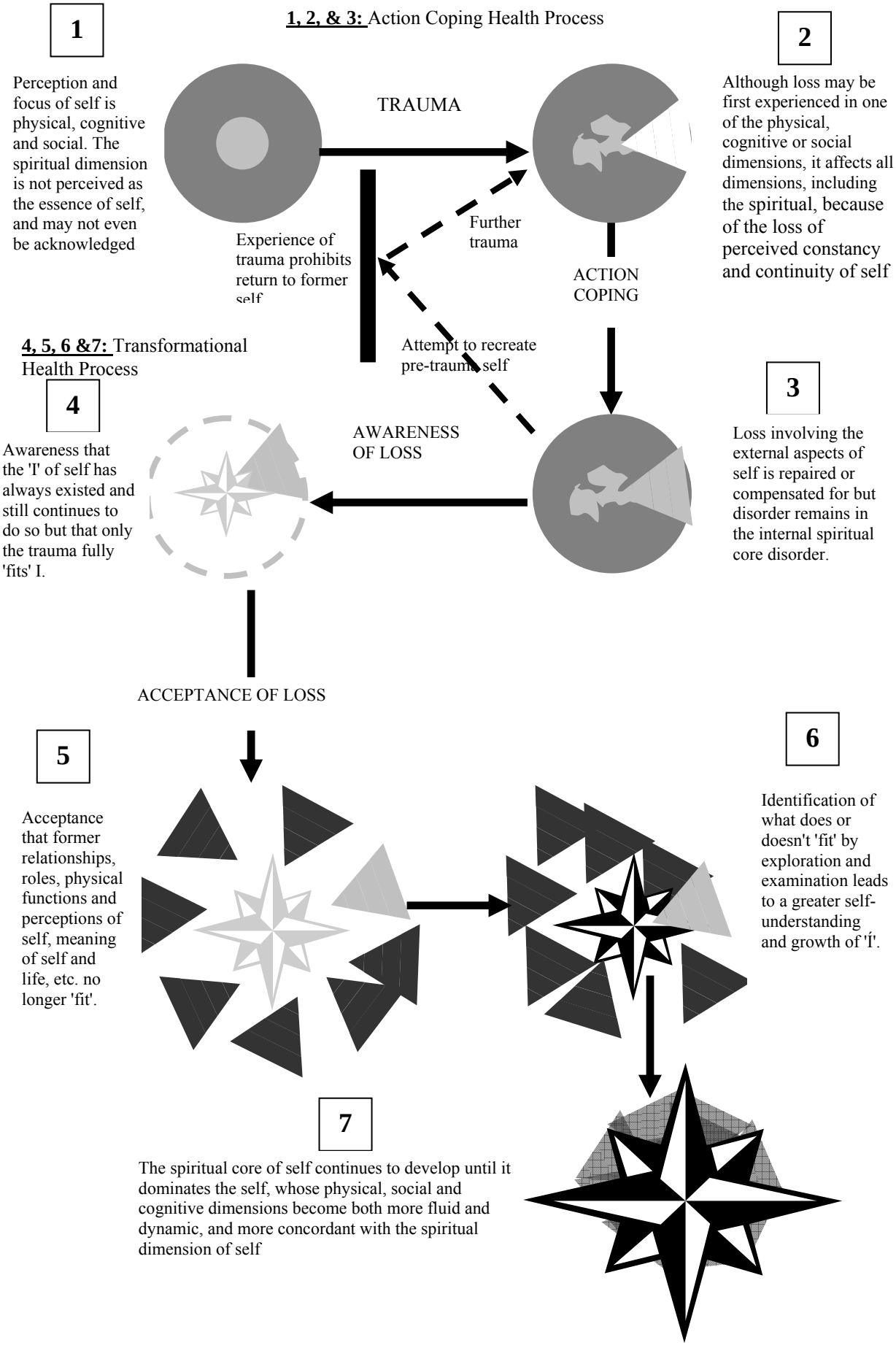
experiences while viewing the future with hope rather than fear, enabling the transcendence of the present to create an altered future.

Action coping is an objectively oriented component of the health process, which aims to conserve pre-threat self. The Health Change Process Theory (Figure 7.2) incorporates this component of the health process but also outlines the radical transformational perceptual change in thought and behaviour required for people to be healthy. The model reflects the Spiritual Theory of Self and provides a health-giving process for change. Acute health intervention may be adequate to reduce or eliminate physical, social or cognitive dysfunction but such a process cannot be guaranteed to result in health. Whether or not dysfunction is removed, one cannot remove an experience that has violated an individual's concept of who they are, their beliefs in self-control and self-determination. Living can be seen as a chronic disease. Consequently, only health interventions that incorporate the Health Change Process Theory can hope to facilitate health.

Consequently, interventions aiming to promote health must accept that the physical, mental and social selves are reliant upon the spiritual self for the perception of the constancy and continuity necessary to construct, maintain and develop a self-identity sufficiently healthy and resilient to deal with significant change. To evaluate the degree that health practice reflects this model and to advance practice it is necessary to develop and validate a measure of this health change process.

To measure such a holistic health status, it is necessary for items to detail physical, social and cognitive aspects of self as expressions of the spiritual self. Returning to the definition of spirituality, it is logical to conclude that these expressions will predominantly concern relationships, connectedness, meaning and clarity of principles. If the resultant measure is indeed a holistic assessment tool in line with thesis theory, it should accurately assess individual position on the Health Change Process Theory, as this model depicts holistic health status. Moreover, the Self Attributes Model provides further detail of the personal factors that should be measured by such an instrument.

Figure 7.2: The Health Change Process Theory



PART 4: DEVELOPING AND TESTING A HOLISTIC HEALTH MEASURE OF THE SPIRITUAL SELF

Chapter 8: The Spiritual Health Questionnaire Development Study.

Chapter 9: Preliminary Reliability and Validity Investigations of the Health Attitudes Scale and the QE Health Scale.

CHAPTER 8: SPIRITUAL HEALTH QUESTIONNAIRE DEVELOPMENT STUDY (SIQS)

Introduction

This study focused on the construction of a holistic health measure based on the Spiritual Theory of Self, the findings of the HSD study (Chapter 6) and the subsequent Health Change Process Theory.

The aim of the SIQS study was to construct a quantitative holistic health measure consisting of items derived from and in the language of consumers of QE Health services who identified spirituality as an important component of their health. Additionally, as these statements needed to be congruent with the constructs and rationale of the Spiritual Theory of Self, the Self Attributes Model and the Health Change Process Theory, the study also investigated the robustness of these theories.

The findings of the HSD Study (Chapter 6) indicated that the characteristics of the spiritual self determined the nature of the relationship, perception, attitude and behaviour of the individual. It was found that, whatever the state of the individual's social, mental and physical self, for those who perceived themselves as healthy; the common characteristic was the presence of a strong, resilient spiritual identity, which enabled them to experience their life as constant and continuous. Consequently, the Health Change Process Theory (Figure 7.2) contends that the essential requirement for health is a resilient self, which can only be attained by an identity that has spirituality as its base.

The Health Change Process Theory predicts that people with a spiritually sourced identity will not perceive limitation and dysfunction of the outer aspects of self as barriers to health, but as opportunities for exploring, experimenting and identifying attitudes and behaviours facilitating expression of the spiritual core. If a person is healthy, self is spiritual and the objective aspects are continually changing media that the individual employs to creatively express the constant and continuous spiritual self. However, if a person is defined by the objective outer aspects of self, when faced with permanent loss and continual change of these, they will lose their wellbeing and become unhealthy. Health status will be

demonstrated by the degree of congruence between the inner and outer self and whether the individual perceives self as whole, constant and continuous.
The HSD Study involved a relatively small sample, possibly not representative of the thesis population. To fully explore the validity of theory developed from HSD Study findings, as well as the Spiritual Theory of Self, it was necessary to investigate the theory with much larger samples. To do so required the use of a quantitative holistic health measure congruent with thesis theory. Next, existing health measures that incorporate spirituality and have been assessed for reliability and validity are reviewed.

Arguably the most widely used spiritual measure, the Spiritual Well Being Scale (Paloutzian & Ellison, 1982), is commonly used in conjunction with measures of the other aspects of health (e.g., Beery, Bass, Fowler & Allen, 2002; Cooper-Effa, Blount, Kaslow, Rothenberg & Eckman, 2001; Tuck, McCain & Elswick, 2001). The assumption is that the spiritual and the physical, social and cognitive dimensions equally determine holistic health status, can be measured independently and totalled to measure holistic health status. Additionally, the Spiritual Well Being Scale (SWBS) aims to measure spiritual and religious wellbeing, implying that formalised religion is an essential component of spirituality.

Spiritual wellbeing is evaluated by measuring such things as satisfaction with life, satisfaction with the direction of life, and sense of purpose and meaning in life. Religious wellbeing is assessed by the characteristics of relationships with God and degree of belief in God (e.g., closeness to God, belief that God loves and looks after them). There is an a priori assumption that 'God' is clearly and universally defined. Likewise, the SWBS implies that a relationship with God is similar to those between people; the SWBS implies that God may be viewed as a supernatural person.

As defined in this thesis, spirituality and formalised religiosity are two distinct concepts. The presence of one does not automatically mean that the other exists. While the above perceptions of God may be the strong beliefs of some, formed as a consequence of personal relationship and connection to the spiritual, they are not necessarily the experience and subsequent beliefs of all, derived from similar

relationships and connections. To measure these two concepts within a single scale that purports to be a measure of spirituality is not congruent with the reasoning forwarded in this thesis.

A second scale reviewed was the Functional Assessment of Chronic Illness Therapy - Spiritual Well-Being Scale (FACIT-Sp). The FACIT-Sp is a member of the collection of QOL measures called the FACIT Measurement System that assesses various types of chronic illnesses (Fisch et al., 2003; Peterman, Fitchett Brady, Hernandez & Cella, 2002). The FACIT-Sp does not use language with overt religious connotations (e.g., 'I find strength in my faith or spiritual beliefs'; 'I know that whatever happens with my illness, things will be okay').

However, the assumption that spiritual and holistic measurement of self and health can be achieved by measurement of each dimension of self is retained. Moreover, the material dimensions of self are titled 'Physical Well Being', 'Social/Family Well Being'; 'Emotional Well Being'; and 'Functional Well Being', but spirituality is titled 'Additional Concerns'. The implication is that spirituality is secondary; an add-on to the more comprehensive and important material items of the measure. Typically, the FACIT-Sp is used in research to assess the level of function of the spiritual component of self and then considered in association with functional scores of the physical, social and cognitive aspects of self (e.g., McClain, Rosenfeld & Breitbart, 2003; Tate & Forchheimer, 2002).

A similar tendency to assume that spirituality is a construct distinct from and equitably comparable to physical, social and cognitive health was found in the other spiritual measures reviewed. Examples include the Life Attitude Profile (Adams, Bezner, Drabbs, Zambarano & Steinhart, 2000; Reker & Peacock, 1981), the Spiritual Involvement and Beliefs Scale (Hatch, Burg, Naberhaus & Hellmich, 1998), the Hope Scale (Synder & Higgins, 1997; Snyder, Irving & Anderson, 1991), the Daily Spiritual Experience Scale (Underwood & Teresi, 2002) and the Temperament and Character Inventory (Cloninger, Svrakic & Przybeck, 1993; Kirk, Eaves & Martin, 1999).

An exception was the Canadian Occupational Performance Measure (Law, Polatajko, McColl, Carswell & Baptiste, 1994; Toomey, Nicholson & Carswell,

1995), which was developed from a spiritual concept of self and health similar to that forwarded in this thesis. However this is an activity measure and is administered by occupational therapists and specific to occupational therapy. It retains the fragmented and material concept of self and health although the theory it is derived from is in line with spiritual theory.

In general, these measures all imply that spirituality is a distinct component of self, which when considered in association with the physical, social and cognitive components provides holistic health measurement. Furthermore, with the exception of the Canadian Occupational Performance Measure, they all aim to assess spirituality directly rather than the effect of spirituality on the other dimensions of self. While it is acknowledged that separation of the different dimensions of self facilitates preciseness and is clinically advantageous, assuming that the sum of these dimensions is an accurate reflection of the holistic health status of the individual is debatable. Moreover, it is a logically flawed argument to assume that identifying dysfunction alone will necessarily aid decision making aimed to improve overall functional wellbeing. Functional wellbeing is dependent on individual ability to use present functions *and dysfunctions* as tools for free expression of self. With respect to chronic conditions, it is enduring potential rather than residual loss that is the key to overall wellbeing. The reviewed health measures tend to reflect the material perspective of self and health and focus on functional loss implying that regaining that which is lost will automatically result in the individual being healthy. Such a view contradicts the theory and evidence presented in this thesis and, therefore, there is a need to develop a measure that reflects holistic health as defined and experienced by the individual.

The rationale presented in Chapters 1, 2 and 3 identified a philosophical flaw in the assumption that a person is an aggregate of spiritual, cognitive, social and physical components. The essence or basis of self cannot be both material and nonmaterial; it must be one or the other. Therefore an assumption that all aspects of self are of equal importance to health is philosophically flawed. A holistic perspective in which the material aspects of self provide an opportunity for acknowledgement, expression and growth of the spiritual self is argued as being the only logical way to incorporate spirituality within the concept of self and therefore in a measure of health.

Consequently, to investigate holistic health status there is a need to identify the degree to which individuals behave and think in manner congruent with the Spiritual Theory of Self. The inner characteristics determining behaviour and thought from this perspective are the individual's values.

An appropriate source of data to develop a measure congruent with this theory is the behaviours and thoughts of people who have experienced permanent cognitive, social or physical loss but retain a perception of themselves as whole and healthy.

Organisational research commonly seeks to identify the ill-defined values that motivate human thought and behaviour. Such research has resulted in theory and associated methodology facilitating identification of the core values that drive behaviour. Of particular relevance is the work of Schein (1997) and his investigation of organisational change. Schein's concepts are congruent with the Spiritual Theory of Self and the Health Change Process Theory. He views the healthy organisation as an organism, similar to an individual. A healthy organisation also has an individual identity based on values and expressed through its functions. Like individuals, an organisation only controls its relationships, connections and how it expresses itself; its activities. The successful, growing and healthy organisation influences but acknowledges that it does not control the external environment. It uses continual experimentation and identification to find its place of value and purpose within the wider system. Acknowledging, exploring and developing the nonmaterial identity enables the organisation to readily change its way of operating without experiencing change as threatening its way of being. It is able to develop a learning culture to creatively problem solve so that it can continue to express and expand its unique and essential self through its activities.

Schein (1997) views culture as the construct that encompasses all aspects of a particular organisation's identity; the behaviours, the explanations for these behaviours and the core values or assumptions about right/wrong and good/bad that culminate in the thinking and behaviour unique to that organisation. Such a concept is congruent with the Spiritual Theory of Self.

Moreover, Schein (1997) asserts that, to identify the core values of an organisation, which he terms the Basic Underlying Assumptions (BUAs), it is necessary to examine the organisational artefacts; the objective expressions of identity including organisational behaviours, art, attire and language. He contends that artifacts do not change over time unless there has been a transformational event that has altered the BUAs. Finally, the explanations provided for the artifacts may or may not be in line with the BUAs. This is dependent on the degree to which the organisation is aware of its intrinsic identity and the degree to which it can clearly verbalise the core BUAs (values). Similar to the spiritual theory proposed in this thesis, explanations (cognitions) need to be aligned with behaviours and values for the organisation to be healthy. Moreover, for an organisation to be healthy, behaviours and artefacts need to be direct expressions of the characteristics of the spiritual core, the BUAs.

A specific methodological approach congruent with this theory is the Echo method, which has been used in organisational and management research to facilitate participant creativity and insightfulness resulting in identification of values and associated beliefs, attitudes and behaviours (Cunningham, 2001). Because values are usually deeply embedded in the subconscious they are generally not readily articulated. The Echo approach was chosen in this study to enable identification of spiritually determined values which result in healthy behaviours and attitudes.

The Echo approach uses a sequence of opposing open-ended questions to assist people to identify what they value and then a cyclical process of group exploration to further clarify values and associated thought and behaviour (Cunningham, 2001). It seeks to assist articulation of deeply embedded beliefs and perceptions of right/wrong, good/bad, important/unimportant, best/worst and so on. Sets of opposing questions facilitate articulation of what is valued, thus displaying the individual's values through identification of the person's attitudes and/or behaviours with respect to the subject of enquiry. For instance, to identify the food people value the most, asking 'What is the food you value the most?' and 'What is the food you value the least?' helps to focus thinking that explores and sequentially orders preferences.

Commonly the Echo approach collects data through direct interaction with individuals to extract initial data. Then the whole participant group analyses and refines this data (Cunningham, 2001). However, the preceding HSD Study used face-to-face interviews and one aim of the present study was to determine whether similar concepts of health would be generated in a different sample using alternative methods. Additionally, the self-administered questionnaire design and subsequent cyclical data collection rounds adopted were believed to be equally effective and provided a way of undertaking the research within the limitations of available resources.

A further component of the Echo approach is the aim to accommodate and report the reality of data collection within the research design. The systematic manner in which procedure is commonly portrayed in qualitative research reports implies that all that occurs in data collection and analysis is pre-planned and orderly (Cunningham, 2001). However, social research tends to contradict the mechanistic approach implied in such reports. In reality, the qualitative research procedure is dynamic and fluid and needs to be so to reflect the nature and demands of the emerging data. In many instances, those agreeing to participate in research possess some sense of ownership and passion for that which is being investigated. Hence, research relies on the input of people who are interested in exploring and defining a concept, issue or problem that is an important part of their lives. There is a dynamic process of interaction between the researcher and the participants as well as the participants and the topic of research. The researcher needs to adapt procedural details to acknowledge the dynamic process and to ensure data 'echoes' participants' reality. This technique complements the grounded theory approach of Strauss and Corbin (1990).

Hence, the Echo approach provided the guiding principles for construction of the initial data collection tool and the cyclical, interactive process of data collection. Moreover, the Echo approach resulted in a procedure that was guided as much by the nature of the data gathered in each round to decide the precise detail of the next round of data collection as by any preconceived plan of data collection.

The aim of the study was to construct a holistic measure of health from the consumers' perspective, which acknowledged spirituality as the core component of self that determines health.

Method

The Echo approach (Cunningham, 2001) was used to guide participant selection and construction of the questionnaire that initiated the research.

Participants

Within the Echo approach there is a need to select participants that reflect the total range of views possible on the topic of concern (Cunningham, 2001). In the present study, the topic of concern was the relationship between spirituality and the perception of being healthy. Therefore, sampling aimed to access the diversity of spiritual views of the research population while limiting participants to those who believed there is a relationship between spirituality and health.

One hundred and forty three people were randomly selected (using computer-generated random numbers) from the most recent complete year (June to June) of the QE Health Rheumatology and Rehabilitation inpatient database and invited to participate in a study '…to develop a questionnaire that measures health from your point of view'. They were informed that the '…study does not focus on you personally but investigates how physical, social, mental and spiritual aspects of who we are fit together and affect wellbeing' (see Information Sheet, Appendix 4). Thirty-seven declined to participate and 106 people were sent the initial questionnaire of which 69 were returned completed. Fifty-nine people indicated that spirituality was important to their health and completed the second round of questionnaire development while 48 of these people completed the final round; the piloting of the developmental measure.

The 59 participants who believed spirituality was important for their health and completed the first round included 81.4% female, 92.9% Pakeha New Zealanders and 3.6% Maori New Zealanders. Their mean age was approximately 55, the majority had lived with their disorders for over six years, and various types of arthritis predominated (see Table 8.1). 'Other' types of disorders included joint

replacement, post polio syndrome, cerebral palsy and Parkinson's disease. The majority (67.2%) ran their own businesses or were working in professional fields and 56.6% had some form of tertiary qualification. A wide range of Christian religions dominated but 22.4% of participants did not identify with any religion and 43.5% did not believe religion was very important.

In contrast, the 10 participants who did not believe spirituality was important to their health included 60% female but no Maori. They tended to be older with most in the 66-75 age range but had lived with their disorder for less time with a higher proportion of people with injury related chronic pain. One had undertaken trade training but none had attended university. Half stated their occupations as either self-employed or professional work. Most identified an association with Christian religions but a large percentage (40%) did not identify with any religion. However, 60% believed religion was necessary and a further 20% thought it was important. Data from these participants was not used in the study.

Design

The study combined qualitative and quantitative methods.

Three rounds of data collection, from the same sample, were used. The first round involved an open-ended qualitative questionnaire based on the principles of the Echo technique (Cunningham, 2001) to generate participant statements which became the items of the quantitative Likert formatted questionnaire used in the second and third rounds of data collection.

Item-total correlation analysis of the second round data identified items with no or low correlation to the rest of the scale and these were removed and the scale structure was identified. The modified scale was then sent out for the third round to test the developmental measure and the same analysis as in round two was repeated to investigate whether scale structure remained the same and if any further items needed to be removed.

The Echo technique (Cunningham, 2001) commonly uses a direct one-on-one or focus group type collaborative approach. In this study, the Delphi technique

(Mead & Moseley, 2001) was employed to provide a similar but indirect collaborative approach to develop the holistic health measure. The Delphi technique aims to maximise the benefits of group feedback, consensual decision making and individual participant input by countering any negative effects of group interaction. Participants formed the expert panel and each panel member worked autonomously, providing data, which the researcher analysed and fed back, also anonymously, to the whole panel. There was no direct contact between participants, reducing the effect of group bias while retaining the capacity to share and develop group data with a problem-solving focus.

In summary, the Echo approach provided a method to construct an instrument to gather values-based data about health. Moreover, the Echo approach provided the methodological strategy that provided sufficient methodological flexibility to alter procedure and analyses in response to data gathered. Both the Echo approach and the Delphi process facilitated a grounded theory type approach (Strauss & Corbin, 1990) as well as the use of statistical analysis to further develop the emergent holistic health questionnaire.

Design Irregularities: Employing the Echo Approach

Consistent with the philosophy of the Echo technique (Cunningham, 2001), procedure did not follow the predetermined design.

Initially, the Echo-type questionnaire concluded with a request for participants to construct questions based on the health factors important for health they had identified in the previous items of the questionnaire. The intent was that the preceding questions would have clarified their thinking and this last request would provide the basis for the items of the holistic health questionnaire. However, the participants produced items that contradicted the factors they had previously identified as important for health. While their earlier responses focused on what people could do either in spite of or because of their impairment, the participant-generated items generally measured the degree of dysfunction. For example, with regard to the participants' perspective on pain, earlier responses focused on what people could do regardless of pain such as 'I need to keep mobile, even if it causes pain, to be healthy'. In contrast, participant responses to the final question resulted in the presentation of items predominantly focused on level of

dysfunction or impairment as the question, 'How severe has your pain been in the last week?' demonstrates.

On reflection, if the researcher had acknowledged the time, effort and skill involved in developing items, participants would not have been asked to complete this final task. Participants recorded what they perceived as important for health in earlier questions but tended to construct items that reflected those which they were familiar with from completing numerous established health questionnaires. When some participants were asked why they wrote items as they had, they reported that they could only recall how others wrote health questions and they believed health professionals seem to want to know these specific things. While they believed other factors were more important, they also felt that health questionnaires were for health professionals and that what participants perceived as important was too imprecise, emotive and 'fluffy' to be of any use.

As the aim of the study was to develop a holistic measure of health from the consumer's perspective, the original plan for participants to develop the items in round one, was abandoned. Instead, the researcher qualitatively analysed participant responses to the rest of the items, identified themes, extracted representative statements and used these as items in the item importance rating questionnaire for the second round of data collection. Such methodology was determined by data produced and reflected the Echo philosophy as well as being a similar process to that used in grounded theory (Strauss & Corbin, 1990).

Procedure

The aim was to develop a questionnaire in which the item content, language and emphasis reflected or echoed the health beliefs and values of the participants. The Participant Health Questionnaire (Appendix 5) began the Delphi process.

Table 8.1: SIQ Study Participant demographics

Demographic	Category	Percent of Participants: spirituality important for health	Percent of Participants: spirituality not important for health
Age	16-25	1.7	
	26-35	3.4	20.0
	36-45	8.5	
	46-55	27.1	10.0
	56-65	20.3	20.0
	66-75	27.1	40.0
	76-85	10.2	10.0
	85 or over	1.7	
Diagnosis	Osteoarthritis	18.5	30.0
	Rheumatoid arthritis	16.7	10.0
	Other arthritis	18.5	10.0
	Fibromyalgia	20.4	
	Injury-related pain	3.7	40.0
	Other	22.2	10.0
Time with Disability	Under 2 years	3.4	
	2-5 years	11.9	40.0
	6-10 years	22.0	30.0
	10-20 years	27.1	30.0
	Over 20 years	35.6	
Education	Primary	3.4	
	Secondary	25.4	50.0
	School certificate	13.6	40.0
	University entrance	5.1	
	Trade/polytechnic	33.9	10.0
	Undergraduate degree	13.6	
	Graduate degree	5.1	
Occupation	Beneficiary	5.1	
	Self-employed	23.7	20.0
	Professional	42.4	30.0
	Service industry	3.4	
	Tradesman	16.9	20.0
	Labourer	3.4	20.0
	Retired	3.4	10.0
Religion	Not applicable	22.4	40.0
	Christian	69.0	60.0
	Other	5.2	
Importance of Religion	More important than anything else	13.6	
	Very important	33.9	10.0
	Important	18.6	10.0
	Necessary but not very important	15.3	60.0
	Of no importance at all	13.6	10.0
	Don't know	5.1	10.0

Analysis and data collection progressed through three rounds. The Delphi approach involves participants selected by and communicating with the researcher but not each other. The procedure was as follows.

1. **Round One**: The Participant Health Questionnaire (see Appendix 5) was sent out.
2. Sixty-nine completed questionnaires were returned to the researcher.
3. Ten participants who responded that spirituality was unrelated to their health were not included in analysis.
4. The data from the remaining 59 indicated that responses to Question 25 tended to contradict the rest of the responses. Question 25 data was discarded.
5. Consequently, data was analysed using the grounded theory coding process of open, axial and selective coding (Strauss & Corbin, 1990).
6. Categories/themes were identified and representative statements selected.
7. The 53-item Rating of Health Statements Questionnaire (Appendix 6) was constructed.
8. **Round Two**: The Rating of Health Statements Questionnaire was mailed to the same 59 people.
9. All 59 returned the questionnaire completed.
10. Data was analysed as follows:

Step 1: Internal consistency was assessed by examination of item-total correlation and the resultant Cronbach alpha.

Step 2: Items with corrected item-total correlations below 0.3 were identified and removed, resulting in 37 items.

Step 3: Principal components factor analysis with a Varimax rotation was run for the remaining items.

Step 4: The researcher and his supervisor examined and edited items that appeared to contain more than one idea/statement or were grammatically incorrect.

Step 6: Items were ordered, beginning with more extrinsic statements and leading to those more intrinsic while ensuring that original category statements were not grouped together.

11. The resultant 38-item measure (Appendix 7) was renamed the 'Health Attitudes Scale: Version 1' (HAS: 1).
12. **Round Three**: The scale was piloted with the same sample. Forty-eight participants returned the completed questionnaire.
13. Analytic steps 1 – 5 were repeated.
14. The 40-item HAS:2 scale resulted .

15. An intent subscale was added to the HAS:2 (Appendix 10) and
16. A second scale (the QE Health Scale) was developed, using the same statements in the same order, but worded in the past tense(Appendix 11) .

Results

Round One: Item Construction

The seven main categories (with the number of quotes associated with each) identified by qualitative analysis of the Participant Health Questionnaire were Pain (74), Reflection (231), Identity (478), Attitude (526), Interaction (374), Acceptance (111) and Intervention (737). Each of the seven main categories and their subcategories are summarised in Table 8.2.

Pain

This category included two opposing subcategories, Control of Pain and Pain as Part of Who You Are and a third category, Managing Pain. Participants recorded how preoccupation with eradication or mastery over pain frequently resulted in loss of health. In contrast, an acceptance of pain as an inevitable component of self and life had the opposite effect on health. The characteristics of the Managing Pain subcategory were determined by the individual's perception of pain represented by the preceding pain subcategories.

Reflection

Subcategories were Time-out enabling solitude, which was closely associated with the Appreciation of Life and resulted in connection with the nonmaterial/spiritual (Experiencing the Supernatural subcategory). This culminated in development and knowing self as an integrated component of life (Searching, Learning, Knowing and Growing Yourself subcategory).

Identity

The Identity category consisted of four subcategories: Uniqueness/Self-awareness, Values/Beliefs and Meaning, Self-expression, and Self-autonomy. Essentially, participants identified acknowledgment and development of awareness of the uniqueness of self as important for health. Doing so allowed for clarification of the personal values of what is right and wrong, good or bad, etc. that guided decision making and subsequent behaviour. Behaviours and attitudes then were

health enhancing expressions of the inner self and focused on choosing to 'be' oneself rather than meeting others' expectations.

Attitude

Being Positive and Strength of Character subcategories dominated this category. Being Positive included acknowledgement of the limitations of one's situation as a prerequisite for exploration of these adverse experiences to learn how to continue to develop self. The individual accepted that there were external factors outside their control without surrendering personal agency for the meaning and purpose of their life. The individual could then alter how they expressed and interacted with life so that they retained and developed their uniqueness. Appreciation of the Opportunities provided by Disability, Humour and Being Kind to Yourself arose from the nature of the Being Positive subcategory. Attitude was not solely a way of thinking but also included consequent ways of behaving. An attitude of accepting personal responsibility to act reflected a belief that one is of value and a contributing member of society; even when the present situation contradicted such a belief. Such behaviour is represented by the Strength of Character and the Planning and Implementing subcategories.

Interaction

The Interaction category was characterised by subcategories involving integration with all life, with a particular focus on connection to specific and personally meaningful aspects of nature, people and the spiritual. As a result of these supportive, consciousness raising experiences, participants reported a stronger and healthier sense of self. They described such experiences as increasing their knowledge and sense of self as an integrated component of the wider system that provided meaning to disease, disability, possibilities, and personal potential and positive attributes of self.

Table 8.2: Participant Health Questionnaire Main and Subcategories

Main Categories	Sub-Categories
Pain	♦ **Pain the focus of life (28)** ♦ **Pain as part of who you are (20)** ♦ **Managing pain (26)**: Exercise, attitude, self-responsibility & strength of identity
Reflection	♦ **Experiencing the supernatural (92)** ♦ **Appreciation of life (56)** ♦ **Time-out (47)** ♦ **Searching, learning, knowing and growing yourself (36)**
Identity	♦ **Uniqueness/Self-awareness (303)** ♦ **Values/Beliefs and Meaning (77)** ♦ **Self-expression (29)** ♦ **Self-autonomy (69)**
Attitude	♦ **Appreciation of the Opportunities of Disability (77)**: Insights, self-awareness, challenges to self, friendships. ♦ **Being Positive (144)**: 'Attitude of gratitude', having faith, an open, learning attitude. ♦ **Humour (9)** ♦ **Being Kind to Yourself (50)**: Anti-perfectionism ♦ **Strength of Character (116)**: Resilient & disciplined to accept responsibility that core self is expressed/doesn't give up when going gets tough. ♦ **Planning and Implementing (130)**
Interaction	♦ **Integration (100)**: Socialising, work, contribution, normalisation & at one with nature. ♦ **Education/Knowledge (57)**: From peers, older family & health professionals ♦ **Encouragement/Support (158)**: Includes people, animals and nature. ♦ **Inspiration (59)**: Loving, intimate natural & supernatural relationships/connection where the truth, however challenging, is told. Uplifting, insightful spiritual or aesthetic experiences.
Acceptance	♦ **Innate wholeness (40)** ♦ **The constancy of Change (30)** ♦ **The constancy of loss (31)** ♦ **Personal responsibility for life (10)**
Intervention	♦ **Physical/body (276)** ♦ **Transcendental: (36)** ♦ **Accessibility (177)**: Finance, equipment/home help, mobility, organisations, work, reliable advice/information. ♦ **Medication (66)** ♦ **Education (118)** ♦ **Characteristics of Interventions (74)**

Bracketed numbers: Total number of sub-category quotes identified.

Acceptance

The three dominant subcategories of Acceptance revolved around awareness and acceptance of the spiritual core of self as whole (Innate Wholeness) and the

changing nature of the material aspects of self (The Constancy of Change). Moreover, participants identified the need for awareness and acceptance that aspects of the material self are inevitably lost through the process of ongoing change (The Constancy of Loss). Participants concluded and frequently forcefully stated, that acceptance of such a reality meant that the individual must embrace and take full responsibility for the state of their life and therefore the state of their health (Personal Responsibility for Life).

Intervention

Unlike the previous categories, Intervention was the only category not consistent with the findings of the Health, Self and Disability Study. Its focus was external to self; consisting of those aspects of health intervention that involved interactions between health professionals and health consumers as well as access to resources.

From this qualitative analysis the 53-item Rating of Health Statements Questionnaire (Appendix 6) was developed. Items were presented by category; Pain (5 items), Reflection (6 items), Identity (6 items), Attitude (6 items), Interaction (7 items), Acceptance (4 items) and Intervention (19 items). Each item was either an individual participant statement or a combination of their statements. The format was a 7-point Likert scale with possible responses ranging from 'Strongly Agree' to 'Strongly Disagree'.

Round Two: 53-item Rating of Health Statements Questionnaire Item and Factor Analysis.

Fifty-nine participants completed the Rating of Health Statements Questionnaire. Principal components factor analysis identified two principal components (see Appendix 12). The first of the two components approximated the Intervention category and the other factors included the remaining items. Twenty-five Varimax iterations failed to resolve these components into any other factors.

Inter-item correlation identified 16 items (Items 1, 2, 3, 20, 24, 26, 36, 38, 39, 40, 43, 44, 45, 46, 49, & 50) with correlations < 0.3. Cronbach's alpha was 0.87 for the 53-item scale (Appendix 13). The correlation matrix of items with correlations of < 0.3 was then examined to identify the degree and trend of correlation with other items throughout the scale. Predictably, the number of

relationships of each of these items with other items ranged from 1-11, with an average of 5.5 but they tended to correlate only with items from item 35 onwards (the Intervention category).

The result of the factor analysis and item-total correlations suggested that the majority of the 16 items were measuring a different concept than measured by the rest of the scale and therefore were removed.

A principal components factor analysis was rerun on the remaining 37 items. All items loaded on the principal component except for item 48 (Appendix 14). A Varimax rotation failed to converge within 25 iterations. Item-total analysis including item 48 resulted in a Cronbach's alpha of 0.91 (Appendix 15). Considering the sample size and the approximation this brought to the process, it was decided to leave all items in the scale at this stage.

Therefore items included in the HAS:1 were 4 - 19, 21 - 23, 25, 27 - 35, 37, 41, 42, 47, 48, 51 – 53: a total of 37 items. Next, the composition and clarity of the items were examined by the researcher and his supervisor, taking into account participant comments. One item (item 17) was split into two separate items, resulting in a total of 38 items. Specific changes can be found in Appendix 8.

Round Three: Piloting HAS:1

Items were rearranged so that extrinsic statements led into statements of a more intrinsic nature while ensuring that those from one category were not all together. The 38-item 7-point Likert scale was renamed the 'Health Attitudes Scale (Version 1)', that is, HAS: 1 and tested with research colleagues for 'flow', clarity and general face validity. It was then sent out to participants, with space provided for comments (see Appendix 7).

Forty eight completed questionnaires were returned and subjected to factor and inter-item analysis. All items possessed a satisfactory item-total correlation with a Cronbach alpha of 0.93 and loaded onto the principal component (with the exception of item 36). The Varimax rotation resulted in eight factors with items generally loading on more than one factor. Because of the small sample size and the interrelationship of items it was decided to retain all items (see Appendix 18).

The results of piloting the HAS:1 identified similar statistical properties to those found with the Rating of Health Statements Questionnaire. However, two further items were identified as consisting of two concepts and were split; these can be seen in Appendix 9.

The HAS now consisted of a 40-item scale. Comments of participants and colleagues as well as the participant score ceiling effect indicated that there was a tendency for people to respond by judging whether or not they believed the statement was a good idea rather than whether or not each idea directly applied to their own lives. As a result of discussions with the researcher's supervisor, work colleagues and clients of QE, it was decided that it was sensible to add a future intent subscale to the HAS. Moreover, it was felt that a separate scale measuring past behaviours and attitudes may be more valid.

Consequently, an intent subscale was added to the HAS (see Appendix 10) and a second measure, the QE Health Scale was developed by converting items to the past tense and beginning each item with 'In the past week, how frequently did you…' (Appendix 11). The reasoning for selecting a week as the interval of time to examine past attitude and behaviour was twofold. First, the aim was to use the developed instrument(s) for assessment of QE Health rehabilitation programmes. These programmes run for three weeks. A time frame any longer than one week would not be able to assess health change between admission and discharge. Secondly, participants reported that they could readily recall what had happened in the past week but recall tended to drop off after that. This is supported by research, which identifies that recall is inversely related to the length of time between an event and when the respondent is asked to recall that event (Tourangeau, Rips & Rasinski, 2000).

Discussion

The seven categories of Pain, Reflection, Identity, Attitude, Interaction, Acceptance and Intervention were found to represent the factors participants regarded as important for them to be healthy. These findings, with the exception of the Intervention category, supported those found in the preceding HSD Study and are in line with the Self Attributes Model. The use of a second research methodology and sample resulting in similar findings strengthened the validity of

both results and added further support to the models proposed in this thesis. The exception, the Intervention category, consisted of statements about the use of prescribed medication/therapy versus alternative therapy; access to resources; and the characteristics of interactions between the consumer and health professionals.

Analysis of the results of the next round (Rating of Importance Statements Questionnaire) indicated that most of the Intervention category statements were not consistent with the concept that the other category items measured. The distinct separation between the Intervention and other categories confirmed the thesis contention of a difference between the experience of health and the provision of services to lessen pain and/or dysfunction. Consequently, the majority of the Intervention category items were omitted and the 38-item HAS:1 developed and tested. On reflection, the Intervention statements that had statistically significant correlations could readily have been included in other categories, such as Interaction and Attitude. In both rounds of statistical analysis, items principally loaded on one factor with no clearly separate sub concepts identified by Varimax rotation, which indicated that the items measured a strongly interrelated concept; in line with the concept of holistic health.

The nonmaterial view of the healthy self contends that the more objective aspects of self need to be congruent with the spiritual core and used to express the values that define this core. Healthy individuals do not perceive or experience self as a body, a brain, relationships and a spirit; they are one interrelated, inseparable entity: a person. Consequently, as all these self aspects are derived from the one source, they are all, in some way, the same and interrelated. Therefore, the items in a measure of holistic health should not be readily separated into distinct components.

The alteration of the HAS:1 to include an intent subscale and the construction of the QE Health Scale (QEHS) resulted from comments from participants and colleagues as well as the researcher's developing knowledge and understanding acquired through analysis of the data. These changes were justified for three reasons.

First, the opinion of the participants, the researcher and his colleagues that the HAS:1 was 'not quite right'.

Secondly, HAS:1 item scores were consistently high, indicating that participants tended to perceive most of the statements were equally important to health as indicated by the ceiling effect.

Thirdly, these results illustrated the issues raised by the two predominant theories of how people respond to questions about attitude; the file drawer and construal models of attitudes (Wilson & Hodges, 1992).

The mechanistic file drawer model contends that attitudes are contained in distinct, independent memory files and attitude responses are simply recalled judgements on a specific issue. A new judgement is only made when no previous evaluation has been made on a particular issue. In contrast, the construal model contests that, along with these evaluations, the memory file drawer contains additional contents, such as emotions, contradictory evaluations and information; in this model, attitudes are more fluid.

However, it appears that an intermediate view is a more likely reflection of reality (Tourangeasu, Rips & Rasinski, 2000). Attitudes seem to be a distinct memory structure containing clear, precise evaluations. However, they also consist of vague impressions, general values, and related feelings and beliefs. Moreover, as the whole brain is interrelated, it is reasonable to assume that the overall present and temporal state of the whole brain will impact on what is recalled. Consequently, when we think about an issue, recall is influenced by external factors, such as the requirements of the task at hand and the personal relevance of the inquiry. We respond by recalling some subset from the attitude memory structure. We may reiterate an existing evaluation, update it, or extend it to cover a new aspect of an issue, or even make an entirely new judgement about the issue.

The aim of this study was to develop a measure that would provide the stimuli to not only extract rigid, readily recalled opinions but also acknowledge the vagueness, dynamism and fluidity of attitude evaluations. But the HAS:1 asked people to rate their opinion of the importance of each statement for health but did

not address whether or not people would or did relate these issues to their own lives. Rather than measuring the holistic health of individuals, it seemed to measure the public perception, societal accepted norms of what holistic health should be. In consequence, the HAS:1 was accessing readily recalled, 'surface', generalised evaluations rather than the deeper, fluid, less readily defined and individualised judgements. The introduction of the intent subscale of the HAS and the QEHS sought to address these issues.

Item content and format of the QE Health Scale was identical to the tested HAS:1. The initial development phase was now complete. The next study tested the psychometric properties and criterion validity of both scales.

Limitations

The major limitation was sample characteristics and size. With the exception of the proportion of Maori participants, the demographics indicate that the sample was reasonably representative of types of disorders prevalent in the research population.

Why proportionately fewer Maori participated is open to speculation but possibly the greatest barrier could have been the research design. Requesting that individuals report their personal values and beliefs concerning health, particularly in relation to spirituality, without an opportunity to meet and know the person requesting such a response probably differs from the manner most Maori prefer to interact. Additionally, the complex, time-consuming and thought-provoking nature of the initial Participant Health Questionnaire required participants to invest a large amount of effort into completing it. If one is already unsure of the researcher's intent and uneasy because of lack of face-to-face interaction, it is unlikely that one would decide to take time to complete the initial questionnaire. Moreover, the three rounds of data collection and time for analysis between rounds meant that data was collected over a period of seven months. These design characteristics suggest that the sample would be self-selective and possibly not representative of those in the research population who believed that spirituality was an important component of health. It is worth noting that the demographic characteristics of the 10 participants who did not believe spirituality was important to their health differed markedly from those who participated in the full

study. What this means is difficult to decipher from just 10 people and may have been purely due to chance.

For the type of statistical analysis performed in this study, convention contends that there is a need for a minimum of five participants per item to reach a reasonably reliable and valid conclusion. The numbers participating fell well short of this, requiring the results to be interpreted with caution. However, the aim of the study was not to test a valid and reliable measure of holistic health but rather to systematically develop such a measure; the next study would begin the process of validity assessment. Consequently, the measures developed, the Health Attitudes Scale: II (HAS:II) and the QE Health Scale (QEHS), were now ready for full psychometric testing.

CHAPTER 9: RELIABILITY AND VALIDITY INVESTIGATIONS OF THE HEALTH ATTITUDES SCALE (HAS:2) AND THE QE HEALTH SCALE QEHS).

Introduction

In the previous study (Chapter 8), statements identifying what people with musculoskeletal disabilities found were important for health were used to construct two measures, the Health Attitudes Scale: Version 2 (HAS:2) and the QE Health Scale (QEHS). Each instrument included 40 items with the same item content. However, the HAS:2 measured the importance of each health statement and intent to act this way in the future (attitudinal scale) while the QEHS measured frequency of related behaviour, thought or attitude over the past week (behavioural scale).

The present study sought to investigate these measures to assess:

1. The degree that responses reflected a normal distribution and in so doing, had the capacity to capture the diversity of possible responses (discriminatory power).
2. Content validity:
   (a) Internal consistency: Assessed by degree of item-total correlation and the resultant Cronbach's alpha.
   (b) Theoretical validity: Assessed using factor analysis to identify the degree to which scale structure was congruent with theoretical predictions. The aim was to develop a holistic health measure, which required that all items were interrelated and primarily loading on the principal factor.
   (c) Concurrent validity: From the conceptual foundation of the spiritual model (Chapter 3), health status is related to the individual's perception of self and their world and whether the past, present or future is viewed as positive (hopeful) or negative (fearful). Therefore, if the content of the developmental measures are a valid representation of such a health state, they should positively correlate with a measure of anxiety and a measure that examines personal comprehension, manageability and meaning of self and life or, broadly speaking, coping strategies.

Therefore, this study advanced the scale development process by assessment of

the developmental scale's reliability and validity against validated measures of constructs predicted to be key components of the HAS:2 and the QEHS.

Method

Participants

Of the 397 randomly selected, 233 (58.7%) returned completed questionnaires with no follow-up or reminder contact. Of the 118 who did not participate, 51 (43.2%) either did not meet selection criteria, or cited extreme ill health, hospitalisation, overseas travel or present personal traumatic events. The remaining 57 were not interested.

Disorders in the study sample included various forms of arthritis (57%), pain syndromes (27%), accidents and injuries (9%) with various other musculoskeletal disorders comprising the remainder (see Table 9.1). The majority of participants were female (70%) while ethnicity consisted of 90% Pakeha and 10% Maori. Age categories ranged from 16-25 to over 85, with the great majority (87%) aged 46 or over and the mean age approximately 60 years. Time living with disability ranged from under two years to over 20 years with a mean of approximately16 years (refer Table 9.1).

Most were not income-earners (55%), identifying themselves as homemaker (11%), retired (20%), sickness, invalid or ACC beneficiary (22%) or student (2%) while 45% were employed. Income of the primary wage earner ranged from $15,000 or less to over $76,000 with a mean of approximately $21,000. The majority had some educational or trade qualification (56%).

Design

The study was a postal survey questionnaire validation study with participants randomly selected from previous QE inpatients listed in the January 2000 – January 2003 QE Health Rheumatology and Rehabilitation inpatient database. Five self-administered questionnaires were employed. These were the developmental Health Attitudes Scale (HAS:2) and QE Health Scale (QEHS); a general demographic information sheet; the Sense of Coherence Scale (SOC); and the State-Trait Anxiety Inventory (STAI).

Table 9.1: HAS Study Participant Demographics

Demographic	Category	Percent of Total Sample
Age	16-25	1.4
	26-35	2.3
	36-45	8.2
	46-55	18.7
	56-65	27.4
	66-75	23.7
	76-85	16.9
	85 or over	1.5
Diagnosis	Osteoarthritis	16.7
	Rheumatoid arthritis	19.4
	Other arthritis	20.8
	Fibromyalgia Syndrome	20.4
	Unspecific chronic pain	6.9
	Accidents/injury-related	9.0
	Other	6.8
Time with Disability	Under 2 years	1.4
	2-5 years	18.3
	6-10 years	21.5
	10-20 years	33.3
	Over 20 years	25.6
Education	Primary	5.9
	Secondary	37.9
	Secondary qualified	23.8
	Tertiary	6.0
	Trade/polytechnic	16.4
	Other	10.0
Employment	Student	2.3
	Homemaker	10.9
	Unemployed	2.7
	Disabled	19.0
	Workforce	45.2
	Retired	19.9
Income	$15,000 or less	28.3
	$16,000-$25,000	29.2
	$26,000-$35,000	15.5
	$36,000-$45,000	9.6
	$46,000-$55,000	5.5
	$56,000-$65,000	5.0
	$66,000-$75,000	2.3
	$76,000 and over	4.6

Data gathered from the HAS:2 and the QEHS was used to test the discriminatory power, reliability, internal consistency and theoretical validity of these measures. The Sense of Coherence Scale (Antonovsky, 1993) and the State-Trait Anxiety Inventory (Spielberger, 1983) were used to test the concurrent validity of the HAS:2 and QEHS.

The HAS:2 and QEHS
See Appendices 10 and 11.

Sense of Coherence Scale (SOC)

Antonovsky (1993) states that sense of coherence is '...a global orientation that expresses the extent that one has a pervasive, enduring though dynamic feeling of confidence that one's internal and external environments are predictable and that there is a high probability that things will work out as well as can be reasonably expected' (p.10). Sense of coherence is viewed as a generalised personality disposition enabling individuals to choose appropriate coping strategies in response to a specific problem or situation. The SOC was designed to identify an individual's perception of their health, their ability to cope healthily with change and their position on the health/ill-health continuum (Antonovsky, 1993). It claims to assess individual worldview, the degree to which coping is successful and awareness of the reality of their circumstances.

The short form of the Sense of Coherence scale (SOC-13) was used in this study. It consists of 13 items in a 7-point Likert scale (Appendix 20). For example, item 2 asks 'Has it happened to you in the past that you were surprised by the behaviour of people whom you thought you knew well?' Possible responses range from ' 7. Never happened' to '1. Always happened'. A high score indicates a healthy sense of coherence.

Antonovsky (1993) presents the findings of 16 studies investigating the content and concurrent validity of the SOC-13. Cronbach's alpha was acceptable, ranging from 0.74 – 0.91 with high levels of content and face validity. Significant correlation was found with measures of similar concepts to the SOC as well as theoretically related components (e.g., anxiety, health, attitudes, behaviours and wellbeing). There was one clear principal component factor structure, indicating that the SOC measures a single predominant concept.

Inherent in the concept is Antonovsky's contention that the individual's perspective of self and life determines their health. Antonovsky argues that because of the reality of the human condition, health is not an absolute state but on a continuum. People are both healthy and unhealthy; no one person is

completely healthy or unhealthy. People move towards health when the individual perceives life as meaningful, comprehensible and manageable. This concept is congruent to that depicted by the Spiritual Theory of Self and the Health Change Process Theory. Therefore, it was expected that there would be strong positive correlations between scores obtained on the SOC, the HAS:2 and the QEHS.

State-Trait Anxiety Inventory (STAI)

The State-Trait Anxiety Scale (STAI) has been extensively used in both research and clinical practice (Spielberger, 1983). It consists of separate trait and state anxiety scales, each of twenty items. Examples of trait anxiety items are, 'I feel calm' and 'I feel confused' with possible answers with scores in brackets, being 'not at all' (1), 'somewhat' (2), 'moderately so' (3) and 'very much so' (4). Scoring for the state scale is identical, with 'I feel pleasant' and 'Some unimportant thought runs through my mind and bothers me' being examples of these items. State anxiety is that attributable to a recent noxious stimulus and the more stable trait anxiety reflects one's perception of self and life in general (Appendix 21).

It was predicted that elements of the HAS:2 and QEHS would measure anxiety because awareness and experience of the essence of self as indestructible, despite loss of objective aspects of self, is predicted to result in lower anxiety about the present and future than will the absence of such awareness and experience. Consequently, it was predicted that the HAS:2 and QEHS would negatively correlate with both the state and trait subscales.

Data Collection Procedure

Those randomly selected from the Rheumatology and Rehabilitation inpatient database were sent an information sheet and then telephoned a minimum of a week later by the researcher and asked if they wished to take part in the study. Those consenting were then sent the questionnaire booklet. Return of the completed questionnaire was assumed to imply consent to participate. If four or less responses on the developmental measures were missing, the average response was used to complete the questionnaire. Those with more than four uncompleted items were excluded from further analysis.

Data Analysis Procedure

All data was analysed using SPSS 11.

1. Total score frequencies were identified to determine if the distribution was normal.
2. Then item-total correlations were calculated to examine internal consistency. Items with a low correlation (<0.3) were sequentially removed and the effect on Cronbach's alpha was examined.
3. Items were removed from further analysis if their removal increased Cronbach's alpha.
4. A principal components factor analysis was then calculated with items being retained if they had a principal factor loading greater than 0.3.
5. This was followed by a Varimax rotation to test for item clusters other than the principal component.
6. No distinct Varimax rotation clusters were found. Consequently, the content of the items not loading on the principal component was examined and compared to the remaining items to identify whether their removal would conceptually and statistically impact on the scale.
7. With these items removed, item-total correlation analysis was repeated to test the remaining items' internal consistency
8. Total scores were calculated for the resultant 33-item QEH, the SOC and the state and trait components of the STAI.
9. Bivariate 2-tailed Pearson's correlations were run between the QEHS total score, the HAS Intent (HASIN) subtotal, the HAS Importance (HASIM) subtotal, the SOC-13 total, the STAI Trait subtotal and the STAI State subtotal scores, and examined to test the content and concurrent validity of the QEHS and HAS:2.

Results

Total score frequencies of the of the QEHS (skewness = -0.38, kurtosis = 0.02) as well as the HAS:2 subscales of HAS importance statements (skewness = -0.57, kurtosis = 0.04) and HAS intent items (skewness = -0.37, kurtosis = -0.17) identified distributions within the acceptable limits of normalcy (see Figures 9.1, 9.2 & 9.3) indicating that statistical analysis of the scores was appropriate. Item means and standard deviations (Appendix 22), the KMO overall statistic of sampling adequacy (0.85) and Bartlett's test of sphericity ($\chi^2 = 2869.33$, $df = 788$,

$p = 0.000$) indicated that the distribution and item correlations were satisfactory for factor analysis.

Figure 9.1: Frequency distribution of QEHS total scores

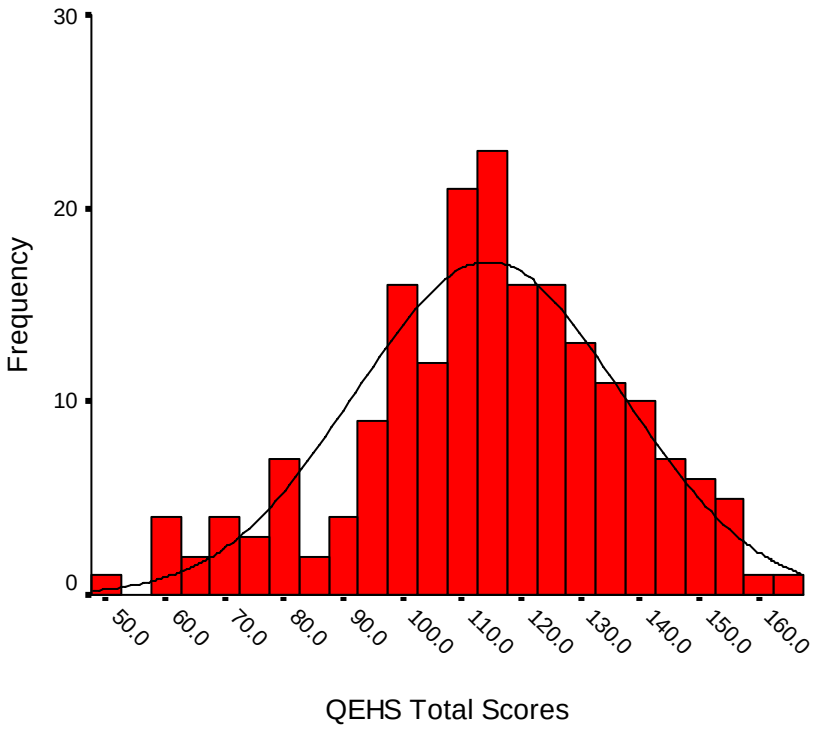


Figure 9.2: Frequency distribution of HASIN total scores

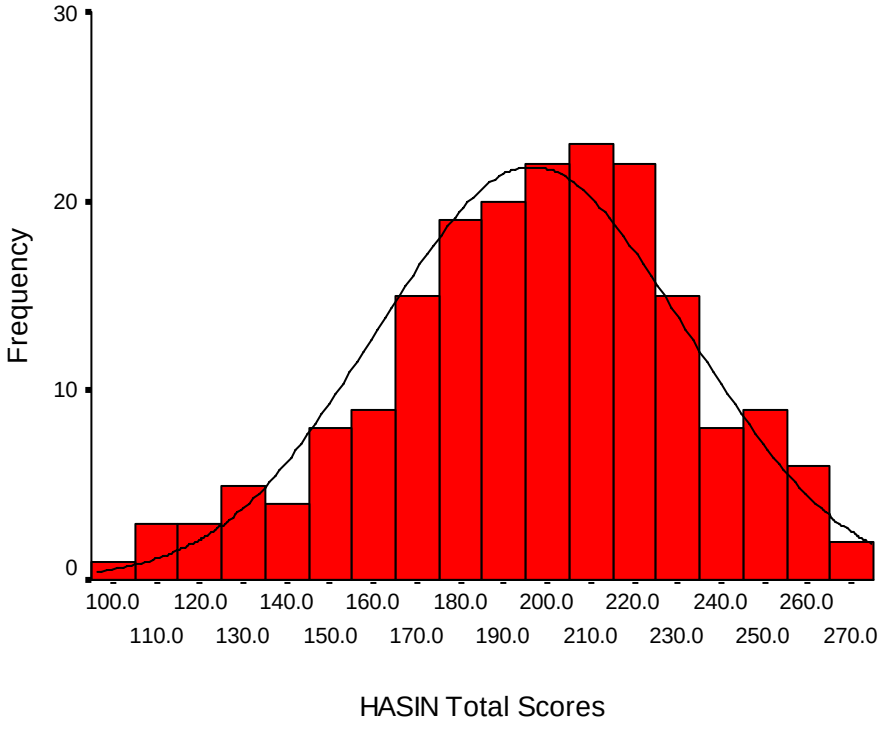
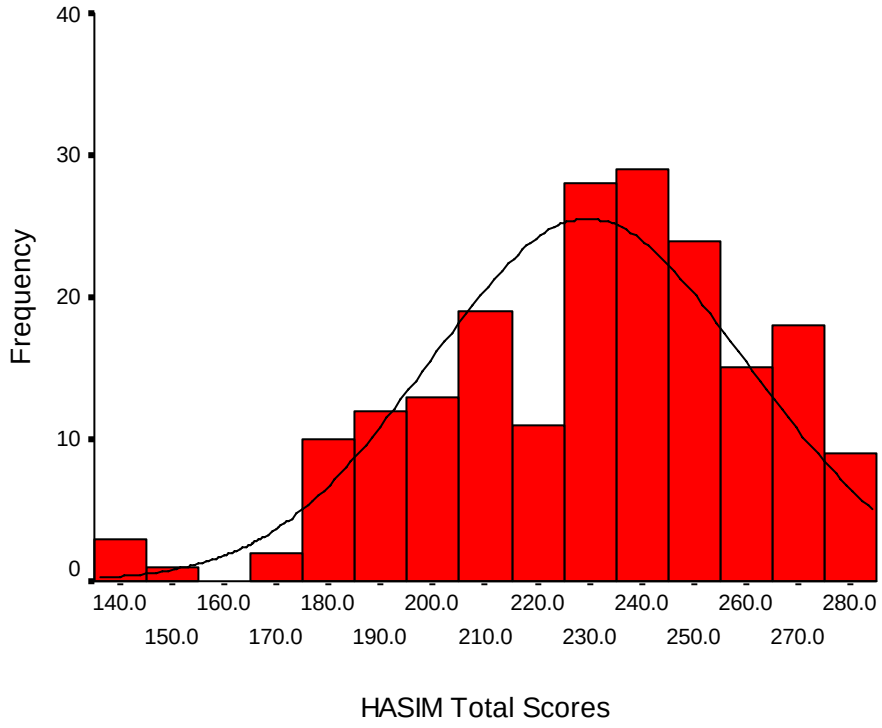


Figure 9.3: Frequency distribution of HASIM total scores



QEHS Results

Item-total correlation analysis of the 40 items resulted in a Cronbach's alpha of 0.91 (Appendix 22). Principal component and Varimax rotation factor analysis of these 40 items (Appendices 23 & 24) showed that those items identified as possessing item-total correlations of <0.3 also loaded across a number of alternative factors; their content consisted of multiple meanings and wordy and therefore confusing; and other items stated similar concepts more clearly. It was reasoned that their removal would not alter the concept measured by the scale. These items were 1, 2, 6, 8, 9, 14, 19 & 30. Consequently, except for item 1, which was believed to be theoretically significant and possibly not a component of other items, these seven items were removed. Item-total analysis of the 33 remaining items was rerun resulting in a Cronbach's alpha of 0.93 (Appendix 25). Principal components factor analysis of these 33 items with strong item-total correlations showed that these items loaded on the principal component (Appendix 26). A Varimax rotation identified eight factors with items tending to load on multiple factors (Appendix 27). The factor analysis results indicated that the QEHS measured one interrelated concept. Bivariate Pearson's correlations were then calculated between all total and sub-total scores. Medium to high correlations were found between the QEHS and all the other measures (Table 9.2).

Table 9.2: Total Score Correlations between Study Measures

	QEHS	SOC-13	STATE STAI	TRAIT STAI	HASIM	HASIN
QEHS		.32**	-.39**	-.35**	.61**	.61**
SOC-13			-.66**	-.74**	.13	.12
STATE STAI				.82**	-.11	-.11
TRAIT STAI					-.11	-.10
HASIM						.998**

** Correlation is significant at the 0.01 level (2-tailed).
HASIM = HAS:2 importance statements
HASIN = HAS:2 intent statements

The outcome was that the 40-item QEHS was reduced to the 33-item final version (Appendix 28).

HAS:2 Importance Statement (HASIM) Results

The same analytic procedure was followed in separate analyses of each subscale (Importance and Intent items) of the HAS:2 (Appendices 29 - 33). The HASIM had an internal consistency of 0.94. All items were strongly correlated and removal of any had little effect on alpha. All except one item loaded on the principal component and the Varimax rotation produced results similar to those found with the QEHS.

Total scores for the HAS:2, SOC-13 and STAI measure were computed and correlations calculated between all the measures (see Table 9.2). Significant correlations were found between the HASIM and HASIN and QEHS.

HAS:2 Intent Statement (HASIN) Results

The same statistical procedures were followed for the HASIN subscale. Internal consistency with all items included resulted in Cronbach's alpha = 0.94. Item 2 was removed, resulting in Cronbach's alpha remaining at 0.94. Factor analysis identified that all items except for 1, 6, and 7 loaded on the principal component. The Varimax rotation identified eight distinct factors. As all items except item 2

were consistent with the concept measured, a total HASIN score was calculated with item 2 removed. High correlations were found between HASIN and HASIM and HASIN and QEHS (see Table 7.2).

Measure Development

The lack of correlation between the validated SOC-13 and STAI measures and both subscales of the HAS:2 indicated that the HAS:2 did not possess adequate content or concurrent validity to be considered as a measure of two key components of holistic health; anxiety and effective coping. Moreover, high correlations between each subscale of the HAS:2 and the QEHS suggested that they were measuring similar constructs. Therefore, the HAS:2 was not considered for further development.

In contrast, the 33-item QEHS correlated significantly ($p > .01$) with the SOC-13 and STAI. Consequently, the QEHS was considered worth testing for clinical validity.

Discussion

The HAS:2 comprised statements generated by people with musculoskeletal disabilities that they perceived as important components of what made them healthy. While these items measured individuals' beliefs concerning what is important for health, they did not assess previous actions or future intent to act. It was unclear which (if any) wording of these items (importance, intent or past attitude and behaviour) would result in a valid and consistent measure of holistic health. Therefore, two scales were developed and tested in the present study, the HAS:2 with importance and future intent subscales, and the reworded QEHS, which deals with past behaviour and attitude. The results indicated that the 33-item QEHS was reliable and possessed content and concurrent validity.

The existence of a strong principal component and the lack of any rotated components suggested that the QEHS measured a singular concept, as one would expect if it is measuring holistic health. Moreover, the relationship between the QEHS, the SOC-13 and STAI support the QEHS as validly measuring a distinct, holistic health concept, indicating that there was sufficient construct and concurrent validity to warrant full clinical investigation of the scale.

Further Research

The QEHS related well to valid measures of anxiety and coping but it was not yet known whether it was a clinically valid and useful tool to aid assessment, treatment and evaluation within a holistic health provision paradigm. Consequently, there was a need to assess the clinical face validity of the scale as well as its predictive validity as an assessment and subsequent treatment decision making tool. Moreover, psychometric properties of the QEHS, such as structure, consistency, content and concurrent validity required further investigation to develop understanding of what the QEHS measured and what it did not measure. Furthermore, a second full scale study involving another sample from the same population would extend testing of the theory upon which the scale is based.

PART 5: CLINICAL APPLICATION AND EVALUATION OF A HOLISTIC HEALTH MEASURE

Chapter 10: Clinical Application and Investigation of the Reliability and Validity of the QE Health Scale (QEHS).

CHAPTER 10: CLINICAL APPLICATION AND INVESTIGATION OF THE RELIABILITY AND VALIDITY OF THE QE HEALTH SCALE (QEHS)

Introduction

The final thesis study examined the reliability, validity and clinical applicability of the QE Health Scale as a holistic health measurement tool. Specifically, the internal consistency and reliability; the face, content, criterion (predictive and concurrent), construct and discriminant validity of the QEHS were investigated.

The HSD Study (Chapter 6) identified self-attributes necessary for health in the study population. Subsequently, the Self-Attributes Model and the Health Change Process Theory were developed. The next study, the SIQS study (Chapter 8), began developing a measure based on these concepts of health. The SIQS Study results reflected the health-related themes and personal attributes found in the previous HSD Study; supporting both the associated theory and the SIQS statements as a valid basis to quantify an individual's position on the Health Change Process Theory. Participants' SIQS statements then became the basis for the items of the HAS and QEHS measures tested in the following HAS Study (Chapter 9). The HAS Study examined the internal consistency, content and criterion validity of the HAS and QEHS measures by investigating the relationship between each of these and validated measures of anxiety (the STAI) and coping (the SOC).

The HAS measure was found not to be significantly correlated with the validated measures and it was not considered in further investigations. In contrast, analysis of the 33-item QEHS demonstrated satisfactory internal consistency and content validity. Moreover, the significant, medium to high correlations found between the QEHS, the SOC-13 and the STAI indicated that the QEHS possessed satisfactory content and criterion validity. The study presented in this chapter sought to substantiate and expand the reliability and validity of the QEHS as a clinically applicable measure of holistic health status.

Assessing Reliability and Validity

Reliability and Stability

A reliable measure needs not only to exhibit strong interrelationships between items at one point in time, and so indicate internal consistency, but also to retain these over time to demonstrate scale stability. The main test of stability in this study was test-retest reliability manifested between QEHS total scores at two measurement points.

While it is important that a reliable instrument possesses internal consistency, demonstrated by high correlation between each item and the total of the rest of the items, it is equally important that the content of items vary to demonstrate that items capture different aspects of the overall construct that is measured, indicated by statistically significant variance between item responses. In this study, this essential scale characteristic was judged as satisfactory if the analysis of variance, Hotelling's T-test indicated a significant difference between items. Furthermore, for parametric statistical analysis, a reliable instrument needs to approximate a normal distribution, which, in this study was assessed by skewness, kurtosis and Tukey's test of linearity. A low Tukey statistic (approximately 1.0) indicates that that a linear scale is appropriate.

Validity

Discussed fully in Chapter Four, validity is the 'meaningfulness of a health status measure' (Brooks, 1995, p.48). Next, each type of validity is discussed in the context of the present study.

Face Validity

Face validity concerns the degree to which those administering, completing and utilising the QEHS view it as a credible measure of holistic health. Face validity from the participants' perspective was assessed in this study but the health professionals' perspective was the focus of assessment, concentrating on instrument sensibility and practicality of the QEHS as a clinical tool. Clinical sensibility concerns whether or not clinicians regard the measure as a sensible and clinically useful tool aiding their practice. Practicality focuses on the logistics of administration, analysis and the simplicity of applying the QEHS to practice.

Content Validity

Content validity examines item meaningfulness by investigating the scale structure, that is, the way items cluster, group and relate to one another as predicted from theory. Factor analysis tests the degree to which the instrument meets the requirements of a holistic measure. A holistic instrument should measure one highly interrelated concept, rather than distinct physical, social, cognitive and spiritual aspects of health. Therefore, all items of the QEHS should be highly correlated and load strongly on the principal component. Moreover, when a factor rotation is applied to identify any other ways items may cluster, there should be no clear-cut and distinct clusters, that is, items should load on multiple factors, reflecting the interrelationships of the different aspects of health. Additionally, for an instrument to be a valid measure of holistic health, items need to assess physical, social and cognitive aspects of health, identified by testing for relationships between the developmental measure and validated measures of these health concepts. Furthermore, the holistic health perspective assumes that aspects of health cannot be separated and assessed separately. Therefore a holistic instrument needs to measure health as a whole. Consequently, each item should assess multiples aspects of health rather than solely physical, social, cognitive or spiritual health.

Criterion Validity

Criterion validity includes concurrent and predictive validity and is the capacity of the scale to measure what it claims to measure. In the present study, the relationship of the QEHS to validated measures of related health constructs was used to assess criterion validity. As in the preceding study, concurrent validity was assessed by examination of the correlations between the QEHS and validated measures at one point in time. However, the focus of the present study was clinical application of the QEHS and consequently, predictive validity was the primary focus of criterion validity testing. Changes in the routinely-applied validated measures were compared to the QEHS changes at two measurement points with a three-week rehabilitation intervention occurring between these points to test whether the new measure changed in a predictable manner.

Construct Validity

Brooks (1995) asserts that construct validity is the crucial test of validity,

stressing that a health measure needs to advance and inform both theory and practice. The Health Change Process Theory provides the theoretical foundation of the QEHS. The QEHS aims to apply this theory to practice and in doing so, test the theory's robustness as well as advance practice. Predictive validity can be viewed as a component of this evaluation but, in this study, identification from QEHS data of participant position on the Health Change Process Theory and the individual's accompanying self-attributes were compared to clinicians' judgments as the primary test of construct validity. Moreover, reported utilisation of the QEHS by clinicians was recorded to evaluate the capacity of the QEHS to inform theory and practice.

Discriminant Validity

Discriminant validity, the degree that the QEHS is a unique health measure, was identified by exploring the characteristics of the relationships of the QEHS with the validated, established quantitative measures, judgments of clinicians' and observations of the impact of the QEHS on practice.

Consequently, the combined results of face, content, criterion, construct and discriminant validity tests were central to identifying the clinical validity of the QEHS.

Study Questions

Therefore, the reliability and validity questions addressed in this study were:

1. Reliability and stability: Is the QEHS reliable and stable?
2. Face validity: Do clinicians' and participants' judge the QEHS items as a credible and meaningful?
3. Content validity: Does the QEHS items measure health holistically?
4. Criterion validity: Does the QEHS measure what it means to measure?
5. Construct validity: Does the QEHS provide meaningful data that informs theory and practice?
6. Discriminant validity: Does QEHS data provide clinically meaningful information that other measures do not?
7. Clinical validity: Is the QEHS a responsive, generalisable, sensible and practical assessment tool, taking into account the aforementioned reliability and validity characteristics of the QEHS?

Method

Participants

Three hundred people were sent study information sheets. Of those, 42 people either were not admitted, were excluded either by nursing staff (predominantly because of medical complications, major personal crises unrelated to admission, or psychological or cognitive issues), were 'missed' on admission, discharged early or did not present for treatment. A further 53 declined to take part in the study. Two hundred and five participants completed both admission and discharge QEHS measures, while 191 completed generic QE Health admission and discharge measures. Some participants also completed four therapist administered study measures at both admission and discharge (details below).

Next, the sample demographics are presented along with those for the research population (In italics. See Chapter 5). The average age of the 205 participants was 58.33 years *(61.51)*, females comprised 80% of the sample *(70%)*; 82% were Pakeha *(88.53%)*, 15.8% Maori *(11.1%)* and 1.5% *(0.77%)* of other ethnicity Non-wage earners included 33.3% *(44.3%)* retired, 20.6% *(9.77%)* under-65 beneficiaries, 10.3% *(13.3%)* homemakers and 3.2% *(1.2%)* students. Wage earners included 4.8% *(6.1%)* employed as unskilled workers, 6.3% *(4.67%)* skilled workers, 14.3% *(5.57%),* professionals and 3.2% *(3.97%)* self-employed while 4.0% *(11.1%)* did not state their occupational status.

Diagnoses of arthritis represented 42.9% *(58.55%)* of the disorders of which 20.3% *(27.66%)* were osteoarthritis, 16.5% *(17.7%)* rheumatoid arthritis, 3.05% *(4.13%)* ankylosing spondylitis, 0.8% (*2.43%)* psoriatic arthritis, 0.8% *(2.2%)* gout and 1.5% *(4.43%)* other forms of arthritis. The remaining 56.1% were predominantly pain disorders of which fibromyalgia syndrome comprised 22.6% *(12.57%)*, chronic pain 13.5% *(3.43%)*, back pain 7.5% *(17.3%)*, post-polio 5.3% *(2.0%)* and other various neurological disorders 8.3% *(3.77%).*

The sample was similar to the research population with regard to age and ethnicity but significantly more females ($\chi = 4.76$, *df* 1, *p* 0.05) participated in the study. Also, those retired, homemakers, students, unskilled workers, skilled workers or self-employed were comparable to the research population but more people who were under-65 beneficiaries ($\chi = 12.0$, *df*1, p 0.01) and professionals ($\chi = 13.68$,

*df*1, $p = 0.05$) took part in the study. With regard to disease type, those with arthritis were slightly less ($\chi = 4.18$, *df*1, *p* 0.05) while fibromyalgia ($\chi = 8.01$, *df*1, *p* 0.01) and chronic pain ($\chi = 29.56$, *df*1, *p* 0.01) were more prevalent.

In summary, the sample included more females, beneficiaries, professionals and those with pain-related disorders than the research population.

Research Design

The major component of the prospective, comparative, test-retest design was quantitative. The developmental QEHS and the routine QE Health generic measures were administered upon admission to inpatient treatment and three weeks later at discharge. However, comments and observed behaviours of clinicians and participants also were a component of the data collected. Furthermore, participants' QEHS responses were qualitatively assessed to identify individual position on the QE Health Process Model, utilising a Patient Profile form. Profiles were compared with clinicians' assessment of the participant's health status.

QE Health Routine Measures

The theoretical basis of this thesis was the Spiritual Theory of Self. The HSD Study operationalised this and produced the Self-Attributes Model. This allowed an approximation of the concept of health from a non-material perspective. These findings, together with findings from the literature resulted in the development of the Health Change Process Theory. Health Change Process Theory therefore conceptualises the process by which a spiritual self, as depicted by the Spiritual Theory of Self, is achieved. Such a conceptualisation allowed prediction that an increased QEHS score would relate to a decreased pain score. Moreover, a high QEHS score would predict higher overall wellness, and greater ability to achieve activities of daily living. Measures of these were the self report McGill Pain Questionnaire and Wellness Visual Analogue Scale, and the Stanford Health Assessment Questionnaire (HAQ) (Appendices 37, 38 & 39).

The McGill Pain Questionnaire (MPQ) was developed from Melzack's (1975) multidimensional theory of pain. Rather than pain being solely sensory experience, Melzack proposed that it also involves emotional and cognitive

components and that painful stimulus sensed by peripheral neural receptors do not fully account for the resultant painful experience. Melzack argues that the unique cognitive-emotional state of the individual determines the nature of the pain experience. Therefore, to measure pain, he believes it is necessary to assess the three dimensions of sensory-discriminative, motivational-affective and cognitive-evaluative pain perception.

Utilising 102 sensory, affective and evaluative adjectives commonly used by patients to describe their pain, Melzack (1975) developed the 20 items of the MPQ. Each item includes a row of adjectives with each descriptor being of purportedly increasing intensity, if read from left to right. For example, item 17 consists of the following choices of adjectives 'spreading, radiating, penetrating, piercing'. The scoring method used at QE Health is the Present Pain Intensity (PPI). The adjectives are set out in up to six columns describing ascending intensity of pain, scored from 1 – 6. Participants respond by circling any of the words on the 20 lines (items) that describe their pain experience. Scoring consists of identifying the highest circled response on any one item and summing the total 20 items. Participants may respond to all or no items and therefore possible total scores range from 0 – 101. McDowell and Newell (1996) identify the MPQ as the leading measure for describing the diverse dimensions of pain and possessing satisfactory reliability and validity.

The Wellness Scale is a 10cm line representing a continuum of 'inner wellbeing' ranging from 'unwell' (0) to 'very well (10). The respondent marks the line indicating their perception of overall wellness. According to McDowell and Newell (1996) the visual analogue instrument possesses acceptable reliability and validity.

The Stanford Health Assessment Questionnaire (HAQ) was developed by Ramey, Raynauld & Fries (1992). The disability subscale of the HAQ, used at QE Health, consists of 20 items measuring eight components of physical function (dressing, grooming, rising, walking, hygiene, reach, grip and outdoor activities). Possible responses range from 'without difficulty' (0) to 'unable to do' (3). The highest scores in each of the eight components are summed and divided by eight, resulting in a 0 – 3 continuous score. McDowell and Newell (1996) state that 0.0 – 0.5

indicates complete self-sufficiency, 0.5 – 1.25 reasonable self-sufficiency, 1.25 – 2.0 self-sufficient but major problems with Activities of Daily Living and 2.0 – 3.0 severe handicap. The HAQ has been shown to be a reliable and valid measure of physical function (McDowell & Newell, 1996).

A further four measures were administered by clinicians to various diagnostic groups. The occupational therapist administered Canadian Occupational Performance Measure (COPM) was completed by 79 participants. Physiotherapists administered the Get Up & Go to 80 participants; the Ward Walk to 85 participants; and the Six-Minute Walk to 61 participants.

The Canadian Occupational Performance Measure (COPM) assesses Occupational performance (OP) consisting of three categories: self care, productivity and leisure (Law, Polatajko, McColl, Carswell & Baptiste, 1994; Toomey, Nicholson & Carswell, 1995). Self-care includes personal care, functional mobility and community-orientated independence activities (e.g., shopping); productivity includes paid/unpaid work; and leisure includes quiet and active recreation and social activities. The intent is to encompass the physical, social, cognitive and spiritual dimensions of self and to capture the client's perceptions of the importance to self of the aspects of the three categories (Appendix 40). The authors' reason that the COPM is an individualised, spiritually based, client-centred and holistic health measure of client-perceived change in OP over time.

The therapist uses a semi-structured interview and a 'typical day' scenario to identify the respondent's difficulties with regard to their wants, needs and expectations across the self-care, productivity and leisure categories. Respondents then rate the importance of each activity they are experiencing difficulties with on a 10-point scale, resulting in a priority list of problems. The respondent then rates level of performance and satisfaction with performance for a maximum of five problems on two further 10-point scales. The COPM Performance (COPMP) and COPM Satisfaction (COPMS) scores of 0-10 are the average of each of these two groups of five responses.

The Health Change Process Theory also predicted relationships between the QEHS score and physical dysfunction. The nature of this relationship was predicted to be complex. Health Change Process Theory perceives physical function as a potential catalyst to increase holistic health status that, in turn, may result in greater physical performance. Therefore, it was predicted that development of a spiritual self (a high QEHS score) would be related to increased physical performance because of, rather than in spite of significant physical impairment. In addition to the HAQ, the three physiotherapist administered measures explored these relationships.

The Get Up and Go and Ward Walk are mainly used for those with limited mobility, flexibility, strength and endurance while the Six Minute Walk is used for those with higher levels of functioning.

The Get Up and Go is assessed by the seconds taken for the client to complete the following task: Seated in an upright chair with arm supports, the person gets up from the chair, walks as fast as possible to and around a cone placed three metres from the front legs of the chair, then returns to sit back down in the chair.

The Ward Walk score is the seconds taken to walk 15.34 metres (50 feet) with the instruction to 'walk as quickly as you are comfortable with to the finish line'.

The Six Minute Walk score is the metres walked around a circuit between two cones placed 10 metres apart over six minutes. The client is instructed to walk 'as fast as they can with comfort' and is informed that they may stop and rest during the test as well as when three minutes and five minutes have elapsed.

The three self-report measures are routinely used at QE Health with all people in the research population, while the therapist-administered measures are routinely used for specific diagnostic groups within the research population.

Procedure

Quantitative Procedure

1. Two Rheumatology Nurse Coordinators each coordinate an inpatient clinical team comprised of rheumatologists, physiotherapists, occupational therapists and a counselor. The Rheumatology nurses were responsible for administering the three generic measures and the QEHS.
2. Approximately two weeks pre-admission before entering the QE Health Rheumatology and Rehabilitation inpatient programmes, all patients were sent the study information sheet (see Appendix 35).
3. Those agreeing to participate completed the three QE Health generic measures and the QEHS on Day 1 of admission.
4. On the second-to-last day of treatment (Day 14), participants again completed the three generic measures and the QEHS.
5. The completed QEHS was checked for missing data by the researcher. Those with three or less items not completed, the average of completed responses was calculated and used for those items not responded to. Questionnaires with more than three items omitted were, where feasible, taken back to the respondent by the Nurse Coordinator or their representative for completion. Where not possible, the QEHS was discarded.
6. The other measures (COPM, Get-up-and-go, Ward walk, and Six-Minute Walk) were administered by the relevant therapist on the participant's first and last appointment with the relevant therapist.
7. An enrolled nurse calculated the total scores of the study measures and entered them into the QE Health database.
8. The researcher sourced participant demographic details and generic measure totals from the QE Health database and entered these into SPSS Version 11.
9. The researcher checked QEHS total scores, analysed the QEHS to identify participant position on the Health Change Process Theory, and entered these and individual QEHS item responses into the SPSS database.

Qualitative Procedure

1. QEHS questionnaires sent to the researcher for quantitative analysis were also analysed qualitatively.
2. The researcher then examined item responses and interpreted these in items of the Self-Attributes Model and Health Change Process Theory, providing an

estimate of position of the person on the Health Change Process Theory, some comments on health state and present perspective of self and health. An example of a researcher-generated patient profile is provided in Figure 10.1. The researcher distributed the profiles and attended the Ward Round meeting where Patient Profiles were evaluated by team members.

3. Approximately four-weeks after commencement of data collection, clinical team members expressed a desire to undertake profiling. Consequently, the researcher worked with clinicians until they felt confident to profile.
4. Subsequently, clinicians and the researcher developed the QEHS Patient Profile Form (see Figure 10.2).

Figure 10.1: Initial version of Patient Profile

Patient Profile

- Action Coping Cycle: unsustainable.
- Low self-worth, high anxiety, no awareness of core self, totally externally focused. Beware of reinforcing this by focusing on 'doing', particularly exercise.
- Ready for change but also needs to experience setting small goals and achieving them.
- Needs to understand positive change. Exposure to the Health Change Process some where down the line would be advantageous but needs to begin to experience self as unique and of value first.

5. At this stage of instrument development, the researcher had limited information about the reliability and validity of the QEHS. Profiling was guided by the underlying Self-Attributes and the Health Change Process theories. Each item was theoretically categorized according to the Personal Attributes detailed on the Patient Profile Form (see Figure 10.2).
6. Over time, the researcher identified informal rules of item association (Appendix 41) to facilitate QEHS interpretation.
7. From this point on, two clinicians from each team collaborated with the researcher to undertake profiling, sequentially rotating this task around the team. The participant's name was hidden to ensure the profilers were blinded. The researcher checked all Patient Profiles and his score of participant position within the Health Change Process Theory were entered into the SPSS database. The altered procedure was as follows:

a. Three days after admission, the clinical team attended the Ward Round meeting in which each patient was discussed and intervention strategies decided. Patient Profiles, forwarded to all team members prior to the meeting, were discussed.
b. Clinical assessment of each participant, based on medical records and routine therapeutic interactions, was compared with their Patient Profile to identify the degree of congruency between them.
c. A consensual assessment by the team of the accuracy of the Patient Profile was then made.

Analysis

Steps taken for quantitative analysis were as follows:

1. All QEHS item responses were reversed and total scores calculated.
2. Total score frequencies of the QEHS were examined for normality.
3. Item total correlations were computed and items with low correlation were systematically removed until Cronbach's alpha no longer improved.
4. Principal components factor analysis was employed to identify component structure and item loadings were examined.
5. The content of any item not loading on the principal component was examined and compared to the remaining items to identify whether its removal would conceptually impact on scale content.
6. After the removal of items, distribution normality was re-examined, item total correlations and principal components factor analysis were re-calculated.
7. A Varimax rotation was then run to investigate for item clusters other than principal component.
8. The QEHS totals for the remaining 28-item QEHS were calculated and bivariate 2-tailed Pearson's correlational analysis was computed to examine the relationships between the QEHS and total scores on each of the MPQ, HAQ, Wellness, Health Change Process Theory, COPM, Get Up and Go, Ward Walk, and Six-Minute Walk measures.

Figure 10.2: QEHS Patient Profile Form

QEHS Patient Profile

Name: **Date:** **HCU No:**

QEHS Score:

Health Change Process Theory Position: (please circle)

Action Coping Cycle	Action Coping to Awareness of Loss
Awareness of Loss: Inertia	Awareness of Loss: Disability Identity
Awareness of Loss	Awareness of Loss to Acceptance of Loss
Acceptance of Loss	Acceptance of Loss to Experimentation and Identification
Experimentation & Identification	Experimentation to Spiritual Identity
Spiritual Identity	

Sustainability: (please circle)

Sustainable	In Between	Unsustainable

Personal attributes: (Please circle)

Anxiety	High	Medium	Low
Self-worth	High	Medium	Low
Motivation to change	High	Medium	Low
Awareness of Possibility to Change	High	Medium	Low
Identity	Internal	Mix	External

Therapist's Comments: _____
_____

Therapist's Signature: _____

Results

The 33-item QEHS approximated a normal distribution, however, five items were found to significantly affect Cronbach's alpha and therefore were removed and analysis re-run with the resultant 28-item QEHS (see Appendices 41 & 42).

Normality of QEHS, Items 1, 2, 3, 5, & 6 Removed

The QEHS total scores upon admission were symmetrical (skewness = -0.07), the curve was somewhat rounded, indicating a wide spread of scores (kurtosis = -0.53). In contrast, discharge QEHS total scores were negatively skewed (-0.79)

and the distribution clustered more tightly around the mean (kurtosis = 0.13). The distributions indicated that the 28-item QEHS was suitable for parametric statistical analysis.

Reliability and Stability of the Resultant 28-item QEHS

Cronbach's alpha at admission (ά = .94) and discharge (ά = .95) indicated that the items were satisfactorily correlated, measuring a single construct and therefore internally consistent (See Appendices 43 & 44). KMO overall statistic of sampling adequacy at admission (0.92) and discharge (0.93) were well above the accepted minimum of 0.60, indicating that partial correlations are sufficiently small to proceed with factor analysis. Means and standard deviations of the items (Appendices 44 & 47), the Bartlett's test of sphericity of admission QEHS scores (χ^2 = 2919.62, *df* = 378, *p* = 0.000) and discharge QEHS scores (χ^2 = 3532.25, *df* = 378, *p* = 0.000) indicated that distribution and correlations between variables were satisfactory for factor analysis to be performed. Hotelling's T-squared was significant (p = .000) indicating a satisfactory variation of item means at both admission (F = 17.30) and discharge (F = 12.53), which demonstrated that each item assessed different aspects of the measured construct. At admission, Tukey's test of power to which responses must be raised to achieve additivity (1.52) indicated that the QEHS admission total scores approximated a linear relationship. However, at discharge, the power that responses must be raised to achieve additivity was 2.96, reflecting the negative skewness of QEHS total scores at this measurement point and interaction of items.

The correlation (*r*=0.53) between test-retest QEHS total scores (see Table 10.1) indicated satisfactory stability. Instrument stability can be assumed if the correlation between two administrations of the instrument, at different time points, results in a correlation of 0.5 or greater (Brooks (1995).

Face Validity

Acceptance and use of Health Change Process Theory and the QEHS indicated that clinicians perceived the QEHS to be a credible measure of holistic health.

Firstly, the original procedure required that the researcher qualitatively analyse QEHS responses to construct Patient Profiles but clinicians expressed a desire to

undertake profiling. They reported that the QEHS and the Patient Profile enhanced their understanding of patients' health needs and identified patient health needs not assessed by established qualitative and quantitative assessments. Consequently, the researcher altered the procedure so that clinicians could undertake blinded patient profiling. Clinicians wished to improve and standardise this assessment process and, in consultation with the researcher, developed the rules of association and the Patient Profile Form (Figure 10.2 and Appendix 45). This profile identified where the participant was on the Health Change Process Theory and significant Personal Attributes that were either impeding or enabling the individual to move towards a holistic health status.

Secondly, counsellors, occupational therapists and, to a lesser degree, nurses reported that they found the QEHS credible as a therapeutic tool and sought to incorporate it in their practice. Conversely, most physiotherapists and all rheumatologists, while acknowledging the usefulness of the QEHS to aid intervention, felt that it was not a credible tool with respect to their own practice. While supportive of its use in the team environment, they believed that it did not have much to do with their area of speciality, that is, physical health.

Thirdly, clinicians expressed frustration that not all inpatients participated in the study and therefore completed the QEHS. During the study, the researcher became aware that counsellors (and in some instances, occupational therapists), on their own initiative and after initial clinical interviews, were requesting patients to informally complete the QEHS to aid interventions. In these instances, the patient retained their completed QEHS, and responses were discussed only with the therapist who requested the information.

Fourthly, the time involved in profiling was clinically acceptable: Clinicians reported that profiling involved two clinicians for 10-15 minutes independently profiling, discussing their results and consensually agreeing on profile results for each participant. In contrast, time taken for profiling by the researcher was approximately three minutes. Clinicians reported that the resultant profile provided information of relevance to treatment, not attainable by clinical interview, that enhanced therapeutic interactions and facilitated movement (where appropriate) through the Health Change Process in an efficient manner. As a

consequence, clinicians believed that there were consistent patterns of responses that identified what type of coping strategy participants were using and the associated self-attributes. Hence, they concluded that it should be possible to develop formulae of item relationships enabling a suitably trained administrator to undertake profiling.

Finally, the QE Health Professional Advisors' decision to introduce the QEHS as a generic measure from the beginning of 2005 and commitment to ongoing development of profiling and evaluation of treatment using the QEHS suggest that the QEHS possesses clinical face validity.

In contrast, although almost all participants' judgements of the face validity of the QEHS were positive, a few participants raised concerns. Overall, those administering the QEHS and the routine QE Health measures reported that participants questioned the content of the Wellness Scale, the MPQ and the HAQ while perceiving the QEHS as a more relevant and credible measure of health. However, a few participants reported that they felt that the QEHS was not a credible measure of health. Through examination of these participants' Patient Profiles and discussions with clinicians, it was determined that this group were people who had either not experienced trauma (as defined in this thesis), or those who perceived that their health and life would return to the pre-trauma state. In terms of the Health Change Process Theory, they were successfully Action Coping and felt there was no need for holistic change but rather a need for curative and/or functional-based intervention; for them, QEHS items appeared irrelevant to their health needs. The reports of therapists as well as participants' comments written on the QEHS identified the following issues with regard to questions of the face validity of the QEHS.

Items 9, 20 and 21 were controversial. Ten participants were identified as objecting to the word 'unique' in item 9, interpreting this to mean 'special', while a similar number found that the word spiritual was too personal. Some objected to the use of 'God', alternatively, others commended its use but objected to the use of 'nature' and 'the 'universe' in connection with spirituality.

Content Validity

Principal component factor analysis of the 28-item QEHS at admission and discharge identified all items loading highly on the principal component (Appendices 46 & 48).

Varimax rotation of the QEHS admission scores resulted in six highly interrelated factors (Appendix 47). Items for each factor were named as follows. Factor 1, Spiritual Identity/Sense of Coherence (items 11, 12, 13, 14, 15, 18, 20, 21, 22, 25, 27); factor 2, Interdependent Interaction (items 7, 23, 24, 28, 32, 33); factor 3, Transformational Perspective (items 17, 26, 29, 30); factor 4, Open-systems Perspective (items 4, 16, 19); factor 5, Self-worth/Resilient Identity (items 8, 9, 10), and factor 6, Acceptance (item 31).

In contrast, Varimax rotation of the QEHS discharge scores resulted in five interrelated factors (refer Appendix 49). Items within each factor were named as follows. Factor 1, Spiritual Identity/Sense of Coherence (items 22, 23, 24, 25, 26, 27, 28, 30, 31, 32, 33); factor 2, Self-worth/Resilient Identity (items 9, 10, 11, 12, 15, 18); factor 3, Interdependent Interaction (Items 13, 14, 16, 19, 20); factor 4, Open-systems Perspective (items 4, 7, 8); and factor 5, Transformational Perspective (Items 17, 21 & 29).

Correlations of the 28-item QEHS totals and the rotated factors indicated that the measurement of physical function, pain, general wellbeing and social function are included in QEHS measurement (refer Tables 10.2 & 10.3).

Correlations of the 28-item QEHS totals with the other study measures indicated that the QEHS was related to the Wellness Scale, MPQ and QE Model stage at both measurement points, the Get Up & Go and Ward Walk on admission and the performance and satisfaction subscales of the COPM at discharge.

In summary, analyses of correlations between QEHS factors and other study measure totals identified wide-ranging relationships across the physical, social and cognitive dimensions of health (Tables 10.2 & 10.3).

Criterion Validity

The concurrent component of criterion validity was assessed by the relationships between the QEHS and the validated study measures at each of the two measurement times. The size and significance of the correlations (Tables 10.1, 10.2 & 10.3) indicated that the QEHS total scores and QEHS factor total scores measured interrelated with physical, social and cognitive aspects of health.

The degree to which scores changed over time in a predictable manner (predictive validity) was assessed by comparing changes in the QEHS to those of the validated measures of pain, physical and social function over the time of the QE Health interventions. In general, all these predictions were borne out (Table 10.1).

Examination of QEHS factor relationships (Tables 10.2 & 10.3) demonstrate moderate negative correlations between the QEHS and the MPQ pain measure. The MPQ scores decreased (indicating less pain) as the holistic health QEHS scores increased. The positive correlation between the QEHS and Wellness Scale scores also confirmed predicted relationships. Overall, Get Up & Go and QEHS scores were positively correlated, suggesting that greater time to complete the task was associated with higher QEHS scores. Additionally, COPM scores were related as predicted but only at discharge. However, level of function or disability (HAQ scores) were generally unrelated to QEHS scores. Finally, Patient Profile assessment of participant position on the Health Change Process Theory was strongly correlated with QEHS total scores.

Table 10.1: 28-item QEHS total score correlations with total scores of study measures

	QEHS1 Total (admission)	QEHS2 Total: (discharge)
QEHS1 Total (admission)		.53**
QEHS2 Total (discharge)	.53**	
McGill1 (admission)	-.14*	
McGill2 (discharge)		-.17*
Wellness1 (admission)	.28**	.19**
Wellness2 (discharge)	.22**	.42**
Get up & go1 (admission)	.29*	.32**
Ward walk1 (admission)	.25*	
COPMP2 (discharge)		.39**
COPMS2 (discharge)		.44**
Health Change Process Theory Position (admission)	.70**	.42**
Health Change Process Theory Position (discharge)	.42**	.89**

* $p \geq 0.05$
** $p \geq 0.01$

Discriminant Validity

Discriminant validity, the degree that the QEHS measures a construct distinct from other health measures, was assessed by the characteristics of the correlations as well as clinicians' judgment of the QEHS's capacity to provide new information of clinical relevance.

The correlations between study measures (Tables 10.1, 10.2 & 10.3) identified significant relationships between QEHS scores and the other study measures. While correlations were statistically satisfactory, their size indicated that the QEHS assesses a related but distinct health construct compared to the other health measures.

Moreover, increasingly, clinicians were observed to utilise the QEHS and the Patient Profile to assess position of the participants on the Health Change Process Theory; identify barriers to positive health change; facilitate discussion and exploration of intervention strategies; and evaluate the outcome of treatments. Such clinical behaviour indicated that the QEHS possessed discriminant validity. This was supported by the clinicians' decisions to introduce the QEHS as a generic measure for QE Health Rheumatology and Rehabilitation inpatient programmes on completion of the study; discontinue using the Wellness scale and evaluate the continued use of the MIQ and HAQ over the following 12 months.

Construct Validity

The following tests of construct validity were employed: clinician and participant perceived relevance and credibility of the QEHS; clinician evaluated accuracy of the Patient Profiles; and the correlations between the QEHS and other study measures.

Clinical relevance and credibility of the QEHS was clearly demonstrated by the fact that clinicians on the staff of QE Health adopted the Health Change Process Theory as the basic model of practice for the institution. Initiated by QE Health management in consultation with clinical staff, the Health Change Process Theory was introduced during data collection, undergoing a continuing developmental process as the QE Health Model of Practice.

Table 10.2: Admission QEHS Factor Correlation with study measures

	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5	Factor 6
McGill 1	-.17*	-.22**				-.19*
McGill2		-.20*				-.16*
QEHS1	.84**	.80**	.65**	.60**	.61**	.50**
QEHS2	.45**	.39**	.39**	.37**	.30**	.24**
HAQ2			-.18*			
Wellness 1	.25**	.23**	.16*	.21**	.20**	.22**
Wellness 2	.19**	.26**		.20*		.21**
Getup&Go1	.36**		-.39**			.26**
Getup&Go2	.36**		.36**			.31**
Wardwalk1	.27*		.31**		.38**	
6minWalk1			-.31*			
COPMP2		.30*				
Health Change Process Theory Position (admission)	.64**	.60**	.50**	.45**	.47**	.36**
Health Change Process Theory Position (discharge)	.40**	.33**	.33**	.31**	.26**	.17*
Factor1 (admission)		.70**	.60**	.61**	.55**	.47**
Factor2 (admission)			.61**	.51**	.47**	.52**
Factor3 (admission)				.39**	.47**	.42**
Factor4 (admission)					.34**	.36**
Factor 5 (admission)						.23**
Factor1 (discharge)	.47**	.40**	.39**	.33**	.25**	.26**
Factor2 (discharge)	.49**	.33**	.34**	.35**	.39**	.22**
Factor3 (discharge)	.51**	.39**	.36**	.36**	.15*	.25**
Factor4 (discharge)	.34**	.36**	.30**	.41**	.28**	.29**
Factor5 (discharge)	.32**	.22**	.27**		.23**	

* $p \geq 0.05$
** $p \geq 0.01$

Table 10.3: QEHS discharge Factor Correlation with study measures

	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5
McGill2	-.26**	-.18*	-.20*		
HAQ2		-.19*		-.18*	
Wellness 1	.22**	.19*	.16*	.19*	
Wellness 2	.47**	.38**	.33**	.38**	.22**
COPMP2	.42**		.37**	.31*	.26*
COPMS2	.47**	.26*	.45**	.33**	.37**
QE Model 1	.40**	.37**	.40**	.36**	.25**
QE Model 2	.79**	.84**	.70**	.64**	.68**
Health Change Process Theory Position (admission)	.45**	.46**	.48**	.42**	.26**
Health Change Process Theory Position (discharge)	.93**	.87**	.82**	.73**	.74*

* $p \geq 0.05$
** $p \geq 0.01$

Over a six-month period, workshops on the Health Change Process Theory took place. Clinicians reported that the model conceptualised and clarified the decision making, practice and client health goals driving intervention. They identified the model as reflecting the key determinants of health for their clientele, enhancing a client-centred approach and providing a process for clients to play a pivotal role in health change. Moreover, increasing exposure to the QEHS through involvement with participants and use of the Patient Profile resulted in clinician awareness of the applicability of the instrument. This implied that it was a useful tool with regard to implementing the QE Health Model of Practice. This result indicated that the QEHS possessed construct validity as it was judged by clinicians as congruent with the theory (the Health Change Process Theory) that it sought to measure.

As shown above, the QEHS correlated in predicted directions with the other study measures, strongly suggesting that it is a valid measure of holistic health status within the study population. Moreover, Patient Profiles resulting from QEHS use were congruent with clinical judgment. The results of Patient Profiling and testing face, content, concurrent and predictive validity of the QEHS therefore support its construct validity.

Discussion

Reliability and Stability

The accepted norm for test-retest reliability indicating that a scale is acceptably stable is a correlation of 0.5 or greater; the resultant 0.53 correlation is acceptable and indicates that the QEHS possesses satisfactory stability.

Moreover, the high and consistent item-total Cronbach's alpha at both measurement points demonstrated that the QEHS remained internally consistent while each item measured a significantly different aspect of holistic health; indicated by significant Hotelling's T-squared results. Tukey's test showed that the scale was approximately linear and normally distributed at admission but at discharge the distribution altered dramatically. This result was reflected by the skewness and kurtosis identified at the two QEHS measurement points. The wider spread of scores upon admission compared to those at discharge possibly resulted from an initially wider variance of participants' health perspectives and consequent larger variance in item interpretation than at discharge.

Moreover, the assumption of Tukey's test for nonadditivity is that when constructing a scale, the intent is to develop each item so that it measures a distinct and separate aspect of the overall concept that is assessed. Tukey's test assumes that if items measure multiple concepts and in some manner interact then it is possible that simply adding item totals may result in a total score that is meaningless. The results of the Tukey's test in this case indicated that, at discharge, the QEHS items interacted with each other, measuring multiple and interrelated aspects of holistic health.

It was expected that respondents would perceive all aspects of self as highly interrelated, as different expressions of the core spiritual self, if they possessed a holistic worldview. In other words, the QEHS aimed to assess what most scales attempt to avoid. Responses to each item were intended to be conditional upon responses to other items, *if* the respondent possessed a spiritual worldview. The issue that needs to be addressed is whether or not the instrument can be used as a linear scale with individual item responses simply added up to give a meaningful total score. The high correlations between the QEHS total score and Patient Profile score demonstrate that addition of the items provides a meaningful result.

Furthermore, QEHS total score correlations with validated measures, both in this study and the previous one (Chapter 9), also indicate that the scale meets the criteria for additivity. Moreover, the significant difference found between items using the Hotelling's T-squared test indicated that each QEHS item measures a distinct aspect of holistic health.

The difference between QEHS admission and discharge Tukey's test results also indicates that, on average, there has been a fundamental change in participants' worldview over this time. The most likely cause of this is the QE Health intervention. Moreover, the negative skewness of discharge QEHS scores was probably attributable to the effect of the QE Health intervention. The QEHS sought to assess level of holistic health with higher scores indicating higher holistic health. Hence, *if* the QEHS did measure QE Health facilitated change and *if* QE Health interventions were efficacious, it would be expected that the mean of QEHS discharge scores would move towards the maximum possible score, that is, demonstrate strong negative skewness. The results show that it did so.

The test-retest, item-total correlations, predictable skewness, Hotelling's T-squared and Tukey's tests all indicate that the QEHS is a reliable and robust measure and suggest that the intervention tended to facilitate development of a nonmaterial perception of self and health in participants.

Face Validity

The results indicated that although the QEHS possessed clinical face validity, there remained questions as to its face validity for some participants, with a small proportion of participants perceiving the QEHS as not a credible measure of health.

Anecdotal evidence, including participant and clinician comments, suggested that some participants interpreted 'spiritual' as equating to religion, which when combined with negative perceptions and experiences of religion, resulted in an adverse reaction to some items or even to the questionnaire as a whole. Additionally, some viewed spirituality or items concerning 'inner' feelings and thoughts as meaningless with regard to their health. Such a worldview is reflected in the material concepts of self discussed in Chapter 1. A material worldview

assumes that external, observable attributes are the self, and that all else is unimportant. Such a perspective results in a focus on the material, the objective, as the determinant of health status. Consequently, items that focus on the nonmaterial were considered to lack relevance and credibility as a measure of health status.

The thesis view of health, discussed in Chapter Two, presented an expanded view of health, encompassing material aspects, but not limited to them. Consequently, the items of the QEHS focus on the inner, subjective self rather than externally observable function as the primary determinant of health status. This characteristic of the QEHS inherently lessens the face validity of the instrument for those possessing a material worldview. Conversely, it can be argued that conventional health measures, based on a material theoretical foundation, will lack credibility for those people with a nonmaterial worldview.

Within the context of this thesis and its research population, it has been found that healthy coping with chronic physical disabilities requires a view of self as constant and continuous. Wellbeing is threatened if an individual experiences a challenge to self whereby previous physical, social and cognitive perceptions of self are permanently lost. Without a coping strategy, as depicted in the Health Change Process Theory, which enables an individual to continue to change and develop personal attributes, as identified in the Self-Attributes Model, the individual will be unhealthy. Such a view is the perspective adopted by QE Health and therefore it is appropriate that an instrument developed within this health context should measure the degree to which its patients have acquired a holistic coping strategy to healthily manage the challenge of physical disability.

Issues of participant perceived face validity of the QEHS, arising from the results of this study, were discussed with QE Health clinicians. Although the QE Health motto 'enhancing mind, body and spirit' is included in all letterheads between the organisation and patients, clinicians commented that those patients who challenged the relevancy of the QEHS could not recall reading this or did not connect this motto to their particular treatment. As a result, clinicians identified a need for patient information to be reviewed, including website information, mail-outs to patients prior to admission, the content of the education class, particularly

the introductory class, and all other appropriate clinician/patient information sharing interactions. The purpose of such a review would be to ensure that potential patients are clearly informed of QE Health's holistic form of health intervention, which includes acknowledging and providing an opportunity for people to address spiritual issues.

In summary, clinicians judged the QEHS as credible, at least within the context of QE Health's Rheumatology and Rehabilitation inpatient service. However, they also acknowledged that it was ethically necessary that the organisation further clarify and communicate the philosophy and model of practice of QE Health.

Content Validity

The results of factor analysis were in line with those from the preceding two studies (Chapters 8 & 9). The final 28-item QEHS loaded on one principal component and the rotation identified highly interrelated sub concepts, indicating that the QEHS was measuring a predominantly singular, interrelated concept, as one would expect if the instrument was assessing holistic health status. Moreover, the characteristics of the factors that resulted from Varimax rotation were consistent with the concepts of the Self-Attributes Model and the Health Change Process Theory that were developed from the initial thesis study (Chapters 6 & 7). Additionally, the numerous correlations between the QEHS total scores, QEHS factor total scores and total scores of the other study measures, demonstrated that the QEHS encompassed aspects of physical, social and cognitive health.

The nature of the relationships indicated by these correlations demonstrates that, within the context of QE Health, the QEHS enhances clinicians' assessment of health by identifying both an individual's position on the Health Change Process Theory and their associated self attributes. However, it does not measure the details of disease activity and physical and social functioning, and specific measures of these may remain necessary as health assessment tools to enhance treatment decision-making.

The Health Change Process Theory describes the process of health attainment *if* an individual experiences some form of personally traumatic and permanent change. It shows how change can be used as a personal resource for growth.

However, not all change is irreversible or personally devastating and therefore not all change personally traumatic; a threat to self. For example, loss of function of a finger may be traumatic for a violinist but possibly not so for a truck driver.

Results indicated that the QEHS content assesses the effect of dysfunction on overall health, without assuming that specific dysfunctions necessarily result in ill-health. Therefore, the results show that the QEHS possesses sufficient content validity as a measure of current holistic health status and the impact of impairment on the individual; but not of severity of disease or dysfunction. It is a measure of the degree of healthy functioning rather than the magnitude of disease or dysfunction.

Criterion Validity

The correlations between study measures indicated that the QEHS possessed adequate concurrent validity, a finding congruent with the results obtained in the previous study (Chapter 9). This result demonstrated that the QEHS is a valid health measure.

Predictive validity was the main focus of criterion validity testing in this study, as it is a critical issue in clinical practice. Clinicians are required to assess current health status, identify and make interventions intended to improve health status and then evaluate the outcome of these interventions. Central to this clinical process is an understanding of the causes of ill-health and the ability to predict the outcome of interventions. Therefore, it was essential for the QEHS to possess predictive validity for it to be a clinically valid instrument. The correlations found (Tables 10.1, 10.2 & 10.3) show that changes in the QEHS scores reflected predicted changes in the scores of the other study measures. Moreover, the correlations indicated that the QEHS measures a holistic individual perception of health rather than functional status.

These results suggest that, on average, the QE Health intervention was effective at changing participant perception of health from a material worldview to a nonmaterial worldview. This intensive health intervention, designed to facilitate fundamental changes in health perspectives, occurred between the two measurement points.

Consequently, it was expected that overall there would be a positive change between admission and discharge in QEHS total scores. While the study did not directly seek to investigate this, it was decided that a post hoc analysis to identify whether or not there was a significant difference between QEHS admission and discharge total scores would add further support to the validity of the QEHS.

If the QEHS is a measure of holistic health and *if* QE Health interventions are effective then it was predicted that those participants with low total QEHS scores on admission would have high QEHS scores on discharge, indicating significant health change. In contrast, participants possessing a holistic perspective of health on admission were expected to score highly on the QEHS at both admission and discharge. It was unknown what constituted a 'high' or 'low' total score. Therefore, a split-plot ANOVA was employed to compare the upper and lower quartile participant groups of admission QEHS scores with their corresponding discharge scores. Results of this analysis demonstrated that QEHS scores behaved as was predicted (Tables 10.4 & 10.5).

Table 10.4: Admission QEHS first and fourth quartile group descriptive statistics at admission and discharge

	Mean	**SD**	**N**
First quartile admission	82.56	10.66	50
First quartile discharge	121.64	22.31	50
Fourth quartile admission	140.26	9.90	51
Fourth quartile discharge	146.51	11.83	51

Table 10.5: Two factor split-plot ANOVA of admission QEHS first and fourth quartile participant groups at admission and discharge.

Source	**SS**	**MS**	**df**	**F**	**p**
Time (Admission cf discharge)	25945.03	25945.03	1	163.02	.000
Quartile (First quartile cf fourth quartile)	86055.31	86055.31	1	326.28	.000
Time x quartile	13601.94	13601.94	1	85.47	.000
Error Time (admission cf discharge)	15755.68	159.15	99		
Error Quartile (first quartile cf fourth quartile)	26110.59	263.74	99		

These results indicated that the QE Health intervention positively altered holistic health status as predicted, and that the QEHS measured this change provided further evidence of its validity.

Further matters concerning criterion validity which require explanation are the relationships between the QEHS and the COPM, and its relationships with the measures obtained of physical function.

Initially, it was predicted that both admission and discharge scores of the QEHS and COPM would be correlated as they each purport to measure holistic health from similar theoretical perspectives. The results identified correlations only between discharge scores of these two measures. The COPM's intent is to measure patients' difficulties holistically with respect to their wants, needs and expectations across the self-care, productivity and leisure categories. On reflection, while such assessment is client-centred, it cannot be assumed to be holistic. A holistic health perspective is determined by the individual's worldview; not the composition of a questionnaire. At best, a questionnaire will only reflect the respondent's worldview by how they interpret items and subsequently respond. Consequently, holistic assessment of an individual's 'wants, needs and expectations' is determined by the worldview held by the individual. A material perspective of the world, self and health will result in identification of radically different personal values, exhibited as 'wants, needs and expectations', than a nonmaterial perspective.

On admission, participants' perception of the world, their self and health probably reflected the diversity of views within the general population, ranging from material to nonmaterial. Similarly, those referred to the QE Health inpatient programmes reflect the full range of healthiness in their coping strategies. Hence the COPM could not be expected to predict QEHS scores in all participants on admission, but only for those who already had a holistic view of their health.

However, while at QE Health, they were exposed to a spiritually based, holistic concept of health. QE Health intervention aims to challenge materialistic perceptions of self and health and promote the nonmaterial alternative as the strategy to enable attainment of health. Hence, significant, positive correlations

could be expected between the QEHS discharge scores and the COPMP and COPMS discharge scores. In other words, on average, intervention facilitated development of a nonmaterial, holistic perspective with an associated tendency to identify 'wants, needs and expectations' and activities congruent with that perspective, resulting in significant correlation between the COPM and QEHS at discharge.

Overall, the relationships of the QEHS with the Get Up & Go, Ward Walk and HAQ indicated that more time needed to achieve physical tasks (physical mobility) was associated with a holistic perception of health. This result is consistent with the Health Change Process Theory, which argues that it is necessary for a health challenge to be personally significant, irreversible, and traumatic to be a precondition for health change.

The HAQ correlations also suggest a reason why discharge Ward Walk and Six-Minute Walk mobility measures were unrelated to discharge QEHS scores. While the HAQ assesses ability to complete tasks of dressing and grooming, rising, eating, walking, hygiene, reach, grip and activities independently; it does not measure time taken to complete these tasks. If a person has a high QEHS score, indicating a spiritual identity, lack of mobility will tend to affect physical function less as the individual will be motivated to explore creatively and to identify ways to continue to carry out functions of personal value; even if it takes some time to complete such tasks. Completion of tasks probably has more to do with self-belief, level of motivation and personal meaning of behaviours than with physical ability.

All the results outlined above support the criterion validity of the QEHS as it meets necessary conditions of concurrent and predictive validity.

Discriminant Validity

The results clearly show that the QEHS possesses discriminant validity. Arguably, the most noteworthy evidence of this was the response of clinicians to the introduction of the QEHS. The accelerated pace of clinical development that accompanied the introduction of the QEHS suggests that the addition of the measure impacted on assessment and evaluation of practice in a manner radically

different from the information derived from the established generic measures. The QEHS became a catalyst for clinical development, which would not have occurred if clinicians did not perceive it as a valid instrument that, in some way, measured health and informed practice differently from the established measures. Finally, the planned introduction of the QEHS as a generic assessment tool within the study population at the conclusion of the study strongly suggests that, from a clinical and organisational perspective, the QEHS possesses discriminant validity.

Construct Validity

Brooks (1995) identifies construct validity as the critical validity criterion for assessing clinical validity of a measure. Construct validity is typically evaluated by comparison of the investigated measure with available instruments that measure similar concepts. Existing holistic health measures encompassing spirituality, reviewed in Chapter Eight, conflict with the concept of health on which the QEHS was based. Consequently, no quantitative instruments were identified with which to compare the QEHS. As a result the concept of 'available instruments' was widened to include the subjective evaluations of clinicians. The intent of the QEHS was not to measure the spiritual, physical, social or cognitive aspects of health as separate, distinct entities but rather the overall health status of the individual. Construct validity was assessed, in the first instance, by the relationship of the QEHS with other measures and clinicians' judgments of the degree to which the QEHS accurately assessed the whole person. However, in essence, construct validity was identified by the degree that the QEHS met the requirements of the other validity criteria already discussed but with particular emphasis paid to the results of patient profiling and correlations between study measures. Instances of the construct validity of the QEHS are outlined below.

The relationships of the QEHS to the measures of pain (MPQ) and overall wellness (Wellness Scale) were as predicted (Tables 10.1, 10.2 & 10.3). Perception and experience of self as constant and continuous (Allport, 1961), with a spiritual core (Jung, 1961) and productively contributing to society (Fromm, 1968) were predicted to result in evaluation of personal pain and dysfunction as of less importance and, to some degree, unrelated to wellbeing and consequent health status. In fact, the experience of pain or any personal dysfunction has been

proposed as the change catalyst enabling acknowledgement and growth of awareness of the core of self, the nonmaterial. Moreover, as represented by May (1981), Rogers 1961), Durie (1997), Pere (1997) and Zohar and Marshall (2001) and discussed in Chapter 1, the nonmaterial, inclusive person views all material characteristics of the world, including physical dysfunction, as resources for self-expression as opposed to barriers to being a constant and continuous complete self.

Consequently, seemingly contradictory results found in this study can be explained. For example, the positive correlation between Get Up & Go scores and the QEHS indicated that as physical dysfunction increased, so did holistic health. The Health Change Process Theory assumes that there is no authentic change, and therefore growth, without meaningful loss of former function, which challenges previous self perceptions and behaviours. This conclusion is supported by the moderate-to-strong negative correlation between admission QEHS Factor 3 (Transformation Coping) and admission Get Up & Go scores. Comparison of correlations at admission and discharge suggest that, in the long term, a holistic worldview correlates with physical function if not physical mobility.

As previously discussed, no relationship was found between the COPM subscales and the QEHS at admission but high correlations were evident at discharge. The COPM is based on a spiritual model which is congruent with that forwarded in this thesis but, in reality, it measures objective functioning. It has already been proposed that the lack of relationship at admission reflected the general tendency at this measurement point for participants to possess a material worldview, in conflict with what the COPM assumes it assesses as well as that which the QEHS measures. In contrast, the correlation of discharge scores may indicate that, on average, participants have acquired a nonmaterial orientated worldview and their responses to the COPM have altered accordingly.

Furthermore, consensus between the Patient Profile and clinician assessment of participants' health status, in terms of the Health Change Process Theory, was demonstrated. Within the clinical context of QE Health, the predominant measure of clients' holistic health status prior to the commencement of the study was the clinicians' subjective assessment. Therefore, the most valid 'available instrument'

for assessing QEHS construct validity was these judgments. The results obtained indicate that the QEHS possesses high construct validity.

Limitations

Demographic differences between the sample and the research population showed that a significantly greater proportion of females, beneficiaries under-65, those in professional occupations and those with chronic pain syndromes participated in the study. While there were significant differences between the sample and the population on these demographics, the majority of the characteristics of the sample were similar to those of the population. Moreover, the theory of this thesis contends that the critical determiner of health outcome is the status of the person as a whole rather than demographic or disease characteristics. Moreover, the theory posits that it is the worldview and related coping strategies that ultimately determine holistic health outcome, not environment or dysfunction. In fact thesis theory contends that the experience of personally adverse events provides an opportunity rather than is a barrier to holistic health attainment. The findings of all four thesis studies, which involved a wide variety of demographics such as disease type, supported such an assertion. The effect of demographic differences on the generalisability of the results to the research population is probably minimal although only further research that investigates the relationship between demographic variables and holistic health status will resolve this issue.

Within the limitations of the generalisability of the findings, participant perceived validity of the QEHS remains an issue. As discussed previously, a small proportion of participants found the instrument irrelevant to their health and believed the majority of items were meaningless, too personal and therefore lacking face validity. However, the majority voiced the opposing opinion; they believed the QEHS was extremely meaningful while challenging the credibility of the existing validated generic QE Health measures. For example, assessing pain levels (MPQ) was viewed as pointless as their pain constantly changed. Likewise, measuring distance walked (HAQ) or time taken to do so (Get Up & Go, Six Minute Walk) only served to remind them of their limitations rather than how well they were. While functional assessments are essential for deciding treatment strategies, the majority of participants were of the opinion that these were not fundamental to their health status.

While divergent participant opinion of the face validity of the QEHS may be an inherent characteristic of the scale, it may not be solvable as which health measures are perceived as credible depends on the respondents' view of self and health. The results demonstrate that those with a strongly materialistic worldview tended to find objective scales more acceptable than the QEHS while those with a nonmaterial worldview held the opposing view.

Conclusion

Overall, the results indicated that the QEHS possessed satisfactory reliability with changes in score distribution explained by the effects of intervention rather than scale instability. Clinician-perceived face validity was clearly demonstrated but there remain some concerns with regard to the patient perspective. The content was shown to encompass a structure, concepts and relationships to other measures which support its validity, as do the results of criterion and discriminant validity testing.

Despite these limitations, evidence presented demonstrated that the QEHS is a reliable and clinically valid measure of holistic health within the QE Health Rheumatology and Rehabilitation inpatient population.

The following chapter discusses the whole thesis, relating its findings to its aims and to other relevant literature, evaluating the theory derived, and suggesting further research in this area.

PART 6: HEALTH AND THE SPIRITUAL SELF

Chapter 11: Implications and Conclusions

CHAPTER 11: IMPLICATIONS AND CONCLUSIONS

In this chapter, the overall thesis goal and associated aims are restated and how each of these was achieved is outlined. The implications of the results are then discussed with respect to theories of self, the Spiritual Theory of Self, Health Change Process Theory and the QEHS. The limitations of the research are outlined, possible future research explored, the scientific and social implications discussed and, finally, conclusions are presented.

The overall goal was to investigate the nature of the healthy human self and the process of achieving health. To achieve this goal, the following sequential aims were addressed.

The first aim was to review and analyse what others had identified as the nature of a healthy self and how this was achieved. Chapter One reviewed the reasoning of the major self-theorists with regard to these issues and Chapter Two critically examined these, and a Spiritual Theory of Self was posited in Chapter Three, which drew the findings of these theorists into a cohesive concept.

The second aim was to test and refine the characteristics of a healthy self by investigating the robustness of the Spiritual Theory of Self when applied to those dealing with a chronic physical impairment. Using the HSD Study data (Chapter 6) and the findings from the self-theorists reviewed in Chapter One, the predicted characteristics of a healthy self were confirmed by the Self-Attributes Model, which supported the robustness of the Spiritual Theory of Self.

The third aim was to develop a theory that explains the process by which people become healthy and predicts how this happens. The HSD Study findings and the critique of relevant literature presented in Chapter Seven achieved this aim with the development of the Health Change Process Theory.

The fourth was to use the Health Change Process Theory to derive factors and develop measures of these factors in order to discriminate a sustainable healthy self from others. The second study, the SIQS Study (Chapter 8) identified factors and then developed two holistic health measures based on these factors.

The fifth aim, addressed in the HAS Study (Chapter 9), was to test the measures developed in the previous SIQS Study for reliability and validity. Reliability was tested statistically, and validity was tested predominantly by using the theory to predict differences in health which the scales should discriminate, and testing whether they succeeded in doing so.

The sixth aim was to test the clinical applicability of the Health Change Process Theory and associated measure for use by health professionals in assisting a person dealing with disability to establish and maintain a healthy self. The QEHS Study (Chapter 10) applied the model, theory and measure to a population dealing with physical disability.

Aim One: To review and analyse what others had identified as the nature of a healthy self and how this was achieved.

A systematic review of theories of self was carried out, categorised according to the assumptions concerning the composition or nature of self (Chapter 1). The three distinct self-theory categories presented were the material, the transitional and the nonmaterial. Theorists' findings were then examined to identify how each theory might innovatively contribute to understanding the nature of self (Chapter 2). The aim was achieved by the development of the Spiritual Theory of Self, which proposed that the nonmaterial is the basis of self (Chapter 3). Health was posited as being achieved when the material physical, social and cognitive aspects of self are recognised as fluctuating and finite and understood as being expressions of the constant and continuous nonmaterial core.

Aim Two: To test and refine the characteristics of a healthy self by investigating the robustness of the Spiritual Theory of Self when applied to those dealing with a chronic physical impairment.

The first thesis study (the HSD Study, Chapter 6) defined the characteristics of a healthy self for those dealing with a chronic physical impairment. Specifically, it investigated how a person can have a healthy self when they have a chronically impaired body, the nature of self and the characteristics of a healthy self. The HSD Study identified the characteristics of a healthy self, resulting in the Self-Attributes Model, which supported the robustness of the Spiritual Theory of Self.

The Spiritual Theory of Self, developed in Chapter Three, posits that for a person to be healthy, the essence of the self needs to be perceived as spiritual. When healthy, the essential self is expressed through the self's physical, cognitive, emotional and social dimensions.

Self-attributes such as reflection, self-perspective, positive attitude, and locus of control impact upon and are affected by the attributes of strength of identity, pain perception, self-worth and acceptance of self and one's reality. The nature of the dynamic interaction between these self-attributes (see Table 8.6, Figures 8.3 & 8.4) indicated that for people to achieve health there is a need to acknowledge that health is subjective and holistic. Health is not so much the level of functioning of the objective aspects of self. Rather, the degree to which individuals perceive themselves as valuable, integrated and functioning components of a greater whole, which results in the full self. Participants did not perceive pain, disease, life or their self as distinct physical, social or cognitive components but rather as a whole greater than the objective self. The whole was greater than a sum of its parts. For example, pain was reported as not simply the result of physical disease or dysfunction but an interaction between physical stimuli and past and present social, psychological and spiritual painful experiences; pain was either magnified or reduced by the characteristics of the whole self and its connection to or separation from its community. Loss of a sense of completeness of self was perceived as associated with unbearable pain while perception of self as integrated into the greater whole resulted in pain becoming bearable.

Health is a subjective experience, centred on the nature of intra-self, inter-self and self-world relationships. These relationships determine whether the individual possesses a predominantly brittle or resilient identity. Perception of 'I' as resilient (constant and continuing) requires the expression of 'I' through interdependent interactions; the perception of self as meaningfully related and connected to a greater whole. While a resilient 'I' involves engagement with a wider system, it also requires disengagement to reflect and explore whether or not relationships, attitudes and activities 'fit' or are congruent with the core self. When healthy, self is viewed as unique and responsible for identifying personally meaningful and unique roles, place and purpose as part of the wider system. The results all point

to the conclusion that identity, the intangible 'I,' is the key determiner of holistic health.

'I' was found not to be limited to the confines of the human body or its tangible interactions but rather was creatively expressed through these. The 'I' encompassed connection to and interactions with that which cannot be directly observed. This connection included acquiring knowledge by nonverbal communication, premonitions and sourcing sustenance from communion with the spiritual realm. It required the capacity to acknowledge and experience the commonality of self and all life forms while nurturing the uniqueness of self in a manner that is collaborative rather than competitive.

Wellbeing or health was perceived by participants as resulting from identification of how to express the 'I' as a contributor to and a component of the wider system. Developing a meaningful self that is a valuable, contributing component of the whole, as opposed to being the whole, resulted in a resilient identity and the sustained experience of being healthy because of, rather than in spite of, ongoing disease or dysfunction.

The 'I' found central to health in this study was congruent with the definition of spirituality in Chapter Three. Spirituality focuses on the intangible nature of relationships that are intensely meaningful to self, which provide understanding of one's place, purpose, roles and unique essence culminating in clarity of personal values and beliefs. This definition is based on the assumption that there is a spiritual realm of existence that is the creative basis of all life. Spirituality, as experienced by the individual, is personal relationships and connections with the spiritual realm, either directly or through relationships with self, others, animals and nature; resulting in a sense of oneness and connection with the world. Experience of such relationships and connection provides access to a meaningful wider, open-systems comprehension of self and the world and perception of self as constant and continuous that culminates in the development of individual values and clear personal principles which guide perception, thinking and behaviour.

Aim 3: To develop a theory that explains the process by which people achieve sustainable health and predicts how this happens.

The HSD Study demonstrated that development of the spiritual essence of self was fundamental to achieving health. Moreover, the data indicated that a process of transformation from a view of self as material to perception of self as nonmaterial was required to achieve holistic health. The findings of post-traumatic growth research (e.g., Tedeschi& Calhoun, 1995) provided the basic structure for interpreting the data from the HSD Study and resulted in the construction of a Health Change Process Theory.

In summary, the key finding of the HSD Study was that being healthy with dysfunction was the product of a spiritually based process. Disease and dysfunction was found to be a catalyst for the achievement of health rather than a barrier to health. Moreover, it was found that there were particular self-attributes and perceptions that determined holistic health status. Those participants who identified their selves as healthy reported radical changes in the nature of these attributes. The HSD Study results indicated that individual personal attributes determined by the characteristics of the spiritual core of the person were the prime determiner of holistic health status. Therefore, the study provided support for a spiritually based concept of self and health and identified the personal attributes necessary for the development of a theoretical foundation, termed the Health Change Process Theory, on which to base a holistic health measure incorporating spirituality.

Aim Four: To use Health Change Process Theory to derive factors and develop measures of those factors in order to be able to discriminate sustainable healthy self from others.

This aim was achieved by undertaking the SIQS Study (Chapter 8), which employed participants who identified spirituality as important to health. They were asked to generate statements of the factors they believed were critical for achieving health. These were then quantitatively analysed to investigate whether they were congruent with the Self-Attributes Model and then formed the basis of the two holistic health measures. It was predicted that these statements would be congruent with those depicted in the Self-Attributes Model and would be congruent with the Spiritual Theory of Self.

Comparison of the factors with Self-Attributes Model categories demonstrated matching concepts, except for the Intervention category. However, subsequent data collection and analysis found the majority of the Intervention statements to be unrelated to the other items and they were removed from the developing questionnaire. The remaining Intervention statements were readily incorporated in other existing categories.

The results met the study aim of developing a holistic health measure consisting of items derived from the health statements of people with physical disabilities, which were congruent with the Health Change Process Theory. However, the developed measure (the HAS) was an attitude scale and could not be assumed to assess actual behaviour. Consequently, an intent subscale was added to the HAS and a second behaviourally-orientated questionnaire, the QE Health Scale (QEHS), was constructed from the HAS items.

Aim Five: To test the measures developed in the previous SIQS Study for reliability and validity.

Reliability was tested statistically, and validity predominantly by using the theory to predict differences in health which the scales should discriminate, and testing whether they succeeded in doing so.

Analysis of item-total correlations and Cronbach's alpha showed that both the HAS and the QEHS possessed high internal consistency.

Anxiety and coping are key constructs of the Health Change Process Theory. Spiritual theory reasons that high anxiety is an indicator of loss of constancy and continuity of self and the perception that self is threatened with non-being (existence without meaning) rather than simply loss of physical function. Therefore, those with a spiritual identity would accept pain and functional loss as part of the life experience rather than perceiving that such experiences threaten the existence of self. Hence, it was predicted that high HAS and QEHS scores would be correlated with low scores on a validated measure of anxiety.

A second key construct of the Health Change Process Theory is coping strategies. In essence, coping strategies are the behaviours that result from the individual's assumption with regard to the fundamental thesis questions. That is, what is self

(self-composition), what can self control (self-agency) and what is a healthy self? Therefore, they reflect the individual's worldview and the degree to which they perceive life as meaningful, comprehensible and manageable. Based on the thesis argument with respect to the characteristics of self and the self-attributes found to be congruent with a healthy self in the HSD Study, it was predicted that those with high HAS and QEHS scores would perceive life as comprehensible, meaningful and manageable and therefore these high scores would be correlated with high SOC-13 scores.

The results demonstrated that the QEHS was significantly correlated with the validated measures of anxiety and coping but that the HAS was not. Consequently, the HAS was not considered for further investigation. Furthermore, factor analysis of the QEHS identified structural properties similar to the findings in the previous SIQS Study, meeting the criteria of a holistic health measure. Therefore, the QEHS warranted full reliability and validity testing in a clinical setting.

Aim Six: To test the clinical applicability of the developed model, theory and measure for use by the health professional in assisting a person dealing with physical disability to establish and sustain a healthy self.
This aim was achieved by applying the Health Change Process Theory and the QEHS measure to a population dealing with physical disability in the QEHS Study (Chapter 10).

The Health Change Process Theory predicted that it is the state of the person as a whole that determines overall wellbeing; not the degree of disease or physical dysfunction. Therefore, as with previous studies, a wide range of physical diseases were included in the sample and the theory predicted that the critical determinant of health status was the state of the person as a whole rather than the disease. Consequently, as this theory was developed from the same participant population as the measure, testing the validity of the QEHS tested the validity of the Health Change Process Theory and, indirectly, the underlying Self-Attributes and Spiritual models.

The results supported previous findings and demonstrated that the QEHS was a reliable, valid and readily applicable measure of holistic health. The QEHS complemented existing assessment and enhanced clinical decision making, therapeutic intervention and client-centred practice within the research population. Additionally, the scale's relationships with therapists' judgements and its correlations with measures of physical mobility and function, overall wellbeing, occupation and pain were congruent with the Spiritual Theory of Self, the Self-Attributes Model and Health Change Process Theory. These results therefore supported the QEHS as a valid measure and also the theoretical predictions concerning the nature of self, health and achievement of health upon which it was based.

Overall Research Goal: To investigate the nature of the healthy human self and the process of achieving health.

The goal was achieved through the specific aims discussed above. Specifically, the review and critique in Chapters One and Two presented a sound rationale for postulating that the essential nature of the healthy self is spiritual. Therefore, it was argued that the process of achieving health needs to focus on developing the spiritual self (Chapter 3). The subsequent HSD resulted in the construction of the Health Change Process Theory and, along with the SIQS studies supported the predictions formulated in Chapter Three. The consequent development of the QEHS provided a quantitative instrument to not only enable achievement of the thesis goal but also to facilitate wider investigations of the nature of the healthy self and the process of achieving health.

Relationship of the Results to Theories of Self

The results of the research showed that the Spiritual Theory of Self was a robust and valid explanation of the nature of self that is compatible with a healthy self. Self as a stable spiritual entity and viewing the associated material aspects of self as a fluid medium for expression of this nonmaterial self provides an explanation of how people remain healthy despite significant loss and change to the extrinsic components of self.

Material views of self assume that when the individual is strong, competent and independent, manifested by the ability to survive and master their world, then

such individuals will be healthy. Transitional self-theorists present a similar view of self, although they tend to explain such behaviour as culminating in the construction of an intrinsic sense of self. However, the essential determinants of health status are assumed to be the same as that of the materialist; to compete with the world, extracting beneficial resources that enhance survival and in doing so, achieve mastery over the world of self. Both groups of theorists generally assume that the primary requirement for self to be healthy is the development of a powerful, competent ego self. That is, the healthy self is separate from the world, independent and in control of the physical, social and cognitive self and its environment. Consequently, any connection with the world, including healthcare, is with the intent of extracting resources that benefit the ego-self. Enrichment of the wider system is only one possible by-product of development of the ego-self.

In contrast, nonmaterial self-theory is based on the assumption that self can only meaningfully exist as part of the greater whole. Self in isolation and without a primary focus on contributing to the whole is non-being and results in ill-health. The distinct ego-orientated component of self is viewed as created to fulfil the purpose of the whole. The central purpose of an individual's life is to examine self potential, explore and experiment how this may contribute to the whole and, in doing so, discover and develop their constant and continuous place, roles and purpose as a component of that whole.

In essence, the nonmaterial view is that the healthy self is striving to be egoless as a component of and inherently interconnected with the greater whole while the materialist view is that self is a servant of the ego, which must strive to master the greater whole.

Material and nonmaterial self-theorists' perspectives reflect the two opposing horns of the metaphysical dilemma, 'What is life?' and 'What is a healthy human being?' As both arguments are based on *a priori* assumptions of truth, each is equally defensible and refutable; science cannot test *a priori* truths such as whether or not a spiritual realm exists. Science can only test the subsequent predictions based on either worldview.

To date, the majority of psychological enquiry has focused on the materialist view and the nonmaterial horn of the dilemma has largely been ignored by the scientific community. Arguably, the two main points of contention limiting scientific investigation of spirituality are that it provides an unnecessarily complex explanation of the nature of self and secondly, as the nonmaterial is subjective, it is not an appropriate focus for scientific investigation.

While it may be argued that the material worldview provides a simpler, parsimonious and comprehensive explanation of human thought and behaviour, the review and discussion of self theories in Chapters One, Two and Three; the findings of the HSD study; and the review of related literature in Chapter Seven suggests that material explanations of self and health do not fully explain the reality of human experience. Moreover, the material theories tend to be fragmentary, each theory competing as a complete explanation for human thought and behaviour. In contrast, nonmaterial theory is inclusive and offers an explanation that encompasses all theory. The seemingly contradictory material/nonmaterial views of self are merged into a harmonious whole.

For example, spiritual theory claims that the core, essential self, sufficient for health is spiritual and its subsequent expression through interactive thought and action results in a whole, healthy self. Maslow's (1973) theory of a hierarchy of needs can be explained from this perspective. From this perspective, Maslow's self-actualisation is the starting point rather than the end result of self-development. Experiences of spiritual connection allow aesthetic needs to be met and cognitive needs are provided with structure, personally meaningful purpose and clarity. Consequently competency and sense of coherence-type esteem needs are evaluated in context of self being part of a system that the individual does not control while attachment needs are primarily satisfied by ensuring spiritual connection. Finally, as the individual views the essence of self as constant, continuous and indestructible, safety needs are also met through spiritual connection.

The people Maslow (1973) derived data from in developing his theory were those deemed to be successful within the Western social system. In Western capitalistic society success is perceived of as inherently including the trappings of material

wealth, which enable the individual to ensure the lower levels of the hierarchy of needs are automatically met. Maslow assumed that these 'needs' must be satisfied before higher needs can be met. But a cursory examination of other cultures and the experiences of a wide range of prominent religious/mystical figures suggest that Maslow's assumption may have not been correct. Peak experiences of wholeness commonly result from the removal of even basic needs such as food, rest, security and freedom from fear. Deprivation, at least short term, of those objective aspects of self we often assume as essential to health seem to provide an opportunity for experience and cognitive clarity of what the essential whole self is.

Maslow (1973) asserts that spiritual experiences are the end product of human development *if* all the preceding human 'needs' are first met. However, research indicates and mystics report that the necessary precursor for experiencing the spiritual and the self as whole is threat of removal or even removal of these 'needs' (Newberg, D'Aquili & Rause, 2002). In essence, within the spiritual perspective, Maslow's hierarchy of needs remains a credible explanation of human development if the pyramid of needs is flipped upside down. Needs are limited to peak experiences and the other levels are viewed as human desires rather than essential needs for health.

Spiritual theory concerns whether self-composition is primarily material or nonmaterial. Material theory argues that the primary determiner of the composition of self is the biological composition of the individual which is determined by inherited genetic characteristics. Any subsequent 'unique' individual identity is in fact the result of interaction of the material self with its environment, which results in reinforcement and the associated learning of what self is.

In contrast, spiritual theory acknowledges genetic make-up but adds a second element, spiritual composition, contending that the individual has the choice to construct self with a focus on material needs of mastery and control of its world or on the spiritually based intrinsic needs of connection, meaning, purpose, transcendence and wholeness.

Therefore, a person with a spiritual worldview who experiences material loss of self will primarily perceive such an event as an opportunity for transformative growth of self. The thesis results suggest that living well with chronic physical impairment requires such a view of self and adverse events.

Such an inviolable perception of self reduces anxiety and results in the perception of life as manageable, comprehensible and meaningful as found in the HAS Study (Chapter 9). Self is perceived as constant and continuous (Allport, 1961); valuable and meaningful (May, 1961); a productive contributor to the greater whole (Fromm, 1968); and with core, unique values (Bandura, 1986). Consequently, health is a subjective, individually-determined experience requiring the individual to possess a resilient core identity (Durie, 1997; Pere, 1997; Rogers, 1961; Zohar & Marshall, 2001). The concepts of these theorists and the others reviewed are encapsulated and interpreted in the perspective of the Spiritual Theory of Self, which provides a robust explanation that addresses the questions:

1. What are people composed of? Are observable body, brain and relationships all that self is? Are 'mind', 'I' and other subjective phenomena real or illusionary components of self?
2. To what degree are we active or passive agents? Are we in control of our lives, determining our destiny and health?
3. What is a healthy person?

Self-composition

The research findings demonstrate that for self to be resilient, its nature needs to be perceived as comprised of a nonmaterial core and that the existence and ever-changing characteristics of the material self provide the impetus for growth and development of this spiritual core. For those with optimal health, the material and nonmaterial aspects of self form a cohesive, congruent whole integrated with the wider system.

Self-agency

Self-agency encompasses Bandura's (1986) concept of reciprocal determinism in that our actions contribute to the nature of the environment but also the environment contributes to the nature of self. However, spiritual theory posits that the way in which the environment contributes to the nature of self differs

markedly to Bandura's contentions. If the individual denies the existence of the spiritual self, the environment determines the nature of self but if the individual perceives the authentic self to be spiritual then the environment will be viewed as a medium, an opportunity, to develop awareness and knowledge of self so that the innate spiritual nature of self is expanded and enhanced.

Participants found that they could not necessarily control or predict the type or course of disease, their physical appearance or others' attitudes and reactions to their impairment, but they could control the meaning they placed on such experiences. They could not control the events they faced in life but could control their interpretation of such events and therefore their consequent behaviours and experiences. In turn, how the individual behaved impacted not only on their physical and social environment but also on perception of the physical, social and cognitive nature of the self.

Self may impact on the environment but participants found that the individual can seldom predict and control the outcome of such interactions. For example, because we love somebody and behave accordingly, we cannot predict how the other might react. Not only social aspects (e.g., socioeconomic level, ethnicity and culture) of self were found to be outside the realm of total control of self but also cognitive (e.g., the stressors encountered, level of intelligence and education) and physical aspects (e.g., presence of disease, impairments) were similarly unpredictable.

Findings supported the contention that the nonmaterial core of self is innate, derived from the spiritual realm and not seen by the individual as created by themselves. Consequently, the nature of the essence of self is also beyond the bounds of individual control. Therefore, there are two potentially opposing forces determining the nature of self: the predetermined nonmaterial core or the material aspects of self.

Hence active self-agency is primarily concerned with the choice of which worldview and composition of self the individual chooses to adhere to.
If the self is viewed as material it will be assumed that the purpose of human existence is to construct a strong, competent and independent self to survive and

master its environment. As a consequence of this worldview, the individual is required to compete to extract resources from its environment and to defend self from environmental threats. The self is required to control that which is outside its realm of control. Therefore, the individual is a reactive agent in the construction of self who responds to rather than initiates self-change.

The alternative nonmaterial view of self contends that the purpose of human existence is to know infinite self through connection with the nonmaterial source of all things and by doing so, discover roles and the place of self within the universal system that allows the unique spiritual core of self to be fully expressed. The core of self is constant and everlasting. As a consequence of this worldview, the individual possesses limited self-agency. The individual can acknowledge and claim their spiritual core and take responsibility to ensure thoughts and behaviours are congruent with this or deny its existence and chose to view self as material, reacting to environmental variables. As the nonmaterial self is indestructible, environmental challenges or personal adversity are not perceived as threats but as opportunities for expression and growth of self. Consequently, the individual is an active agent in the construction of self and health, determining whether self is proactively authentic or passively reactive to changing circumstances.

Healthy Self

Possessing a material or nonmaterial worldview establishes the individual's view of self-composition, and that, in turn, determines their assumptions of self-agency. Together, these then result in the self-attributes that determine holistic health status.

The thesis results, encapsulated in the Health Change Process Theory, demonstrate that if an individual possesses a material view of self-composition, they will define self as complete and healthy if the material aspects of self are perceived as complete and continuous. Completeness will require that the physical, social and cognitive characteristics of self to be unchanged or constant. Changes to these aspects of self will be viewed as threats to self that need to be regained to enable self to be constant and continuous. Therefore, the individual will assume that self-mastery or unequivocal active self-agency (control) of events

encountered and outcomes of such events is fundamental to the achievement of health; a competent self will be the master of their life.

However, when faced with loss of assumed mastery, such as the onset of significant chronic physical impairment, such assumptions about the nature of self-agency are no longer tenable. The thesis results clearly show that such a material view of self results in a decline in health status as the individual attempts to master the unconquerable reality of physical loss, which results in diminished self-worth and increased chronic anxiety.

In contrast, the findings demonstrated that those possessing a nonmaterial worldview perceived self to be composed of an innate spiritual core that was constant and continuous, irrespective of the changing nature of the material aspects of self or environmental challenges. The locus of control or active agency was not the external world or material components of self but rather ensuring that the actions and thoughts of self were an authentic reflection of the spiritual core. Self-agency was primarily concerned with 'being' rather than 'doing'. Consequently, a positive health state was experienced when there was congruency between the nonmaterial and material aspects of self and the individual identified ways to creatively express this core self through their thoughts and actions. Change and loss of material aspects of self were then not primarily viewed as loss of health but rather an opportunity for greater health.

The Spiritual Theory of Self

The central tenet of the Spiritual Theory of Self is that for a person to be healthy, the spiritual core or 'I' of self needs to be perceived as constant and continuous. This thesis argues that the core of self is spiritual. This requires that physical, social and cognitive thoughts and behaviours match the unique values of the innate spiritual core of self for a person to be healthy. They need to be an expression of self, rather than the self.

Hence, the theory predicted, and the thesis results supported the predictions, that to be healthy, people need to acknowledge and accept seven key realities of human existence.

1. Change is a universal human condition. Change involves loss, including loss of former function, roles, relationships, knowledge and appearance. However, change also encompasses an inherent potential for gain and growth in such aspects of self.
2. We cannot predict or control the timing, the probability or the nature and magnitude of threats to self.
3. Experience of authentic challenge to self enables people to undergo transformational change.
4. Self will be defined by the outer dimensions, which are beyond the realm of individual control, unless self is acknowledged as essentially spiritual.
5. The very existence of self will be perceived to be at risk, resulting in heightened, prolonged anxiety and ill-health, if self is defined by the outer self dimensions.
6. The determinant of holistic health status is the individual's perception of self and their world.
7. Therefore, the individual is primarily responsible for their health by confronting change, creatively problem-solving to ensure that the core of self continues to develop and be expressed as a contributing valued member of the greater whole. This is achieved by the continually dynamic changing of physical, social and cognitive realities manifested by changes in attitudes, behaviours and thought.

Within the Spiritual Theory of Self, level of anxiety (but not necessarily emotional distress) is a direct indicator of the degree an individual perceives self as at risk of non-being; this may be termed spiritual distress. Prolonged, high anxiety is exhibited as chronic stress. The interrelationship of stress, social support and physical health is well documented.

For example, meaningful relationships with others and our interpretations and perceptions of experience are all factors that influence stress levels (Lazarus & Folkman, 1984; Oulette-Kobasa, 1983; Scheier & Carver, 1988). Moreover, strong relationships exist between the level and duration of stress and the prevalence of illnesses such as cancer, cardiovascular diseases, chronic pain and fatigue syndromes, asthma, diabetes and some forms of arthritis (Cohen &

Williamson, 1991; Frese, 1985; Jemmott & Magloire, 1988; Moss, Moss & Peterson, 1989; Taylor, 1991).

Consequently, anxiety originating from experience and belief that one is incomplete, brittle, threatened with loss of the constancy and continuity of self (non-being) was found to be related to prolonged and high levels of stress, which, in turn, are related to reductions in physical, social and cognitive function and holistic health status.

The Health Change Process Theory

Spiritual Theory of Self was the core concept of the Health Change Process Theory, which provided the conceptual foundation to address the thesis goal of investigating the nature of the healthy human self and the process of achieving health.

While a physical impairment may trigger the anxiety-stress cycle, it cannot be assumed to be the cause. Both Spiritual Theory of Self and the Self-Attributes Model assert that people experience life holistically rather than as separate physical, social, cognitive and spiritual components. For example, the HSD Study found that experiences of physical, emotional or spiritual pain, whether past or present, are related. Pain is simply pain; it is experienced and perceived as an interrelated whole that is greater than a sum of the parts. Experience gained from a lengthy period of rheumatology practice and research has led Wolfe (1999) to conclude that 'What the patient brings to the illness appears to be more important than the illness itself' (p.132). He identifies the critical role that personal characteristics, congruent with the Self-Attributes Model, play in determining holistic health status as well as the existence and severity of disability.

In conclusion, the research results and related research all indicate that it is the person that determines holistic health status, rather than the nature or severity of the disease process. Moreover, the experience of disease and dysfunction appears to provide an opportunity for increased health rather than necessarily being a threat to health.

The Spiritual Theory of Self and the results of the HSD Study lead to the development of the Health Change Process Theory and, in turn, the QEHS that quantified individual position on the Model and associated Self-Attributes. The studies that developed and validated the QEHS also provided data that demonstrated this theory to be robust. Consequently, the Health Change Process Theory has been shown to be useful as:

1. A theoretical basis for the development of a holistic measure of health.
2. A theoretical basis for scientific investigation of the experience of chronic conditions.
3. The basis for the evaluation of chronic healthcare delivery.
4. An educational tool for people with disabilities and healthcare professionals.
5. A therapeutic tool to increase holistic health and to aid chronic healthcare interventions.
6. A theory that conceptually draws together findings on the topic of achieving health for those who have experienced a life-changing trauma.

The first two uses of the Health Change Process Theory were explored in the thesis studies. The third use was explored briefly in the last of these studies with the introduction of the QEHS as a generic measure at QE Health. The intent is to establish a system for ongoing, quarterly internal team audit of treatment outcomes to promote reflective practice and continual quality improvement.

Within the educational area at QE Health, Health Change Process Theory (termed the QE Health Model of Practice) has been the basis of increased clinical development as reported in the final QEHS study. Subsequently it was introduced as a key component of the QE Health staff orientation programme and as the foundation of inpatient education classes. The content of these classes is presently being reviewed to ensure it is in line with this theory. Furthermore, the theory has been used as the primary tool in educational seminars for other health professionals outside QE Health. Additionally, numerous presentations have been made to disability support groups, ranging from those with head injury to those with musculoskeletal disabilities. Both health professionals and consumers have found the model credible, applicable and useful in either working with people

with disabilities or gaining knowledge of how to live healthily with a chronic condition.

With regard to therapeutic applicability, the Health Change Process Theory, combined with the QEHS, has been found to be an effective therapeutic tool. First, the QEHS and associated Patient Profile identifies worldview and consequently facilitates decision making with regard to person-specific treatment strategies that will be effective. Moreover, the QEHS highlights issues that are potential barriers to health change and movement through the Health Change Process. Furthermore, counsellors report that this facilitates a client-centred holistic approach by enabling the individual to identify their sources and reasons for distress and to fully participate collaboratively in the counselling sessions. Similarly, occupational therapists at QE Health are in the process of exploring and identifying what and how to apply their interventions at each stage of the theory to ensure they are working from where the client is at and providing the most effective interventions to enable the individual to maximise their health.

In essence, the Health Change Process Theory provides a conceptual tool to inform patients and clinicians to collaboratively plan and implement effective health change. Moreover, it provides a clear rationale for therapists' actions and treatment goals. For people with disabilities, it normalises and universalises the process of achieving gain through loss resulting in reduction in anxiety and stress while raising awareness of innate potential. The focus of the patient and clinician then shifts from minimising dysfunction to maximising function.

These results support the contention of the Spiritual Theory of Self that the degree to which the individual possesses a nonmaterial worldview of their self and their world and related self-attributes is the primary determinant of health status. A holistic worldview enables the individual to healthily cope with adversity by managing the effect of such events, resulting in self-development rather than lessening of self.

Further Support of the Health Change Process Theory

The Health Change Process Theory conceptually draws together theory and findings of others research to provide a universal template to understand the

process of achieving health for those who have experienced significant life-changing trauma. As previously discussed, the theory was based on the findings of others with regard to theories of self but also sourced knowledge from the coping literature and posttraumatic growth research. However, there is a wealth of other research that can be seen as congruent with Health Change Process Theory.

For example, Thoren-Jonsson (2001) investigated coping strategies employed by people with post-polio syndrome resulting in the concept of 'conception of occupational self', the characteristics of which she posits are the key determinants of the healthy coping. Conception of occupational self is remarkably similar to healthy change depicted by Health Change Process Theory and is comprised of one's 'body image, sense of competence and values and goals' (p.342).

While the terminology employed by Thoren-Jonsson (2001) for each phase of change is different, the results support the robustness of Health Change Process Theory. She terms the stable phase of polio, when there is no major physical loss, *the inattentive phase.* This phase is represented by the pre-trauma state of Health Change Process Theory. The next two phases, *the phase of overloading* and *emotional crisis* are represented in Health Change Process Theory by trauma, which is experienced both prior to entering and during the Action Coping cycle. Following this is the *phase of gradual change*, which equates to Action Coping strategies but also to behaviours common to the Experimentation and Identification phase of the Health Change Process Theory. The *withdrawal phase* reflects Awareness of Loss, the *flexible phase* Acceptance of Loss, which then moves to Experimentation and Identification, termed *the process of realisation and integration*. She identifies this final process as including the processes of *insight* and *reorganisation*. Health Change Process Theory provides reasoning for the existence of the experiences of people with post-polio syndrome that Thoren-Jonsson's research describes.

A second example is a study that tested the hypothesis that some aspects of chronic illness, and how one responds to it are independent of diagnosis (McPherson, Brander, Taylor & McNaughton, 2004). McPherson, et al. posit that there is a universal process by which people with chronic disorders can

achieve health, regardless of the specific characteristics of the disorder. This is the assertion of the Health Change Process Theory. The samples investigated were those with rheumatoid arthritis, stroke and chronic pain. The findings confirmed that five interrelated themes applied to all groups.

Four themes, Personal/Intrinsic Factors, External/Extrinsic Factors, Future Issues and Perceptions of Normality radiated from the central theme of Taking Charge. The theme that differed markedly across groups was Personal/Intrinsic Factors, defined as personal state and function (bodily state, activity level, emotional state and participation in life). The difference was attributed to the unique characteristics of each disorder. While there were differences within the External/Extrinsic (interpersonal, societal and environmental variables) and Future Issues (confronting uncertainty, hopes and fears, employing coping strategies) the main finding was that these issues were equally important across all groups in determining health outcome. Similarly, Perceptions of Normality (perception of self and associated behaviours) and Taking Charge (ideas of acceptance/adaptation, sense of autonomy/control, and a sense of moving on) were common to all groups.

Of particular interest is the match between these themes and the predictions of the Health Change Process Theory as well as the congruence between these themes and those illustrated in the Self-Attributes Model. Taking Charge, the central theme of the McPherson et al. (2004) model, matches the issues confronted within transformational coping in the Acceptance of Loss, Experimentation and Identification and Spiritual Identity phases. Moreover, the Taking Charge themes mirror the characteristics of self-attributes necessary for health, which is achieved by acquiring a concept of self as represented by the Spiritual Theory of Self. Consequently, these results provide further support of the robustness of Health Change Process Theory.

A third example is Nair's (2003) review of research on life goals as applied to rehabilitation. He defines life goals as 'the desired states that people seek to obtain, maintain or avoid. These goals are the ends that individuals try to achieve by means of their cognitive and behavioural strategies' (p. 193). This is particularly relevant to Health Change Process Theory as a fundamental issue

addressed in this theory is whether activities and thought are directed towards the goal of preserving the extrinsic self or increasing expression of the intrinsic self. Also, Health Change Process Theory contends that there is no authentic change until there is behavioural change. Consequently, Health Change Process Theory predicts that goals which facilitate expression of the spiritual self will result in health while goals that solely aim to conserve the material self will result in ill-health.

Nair (2003) cites research showing that goal-orientated treatment programmes have been found to be successful in rehabilitation. However, Nair's review identified that action plans and associated activities, so often assumed to be identical with goal setting in rehabilitation, represent only the tip of the iceberg and are ineffectual unless a hierarchy of individual goals is explored. The hierarchal model of life goals and goal-setting begins with the idealised self. The goal is to match thought and subsequent actions with this idealised self, which can be interpreted as synonymous with the spiritual self. Hence, Nair is proposing that for life goals to be meaningful and health-giving, they need to first acknowledge and then be congruent with the characteristics of the inner self.

The next goal level is abstract motivations, such as power, fame and fortune. In this thesis, it is argued that what the individual perceives as power, fame and fortune is determined by the nature of the inner self. For example, a material perspective will mean that power concerns dominance over other people and the environment; fame is the adulation of others; and fortune is the accumulation of material resources. In contrast, from a nonmaterial perspective, power includes claiming and expressing the core self and spiritual relationship and connection with all aspects of life; fame is about being an integral and valued part of the whole; and fortune is experiencing the richness of life.

The three other goals, which are personal goals (career, family and relationships), contextual goals (striving to improve performance) and immediate goals (skill development) are ways to operationalise or express the inner self. The nature of these goals is dependent upon the characteristics of the inner self.

Consequently, meaningful extrinsic goals are established firstly by acknowledging and exploring what is important to the idealised (spiritual) self and the abstract motivations (values) of the individual, as predicted by the Spiritual Theory of Self. Health Change Process Theory illustrates the process and phases that are preconditions to the establishment of goals that enable people with chronic disorders to be healthy.

Health Change Process provides a conceptual framework to explain, understand and hypothesise about the relationships between health and such constructs as anxiety, depression, life satisfaction, motivation, life-goals, identity, self-esteem, posttraumatic stress, burnout, illness perceptions, acute and chronic healthcare, to name just a few. Consequently, this theory is a sound conceptual basis for both investigations and interventions, potentially across the full breadth of studying the relationship between healthy coping and personally significant change.

The QEHS

The QEHS was developed from the Spiritual Theory of Self theoretical perspective and aimed to assess change in holistic health status. Consequently, it was intended to identify the individual's phase position with respect to Health Change Process Theory. The thesis results demonstrated that the QEHS was a reliable and accurate measure of this. The capacity objectively to link theory with practice provides therapists with the opportunity to develop holistic evidence-based practice, supported by robust theoretical reasoning. Consequently, therapists using the QEHS can provide authentic client-centred chronic (as opposed to acute) healthcare and examine their ability to do so.

Furthermore, the QEHS consists of items congruent with thesis theory. Therefore, the development and testing of the QEHS not only resulted in a reliable and valid holistic health measure but also provided evidence of the robustness of thesis theory.

Moreover, participants and clinicians found the QEHS and the accompanying Patient Profile valid and effective therapeutic tools that often activated positive health change. The ability of these tools to identify and highlight factors that were impeding progress towards health achievement in an ethically appropriate and

empowering manner enhanced outcomes and increased the effectiveness and efficiency of interventions.

Finally, the QEHS and the Patient Profile provide quantitative tools to investigate Health Change Process Theory and derived hypotheses and as a consequence advance knowledge concerning the characteristics of this theory, the role of spirituality in health, the effectiveness of chronic healthcare and provision of holistic healthcare.

Limitations

The limitations concern three main areas. First is the robustness of the theoretical reasoning that formed the foundation for enquiry and which underpins and establishes the credibility of the overall research design and the conclusions made. Secondly, the demographic characteristics of participants determine the degree that the results may be generalised to others in the research population and then to all people. Thirdly, the design, procedure and data gathering tools employed determine the reliability and validity of the results obtained.

Theoretical Issues

The foundational theory on which the thesis research was based was the Spiritual Theory of Self. Evidence presented in Chapter One and the rationale outlined in Chapters Two and Three and expanded in Chapter Seven, resulting in the Health Change Process Theory, was based on an extensive review of others' findings in this field of enquiry. The theoretical conclusions made drew together these distinct theories of self and health to provide an inclusive explanation of the healthy self. The resultant Spiritual Theory of Self provided a sound basis for explanation and prediction of the healthy self which encompassed the findings of other self-theorists. The Health Change Process Theory incorporated this construct to provide an explanation of how people could be healthy while experiencing significant, ongoing loss.

However, the thesis addresses only one horn of the metaphysical debate concerning the nature of humankind. The crux of this argument is whether self-composition is material or nonmaterial. While scientific enquiry can support or challenge either position, each position is not entirely philosophically defensible.

Consequently, the position taken by the scientist must be based on *a priori* assumptions, that is, personal beliefs about the nature of humankind. While the majority of self-theorists and scientists have chosen the material *a priori* assumption and therefore the predominance of scientific evidence supports this worldview, this does not result in the alternative view being less philosophically credible. One of the reasons this alternative view has not been fully investigated is the perceived difficulties of applying scientific methodology to abstract concepts. The thesis sought to explore self theory, establish a robust nonmaterial theory of self and consequent health and to develop a tool enabling further scientific investigation of the nonmaterial argument.

While it is believed that the theories derived are robust and credible, the fact that the research is based on the *a priori* position that has less scientific support is an inherent limitation. Those who hold strong views that spirituality is the essence of all life will tend to consider the results and conclusions to be credible while those with the opposing view may be less generous, particularly as there is a paucity of scientific evidence to support such a claim. Simply put, the research concerns the basic questions of life, which has relevance to everyone but different people (including different scientists) tend to hold strong and opposing beliefs about the nature of life. Therefore, an inherent weakness of this research is that it clearly aligns itself with the nonmaterial position.

Issues of Representativeness

Assessment of participant representativeness needs to consider the theoretical basis of the thesis. Thesis theory contends that the critical determiner of health outcome is the status of the person as a whole rather than any particular demographic or disease characteristics. It is reasoned that the worldview and related coping strategies of the individual, not environment or dysfunction, ultimately determine holistic health outcome. The findings of all four studies, which involved a wide variety of demographics, supported such an assertion. The effect of the minor demographic differences on the generalisability of the results from the samples to the research population is probably minimal. Further research that investigates the relationship between demographic variables and holistic health status would fully resolve the contention that demographic variables do not

determine holistic health status but research with different populations would also achieve this goal of fully assessing generalisability.

The reasoning that the state of the person as a whole rather than the specific trauma encountered determines holistic health status applies to the generalisability of the study beyond the research population. The thesis does not investigate this prediction but anecdotal evidence gathered by the author when presenting these concepts and research findings to various consumer groups and health professionals suggests that the findings may be applicable to the majority of people. However, at this stage, there is only adequate evidence to claim that the theory and QEHS is valid within the research population and possibly to others with chronic musculoskeletal disorders.

Design Issues

The most contentious design issue centres on whether or not spirituality is an appropriate subject of scientific investigation in healthcare. Many health professionals have raised concerns about holistic healthcare and, specifically, the integration of spirituality in healthcare research and delivery. Sloan, Bagiella & Powell (1999) succinctly summarise the three major ethical issues with regard to religion/spirituality and healthcare. Although this thesis distinguishes religion and spirituality as quite distinct constructs, those authors, like many people, do not.

The first issue concerns the parameters of health professional knowledge and influence. 'When doctors depart from areas of established expertise to promote a non-medical agenda, they abuse their status as professionals' (Sloan, Bagiella and Powell, 1999, p.666). While that certainly applies to delving into a patient's religion, it does not pertain to a spiritual issue such as acknowledging and treating the whole person. The thesis findings showed that for many in this population treatment of the physical alone does not necessarily promote and may impede health. Furthermore, multidisciplinary assessment of biological, social and cognitive dimensions of health cannot be assumed to equate to holistic healthcare. Holism assumes that the whole person is greater than a sum of the parts; there is much more to being healthy than physical, social or cognitive function/dysfunction. Moreover, multidisciplinary assessment of every person who accesses health services is logistically and financially difficult and perhaps

impossible. Consequently, assessment of the effect of disease on the health of the whole person and determining appropriate health interventions commonly rests with the doctor. Arguably at present, such assessments result in only acute-type interventions rather than activation of the individual's inherent potential and the problem solving necessary to cope successfully with changed function. The QEHS has the potential to be an assessment tool that holistically identifies the present health status and its sustainability, aiding decision making with regard to intervention. Professionals may need to increase their skills in such areas rather than avoid consideration of the whole person.

The second point discussed by Sloan, Bagiella & Powell (1999) concerns the factors scientifically linked to ill-health and the ethical issue of doctors acknowledging and discussing these with patients. They use the example of marital status, citing that evidence suggests that those who are married live longer. Because of this evidence, should a doctor advise an unmarried patient to marry? The parallel question is that if the evidence links spirituality to health, should a physician advise the individual to become spiritual? The authors make two critical assumptions; long life equates to health and the patient will do exactly as the doctor advises.

From the spiritual perspective, life is continuous, irrespective of the time the body exists, and health is a client-centred worldview, not a body state. Chronic healthcare is markedly different from acute interventions. In acute healthcare the patient is predominantly a passive recipient of the health professional's curative expertise but for those with chronic conditions, professionally administered curative expertise has often been exhausted; the patient alone has the power to 'cure'. 'Cure' requires developing individual expertise concerning how to live as a whole person while objective aspects of self are often less than whole. Consequently, such people tend to consider information provided by a health professional in the context of their own reality, rather than that of the health professional. They do not automatically consider the information as credible just because it is delivered by someone with a healthcare qualification.

Therefore, the health professional cannot deliver health but can provide specialist techniques and information that the individual may or may not perceive as

credible to enable an increase in holistic health status. The Health Change Process Theory outlines an effective coping strategy for those with ongoing impairment *when* Action Coping (curative interventions) prove ineffectual. The health professional should make available any information they are aware of that has the potential to increase health status. To withhold such information is unethical.

The last point concerns doing no harm and is highly contentious but, from personal experience, it is frequently raised. For instance, Sloan, Bagiella & Powell (1999) state, 'Attempts to link religious and spiritual activities to health are reminiscent of the now discredited research suggesting that different ethnic groups show differing levels of moral probity, intelligence, or other measures of social worth. Since all human beings, devout or profane, ultimately will succumb to illness, we wish to avoid the additional burden of guilt for moral failure to those whose physical health fails before our own' (p.666).

This emotive statement indicates a lack of awareness of the distinct difference between the concepts of spirituality and religion. While many may argue that religion limits, controls and entraps people, the opposite is true of spirituality as defined and understood in this thesis. Comparing investigations of the link between spirituality and health to research of ethnic groups raises negative emotions but does little to promote logical and reasoned discussion. This statement also assumes that physical health equates to overall wellbeing and health. Additionally, it assumes that the health professional's role is to look after a body; not a person. Finally, there is a strong implication of no responsibility by the patient for their actions; this in itself is disempowering. It is not ethically justifiable for a physician to decide what a patient will and will not know concerning their own health.

The QEHS and the Health Change Process Theory seek to raise health issues of critical importance to the majority of those with chronic conditions. They are tools that enable the health professional to identify issues crucial to holistic health unique to the individual; they facilitate client-centred, holistic practice. The QEHS is a measure of generalised perspective concerning self, health, the world

and life, identifying holistic wellbeing, which acknowledges but does not seek to identify an individual's unique personal beliefs.

With respect to more mundane design limitations, the studies employed a variety of established qualitative and qualitative methods. The quantitative component of the thesis followed conventional scale development methodology and used widely validated tools to assess the validity of the QEHS. Consequently, these results can be considered as providing evidence that the QEHS is a reliable and valid measure within the research population.

The scientific credibility of the qualitative methodology is not so readily defensible, as the process of data collection is not as transparent, structured or readily communicated as is that of quantitative research. However, all research focuses on the tangible and as discussed in Chapter Four, the instrumental approach was adopted in designing the studies. This approach assumes that there is no fundamental philosophical difference between methodologies. Methodology was chosen based on which type (qualitative, quantitative or qualitative and quantitative) was most likely to address the concerns of each study.

In essence, the instrumental approach posits that data collection, whether qualitative or quantitative, requires objective information. Whether gathered by direct numerical measurement, questionnaire, observation or interview, researchers only have access to that which is observable. Typically, an abstract concept (an informal or formal theory) provides the rationale for initiating any scientific inquiry. The collection of objective data then tests the degree of support there is for the theory. However, the theory that initiates scientific investigations is often intangible and only one possible view of the reason for observable events. Consequently, the 'truth' of a theory cannot be proven; it can only be found to be supported, or not, through scientific investigations.

The Spiritual Theory of Self is such a theory. The effect of spirituality on the self can be scientifically investigated *if* theory is developed providing a rationale to guide research. Moreover, a data collection tool, based on that theory and predicted to measure objective expressions of the spiritual self, enables

investigation of theory and related health practice. By doing so the validity of both the measurement tool and theory is tested.

Some believe that investigation of spirituality, health and self is pointless and unscientific as data should be interpreted with the least embellishment possible: science is parsimonious (McBurney, 2001). Many of the self-theorists reviewed in Chapter One would each probably argue that all human behaviour and thought is adequately explained by their theories. The introduction of spirituality as the core component of self and health may be argued as unnecessarily complicating the concepts of self and health. However, science is also tentative, self-correcting, progressive, concerned with theory and empirical (McBurney, 2001). Theory is tentatively proposed and if data collected does not support the theory, the theory is altered, if possible, to accommodate findings. The material and transitional theories of self and health, reviewed in Chapter One, do not adequately explain the full reality of self, health or the relationship between them.

The final design limitation was researcher bias. However, if the researcher acknowledges their own worldview, research can be designed to counter, at least to some extent, the researcher's inherent bias. Moreover, a researcher's acknowledgement of their own worldview enables the reader to take this bias into account when considering findings. Furthermore, study designs in this thesis sought to counter such researcher bias by employing people experienced with health challenges as participants, data collectors, developers of theory and the holistic health measure. Moreover, not only one, but four studies involving both qualitative and quantitative designs and different samples, achieved compatible results.

Possibly the greatest counter to researcher bias was the nature of the research setting. Within healthcare it is widely accepted that there has been significant advancement in the development of techniques, pharmaceuticals and procedures that extend the physical life of people. Naturally, for many, this is assumed to equate to health. Although there has been a general trend to acknowledge the role of 'psychosocial' and sometimes even 'cultural' issues as important to physical life, the tendency has been to base and evaluate health research and healthcare

delivery by their capacity to extend physical life. This in itself is a worthy aim but it does not necessarily mean that the individual who lives longer is healthier.

This reality has promoted a health culture which is, at the least, sceptical of the role of spirituality in health and, at the worst, strongly dismissive of such a notion. In addition, it appears that many scientists (e.g., Bandura, Freud and Skinner, cited in Monte, 1991) tend to hold similar views. Consequently, the credibility of research that explores the role of spirituality in health is intensely examined for validity, which the author has found to be a natural foil to researcher bias.
If major limitations of design, methodology and procedure existed in the qualitative components of the research, the subsequent quantitative research would have identified such defects, because the larger samples and focus on general trends inherent in quantitative design would expose any contradiction. On the contrary, the thesis evidence demonstrates that the qualitatively developed theory and instrument items were supported by the later quantitative investigations.

Study Measures

The study measures used to assess the QEHS were established valid instruments; however, the QEHS possesses some inherent limitations. It is a new measure and while the results clearly indicated that, in its present form and within the research population, it is a reliable and valid holistic health measure, there is need for more developmental research before a wider interpretation of validity can be applied. For example, to be a completely valid measure of holistic health, congruent with Health Change Process Theory, it would also need to be shown to be reliable and valid for any human sample, with or without a medical diagnosis, undergoing life-altering trauma.

The inherent limitation to face validity of an instrument that clearly assesses the less well known and accepted nonmaterial view of self and health has already been discussed with regard to clinical and respondent credibility. But further limitations are raised by the inclusive item language employed as opposed to the conventional precise, impersonal language of conventional health measures whereby the reader can readily understand what particular aspect of function an item is assessing. The QEHS and the Health Change Process Theory are the two

main findings of this thesis. The measure and the theory represent a novel way of viewing and measuring health. Consequently, the QEHS is distinctly different from other measures in the health field with which scientists are familiar. Additionally, to the author's knowledge, there are no other similar instruments to provide support for such a measure. Therefore, because the findings are innovative, there is an increased likelihood that the results might not be viewed as credible.

Overall, the thesis needs to be viewed as providing formative theory and an associated measure that requires further research and development. While the findings demonstrated the applicability of both to the thesis population only further research will identify whether or not either possess wider validity.

Future Research

The Patient Profile

From the investigative perspective, the key result was the QEHS, as this measure is the tool enabling scientific exploration of thesis theory. The results clearly indicated that the Patient Profile is critical to the application of the QEHS. Therefore, while results demonstrated that the QEHS was a reliable and valid measure in the research population, there remains the need to develop further the process of item analysis used to construct the associated Patient Profile. While some clinicians utilised the actual responses to the QEHS to aid therapy and participants commonly found using the QEHS enhanced their capacity to identify their personal barriers to change, it was the Patient Profile that had the greatest clinical impact.

In essence the Patient Profile is a summary sheet identifying an individual's position with respect to Health Change Process Theory and the key indicators impacting on acquisition of a whole, healthy self as illustrated by the Spiritual Theory of Self. It provides a concise, readily usable summary of the holistic health status of the individual. Overall, clinicians at QE Health have been quick to recognise the potential usefulness and applicability of the Patient Profile to aid assessment, clinical decision making and evaluation of outcomes within the research setting.

The results demonstrated that the QEHS and the Patient Profile possessed clinical face validity. The reliability and validity of the Patient Profile was indicated by the strong and significant correlation found between total QEHS scores and estimation of participant position in the QEHS Study (see Table 10.1).

Moreover, a subsequent study provides further support for its validity (Brodie, Faull & Jones, 2005). In this study, 143 people with musculoskeletal impairments attending a rheumatology outpatient clinic were seen by one of four rheumatologists. Each participant completed a 10cm visual analogue global health scale, a SF-36 (Medical Outcomes Trust, 1992) and a QEHS. After their appointment, each rheumatologist also estimated their respective participants' health on an equivalent global health scale. Finally, the QEHS was delivered to the thesis author who then constructed a Patient Profile from QEHS responses then estimated each participant's global health on a third visual analogue scale. The results showed a strong correlation between the QEHS total score and the QEHS global health score ($r=0.89$, $p > 0.01$) providing further support for the reliability and validity of the Patient Profile.

Moreover, there was a larger correlation between QEHS derived global score and participant global health score (0.47, $p > 0.01$) than between the physician and participant health global scores (0.40, $p > 0.01$). Additionally, while the participant global assessment was strongly correlated to their SF-36 scores, the rheumatologists' global scores tended to relate strongly only to the Physical Function, Role Physical, Bodily Pain, Vitality and Social Function SF-36 subscales. In comparison, strong correlations were found between the QEHS global and the General Health, Vitality, Social Function and Mental Health SF-36 subscales while moderate correlations were evident with the Physical Function, Role Physical and Role Emotional subscales but no correlation with the Bodily Pain subscale. These results indicated that the QEHS-derived global and the rheumatologist global both assessed holistic health but that each assessed different aspects of health more accurately, when compared to the participants assessment of their own health. Furthermore, the QEHS-derived global was completed without case notes, previous interactions with the participants, specialist knowledge of health assessment and with the QEHS-derived global health assessor being completely blinded. Also, the QEHS took approximately 10

minutes to complete and the QEHS-derived global a further five minutes while rheumatologist visits ranged from 15 minutes for previous clients, with no medical complications, to at least 40 minutes for new clients.

These later results, combined with those obtained from the thesis studies, suggest that the Patient Profile has the potential to be a highly effective clinical tool providing assessment of holistic health status based on a clear theoretical rationale. The relationships with the SF-36 are similar to those found in the thesis studies. According to the Self-Attributes Model, when a person is healthy, identity replaces pain and therefore one central concept the QEHS seeks to measure is identity, not pain. Similarly, physical strength, ability and mobility are secondary to whole person strength, ability and mobility. The results suggest this is exactly what the QEHS is measuring. However, there is a need for further studies to fully understand what the QEHS assesses.

With regard to the Patient Profile, while the author has developed some rudimentary relationship rules of QEHS item associations, which have been applied by other therapists with reasonable success, demonstrated as satisfactorily accurate and reliable according to the thesis and the Brodie, Faull and Jones (2005) results, the basis of item interpretation remains subjective. Moreover, Patient Profile training requires one-on-one instruction and considerable experience involving a considerable amount of time.

Therefore, for the QEHS to be used to its potential there is a need to objectify Patient Profile analysis so that both may be used widely by other investigators. Hence, a prerequisite for wide use of the Patient Profile is the need to identify and test the laws of association between items. For example, there is a need to know what the item relationships are that identify Action Coping with associated low anxiety, high self-worth, low motivation to change, low awareness of possibility of change and external identity. Alternatively, there is a need to ascertain what the characteristics of item association are when the person is Action Coping but it is not sustainable (Action Coping to Awareness of Loss). These are only two of numerous combinations and possible outcomes. Discussions with clinicians constructing Patient Profiles clearly indicate that rules of item association do exist and the first steps of constructing the mathematical formulae of association are

underway. However, this is a laborious hit-and-miss activity without appropriate expertise and research.

It is beyond the expertise of the author to identify such combinations alone but collaboration with a suitably skilled mathematician/statistician, using the data gathered from present studies, would provide sound hypothesised laws of relationships which could then be tested in subsequent studies. The aim is to load QEHS data electronically and then use a software programme to construct the Patient Profile. This would enable any clinician or researcher to construct the Patient Profile.

Applying the QEHS to other Populations

The next logical step is to assess the reliability, validity and generalisability of the QEHS and the associated Patient Profile in other populations. However, real life is never quite so simple and structured.

Health professionals and health organisations in New Zealand are under increasing pressure to provide holistic healthcare (e.g., the Health Services for Older People Strategy, Ministry of Health, 2004). However, training and practice in acute-type healthcare predominates and there appears to be a lack of acknowledgement of the differences between acute and chronic healthcare. Generally, there appears to be an assumption that chronic healthcare requires the same interventions as those applied in acute healthcare; but just a greater intensity, variety and duration of intervention. However, such an assumption and the associated interventions require clinical and financial resources probably beyond the capacity of the New Zealand health system. Consequently, any idea or way forward that appears to provide a rationale and the basis for structuring such healthcare is examined with intense interest. In this environment there is an inherent danger that only aspects of such concepts will be adopted or that innovative interventions will not be developed or, if developed, not evaluated systematically and scientifically.

The thesis findings provide a foundation for development of holistic healthcare but it cannot be overemphasised that unless this is carried out in a controlled, systematic and progressive manner, such endeavours may be ineffectual. The

author has designed two programmes in response to interest from two New Zealand health funding organisations, based on thesis theory but, if implemented, it is unknown if and how these will be evaluated. At this stage, there is definitely no controlled, systematic, progressive and scientific plan to ensure objective testing of any such innovative approaches.

Consequently, there is a need to implement a research strategy that not only assesses the reliability, validity and generalisability of the QEHS and the associated Patient Profile but also explores and evaluates the implementation of thesis theory to practice. The aim must be to identify which combination of therapies are effective in different populations to achieve an increase in holistic health status, possibly best summed up by people remaining or returning to their communities as valued, fully contributing members. Components of a programme need to firstly be constructed according to Health Change Process Theory predictions and then altered systematically to enable identification of the effect of each element on outcome.

Therefore, investigations need to be designed not only to test the properties of the QEHS and Patient Profile but also to trial innovative interventions developed from Health Change Process Theory. Development of such interventions could then be investigated to promote enhanced client-centred, evidence-based holistic healthcare for those with chronic conditions.

Scientific Implications

As the thesis focused on a central and fundamental psychological issue, the nature of humankind, the findings potentially impact on a wide range of psychological endeavour. While acknowledging the scientific limitations of this series of four studies, the results demonstrate that the Health Change Process Theory is robust. Moreover, the core construct of this theory is the Spiritual Theory of Self, which provides an explanation for human thought and behaviour arguably more comprehensive than established theories, which is supported by the thesis data.

Self-theory is the foundational theory of psychology and from this base all aspects of psychological enquiry that involves human thought and behaviour has evolved. While foundational leaders in this field, such as William James (1963) recognised

the link between science and philosophy, with a particular emphasis on the ontological questions discussed in this thesis, psychology has since evolved and such are seldom a focus of investigation. The frequent classification of self-theories as Freudian/pseudo-Freudian, behavioural/cognitive-behavioural and existential/humanitarian has lost its connection to the material-nonmaterial philosophical foundation of all psychology.

Furthermore, the majority of psychology enquiry has focused on the objective, tangible aspects of humanity, which is essential for any endeavour that claims to be scientific. However, as discussed in the thesis, measuring the tangible does not negate the possibility that what we are measuring is possibly an expression, an outcome of the intangible. In fact, while models attempt to represent the concrete, theories all aim to illustrate the abstract.

There are many possible reasons to explain why psychology has moved away from the material/nonmaterial argument. Arguably, the predominant reason may be that when psychology emerged as a distinct discipline, spirituality was the domain of religion and as science has continually attempted to free itself of dogma to enable objective exploration of reality, the nonmaterial horn of the philosophical dilemma of self was largely ignored. Possibly, the lack of attention given to the concept of the spiritual self and the immaterial philosophical position is an understandable outcome of the environment at that time. However, the social environment and the role of religion in Western society is radically different in the 21st Century than it was in the 19th Century. Moreover, while the evidence gathered over the intervening period provides strong support for the material worldview, it also has exposed some flaws in such a view as fully explaining human thought and behaviour. There appears to be an increasing impetus within psychology to explore human thought and behaviour from the nonmaterial perspective in an attempt to provide a possible explanation concerning the unanswered questions about self and health.

Moreover, while some still strongly challenge the scientific validity of any investigation involving such a tenuous concept as spirituality, the majority seem to be more concerned that any such investigations are scientifically robust (e.g., Sloan, Bagiella and Powell, 1999). A desired outcome of the thesis was to

provide a foundation for such investigations, providing a starting point to increase knowledge and understanding of human thought and behaviour and delivery of effective chronic healthcare.

In summary, the results of this thesis have the following impacts on the science of psychology.

1. It demonstrates that spirituality is an appropriate focus of scientific investigation.
2. It provides a tool to quantitatively investigate the relationships of spirituality, self and health.
3. It identifies an equally scientifically plausible nonmaterial explanation of human thought and behaviour.
4. Overall, the findings provide an opportunity to address the imbalance of quantitative psychological enquiry with regard to the nature of self.

The thesis has wider scientific implications beyond the field of psychology, particularly for those scientists involved in healthcare research. The QEHS has the potential to provide scientists, clinicians and policy-makers with a reliable and valid tool to initiate, develop and evaluate client or person-centred holistic healthcare. The QEHS is constructed in the language of those who have experienced loss of health and then found a way to achieve health that is more resilient, empowering and meaningful than previously experienced. The Health Change Process Theory and QEHS have the potential to provide a foundation for the investigation of any human experience where there is a need for major change.

Social Implications

The results of the thesis provide an alternative view of health and its assessment. In essence, it was assumed that a person is well when they say they are, not when others judge they are. People with ill-health experiences and others facing a significant identity trauma frequently comment that the QEHS and the Health Change Process Theory is relevant to their lives. The research demonstrates that, while a small minority may not identify or comprehend either of these, the vast majority report that the theory encapsulated their life experiences and the QEHS voiced their own beliefs of what is important for health.

Moreover, the QEHS employs language directly sourced from people who are healthy with chronic physical impairment. For example, words such as 'fun', 'peace', 'love', 'God', 'spiritual', 'exciting', 'value' 'choice', 'accept' and 'listen'. These words are not commonly associated with healthcare, used by health professionals or common to health settings. However, everyday, these are words frequently used by all people with regard to their health. The questionnaire gives people the ability to openly acknowledge and address the constructs behind these words, just as they do in their everyday life. This accommodates person-to-person rather than clinician-to-patient interactions by facilitating an equal relationship between two people with different skills and resources; the health professional and the client. As a consequence, the QEHS and Health Change Process Theory facilitate client-centred, evidence based practice as the clinician assesses and then must address the person as a whole.

Furthermore, QEHS items do not attempt to fragmentally assess people. The items assess the person and health as perceived by the person; as a whole with their own unique interpretations of what words, concepts and their lives mean to them. Simply put, items, like people, are integrated, possess more than one meaning and are unique to the individual. Therefore, the QEHS assesses meaning; whether experiences, life and self are personally valued and meaningful and the presence or absence of such individual characteristics are indicative of level of overall wellbeing, that is, holistic health status.

However, while the QEHS assesses holistic health status and, in combination with the Health Change Process Theory, it facilitates holistic healthcare, it does not attempt to precisely measure physical, social or cognitive function. Therefore, those working in the health arena should view the QEHS as enhancing health assessment and treatment by complementing current measures of dysfunction.

Thesis Conclusions

The overall goal of the thesis research was to investigate the nature of the healthy human self and the process of achieving health. This was achieved by reviewing established self-theory, developing an inclusive self-theory that was congruent with previous findings but positioned spirituality as the essential core of self. From this foundational theory, the Health Change Process Theory was developed

to explain how people achieve sustainable health. The following studies resulted in the construction and testing of a quantitative measure which enabled scientific investigation of the nature of the healthy self and the process of achieving health.

The thesis results advance psychological knowledge with implications for all fields of psychology involved in the study of people. Moreover, the evidence provides a basis for enhancing research, professional development and practice within the health arena, particularly with respect to chronic healthcare delivery.

The QEHS and associated theory provide a tool and basis for investigations where people are experiencing traumatic, irreversible crises. However, the aim should be to refine the QEHS and the associated Patient Profile and then have health professionals use the model, theory and measure in the field to study its applicability as an aid toward achieving and maintaining a healthy self.

Consequently, the thesis results demonstrate that the Spiritual Theory of Self, the Self-Attributes Model and, specifically, the Health Change Process Theory provide valid explanations of the constructs that enable people with musculoskeletal disorders to remain healthy with such conditions. Furthermore, the relationship between the findings and established self-theories suggest that these theories may advance knowledge of the predictors and interventions that enable all people to undertake a health-giving process of change when confronted with adversity.

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APPENDICES

Appendix 1: HSD Study Information Sheet

The Health, Self and Disability Study
INFORMATION SHEET 17/8/2000

What is it?
You are invited to take part in a study (approved by the Bay of Plenty Ethics Committee) investigating how people with disabilities define health. The study does not focus on you personally but is interested in finding the health perceptions and goals for those with disabilities.

What would I need to do if I agreed to take part?
The Principal Researcher Kieren Faull, will be contacting you by telephone to discuss the study. If you are interested in taking part, then he will ask you which of two possible dates would suit you to attend a discussion about health, self and disability at Queen Elizabeth Hospital, Rotorua. The workshop agenda is:

9.00am - 9.30am	Welcome and introduction of facilitators by Principal Researcher, Kieren Faull.
9.30am - 10.00am	Refreshments, signing of Consent Forms, and formation of discussion groups.
10.00am - 11.15am	Discussion of personal health experiences
11.15am - 11.30am	Refreshment break
11.30am - 12.00am	Discussion of the what it means to be healthy for each person
12.00am - 1.00pm	Lunch
1.00pm - 2.30pm	Discussion of what are the most important things needed to be healthy
2.30pm - 3.00pm	Afternoon tea
3.00pm - 4.00pm	From the things identified as necessary for good health, what are the most important, not as important and so on down to least important of these things for health.

Food and refreshments will be provided.
Discussions will take place in groups of no more than 10 people with disabilities. The facilitators are people with disabilities who have also been patients at Queen Elizabeth Hospital and have received training in facilitation. They will lead the groups and record key points identified. Where discussions are too intensive and complex for the facilitators to record all the information, audio recorders may be used.

What will be done with the information?
After the workshops, the information from the discussions will be analysed by the facilitators to identify common themes or issues that arise. Once the facilitators reach agreement with regard to the characteristics of the data, the results will be

used to identify questionnaires capable of measuring the identified themes of health.

Who will know it was me that took part?
Kieren Faull, Principal Researcher, the facilitators and other participants. There will be no identification that may connect an individual to the information that is to be analysed.

Who else is taking part?
A maximum of 100 people within a 80 km (50 mile) radius of Queen Elizabeth Hospital, Rotorua who have been randomly selected from the Queen Elizabeth Hospital Rheumatology and Rehabilitation inpatient data base.

What are the benefits of the study?
Identification of the health goals for those with disabilities will increase the likelihood of these goals being acknowledged and focused on.

What can I do if I wish to talk to somebody about this?
After receiving this Information Sheet you may wish to write down any questions you may want to ask Kieren Faull when he rings. Alternatively, you can contact Kieren Faull on (07) 348 0189. Any participant in this research project who has concerns about treatment can contact the Health Consumer Service. The freephone number is: 0800 223 238.

Thank you for your time.

Kieren Faull
Research Supervisor
Queen Elizabeth Hospital
Whakaue St.,
PO Box 1342,
Rotorua.
Ph. (07) 348 0189

Appendix 2: HSD Study Consent Form

CONSENT FORM 2/12/2000

The Health, Self and Disability Study

I have read and I understand the information sheet dated 17/8/2000 for volunteers taking part in the study designed to investigate what it means to be healthy for those with disabilities. I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.

I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study anytime and this will in no way affect my continuing healthcare.

I understand that my participation in this study is confidential and that no material that could identify me will be used in any reports on this study.

I have had time to consider whether or not to take part.

I understand that if I have any queries or concerns about my rights as a participant in this study I can contact the Health Consumer Service. The freephone number is 0800 223 238.

I _____ (full name) hereby consent to take part in this study.

Signature: _____

Date: _____

I have explained the study to the participant and I am satisfied that they understand the information.

Name: Kieren Faull Designation: Principal Investigator

Signature: _____ Date: _____

One copy of the consent form is to be retained kept by the participant and the other placed in the research files.

Appendix 3: HSD Co-Researcher Training Manual

THE HEALTH, SELF AND DISABILITY STUDY MANUAL

Kieren Faull

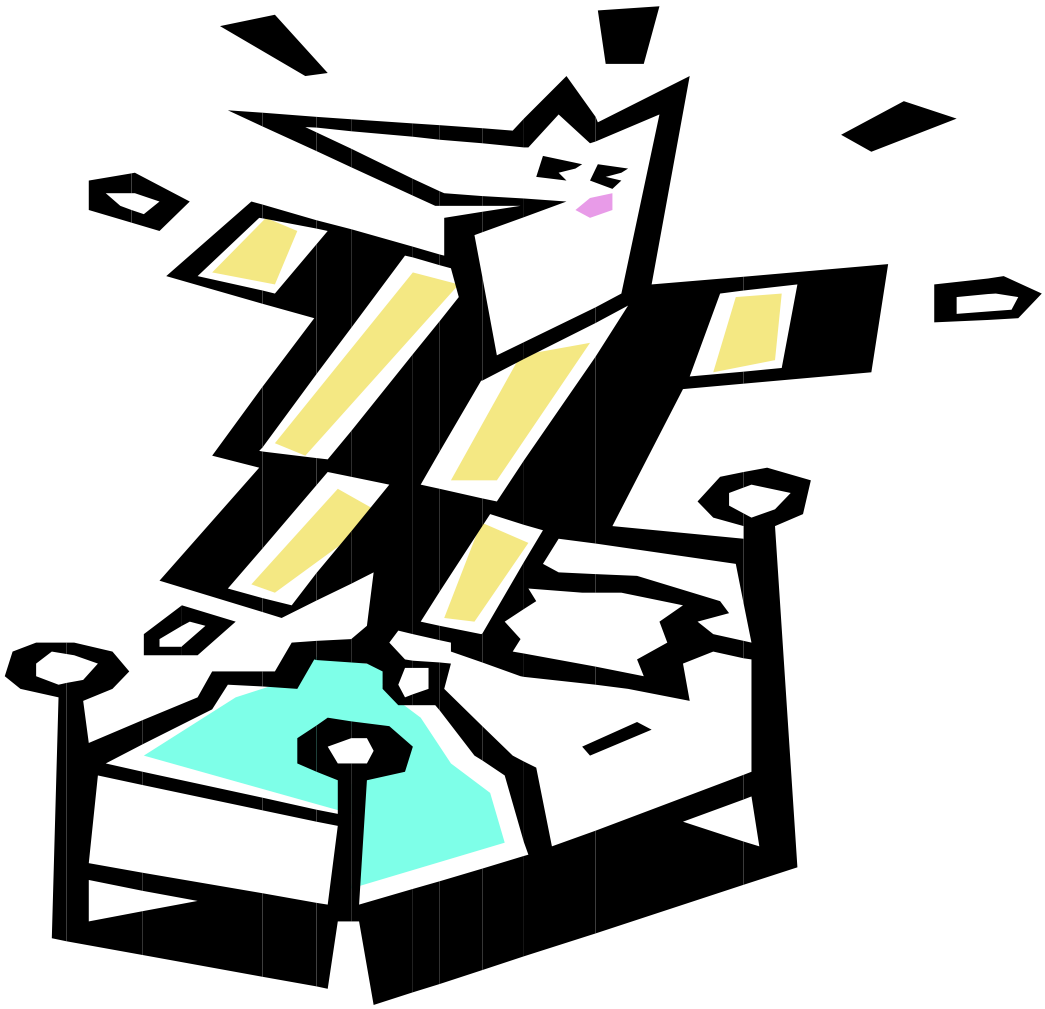
August 2000

THE HEALTH, SELF AND DISABILITY STUDY

PART ONE

FACILITATION SKILLS

Kieren Faull



WORKSHOP AIMS

- To find out what it means to be healthy for those with disabilities
- To identify what the key components of good health are
- To identify the importance of each component to overall health

FOR THOSE WITH DISABILITIES

HOW?

Discussing these issues in groups of no more than 10 people

with

People with disabilities trained in group dynamics, facilitation and data collection leading the groups

to

- Ensure discussions remain focused on the aims
- Record all major points
- Be responsible for ensuring all views are equally voiced
- Facilitating discussion towards identification and prioritisation of the key components of health for the group

GROUND RULES

- The facilitator is the group leader

Group members will:

- Allow others to speak without interruptions
- Encourage all group members to speak
- Promote the sharing of reasons and explanations for views
- Respect all members views

FACILITATOR TRAINING

1.1 GROUP DYNAMICS

Research indicates that when people join together for a common purpose (definition of a group) a number of rather interesting things may occur. Without prior knowledge of what may happen when people form a group, there is a strong possibility that the facilitators may not be able to obtain data that is meaningful. Although a group may be formed to fulfil a specific task without effective leadership tasks more important to the group members may take priority. For example, whether or not members like one another, whether or not one individual's opinions can be forced on the other members or deciding whom in the group is the 'expert'.

There are a number of strategies to facilitate group processes and ensure that the original purpose for the group is retained as the central focus of the group's function. These include prior establishment of ground rules, acceptance, acknowledgement and formal agreement to the group agenda. The process of discussion and decision making can be promoted by the use of an external mediator, in this case, the Principal Researcher.

However, for facilitators to understand anticipate and effectively lead groups there is a need to be aware of the basic dynamics involved within groups. Part One of the Manual contains a summary of group dynamics, tactics useful in providing effective facilitation and two activities to advance understanding of group dynamics and leadership. Part Two explores the meanings and concepts associated with health, self and disability. Part Three focuses on the 'how to' of data collection for this study.

ACTIVITY ONE

AIM

To start participants becoming involved and talking to each other in an open and relaxed way, in preparation for the complex and difficult discussion to follow.

OBJECTIVE

By the end of the activity, participants will have tried different strategies to gain a commitment from each other member of the group on a given subject.

TIMING

- 5 minutes for each discussion
- 10 minutes at the end for summarising

MATERIALS REQUIRED

One copy of the attached statements, cut into strips

BACKGROUND

Many icebreakers are activities to start everyone talking. This icebreaker uses our 'instinctive' reactions, doesn't rely on prior knowledge or study and is based on the issue of persuasion. In all of life we all need to be able to influence people or 'sell' an idea. Most of the time we do it 'instinctively', without thinking what we do, but could success come more often with a thought-out strategy?

METHOD

1. Welcome participants to the session. Explain that instead of asking everyone to introduce themselves you want them to get to know each other more quickly.

2. Distribute one statement to each participant and a blank sheet of paper.

3. Ask participants to stand up and walk about, speaking to everyone in their group in turn. Their task is to get the other person to agree with the statement written on their strip of paper. They should take note of that person's name, occupation and anything they learn about them in the process.

4. Allow 5 minutes for <u>each</u> discussion. Call out the time at regular intervals.

DEBRIEFING

1. When everyone has spoken to everyone else, ask participants to sit down again.
2. Ask participants to work out their success rate as a rough percentage
3. Ask them to call out the percentages. Locate those who had a low success rate and ask if they have any idea why. Then ask the people with a high success rate what led to their success.
4. Summarise what happened by listing the strategies that worked and asking participants to make a note of them for future use.
5. End up by saying you expect them to use what they have learned in this workshop.

STATEMENTS

1. People with disabilities should be pitied

---

2. Another world war is needed to fix our economy

---

3. Health is being pain-free

---

4. You are in complete control of your future

---

5. Computers have made life more difficult

---

6. The New Zealand soccer team is the best in the world

---

7. Women make better employers than men

---

8. Buck Shelford should be Prime Minister

---

9. More doctors would solve the problems of people with disabilities

---

10. Broccoli should be served with all main meals

1.2 GROUP DEVELOPMENT

People do not just meet, sit down, smile then begin working together as a group. Groups function as one living organism in that they strive to achieve a common goal with members all performing different tasks but all aimed towards the same end. A group can be compared to a person walking to a shop to get some bread. The purpose is to purchase bread and all parts of the body are being used to achieve this purpose. A group leader can be likened to the person's head that provides the body with direction, coordination and responsibility for the body working together to achieve this purpose. Hence, the role of the facilitator/coordinator/leader is pivotal IF the stated aim of the group is to be achieved.

So how do we manage to get a collection of individual's, all with their own thoughts, needs, desires, agendas, views about what the group is about and personalities to perform in a unified manner?

ACTIVITY TWO

AIM
To improve facilitators' skills of leadership to ensure inclusion and contribution of all group members

OBJECTIVE
By the end of the activity facilitators' will have identified effective ways of dealing with 'difficult' group members.

TIMING
- 10 minutes for introduction and individual work
- 30 minutes for subgroup work
- 60 minutes for debriefing

Total time: one hour and 40 minutes

MATERIALS REQUIRED
- A copy of the five documents for each facilitator
- Paper and pens

BACKGROUND
These strategies are extremely important when dealing with difficult styles or negative behaviours. Remember that the aim of the training is to allow each facilitator to lead a group so that ALL members share THEIR knowledge and opinions - anything less puts in jeopardy the scientific validity of the data.

METHOD

1. Introduce the subject of effective group communication and the importance of equality of input

2. Split the group into four subgroups. Each subgroup will be assigned one of the four difficult group types

3. Give out the appropriate documents to each subgroup and ask the participants to work individually.

4. After 10 minutes ask the subgroups to go to separate parts of the room

5. Circulate among the subgroups. Note any comments which you want to bring to the attention of the whole group

6. After 30 minutes bring the subgroups back together

7. Hand out copies of all the group type scenarios so that all facilitators now have copies of the four group types

8. To debrief, ask each subgroup to present their ideas for dealing with each type

9. After each presentation ask for comments and additions. Add any other points you may want to emphasise or any notes you have made while you monitored the subgroups

10. Summarise the main issues of dealing with each group type and hand out a copy of the suggested answers to each facilitator

DOCUMENT 1 - TRICKY TYPE 'A'

You are the facilitator of a group discussing how to define what it means to be healthy. The Principal Researcher is available in the role of workshop supervisor to assist where the facilitators believes there is a need for reinforcement of their authority or assistance on a one-to-one basis.

Vivacious Vicky

Vicky is very enthusiastic, she loudly and constantly voices her support for certain ideas that have been put forward by others, and she provides substantial and valuable input. However, she is equally vigorous and forceful in quickly arguing against any ideas that are not in complete agreement with her own. In fact, when one group member, frustrated with Vicky's inability to see some possible inconsistencies in her ideas and the logic of other ideas' firmly told her that they all had to discuss the idea and aim for a group consensus of what health is, Vicky withdrew from the conversation.

How might you, as facilitator, deal with Vicky in a way that would make use of her ideas and enthusiasm?

DOCUMENT 2 - TRICKY TYPE 'B'

You are the facilitator of a group discussing how to define what it means to be healthy. The Principal Researcher is available in the role of workshop supervisor to assist where the facilitators believes there is a need for reinforcement of their authority or assistance on a one-to-one basis.

Peaceful Paul
Paul has so far hardly said anything. The other members of the group do not have trouble with voicing their opinion, whereas Paul seems to have more problems. When asked a direct question he answers, but often he does not complete his idea before someone else makes a comment or carries on the discussion.

How would you ensure Paul contributed to the discussion?

DOCUMENT 3 - TRICKY TYPE 'C'

You are the facilitator of a group discussing how to define what it means to be healthy. The Principal Researcher is available in the role of workshop supervisor to assist where the facilitators believes there is a need for reinforcement of their authority or assistance on a one-to-one basis.

Incompatible Irene
During discussions Irene does not seem to be thinking of anybody but herself. She insists, because of her disability, she cannot sit for more than 10 minutes and must get up and move around. In doing so, she makes a great deal of fuss and noise and moves around at such a distance from the group that she cannot hear what is said, which means that when she returns everything discussed needs to be repeated to her. In the formal break for morning tea, she leaves the room and returns 15 minutes late. These actions delay the discussion.

How would you enlist her support and make her part of the group rather than against it?

DOCUMENT 4 - TRICKY TYPE 'D'

You are the facilitator of a group discussing how to define what it means to be healthy. The Principal Researcher is available in the role of workshop supervisor to assist where the facilitators believes there is a need for reinforcement of their authority or assistance on a one-to-one basis.

Agreeable Agnes
Agnes is very easy to get on with and is liked by everybody. Her problem is that she is often too easy to get on with, never arguing with anybody or putting forward a contradictory idea. Agnes also seems to support the strongest point of view, even when it means changing her own ideas after she has expressed them.

How can you be sure to elicit Agnes's honest personal views?

DOCUMENT 5 - GROUP TYPE SUGGESTED SOLUTIONS

The main guideline for any group is that each member should contribute effectively. This can mean that time is shared equally, or it can mean that trust and rapport is established so that members feel able to share their opinions.

Vivacious Vicky
It is vital to keep Vicky involved in active discussion as her ideas and enthusiasm are valuable and may challenge other opinions. Allocate equal time to each group member, start with Vicky and ask for no interruptions when each member is talking. After the first round, each member will have been allowed to give his or her opinion. Leave these ideas on the table without discussion. Make sure that Vicky sees that no decision has been made. Continue this process until you have a series of comments and thoughts on the focus of discussion. Record ALL points. Maybe officially acknowledge Vicky's contribution by listing the points she makes on a whiteboard to indicate they are noted and will be returned to later.

If possible, avoid a clear rejection of Vicky's ideas, if not, delay such action until you believe there is no more that can be added to the discussion and talk appears to be just returning to the same points repeatedly.

If Vicky is beginning to exhibit behaviours that may be seen as sulking or withdrawal, either confront the behaviour and assertively ask for a positive contribution or praise the contribution and the enthusiasm. Explain that this is a one-off opportunity for people to voice their opinions and that we cannot put the process at risk for the sake of any individual group members.

Peaceful Paul
Paul is the type that is introspective and needs time to consider and express his thoughts and is probably lacking in assertiveness. For such a person within a group to be able to contribute, the facilitator needs to strictly adhere to the ground rules. Ensure he can speak without interruptions and that there is an orderly process of discussion with everybody having a turn in the order that has been accepted as part of the ground rules. There is also a need for the facilitator to invite him to share his opinion, ask questions as to what his opinion is and praise his contribution.

Incompatible Irene
One of the main aims of setting an agenda and spending time explaining and getting agreement as to what the ground rules are is to obtain the commitment required from group members and to ensure acceptance of their responsibilities as group members.

In the case of Irene, every opportunity should be taken to prevent her asserting her independence and non-membership to the group. If Irene continues to make difficulties and act independently it may be necessary to remind her of the ground rules and her responsibilities if she wishes to be a member of this group. Renegotiation of her commitment to the process should preferably occur in private. There may be the need for the external mediator to become involved and a private discussion may identify some anxiety or other problem that may be readily addressed. If there appears to be no solution to the problem and Irene persists in refusing group membership, then the facilitator is left with no alternative than to

protect the validity of the group process by omitting Irene from any further participation.

Agreeable Agnes
Again, the facilitator will need to make the ground rules clear, perhaps even taking the time to explain how her honest opinion is essential if the process is to result in valid information. The difference between being aggressive and being assertive needs to be clarified for Agnes. Likewise, the fact that good discussion and differences in opinions are natural and necessary in the process of reaching a genuine group consensus.

The facilitator may need to challenge Agnes, question and probe her apparent agreement with others with the aim of ensuring Agnes is giving her opinion. Also, it may be useful to inform Agnes that her opinion is the result of not only what she has experienced but also represents others who have shared their experiences and opinions with her - as such, she has a responsibility to not only represent herself but others she knows who have not been given the opportunity to participate in the group.

1.3 GROUP PROCESSES

Research has identified four stages of group development:

1. **Forming**
2. **Storming**
3. **Norming**
4. **Performing**

Our aim is to get to the last stage, performing, as smoothly as possible, hopefully with the group still intact. I will explain what each stage is and the feelings and behaviours that commonly occur in each stage.

REMEMBER! IT IS 'PERFORMING WE WISH TO REACH - OUR AIM IS TO PROVIDE A STRUCTURE, LEADERSHIP, MATERIALS AND AN ENVIRONMENT SO THAT MOST OF WHAT HAPPENS IN 'FORMING', 'STORMING' AND 'NORMING' HAS ALREADY BEEN SET UP OR ARE UNDERTAKEN IN THE MOST EFFICIENT WAY POSSIBLE.

Forming
This is the initial stage where individuals find out what is going on. Remember that people come with their own expectations, desires and ideas as to how things should be run. Whether they have thought about such things or not, the idea of 'Group Workshops' will trigger a diverse range of images and definitions of workshops that are dependent on their experience, whether actual or observed on TV, etc. of what a group workshop is.

People will be experimenting or testing to see how well this thing they are meant to take part in fits with what they want to do and how much they can influence the process to match what they see as the 'proper' way to go about this thing. Even when tight guidelines, ground rules and agendas are provided, individuals will offer their suggestions for improvements and even argue that if these aren't

implemented they believe that whatever the group does will be pointless. Hence, there will be a testing of what the boundaries are, how rigid these boundaries are (can they be altered to what I think?), direct and indirect challenges of the group leaders. This is normal but must be acknowledged for the two opposite possible outcomes from such interactions. First, it may be developed as a positive way of establishing group relationships, identifying personality types and how individual members may work together to achieve the group goals. Secondly, if this process isn't managed effectively by the group leader, strong individual members may hijack the group and work towards goals that may have little to do with the reason the group was first formed.

Feelings of group members that will probably be evident are:

- Excitement, anticipation, optimism
- Pride at being told that their knowledge is important and they are being asked to contribute
- Initial, tentative communication with all group members and attachment to the group
- Suspicion, fear and anxiety about the subject of discussion and doubts as to their own knowledge or worth to the group

Behaviours that group members may exhibit are:

- Attempts to define/redefine the tasks on the agenda or even the agenda
- Attempts to define acceptable group behaviour and how to deal with group problems
- Attempts to change the information that should be gathered
- Lofty, abstract discussion of concepts and issues; or, for some members, impatience with these discussions.
- Discussions that start with the subject but quickly are transferred to some totally unrelated and irrelevant subject - difficulty dealing with the central issues
- Complaints about the environment, the weather, things at home, stress they are under, why particular people were selected as facilitators, the sacrifice they have made to attend, the impossibility of the task and other 'problems'.

ACTIVITY 3 -CHARADES

AIM
To practice role playing

OBJECTIVE
By the end of the activity participants will be more familiar and at ease with performing roles that are out of character

TIMING
30 minutes

BACKGROUND
People do not naturally assume character-types they do not identify as similar to their own. Practice by undertaking a game such as charades allows individuals to move out of character in an environment that is relaxed and fun-focused.

METHOD

1. Each participant will be given a slip of paper with a easily recognised character written on it

2. Each participant will take turns to act out the character and other participants will attempt to guess who it is.

3. Each charade will be acted out for a maximum of 5 minutes

4. 5 minutes of debriefing will conclude the activity

ACTIVITY 4 - ROLE PLAY - STORMING

AIM
To understand and effectively provide leadership through the group process of storming

OBJECTIVE
By the end of activity participants will have identified derailing tactics and effective ways to of countering such behaviours.

TIMING
- 10 minutes for introduction
- 20 minutes for storming role play
- 20 minutes for debriefing

MATERIALS REQUIRED
- Pen and piece of paper for each participant
- Five documents detailing individual roles to be played

BACKGROUND
Storming is the stage that sets the stage for all other processes. Commonly, leadership is tested more frequently at this stage than any other. Hence, facilitators must have a clear understanding of what may occur and how to counter any behaviour destructive to group process and purpose. The right attitude is essential. Facilitators cannot fall into the trap of wanting to be liked and accepted by the group. Their primary responsibility is to ensure that the stated purpose of the group is maintained as the activity of the group rather than some other purpose such as keeping all members happy.

METHOD

1. Introduce the process of storming and explain that the participants will be developing an understanding of what is really occurring and how to deal with group issues that may arise.

2. The course leader will select an individual to play the role of facilitator; others will play roles as group members.

3. Distribute appropriate documents to each participant

4. Begin storming role-play, providing prompting, support and guidance to the facilitator. Ensure others play their roles effectively.

5. Circulate around members reminding them to take notes of anything they observe or experience that they feel is important

6. After 20 minutes, draw the session to a conclusion

7. To debrief, ask individual members to comment on what they observed and experienced with the facilitator commenting last

8. Discuss how the process went, whether the process was derailed from the original purpose and other options for dealing with such destructive behaviour effectively.

9. Summarise what occurred and provide the Solutions document

DOCUMENT ONE - STORMING ROLE-PLAY

FACILITATOR

All members of the taskforce have the following information. A number of experts have been approached by the Prime Minister, Helen Clark, to discuss and provide recommendations to her on the priorities of health spending for disability.

Presently, funding for elderly support and care in rest homes, etc. eats up 80% of the disability budget. There is no more money available and while Helen acknowledges there is real and desperate need for people with disabilities, the reality is that it must be a balancing act within the confines of the present budget. She wishes the taskforce to provide her with answers to the following questions:

- Should there be redistribution of the disability budget?
- If not redistributed, why not? And how do we alleviate the plight of all the rest of the people with disabilities given that there is no more money?
- If redistributed, why? And how do we counter the lower level of funding for the elderly?
- If redistributed, what are the four top priority areas for increased funding (in order of importance) and why are these most important?

All group members have a high degree of experience and expertise in the disability arena.

Additional Information for the Facilitator
Helen and you have been personal friends for years and this task force is just one of many that your friend Helen has appointed you to. She depends heavily on your input and trusts you implicitly to get the results she asks for. She has already commented that the group members are a diverse and independent bunch of people but their level of expertise is unsurpassed in this country and their contribution is pivotal in determining what is to be done. Helen is totally depending on you personally to provide the answers to these questions from the taskforce. In comparison to the other group members, your knowledge of disability issues is somewhat limited. One last thing - you have five meetings to achieve these objectives.

DOCUMENT TWO - STORMING ROLE-PLAY

TASKFORCE MEMBER 1

All members of the taskforce have the following information. A number of experts have been approached by the Prime Minister, Helen Clark, to discuss and provide recommendations to her on the priorities of health spending for disability.

Presently, funding for elderly support and care in rest homes, etc. eats up 80% of the disability budget. There is no more money available and while Helen acknowledges there is real and desperate need for people with disabilities, the reality is that it must be a balancing act within the confines of the present budget. She wishes the taskforce to provide her with answers to the following questions:

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- If not redistributed, why not? And how do we alleviate the plight of all the rest of the people with disabilities given that there is no more money?
- If redistributed, why? And how do we counter the lower level of funding for the elderly?

All group members have a high degree of experience and expertise in the disability arena.

Additional Information for Taskforce Member 1
You are a qualified medical practitioner, specialising in rehabilitation medicine for musculoskeletal disabilities with 25 years experience in this field and a worldwide reputation as a leading practitioner and researcher of disability. You are the Clinical Director of a rehabilitation hospital, a partner in a private practice, Director of three private health companies, President of the local golf club and Commodore of the local yacht club. You have served on various taskforces, etc over the years and presented numerous papers on disability.

You have strong ideas on the need for more effective health intervention and promotion of medical research, specifically for those with musculoskeletal disabilities. Studies undertaken by you have identified that in countries where effective and efficient private organisations have been funded to provide early intervention for such people; there are major long-term gains in client function. Such gains seem to be sustained and you have calculated that investment in such

care would drastically reduce the need for later interventions, hence leading to significant long-term financial cost savings. This money could then be reallocated to other health areas.

DOCUMENT THREE - STORMING ROLE-PLAY

TASKFORCE MEMBER 2

All members of the taskforce have the following information. A number of experts have been approached by the Prime Minister, Helen Clark, to discuss and provide recommendations to her on the priorities of health spending for disability.

Presently, funding for elderly support and care in rest homes, etc. eats up 80% of the disability budget. There is no more money available and while Helen acknowledges there is real and desperate need for people with disabilities, the reality is that it must be a balancing act within the confines of the present budget. She wishes the taskforce to provide her with answers to the following questions:

- Should there be redistribution of the disability budget?
- If not redistributed, why not? And how do we alleviate the plight of all the rest of the people with disabilities given that there is no more money?
- If redistributed, why? And how do we counter the lower level of funding for the elderly?

All group members have a high degree of experience and expertise in the disability arena.

Information for Taskforce Member 2
You have a significant disability and have been active in the promotion of disability issues over 40 years. You are a leader in DPA, have a Doctorate in Political Science and are lecturing in disability at Massey University. You are current editor of the New Zealand Disability Journal, a member of the Board of Directors of Workbridge and have served on numerous governmental committees and taskforces.

You are rather cynical about this latest group as your experience has shown that all the discussions in the world do not seem to change anything. Your disability has recently deteriorated so that the level of function you previously enjoyed seems to have been permanently diminished. Also, staff cuts are occurring at Massey and you have been informed that both your position and the future of the whole disability course are under review. It seems again, that it is those with the power and money who are changing things for so-called improvement and, again, those with disabilities are going to be the losers.

DOCUMENT FOUR - STORMING ROLE-PLAY

TASKFORCE MEMBER 3

All members of the taskforce have the following information. A number of experts have been approached by the Prime Minister, Helen Clark, to discuss and provide recommendations to her on the priorities of health spending for disability.

Presently, funding for elderly support and care in rest homes, etc. eats up 80% of the disability budget. There is no more money available and while Helen acknowledges there is real and desperate need for people with disabilities, the reality is that it must be a balancing act within the confines of the present budget. She wishes the taskforce to provide her with answers to the following questions:

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- If not redistributed, why not? And how do we alleviate the plight of all the rest of the people with disabilities given that there is no more money?
- If redistributed, why? And how do we counter the lower level of funding for the elderly?

All group members have a high degree of experience and expertise in the disability arena.

Information for Group Member 3
You are a specialist in geriatric medicine and have practiced in the rehabilitation for elderly arena for 10 years. Your major achievement has been as head of a geriatric rehabilitation unit in a mid-sized regional centre. This unit was at the brink of closure when you were employed. In fact, it was widely known that cost overrun's, inefficient clinical scheduling and practice not only threatened the unit but severely effected the financial position of the whole hospital.

Within 3 years you achieved a profit for the unit, lowered waiting times and response times. You also introduced up to date practitioner practices and disability technology that have markedly increased clients return to independence. Regrettably, this required that you lay off all the old staff but most were offered new contracts although at substantially lower pay rates. The hardest decision was to close the long-term stay ward and limit length of inpatient times. Inpatient and outpatient throughput has doubled, staff numbers reduced and community nursing halved. Rest homes have experienced a period of rapid growth but have been able to accommodate the majority of people discharged from the unit but unable to return to their homes.

You believe there is still plenty of room for improvement but there needs to be an increase of funds for rest homes and resources to help the elderly achieve independence.

DOCUMENT FIVE - STORMING ROLE-PLAY

TASKFORCE MEMBER 4

All members of the taskforce have the following information. A number of experts have been approached by the Prime Minister, Helen Clark, to discuss and provide recommendations to her on the priorities of health spending for disability.

Presently, funding for elderly support and care in rest homes, etc. eats up 80% of the disability budget. There is no more money available and while Helen acknowledges there is real and desperate need for people with disabilities, the reality is that it must be a balancing act within the confines of the present budget. She wishes the taskforce to provide her with answers to the following questions:

- Should there be redistribution of the disability budget?
- If not redistributed, why not? And how do we alleviate the plight of all the rest of the people with disabilities given that there is no more money?
- If redistributed, why? And how do we counter the lower level of funding for the elderly?

All group members have a high degree of experience and expertise in the disability arena.

Information for Group Member 4
Your career began some 50 years ago in retail. Your interest in disability issues arose when you became a parent of a child with intellectual disabilities. Involvement with IHC eventually led to a position as Executive Officer for the organisation, responsible for all the organisation activities throughout New Zealand. You are a director for a wide range of companies throughout Australasia and are well respected for your knowledge, skill and expertise in both the areas of management and disability. IHC has struggled over the last 15 years to provide the necessary services within the tight economic environment. However, you have managed to not only maintain services but also improve and increase services to clients of IHC. The key to these improvements have been a greater use of volunteers combined by a reduction in the wage bill through restructuring and renegotiations of salaries possible under the Employment Contracts Act (ECA). A niggling concern that seems to be growing by the day is that these key elements no longer appear stable. The ECA looks like it is going to disappear and there has been a sharp decline in the number of volunteers available. It looks as though everything you have managed to build is threatened and IHC may be right back where it started when you took over.

Storming
While the facilitator will establish their leadership role in the first stage (forming) and participants will accept and start working within the ground rules of the group, we have yet to address the real task for which the group has been formed. Realisation that that the agenda cannot be altered and de facto control of the process by dominant group members is unlikely does not necessarily mean that the facilitators' role remains unchallenged. At the stage of storming, the focus is the purpose of the group or task to be completed. Realisation that the task is different and more difficult than imagined often results in testy, blameful and overzealous behaviours commonly directed at the facilitator.

Feelings often present are:

- Resistance to the task and ideas about the subject that individual members are uncomfortable with
- Sharp fluctuations in attitude about the group and the chance of success in achievement of goals.

Behaviours often observed include:

- Arguing among members even when they seem to have similar ideas
- Defensiveness and competition - factions and 'choosing sides'
- Challenging the appropriateness of the research topic and why people are chosen to be included and why others have not been
- Establishing unrealistic goals - overstating the aims of the process and then pointing out that this is too much work for the time available
- A perceived 'pecking order' within the group with accompanying disunity, jealousy and increase in tension.

ACTIVITY FIVE
STORMING ROLE PLAY

Participants will follow the same method and assume the same roles as in Activity Four

Norming

At this stage, which is really the endpoint of the first two stages and movement towards the final stage, members fully accept the role of the facilitator, other members and begin to work together to achieve the group goals. They begin to realise that the process works, the goals are achievable and other members have something to contribute and that the process not only allows for such contribution but also guarantees their opportunity to contribute.

Feelings evident in this stage include:

- A new ability to express criticism constructively
- Acceptance of membership in the group
- Relief that it seems everything is going to work out

Behaviours often observed are:

- An attempt to achieve harmony by avoiding conflict
- More friendliness, confiding in each other and sharing of personal experiences - discussion of the group dynamics
- A sense of group cohesion, a common spirit and goals
- Establishment and maintenance of group ground rules and boundaries (the 'norms)

ACTIVITY SIX
NORMING ROLE PLAY

Participants will follow the same method and assume the same roles as in Activity Four

Performing

Group dynamics are now established, hence, members can concentrate on achievement of group goals. Members accept each others strengths and weaknesses and start performing to address the issues and work towards consensual agreement on these issues.

Feelings present include:

- Members having insights into personal and group processes, and better understanding of each other's strengths and weaknesses
- Satisfaction at the group's progress

Behaviours common are:

- Constructive self change/adaptation of ideas
- Ability to prevent or work through group problems
- Close attachment to the group

ACTIVITY SIX
NORMING ROLE PLAY

Participants will follow the same method and assume the same roles as in Activity Four

The Role of Leadership

Commonly, facilitators attempt to use a collaborative or supposedly democratic leadership style. The facilitator will consciously offer no direct opinion and will attempt to be a neutral promoter of open discussion. Input will normally be in the form of challenges to members reasoning, for example, 'But don't you think that there are other possibilities?' A common reply might 'Like what?' and may be met with a response such as 'Well, I don't really know, but surely there could be other options'. Such interaction is assumed to empower the members and minimise the chance of the facilitator inhibiting responses and influencing what is discussed.

While it is acknowledged that such a strategy is a useful tool and should be employed at specific instances throughout the facilitation process, it is felt that the facilitator's covert intent may cause as much information bias as more overt interaction. Furthermore, time restraints, the diversity of experiences and expectations of participants generally demand a certain degree of facilitator control of the process. All the relevant areas need to be discussed with assurance that the goals that led to formation of the groups are reached.

Hence, there is a need for facilitators to be fully knowledgeable of the responsibilities of leadership to achieve the goals of the process. Therefore, facilitators need to understand and support the purpose of the exercise, rather than embark on some personal agenda. Furthermore, sound background knowledge of the issues involved, in this case definition of health, self and disability, is essential to understand the underlying concepts that are discussed and to identify what maybe crucial statements.

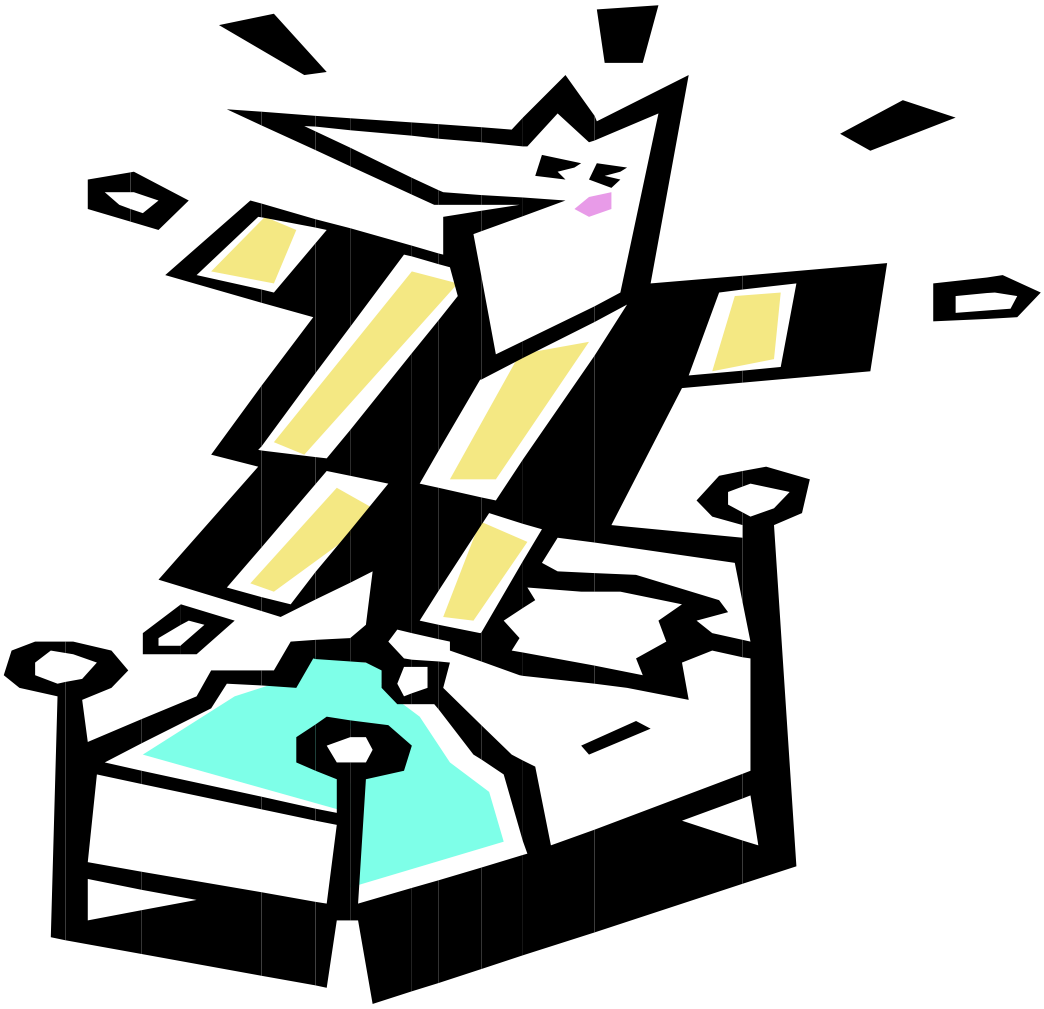
However, the goal is not perfection of performance. The aim of group activity is to reach a consensual conclusion. Consensus implies total agreement. However, it does not imply that group members agree to see or believe the same thing. It means that there is total agreement about what they do conclude, even if these conclusions are in total disagreement. Even if differing views emerge, there will also be areas of commonality and both are vital results of the group process that need to be formally acknowledged. The strength of the group process is it allows diverse ranges of knowledge to be forwarded, discussed, challenged and expanded rather than destroyed through violent verbal combat. There is no place in the group process for a debating contest, point scoring and devaluing other group members.

THE HEALTH, SELF AND DISABILITY STUDY

PART TWO

HEALTH, SELF and DISABILITY DEFINITIONS

Kieren Faull



DEFINITIONS

HEALTH DEFINITIONS

Health, in New Zealand, tends to be defined as a primarily a matter of physical wellbeing. Although the cognitive and social characteristics of both the individual and society are generally acknowledged as factors that determine health outcomes, it is the physical dimension that is perceived as the primary indicator of good health. Consideration of spirituality as a major determinant of health is rare (refer Ministry of Health, 1999).

Similarly, those who define health in relation to disability, seldomly seem to have direct experience of disability. For example the National Advisory Committee in Health and Disability (NHC) largely comprises people who have tended to make a living from those who experience 'poor health' rather than those who live with such experiences (NHC, 1999). It is such health professionals who traditionally are given the task of defining what health is, what the aims of healthcare are and what the state of self should be that we all should aspire to achieve.

ACTIVITY ONE

WHAT IS HEALTH?

AIM

To explore participant's definition of health, how they arrived at this and to identify possible alternatives

OBJECTIVE

By the end of the activity participants will have a greater awareness and understanding of differing perspectives of health.

TIMING

- 10 minutes for introduction and individual work
- 30 minutes for group work
- 60 minutes for debriefing

Total time: one hour and 40 minutes

MATERIALS REQUIRED

- A copy of the question sheet
- Paper and pens

BACKGROUND

We all base our beliefs and definitions on past experiences/learning. From this we formulate what we believe to be true and seldomly critically examine these beliefs to evaluate whether or not the assumptions we have are based on sound principles. The activity seeks to facilitate identification, examination and challenging of beliefs so that the participants become aware of the diversity of opinion and the individualistic nature of truth.

METHOD

1. Welcome participants to the session. Explain that we are not seeking the 'right' definition but want a free-thinking discussion of what health may mean and not necessarily what it means for the individual. Use examples from Document One to facilitate the process. Present as an overhead.

2. Ask participants to spend 5-10 minutes, on their own, noting down all the possible meanings of health they can think of. Ask them to look at the examples and try to see in what ways these people might be healthy/unhealthy.

3. With the course controller facilitating discussion, ask participants to discuss their ideas.

4. Debrief by identifying the aspects of human existence that are part of what it is to be healthy.

DOCUMENT ONE

HEALTH DEFINITIONS

Identify in what ways the following people might be healthy/unhealthy

1. I am a female, married with four children and five grandchildren. All my children have professional careers, as have I and my husband of 20 years. My husband and I were childhood sweethearts and have been in love ever since. My children all live close by, we are in regular contact and we constantly have the most fantastic family get togethers.

I have been diagnosed with breast cancer and have undergone extensive chemo-therapy and radiation treatment. My specialist has informed me that these treatments have been unsuccessful and tells me I have no more than 12 months to live.

2. I am a university lecturer and researcher. I have an international reputation in my field of research; I travel extensively and are in constant demand as a public speaker. I am physically active and enjoy a wide variety of sports (including pursuit and conquest of those of the opposite gender). I have four children from three marriages that I usually see at Christmas/birthdays or whatever. If I don't manage to see them, I always send presents. I presently live alone and have no immediate plans to re-enter the mess that is long-term relationships.

3. Lately, I have been experiencing severe and constant headaches. I am still able to play tennis and squash but I am finding these activities to be more of a chore than an enjoyment. I do not sleep too well and seem to be suffering from the effects of setting up and running my own business. My employees are now capable of managing the day to day business affairs and we are fortunate to be in the right business at the right time. Financially, we have all we ever hoped for and more. My partner and the children are very loving and supportive and

everybody seems to be happy to have me around more often. I just don't see the point of it anymore.

4. I am a 25 year old paraplegic. Before the accident I was a keen rugby player and surfer. I have my share of girlfriends but these seem to be drying up a bit lately. However, I've recently got involved with basketball and am meeting plenty of new and exciting people. Boy! Have they opened my eyes! I'm off to university next year and I am going to do that engineering degree I always talked about but somehow didn't get around to. I really are enjoying life and I didn't realise what was out there until all these things happened to me - I could've spent the rest of my life in that town and working in the factory - I'm free!

SELF DEFINITIONS

There have been copious quantities of material written about and discussions on the subject of what and who we are, that is the self. Psychology has been at the forefront of such investigations and those in this field fell deeply in love with the established sciences of biology, chemistry and physics. The one thing psychology seems to have wanted most of all over it's brief 100 year lifetime is to grow up to be just like these 'real' sciences. Unfortunately, at times this seems to have become more important than that for which it was originally born, that, is, the investigation and understanding of the reality of the human experience.

Because of psychology's preoccupation with the scientific method of other sciences, it has tended to want to investigate only the bits of self that can be easily measured. This has led to a concentration on the observable parts of us and a lack of attention to the more subjective parts. Furthermore, this type of scientific focus demands that only those things that can be rationally explained should be considered. Anything that cannot be explained rationally is assumed to be nonexistent or, at best, the result of something that is rationally explainable but, as yet, unidentified. Hence, the concept of spirituality has generally be not considered as worthy of discussion or investigation.

ACTIVITY TWO

AIM
To examine individual life histories and identify significant personal life events to determine to what extent planning or 'chance' played in, first, them happening and, secondly, the outcome of these events.

OBJECTIVE
By the end of the activity participants have identified the extent to which their personal, rational planning and control has played a part in their life histories.

TIMING
- 10 minutes for introduction and individual work
- 60 minutes for individual work
- 30 minutes for debriefing

Total time: one hour and 40 minutes

MATERIALS REQUIRED

- Paper and pens

BACKGROUND

Assumptions of who we are and the degree to which we have control and knowledge of what we will become tend to reflect the influence of conventional models of self. These rationally based models leave little room for the possibility of a limit to self-knowledge or self control over one's future. The possibility of personal destinies or that human beings are more irrational than rational tends to have been dismissed. Analysis of personal histories will enable such issues to be explored.

METHOD

1. Welcome participants to the session. Provide a personal life history to illustrate and introduce the activity.

2. Ask participants to spend up to 60 minutes, on their own, developing a timeline of major life events and the role they played in bringing them about and determining the outcome of these events.

3. With the course controller facilitating discussion, ask participants to discuss what they have found from this activity.

4. Debrief by discussing the possibility that the self is much more than observable, rational and objective elements.

DISABILITY DEFINITIONS

The major point I wish to raise here is that disability definitions are about power. There is plenty of literature available that discusses the different definitions (these are included in the recommended readings) and it is not our aim to describe or discuss these. It is enough to note that disability definitions tend to differ in identifying who is the disabled and who must do the changing. For example, the medical model of disability argues that disability is a physical problem that health professionals must fix to enable the victim to regain a functional state as close to the physically ideal as possible. Hence, it is the health professionals that have the power and the person with a disability who must change. One does not have to be a genius to conclude that medically focused health professionals have developed this model, in the main.

In contrast, the social model of disability has been developed by those with disabilities. Guess who has to do the changing now and who is in the powerful 'expert' position to advise and help implement those changes? You guessed it, people with disabilities, in fact the social model's basic tenant is that those with disabilities are society in general. So-called 'people with disabilities' do not actually have disability, rather they have an impairment and disability only comes about because society is so disabled it is unaware of the barriers and obstacles that turn a simple impairment into a major social obstacle.

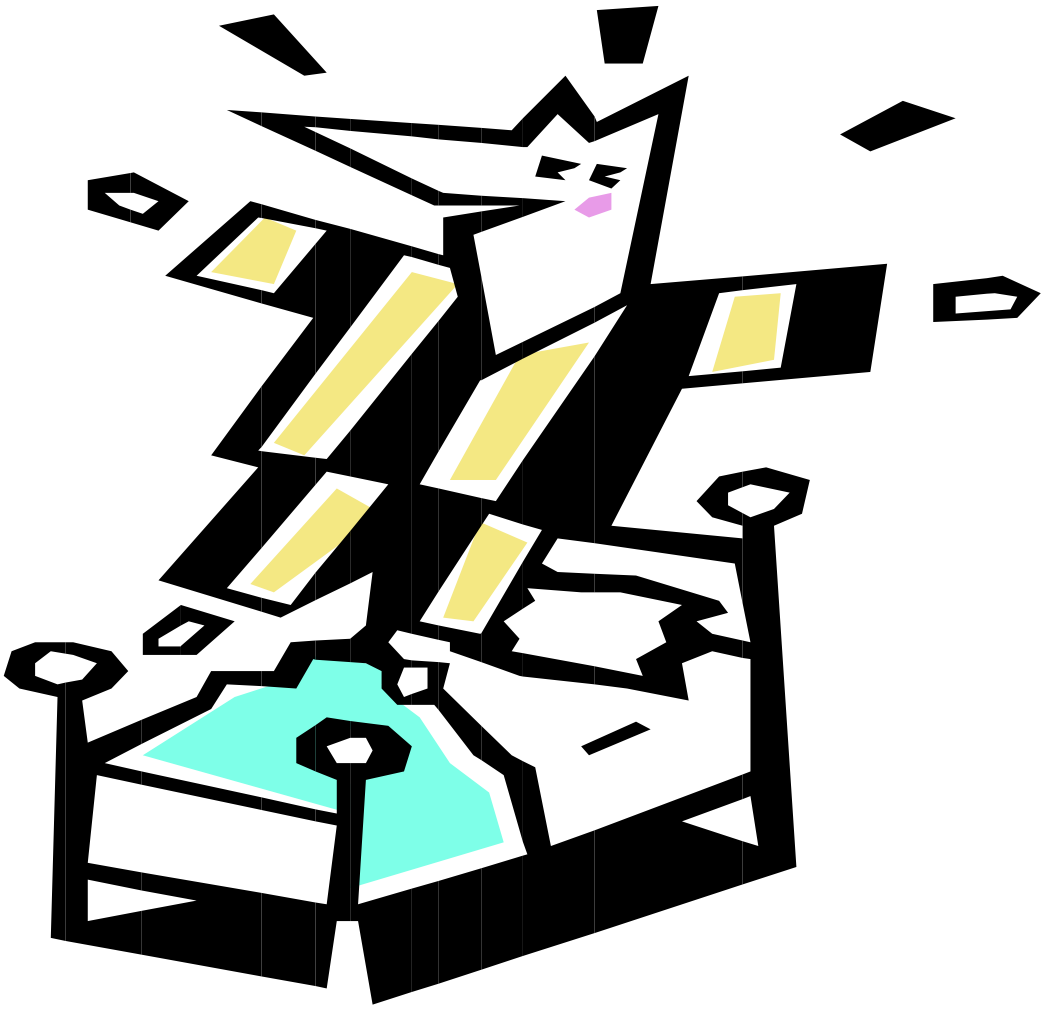
The same trend has followed across all disability definitions, sometimes attributing the need to change to one group (and the power to another) and voce versa. The only constant has been the continual themes of power and change. How does a spiritual model of self fit into all this? If we have a spiritual model incorporated into rehabilitation, who has the power and who has to change? I believe this is why everybody finds such a concept so frightening and challenging. From such a perspective, there is no option of looking to others to change or attributing disability to anyone because such a model proposes that we are all to some measure healthy and disabled. Furthermore, the power for change is not attributed to any individual but identified as connection and relationship to the spiritual.

THE HEALTH, SELF AND DISABILITY STUDY

PART THREE

QUALITATIVE DATA COLLECTION

Kieren Faull



THE DELPHI TECHNIQUE

There are many different ways to gather data qualitatively. The Delphi Technique is an established method for the collection and analysis of data. The process is sufficiently robust to be able to be adapted to provide a method to gather a broad and diverse range of information. Furthermore, this technique provides an efficient way to identify meanings and general themes from information or data.

The Delphi technique is a group decision making technique that often results in better results when time and money warrant the extra effort. Multiple 'experts' provide opinions/ideas/answers to the same statement/question, then compare results. These shared results are considered with aim of reaching a consensual agreement on the answer to the statement. The process is repeated until the experts are no longer progressing towards consensus. There are two basic types of technique, the accelerated and traditional Delphi techniques. Both techniques follow the same process as outlines. However, the accelerated method brings the group members together to discuss and debate the statement face to face, which speeds the process up. The traditional method seeks to foster anonymity and usually uses a coordinator as the point of contact for all members who normally are unaware of the identity of other members.

In the present study, a combination of both techniques will be used.

The Expert Panel

The core of the method is the expert panel who is made of people who are knowledgeable on the topics that the group wishes to find answers to. In this particular case, we are seeking answers to questions about the impact of disability on who we are, what helps us become that makes us believe we are healthy and how that health can be described or defined. Hence, the workshops have two aims. First, to allow as many people with disabilities as practical to voice their opinions and record these opinions, secondly, increase the range of knowledge and expertise of the facilitators/expert panel on these topics.

In the Health, Self and Disability Study, people with disabilities will take part in a workshop and, in groups of 10, discuss the research questions. These are:

- What does it mean, if you say 'I am healthy'?
- What are the main things you need for health?
- What are the main things that others, including health professionals, can do for you to help you to be healthy?

Facilitators will lead each group and ensure the key points are recorded. It is essential that the facilitators take careful note of ALL the opinions/ideas as it is intended that the participants' knowledge will widen the facilitator's knowledge so that ALL opinions/ideas contribute to the study results.

In this study there is a fundamental difference from the conventional approach used in the Delphi technique. Although the actual method is exactly the same, assumptions about what the consensual agreement is, or even what consensus maybe are markedly different. Commonly, it is assumed consensual agreement is reached when points or ideas have been rigorously challenged and debated until one opinion is identified and agreed by the group as the 'right' one. I believe this is not necessarily so. Why can't consensus mean when ALL group members identify

what the main points are, even if those points are vastly different? Hence, in this study,

All opinions/ideas must be forwarded, rigorously tested and examined for rational, reasoned legitimacy. Group consensus (in the workshops) will be reached when ALL group members agree that ALL the legitimate opinions/ideas of note to arise from the discussion that are relevant to the question addressed have been recorded.

Hence, the aim of the group discussions is not to arrive at one group opinion but to ensure all reasoned opinions are recorded so that they can be used by the expert panel to increase their knowledge, awareness and expertise on the relevant issues.

Note: In the strictest sense, such a workshop is not part of the Delphi methodology. However, this investigation is providing a process that allows the expert panel to expand the expertise and be better able to critically examine their own opinions/ideas.

Delphi Data Analysis
After the workshops, the data collected by the facilitators will be given to the Principal Researcher. Once the data has been examined for clarity and comprehensibility, it will be distributed to panel members. Each panel member will receive data from a different group than they lead in the workshops.

Utilising this data and their own expertise, members will provide answers to the research questions that will then be circulated to other members. It is envisaged that the in initial rounds of analysis answers will be quite long and unfocussed. This traditional Delphi technique approach to the analysis will continue until the Principal Researcher identifies that further progress is minimal. At this stage, the group may come together for a day session and use the accelerated technique.

Pitfalls of the Delphi Technique
The aim is to achieve a consensus (as defined here) NOT **the one answer**. The Principal Researcher is assuming that there is no one right answer but that, for such a topic, multiple truths will be evident. **Our aim is to reach a consensus as to what those multiple truths are.**

The Delphi technique has a history of being misused to put in place the aims, thoughts and objectives of those with power. Under the guise of consensus, facilitators sometimes assume a dominant role of controlling the voices that are heard and interpretation of those voices. It has been found that, in some instances, facilitators with expert knowledge of group dynamics and psychology have used this technique to actually hinder open discussion of ALL viewpoints and misused it to achieve confirmation of their own views. Hence, the need for facilitators to be clear that their role is that of ensuring ALL participants at the workshops voice their opinion where possible and that the facilitators **do not** hijack the process to forward their own viewpoints.

Appendix 4 : SIQS Study Information Sheet

Spiritual Model of Health Questionnaire Development Study.

INFORMATION SHEET 2/10/02

What is it?
You are invited to take part in a study, approved by the Bay of Plenty Ethics Committee and the University of Waikato's Psychology Department Ethics Committee, to develop a questionnaire that measures health from your point of view. The study does not focus on you personally but investigates how physical, social, mental and spiritual aspects of who we are fit together and affect wellbeing. "Level of wellbeing" is how the World Health Organisation defines health.

What would I need to do if I agreed to take part?
Within a week of receiving this Information Sheet the researcher, Kieren Faull (Queen Elizabeth Hospital) will telephone you to ask if there is anything you wish to discuss about the study and whether or not you are interested in taking part.

If you are, he will send you a questionnaire that asks some personal details, what you think are the important things for health and what questions should be asked about these things to measure your health.

If you have email, he will send it as an attachment. If not, he will post the questionnaire to you with a stamped, return-address envelope. You may wish to spend up to an hour or more thinking and writing your answers to these questions. Completion of the questionnaire and returning it by either email or post to Kieren Faull at Queen Elizabeth Hospital will be taken as your consent to participate.

The information from this questionnaire will start the rounds of analysis and information gathering, which is shown on the next page.

The total time involved for you in this study is approximately four (4) hours, spread over about six (6) weeks. Taking part in this study is voluntary (your choice). You may stop at any time. This will in no way affect your continuing health care.

What Kieren will do	What you will do
Send you a copy of the Participant Health Questionnaire	
	Complete the Participant Health Questionnaire and send back to Kieren. This should take about one (1) hour.
Categorise questionnaire information into common themes and send these back to you.	
	Rate what you feel are the ten most important statements/questions in each theme from one (1) to ten (10) and send these ratings back to Kieren. This should take about one (1) hour.
Kieren will work out the average rating for each statement/question. He will send you the overall scores and a note telling you of any of your ratings that are very different from the average that he will calculate from everybody's ratings.	
	After you have reconsidered your rating, in light of now knowing how others have responded, you will send back to Kieren your new ratings. These may or may not be different from your original ratings. This exercise should take no longer than one (1) hour.
Kieren will select the top rating four or five questions in each theme and any other questions that seem to be very important to some people and send these back to you.	
	Your task now will be to look at these questions, rate their importance and suggest changes. You will then send these suggestions back to Kieren. This exercise should take no longer than one (1) hour.
These questions will form the basis of a draft questionnaire which will be trialed in another study.	
Kieren will send you a summary of the study results and invite you to a presentation of the research findings at Queen Elizabeth Hospital	

Who will know it was me that took part?
Kieren Faull will be the only person who knows you took part. You will not be told who else is taking part because it is important that it is your answers we get and that nobody else influences you. Your name will be removed from the initial participant questionnaire and replaced with a number as soon as Kieren Faull receives it. What number fits what name will be stored separately from your answers and ratings and known only by Kieren.

Who else is taking part?
100 other people, selected randomly, who have been inpatients of the Queen Elizabeth Hospital Rheumatology and Rehabilitation Unit.

What are the benefits of the study?
The study will lead to a better understanding of the experience of disability, the role of spirituality in health and help to provide a measure the effectiveness of treatments from the point of view of the people in the study. It is probable that these results will also useful for all people with chronic ill-health problems and those that treat them.

What can I do if I wish to talk to somebody about this?
After receiving this Information Sheet you are welcome to ring Kieren Faull at Queen Elizabeth Hospital, or make an appointment to discuss any issues about the study that may concern you. Kieren Faull will ring within a week of your receiving this Information Sheet and he welcomes anything you may wish to discuss about the study. His Supervisor, Dr Michael Hills, Department of Psychology, University of Waikato, Hamilton, Ph (07) 838-4466, xt 8296 can also be contacted if you wish. The Health Consumer Service is available to all patients in the Midland Health Area. Any participant in this research project who has concerns about treatment can contact the Health Consumer Service. The freephone number is: 0800 223 238.

Thank you for your time.

Kieren Faull
Researcher
Queen Elizabeth Hospital
Whakaue St.,
PO Box 1342,
Rotorua.
Ph. (07) 348 0189 ext. 877

Appendix 5: SIQS Study Initial Echo Technique Questionnaire

PARTICIPANT HEALTH QUESTIONNAIRE

PART ONE

This section of the questionnaire is concerned with general information about you.

Name:

_____

Please circle one

1. Are you Male Female

Please circle one

2. Are you 16 - 25

26 -35

36 - 45

46 - 55

56 - 65

66 - 75

76 - 85

85 or over

3. New Zealanders identify with a number of ethnic group(s), for example, New Zealand Pakeha, New Zealand Maori, New Zealand Pacific Islander, New Zealand Asian, and so on. Please write which group(s) you identify with.

_____

4. How long have you had your disability/illness?

Please circle one

Under 2 years	2 - 5 years
6 - 10 years	10 - 20 years
Over 20 years	

5. What is your disability/illness?

_____

6. What is the **highest** level of education you have achieved?

Please circle one

Primary School

Secondary School

School Certificate

University Entrance/Sixth Form Certificate

University Bursary

Polytechnic or other trade training (certificate)

Undergraduate/Bachelor degree

Graduate/Masters degree

Other _____

7. What religion, if any, do you belong to?

_____

8. How important is your religion to you?

Please circle one

More important than anything else

Very important

Important

Necessary but not very important

Of no importance at all

Don't know

9. What was, or is, the occupation of the major income earner in your home?

_____

PART TWO

This section asks your opinion about the importance of spirituality to health for you.
Research has identified spirituality as consisting of four main themes:

- Relationships: The experience that other things (for example, animals, the natural world of trees, plants, animals, water and earth, people, a creative force, energy or being) are in some way related to, or in a relationship with us.

Relationships or relatedness is closely associated to the second theme of connection.

- Connection: The experience that one not only has a relationship with many things but that some of these things are an essential part of oneself and cannot be separated from that self.

- Beliefs: Experiences of personally meaningful relationships and connections increase the individual's awareness of their place in the world and their ability to contribute to their community. This experience of heightened self-awareness provides them with a sense of wholeness, purpose and direction. This process leads to a healthy, reality-based understanding of what is right/wrong, good/bad, important/unimportant, etc.

- Meaning: Closely associated with meaning is purpose. The individual's beliefs/values system allows them to develop their unique understanding about the meaning of life and in particular the meaning of their own life.

10. In **YOUR OPINION**, has spirituality, as defined here, got anything to do with your health **(please tick box)**

Yes□ No□

If you answered 'No' go straight to Question 25

If you answered 'Yes', go to the next question and carry on to complete the rest of the questionnaire

PART THREE

The aim of this section is for you to provide the researcher with statements and questions that can be used to begin the development of a questionnaire of health, based on the spiritual model of self, which reflect the opinions of people with physical disabilities.
There are no right or wrong answers, so feel free to tell me what you think.

11. What might others do to make it easier for you to achieve better health?

12. What might others do to make it harder for you to achieve better health?

13. What might you do which makes it easier for you to achieve better health?

14. What might you do which makes it harder for you to achieve better health?

15. What are the *most* valuable things others might do to make it easier for you to achieve better health? You may reuse answers from earlier questions, or introduce new ideas.

16. What are the *most* valuable things you yourself might do to make it easier for you to achieve better health? You may reuse answers from earlier questions, or introduce new ideas.

17. What are the *least* valuable things others might do to make it easier for you to achieve better health? You may reuse answers from earlier questions, or introduce new ideas.

18. What are the *least* valuable things you yourself might do to make it easier for you to achieve better health? You may reuse answers from earlier questions, or introduce new ideas.

19. Give us examples of things which you feel greatly helped you to be healthy.

20. Give us examples of things which you feel did little to help you to be healthy.

21. What do you not enjoy about trying to become healthy?

22. What do you enjoy about trying to become healthy?

23. What external resources (ie; resources outside yourself) do you need to achieve better health?

24. What losses of external resources make it harder for you to achieve better health?

25. You are now invited to write questions or statements that we might use to measure a person's health, taking into account all its aspects: physical, mental, social and spiritual.

When writing a question,

- Think about behaviours that illustrate or show good health.
- Write in such a way that you and others can easily understand what is being asked.
- Try to include how you think people should answer for each question (for example, true-false, multiple choice, a scale of 1 to 10, etc.). It will help to understand the question if we know how it should be answered.
- A question shouldn't sound as though it comes from a textbook. Just suggest important questions that reflect the basic aspects of health.

Examples of possible ways to ask questions and ways to answer that may help you are provided at the end of this questionnaire.
You do not have to use any of these types.
Invent your own!
These are only to help you

Thank you for your time

Please either: 1. Return as an email attachment to research@qehospital.co.nz

OR

2. Place in the attached return-addressed envelope and return to us

Question and Answer Examples

Example One

I think Shortland Street is

1. Terrible
2. Not too good
3. All right
4. Pretty good
5. Very good

Example Two

The All Blacks are the best rugby team in the world

True False

Example Three

My ability to write a letter is

Good Good to Fair Fair Fair to Poor Poor

Example Four

Mark with a cross (X) on the line below how you would rate the Prime Minister's looks

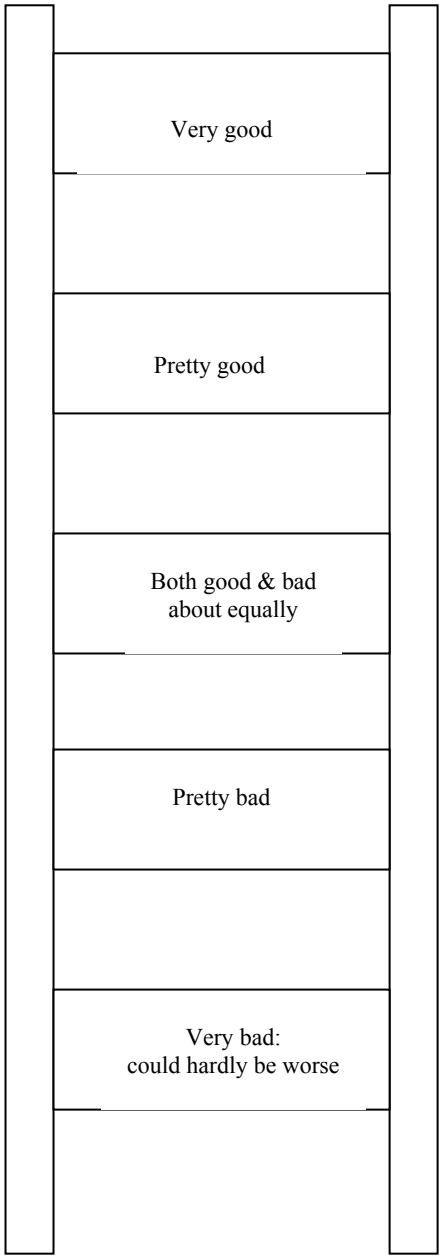
Extremely Good Looking — Extremely Ugly

Example Five

	STRONGLY AGREE				STRONGLY DISAGREE
I think the Queen of England is good looking	1	2	3	4	5

Example Six

Over the last year, New Zealand sports team performances have been:



Appendix 6: SIQS Study Rating Of Health Statements Questionnaire

Rating of Health Statements Questionnaire

To: Spiritual Model of Health Questionnaire Development Study participants.

First, I would like to apologise for the time it has taken to return the attached information to you. Some people wrote their own questions but some did not. Everybody provided me with a large amount of information to the rest of the questions, so I decided to use these statements as the basis for developing a questionnaire. I transcribed all the answers to the questions, identified common groups or themes (there were 139 of these), counted up the number of times each theme appeared, reduced these by removing the least frequent and combining others that were similar until I had a questionnaire that was not too long. These were then developed into the statements that appear in this questionnaire. We are developing a composite health measure that reflects your perspective of health but the attached questionnaire is **not** this health measure. It is part of the process of developing a health measure.

The questionnaire is really a **rating scale** to see **how much you agree or disagree** with each statement. All you need to do is read the statement and **circle** the **number** on the scale provided after each statement that is closest to how much you agree or disagree with the statement. This should take you no longer than one (1) hour.

Some of you who receive this letter found the first round a little difficult and did not complete it. I am sending this package to you so that you may continue to take part in the study if you wish. You are not obligated to take part and if you do not wish to then simply do not return the questionnaire in the prepaid envelope.

Thank you for taking the time to fill out the questionnaire. If you have any further questions you may contact me.

Kieren Faull
Phone: 07 348 0189 ext.877
email: research@qehospital.co.nz

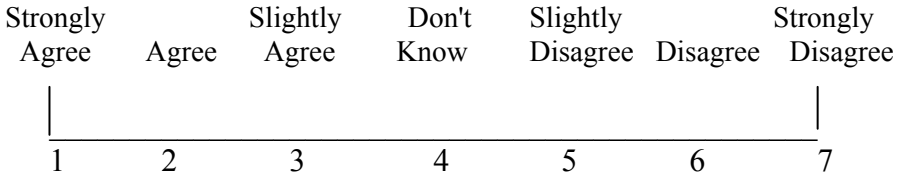
Rating of Health Statements

Questionnaire

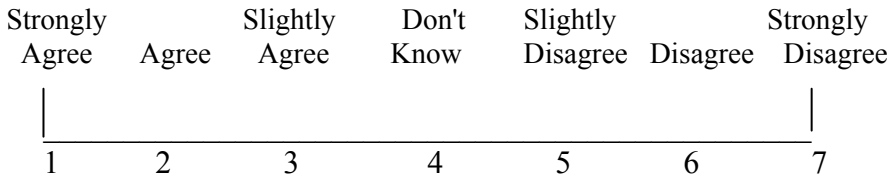
Please **circle the answer** to each statement on the scale provided. **Circle the answer that is closest to how much you agree or disagree with each statement**

PAIN

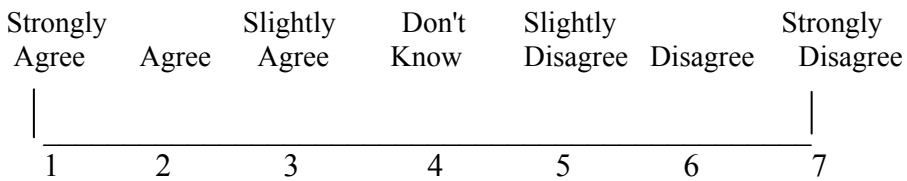
1. When pain becomes a 'background noise', I am healthier.



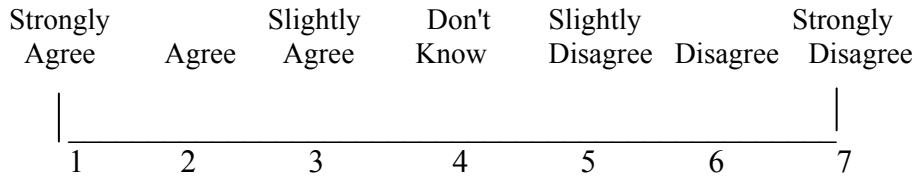
2. I am healthy only when I have no pain.



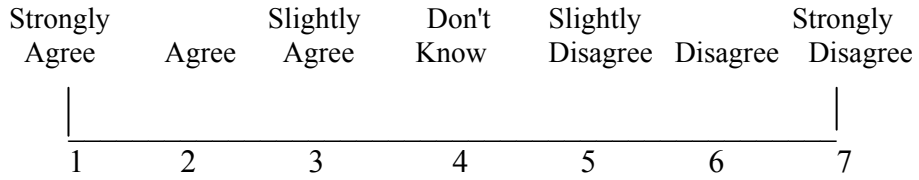
3. Talking about my pain whenever I can helps me to be healthy.



4. I need to keep mobile, even if it causes pain, to achieve health.

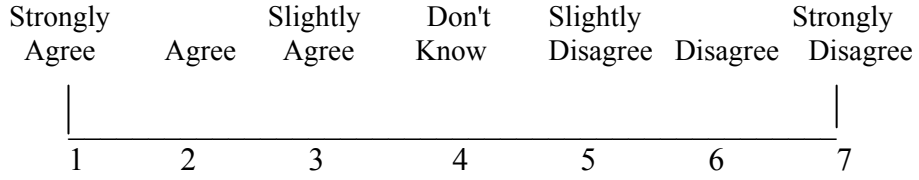


5. If I stop fighting and trying to make the pain go away, and accept it as part of me rather than as an enemy, I can be healthy in spite of pain.

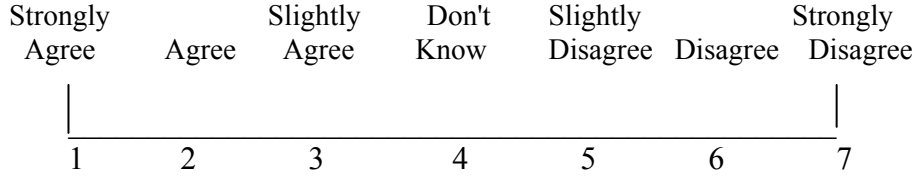


REFLECTION

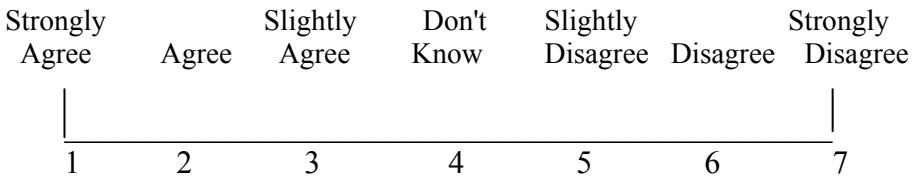
6. Turning to or connecting to something beyond myself and other people (eg, the spiritual, the divine, the supernatural, the universe, etc.) gives me the faith, hope, strength, peace, guidance, knowledge, love, warmth, etc. which are important for my health.



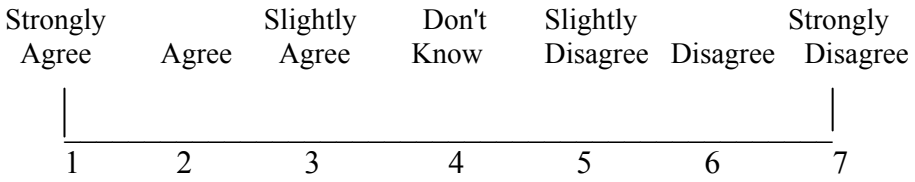
7. Understanding, belonging and feeling part of the greater world (eg, nature, people and life in general) is important for my health.



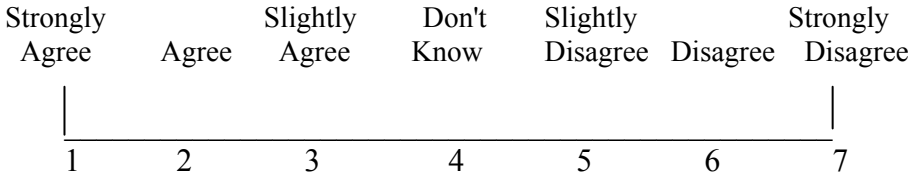
8. To be healthy, it is important for me to live with an attitude of gratitude and to appreciate the wonders of life (eg, beautiful earth, sky, music and people).



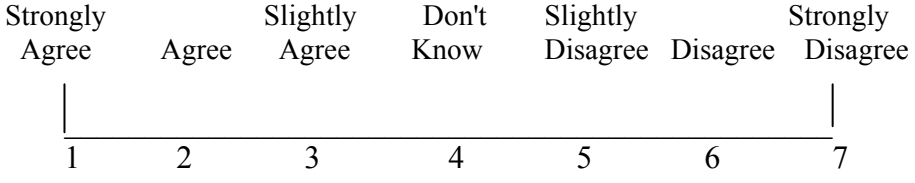
9. To be healthy, I need to make time alone, so that I can reflect, appreciate, understand and be who I am.



10. To be healthy, I have to be at peace with my life and myself.

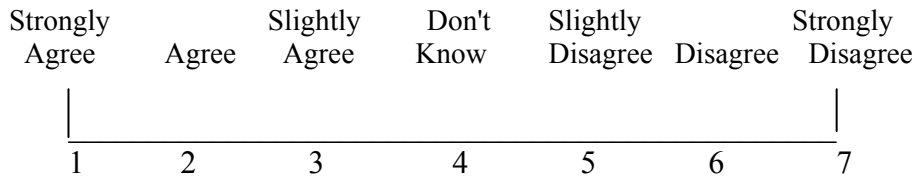


11. I need to take time to really look at myself and understand what makes my illness worse or better, because no one else lives in my body with the full understanding of what that means.

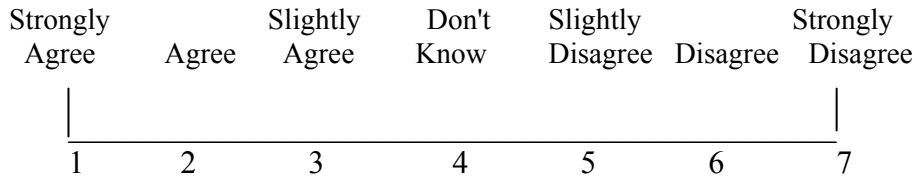


IDENTITY

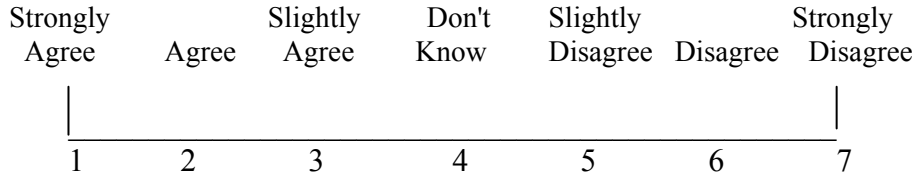
12. To be healthy, I need to see myself as a unique person.



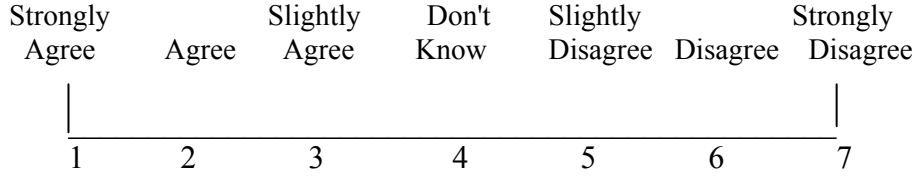
13. If I understand, accept and value myself, warts and all, I can develop a health-giving inner strength that is real, enduring, and indestructible.



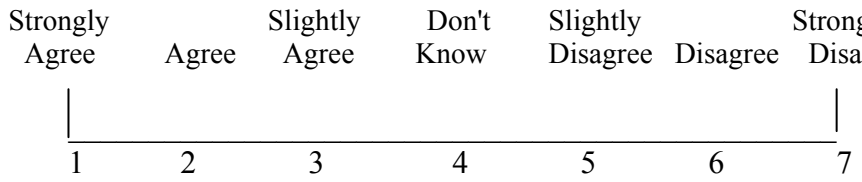
14. I need to have a purpose and meaning for my life if I am to be healthy.



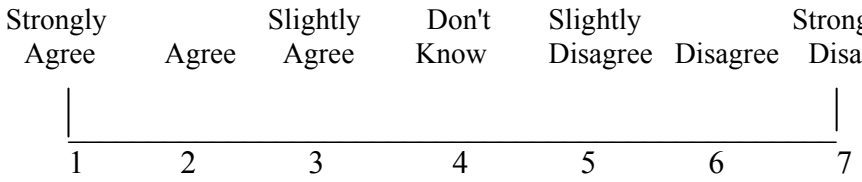
15. Physical health is not the sum of who I am; it is a big part of me but not the only part, and if I look after my spiritual, emotional and mental aspects, my physical condition is also better.



16. Only by caring for the people, animals and aspects of the natural world that are important to me can I be healthy.

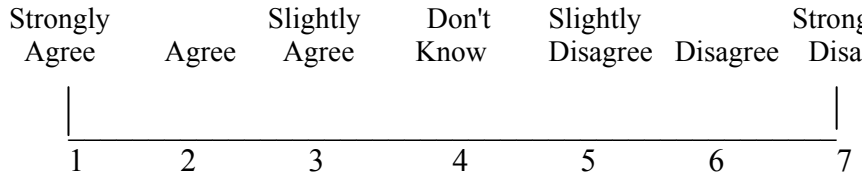


17. I need to listen to myself, work out what is right for me, choose what I need to do and then do it.

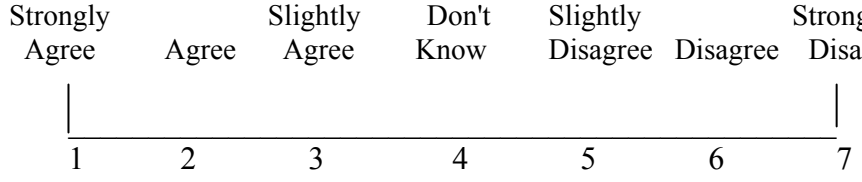


ATTITUDE

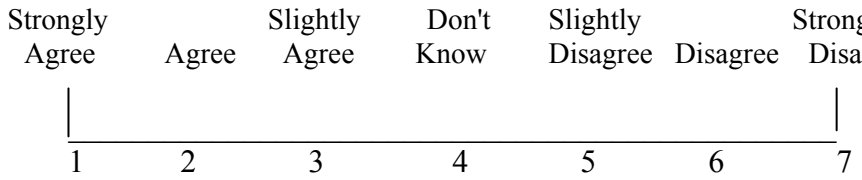
18. My disease/illness/disability has allowed me to see life and be healthy in a way I previously would not have believed possible.



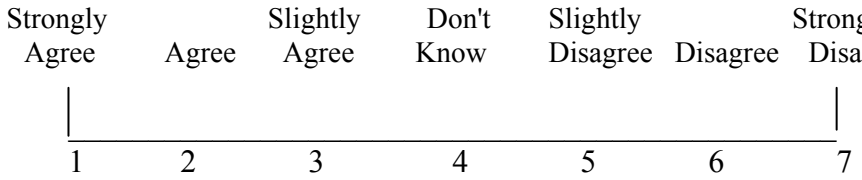
19. My disease/illness/disability is an exciting challenge that has provided me with an opportunity to be whole and indestructible.



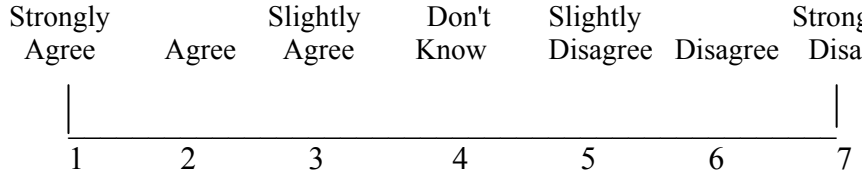
20. Anger, pity, hatred and selfishness are a normal reaction to my condition, and I need others' sympathy for what I am going through to be healthy.



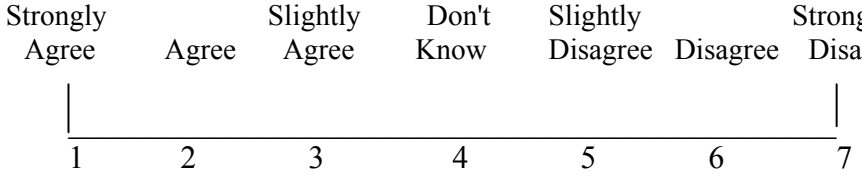
21. I need to go easy on myself and not worry if I don't get it 'right' every time. I need to love myself for who I am and be my own good company to be healthy.



22. To be healthy, I need to have an ultimate goal, but I need to make sure I set myself small, achievable steps to reach it.

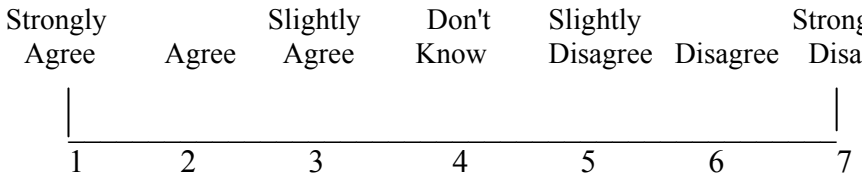


23. For health, I need to see my plans working and goals being achieved.

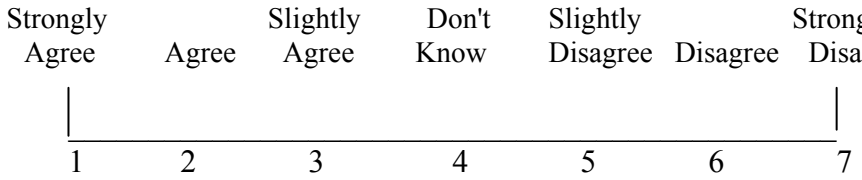


INTERACTION

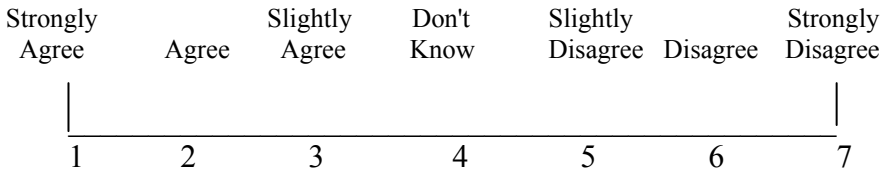
24. To be healthy, I need to be included, to share with others and to be treated as normal.



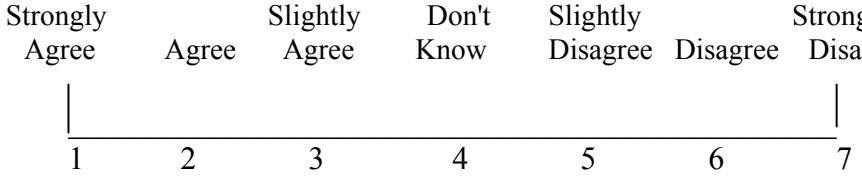
25. To be healthy, I need to make a difference by serving, helping, sharing, listening, or educating others so that they are happy and fulfilled.



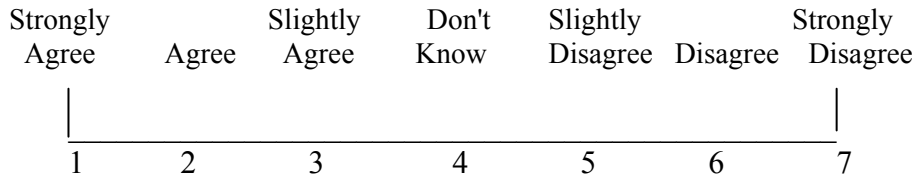
26. To be healthy, I need to be able to share with people who have had similar experiences, who can understand and not judge, but who can help me to understand and accept what is happening to me.



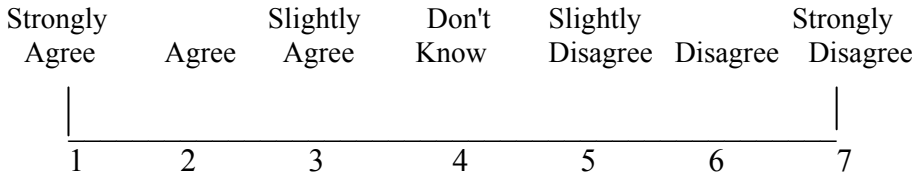
27. Fun, lots of laughter, and sharing with those around me, makes me healthy.



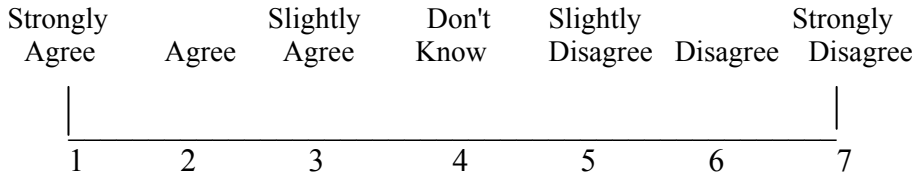
28. For health, I need to mix with people who see obstacles and ask me how we are going to do it anyway, rather than people who see obstacles and then tell me why I can't do it or what I should be doing.



29. To be able to be healthy I need a safe, secure and positive environment in which I make the choices but others are honest and tell the truth, even if it's hard to take.

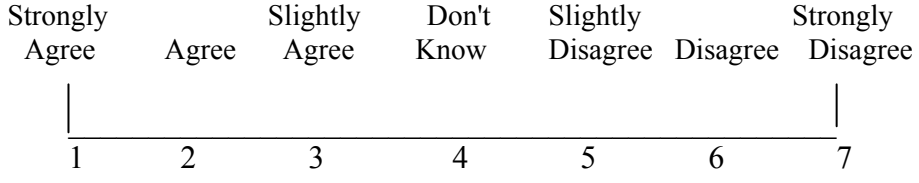


30. For me to be healthy, I need to give and receive love in a way that makes me feel at one with other people, nature and God/the universe/the spiritual world.

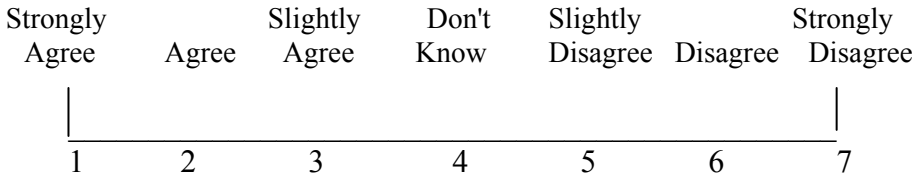


ACCEPTANCE

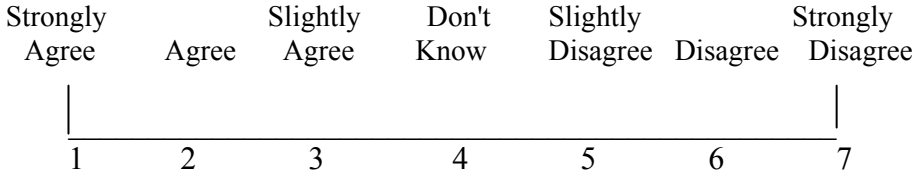
31. I am whole and have value because I am me.



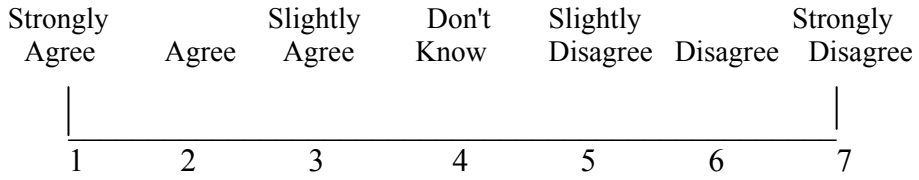
32. I can never be what I once was but I can be something more than I was.



33. The things I did in the past are not necessarily the same as the things I do now, which in turn are different from what I will be doing in the future.

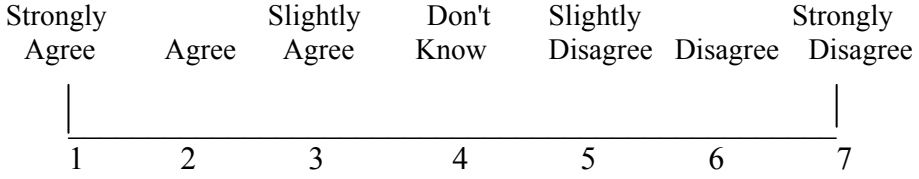


34. Life is about accepting and facing up to my own limitations; we've all got them. I can only be me if I accept all I am - warts and all!

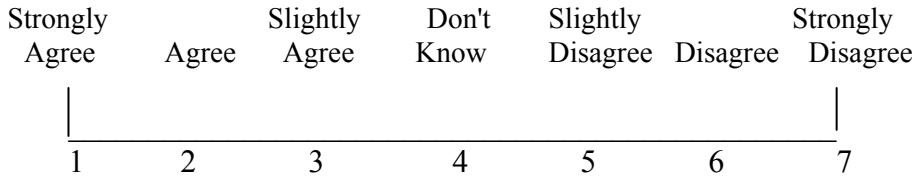


INTERVENTION

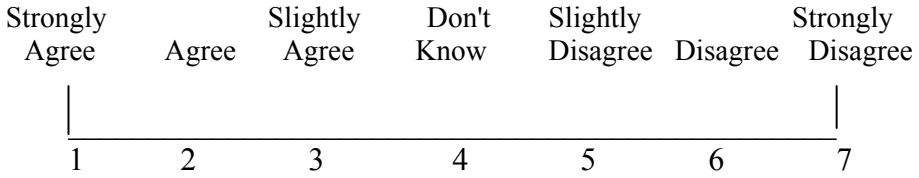
35. I need regular physical exercise (for example, walking, going to the gym, swimming, going to the pools/hot pools) to be healthy.



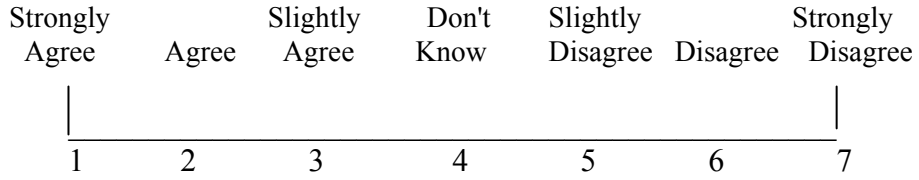
36. Diet is important for my health.



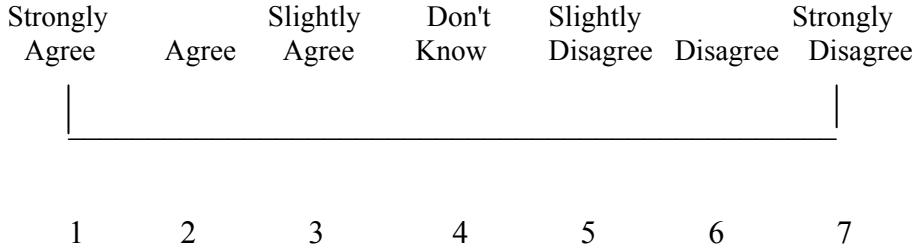
37. Being able to obtain the right aids (for example, hand braces, shoes built up, walking stick, high toilet seat, 'pick-a-upper' utensils, fat-handle pens, knives, cups, tap-turners, etc, rail to walk up/down stairs) is necessary for me to be healthy.



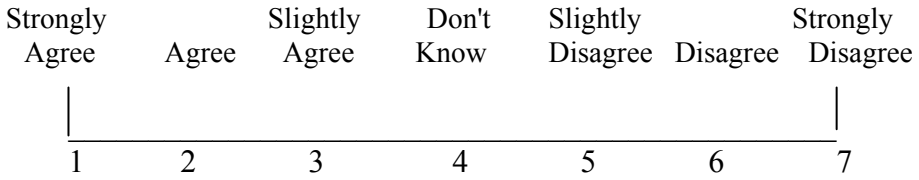
38. Conventional therapists (for example, specialists, surgeons, GP, Physiotherapy, occupational therapy, counselling, Podiatry, etc.) are important for my health.



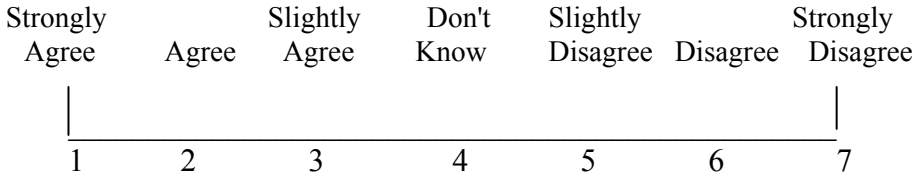
39. Alternative therapists (for example, meditation, massage, FeldenKrais movement classes, Tai chi, Reiki, faith healing, colour therapy, positive visualisation, etc) are important for my health.



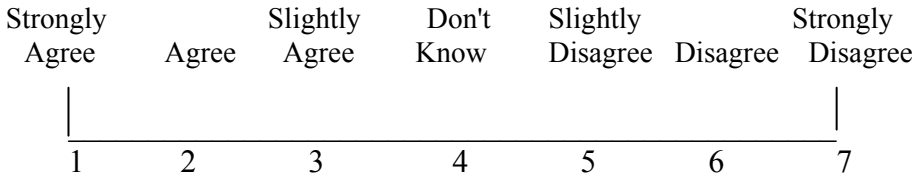
40. I need the financial resources (income, subsidies, etc) to be able to afford access to the treatments, medications, aids and help I need to be healthy.



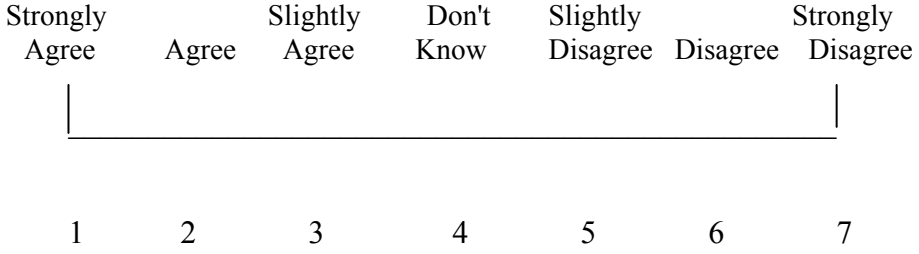
41. I need good access to public places, such as shops, toilets, medical centres, libraries, etc. to be healthy



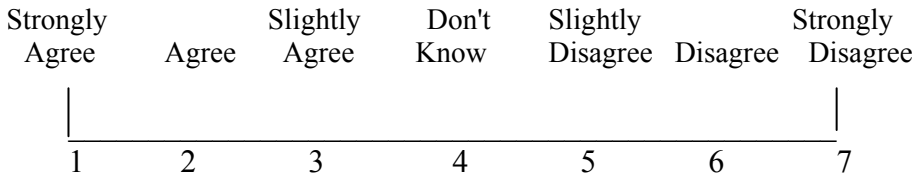
42. I need to be able to contribute to my community (for example, a paid job, voluntary work, teaching, helping others with disabilities/illnesses, being involved in the day-to-day activities of family, etc.) to be healthy.



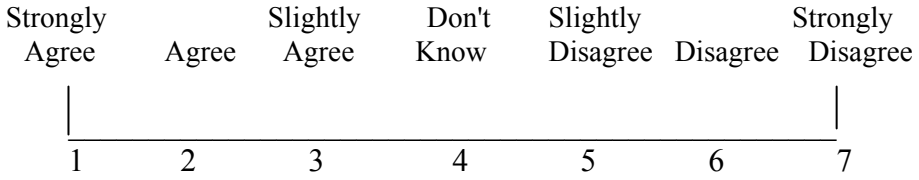
43. I need to take drugs but I also need to fully understand my condition, drug make-up and side effects and not blindly follow medical advice so that I get the right medication.



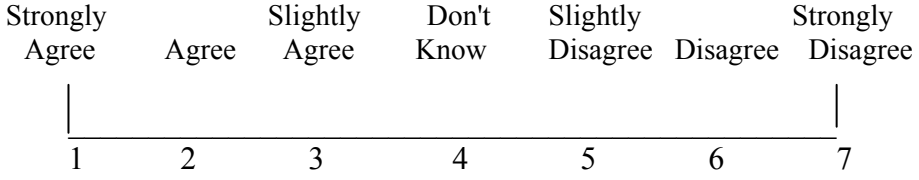
44. Drugs do not make me healthy.



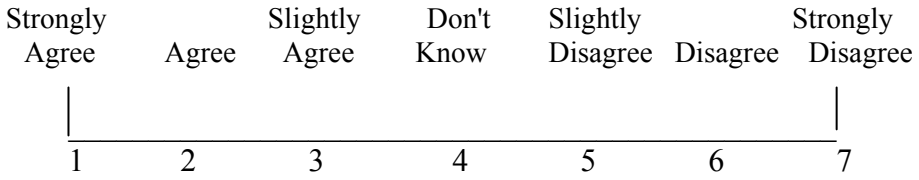
45. The medical profession needs to start using natural alternatives to drugs.



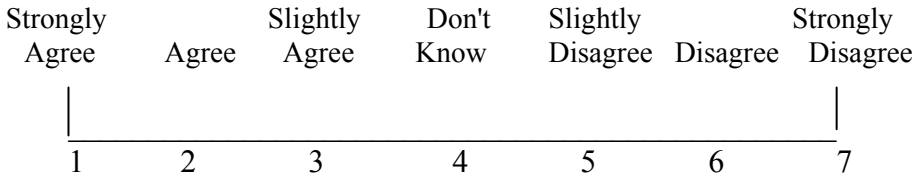
46. Alternative medicines are a waste of time and money.



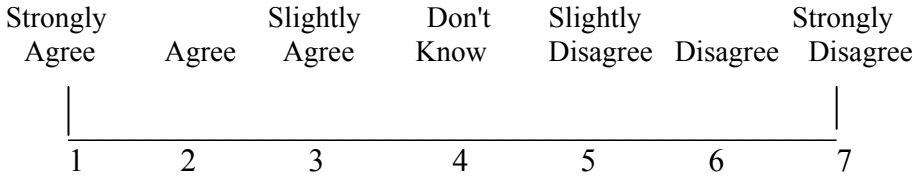
47. Access to information (eg: books, videos, the internet, email, etc.) is important for me to be healthy.



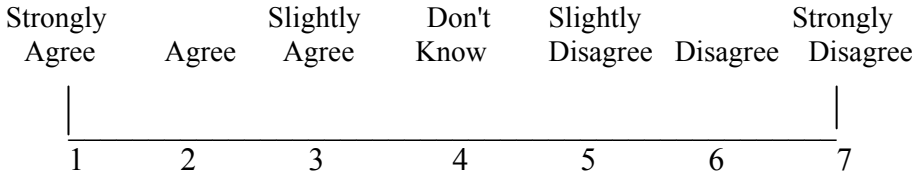
48. Educational programmes and courses which focus on being healthy with the disease, rather than just on how to control it, help me to be healthy.



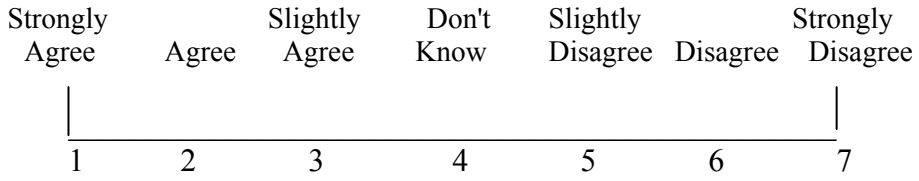
49. Informed professional follow-up, advice and support needs to be ongoing for my health.



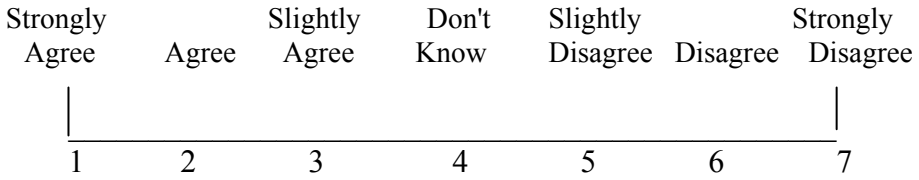
50. Advice and support from people with similar experiences needs to be ongoing for my health.



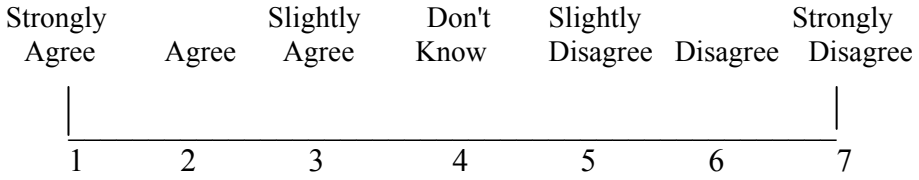
51. To be healthy I need caring health professionals who treat me as normal and don't patronise me or underestimate my capabilities.



52. A health professional that helps me solve problems, rather than telling me what to do, will empower me to believe that things can be improved.



53. Professional support which is honest and challenging, yet respects my own research and self-education, helps me to be healthy.



Appendix 7 : SIQS Study: HAS:1 Questionnaire

Pilot Study of the Health Attitudes Scale (HAS), Version 1

To: Spiritual Model of Health Questionnaire Development Study participants.

By statistical analysis of the data from the last round, I have been able to determine what are the most important statements that represent health within our study group. Your comments have also helped me to identify statements that were misleading or confusing.

The resulting **Pilot** Health Attitudes Scale is attached. I need to be able to confirm that my changes have not drastically altered the way the questionnaire works. After this, I will test it fully on about 200 other people who have been to Queen Elizabeth Hospital to see if it is an accurate and valid measure of health attitudes. The questions are basically the same ones you have already answered, but we need to repeat this process to ensure we have it as right as possible. So, I would appreciate if you could take the time to complete the questionnaire and send it back to me.

If there is anything you find difficult, confusing, etc. please write your comments on the lines provided at the end of the questionnaire. If you need more space, please use the back of this letter.

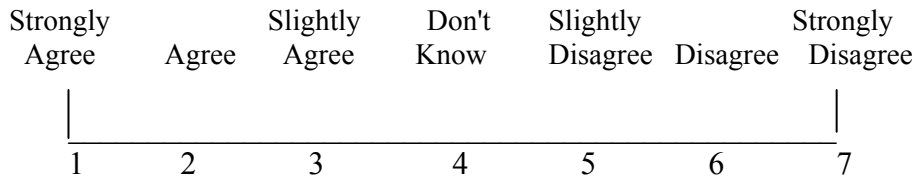
Thankyou for taking part in the study.
If you have any further questions, please contact me.

Kieren Faull
Phone: 07 348 0189 ext.877
email: research@qehospital.co.nz

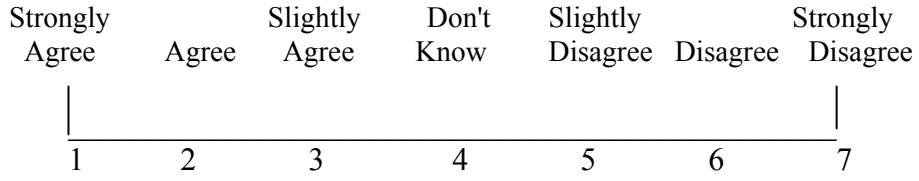
<u>Health Attitudes Scale</u> (Version 1)

Please read each question and **circle the answer** to **each** statement that is **closest** to how much you agree or disagree with each statement. There are no right or wrong answers; we simply seek to find out your attitude with respect to each statement. **It is important that you answer ALL QUESTIONS.**

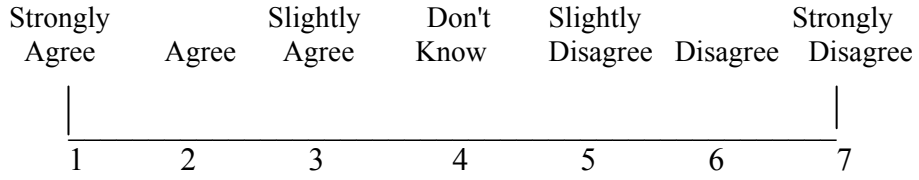
1. I need to keep mobile, even if it causes pain, to achieve health.



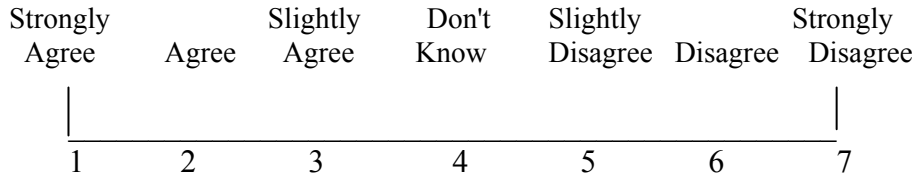
2. Being able to obtain the right aids (e.g., hand braces, built up shoes, walking frame, high toilet seat, 'pick-a-upper' or fat-handle utensils, tap-turners, rail to walk up/down stairs, etc.) is necessary for me to be healthy.



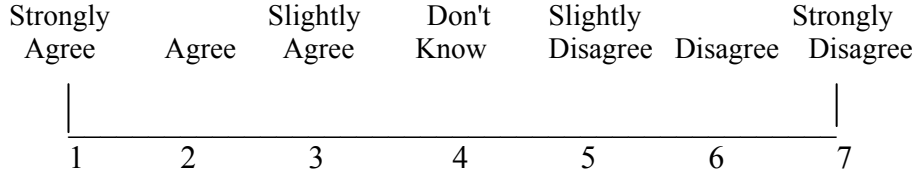
3. Access to information (eg: books, videos, the internet, email, etc.) is important for me to be healthy.



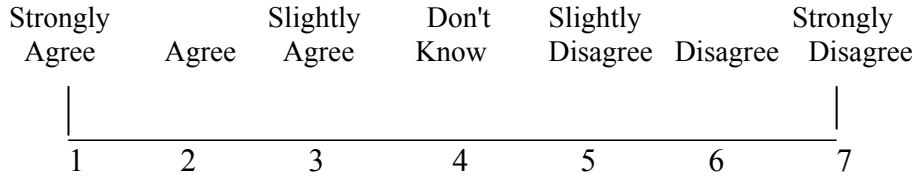
4. Educational programmes and courses which focus on being healthy with my disorder, rather than just on how to control it, help me to be healthy.



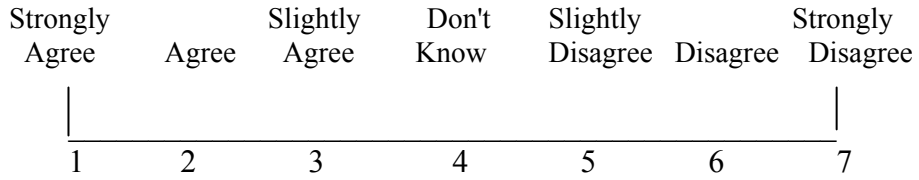
5. Fun, lots of laughter, and sharing with those around me, makes me healthy.



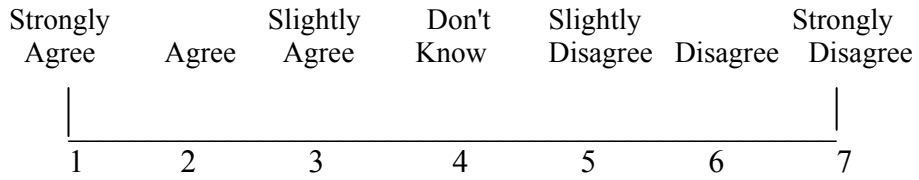
6. I need regular physical exercise to be healthy.



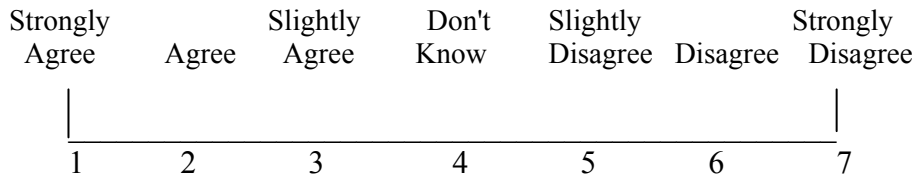
7. I need good access to public places, such as shops, toilets, medical centres, libraries, etc. to be healthy



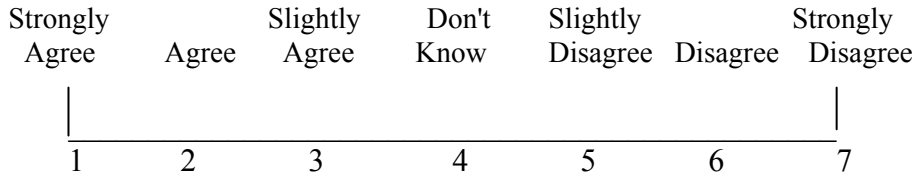
8. I need to be able to contribute to my community (e.g., a paid job, voluntary work, teaching, helping others with disabilities/illnesses, being involved in the day-to-day activities of family, etc.) to be healthy.



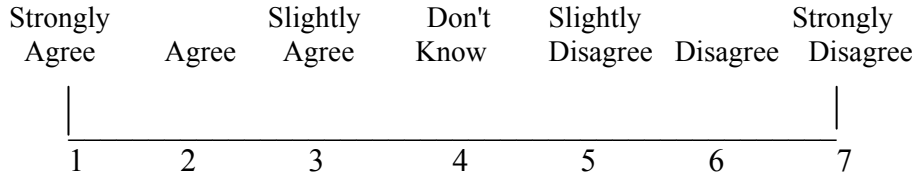
9. If I stop fighting and trying to make the pain go away, and accept it as part of me rather than as an enemy, I can be healthy in spite of pain.



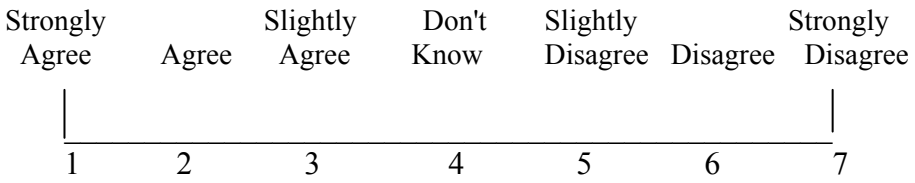
10. Professional support, which is honest and challenging, yet respects my own research and self-education, helps me to be healthy.



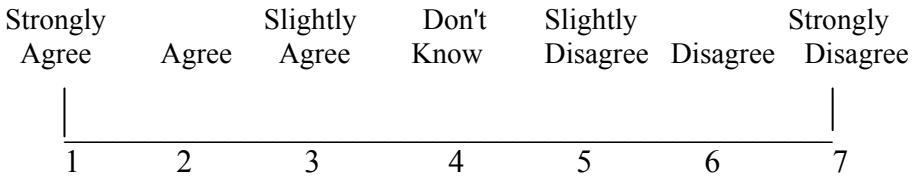
11. Understanding, belonging and feeling part of the greater world (e.g., nature, people and life in general) is important for my health.



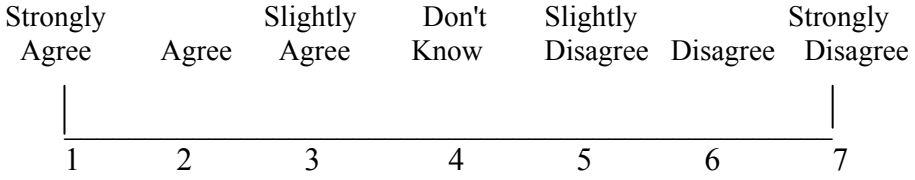
12. I need to take time to really look at myself and understand what makes my illness worse or better.



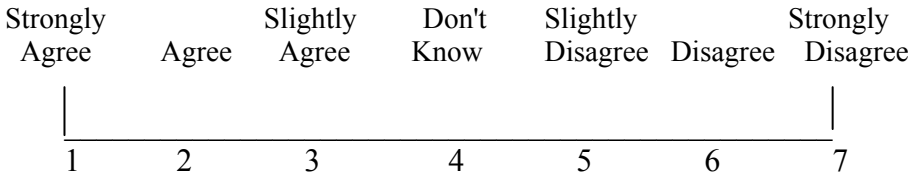
13. To be healthy, I need to see myself as a unique person.



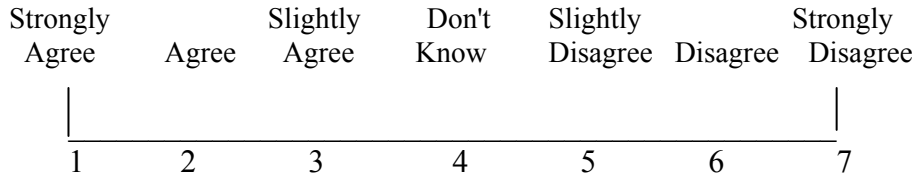
14. To be healthy I need caring health professionals who don't patronise me or underestimate my capabilities.



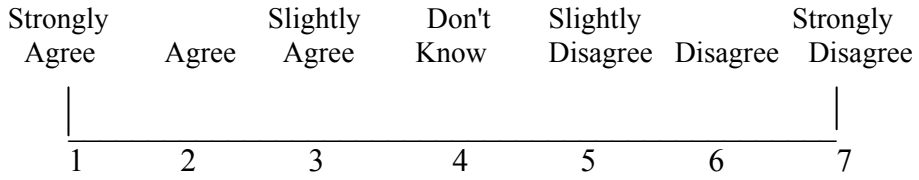
15. If I understand, accept and value myself, warts and all, I can develop a health-giving inner strength that is real and enduring.



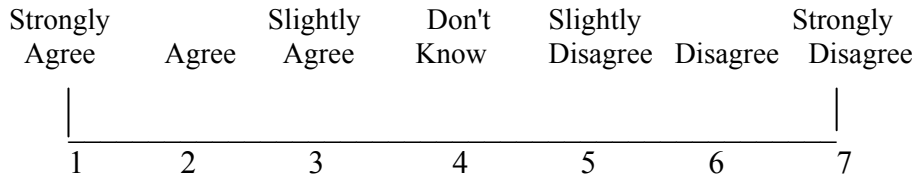
16. I need to have a purpose and meaning for my life if I am to be healthy.



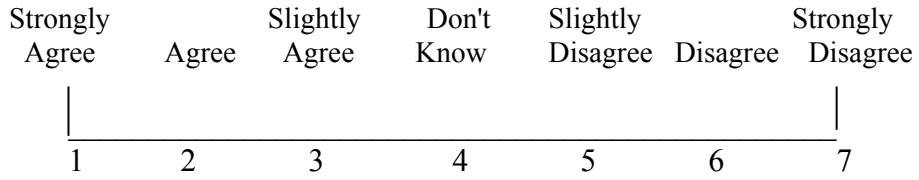
17. To be healthy, it is important for me to live with an attitude of gratitude and to appreciate the wonders of life.



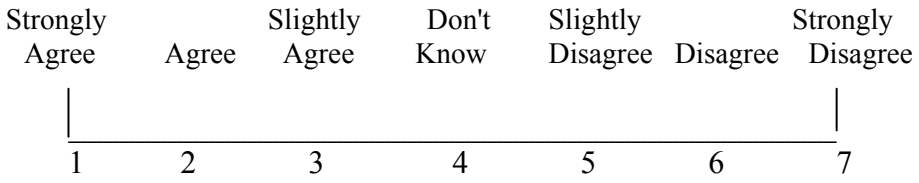
18. To be healthy, I need to make time to be alone.



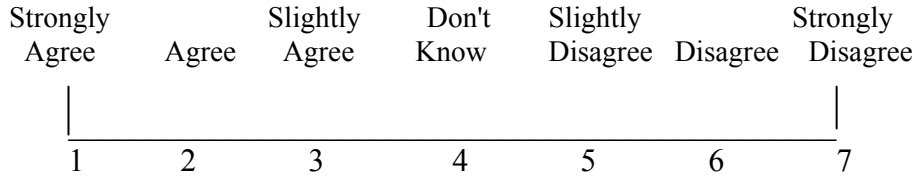
19. To be healthy, I have to be at peace with my life and myself.



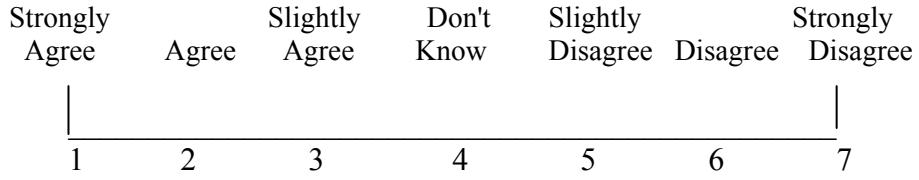
20. Physical health is not the sum of who I am; it is a big part of me but not the only part, and if I look after my spiritual, emotional and mental aspects, my physical condition is also better.



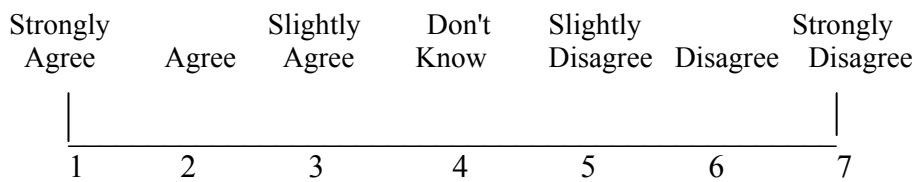
21. By caring for the people, animals and aspects of the natural world that are important to me I can be healthy.



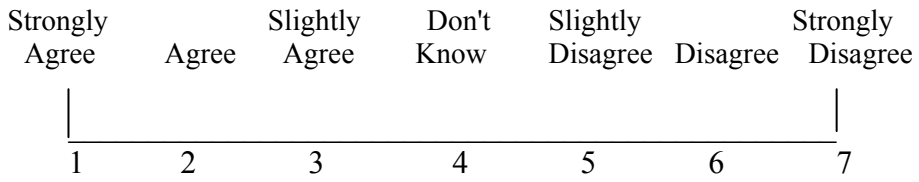
22. My disease/illness/disability has allowed me to see life and be healthy in a way I previously would not have believed possible.



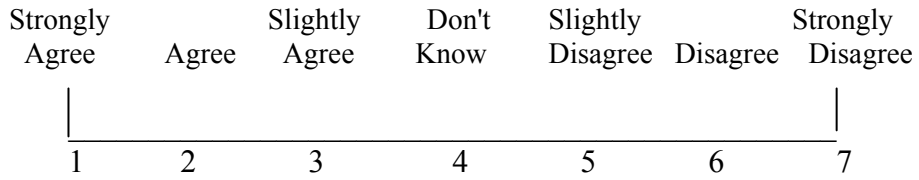
23. I need to love myself for who I am and be my own good company to be healthy.



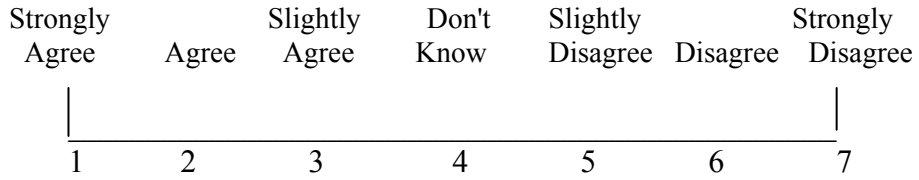
24. To be healthy, I need to make a difference by serving, helping, sharing, listening, or educating others so that they are happy and fulfilled.



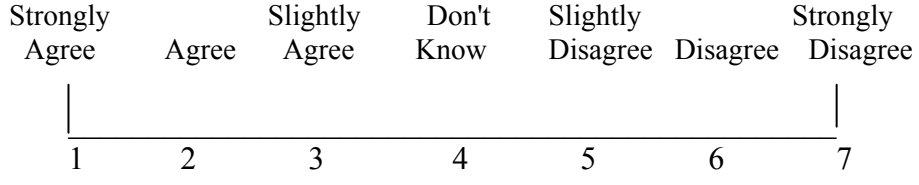
25. For me to be healthy, I need to give and receive love in a way that makes me feel at one with other people, nature and God/the universe/the spiritual world.



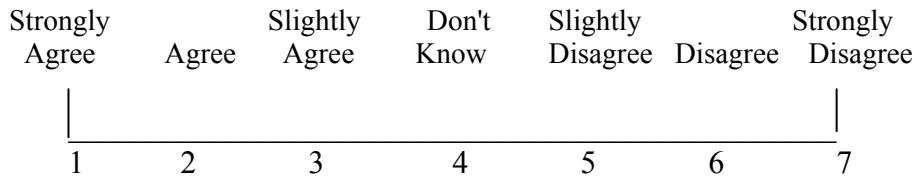
26. Turning to or connecting to something beyond myself, other people or the natural world (e.g., the spiritual, the divine, the supernatural, the universe, etc.) gives me the faith, hope, strength, peace, guidance, knowledge, love, warmth, etc. which are important for my health.



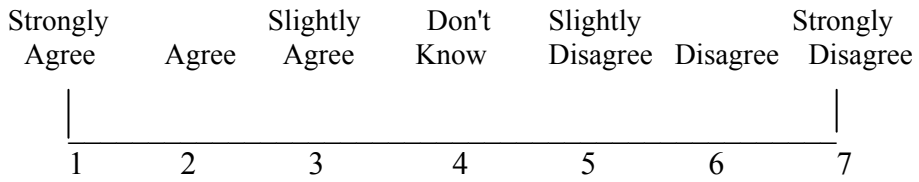
27. My disease/illness/disability is an exciting challenge that has provided me with an opportunity to be whole and resilient.



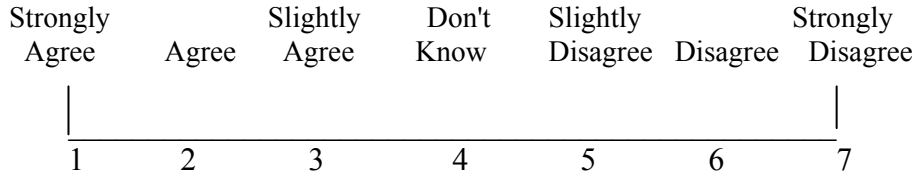
28. To be healthy, I need to go easy on myself and not worry if I don't get it 'right' every time.



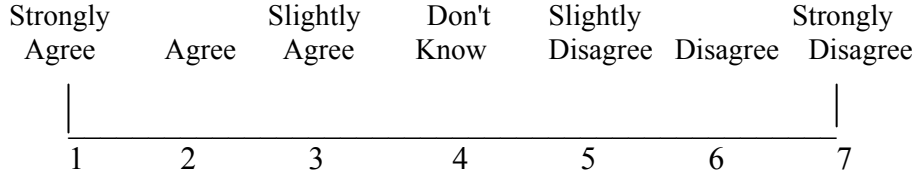
29. For health, I need to mix with people who see obstacles and ask me how we are going to do it anyway, rather than people who see obstacles and then tell me why I can't do it or what I should be doing.



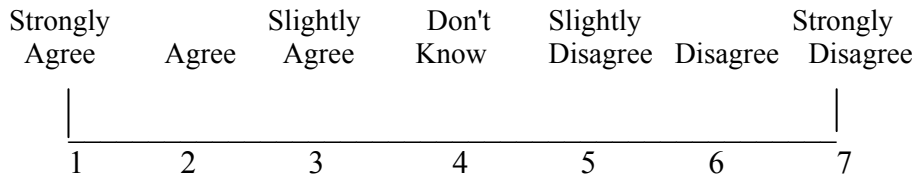
30. To be able to be healthy I need a safe, secure and positive environment in which I make the choices where others are honest and tell the truth, even if it's hard to take.



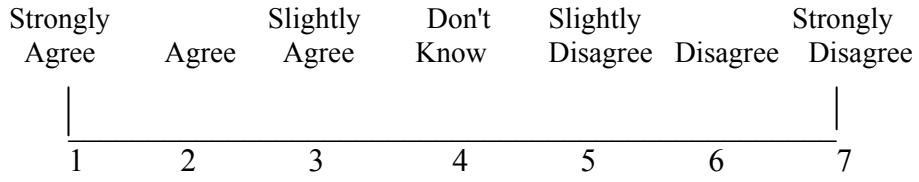
31. I can never be what I once was but I can be something more than I was.



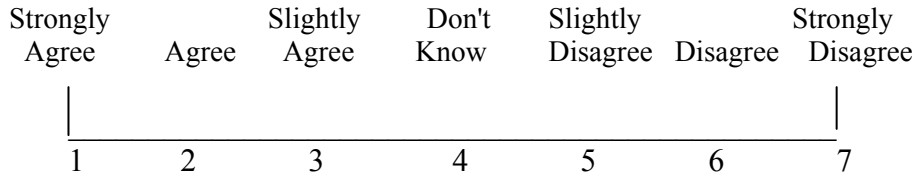
32. To be healthy, I need to have an ultimate goal, but I need to make sure I set myself small, achievable steps to reach it.



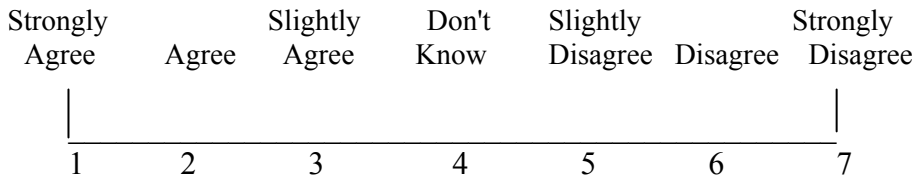
33. I am whole and have value because I am me.



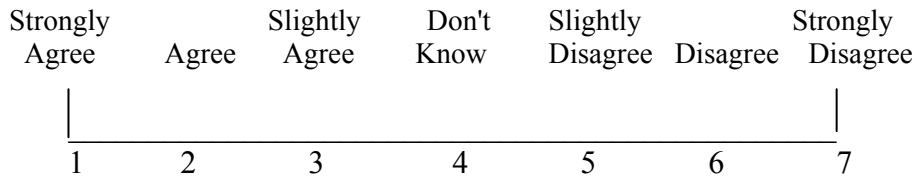
34. To be healthy, I need health professionals that help me solve problems, rather than telling me what to do.



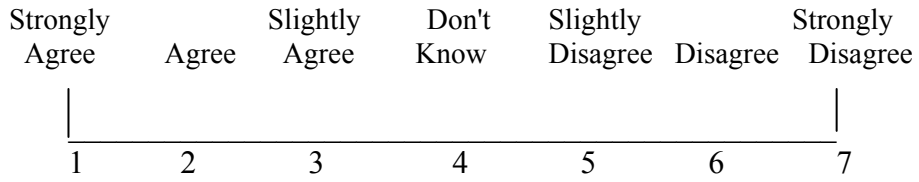
35. The things I did in the past are not necessarily the same as the things I do now, which in turn are different from what I will be doing in the future.



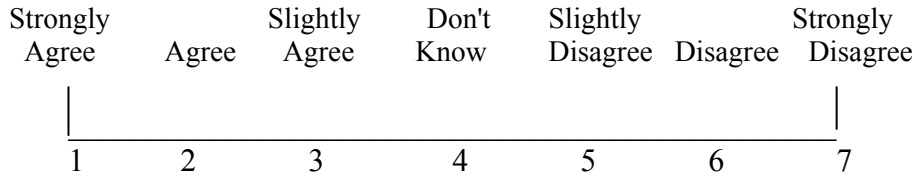
36. I need to listen to myself, work out what is right for me, choose what I need to do and then do it.



37. Life is about accepting and facing up to my own limitations; we've all got them. I can only be me if I accept all I am.



38. For health, I need to see my plans working and goals being achieved.



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Have you answered ALL the questions?

Thank you for you time

Appendix 8: SIQS Study - Changes To Round Two Importance Statement Items

Grammatical changes made were:

1. Item 8: 'I need to take time to really look at myself and understand what makes my illness worse or better, because no one else lives in my body with the full understanding of what that means (leading statement).
   Changed to: 'I need to take time to really look at myself and understand what makes my illness worse or better'.
2. Item 10: 'If I understand, accept and value myself, warts and all, I can develop a health-giving inner strength that is real, enduring and indestructible' (indestructible was seen as confusing. Many agreed with the overall statement but felt that 'indestructible' implied no loss, which did not equate to their experiences.
   Changed to: 'If I understand, accept and value myself, warts and all, I can develop a health-giving inner strength that is real and enduring'.
3. Item 17: 'I need to go easy on myself and not worry if I don't get it 'right' every time. I need to love myself for who I am and be my own good company to be healthy' (two ideas). Split into two items.
   Changed to: 'To be healthy, I need to go easy on myself and not worry if I don't get it 'right' every time'.
   And: 'I need to love myself for who I am and be my own good company to be healthy'.
4. Item 29: 'I need regular physical exercise (for example, walking, going to the gym, swimming, going to pools/hot pools) to be healthy'. Many stated they could not exercise in such ways because of their disabilities, finances or lack of adequate resources where they lived. The question is leading and tends to restrict definition of physical exercise.
   Changed to: 'I need regular physical exercise to be healthy'
5. Item 30: 'for example' was changed to 'e.g.' - this common abbreviation is well known.
6. Item 35: 'To be healthy I need caring health professionals who treat me as normal and don't patronise me or underestimate my capabilities'. Many participants perceived the term 'normal' as a highly emotive concept.

Changed to: 'To be healthy I need caring health professionals who don't patronise me or underestimate my capabilities'.

7. Item 36: 'A health professional that helps me solve problems, rather than telling me what to do, will empower me to believe that things can be improved' (leading statement).
   Changed to: 'To be healthy, I need health professionals that help me solve problems, rather than telling me what to do'.

Appendix 9 : Changes To HAS:1 Items

1. Item 15: ‘If I understand, accept and value myself, warts and all, I can develop a health-giving inner strength that is real and enduring’.
   Changed to: ‘If I understand, accept and value myself, warts and all, I can be healthy’
   And: To be healthy I need to develop a health-giving inner strength that is real and enduring’.
2. Item 30: ‘To be able to be healthy I need a safe, secure and positive environment in which I make the choices where others are honest and tell the truth, even if it’s hard to take’
   Changed to: 'To be able to be healthy I need a safe, secure and positive environment' And: 'To be healthy I need to be able to make choices in an environment where others are honest and tell me the truth, even if its hard to take'.

Appendix 10: SIQS Study: HAS:2

Health Attitudes Scale: Version 2 (HAS:2)

Please read each question and circle the number for each statement that is closest to whether or not you agree or disagree/very likely or unlikely. There are no right or wrong answers; we simply seek to find out your attitude with respect to each statement.

It is important that you answer all the questions.

	Strongly Agree	Agree	Slightly Agree	Don't Know	Slightly Disagree	Disagree	Strongly Disagree
1. I need to keep mobile, even if it causes pain, to achieve health----------	**1**	**2**	**3**	**4**	**5**	**6**	**7**
♦ How likely do you think it is that you will do this in the next week--	Very Likely **1**	**2**	**3**	**4**	**5**	**6**	Very Unlikely **7**
2. Being able to obtain the right aids (e.g., hand braces, built up shoes, walking frame, high toilet seat, 'pick-a-upper' fat-handle utensils, tap-turners, rail to walk up/down stairs, etc.) is necessary for me to be healthy----------	Strongly Agree **1**	Agree **2**	Slightly Agree **3**	Don't Know **4**	Slightly Disagree **5**	Disagree **6**	Strongly Disagree **7**
♦ How likely do you think it is that you will use aids in the next week----------	Very Likely **1**	**2**	**3**	**4**	**5**	**6**	Very Unlikely **7**
3. Access to information (eg: books, videos, the internet, email, etc.) is important for me to be healthy----------	Strongly Agree **1**	Agree **2**	Slightly Agree **3**	Don't Know **4**	Slightly Disagree **5**	Disagree **6**	Strongly Disagree **7**
♦ How likely do you think it is that you will access such information in the next week----------	Very Likely **1**	**2**	**3**	**4**	**5**	**6**	Very Unlikely **7**
4. Educational programmes and courses which focus on being healthy with my disorder, rather than just on how to control it, help me to be healthy----------	Strongly Agree **1**	Agree **2**	Slightly Agree **3**	Don't Know **4**	Slightly Disagree **5**	Disagree **6**	Strongly Disagree **7**
♦ How likely do you think it is that you will use this sort of information in the next week----------	Very Likely **1**	**2**	**3**	**4**	**5**	**6**	Very Unlikely **7**

5. Fun, lots of laughter, and sharing with those around me, makes me healthy----------

Strongly Agree	Agree	Slightly Agree	Don't Know	Slightly Disagree	Disagree	Strongly Disagree
1	**2**	**3**	**4**	**5**	**6**	**7**

- How likely do you think it is that this will happen in the next week----------

Very Likely						Very Unlikely
1	**2**	**3**	**4**	**5**	**6**	**7**

6. I need regular physical exercise to be healthy----------

Strongly Agree	Agree	Slightly Agree	Don't Know	Slightly Disagree	Disagree	Strongly Disagree
1	**2**	**3**	**4**	**5**	**6**	**7**

- How likely do you think it is that you will do this in the next week----------

Very Likely						Very Unlikely
1	**2**	**3**	**4**	**5**	**6**	**7**

7. I need good access to public places, such as shops, toilets, medical centres, libraries, etc. to be healthy--

Strongly Agree	Agree	Slightly Agree	Don't Know	Slightly Disagree	Disagree	Strongly Disagree
1	**2**	**3**	**4**	**5**	**6**	**7**

- How likely do you think it is that you will find places with good access in the next week----------

Very Likely						Very Unlikely
1	**2**	**3**	**4**	**5**	**6**	**7**

8. I need to be able to contribute to my community (e.g., a paid job, voluntary work, teaching, helping others with disabilities/illnesses, being involved in the day-to-day activities of family, etc.) to be healthy----------

Strongly Agree	Agree	Slightly Agree	Don't Know	Slightly Disagree	Disagree	Strongly Disagree
1	**2**	**3**	**4**	**5**	**6**	**7**

- How likely do you think it is that you will contribute in the next week----------

Very Likely						Very Unlikely
1	**2**	**3**	**4**	**5**	**6**	**7**

PLEASE TURN OVER

9. If I stop fighting and trying to make the pain go away, and accept it as part of me rather than as an enemy, I can be healthy in spite of pain--------

Strongly Agree	Agree	Slightly Agree	Don't Know	Slightly Disagree	Disagree	Strongly Disagree
1	**2**	**3**	**4**	**5**	**6**	**7**

- How likely do you think it is that you will do this in the next week----------

Very Likely						Very Unlikely
1	**2**	**3**	**4**	**5**	**6**	**7**

10. Professional support, which is honest and challenging, yet respects my own research and self-education, helps me to be healthy----------

Strongly Agree	Agree	Slightly Agree	Don't Know	Slightly Disagree	Disagree	Strongly Disagree
1	**2**	**3**	**4**	**5**	**6**	**7**

- How likely do you think it is that you will experience this in the next week---------

Very Likely						Very Unlikely
1	**2**	**3**	**4**	**5**	**6**	**7**

11. Understanding, belonging and feeling part of the greater world (e.g., nature, people and life in general) is important for my health--

Strongly Agree	Agree	Slightly Agree	Don't Know	Slightly Disagree	Disagree	Strongly Disagree
1	**2**	**3**	**4**	**5**	**6**	**7**

- How likely do you think it is that you will experience this in the next week---------

Very Likely						Very Unlikely
1	**2**	**3**	**4**	**5**	**6**	**7**

12. I need to take time to really look at myself and understand what makes my illness worse or better----------

Strongly Agree	Agree	Slightly Agree	Don't Know	Slightly Disagree	Disagree	Strongly Disagree
1	**2**	**3**	**4**	**5**	**6**	**7**

- How likely do you think it is that you will do this in the next week----------

Very Likely						Very Unlikely
1	**2**	**3**	**4**	**5**	**6**	**7**

13. To be healthy, I need to see myself as a unique person----------

Strongly Agree	Agree	Slightly Agree	Don't Know	Slightly Disagree	Disagree	Strongly Disagree
1	**2**	**3**	**4**	**5**	**6**	**7**

- How likely do you think it is that you will believe this is true in the next week------

Very Likely						Very Unlikely
1	**2**	**3**	**4**	**5**	**6**	**7**

14. To be healthy I need caring health professionals who don't patronise me or underestimate my capabilities----------

Strongly Agree	Agree	Slightly Agree	Don't Know	Slightly Disagree	Disagree	Strongly Disagree
1	**2**	**3**	**4**	**5**	**6**	**7**

- How likely do you think it is that you will experience this in the next week---------

Very Likely						Very Unlikely
1	**2**	**3**	**4**	**5**	**6**	**7**

15. If I understand, accept and value myself, warts and all, I can be healthy ----------

Strongly Agree	Agree	Slightly Agree	Don't Know	Slightly Disagree	Disagree	Strongly Disagree
1	**2**	**3**	**4**	**5**	**6**	**7**

- How likely do you think it is that you will do this in the next week----------

Very Likely						Very Unlikely
1	**2**	**3**	**4**	**5**	**6**	**7**

16. To be healthy I need to develop an inner strength that is real and enduring ----------

Strongly Agree	Agree	Slightly Agree	Don't Know	Slightly Disagree	Disagree	Strongly Disagree
1	**2**	**3**	**4**	**5**	**6**	**7**

- How likely do you think it is that you will do this in the next week----------

Very Likely						Very Unlikely
1	**2**	**3**	**4**	**5**	**6**	**7**

PLEASE TURN OVER

17. I need to have a purpose and meaning for my life if I am to be healthy----------

Strongly Agree	Agree	Slightly Agree	Don't Know	Slightly Disagree	Disagree	Strongly Disagree
1	**2**	**3**	**4**	**5**	**6**	**7**

- How likely do you think it is that you will feel this way in the next week----------

Very Likely						Very Unlikely
1	**2**	**3**	**4**	**5**	**6**	**7**

18. To be healthy, it is important for me to live with an attitude of gratitude and to appreciate the wonders of life

Strongly Agree	Agree	Slightly Agree	Don't Know	Slightly Disagree	Disagree	Strongly Disagree
1	**2**	**3**	**4**	**5**	**6**	**7**

- How likely do you think it is that you will feel this way in the next week----------

Very Likely						Very Unlikely
1	**2**	**3**	**4**	**5**	**6**	**7**

19. To be healthy, I need to make time to be alone ----------

Strongly Agree	Agree	Slightly Agree	Don't Know	Slightly Disagree	Disagree	Strongly Disagree
1	**2**	**3**	**4**	**5**	**6**	**7**

- How likely do you think it is that you will do this in the next week----------

Very Likely						Very Unlikely
1	**2**	**3**	**4**	**5**	**6**	**7**

20. To be healthy, I have to be at peace with my life and myself ----------

Strongly Agree	Agree	Slightly Agree	Don't Know	Slightly Disagree	Disagree	Strongly Disagree
1	**2**	**3**	**4**	**5**	**6**	**7**

- How likely do you think it is that you will feel this way in the next week----------

Very Likely						Very Unlikely
1	**2**	**3**	**4**	**5**	**6**	**7**

21. Physical health is not the sum of who I am; it is a big part of me but not the only part, and if I look after my spiritual, emotional and mental aspects, my physical condition is also better ----------

Strongly Agree	Agree	Slightly Agree	Don't Know	Slightly Disagree	Disagree	Strongly Disagree
1	**2**	**3**	**4**	**5**	**6**	**7**

- How likely do you think it is that you will experience this in the next week---------

Very Likely						Very Unlikely
1	**2**	**3**	**4**	**5**	**6**	**7**

22. By caring for the people, animals and aspects of the natural world that are important to me I can be healthy

Strongly Agree	Agree	Slightly Agree	Don't Know	Slightly Disagree	Disagree	Strongly Disagree
1	**2**	**3**	**4**	**5**	**6**	**7**

- How likely do you think it is that you will do this in the next week----------

Very Likely						Very Unlikely
1	**2**	**3**	**4**	**5**	**6**	**7**

23. My disease/illness/disability has allowed me to see life and be healthy in a way I previously would not have believed possible----------

Strongly Agree	Agree	Slightly Agree	Don't Know	Slightly Disagree	Disagree	Strongly Disagree
1	**2**	**3**	**4**	**5**	**6**	**7**

- How likely do you think it is that you will experience this in the next week---------

Very Likely						Very Unlikely
1	**2**	**3**	**4**	**5**	**6**	**7**

24. I need to love myself for who I am and be my own good company to be healthy----------

Strongly Agree	Agree	Slightly Agree	Don't Know	Slightly Disagree	Disagree	Strongly Disagree
1	**2**	**3**	**4**	**5**	**6**	**7**

- How likely do you think it is that you will do this in the next week----------

Very Likely						Very Unlikely
1	**2**	**3**	**4**	**5**	**6**	**7**

PLEASE TURN OVER

25. To be healthy, I need to make a difference by serving, helping, sharing, listening, or educating others so that they are happy and fulfilled ----------

Strongly Agree	Agree	Slightly Agree	Don't Know	Slightly Disagree	Disagree	Strongly Disagree
1	**2**	**3**	**4**	**5**	**6**	**7**

- How likely do you think it is that you will do this in the next week----------

Very Likely						Very Unlikely
1	**2**	**3**	**4**	**5**	**6**	**7**

26. For me to be healthy, I need to give and receive love in a way that makes me feel at one with other people, nature and God/the universe/the spiritual world ----------

Strongly Agree	Agree	Slightly Agree	Don't Know	Slightly Disagree	Disagree	Strongly Disagree
1	**2**	**3**	**4**	**5**	**6**	**7**

- How likely do you think it is that you will experience this in the next week---------

Very Likely						Very Unlikely
1	**2**	**3**	**4**	**5**	**6**	**7**

27. Turning to or connecting to something beyond myself, other people or the natural world (e.g., the spiritual, the divine, the supernatural, the universe, etc.) gives me the faith, hope, strength, peace, guidance, knowledge, love, warmth, etc. which are important for my health ----------

Strongly Agree	Agree	Slightly Agree	Don't Know	Slightly Disagree	Disagree	Strongly Disagree
1	**2**	**3**	**4**	**5**	**6**	**7**

- How likely do you think it is that you will experience this in the next week---------

Very Likely						Very Unlikely
1	**2**	**3**	**4**	**5**	**6**	**7**

28. My disease/illness/disability is an exciting challenge that has provided me with an opportunity to be whole and resilient ----------

Strongly Agree	Agree	Slightly Agree	Don't Know	Slightly Disagree	Disagree	Strongly Disagree
1	**2**	**3**	**4**	**5**	**6**	**7**

- How likely do you think it is that you will find this to be true in the next week-----

Very Likely						Very Unlikely
1	**2**	**3**	**4**	**5**	**6**	**7**

29. To be healthy, I need to go easy on myself and not worry if I don't get it 'right' every time ----------

Strongly Agree	Agree	Slightly Agree	Don't Know	Slightly Disagree	Disagree	Strongly Disagree
1	**2**	**3**	**4**	**5**	**6**	**7**

- How likely do you think it is that you will do this in the next week----------

Very Likely						Very Unlikely
1	**2**	**3**	**4**	**5**	**6**	**7**

30. For health, I need to mix with people who see obstacles and ask me how we are going to do it anyway, rather than people who see obstacles and then tell me why I can't do it or what I should be doing

Strongly Agree	Agree	Slightly Agree	Don't Know	Slightly Disagree	Disagree	Strongly Disagree
1	**2**	**3**	**4**	**5**	**6**	**7**

- How likely do you think it is that you will experience this in the next week---------

Very Likely						Very Unlikely
1	**2**	**3**	**4**	**5**	**6**	**7**

31. To be able to be healthy I need a safe, secure and positive environment ----------

Strongly Agree	Agree	Slightly Agree	Don't Know	Slightly Disagree	Disagree	Strongly Disagree
1	**2**	**3**	**4**	**5**	**6**	**7**

- How likely do you think it is that you will experience this in the next week-------

Very Likely						Very Unlikely
1	**2**	**3**	**4**	**5**	**6**	**7**

32. I can never be what I once was but I can be something more than I was --

Strongly Agree	Agree	Slightly Agree	Don't Know	Slightly Disagree	Disagree	Strongly Disagree
1	**2**	**3**	**4**	**5**	**6**	**7**

- How likely do you think it is that you will feel this way in the next week----------

Very Likely						Very Unlikely
1	**2**	**3**	**4**	**5**	**6**	**7**

PLEASE TURN OVER

33. To be healthy, I need to have an ultimate goal, but I need to make sure I set myself small, achievable steps to reach it ----------

Strongly Agree	Agree	Slightly Agree	Don't Know	Slightly Disagree	Disagree	Strongly Disagree
1	**2**	**3**	**4**	**5**	**6**	**7**

- How likely do you think it is that you will do this in the next week----------

Very Likely						Very Unlikely
1	**2**	**3**	**4**	**5**	**6**	**7**

34. I am whole and have value because I am me----------

Strongly Agree	Agree	Slightly Agree	Don't Know	Slightly Disagree	Disagree	Strongly Disagree
1	**2**	**3**	**4**	**5**	**6**	**7**

- How likely do you think it is that you will feel this way in the next week----------

Very Likely						Very Unlikely
1	**2**	**3**	**4**	**5**	**6**	**7**

35. To be healthy, I need health professionals that help me solve problems, rather than telling me what to do ----------

Strongly Agree	Agree	Slightly Agree	Don't Know	Slightly Disagree	Disagree	Strongly Disagree
1	**2**	**3**	**4**	**5**	**6**	**7**

- How likely do you think it is that you will experience this in the next week---------

Very Likely						Very Unlikely
1	**2**	**3**	**4**	**5**	**6**	**7**

36. The things I did in the past are not necessarily the same as the things I do now, which in turn are different from what I will be doing in the future ----------

Strongly Agree	Agree	Slightly Agree	Don't Know	Slightly Disagree	Disagree	Strongly Disagree
1	**2**	**3**	**4**	**5**	**6**	**7**

- How likely do you think it is that you will believe this to be true in the next week--

Very Likely						Very Unlikely
1	**2**	**3**	**4**	**5**	**6**	**7**

37. I need to listen to myself, work out what is right for me, choose what I need to do and then do it ----------

Strongly Agree	Agree	Slightly Agree	Don't Know	Slightly Disagree	Disagree	Strongly Disagree
1	2	3	4	5	6	7

- How likely do you think it is that you will do this in the next week----------

Very Likely						Very Unlikely
1	2	3	4	5	6	7

38. Life is about accepting and facing up to my own limitations; we've all got them. I can only be me if I accept all I am ----------

Strongly Agree	Agree	Slightly Agree	Don't Know	Slightly Disagree	Disagree	Strongly Disagree
1	2	3	4	5	6	7

- How likely do you think it is that you will feel this in the next week----------

Very Likely						Very Unlikely
1	2	3	4	5	6	7

39. To be healthy I need to be able to make the choices in an environment where others are honest and tell the truth, even if it's hard to take ---------

Strongly Agree	Agree	Slightly Agree	Don't Know	Slightly Disagree	Disagree	Strongly Disagree
1	2	3	4	5	6	7

- How likely do you think it is that you will experience this in the next week---------

Very Likely						Very Unlikely
1	2	3	4	5	6	7

40. For health, I need to see my plans working and goals being achieved---

Strongly Agree	Agree	Slightly Agree	Don't Know	Slightly Disagree	Disagree	Strongly Disagree
1	2	3	4	5	6	7

- How likely do you think it is that this will happen in the next week----------

Very Likely						Very Unlikely
1	2	3	4	5	6	7

Have you completed all these questions? **Thank you for your time**

Appendix 11: QE Health Scale: 40 Item

QE Health Scale

Please read each question and **circle the number** to **each** statement that is **closest** to how **often in the past week** you have done any of the following.

In the past week, how frequently did you....	**All the Time**				**Never**
1. Keep mobile, even if it caused pain----------	**1**	**2**	**3**	**4**	**5**
2. Use aids (e.g., hand braces, built up shoes, walking frame, high toilet seat, 'pick-a-upper', fat-handle utensils, tap-turners, rail to walk up/down stairs, etc.) ----------	**1**	**2**	**3**	**4**	**5**
3. Read books, watched videos, surfed the Internet, using emailed, etc. for information to help you to be healthy----------	**1**	**2**	**3**	**4**	**5**
4. In your daily life, use knowledge gained from educational programmes and courses which focused on being healthy with your disorder, rather than just on how to control it----------	**1**	**2**	**3**	**4**	**5**
5. Have fun, lots of laughter, and sharing with those around you----------	**1**	**2**	**3**	**4**	**5**
In the past week, how frequently did you....					
6. Physically exercise----------	**1**	**2**	**3**	**4**	**5**
7. Access public places, such as shops, toilets, medical centres, libraries, etc.----------	**1**	**2**	**3**	**4**	**5**
8. Contribute to your community (e.g., a paid job, voluntary work, teaching, helping others with disabilities/illnesses, being involved in the day-to-day activities of family, etc.)----------	**1**	**2**	**3**	**4**	**5**
9. Find you were in pain but did not fight the pain and try to make it go away----------	**1**	**2**	**3**	**4**	**5**
10. Find that health professionals were honest and supportive but challenging while respecting your own research and self-education----------	**1**	**2**	**3**	**4**	**5**

PLEASE TURN OVER

In the past week, how frequently did you....	**All the Time**				**Never**
11. Find you could understand what was happening to yourself and others because you felt you belonged to and were a part of nature, people and life in general----------	**1**	**2**	**3**	**4**	**5**
12. Take time to really look at yourself and understand what makes your illness worse or better----------	**1**	**2**	**3**	**4**	**5**
13. See yourself as unique----------	**1**	**2**	**3**	**4**	**5**
14. Find that health professionals weren't patronising you or underestimated your capabilities----------	**1**	**2**	**3**	**4**	**5**
15. Discover that you have an inner strength that was real and enduring ----------	**1**	**2**	**3**	**4**	**5**
16. Understand, accept and value yourself, warts and all----------	**1**	**2**	**3**	**4**	**5**
17. Feel your life had purpose and meaning----------	**1**	**2**	**3**	**4**	**5**
18. Feel grateful for your life and appreciated the wonders of life----------	**1**	**2**	**3**	**4**	**5**
In the past week, how frequently did you....					
19. Have time alone----------	**1**	**2**	**3**	**4**	**5**
20. Feel at peace with your life and yourself----------	**1**	**2**	**3**	**4**	**5**
21. Look after your spiritual, emotional and mental self, and find your physical condition was also better----------	**1**	**2**	**3**	**4**	**5**
22. Care for people, animals or the environment that are important to you----------	**1**	**2**	**3**	**4**	**5**
23. See life and health in a way you previously would not have believed possible----------	**1**	**2**	**3**	**4**	**5**
24. Feel you loved yourself and enjoyed your own company----------	**1**	**2**	**3**	**4**	**5**

In the past week, how frequently did you....	**All the Time**				**Never**
25. Make a difference by serving, helping, sharing, listening, or educating others so that they were happy and fulfilled----------	**1**	**2**	**3**	**4**	**5**
26. Give and receive love in a way that made you feel at one with other people, nature and God/the universe/the spiritual world----------	**1**	**2**	**3**	**4**	**5**
27. Connect to something beyond yourself that was spiritual, which increased your faith, hope, strength, peace, guidance, knowledge, love, warmth, etc.----------	**1**	**2**	**3**	**4**	**5**
28. Find your disease/illness/disability provided you with An exciting challenge that helped you to be whole and resilient----------	**1**	**2**	**3**	**4**	**5**
29. Go easy on yourself and not worry when you didn't get it 'right'----------	**1**	**2**	**3**	**4**	**5**
In the past week, how frequently did you....					
30. Mix with people who saw obstacles and asked you how you were going to do it anyway, rather than people who saw obstacles and then told you why you couldn't do it or what you should be doing----------	**1**	**2**	**3**	**4**	**5**
31. Feel that you were in a safe, secure and positive environment----------	**1**	**2**	**3**	**4**	**5**
32. Realise you were no longer what you were but were something more than you were----------	**1**	**2**	**3**	**4**	**5**
33. Have an ultimate goal, and set small, achievable steps to reach it----------	**1**	**2**	**3**	**4**	**5**
34. Feel you were whole and had value because you are you----------	**1**	**2**	**3**	**4**	**5**

PLEASE TURN OVER

In the past week, how frequently did you....	**All the Time**				**Never**
35. Find that health professionals helped you to solve problems, rather than telling you what to do----------	**1**	**2**	**3**	**4**	**5**
36. Find that what you are doing now, was different from what you were doing in the past and believed that this would be different from what you would be doing in the future----------	**1**	**2**	**3**	**4**	**5**
37. Listen to yourself, work out what was right for you, choose what you needed to do and then did it----------	**1**	**2**	**3**	**4**	**5**
38. Face up to and accept you own limitations as a part of who you are----------	**1**	**2**	**3**	**4**	**5**
39. Find that you could make choices because you were in an environment where others told you the truth, even though it was hard to take---------	**1**	**2**	**3**	**4**	**5**
40. Find that your plans were working and you were achieving your goals----------	**1**	**2**	**3**	**4**	**5**

Have you answered ALL these questions?

Thank you for you time

Appendix 12: Rating of Health Statements Questionnaire (53-Item)
Principal Components Factor Analysis

Component	1	2	3	4	5	6	7	8	9
Item							.361	.306	
1		-.329							.420
2			.408		.545			.382	
3			.368		.394				
4	.360				.343				
5	.378	-.423							.335
6	.684								
7	.640			.449					
8	.516								
9	.494			.369	-.368		-.332		
10	.475				-.302		.468		
11	.539		.371						
12	.515				.341				
13	.639				..377				
14	.517		.350						-.325
15	.705				.450				
16	.379	-.360			-.437				.313
17	.651								
18	.600								.324
19	.374	-.487				.429			
20				.602					
21	.375		.402			-.436			.370
22	.539			.315			.483		
23	.547								
24							.308	.480	
25	.440		-.351	-.470		.316			
26		.570				.456			
27	.553	.330						-.465	
28	.504								
29	.516								
30	.514			-.314	-.388				

Appendix 12 Continued Next Page

Appendix 12: Continued

Component	1	2	3	4	5	6	7	8
Item					.395			
31	.574						.320	
32	.635							
33	.549							
34	.494				.379			
35	.330	.366	.516				.452	
36					.378			
37	.431							
38		.473	.416					.333
39		.549				.415		
40		.411	-.382					
41	.457	.407	-.424					
42	.588							-.378
43		.448	.529			.351		
44			.314	-.545				
45			-.414	.479		.326		
46		.438		.319		.469		
47	.520	.476	.327					
48		.678	.439					
49		.348			-.347	-.488		
50		.654						
51	.660	.339	-.310					
52	.520	.366	-.327					
53	.753		-.333					

Appendix 13: Rating Of Health Statements Questionnaire (53 Item) Inter-Item Correlation

Item	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item Total Correlation	Cronbach alpha if Item Deleted
1	116.51	653.30	.25	.87
2	116.57	664.69	.11	.88
3	116.80	652.68	.23	.87
4	117.40	652.49	.30	.87
5	117.20	645.08	.37	.87
6	117.51	630.74	.59	.87
7	118.14	654.40	.56	.87
8	117.65	647.63	.45	.87
9	117.86	653.16	.44	.87
10	117.94	659.26	.42	.87
11	118.18	656.59	.51	.87
12	117.57	646.97	.48	.87
13	118.01	656.02	.57	.87
14	118.16	659.46	.41	.87
15	118.08	651.51	.62	.87
16	116.67	652.43	.31	.87
17	117.90	647.37	.62	.87
18	117.10	630.13	.57	.87
19	115.43	642.90	.34	.87
20	117.35	688.79	-.13	.88
21	117.75	653.39	.38	.87
22	117.96	651.28	.50	.87
23	117.45	646.61	.49	.87
24	117.98	670.26	.24	.87
25	117.14	649.16	.32	.87
26	117.39	661.24	.25	.87
27	118.00	657.52	.48	.87

Appendix 13 Continued Next Page

Appendix 13 (Cont.)

Item	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item Total Correlation	Cronbach alpha if Item Deleted
28	118.02	662.30	.40	.87
29	117.96	657.08	.45	.87
30	117.71	645.77	.43	.87
31	117.80	647.96	.50	.87
32	117.63	640.04	.52	.87
33	118.02	661.82	.45	.87
34	118.04	656.80	.43	.87
35	117.96	656.16	.35	.87
36	117.51	645.58	.17	.88
37	117.86	661.12	.37	.87
38	117.65	670.91	.10	.88
39	116.71	669.85	.08	.88
40	118.04	672.00	.12	.87
41	117.77	654.50	.36	.87
42	117.94	656.02	.47	.87
43	118.18	670.07	.15	.87
44	114.84	656.62	.19	.88
45	116.90	669.25	.10	.88
46	117.16	665.66	.17	.87
47	117.35	639.11	.56	.87
48	117.88	658.47	.37	.87
49	118.08	671.07	.19	.87
50	117.08	661.23	.22	.87
51	118.35	660.67	.60	.87
52	118.28	664.64	.45	.87
53	118.31	658.42	.67	.87

Appendix 14: Rating Of Health Statements Questionnaire (37- Item) Principal Components Factor Analysis

Component	1	2	3	4	5	6	7	8	9	10
Item 4	.373			.363	-.570					.346
Item 5	.400	-.519					.371			
Item 6	.691							-.303		
Item 7	.659		.396							
Item 8	.527	-.396								.423
Item 9	.498		.382	-.388						
Item 10	.492		.303			-.470				
Item 11	.548		.514							
Item 12	.515		-.415				-.309			
Item 13	.637		-.333							
Item 14	.536						.323	.331		
Item 15	.719		-.341	.445						
Item 16	.396	-.450					.333			
Item 17	.663		.398							
Item 18	.616							-.400		
Item 19	.410	-.572					-.323			
Item 21	.373		.407				.436			
Item 22	.538		.354			-.612				
Item 23	.552						-.333			
Item 25	.436		-.445	-.375						
Item 27	.543	.357			.338	.396				
Item 28	.504	.306						.364		.339
Item 29	.501							.553		
Item 30	.525	-.302			.539					
Item 31	.574			.436			.396			
Item 32	.649		-.356			-.377				
Item 33	.545				-.306					
Item 34	.505		-.339	.371					.328	
Item 35	.308		.338	.434	.540					
Item 37	.409	.351							.376	
Item 41	.426	.521								
Item 42	.587	.344								
Item 47	.497	.418								
Item 48		.474							.399	
Item 51	.649	.495								
Item 52	.504	.513							-.320	
Item 53	.744	.413								

Appendix 15: Rating Of Health Statements Questionnaire (37-Item)

Inter-Item Correlation

Item	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Cronbach alpha if Item Deleted
4	74.89	441.72	.31	.91
5	74.55	431.91	.42	.91
6	74.96	421.08	.65	.91
7	75.55	442.33	.61	.91
8	75.09	433.74	.53	.91
9	75.26	441.70	.47	.91
10	75.34	445.73	.47	.91
11	75.57	444.94	.53	.91
12	74.96	438.00	.48	.91
13	75.47	444.29	.60	.91
14	75.55	444.29	.51	.91
15	75.49	439.41	.68	.91
16	74.02	434.71	.41	.91
17	75.30	437.18	.65	.91
18	74.53	423.56	.58	.91
19	72.77	428.56	.41	.91
21	75.15	445.17	.34	.91
22	75.36	441.81	.49	.91
23	74.87	435.96	.53	.91
25	74.59	433.06	.41	.91
27	75.42	446.09	.50	.91
28	75.43	449.25	.43	.91
29	75.36	446.20	.45	.91
30	75.11	431.49	.52	.91
31	75.21	438.13	.52	.91
32	75.04	428.08	.60	.91
33	75.45	449.45	.46	.91
34	75.43	444.06	.47	.91
35	75.36	450.04	.26	.91
37	75.26	451.08	.33	.91
41	75.21	445.86	.32	.91
42	75.38	443.47	.51	.91
47	74.76	437.42	.45	.91
48	75.28	457.02	.15	.91
51	75.76	449.77	.57	.91
52	75.70	453.14	.41	.91
53	75.74	447.35	.66	.91

Appendix 16: HAS Principal Components Factor Analysis

Component	1	2	3	4	5	6	7	8	9
Item 1	.328		.583				.342		.340
Item 2	.561		-.383						.333
Item 3	.571	.376	-.387						
Item 4	.394		.531		.373			-.414	
Item 5	.574	-.308			-.402		.433		
Item 6	.351		.759						
Item 7	.431	.484							.380
Item 8	.437	.504					.453		
Item 9	.478	-.516			.301				
Item 10	.564	.608							
Item 11	.696					-.316			
Item 12	.487		.361	.355				.301	
Item 13	.505					-.561			
Item 14	.444	.346				-.670			
Item 15	.605	-.563							
Item 16	.625	-.315			-.416				
Item 17	.506			.592					
Item 18	.640				-.358			-.322	
Item 19	.738	-.346		-.370					
Item 20	.697	.349							
Item 21	.652		-.424		.346				
Item 22	.516				.580				
Item 23	.647				-.306				
Item 24	.334			.652					
Item 25	.784			.328					
Item 26	.459	.355	-.347					-.382	
Item 27	.459				.403	.413			
Item 28	.527	-.372	-.377	-.459					
Item 29	.726								
Item 30	.692	.333					-.300		
Item 31	.700								
Item 32	.720				-.315				
Item 33	.650	-.333							
Item 34	.673	.412							
Item 35	.524		.493						
Item 36		.314	.389				-.413	.401	
Item 37	.594	-.519		-.301					
Item 38	.614		.429	-.339	.341				

Appendix 17: HAS Varimax Rotation

Component	1	2	3	4	5	6	7	8	9	10
Item 1				.801						
Item 2	.456							.627		
Item 3	.323				.472		.445	.397		
Item 4				.749			.461			
Item 5		.841								
Item 6				.802						
Item 7					.338			.763		
Item 8					.877					
Item 9	.614					.305		-.322		
Item 10			.326		.812					
Item 11		.458			.516		.474			
Item 12						.450	.372			-.512
Item 13	.627						.548			
Item 14							.878			
Item 15	.852									
Item 16		.827								
Item 17		.495				.668				
Item 18		.551	.610							
Item 19	.816		.420							
Item 20					.597					
Item 21	.510						.394			.341
Item 22						.737				
Item 23	.330	.643								
Item 24						.798				
Item 25		.734								.314
Item 26					.307					.787
Item 27						.720				
Item 28	.783									
Item 29		.455	.355				.497			
Item 30			.796							
Item 31			.621	.413		.307				
Item 32		.375	.722						.317	
Item 33	.361	.584					.357			
Item 34			.582		.413				.391	
Item 35				.474					.674	
Item 36									.762	
Item 37	.838									
Item 38	.460			.711						

Appendix 18: HAS Inter-Item Correlation

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Cronbach alpha if Item Deleted
Item 1	74.75	528.15	.29	.94
Item 2	74.40	508.94	.54	.93
Item 3	74.15	511.26	.54	.93
Item 4	74.70	531.43	.35	.93
Item 5	74.94	522.58	.53	.93
Item 6	74.75	531.02	.31	.93
Item 7	74.62	526.33	.37	.93
Item 8	74.55	520.25	.40	.93
Item 9	74.02	505.28	.48	.93
Item 10	74.81	523.85	.51	.93
Item 11	74.89	520.23	.64	.93
Item 12	74.75	530.19	.46	.93
Item 13	73.96	510.26	.47	.93
Item 14	74.89	529.49	.38	.93
Item 15	74.66	513.06	.58	.93
Item 16	74.83	519.45	.57	.93
Item 17	74.49	508.65	.50	.57
Item 18	74.40	506.07	.59	.93
Item 19	74.55	502.60	.71	.93
Item 20	74.85	516.61	.66	.93
Item 21	74.38	509.68	.64	.93
Item 22	73.79	502.43	.52	.93
Item 23	74.47	512.91	.60	.93
Item 24	74.45	522.69	.34	.93
Item 25	74.53	506.30	.76	.93
Item 26	74.38	514.02	.44	.93
Item 27	72.83	500.14	.47	.93
Item 28	74.30	515.17	.49	.93
Item 29	74.70	522.17	.66	.93
Item 30	74.64	515.32	.63	.93
Item 31	74.45	505.73	.67	.93
Item 32	74.60	508.64	.65	.93
Item 33	74.55	512.73	.62	.93
Item 34	74.85	519.13	.61	.93
Item 35	74.77	527.92	.48	.93
Item 36	74.85	539.70	.16	.93
Item 37	74.72	511.29	.59	.93
Item 38	74.47	514.86	.58	.93

Appendix 19: HAS Study Information Sheet

The Health Attitudes Scale (HAS) and Q E Health Scale (QEHS) Study.

INFORMATION SHEET 6/11/03

What is it?

You are invited to take part in a study, approved by the Bay of Plenty Ethics Committee and the University of Waikato, Psychology Department Ethics Committee to test a measure of health developed from the viewpoint of those with musculoskeletal disabilities. The study does not focus on you personally but seeks to investigate two scales we have developed, the Health Attitudes Scale (HAS) and the QE Health Scale (QEHS), for reliability (the extent to which the scale is stable) and the validity (whether or not we are measuring what we think we are).

One of the things that tests validity is comparison of these scales with other questionnaires to see how the scores relate. To do this, we need you to complete two other questionnaires, the Self-Evaluation Questionnaire and the Sense of Coherence questionnaire. Also, things like age, ethnicity, gender, type of disability, length of time with disability, education and income level have been shown to be related to health. Therefore, we will include a questionnaire asking you for this information as well. In total, you will be asked to complete four relatively short questionnaires.

The HAS and QEHS each contain 40 statements that people with musculoskeletal disorders believe are important to health. It is important to note that not all these people thought all these statements are equally important. We have tested the HAS in a pilot study with 52 people but this by no means is representative. Therefore, we need to carry out this study of a representative group of people who have used QE Health services and make any necessary alterations before we can begin using it as an assessment tool in research or healthcare.

What would I need to do if I agreed to take part?

Within two weeks of receiving this Information Sheet the researcher, Kieren Faull (QE Health) will telephone you to ask if there is anything you wish to discuss about the study and whether or not you are interested in taking part. If you are, he will send you the questionnaires.

The total time involved for you in this study is approximately one (2) hours. It is best to answer the questions promptly rather than spending a long time thinking about them. Taking part in this study is voluntary (your choice). You may stop at any time. This will in no way affect your continuing health care.

Who will know it was me that took part?
Kieren Faull will be the only person who knows you took part. A number (participant code) will be entered next to your name on the code key file and will be accessible only by Kieren Faull. This code key will be destroyed on completion of the study. Questionnaires will only have your code number on them.

Who else is taking part?
250 people, selected randomly, who have been inpatients of the QE Health Rheumatology and Rehabilitation Department.

What are the benefits of the study?
Measures that are sensitive to and more accurately capture the factors essential for health, as perceived by you (the health consumer), have the potential to more sensitively measure meaningful health change, thereby informing researchers and practitioners of the effectiveness of practice. Such advancement of knowledge will facilitate increased effectiveness of health delivery.

What can I do if I wish to talk to somebody about this?
After receiving this Information Sheet you are welcome to ring Kieren Faull at QE Health, or make an appointment to discuss any issues about the study that may concern you. Kieren Faull will ring approximately two weeks after you have received this Information Sheet and he welcomes anything you may wish to discuss about the study. His Supervisor, Dr Michael Hills, Department of Psychology, University of Waikato, Hamilton, Ph (07) 838-4466, xt 8296 can also be contacted if you wish. The Health Consumer Service is available to all patients in the Midland Health Area. Any participant in this research project who has concerns about treatment can contact the Health Consumer Service. The freephone number is: 0800 223 238.

This research is partially funded by a HRC Bright Futures Scholarship

Thank you for your time.

Kieren Faull
Researcher
QE Health
Whakaue St.,
PO Box 1342,
Rotorua.
Ph. (07) 348 0189 ext. 877

Appendix 20: Sense Of Coherence 13-Item Scale

SOC-13 Scale

Please circle the number that best describes you.
Please complete all the questions (13) on both sides of this paper

1. Do you have the feeling that you don't really cares what goes on around you?	Very Seldom or Never						Very Often
	1	2	3	4	5	6	7
2. Has it happened to you in the past that you were surprised by the behaviour of people whom you thought you knew well?	Never Happened						Always happened
	1	2	3	4	5	6	7
3. Has it happened that people you counted on disappointed you?	Never happened						Always happened
	1	2	3	4	5	6	7
4. Until now your life has had:	No clear goals or purpose						Very clear goals and purpose
	1	2	3	4	5	6	7
5. Do you have the feeling that you're being treated unfairly?	Very Often						Very Seldom or Never
	1	2	3	4	5	6	7
6. Do you have the feeling that you are in an unfamiliar situation and don't know what to do?	Very Often						Very Seldom or Never
	1	2	3	4	5	6	7
7. Doing the things you do everyday is:	A source of deep pleasure and satisfaction						A source of pain and boredom
	1	2	3	4	5	6	7

8. Do you have very mixed-up feelings and ideas?

Very Often						Very Seldom or Never
1	2	3	4	5	6	7

9. Does it happen that you have feelings inside you that you would rather not feel?

Very Often						Very Seldom or Never
1	2	3	4	5	6	7

10. Many people - even those with a strong character - sometimes feel like sad sacks (losers) in certain situations. How often have you felt this way in the past?

Never						Very often
1	2	3	4	5	6	7

11. When something happened, have you generally found that:

You over estimated or underestimated its importance						You saw things in the right proportion
1	2	3	4	5	6	7

12. How often do you have feelings that there's little meaning in the things you do in daily life?

Very Often						Very Seldom or Never
1	2	3	4	5	6	7

13. How often do you have feelings that you're not sure you can keep under control?

Very Often						Very Seldom or Never
1	2	3	4	5	6	7

Have you answered all the questions?

Thank you for your time

Appendix 21: State-Trait Anxiety Scale

SELF-EVALUATION QUESTIONNAIRE
STAI Form Y-1

A number of statements which people have used to describe themselves are given below. Read each statement and then circle the appropriate number to the right of the statement to indicate how you feel *right* now, that is, at *this moment.* There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feelings best.

	NOT AT ALL	SOMEWHAT	MODERATELY	VERY MUCH SO
1. I feel calm……	**1**	**2**	**3**	**4**
2. I feel secure..……....	**1**	**2**	**3**	**4**
3. I am tense……...……..	**1**	**2**	**3**	**4**
4. I feel strained……...……	**1**	**2**	**3**	**4**
5. I feel at ease……...……..	**1**	**2**	**3**	**4**
6. I feel upset……..…….	**1**	**2**	**3**	**4**
7. I am presently worrying over possible misfortunes……	**1**	**2**	**3**	**4**
8. I feel satisfied……..	**1**	**2**	**3**	**4**
9. I feel frightened……...	**1**	**2**	**3**	**4**
10. I feel comfortable…….....	**1**	**2**	**3**	**4**
11. I feel self-confident…….	**1**	**2**	**3**	**4**
12. I feel nervous……...	**1**	**2**	**3**	**4**
13. I am jittery……...	**1**	**2**	**3**	**4**
14. I feel indecisive……...	**1**	**2**	**3**	**4**
15. I am relaxed…….....	**1**	**2**	**3**	**4**
16. I feel content…….....	**1**	**2**	**3**	**4**
17. I am worried…….....	**1**	**2**	**3**	**4**
18. I feel confused…….....	**1**	**2**	**3**	**4**
19. I feel steady…….....	**1**	**2**	**3**	**4**
20. I feel pleasant……...…	**1**	**2**	**3**	**4**

SELF-EVALUATION QUESTIONNAIRE
STAI Form Y-2

A number of statements which people have used to describe themselves are given below. Read each statement and then circle the appropriate number to the right of the statement to indicate how you *generally* feel.

	NOT AT ALL	SOMEWHAT	MODERATELY	VERY MUCH SO
21. I feel pleasant..…….……	**1**	**2**	**3**	**4**
22. I feel nervous and restless.……....	**1**	**2**	**3**	**4**
23. I feel satisfied with myself……..	**1**	**2**	**3**	**4**
24. I wish I could be as happy as others seem to be…...……...	**1**	**2**	**3**	**4**
25. I feel like a failure..……..	**1**	**2**	**3**	**4**
26. I feel rested…….…….	**1**	**2**	**3**	**4**
27. I am "calm, cool, and collected"…….	**1**	**2**	**3**	**4**
28. I feel that difficulties are piling up so that I cannot overcome them...	**1**	**2**	**3**	**4**
29. I worry too much over something that really doesn't matter..……	**1**	**2**	**3**	**4**
30. I am happy……..…….	**1**	**2**	**3**	**4**
31. I have disturbing thoughts.……..	**1**	**2**	**3**	**4**
32. I lack self-confidence……..	**1**	**2**	**3**	**4**
33. I feel secure…….……	**1**	**2**	**3**	**4**
34. I make decisions easily……	**1**	**2**	**3**	**4**
35. I feel inadequate.…….	**1**	**2**	**3**	**4**
36. I feel content……	**1**	**2**	**3**	**4**
37. Some unimportant thought runs through my mind and bothers me…	**1**	**2**	**3**	**4**
38. I take disappointments so keenly that I can't put them out of my mind…….	**1**	**2**	**3**	**4**
39. I am a steady person.……..	**1**	**2**	**3**	**4**
40. I get in a state of tension and turmoil as I think over my recent concerns and interests……..	**1**	**2**	**3**	**4**

Appendix 22: Item and Overall Means and Standard Deviations of the 40 Items of QEHS

Item	M	SD
1	4.31	0.88
2	2.78	1.58
3	2.60	1.35
4	3.25	1.30
5	3.72	1.06
6	3.46	1.10
7	3.57	1.16
8	3.34	1.42
9	3.07	1.36
10	3.41	1.37
11	3.71	1.17
12	3.55	1.24
13	2.69	1.55
14	3.06	1.53
15	3.82	1.15
16	3.81	1.14
17	3.73	1.22
18	4.06	1.17
19	3.09	1.02
20	3.53	1.16
21	3.22	1.29
22	4.21	1.04
23	3.14	1.31
24	3.46	1.25
25	3.35	1.16
26	3.44	1.29
27	2.91	1.51
28	2.72	1.30
29	3.23	1.14
30	2.62	1.27
31	4.02	1.14
32	3.07	1.30
33	3.75	1.21
34	3.75	1.20
35	2.95	1.53
36	3.47	1.27
37	3.89	1.11
38	4.01	1.12
39	3.45	1.22
40	3.47	1.14
Total Means	3.42	1.24

N = 192

Appendix 23: QEHS 40-Item: Item-Total Correlation

Item	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Cronbach Alpha if Item Deleted
1	133.05	541.81	.28	.91
2	134.55	542.96	.12	.92
3	134.75	531.92	.33	.91
4	134.08	525.86	.44	.91
5	133.62	532.22	.44	.91
6	133.83	542.13	.21	.91
7	133.79	535.61	.31	.91
8	133.99	538.37	.21	.91
9	134.32	544.70	.11	.91
10	133.96	526.34	.41	.91
11	133.62	525.38	.50	.91
12	133.81	522.80	.52	.91
13	134.61	526.38	.36	.91
14	134.26	533.64	.25	.91
15	133.52	517.69	.67	.91
16	133.52	521.25	.63	.91
17	133.63	518.22	.61	.91
18	133.27	523.10	.57	.91
19	134.21	554.38	-.03	.92
20	133.80	527.71	.48	.91
21	134.08	518.83	.59	.91
22	133.11	533.16	.42	.91
23	134.20	518.31	.57	.91
24	133.90	522.01	.54	.91
25	133.95	524.30	.54	.91
26	133.86	517.57	.60	.91
27	134.46	517.25	.50	.91
28	134.62	517.72	.58	.91
29	134.12	529.46	.44	.91
30	134.68	534.64	.29	.91
31	133.27	536.93	.32	.91
32	134.26	522.46	.52	.91
33	133.56	522.96	.54	.91
34	133.57	518.69	.63	.91
35	134.32	518.79	.47	.91
36	133.78	529.87	.39	.91
37	133.37	522.49	.62	.91
38	133.31	526.51	.52	.91
39	133.87	523.27	.53	.91
40	133.81	519.86	.65	.91

Alpha = .91

Appendix 24: QEHS - 33 Item: Item Total Correlation

Item	Scale Mean of Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Cronbach Alpha if Item Deleted
1	111.19	464.89	.26	.93
3	112.87	455.53	.33	.93
4	112.21	449.39	.44	.92
5	111.75	454.68	.46	.92
7	111.91	460.67	.27	.93
10	112.12	449.42	.42	.93
11	111.76	448.86	.52	.92
12	111.93	447.51	.52	.92
13	112.75	452.04	.33	.93
15	111.64	442.65	.66	.92
16	111.66	444.21	.65	.92
17	111.76	441.57	.64	.92
18	111.41	444.93	.61	.92
20	111.94	449.63	.51	.92
21	112.20	442.43	.60	.92
22	111.24	456.85	.42	.92
23	112.35	442.08	.58	.92
24	112.03	445.85	.55	.92
25	112.08	449.13	.53	.92
26	112.01	440.71	.71	.92
27	112.58	442.40	.49	.92
28	112.75	443.15	.57	.92
29	112.24	452.62	.62	.92
31	111.42	457.97	.36	.93
32	112.41	446.01	.53	.92
33	111.70	447.51	.50	.92
34	111.72	442.50	.63	.92
35	112.46	443.53	.47	.92
36	111.93	453.47	.39	.93
37	111.53	445.38	.64	.92
38	111.44	448.13	.57	.92
39	112.01	447.85	.52	.92
40	111.98	443.54	.65	.92

Alpha = .93

Appendix 25: QEHS – 40 Item Factor Analysis Principal Components

Component	1	2	3	4	5	6	7	8
Item 15	.712							
Item 40	.708							
Item 37	.699							
Item 16	.692		-.332					
Item 17	.688							
Item 34	.677							
Item 18	.649		-.377					
Item 26	.641				-.385			
Item 21	.631						.311	
Item 38	.606							
Item 23	.605							
Item 28	.596	.359						
Item 33	.587							
Item 24	.582							
Item 25	.577					-.457		
Item 39	.572							
Item 12	.568							
Item 11	.561							
Item 20	.558		-.462					
Item 32	.553							
Item 35	.508		.334			.355		
Item 5	.508	-.362			-.349			
Item 29	.502						-.382	
Item 22	.456							.418
Item 4	.455		.407					
Item 10	.453		.395			.440		
Item 36	.441				.338	-.310		
Item 27	.526	.592						
Item 13	.368	.526					-.317	
Item 31	.388	-.484						
Item 19		.446						
Item 3	.337		.482					
Item 6			.427	.362			.304	
Item 8				.596				
Item 9		.360		.555				.349
Item 7	.334			.453				
Item 1				.425				
Item 2								.602
Item 14						.382		
Item 30		.331					-.313	

Appendix 26: QEHS – 40 Item Factor Analysis Varimax Rotation

Component	1	2	3	4	5	6	7	8	9
Item 16	.773								
Item 17	.750								
Item 18	.742								
Item 20	.716								
Item 34	.573	.362							
Item 24	.375		.335						.313
Item 36		.634							
Item 37	.437	.620							
Item 33		.613							
Item 29	.303	.586							
Item 38	.420	.534							
Item 40	.416	.478							
Item 12		.467							
Item 23		.432	.429		.338				
Item 27			.788						
Item 26			.665						
Item 21	.403		.657						
Item 13			.530					.401	
Item 28			.524		.340	.333			
Item 32		.455	.518						
Item 25		.390	.452				.430		
Item 15	.353	.334	.413						
Item 31	.320			.665					
Item 11				.648					
Item 39				.642					
Item 35				.481	.392				
Item 3					.745				
Item 4					.629				
Item 10				.307	.558				
Item 6					.323	.697			
Item 7	.337					.602			
Item 1						.599			
Item 8						.363	.610		
Item 22				.376			.608		
Item 5	.444						.459		
Item 30								.727	
Item 9				-.301			.325	.444	.378
Item 19									.727
Item 2					.326				.567
Item 14									

Appendix 27: QEHS - 33 Item Factor Analysis Principal Components

Component	1	2	3	4	5	6	7	8
Item 16	.702				-.343			
Item 40	.700							
Item 17	.695							
Item 15	.692							
Item 37	.685			.316				
Item 34	.685							
Item 18	.672							
Item 26	.654			-.319				
Item 21	.640		-.351					
Item 38	.624				-.352			
Item 23	.613	.304						
Item 28	.597	.365						
Item 24	.596							
Item 20	.582	-.480						
Item 33	.570							
Item 11	.562							
Item 25	.561				.400			
Item 12	.556							
Item 32	.554							-.475
Item 39	.551		.383				-.372	
Item 5	.507							
Item 29	.506			.383				
Item 35	.489		.385			.330	-.313	
Item 4	.467						.466	
Item 22	.457		.362			-.317		
Item 10	.442		.397	-.326		.382		
Item 36	.431			.362		-.332		
Item 3	.340	.524						
Item 31	.409	-.464						
Item 27	.533	.393	-.540					
Item 13	.358	.361	-.384				-.326	
Item 1					.494	.388	.327	
Item 7	.309					.385		

Appendix 28: QEHS - 33 Item Factor Analysis Varimax Rotation

Component	1	2	3	4	5	6	7	8
Item 16	.798							
Item 18	.762							
Item 20	.751						.337	
Item 17	.736							
Item 34	.590	.309						
Item 24	.469						.364	
Item 21	.451		.409				.413	
Item 36		.635						
Item 37	.388	.633						
Item 33		.627						
Item 40	.361	.546						
Item 38	.476	.527						
Item 29	.390	.505						
Item 12		.387	.302					
Item 13			.793					
Item 27			.672				.441	
Item 15	.346		.508		.303			
Item 35				.737				
Item 39				.662		.303		
Item 10				.648	.485			
Item 11				.527				
Item 31	.382			.389		.309	.319	
Item 3					.719			
Item 4					.707			
Item 23					.525			
Item 22						.599		
Item 5	.418					.595		
Item 25		.392	.433			.542		
Item 26			.436			.512	.330	
Item 32		.345					.705	
Item 28			.342		.451		.463	
Item 1								.822
Item 7								.606

Appendix 29: QEHS 33-Item

QE Health Scale: 33-Item

Please read each question and **circle the number** to **each** statement that is **closest** to how **often in the past week** you have done any of the following.

It is important that you answer all the questions.

In the past week, how frequently did you....	**All the Time**				**Never**
1. Keep mobile, even if it caused pain----------	**1**	**2**	**3**	**4**	**5**
2. Read books, watched videos, surfed the Internet, used email, etc. for information to help you to be healthy----------	**1**	**2**	**3**	**4**	**5**
3. In your daily life, use knowledge gained from educational sources which focused on being healthy with your disorder, rather than just on how to control it----------	**1**	**2**	**3**	**4**	**5**
4. Had fun, lots of laughter, and sharing with those around you----------	**1**	**2**	**3**	**4**	**5**
5. Access public places, such as shops, toilets, medical centres, libraries, etc.----------	**1**	**2**	**3**	**4**	**5**
6. Find that health professionals were honest and supportive but challenging while respecting your own knowledge and self-education----------	**1**	**2**	**3**	**4**	**5**
7. Find you could understand what was happening to yourself and others because you felt you belonged to and were a part of nature, people and life in general----------	**1**	**2**	**3**	**4**	**5**
8. Take time to really look at yourself and understand what makes your illness worse or better----------	**1**	**2**	**3**	**4**	**5**

In the past week, how frequently did you....	**All the Time**				**Never**
9. See yourself as a unique person----------	**1**	**2**	**3**	**4**	**5**
10. Discover that you have an inner strength that was real and enduring ----------	**1**	**2**	**3**	**4**	**5**
11. Understand, accept and value yourself, warts and all----------	**1**	**2**	**3**	**4**	**5**
12. Feel your life had purpose and meaning----------	**1**	**2**	**3**	**4**	**5**
13. Feel grateful for your life and appreciated the wonders of life----------	**1**	**2**	**3**	**4**	**5**
14. Feel at peace with your life and yourself----------	**1**	**2**	**3**	**4**	**5**
15. Look after your spiritual, emotional and mental self, and find your physical condition was also better----------	**1**	**2**	**3**	**4**	**5**
16. Care for people, animals or the environment that are important to you----------	**1**	**2**	**3**	**4**	**5**
17. See life and health in a way you previously would not have believed possible----------	**1**	**2**	**3**	**4**	**5**
18. Feel you loved yourself and enjoyed your own company----------	**1**	**2**	**3**	**4**	**5**
19. Make a difference by serving, helping, sharing, listening, or educating others so that they were happy and fulfilled----------	**1**	**2**	**3**	**4**	**5**
20. Give and receive love in a way that made you feel at one with other people, nature and God/the universe/the spiritual world----------	**1**	**2**	**3**	**4**	**5**

In the past week, how frequently did you....	**All the Time**				**Never**
21. Connect to something beyond yourself that was spiritual, which increased your faith, hope, strength, peace, guidance, knowledge, love or warmth, etc.----------	**1**	**2**	**3**	**4**	**5**
22. Find your disease/illness/disability provided you with an exciting challenge that helped you to be whole and resilient----------	**1**	**2**	**3**	**4**	**5**
23. Go easy on yourself and not worry when you didn't get it 'right'----------	**1**	**2**	**3**	**4**	**5**
24. Feel that you were in a safe, secure and positive environment----------	**1**	**2**	**3**	**4**	**5**
25. Realise you were no longer what you were but were something more than you were----------	**1**	**2**	**3**	**4**	**5**
26. Have an ultimate goal, and set small, achievable steps to reach it----------	**1**	**2**	**3**	**4**	**5**
27. Feel you were whole and had value because you are you----------	**1**	**2**	**3**	**4**	**5**
28. Find that health professionals helped you to solve problems, rather than telling you what to do----------	**1**	**2**	**3**	**4**	**5**

In the past week, how frequently did you....	**All the Time**				**Never**
29. Find that what you are doing now, was different from what you were doing in the past and believed that this would be different from what you would be doing in the future----------	**1**	**2**	**3**	**4**	**5**
30. Listen to yourself, work out what was right for you, choose what you needed to do and then did it----------	**1**	**2**	**3**	**4**	**5**
31. Face up to and accept you own limitations as a part of who you are----------	**1**	**2**	**3**	**4**	**5**
32. Find that you could make choices because you were in an environment where others told you the truth, even though it was hard to take---------	**1**	**2**	**3**	**4**	**5**
33. Find that your plans were working and you were achieving your goals----------	**1**	**2**	**3**	**4**	**5**

Have you answered ALL the questions?

Thank you for your time

Appendix 30 : Item and Overall Means and Standard Deviations of the 40 Items of HASIM

Item	M	SD
1	6.58	0.61
2	5.48	1.81
3	5.18	1.72
4	5.68	1.43
5	6.32	0.91
6	6.44	0.76
7	5.78	1.54
8	5.67	1.48
9	5.28	1.74
10	5.87	1.25
11	6.06	1.20
12	5.77	1.42
13	4.92	1.69
14	6.17	1.20
15	5.51	1.58
16	5.99	1.19
17	6.23	0.95
18	5.71	1.45
19	5.43	1.57
20	6.03	1.21
21	5.81	1.35
22	5.73	1.30
23	5.15	1.71
24	5.69	1.41
25	5.44	1.44
26	5.71	1.46
27	5.11	1.95
28	4.33	1.90
29	5.93	1.26
30	5.79	1.28
31	6.13	1.07
32	5.40	1.63
33	6.06	1.15
34	5.93	1.25
35	6.30	0.91
36	6.04	1.08
37	6.33	0.77
38	6.40	0.80
39	6.17	0.92
40	5.90	1.12
Total Means	5.79	1.31

Appendix 31: HASIM Subscale Item-Total Correlation

Item	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Cronbach Alpha if Item Deleted
1	224.69	903.18	.22	.94
2	225.82	871.75	.34	.94
3	226.13	858.09	.49	.94
4	225.61	869.51	.47	.94
5	224.98	882.45	.53	.94
6	224.81	895.81	.36	.94
7	225.56	865.41	.47	.94
8	225.63	866.57	.48	.94
9	226.13	861.43	.45	.94
10	225.39	872.86	.50	.94
11	225.26	864.73	.63	.94
12	225.53	865.87	.51	.94
13	226.35	847.74	.61	.94
14	225.13	881.83	.39	.94
15	225.80	852.94	.60	.94
16	225.31	866.24	.61	.94
17	225.03	880.17	.58	.94
18	225.61	859.92	.57	.94
19	225.92	858.86	.54	.94
20	225.27	867.26	.59	.94
21	225.47	863.66	.58	.94
22	225.59	858.68	.66	.94
23	226.14	846.05	.62	.94
24	225.64	856.59	.63	.94
25	225.86	850.96	.69	.94
26	225.59	850.59	.67	.94
27	226.19	846.46	.54	.94
28	226.92	852.10	.51	.94
29	225.37	873.30	.48	.94
30	225.50	863.25	.61	.94
31	225.16	875.50	.55	.94
32	225.87	856.74	.54	.94
33	225.24	865.34	.65	.94
34	225.36	872.03	.51	.94
35	224.98	886.72	.46	.94
36	225.24	883.08	.43	.94
37	224.98	888.38	.49	.94
38	224.89	890.54	.43	.94
39	225.12	881.49	.53	.94
40	225.36	868.11	.63	.94

Alpha = .94

Appendix 32: HASIM Principal Components Factor Analysis

Component	1	2	3	4	5	6	7	8
Item 25	.709		-.326					
Item 26	.705		-.313					
Item 33	.703			-.360				
Item 22	.693							
Item 40	.683							
Item 11	.666							
Item 24	.657							
Item 16	.652							
Item 30	.643							
Item 23	.641							
Item 13	.639							
Item 17	.635							
Item 15	.630			.356				
Item 20	.623					-.467		
Item 21	.603							
Item 18	.598							-.330
Item 31	.585						.384	
Item 19	.576					-.377		
Item 39	.572			-.329		.305		
Item 32	.569	-.480						
Item 5	.567		.386					
Item 27	.565		-.436					
Item 12	.552				-.315			
Item 34	.549	-.410						
Item 37	.540		.305	-.362				.303
Item 28	.528						.423	
Item 10	.526	.369			-.393			
Item 8	.518							
Item 3	.509	.502						
Item 29	.508					-.302		
Item 35	.502			-.305				
Item 36	.473							
Item 38	.467			-.373				
Item 14	.427		.333		-.401			
Item 4	.475	.633						
Item 7	.479	.519						
Item 2	.351	.505				.326	.305	
Item 6	.390		.548					
Item 9	.464			.492	-.315			
Item 1					.477			

Appendix 33: HASIM Factor Analysis Varimax Rotation

Component	1	2	3	4	5	6	7	8
Item 26	.739							
Item 27	.737							
Item 25	.680							
Item 21	.566			.339				
Item 18	.555							.439
Item 22	.545			.379		.425		
Item 28		.691						
Item 32		.655						
Item 23	.350	.646						
Item 9		.639		.444				
Item 15		.575		.495				
Item 34		.439						
Item 13		.434		.321				
Item 6			.701					
Item 5			.652	.327				
Item 37			.574					
Item 40			.538				.376	
Item 17	.327		.530			.438		
Item 8	.398		.458					
Item 10				.700	.352			
Item 11	.320		.317	.570				
Item 14				.563		.317		.381
Item 16	.335			.523				
Item 4					.747			
Item 2					.736			
Item 3					.707			
Item 7					.580			.556
Item 35						.703		
Item 36		.313				.537		
Item 33			.379			.489		
Item 12				.362		.448		
Item 38							.745	
Item 39						.319	.664	
Item 20	.344							.618
Item 19								.544
Item 31			.460					.475
Item 29								
Item 30						.333		
Item 1								
Item 24	.344	.384						

Appendix 34: Item and Overall Means and Standard Deviations of the 40 Items of HASIN Subscale

Item	M	SD
1	6.24	0.99
2	4.64	2.47
3	4.17	2.09
4	4.04	1.96
5	5.76	1.44
6	5.78	1.44
7	5.45	1.54
8	5.27	1.89
9	5.02	1.76
10	4.19	1.92
11	5.46	1.55
12	4.96	1.64
13	4.43	1.79
14	4.31	1.98
15	4.75	1.76
16	5.23	1.55
17	5.49	1.39
18	5.26	1.61
19	5.11	1.79
20	5.26	1.49
21	5.17	1.51
22	5.58	1.47
23	4.72	1.85
24	5.13	1.66
25	4.95	1.66
26	5.06	1.61
27	4.51	2.11
28	4.07	1.90
29	5.15	1.55
30	4.75	1.66
31	5.64	1.34
32	4.91	1.68
33	5.31	1.44
34	5.34	1.48
35	4.39	1.94
36	5.50	1.38
37	5.60	1.36
38	5.76	1.30
39	5.18	1.50
40	4.86	1.51
Total Means	5.06	1.65

N = 192

Appendix 35: HASIN Subscale Item-Total Correlation

Item	Scale Mean if Item Deleted	Scale Variance if item Deleted	Corrected Item-Total Correlation	Cronbach Alpha if Item Deleted
1	196.23	1268.17	.22	.94
2	197.51	1251.09	.16	.94
3	198.30	1220.19	.41	.94
4	198.51	1212.97	.50	.94
5	196.79	1236.60	.45	.94
6	196.70	1259.41	.23	.94
7	197.06	1251.07	.28	.94
8	197.25	1227.72	.41	.94
9	197.54	1231.50	.40	.94
10	198.32	1202.70	.58	.94
11	197.06	1215.64	.61	.94
12	197.56	1215.33	.58	.94
13	198.00	1207.79	.60	.94
14	198.24	1211.43	.50	.94
15	197.78	1198.13	.68	.93
16	197.30	1211.88	.64	.93
17	196.98	1225.85	.60	.94
18	197.22	1214.37	.60	.94
19	197.44	1238.17	.35	.94
20	197.25	1216.63	.63	.94
21	197.32	1216.14	.63	.94
22	196.93	1236.43	.45	.94
23	197.82	1191.44	.70	.93
24	197.39	1209.67	.63	.93
25	197.55	1203.85	.67	.93
26	197.43	1212.93	.62	.94
27	197.98	1201.11	.54	.94
28	198.39	1208.76	.55	.94
29	197.33	1224.04	.54	.94
30	197.74	1220.25	.53	.94
31	196.87	1232.68	.53	.94
32	197.60	1204.70	.66	.93
33	197.20	1222.39	.61	.94
34	197.14	1225.22	.56	.94
35	198.13	1221.17	.44	.94
36	197.01	1248.32	.36	.94
37	196.91	1237.52	.47	.94
38	196.71	1241.38	.48	.94
39	197.32	1230.92	.50	.94
40	197.63	1218.27	.62	.94

Alpha = .94

Appendix 36: HASIN Principal Components Factor Analysis

Component	1	2	3	4	5	6	7	8	9
Item 23	.738								
Item 15	.723								
Item 25	.716								
Item 32	.705								
Item 16	.684								
Item 24	.676								
Item 20	.663								
Item 26	.661				-.303				
Item 21	.661						-.384		
Item 40	.657								
Item 17	.649	.304							
Item 11	.645				-.355				
Item 13	.642								
Item 33	.639								
Item 18	.635					.379			
Item 34	.614		-.363						
Item 12	.609								-.366
Item 10	.598	-.442							
Item 28	.593				.324				
Item 27	.576	-.351							
Item 29	.572				.375		-.311		
Item 30	.558								
Item 31	.556					-.307			
Item 39	.527								.367
Item 38	.523			.332					
Item 14	.521	-.410		.388					
Item 37	.510	.378						.308	
Item 22	.499			-.385	-.473				
Item 4	.495		.444						
Item 5	.491	.353							
Item 8	.437			-.332					
Item 9	.426			-.302				-.403	
Item 1		.573							
Item 6		.482							
Item 36	.392	.407					.359		
Item 7			.557						
Item 3	.410		.520			.321			
Item 35	.469	-.361		.490					
Item 2			.507			.518			
Item19	.362			-.314				.401	.376

Appendix 37: HASIN Varimax Rotation Factor Analysis

Component	1	2	3	4	5	6	7	8	9
Item 22	.730								
Item 25	.709		.324						
Item 26	.651				.305				
Item 18	.604		.336						
Item 27	.558								
Item 16	.535								.384
Item 40	.495	.377							
Item 17	.463	.343						.432	
Item 37		.712							
Item 38		.697							
Item 34		.660	.384						
Item 33		.578			.405				
Item 28			.739						
Item 9			.688						
Item 32		.498	.539						
Item 23	.421	.308	.503						
Item 15			.487						.420
Item 13	.355		.448						.347
Item 35				.855					
Item 14				.791					
Item 10				.668		.340			
Item 39	.365			.425				.301	-.327
Item 5					.640				
Item 31					.587				
Item 29		.361	.424		.532				
Item 11	.493				.504				
Item 30				.347	.435				
Item 3						.799			
Item 4						.686			
Item 7					.401	.499			
Item 19							.790		
Item 20			.350				.611		
Item 24	.410	.325					.547		
Item 21	.430				.309		.544		
Item 1								.731	
Item 36		.365						.580	
Item 6								.491	
Item 12									.605
Item 2						.472			
Item 8						.324			

Appendix 38: QEHS Study Information Sheet

Investigation of the Content and Concurrent Validity of the QE Health Scale (QEHS) in a Clinical Setting

INFORMATION SHEET 1/04/04

What is it?

You are invited to take part in a study, approved by the University of Waikato, Psychology Department Ethics Committee to test a measure of health developed from the viewpoint of those with musculoskeletal disabilities. The study does not focus on you personally but seeks to investigate the QE Health Scale (QEHS) for reliability (the extent to which the scale is stable) and the validity (whether or not we are measuring what we think we are).

One of the things that tests validity is comparison with other questionnaires to see how the scores relate. To do this, we need you to complete the QEHS as well as the routine measures all patients fill out while undergoing rheumatology and rehabilitation treatment at QE Health. Also, things like age, ethnicity, gender, type of disability, length of time with disability, education and income level have been shown to be related to health. Therefore, we will include a questionnaire asking you for this information as well.

The QEHS contain 33 statements we have found from previous studies that people who have been inpatients of QE Health believe are important to health. It is important to note that not all these people thought all these statements are equally important for their health.

What would I need to do if I agreed to take part?

Upon admission for treatment your nurse coordinator will ask you if you have any queries about the research and whether or not you would like to take part. If you wish to participate you will be asked to sign the consent form. You will then fill out the QEHS as well as complete the other assessments routinely done by all inpatients. At the end of your stay you will be asked to complete all these measures again, including the QEHS.

The total time involved for you to complete the extra questionnaire, the QEHS, is no more than one (1) hour. It is best to answer the questions promptly rather than spending a long time thinking about them. Taking part in this study, that is completing the QEHS, is voluntary (your choice). You may stop at any time. This will in no way affect your continuing health care.

Who will know it was me that took part?

Your clinical rheumatology and rehabilitation team and Kieren Faull will be the only people who know you took part. Questionnaires will have your code number on them.

The clinicians involved in your care will have access to the results of the tests to aid your treatment

Who else is taking part?
200 people admitted to the QE Health Rheumatology and Rehabilitation Department.

What are the benefits of the study?
A measure that more accurately captures the things essential for health from the consumer's perspective has the potential to improve the effectiveness of health interventions and so assist in providing the consumer with a better health service.

All participants will be sent a summary report sheet. The full research report will be available upon request.

What can I do if I wish to talk to somebody about this?
After receiving this Information Sheet you are welcome to ring Kieren Faull at QE Health, or make an appointment to discuss any issues about the study that may concern you. Kieren Faull will ring approximately two weeks after you have received this Information Sheet and he welcomes anything you may wish to discuss about the study. His Supervisor, Dr Michael Hills, Department of Psychology, University of Waikato, Hamilton, Ph (07) 838-4466, xt 8296 can also be contacted if you wish. The Health Consumer Service is available to all patients in the Midland Health Area. Any participant in this research project who has concerns about treatment can contact the Health Consumer Service. The freephone number is: 0800 223 238.

This research is partially funded by a HRC Bright Futures Scholarship

Thank you for your time.

Kieren Faull
Researcher
QE Health
Whakaue St.,
PO Box 1342,
Rotorua.
Ph. (07) 348 0189 ext. 877

Appendix 39: QEHS Study Consent Form

QEHS STUDY CONSENT FORM

Participant's Copy

Research Project: Investigation of the Content and Concurrent Validity of the QE Health Scale (QEHS)
Name of Researcher: Kieren Faull
Name of Supervisor (if applicable): Dr Michael Hills

I have received an information sheet about this research project. I have had the chance to ask any questions and discuss my participation with other people. Any questions have been answered to my satisfaction.

I agree to participate in this research project and I understand that I may withdraw at any time. If I have any concerns about this project, I may contact the convenor of the Psychology Department's Research and Ethics Committee, University of Waikato.

Participant's
Name:_____Signature:_____Date:_____

==========

QEHS STUDY CONSENT FORM

Researcher's Copy

Research Project: Investigation of the Content and Concurrent Validity of the QE Health Scale (QEHS)
Name of Researcher: Kieren Faull
Name of Supervisor (if applicable): Dr. Michael Hills

I have received an information sheet about this research project. I have had the chance to ask any questions and discuss my participation with other people. Any questions have been answered to my satisfaction.

I agree to participate in this research project and I understand that I may withdraw at any time. If I have any concerns about this project, I may contact the convenor of the Psychology Department's Research and Ethics Committee, University of Waikato.

Participant's
Name: _____Signature:_____ Date:_____

Appendix 40: Stanford Health Assessment Questionnaire (HAQ)

Stanford Questionnaire

We are interested in learning how your illness affects your ability to function in daily life. Please feel free to add any comments.

Please Tick The One Response Which Best Describes Your Usual Abilities Over The Past Week:

		Without ANY Difficulty	With SOME Difficulty	With MUCH Difficulty	Unable To Do
1.	**Dressing and Grooming** - are you able to:				
	- dress yourself, including tying shoelaces and doing buttons?	.....	.....	.....	.....
	- shampoo your hair?	.....	.....	.....	.....
2.	**Rising** - are you able to:				
	- stand up from an armless straight chair?	.....	.....	.....	.....
	- get in and out of bed?	.....	.....	.....	.....
3.	**Eating** - are you able to:				
	- cut your meat?	.....	.....	.....	.....
	- lift a full cup or glass to your mouth?	.....	.....	.....	.....
	- open a new packet of soap powder?	.....	.....	.....	.....
4.	**Walking** - are you able to:				
	- walk outdoors on flat ground?	.....	.....	.....	.....
	- climb up five steps?	.....	.....	.....	.....

Please Tick Any **Aids Or Devices** That You Usually Use For Any Of These Activities:

.....	Cane	.....	Devices used for dressing (button hook, zipper pull, long handled shoehorn, etc)
.....	Walking frame	.....	Built up or special utensils
.....	Crutches	.....	Special built up chair.
.....	Wheelchair		

Other (specify) .....

Please Tick Any Categories For Which You Usually **Need Help From Another Person:**

.....	Dressing and grooming	.....	Eating
.....	Rising	.....	Walking

Comments:-

Please Tick The One Response Which Best Describes Your Usual Abilities Over The Past Week:

	With To Do	Without ANY Difficulty	With SOME Difficulty	Unable MUCH Difficulty	
5.	**Hygiene** - are you able to:				
	- Wash and dry your entire body?	.....	.....	.....	.....
	- Take a bath?	.....	.....	.....	.....
	- Get on and off the toilet?	.....	.....	.....	.....
6.	**Reach** - are you able to:				
	- Reach and get down a 5lb object (eg a bag of potatoes) from just above your head?	.....	.....	.....	.....
	- Bend down to pick up clothing from the floor?	.....	.....	.....	.....
7.	**Grip** - are you able to:				
	- Open car doors?	.....	.....	.....	.....
	- Open jars which have been previously opened?	.....	.....	.....	.....
	- Turn taps on and off?	.....	.....	.....	.....
8.	**Activities** - are you able to:				
	- Run errands and shop?	.....	.....	.....	.....
	- Get in and out of a car	.....	.....	.....	.....
	- Do chores such as vacuuming, housework or light gardening?	.....	.....	.....	.....

Please Tick **Any Aids Or Devices** That You Usually Use For Any Of These Activities:

..... Raised toilet seat ..... Bath rail ..... Bath seat ..... Long handled appliances for reach
..... Jar opener (for jars previously opened) Other (specify)
.....
.....
.....

Please Tick Any Categories For Which You Usually **Need Help From Another Person:**

..... Hygiene ..... Gripping and opening things
..... Reach ..... Errands and housework

Comments:-

Appendix 41: McGill Pain Questionnaire (MPQ)

McGill Pain Questionnaire

All of the words below have been used by people to describe different sorts of pain. Some of these words will describe your present pain. Please circle those words which best describe how your pain feels over the last few days. Choose only **one** word per horizontal line, but use as many, or as few lines as you need to describe your typical recent pain.

1.	Flickering	Quivering	Pulsing	Throbbing	Beating	Pounding
2.	Jumping	Flashing	Shooting			
3.	Pricking	Boring	Drilling	Stabbing	Lancinating	
4.	Sharp	Cutting	Lacerating			
5.	Pinching	Pressing	Gnawing	Cramping	Crushing	
6.	Tugging	Pulling	Wrenching			
7.	Hot	Burning	Scalding	Searing		
8.	Tingling	Itching	Smarting	Stinging		
9.	Dull	Sore	Hurting	Aching	Heavy	
10.	Tender	Taut	Rasping	Splitting		

11.	Tiring	Exhausting			
12.	Sickening	Suffocating			
13.	Fearful	Frightful	Terrifying		
14.	Punishing	Gruelling	Cruel	Vicious	Killing
15.	Wretched	Blinding			

16	Annoying	Troublesome	Miserable	Intense	Unbearable

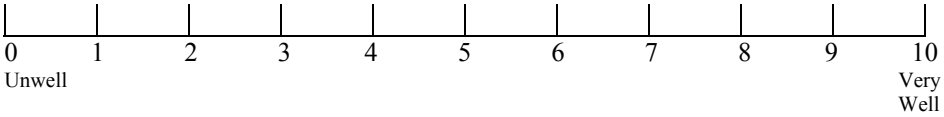
17.	Spreading	Radiating	Penetrating	Piercing	
18.	Tight	Numb	Drawing	Squeezing	Tearing
19.	Cool	Cold	Freezing		
20.	Nagging	Nauseating	Agonizing	Dreadful	Torturing

Appendix 42: Wellness Visual Analogue Scale

QE HEALTH

Wellness Scale

Please indicate on the line below how well you are feeling.



The Wellness Scale depicts your "inner" wellbeing.

The scale is 1 to 10 with 1 being unwell and 10 being very well.

This scale tells us how your disability and pain is affecting your overall wellbeing.

Appendix 43: Canadian Occupational Performance Measure (COPM)

CANADIAN OCCUPATIONAL PERFORMANCE MEASURE

SECOND EDITION

Authors:
Mary Law, Sue Baptiste, Anne Carswell,
Mary Ann McColl, Helen Pollatajko, Nancy Pollock

The Canadian Occupational Performance Measure (COPM) is an individualized measure designed for use by occupational therapists to detect self-perceived change in occupational performance problems over time.

Client Name:		
Age:	Gender:	ID#:
Respondent (if not client:)		
Date of Assessment:	Planned Date of Reassessment:	Date of Reassessment:

Therapist:
Facility/Agency:
Program:

STEP 1: **IDENTIFICATION OF OCCUPATIONAL PERFORMANCE ISSUES** To identify occupational performance problems, concerns and issues, interview the client, asking about daily activities in self-care, productivity and leisure. Ask clients to identify daily activities which they want to do, need to do or are expected to do by encouraging them to think about a typical day. Then ask the client to identify which of these activities are difficult for them to do now to their satisfaction. Record these activity problems in Steps 1A, 1B, or 1C.		**STEP 2:** **RATING IMPORTANCE** Using the scoring card provided, ask the client to rate, on a scale of 1 to 10, the importance of each activity. Place the ratings in the corresponding boxes in Steps 1A, 1B, or 1C.
STEP 1A: Self-Care **Personal Care** (e.g., dressing, bathing, feeding, hygiene) **Functional Mobility** (e.g., transfers, indoor, outdoor) **Community Management** (e.g., transportation, shopping, finances)		IMPORTANCE
1B: Productivity **Paid/Unpaid Work** (e.g., finding/keeping a job, volunteering) **Household Management** (e.g., cleaning, laundry, cooking) **Play/School** (e.g., play skills, homework)		IMPORTANCE

1C: Leisure		IMPORTANCE
Quiet Recreation (e.g., hobbies, crafts, reading)		
Active Recreation (e.g., sports, outings, travel)		
Socialization (e.g., visiting, phone calls, parties, correspondence)		

STEPS 3 & 4: SCORING – INITIAL ASSESSMENT AND REASSESSMENT

Confirm with the client the 5 most important problems and record them below. Using the scoring cards, ask the client to rate each problem on performance and satisfaction, then calculate the total scores. Total scores are calculated by adding together the performance and satisfaction scores for all problems and dividing by the number of problems. At reassessment, the client scores each problem again for performance and satisfaction. Calculate the new scores and the change score.

Initial Assessment			**Reassessment:**	
OCCUPATIONAL PERFORMANCE PROBLEMS:	PERFORMANCE 1	SATISFACTION 1	PERFORMANCE 2	SATISFACTION 2
1. _____				
2. _____				
3. _____				
4. _____				
5. _____				

SCORING:	PERFORMANCE SCORE 1	SATISFACTION SCORE 1	PERFORMANCE SCORE 2	SATISFACTION SCORE 2
Total Score = Total performance or satisfaction score **divided by** number of problems				

CHANGE IN PERFORMANCE = Performance Score 2 – Performance Score 1 =

ADDITIONAL NOTES AND BACKGROUND INFORMATION:

Initial Assessment:

Reassessment:

Appendix 44: 33-Item QEHS Admission Means and Standard Deviations

Item	M	SD
1	4.12	0.88
2	2.68	1.35
3	2.99	1.28
4	3.53	1.12
5	3.46	1.22
6	3.54	1.34
7	3.49	1.23
8	3.45	1.19
9	3.16	1.48
10	3.57	1.18
11	3.46	1.22
12	3.53	1.23
13	3.88	1.19
14	3.34	1.20
15	3.14	1.19
16	4.33	0.95
17	3.18	1.19
18	3.28	1.20
19	3.74	1.08
20	3.58	1.18
21	2.79	1.42
22	2.78	1.27
23	3.02	1.22
24	3.72	1.54
25	2.85	1.30
26	3.51	1.28
27	3.32	1.26
28	3.35	1.38
29	3.44	1.22
30	3.66	1.10
31	3.54	1.23
32	3.31	1.24
33	3.35	1.20
Total Means		

N = 199

Appendix 45: 33-Item QEHS Admission Item-Total Reliability Analysis

Item	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-total Correlation	Squared Multiple Correlation	Alpha if Item Deleted
QEHS1	107.82	507.25	.30	.37	.93
QEHS2	109.36	505.82	.20	.33	.93
QEHS3	109.01	503.04	.26	.29	.93
QEHS4	108.43	594.79	.46	.48	.93
QEHS5	108.56	504.05	.25	.36	.93
QEHS6	108.47	496.17	.35	.52	.93
QEHS7	108.47	479.47	.70	.65	.93
QEHS8	108.54	493.96	.45	.53	.93
QEHS9	108.87	493.70	.35	.39	.93
QEHS10	108.42	485.69	.61	.64	.93
QEHS11	108.53	483.47	.65	.73	.93
QEHS12	108.46	479.62	.71	.73	.93
QEHS13	108.10	483.21	.66	.64	.93
QEHS14	108.66	481.98	.67	.73	.93
QEHS15	108.91	485.67	.61	.53	.93
QEHS16	107.65	499.88	.45	.43	.93
QEHS17	108.85	491.97	.49	.52	.93
QEHS18	108.72	486.85	.59	.51	.93
QEHS19	108.27	490.33	.57	.58	.93
QEHS20	108.41	481.96	.71	.67	.93
QEHS21	109.25	488.07	.47	.50	.93
QEHS22	109.27	481.18	.65	.58	.93
QEHS23	108.97	486.58	.58	.55	.93
QEHS24	108.24	485.17	.65	.62	.93
QEHS25	109.19	482.29	.62	.54	.93
QEHS26	108.48	483.67	.61	.56	.93
QEHS27	108.68	477.92	.72	.67	.93
QEHS28	108.69	488.22	.48	.59	.93
QEHS29	108.58	495.14	.42	.52	.93
QEHS30	108.33	489.52	.59	.66	.93
QEHS31	108.44	489.95	.51	.50	.93
QEHS32	108.69	491.24	.48	.47	.93
QEHS33	108.62	484.64	.64	.64	.93

Tukey estimate of power to which observations must be raised to achieve additivity = 1.3023

Hotelling's T-Squared = 699.9702 F = 18.0858 Prob. = .0000
Degrees of Freedom: Numerator = 32 Denominator = 148

Alpha = .9324

Appendix 46: 28-Item QEHS Admission Item-Total Reliability Analysis

Item	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-total Correlation	Squared Multiple Correlation	Alpha if Item Deleted
QEHS4	91.70	420.56	.45	.44	.94
QEHS7	91.74	406.35	.69	.64	.94
QEHS8	91.81	421.03	.41	.44	.94
QEHS9	92.14	419.29	.35	.37	.94
QEHS10	91.68	411.51	.61	.63	.94
QEHS11	91.79	408.46	.67	.70	.94
QEHS12	91.73	404.97	.73	.71	.93
QEHS13	91.37	408.76	.67	.63	.94
QEHS14	91.92	407.29	.69	.72	.94
QEHS15	92.17	411.10	.62	.51	.94
QEHS16	90.92	425.25	.44	.42	.94
QEHS17	92.12	417.23	.49	.50	.94
QEHS18	92.00	412.06	.60	.49	.94
QEHS19	91.54	416.00	.57	.55	.94
QEHS20	91.67	407.98	.71	.65	.93
QEHS21	92.52	413.01	.48	.44	.94
QEHS22	92.54	406.75	.66	.55	.94
QEHS23	92.24	412.18	.58	.55	.94
QEHS24	91.51	411.53	.64	.60	.94
QEHS25	92.46	408.79	.61	.51	.94
QEHS26	91.75	409.25	.62	.53	.94
QEHS27	91.95	403.49	.73	.66	.93
QEHS28	91.96	414.96	.47	.59	.94
QEHS29	91.84	419.80	.42	.51	.94
QEHS30	91.59	414.30	.61	.64	.94
QEHS31	91.71	414.77	.52	.49	.94
QEHS32	91.96	416.32	.48	.46	.94
QEHS33	91.89	410.74	.64	.58	.94

Tukey estimate of power to which observations must be raised to achieve additivity = 1.5217

Hotelling's T-Squared = 546.4329 F = 17.2986 Prob. = .0000
Degrees of Freedom: Numerator = 27 Denominator = 153

Alpha = .9380 Standardized item alpha = .9391

Appendix 47: 33-Item QEHS Discharge Means and Standard Deviations

Item	M	SD
1	4.42	0.85
2	3.05	1.26
3	3.87	0.98
4	4.34	0.81
5	3.49	1.28
6	4.55	0.73
7	4.31	0.82
8	4.26	0.82
9	3.73	1.26
10	4.03	0.95
11	4.09	0.95
12	4.12	0.95
13	4.32	0.95
14	4.01	1.00
15	3.97	0.97
16	4.36	0.88
17	3.90	0.94
18	3.88	1.08
19	4.22	0.81
20	4.02	1.02
21	3.51	1.27
22	3.65	1.13
23	3.75	0.99
24	4.57	0.73
25	3.81	1.10
26	4.28	0.82
27	4.01	1.02
28	4.53	0.80
29	4.01	0.95
30	4.19	0.85
31	4.22	0.91
32	4.32	0.88
33	4.18	0.89
Total Means	4.06	0.96

N = 199

Appendix 48: 33-Item QEHS Discharge Item-Total Reliability Analysis

Item	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-total Correlation	Squared Multiple Correlation	Alpha if Item Deleted
QEHS1	128.69	348.81	.23	.23	.95
QEHS2	130.08	377.97	.27	.39	.95
QEHS3	129.22	374.56	.47	.45	.95
QEHS4	128.80	377.32	.51	.40	.95
QEHS5	129.65	378.31	.26	.23	.95
QEHS6	128.56	378.48	.49	.51	.95
QEHS7	128.81	373.42	.59	.61	.95
QEHS8	128.86	374.50	.56	.59	.95
QEHS9	129.43	366.43	.52	.70	.95
QEHS10	129.08	365.94	.72	.76	.95
QEHS11	129.03	368.33	.66	.70	.95
QEHS12	129.01	365.02	.74	.72	.95
QEHS13	128.81	366.40	.69	.72	.95
QEHS14	129.10	365.16	.70	.72	.95
QEHS15	129.16	363.94	.76	.69	.94
QEHS16	128.74	376.89	.45	.53	.95
QEHS17	129.21	368.90	.65	.61	.95
QEHS18	129.24	360.93	.75	.73	.94
QEHS19	128.23	374.87	.56	.61	.95
QEHS20	129.11	367.91	.61	.72	.95
QEHS21	129.66	365.61	.54	.62	.95
QEHS22	129.50	363.17	.66	.62	.95
QEHS23	129.36	366.73	.66	.63	.95
QEHS24	128.53	374.16	.65	.62	.95
QEHS25	129.31	364.79	.64	.65	.95
QEHS26	128.83	371.55	.66	.71	.95
QEHS27	129.14	361.89	.77	.80	.94
QEHS28	128.58	373.98	.59	.61	.95
QEHS29	129.11	376.66	.41	.42	.95
QEHS30	128.93	367.51	.77	.71	.94
QEHS31	128.92	369.23	.65	.67	.95
QEHS32	128.80	368.53	.70	.66	.95
QEHS33	128.93	370.34	.64	.60	.95

Tukey estimate of power to which observations must be raised to achieve additivity = 1.9117

Hotelling's T-Squared = 624.2323 F = 16.0517 Prob. = .0000
Degrees of Freedom: Numerator = 32 Denominator = 144

Alpha = .9474 Standardized item alpha = .9507

Appendix 49: 28-Item QEHS Discharge Item-Total Reliability Analysis

Item	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-total Correlation	Squared Multiple Correlation	Alpha if Item Deleted
QEHS4	109.51	309.20	.52	.36	.95
QEHS7	109.52	307.18	.58	.55	.95
QEHS8	109.57	308.45	.53	.56	.95
QEHS9	110.14	301.29	.50	.69	.95
QEHS10	109.79	300.46	.70	.75	.95
QEHS11	109.74	302.41	.65	.69	.95
QEHS12	109.72	299.34	.73	.72	.95
QEHS13	109.52	300.15	.70	.70	.95
QEHS14	109.81	298.86	.72	.71	.95
QEHS15	109.87	298.08	.76	.67	.95
QEHS16	109.45	309.83	.46	.52	.95
QEHS17	109.92	302.25	.66	.61	.95
QEHS18	109.95	295.34	.75	.71	.95
QEHS19	109.64	307.82	.57	.59	.95
QEHS20	109.82	301.46	.62	.68	.95
QEHS21	110.37	299.40	.54	.60	.95
QEHS22	110.21	297.24	.66	.61	.95
QEHS23	110.07	300.45	.67	.60	.95
QEHS24	109.24	307.48	.65	.60	.95
QEHS25	110.01	298.70	.65	.63	.95
QEHS26	109.54	304.84	.67	.70	.95
QEHS27	109.85	295.90	.79	.79	.95
QEHS28	109.30	307.10	.60	.60	.95
QEHS29	109.82	310.15	.40	.40	.95
QEHS30	109.64	301.10	.78	.71	.95
QEHS31	109.63	303.05	.65	.67	.95
QEHS32	109.51	302.21	.71	.63	.95
QEHS33	109.74	303.74	.65	.59	.95

Tukey estimate of power to which observations must be raised to achieve additivity = 2.9605

Hotelling's T-Squared = 397.4222 F = 12.5325 Prob. = .0000
Degrees of Freedom: Numerator = 27 Denominator = 149

Alpha = .9530 Standardized item alpha = .9545

Appendix 50: Interpretation of QEHS Responses to Construct Patient Profile

- At this stage, be wary of Item 6 – maybe misleading as people may not have seen a health professional in the last week
- Beware! Some people think in Item 9 'unique' = 'special'/'better than others' and respond low because of this interpretation
- **Remember scores are reversed (so that a response of 5 = 1 and vice versa – therefore what reads on the scale as a high score is on fact what I refer to below as a low score.**
- **No item can be interpreted independently – all items must be interpreted in the context to the way the whole questionnaire has been answered.**

Indicators

Action Coping

If items 1, 16 & 19 are high and items 9-12 & 23 are low (on average): The person is 'doing' or obtaining their identity externally by doing things for others/pleasing others and trying to keep busy. This is a brittle identity, attempting to return to former self, control external aspects of self with little awareness of the constancy and continuity of the resilient, spiritual self.

Level of anxiety indicates whether or not Action Coping is satisfying the person or creating unsustainable levels of fear and stress. Fear of remaining where you are has to be greater than the courage to go where you have not been for any of us to move/change.

Inertia Coping

So far, always been at Awareness of Loss stage. Action type behaviours are more or less nonexistent. May have high or low self worth, high or low anxiety. High anxiety and low self-worth indicates that it is unsustainable for the person to stay at this stage but is aware that cannot go back – ideal in our case because they are ready and primed for change. If low anxiety and high self-worth, there is something reinforcing the person staying in a disability, sufferer, pain, victim identity. Then you guys are really going to earn your money.

Anxiety

If items 1, 16, 19, are high and item 23 low while items 12, 13, 14, 15, 20, 21 & 24 are (on average) low: The person will have high anxiety. The overall average but with particular emphasis on the mix of items 9-15 will indicate the level of anxiety.

Level of Awareness that Change can be Positive

If items 17, 22, 25 , 29 & 32 are high this indicates the individual has experienced growth through radical change. If low, and most other indicators are high, the person is probably stuck at Acceptance of Loss with no idea how to move forward.

Resilient identity: Transformational Coping

If items 9-12 are high but items 4, 7, 8, 18, 19, 20, 21, 27, 30, 31 are (on average) low: Indicates a strong but brittle identity. If both sets of items tend to be high this indicates a strong, resilient identity.

Transformation Change vs Action vs Inertia Coping

Inertia: All scores are generally low, particularly interaction and behavioural items. But there are still indications of some level strength of identity while anxiety if not a concern. The person will possess little self-awareness and may even believe they are reflective – there will be inconsistencies across items with similar content. There answers will appear confused and in the case of change, they will either respond in the middle (3) which is sometimes a 'I don't know' response or low.

Transformation/Action: If items 12, 14, 15, 22, 25, 26, 29, 31 & 32 are (on average) high: The person understands and lives transformational change while experiencing self as whole, free of fear and growing. If low, they are not aware of the transformational coping strategy.

Appendix 51: Admission QEHS 28-Item Principal Components Factor Analysis

Component	1	2	3	4	5	6
QEHS27	.770					
QEHS12	.769					
QEHS20	.745					
QEHS14	.742	-.335				
QEHS7	.721					
QEHS13	.719					
QEHS11	.705		.345			
QEHS22	.701					
QEHS24	.677					
QEHS33	.670		-.339			
QEHS26	.658					
QEHS15	.658					
QEHS25	.646					
QEHS18	.645					
QEHS10	.643		.420			
QEHS30	.633	.484				
QEHS23	.625				-.338	
QEHS19	.610				.458	
QEHS31	.572		-.365			-.394
QEHS21	.524	-.334				
QEHS17	.515	.377				
QEHS32	.510	.395				
QEHS28	.502	.301				
QEHS4	.498	-.387				
QEHS29	.449	.551				
QEHS9	.376		.538	.459		
QEHS8	.441	.309		.552		
QEHS16	.472			.390	.478	

Appendix 52: Admission QEHS 28-Item Varimax Rotation Factor Analysis

Component	1	2	3	4	5	6
QEHS14	.787					
QEHS18	.720					
QEHS13	.704					
QEHS11	.660				.428	
QEHS12	.647			.396		
QEHS20	.604		.324	.422		
QEHS27	.603		.365			
QEHS15	.531					
QEHS25	.516		.480			
QEHS22	.495	.419	.405			
QEHS21	.465			.345		-.432
QEHS7	.311	.678			.312	
QEHS23	.455	.654				
QEHS33		.588				
QEHS24	.448	.537		.316		
QEHS32		.521	.411			
QEHS28		.505	.498			
QEHS29			.796			
QEHS17			.686			
QEHS30		.302	.526			.480
QEHS26		.353	.403	.325		.339
QEHS16				.796		
QEHS19	.331			.705		
QEHS4	.370	.369		.436		
QEHS9					.767	
QEHS8		.425			.614	
QEHS10	.512				.570	
QEHS31	.355	.311				.648

Appendix 53: Discharge QEHS 28-Item Varimax Rotation Factor Analysis

Component	1	2	3	4	5
QEHS27	.810				
QEHS30	.809				
QEHS15	.785				
QEHS18	.776				
QEHS12	.763				
QEHS14	.757		-.325		
QEHS32	.747				
QEHS13	.744		-.399		
QEHS10	.723	-.380			
QEHS26	.713				
QEHS23	.699				
QEHS31	.696				
QEHS24	.692			.375	
QEHS33	.687				
QEHS22	.686				-.308
QEHS17	.686				
QEHS11	.686	-.521			
QEHS25	.667		.307		-.394
QEHS20	.644	.416			
QEHS28	.641			.346	
QEHS7	.609			.317	.416
QEHS19	.607	.438			
QEHS21	.563		.485		
QEHS8	.563	-.384			
QEHS4	.553				.386
QEHS9	.521	-.441	.393	-.417	
QEHS16	.495			-.392	
QEHS29	.420		.586		

Appendix 54: Discharge QEHS 28-Item Varimax Rotation Factor Analysis

Component	1	2	3	4	5
QEHS28	.698				
QEHS25	.648				.460
QEHS24	.621			.449	
QEHS33	.618				
QEHS32	.605		.429		
QEHS27	.579	.476	.335		
QEHS22	.577	.325			.343
QEHS30	.536		.481		
QEHS26	.532		.516		
QEHS23	.524	.508			
QEHS31	.509	.404		.398	
QEHS9		.794			.413
QEHS11		.743		.365	
QEHS12	.353	.656	.341		
QEHS10		.654		.461	
QEHS18	.322	.516	.431		
QEHS15	.342	.440	.409		
QEHS19			.702		
QEHS16			.701		
QEHS20			.692		.379
QEHS13	.432	.328	.617		
QEHS14	.427	.418	.468	.319	
QEHS7				.718	
QEHS8		.380		.592	
QEHS4			.364	.546	
QEHS29				.347	.685
QEHS21			.333		.678
QEHS17	.433				.495