

Copyright is owned by the Author of the thesis. Permission is given for a copy to be downloaded by an individual for the purpose of research and private study only. The thesis may not be reproduced elsewhere without the permission of the Author.

**AN INVESTIGATION OF THE STABILITY OF THE SENSE OF
COHERENCE FOR THOSE ATTENDING A THREE - WEEK
REHABILITATION PROGRAMME**

A thesis in partial fulfilment of the requirements for the degree of

Masters of Arts

in

Rehabilitation

at Massey University, Palmerston North,

New Zealand.

Toni Jacqueline Hocquard

2005

TABLE OF CONTENTS

Table of Contents	i
Abstract	iii
Acknowledgements	iv
List of Appendices	vi
List of Tables	vii
Introduction	1
Disability, Chronic Illness and Health.....	2
The Sense of Coherence	4
Identification of the Research Question	6
Purpose of the Research	8
Literature Review.....	9
Relationship between the SOC, CI and Disability	10
Overview of Studies	11
SOC as a Stable Personality Trait.....	12
SOC as a State	15
The SOC as a Focus of Intervention.....	17
Summary and Conclusions	20
Research Questions, Hypothesis.....	22
Methodology	23
Methodological Approach	23
Methods.....	24
The Intervention	24
Participants	25
Research Design	25
Consultation.....	26
Procedure	26
Dependant Measures.....	28
Sense of Coherence -29 (SOC-29)	28
Short-form-36 Health Survey (SF-36).....	28
Acceptance of Disability Scale, Modified (ADM).....	30
Analysis	31
Results.....	33
SOC-29	35

ADM.....	37
SF-36	38
Relationship Between the Sense of Coherence, Adjustment and Health Status....	38
Discussion	42
Post Hoc Analysis.....	43
Low, Medium and High SOC Scores	43
Limitations.....	46
Recommendations for Further Research	47
Conclusions	51
References.....	53
Appendix A SOC as a Stable Personality Trait	63
Key: Appendix A.....	68
Appendix B SOC as a State	69
Key: Appendix B.....	70
Appendix C SOC as a Focus of Intervention.....	71
Key: Appendix C.....	73
Appendix D Information Letter	74
Appendix E Demographic Questionnaire	78
Appendix F Consent Form.....	80
Appendix G Sense of Coherence-29 (SOC-29).....	81
Appendix H SF-36v2 Health Survey	86
Appendix I Acceptance of Disability Scale (MOD.)	89
Appendix J The Impact of SOC-29 Scores on Drop Out Rate	97
Appendix K The Impact of SOC-29 Scores T1 to T4.....	98
Appendix L Means and SDs of Published Studies Using the SOC Scale.....	99
Appendix M Means and SDs of Published Studies Using the ADM.....	100
Appendix N Means and Standard Deviations for SF-36 and US General Population Means.....	101
Appendix O Massey University Ethics Committee Approval.....	102
Appendix P Bay of Plenty Ethics Committee Approval.....	103
Appendix Q Kuini Riripeti Kaunihera Letter of Support.....	105
Appendix R Queen Elizabeth Hospital Community Trust Letter of Support.....	106

ABSTRACT

Those with chronic illnesses or disabilities face numerous obstacles and issues as they come to terms with and manage the realities of their situation. How well health care providers and funders understand this can determine the types and quality of services offered. Antonovsky (1993) has developed the Sense of Coherence (SOC) concept, which introduces a salutogenic (health promotion) model of health. This challenges the pathogenic model (origins of disease) that dominates health care. A relationship between the SOC and coping has been established in the literature. Currently, the SOC is widely viewed as a stable personality trait, but emerging evidence suggests that the SOC may be amenable to change. The purpose of the study was essentially to investigate the stability of the SOC in relation to an intervention over time. The study was conducted using a time series design (Pre-admission (T1), admission(T2), discharge (T3), 6-month follow up(T4)). A convenience sample of 120 participants (93 women, 27 men) was recruited for the study. The instruments used as dependant measures were the SOC-29, the Acceptance of Disability Scale ADM (modified) and the SF-36. Analysis of the SOC-29 revealed a significant change over time ($p = .05$), with the follow up analysis indicating that this change occurred following the intervention. This same finding was also true of the ADM scores ($p = 0.0005$). This was not sustained at 6-month follow up for either the SOC or the ADM. Analyses of the SF-36 scores showed a significant improvement from admission to the 6-month follow up on all scores except general health. Only 72 participants completed at the 6-month follow up and this reduced the power of the study to yield a statistically significant result. Furthermore, a post-hoc analysis revealed that over 93% of the participants had medium to high SOC scores at the beginning of the study and this may have impacted on the outcome. There were significant correlations between the scores on the SOC-29 and the ADM and all scales of the SF-36 except physical function. As the significant change in SOC-29 scores was not sustained at the six-month follow up it could suggest that the SOC is indeed a stable trait. However, there were other factors identified, related to the characteristics of the sample and to wider factors that could have had an impact on the outcome of this study. In particular it is possible that a 3-week programme is not long enough to effect a lasting change in the SOC and this raises questions about health care delivery for those who have chronic illness or disability.

ACKNOWLEDGEMENTS

I would like to thank my supervisor Professor Steve LaGrow, who challenged and teased out of me a piece of work that I would not have believed I was capable of. It was your support and encouragement during the post-graduate papers that enabled me to even attempt this thesis. During the tough times you reminded me of my passion for the topic, which helped me to keep going when I could have easily given up. I have particularly appreciated your expert guidance and willingness to be available at a distance and for putting up with me when I was being less than intelligent.

To my second supervisor Dr Kieren Faull, whose support and enthusiasm got me started in the first place, I would like to thank you for planting the seed and supporting me throughout. You said I could do it and I have. With Steve in Palmerston North, it was you I 'bugged' the most and who proofread my numerous re-writes.

This study would not have been possible without the support of QE Health. I would particularly like to thank Ben Smit the Chief Executive and The QE Health Community Trust (who supported the project financially). Special thanks go to Maureen Harker who loaded much of the data into the computer and performed other tasks when needed. To Francie Denton, Kerry Hutchings and Jenny McQueen who delivered and collected questionnaires, a big thank you I know at times it was an additional burden to your already busy days. And to all the staff at QE Health who encouraged me and showed interest in the study from the start.

I would also like to thank Deanna Hape who proofread the final draft, and to Janet Toni who helped me to format it all and who literally saved my sanity.

My sincere thanks go to all those who participated in this study. It was a huge commitment that lasted over six-months, and I appreciate the giving of your time.

Finally, I would like to thank my family. To my husband, Laurie, for your unwavering belief and pride in me, cups of tea and help during computer crises not to mention all of the other jobs you picked up, I cannot express my thanks enough. To my son Chris, who must think that I am permanently attached to a computer, thank you for your

understanding when Mum was stressed, I will support you when it is your turn. Lastly, thank you to all the family and friends who have supported, encouraged and loved me through this process, I could not have done it without you.

LIST OF APPENDICES

Appendix A	SOC as a Stable Personality Trait	63
Appendix B	SOC as a State	69
Appendix C	SOC as a Focus of Intervention	71
Appendix D	Information Letter	74
Appendix E	Demographic Questionnaire	78
Appendix F	Consent Form	80
Appendix G	Sense of Coherence-29 (SOC-29)	81
Appendix H	SF-36v2 Health Survey	86
Appendix I	Acceptance of Disability Scale (MOD.)	89
Appendix J	The Impact of SOC-29 Scores on Drop Out Rate	97
Appendix K	The Impact of SOC-29 Scores T1 to T4.....	98
Appendix L	Means and SDs of Published Studies Using the SOC Scale.....	99
Appendix M	Means and SDs of Published Studies Using the ADM.....	100
Appendix N	Means and Standard Deviations for SF-36 and US General Population Means.....	101
Appendix O	Massey University Ethics Committee Approval	102
Appendix P	Bay of Plenty Ethics Committee Approval.....	103
Appendix Q	Kuini Riripeti Kaunihera Letter of Support.....	105
Appendix R	Queen Elizabeth Hospital Community Trust Letter of Support	106

LIST OF TABLES

Table 1. Data Collection Times	28
Table 2. Meaning of Scores	30
Table 3. Demographic Data	34
Table 4. Means and SDs for SOC-29 over time	35
Table 5. Mean and SDs of the Subscales of the SOC-29 Over Time	36
Table 6. Means and SDs for ADM over time	37
Table 7. Means and Standard Deviations for SF-36	38
Table 8. Correlations between the SOC-29, the ADM and SF-36 (T2, n=112)	39
Table 9. Shared variance (%) between the SOC-29 and the ADM and the SOC-29 and the SF-36.....	40

INTRODUCTION

Advances in medical technology, knowledge and treatment over the past century have meant that people now survive the conditions that they once would not (Tennant, 1996). The experience of this survival, along with the identification of illnesses that defy physical explanation (e.g. fibromyalgia, chronic back pain) have raised a number of issues and have challenged long-standing beliefs about health (Hadler, 1992,1996, 1997). Essentially, health can no longer be viewed as a lack of illness, nor can the achievement of health be confined to a simple model of identifying pathology to be treated, resulting in cure. Indeed, the emergence of mind/body medicine (Goleman & Gurin, 1993) would suggest that both what it means to be healthy and the factors needed to achieve health may be radically different from those associated with pathology and sickness (Petrie & Azariah, 1990).

Health care providers are beginning to acknowledge the impact and importance of the subjective experience on health outcomes (Chapman & Gavrin, 1999). This change in focus has impacted on how we define and think about health, and is in a constant state of evolution (McDowell & Newell, 1996). However, the conceptual difficulty involved in measuring this aspect of health has meant that the focus of measurement has often stayed with the tangible as opposed to the more subjective elements of health (Taylor & Macpherson, 1999). To illustrate, models of disablement have been presented (Fuhrer, 1994; Whiteneck, 1994) that attempt to identify distinct consequences of disease or injury. However, these are subject to continuous debate and development as there still does not appear to be an adequate 'fit'. For example, in the 1980s The World Health Organisation's (WHO) presented the International Classification of Impairment, Disability and Handicap (ICIDH) (Bornman, 2004; Whiteneck, 1994).

Although widely accepted at the time, this model has now been challenged for its focus on functional limitations as the primary determinant of disability and the power this has had to influence policy decisions. Imrie (2004) argues that the ICIDH model has resulted in health care delivery that focuses on impairment. Medical intervention and treatment are therefore seen as a priority. In response to this level of criticism, WHO have now replaced the ICIDH with the International Classification of Functioning, Disability and Health (ICF) (Bornman, 2004). The ICF seeks to move away from the

over-medicalisation of the ICDH and reflect a more biopsychosocial model of disablement (Imrie, 2004). It is reasoned that the ICF integrates both the medical and social aspects of a health condition, and aims to focus on strengths as opposed to weaknesses (Bornman, 2004).

However, the focus still appears to be on function and identifying what is 'wrong'. The pathological approach prevails with no attempt to identify factors that promote health. This focus continues to influence decisions about health care delivery (Cowley and Billings, 1999). Consequently, health care is delivered from an acute care model with only the urgent needs of patients being responded to (WHO, 2002). Furthermore, there remains a dominant belief in the health care arena that increased function will lead to a reduction in disability and an increased quality of life (Hochstenbach, 2000). However, this belief may not always prove to be the case.

Hadler (1992,1996, 1997) has argued that disability has little or nothing to do with impairment or function. He states, - "those who choose to be patients do so because they have exhausted their reserves" (Hadler, 1992.p.598). Hochstenbach (2000) has also found that there is no correlation between improvement in function and quality of life.

In fact, many have noted a discrepancy between physical impairment and levels of illness/disability experienced (Broderick, 2000; Hadler 1992,1996, 1997; Hochstenbach 2000) and have questioned why some people remain healthy and adapt well, while others adapt poorly to illness (Hawley, Wolfe & Cathey, 1992; O'Leary, 1998). Chapman and Gavrin (1999) argue that the inability to function as one feels one should, is a threat to 'self' and ultimately results in "suffering" (p.2233). This 'suffering' seems to be related more to the perceptions of the individual about their disability than the severity of the disability itself (Frank, 2002). Clarifying the issues involved could have a significant impact on service delivery and funding allocation.

Disability, Chronic Illness and Health

Developing a disability or the onset of a chronic illness can be one of the most shattering human experiences (Antonak & Livneh, 1991). Faced with rebuilding or restructuring their lives, individuals move through a psychological adjustment as they come to terms with their situation (Fillary, 2000). How human beings make this

adjustment, and why some do not, has been the focus of many debates (Frank, Van Vallin & Elliot, 1987). Furthermore, how well this adjustment is made can impact on overall health status and is related to the development of secondary conditions (e.g. depression, mobility issues, chronic pain). These secondary conditions can, in turn, increase the level of disability and decrease quality of life. In addition, secondary conditions can be difficult and costly to treat (Ravesloot, Seekins & Young, 1998).

Seligman (2002) believes that a piece of the puzzle is missing in terms of understanding why some people adjust in a timely fashion and others do not. He states that “we need a psychology of rising to the occasion” (p.12) and an approach to health that nurtures strengths, competencies and virtues. Measurements are needed that capture this element of health and human functioning. Health practices can then be developed that promote adjustment and therefore health, despite the existence of a disability or chronic illness. Vash (1991) sees this as the psycho-spiritual dimension, and the place of true empowerment.

Other cultures (Moore, 1995) have long recognised this important aspect of health, and it is only “western medicine’s dualistic ontology” (McWhinney, Epstein & Freeman, 1997, p.748) that denies this reality. Breakwell (1983) describes the onset of a chronic illness or disability as a threat to self, and sees an individual as having three options in terms of their response to this threat. These are, (1) inertia – do nothing, almost an anti-response, (2) mobility or change – involves either moving away from or eradicating the source of the threat and (3) reconstrual- requiring a reinterpretation of the threat or a redefining of self, or both.

Although, it is now recognised that there is a ‘continuum’ of health that requires different interventions at different times (Johnston, Stineman, & Velozo, 1997) only one approach (that is response) or model seems to be promoted. Applying Breakwell’s concepts to traditional health and rehabilitation interventions reveals that most would operate under mobility or change. This is because of their focus on function and implicit belief that this will reduce disability (i.e. eradicating the source of the threat). Rehabilitation has been defined as re-enabling (La Grow, 1999) and if this were the case then maybe interventions would be better focused on reconstrual, as people with disabilities or chronic illness can neither move away from nor eradicate their disability.

To achieve this, the definitions and models of disability and health need to be widened to include this spiritual domain (Christopher, 1999). It may also require a move toward health measures that are more subjective in nature. While there are a number of instruments that measure psychological functioning (Hawley et al, 1992) and quality of life (McDowell & Newell, 1996), there appear to be very few that explore the spiritual aspects of health. It is time to take a quantum leap, recognising that while subjective reality may be related to the objective measurement of impairment and disability, it may also be totally distinct (Whiteneck, 1994).

The Sense of Coherence

Aaron Antonovsky (1987) has presented a theoretical model designed to explain the relationship between stressors, coping and health. His work began by exploring the ability of concentration camp victims to survive in the face of incredible stress and adversity (Hawley et al, 1992). He concluded that some inner strength enabled these victims to survive, and this he has called a “sense of coherence” (Hawley et al, 1992, p.1912).

The SOC is seen as a generalised personality disposition that enables individuals to choose appropriate coping strategies in response to a specific problem or situation (Flannery & Flannery, 1990). It was designed to predict and explain movement towards “the healthy end of the health ease/disease continuum” (Antonovsky, 1993, p.725), and focuses on factors that promote health. This has been termed salutogenesis (i.e. health promotion and disease prevention) as opposed to pathogenesis (i.e. origins of disease) (Wolff & Ratner, 1999). Viewed another way, Antonovsky may well be describing a model that captures the essence of ‘rising to the occasion’.

The SOC is developed throughout childhood and adolescence, and can be affected by age, emotional closeness, communication, stable community and gender. An individual develops and becomes aware (or not) of a wide range of resources that can promote a healthy response to stressful situations. These are known as generalised resistance resources (GRRs) and include (a) material resources, (b) identity, (c) knowledge, (d) flexible and rational coping strategies, (e) social supports and commitment to a social group, (f) cultural stability, (g) magic, (h) religion, (i) preventative health strategies, (j)

constitutional and genetic strengths and (k) answers to life's problems that seem stable and reliable (Sullivan, 1993).

Ideally, the SOC becomes stable by about the age of thirty (Antonovsky & Sagy, 1986). However, major changes in patterns of life experiences can affect this (Antonovsky, 1993).

The SOC is defined as “ a global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence that (1) the stimuli deriving from one's internal and external environments in the course of living are structured, predictable, and explicable; (2) the resources are available to one to meet the demands posed by this stimuli; and (3) these demands are challenges worthy of investment and engagement” (Antonovsky, 1993, p.725). These three components are called comprehensibility, manageability and meaningfulness respectively, and form the SOC construct.

The SOC can be measured objectively and is operationally defined as the *Orientation to Life Questionnaire* (Antonovsky, 1993); now known as the SOC-29. The SOC-29 is a systematic closed-ended questionnaire, consisting of 29 questions that can be used in an interview format or by self-completion. The SOC-29 was developed using a facet theoretical design, an approach developed by Louis Guttman (see Antonovsky, 1993). Successful field-testing led to a large-scale empirical study. This was a longitudinal study looking at the health consequences of retirement. The SOC-29 was published in Antonovsky's 1987 book and this has led to research in over twenty countries (Antonovsky, 1993). A short form SOC-13 is also available (Antonovsky, 1993), with other researchers modifying the SOC further using even shorter forms (3, 6 and 9 questions) (Hall-Lord, Larsson & Steen, 1999; Jahnsen, Villien, Stanghelle & Holm, 2002; Kivimaki, Feldt, Vahtera & Nurmi, 2000; Larsson, Johansson & Hamrin, 1995).

The SOC scale seems to correlate highly with other measures, particularly those related to stress, anxiety, depression, self-efficacy, internal locus of control, hardiness and mastery (Antonovsky, 1993; Antonovsky & Sagy, 1986; Buchi, Sensky, Allard, Stoll, Schnider, Klaghofer & Buddeberg, 1998; Flannery & Flannery, 1990; Callahan & Pincus, 1995; Hawley et al, 1992). While some argue that the SOC scale is measuring

the same variables (Geyer, 1997), others believe that the SOC construct goes one-step further (Sullivan, 1993).

Strang and Strang (2001) have found that the SOC has a spiritual component, which is becoming recognised as being important for health (Faull, 2000; Vash, 1991). In general, spirituality is recognised as having four basic dimensions (1) a feeling that life has meaning, (2) interconnectedness, (3) transcendence of life and (4) a belief in the sacredness of life (Riley, Perna, Tate, Forcheimer, Anderson & Leura, 1998).

From the outset, the salutogenic model of health, and the SOC construct, was immediately attractive to those working in the health professions (Sullivan, 1993). This is particularly true for those working in rehabilitation settings with people who have chronic illness and disability, and who have long challenged the stronghold of the medical model (Fuhrer, 1994; Ravesloot et al., 1998). “The pathogenic approach pressures us to focus on the disease, on the illness...it blinds us to the subjective interpretations of the person who is ill” (Antonovsky, 1979, p.36). Assumptions are made as to why a person has entered the health care system, with the conclusion often being drawn that it is because of their disability or illness. Failure to ask an individual why they have come (to a health care facility) often leads to wasted time, resources and ineffective outcomes (Antonovsky, 1979; Hadler, 1992).

Furthermore, Frank (2002) asserts that the experience of a disability or illness is completely unique for each individual and does not follow some prescribed sequence, but instead is a complex interaction of many factors. Failure to try to understand this can lead to costs to the individual that may result in further suffering (Frank, 2002).

Identification of the Research Question

It would appear from the literature that a relationship between the SOC and coping with chronic illness and/or adjustment to disability exists. More specifically, the SOC may operate as a buffer or protective factor against the development or impact of secondary conditions. These conditions, which include anxiety, depression and problems with pain, further reduce people’s quality of life (QOL) and impact on physical functioning (see literature review). This then places greater demands on health care resources.

Cowley and Billings (1999) have identified that in the current environment of health funding rationalisation, it is services aimed at promoting health that often get cut. The “eye-catching aspects” (Hochstenbach 2000, p.201) of physical impairment and disability, on the other hand, continue to attract financial investment. With escalating health care costs and the advent of managed care, the need for the justification of services is paramount. Freeman, Hobart and Thompson (1996) explain that the reasons for this are primarily to prioritise available resources around the most effective treatments offered.

Decisions are made based on the availability of objective data. Unfortunately, most ‘data’ is presented from a pathogenic perspective and maintains this worldview. Services promoting health within this environment are difficult to establish in terms of their effectiveness and their importance. This is due, not only, to a lack of quantitative data, but also the reluctance of health professionals to move away from the more traditional approach and measurement of health (Higginson & Carr, 2001). If this is the case, rehabilitation is at serious risk of being confined to medical rehabilitation.

WHO (2002), in a global report, has identified that worldwide health outcomes for those with chronic conditions is poor. This is of concern when WHO’s research indicates that by 2020 chronic conditions will be responsible for 78% of the “global disease burden” (WHO, 2002, p.13). Perhaps the rehabilitation services that are currently offered are guided by a philosophy that measures (and possibly targets) the wrong things (Whiteneck, 1994).

To illustrate, most health-related QOL measures (Taylor & Macpherson, 1999) contain mainly questions related to pain, and how well certain functions can be performed (Lorig, Holman, Sobel, Laurent, Gonzalez & Minor, 1996; McDowell & Newell, 1996). In addition, it is the impact of the condition that is measured (Taylor & Macpherson, 1999), not a person’s experience of it or ability to respond to it. As Antonovsky (1979) states, “how one poses the question is crucial to the direction one takes in looking for the answer” (p.12).

Viewing health differently (salutogenesis vs. pathogenesis) allows for the development of a more positive approach. That is, one that focuses more on a person’s

inherent strengths, and the opportunity for personal growth in overcoming adversity (Faull, Hills, Cochrane, Gray, Hunt, McKenzie & Winter, 2004; O’Leary, 1998, Seligman, 2002). The power of an injury or disease, to control a person’s life and define them as disabled, is then also reduced.

Of great importance is the emerging evidence that the SOC is amenable to change (Ravesloot, et al, 1998; Delbar & Benor, 2001). This challenges the idea that the SOC is a stable personality trait, an assumption underlying most research utilising the SOC (see literature review). Seligman (2002) states that personality traits are 50% inherited. However, even “high heritability does not determine how unchangeable a trait is” (Seligman, 2002, p. 47), indicating that there may be a state-like component of even the strongest trait. As Seligman (2002) suggests, we can fight the “steersman” (p.47), indicating that even if the SOC is essentially a trait, it may still have a dynamic orientation.

On another level, viewing the subscales differently may also reveal information that could be used to guide appropriate interventions (Larsson, Johansson & Hamrin, 1995; Lustig, Rosenthal, Strauser & Haynes, 2000). Accepting the SOC as a stable trait has meant that important information has, perhaps, been overlooked.

Changing perspective and viewing the SOC as something that can be influenced/enhanced, allows for the evaluation of current programmes and/or the development of new ones that really address the issues related to chronic illness and disability. In fact many rehabilitation programmes may already have a positive impact on the SOC, but as this is not measured, it is neither recognised nor valued.

Purpose of the Research

The purpose of the research is essentially to investigate the stability of the SOC (as measured by the SOC-29) in relation to an intervention over time. Furthermore, this study will allow for the analysis of the SOC-29 subscales (comprehensibility, manageability and meaningfulness) and for comparison with other measures related to disability. The scope of this study does not allow for an in-depth analysis of the intervention, or for the identification of the ‘active ingredients’.

LITERATURE REVIEW

Over the last twenty years research into health has taken a different focus. Antonovsky's work and the development of the salutogenic model seem to have, at least in part, influenced this shift (Pallant & Lae, 2002). The SOC construct and versions of the SOC scale (SOC-3 – SOC-29) have been used in numerous studies.

Studies have been conducted that look at the relationship of the SOC to the preservation of health (Cowley & Billings, 1999; Kivimaki et al, 2000; Pallant & Lae, 2002; Suominen, Blomberg, Helenius & Koskenvuo, 1999), workplace stress (Tuomi & Seitsamo, 1999; Soderfeldt, Soderfeldt, Ohlson, Theorell & Jones, 2000) and wellness (Adams, Bezner, Drabbs, Zambarano & Steinhardt, 2000; Gana, 2001). The stability of the SOC within healthy populations has also been investigated (Feldt, Leskinen, Kinnunen & Ruoppila, 2003; Kivimaki et al, 2000).

Kivimaki et al (2000) looked at the stability of the SOC and the relationship between SOC and health in two cross-lagged longitudinal samples (study 1 $N = 577$, study 2 $N = 320$). They found that scores on the SOC scale were relatively stable over time, although they did find temporary changes following a threat. The results indicated that scores on the SOC scale were able to predict sickness absence from work among female employees, and that there was a strong association between the SOC scale and health complaints in men. Furthermore, scores on the SOC scale was strongly correlated with psychological complaints, particularly, depression and anxiety.

However, they found that there was no difference between those with high SOC scale scores and those with low SOC scale scores in terms of developing health problems. Therefore, Kivimaki et al (2000) concluded that high SOC scale scores did not equate to greater physical health. But Antonovsky did not posit that high SOC scale scores protect people from developing health problems, in fact he argues that ill-health is very much part of the human condition (Antonovsky, 1979). What he does suggest is that a stronger SOC will assist a person to react to, manage and experience an ill-health event in a healthy manner. Kivimaki et al (2000) did find support for this in their study as they found that low scores on the SOC Scale “predicted significantly more adverse health prospects than a high SOC” (p.593).

Gana (2001) conducted a study in France, using a convenience sample ($N = 193$), aimed to explore the SOC as a mediator of adversity. The results indicate that there was a statistically significant effect of adversity on well-being ($p < 0.05$). When analysing the SOC in relationship to this it was found that higher scores on the SOC scale seemed to mediate the adversity/well-being relationship (the researcher claims completely mediates adversity, p. 81). Furthermore, the SOC also seems to have a buffering effect.

Pallant and Lae's (2002) findings support this. They found that subjects with higher scores on the SOC scale had better overall physical health, less physical symptoms of stress, fewer days absent from work due to physical illness and made fewer visits to the doctor than those with lower scores on the SOC scale.

Perhaps due to the role that the SOC seems to play in relation to health, the stability of the SOC is also now being explored. Feldt et al (2003) conducted a 5-year follow-up study in Finland ($N = 352$). They divided their subjects into two age groups (25-29, $n = 141$ and 35-40, $n = 211$). They found that for both age groups the mean level of scores on the SOC scale was lower in 1992 than 1997. There were radical changes in Finnish working life in 1992, resulting in deep economic depression and high rates of unemployment. They concluded that environmental events might modify the level of SOC in adulthood, suggesting that the SOC should be viewed as a dynamic orientation rather than a stable trait. Unfortunately, the researchers did not explore the significance of this change on health.

It would appear that the SOC plays a part in the health outcomes for healthy populations, and is subject to change under certain circumstances. This observation may have implications for all, but especially for those with chronic illness or disability as they have "a narrower margin of health" (Ravesloot, Seekins and Young, 1998, p. 76). The significance of the SOC for people with chronic illness and/or disability, therefore, needs to be explored.

Relationship between the SOC, CI and Disability

The purpose of this review is to examine the relationship between the SOC and coping with or adjusting to chronic illness and/or disability.

Articles were included in the review if they met the following criteria: they (a) used the SOC scale as a measure (b) drew samples from populations who experienced chronic illness/health problems and/or disability (c) were conducted with adults (d) were written in English and (e) were available either on line or from libraries in New Zealand. A computerised search of the Massey University databases (Medline, CINAHL, Web of Science, Ebsco mega file, EBM Reviews, PsycInfo, Pub Med) yielded 30 studies that met these criteria. All 30 studies will be reviewed in this chapter. Twenty-one of these studies will be discussed first. This will be followed by the discussion of 9 studies that shed new light on the SOC.

Overview of Studies

All of the studies reviewed used non-experimental designs, except one. These studies were predominantly correlational, descriptive or proscriptive. Some had small or convenience samples, and/or study design limitations. Several of the studies (Bengtsson & Hansson, 2001; Berglund, Mattiasson & Nordstrom, 2003; Delbar & Benor, 2001; Jahnsen et al, 2002; Lustig, Rosenthal, Strauser & Haynes, 2000; Malmgren-Olsson & Branholm, 2002; Nilsson, Holmgren & Westman, 2000; Richardson, Adner & Nordstrom, 2001; Schnyder, Buchi, Sensky & Klaghofer, 2000; Weissbecker, Salmon, Studts, Floyd, Dedert & Sephton, 2002) used participants who were younger than 30, despite Antonovsky indicating that the SOC was not stable until this age (Antonovsky & Sagy, 1986). The significance of this in terms of the findings is unknown. Therefore, for all of these reasons the information drawn from the studies should be interpreted with caution. However, some interesting themes emerge, which will now be discussed.

Overall, the studies indicated that the SOC has been studied with a number of populations. These include those with; arthritis (Buchi et al, 1998; Callahan & Pincus, 1995; Germano, Misajon & Cummins, 2001; Hawley et al, 1992; Schnyder et al, 2000; Soderberg, Lundman & Norsberg, 1997; Weissbecker et al, 2002), chronic pain (Petrie & Azariah, 1990), musculoskeletal disorders (Malmgren- Olssen & Branholm, 2002), cerebral palsy (CP) (Jahnsen et al, 2002), chronic renal failure (CRF) (Klang, Bjorvell & Cronqvist, 1996), cancer (Boman, Bjorvell, Languis & Cedermark, 1999) diabetes (Richardson et al, 2001; Sanden-Eriksson, 2000) human immunodeficiency virus (HIV) (Cederfjall, Languis-Eklöf, Lidman & Wredling, 2001) peripheral vestibular disorder

(PVD) (Mendal, Bergenius & Languis, 2001), schizophrenia (Bengtsson-Tops & Hansson, 2001), acute myocardial infarction (AMI) (Drory, Kravetz & Hirschberger, 2002), Ehlers-Danlos syndrome (Berglund, Mattiasson & Nordstrom, 2003) disabilities (Lustig et al, 2000) and older people with a variety of chronic illnesses and health problems (Forbes, 2001; Hall-Lord et al, 1999; Larsson, Johansson & Hamrin, 1995; Nesbitt & Heidrich, 2000; Nilsson, Holmgren & Westman, 2000; Rennemark & Hagberg, 1999).

Some of the studies reported a positive correlation between scores on the SOC scale and level of education (Callahan & Pincus, 1995; Delbar & Benor, 2001) and scores on the SOC scale and age (Callahan & Pincus, 1995; Malmgren-Olsson & Branholm, 2002; Nilsson, Holmgren & Westman, 2000). The last point is particularly interesting as the SOC is supposed to be stable in relation to age.

On the whole the mean scores on the SOC scale from these populations do not seem to differ from those of the general population as indicated by Hawley et al (1992). In one study (Mendal et al, 2001) the patient sample had a higher mean score on the SOC scale than the healthy reference group. Therefore, people with chronic illness or disabilities do not automatically score lower on the SOC scale.

However, some studies did find that their subjects scored lower on the SOC scale than the general population (Germano et al, 2001; Jahnsen et al, 2002). In all cases though, the level of the SOC scale for individuals within these populations appears to impact on their experience of their chronic illness or disability.

SOC as a Stable Personality Trait

Most studies involving the SOC have accepted Antonovsky's view that it is a stable personality trait. They have therefore used the SOC scale as an independent variable. These studies have been summarised in Appendix A and will be reported on first.

Several of the studies found that scores on the SOC scale were negatively correlated with measures of anxiety and depression (Berglund et al, 2003; Buchi et al, 1998; Callahan & Pincus, 1995; Cederfjall et al, 2001; Drory, et al, 2002; Hawley et al, 1992; Mendal et al, 2001; Rennemark & Hagberg, 1999; Weissbecker et al, 2002). However,

this was not necessarily related to functional ability or disease process. For example, Hawley et al (1992) found that women with rheumatoid arthritis (RA) had greater functional disability, but that woman with fibromyalgia (FMS) scored higher on the anxiety and depression scales, and lower on the SOC scale. It has also been suggested that the SOC can operate as a protective factor for depression and anxiety (Buchi et al, 1998; Drory et al, 2002) and that it explains the variation in clinical status (Callahan & Pincus, 1995).

The SOC seems to influence the perception of pain and the identification and awareness of symptoms (Hall-Lord et al, 1999; Hawley et al, 1992; Malmgren-Olssen & Branholm, 2002; Nesbitt & Heidrich, 2000; Petrie & Azariah, 1990; Rennemark & Hagberg, 1999). Those with a lower score on the SOC scale not only report higher levels of pain and number of symptoms, but also seem to be more distressed by them (Berglund et al, 2003). Furthermore, they perceive their health to be poor and their lives to be less meaningful (Hall-Lord et al, 1999; Nilsson et al, 2000, Weissbecker et al, 2002). These findings raise questions about the impact of the SOC on quality of life.

Nesbitt and Heidrich (2001) found that scores on the SOC scale were significantly correlated with Illness Appraisal (IA) and that together these factors had significant mediating effects between Physical Health Limitations (PHL) and QOL.

Interestingly, Germano et al (2001) suggested that the SOC was not a predictor of subjective QOL. Their study looked at the experiences of three groups. Group 1 included people with arthritis receiving support from the Arthritis Foundation of Victoria, group 2 included people with arthritis not receiving support and group 3 included individuals from the general population. They found that Groups 1 and 2 had lower SOC scale scores than group 3, but that this was not correlated with subjective QOL. However, they also found that Groups 1 and 2 reported a greater fear of being unloved, lowered mood, increased negative affect and decreased positive affect than Group 3. They concluded that the SOC scale was a measure of negative affectivity. However, they were unable to explain how this did not relate to subjective QOL.

Coping strategies are often linked with QOL (Nesbitt & Heidrich, 2000) and so deserve exploration with respect to the SOC. Klang et al (1996) found that scores on the SOC

scale were significantly correlated with the coping strategies used. Those with lower scores on the SOC scale tended to use more emotive (e.g. worry) and palliative (e.g. withdraw) styles of coping, and less confrontational (e.g. problem solving) styles than those with a higher SOC scale score.

Taken one step further, the SOC also seems to be related to an individual's ability to adjust to and manage their chronic illness or disability (Berglund et al, 2003; Lustig et al, 2000; Richardson et al, 2001; Sanden-Eriksson, 2000). This adjustment (or not) seems related to subsequent functional and psychosocial health status (Berglund et al, 2003). Rennemark and Hagberg (1999) conclude that the SOC serves as a buffer against the experience of illness. Mendal et al (2001) state that the SOC seems crucial in predicting an individual's ability to cope.

Jahnsen et al (2002), whose study looked at the experience of people with CP, suggested that care received during childhood may have an impact on the development of the SOC, and that this has implications for later life. They propose that being part of the result (i.e., being involved in decisions and choices about their lives) develops meaningfulness, and that many children with CP do not have this experience. They found that the CP group they studied had lower SOC scale scores than the reference group. Furthermore, they found those with the lowest SOC scale scores had an increased risk of experiencing chronic fatigue and had higher scores on the bodily pain subscale of the SF-36.

The SOC seems to have other predictive values as well. Boman et al (1999) found that scores on the SOC scale were significantly correlated with post-surgical outcomes. In addition, scores on the SOC scale are a stronger predictor of health and well-being than psycho-social, clinical or demographic variables (Forbes, 2001; Drory et al, 2002; Nilsson et al, 2000; Soderberg et al, 1997). These scores can also be used to predict future care needs (Larsson et al, 1995).

Also of note amongst the studies was the issue relating to the subscales of the SOC scale (manageability, comprehensibility, meaningfulness). There is debate as to the statistical integrity of using the subscale scores and even Antonovsky (1993) warned against the appropriateness of analysing the subscales having conducted his own factor

analysis of these scales. However, several studies did conduct a factor analysis to determine if they would use the subscales or just the total SOC scale score. Germano et al (2001) identified two factors, but decided to use the total SOC scale score. Two studies (Callahan & Pincus, 1995; Hawley et al, 1992) argued that the subscales of the SOC scale were measuring the same thing, and so only utilised the total SOC scale score.

However, other studies did not support this, and found that utilising the separate subscales revealed interesting findings (Larsson et al, 1995; Lustig et al, 2000, Petrie & Azariah, 1990).

Larsson et al (1995) found that scores on the comprehensibility subscale was the strongest predictor of who returned home or moved to an institution following treatment at surgical or orthopaedic units (1 month later). An unexpected finding was that some of the patients had died. Interestingly, these people scored lowest on the meaningfulness subscale at time of discharge.

Petrie and Azariah (1990) found that individual scores on the meaningfulness subscale had value in identifying/predicting an individual's response to a pain management programme and their subsequent reporting of pain intensity 6 months later ($p < 0.01$). Lustig et al (2000) have also found that scores on the meaningfulness subscale to be of consequence and states that it seems to be the most important predictor for adjusting to disability. Jahnsen et al (2002) found that scores on the comprehensibility subscale were also correlated with adjustment and may therefore play a major role.

The studies discussed so far have viewed the SOC as a stable trait; other studies were found that looked at the SOC differently and these will now be discussed.

SOC as a State

Four studies were found that raise questions about the stability of the SOC over time particularly with regard to life's events. These studies are summarised in Appendix B.

A study by Nilsson, Holmgren, Stegmayr and Westman (2003) investigated the stability of scores on the SOC scale for a general population in Sweden between 1994-1999.

While the participants for this study do not strictly meet the criteria for inclusion, the results are worthy of mentioning at this time.

The researchers found that there was a significant decrease in SOC scale scores ($p < 0.0001$) over the 5-year period, particularly for those aged 45-74 and who had an identified disease. Those who experienced a change in perceived good health and social support showed the most significant loss. It was found that scores on the SOC scale were only stable for those who had high SOC scale scores at the beginning of the study. This indicates that perhaps the onset of a condition can have an impact on scores on the SOC scale. This is reflected in the next three studies.

Schnyder et al (2000) looked at two different populations, patients with rheumatoid arthritis (RA) ($n = 60$) and severely injured accident victims ($n = 96$). Measures were administered repeatedly over 6-12 months. For the RA group they found that scores on the SOC scale were relatively stable over time, but that they correlated negatively and highly significantly with scores for anxiety and depression ($p < 0.01$). For the accident victims the picture was somewhat different. In the first 6 months after the accident, the mean SOC scale scores significantly decreased. They then remained stable in the second 6 months. There appeared to be a delayed but permanent decrease in scores on the SOC scale following injury. The correlations between the SOC scale scores and the measures of anxiety became increasingly stronger over time.

The researchers concluded that although the SOC can be considered a trait, under certain circumstances, the SOC could also be subject to significant and lasting change. They suggest that therapies need to focus on assets like the SOC, to ensure that individual's ability to respond to subsequent challenges is not permanently compromised.

This picture is further reflected in the study by Caap-Ahlgren and Dehlin (2004) who investigated the experiences of people with Parkinson's disease. They found that within a 1-year period participant's scores on the SOC scale had decreased significantly ($p < 0.0001$). There was also deterioration on the Hoehn and Yahr Scale, a functional measure ($p < 0.01$) and the PDQ-8, a subjective health measure ($p < 0.01$). The other measures used (SF-36, Geriatric Depression Scale and Insomnia measure) showed no

change at all and this they were unable to explain. The researchers point out that they are unsure if the change in the SOC scale scores were temporary or permanent, having only two measurements.

Bengtsson-Tops and Hansson (2001) essentially conducted their study to examine the construct and predictive validity of the SOC for people with schizophrenia. They found a strong correlation between scores on the SOC scale and measures of QOL, particularly with respect to measures of mastery, self-esteem and social integration. They took a second measurement 18 months after the first and found that the SOC scale scores had changed, and that changes were positively correlated with overall subjective QOL, global well-being and global psychosocial functioning. Unfortunately, the researchers did not statistically report the changes found, and although they indicate that all scores increased this is not clear. They did mention that, at the time of the study, a new care initiative was introduced within the community, focusing on the needs of this patient group but details are not given. It is not clear if the participants in this study received this intervention. However, they conclude that it might be possible to enhance an individual's SOC and that this is related to an improved quality of life, adjustment and coping.

Exploring interventions that have the potential to enhance the SOC would seem appropriate given the information already presented. The remaining studies seek to do this.

The SOC as a Focus of Intervention

Five studies were located that examined the effect of specific interventions on the SOC (Appendix C). The first of these to be reviewed, a study by Karlsson, Berglin and Larsson (2000) indicates that scores on the SOC scale can be affected by a surgical intervention. SOC scale scores of participants ($N = 111$) were taken 1 week before, the day before and 3, 6, and 12 months after coronary artery bypass grafting (CABG) surgery. There was no mean difference before or after surgery. However, at the 12 month follow up 14.7% of participants increased their SOC scale scores by more than 10%. Other participants showed a decrease in their SOC scale scores of greater than 10% (26.6% of participants). The remaining 58.7 % of participants seemed to have stable scores on the SOC scale (changes less than 10%).

The researchers also did an analysis of strong, moderate and weak SOC scale scores. They found that those with decreased or unchanged moderate/weak SOC scale scores reported a significant increase in loneliness ($p < 0.003$) post-operatively. Furthermore, 42% of this group reported chest pain at the 12-month follow up compared to 21% of those with an increased or unchanged strong SOC scale score. Scores on the SOC scale correlated with improved QOL and surgical outcomes and the researchers suggest that the SOC scale needs to be explored further as an outcome measure.

The aim of the next study was to compare three physiotherapy approaches for people with non-specific musculoskeletal disorders ($N = 71$). Malmgren-Olsson and Branholm (2002) compared Body Awareness Therapy (BAT) ($n = 23$), Feldenkrais (FK) ($n = 22$) and conventional physiotherapy (TAU) ($n = 26$). Both BAT and FK are based on a framework of the interaction between mind and body. SOC scale scores were obtained, as were scores on the SF-36. Scores on the SOC scale correlated with those from the SF-36 on all subscales except the three physical ones ($p < 0.05$ - $p < 0.01$). Those with high SOC scale scores improved significantly on the subscale of physical function ($p < 0.05$) in all three groups. In the FK group, those with a low SOC scale score improved on the subscales of mental health ($p < 0.01$) and role emotional ($p < 0.05$). For the TAU group those with a high SOC scale score improved on the subscale of bodily pain.

With regard to the stability of the SOC, the researchers did not find any significant difference between the three treatment groups or between the two measurement times. However, measurements were taken before the intervention and at 1-year follow-up. It is impossible to know what may have happened within that 12-months, but measures taken at the end of the programmes may have revealed more. Furthermore, whilst BAT and FK are based on mind body principles, they are still essentially physiotherapy treatments and remain focused on improving physical function. As such they may be 'pathogenic' in their orientation and their ability to enhance the SOC may be questionable.

In contrast, the remaining three studies investigated interventions that do appear more 'salutogenic'. Furthermore, they appear to target the GRR's (see Introduction) associated with the development of a strong and healthy SOC.

The first of these to be reviewed, that by Ravesloot et al (1998) found that a health promotion intervention called “Living Well With Disability” suggested that a positive change in SOC scale scores was possible. The intervention was a series of health seminars exploring topics such as; goal setting, problem solving, healthy reactions, what to do when you have the blues, healthy communication, information seeking and managing your health, increasing physical activity, eating well, advocacy and maintenance. The seminars were conducted once a week for 2-hours over an eight week period. A convenience sample of 22 people with spinal cord injuries was recruited for the study.

Mean scores on the SOC scale between pre-test and follow-up indicated improvement, but this did not reach statistical significance ($p = 0.10$). However, increases in the SOC scale scores correlated with decreases in functional limitations due to secondary conditions and use of physician time (45%). Participants also reported positive changes in employment status, residence and relationship status following participation in the programme. However, only 14 participants completed the study so its power to yield a statistically significant result must have been limited.

Weissbecker et al (2002) conducted a randomized controlled trial ($N = 91$) to explore the capacity of an 8-week Mindfulness Stress Reduction Programme (MBSR) to enhance the SOC. Fifty-one participants with FMS were assigned to an immediate treatment group and 40 were wait-listed to receive the programme 4-months later. Data was collected before and after intervention. The MBSR provides instruction in mindfulness meditation. Participants met for 2.5hours a week and were encouraged to develop a daily meditation practise.

Participation in the MBSR resulted in a significant increase in the mean score for that group on the SOC scale ($p < 0.01$) compared to the wait-list control group. Furthermore, the scores on the SOC scale correlated negatively with measures of perceived stress and depression.

Delbar and Benor (2001) also found that an intervention could enhance the SOC and improve health outcomes. They investigated the impact of a structured nursing

intervention focused on case management and patient empowerment on scores on the SOC scale. Forty-eight cancer patients were visited in their homes bi-weekly over a period of three months. A wait-list control group were also assessed over the same time period. The nurses were trained to advise, guide, support, educate and transfer responsibility for symptom control over to the participants following the self-care model.

The intervention led to a significant increase in total SOC scale scores for the intervention group ($p < 0.001$). This was noteworthy as the wait-list control group's SOC scale scores significantly decreased over the same time period ($p < 0.05$). Analysis of the subscale scores revealed significant increases in manageability ($p < 0.001$), meaningfulness and comprehensibility ($p < 0.01$) for the intervention group. In addition scores on the SOC scale were correlated with increased internal locus of control and more control over symptoms with less perception of their intensity. However, the researchers did not do a follow-up measurement and were unable to say if the changes were sustained over time.

Although these studies used relatively small sample sizes, and may have design limitations that make generalisation unsound, they do raise issues for further exploration and debate.

Summary and Conclusions

The studies reviewed raise numerous questions about the relationship between the SOC and chronic illness and/or disability, and about the SOC construct itself. Exploring the issues involved could lead to a revolution in terms of the perception of health and health care provision.

There appears to be a particular link between the SOC and adjustment and coping, with scores on the SOC scale correlating with a number of different health measures. Of particular interest is the emerging evidence that scores on the SOC scale may change in response to traumatic situations (including the on-set of a chronic illness and/or disability). Antonovsky (1979) did indicate that the SOC might be subject to temporary changes, but that this would occur around a stable location. This does not seem to be the

case for those experiencing the onset of a chronic illness or disability, with some experiencing significant and lasting changes.

The effect this has on health outcomes can be quite considerable. Antonovsky (1979) acknowledged this himself and stated that “for the physician to cure he or she must cope with the problem of a lessened sense of coherence” (p. 204). This does not seem to be widely acknowledged in current health care practices.

However, interventions that appear to have a ‘salutogenic’ approach do seem to have the ability to positively affect the SOC, with subsequent improvements in health outcomes. In addition, it would also appear that changes in the SOC might only need to be relatively small to result in a positive effect (e.g. Ravesloot et al, 1998). What does not appear to have been established is if these interventions can result in lasting improvements. The question then becomes, can an intervention help to enhance an individual’s SOC that may have been affected by the onset of a chronic illness or disability?

Of primary importance then is to subject the SOC scale to further empirical testing, particularly to see if lasting changes do occur following intervention. In addition, further analysis of the subscales (comprehensibility, manageability, meaningfulness) would also be valuable.

However, care needs to be taken as to how the SOC is portrayed (Feldt et al, 2003; Malmgren-Olsson & Branholm, 2002). Unfortunately some of the studies reviewed may give the impression that the SOC scale is like any other measurement of a psychological trait or state, with the direction of the score on the SOC scale interpreted as a sign of strength or weakness. This would result in a further reinforcement of the pathogenic model of health, and the identification of things that were wrong with the individual, and that needed to be treated.

The SOC is a sociological construct (Antonovsky, 1979, 1987) and promotes a salutogenic model of health. If used appropriately research should lead to the identification of factors that help people to stay well despite chronic illness and/or disability. Taking a more holistic approach and looking at programmes that aim to

address all issues (physical, emotional, mental, spiritual etc.) related to chronic illness and/or disability and promote health could reveal useful information. This study aims to take the first steps.

Research Questions, Hypothesis

The research questions are:

1. Is the SOC a trait or a state?
2. Can an intervention change the SOC?
3. What does analysing the subscales reveal?
4. How does any change correlate with adjustment and coping with a chronic illness/disability?

The null hypothesis is that: The intervention will have *no* impact on the SOC.

The alternative hypothesis is that: The intervention *will* have an impact on the SOC.

METHODOLOGY

Methodological Approach

The aim of any research within the health field should be to test and generate theories to allow a greater understanding of how to promote health (Minichiello, Sullivan, Greenwood and Axford, 1999). If, as the research suggests, the SOC does play such a vital role in chronic illness and the adjustment to disability, and with emerging evidence that it may be sensitive to change, it's relationship to health outcomes needs to be explored.

For the SOC to be viewed as an important component for health change, it needs to be shown to be dynamic rather than to be a measure of an unchanging trait, which many have assumed it to be. To test whether the SOC is related to health change the SOC-29 would need to correlate with other (already accepted) measures to gain any credibility.

Fortunately, the SOC lends itself to empirical investigation. It is operationally defined, and can be measured objectively, using an existing measure. Furthermore, a hypothesis (null) can be stated (that intervention X will have no impact on the SOC), and then tested, and measures of control can be utilised.

For this study, the conditions for a true experimental design could not be organised as the researcher did not have control over random allocation of participants. However, other experimental procedures could be applied so the most appropriate methodology for this study was a quasi-experimental design.

METHODS

The Intervention

The intervention for this study was a 3-week in-patient rehabilitation programme. For this study the participants were required to attend the programme at QE Health formerly Queen Elizabeth Hospital, Rotorua, New Zealand.

Queen Elizabeth Hospital (QEH) was opened in 1942 as a rehabilitation hospital for returned servicemen. The philosophy of the hospital, developed and promoted by the Medical Superintendent Dr W.S. Wallis, appears to be in line with a salutogenic model of health (Faull, Kalliath & Smith, 2004).

Wallis believed that it was the individual who determined how they coped and experienced disability, the role of the health professional was to provide the right environment and identify the options available. The perception of self-worth, self-belief and sense of 'I' was seen as crucial to the rehabilitation process (Faull et al, 2004).

Wallis advocated for the rights and needs of patients, believing that all could return to full participation in society, given the opportunity to fulfil their potential (Faull et al, 2004).

This philosophy has continued at QE Health (QEH), which now provides rehabilitation services for people with arthritis and other musculoskeletal conditions. Combining modern therapies (physiotherapy, occupational therapy, counselling) with the older more traditional spa therapies, QEH is recognised for providing a holistic approach to health care. (Faull et al, 2004; QEH Website).

QEH offers both in-patient and outpatient programmes. The focus of this study is on the in-patient programmes. In general, patients are admitted for a 3-week programme, although longer and shorter stays are common. Patients work with a multidisciplinary team (Occupational Therapist, Counsellor, Nurse, Physiotherapist, Balneotherapist, Orthotist, Doctor) to improve self-management of their condition. Individual goals are identified through assessment. Education is a key component as is reflection time and association with other patients. The programmes appear to focus on the strengthening of generalised resistance resources (GRRs, see Introduction). It is believed that it is this

type of programme that could have a positive impact on the SOC, as well as, impacting on an individual's adjustment to and management of a chronic illness and/or disability. This may also result in a positive improvement in general health.

Participants

The participants for this study constituted a convenience sample of the first 120 patients (from March 2004) admitted to QEH who both agreed to participate, and who met the criteria for inclusion into the study. Potential participants were identified from the QEH booking list for in-patient admissions. The number of participants was derived following a power analysis. The criterion of significance (alpha) was set at 0.05. A sample size of 120 has the power of 80% to yield a statistically significant result. This computation was based on results from published studies.

Participants were included in the study if they met the following criteria; that they were being admitted for rehabilitation, not medical or surgical interventions, were 30 years of age or older (the SOC is not said to be stable until age 30), had a diagnosed chronic, musculoskeletal condition, were literate, had a good understanding of English, and who were to complete a three week programme.

Research Design

This study was conducted using a time-series experimental design (Campbell & Stanley, 1963). This design uses repeated measurement over time with the introduction of an intervention within the time series. The intervention is said to have an effect if it results in discontinuity in the measurements recorded in the time series. This design can be diagrammed thus:

O1 O2 X O3 O4

This design allows the participants in the study to be used as their own controls. McBurney (2001) argues that this design is appropriate for experiments that are exploring subjective experiences. Furthermore, this approach provides a partial control technique, as it reduces the variation caused by the differences that exist between people (Minichiello, Sullivan, Greenwood & Axford, 1999).

This approach will allow for the comparison of SOC scores (and the other measures to be used; SF-36, ADM) before and after the admission to QEH. It will not allow for the identification of any causal factors, if indeed any change occurs (McBurney, 2001). However, this could be implied if change does occur.

Consultation

The perception and definition of health is pivotal to health delivery. This study aims to look at health from a different perspective and provide an additional dimension to the pathogenic view. The pathogenic view of health can fail to recognise the importance of the subjective and spiritual elements. A previous study within this population indicated that health is both subjective and spiritual in nature (Faull, 2000). Such a view of health complements that commonly expressed by Maori and therefore the study has the potential to be useful in advancing practice and knowledge of such a worldview.

Maori acknowledge spirituality as an integral component of health, and have consistently identified that this is not acknowledged within the pathogenic view. Recognition of the subjective nature of health inherently acknowledges the presence of more than one worldview and way of perceiving health, and the possibility that there is a need to include, within healthcare delivery, a view and method of measurement of health that more accurately reflects this.

To ensure that this study was culturally appropriate and safe, advice was sought from the QE Health Maori Liaison Officer. This led to a meeting with the Kuini Riripeti Kaunihera who made recommendations for the study. Comments from the meeting indicated that the group felt that the SOC questionnaire was more appropriate for Maori than the other two questionnaires (Acceptance of Disability and SF-36), as it seemed to reflect a spiritual perspective.

Procedure

All patients, who were to be admitted to QEH for a 3-week rehabilitation programme and who fitted the criteria for inclusion were approached to participate in the study. Approximately 236 people were sent information letters (Appendix D) and contacted by phone, one week later, to see if they wanted to participate in the study and to clarify issues or answer questions. Participants were informed (throughout the study) that they

could choose to withdraw consent at any time and choose not to participate/withdraw from the study without penalty or the withholding of treatment.

One hundred and thirty people agreed to participate in the study and were sent the first pack of questionnaires. This pack contained (a) a demographic questionnaire (Appendix E) collecting data on; age, diagnosis, disease duration, gender, ethnic origin, education, source of income, marital status, (b) a consent form (Appendix F) and (c) the SOC-29, with instructions to be completed and returned in the stamped address envelope supplied prior to admission. This was Time One (T1). Of these 120 were returned, and these people became the sample for the study.

While the researcher was aware of the participant's identity initially, all participants were coded so that their data could be compared later, and confidentiality maintained.

On admission, a package of questionnaires was delivered to the participants. This included the SOC-29, the SF-36 Health Survey and the Acceptance of Disability Scale (ADM) (see study measures). Instructions were given to participants to complete the questionnaires and return to the nursing staff if they still consented to be included in the study. This was Time Two (T2). All measures were self-administered, but a reader/writer was available if required. Data was also collected on discharge (in the morning of the last day, whilst at QEH) (T3) and at 6-month follow-up (mail-out) (T4). The SOC-29 was assessed at all four times, the ADM at times 2, 3 and 4 and the SF-36 at times 2 and 4 only (see Table 1, Data Collection Times).

Patients are admitted to QEH for periods of 1-4 weeks, with the majority staying for 3 weeks. To minimise the impact of different variables those who were admitted for less/more than 3 weeks were excluded. During the course of the study some participants were not able to complete their 3-week programme, they therefore did not complete the study. Other participants were offered a fourth week. However, they completed the questionnaires at the end of their third week again to eliminate confounding variables. Patients were also excluded from the study if they received therapeutic intervention from the researcher.

Table 1. Data Collection Times

	T1	T2	T3	T4
SOC-29	X	X	X	X
SF-36		X		X
ADM		X	X	X

Dependant Measures

While the main aim of the study was to collect and analyse data about the SOC, other measurements were collected to allow for analysis and comparison to the SOC. The measurements used in this study were:

- Sense of Coherence-29 (SOC-29) see Appendix G.
- Short-form-36 Health Survey (SF-36) see Appendix H.
- Acceptance of Disability Scale Modified (ADM) see Appendix I.

Sense of Coherence -29 (SOC-29)

The questionnaire has 29 items divided into (a) 11 items related to comprehensibility (when you talk to people, do you have the feeling that they don't understand you? Q1), (b) 10 related to meaningfulness (how often do you have the feeling that there's little meaning in the things you do in your daily life? Q28) and (c) 8 related to manageability (do you have the feeling that you are being treated unfairly? Q9) (Hawley et al, 1992). A seven-point semantic differential scale with two anchoring phrases is used; respondents are asked to select a response on this scale for each of the 29 questions. Thirteen items are negatively formulated, and are reversed for scoring. The 29 items can be summed for a total SOC score. A high score always expresses a strong SOC, with scores ranging from 29-203.

The psychometric properties and quality of this measurement appear to be sound (Flannery & Flannery, 1990). This measure has also proven reliability. Based on a number of studies, internal consistency appears to be high using the Cronbach alpha measure (lowest alpha 0.85) (Antonovsky, 1993; Hawley et al, 1992). The reliability coefficient for the total SOC score was 0.948, in Hawley et al's (1992) study.

Short-form-36 Health Survey (SF-36)

The SF-36 is a well-recognised, valid and reliable measure designed as a generic indicator of health status (Ware, 1999; McDowell & Newell, 1996). It contains eight

sub-scales; (a) Bodily pain, (b) Role limitation due to physical health problems, (c) Role limitation due to emotional problems, (d) Physical functioning, (e) General health perception, (f) Social functioning, (g) General mental health (including psychological distress and well-being) and (h) Vitality. One further question measures the change in health status over the previous year.

The SF-36 has been standardized for US populations. Scores range from 0-100 with all scales being norm-based to achieve the same means and standard deviations (mean 50, standard deviation 10) across all scales (Ware, 1999). This allows for comparisons with other populations (McDowell & Newell, 1996).

All items in a scale are computed using a simple algebraic sum of responses. This provides the raw score. Raw scores are transformed and a score is calculated for each of the eight scales. The raw score is transformed to a 0 to 100 scale using the formula below (Ware, 1993).

$$\text{Transformed scale} = \frac{[\text{Actual raw score} - \text{lowest possible raw score}]}{\text{Possible raw score range}} \times 100$$

The measure is known to have both a floor and ceiling effect (Ware, 1993). Higher scores indicate better functioning. Table 2 indicates how to translate the scores and identify meaning.

Table 2. Meaning of Scores

Concepts	Lowest Possible (floor)	Highest Possible (ceiling)
Physical functioning	Limited a lot in performing all physical activities including bathing or dressing due to health	Performs all types of physical activities including the most vigorous without limitation due to health
Role-Physical	Problems with work or other daily activities as a result of physical health	No problems with work or other daily activities as a result of physical health
Bodily Pain	Very severe and extremely limiting pain	No pain or limitations due to pain
General Health	Evaluates personal health as poor and believes it is likely to get worse	Evaluates personal health as excellent
Vitality	Feels tired and worn out all of the time	Feels full of pep and energy all of the time
Social Functioning	Extreme and frequent interference with normal social activities due to physical or emotional problems	Performs normal social activities without interference due to physical or emotional problems
Role Emotional	Problems with work or other daily activities as a result of emotional problems	No problems with work or other daily activities as a result of emotional problems
Mental Health	Feelings of nervousness and depression all of the time	Feels peaceful, happy, and calm all of the time

(Ware, 1993, p. 2)

Acceptance of Disability Scale, Modified (ADM)

For the purposes of this study, a modified version of the AD Scale will be used to measure acceptance and adjustment to chronic illness/disability. The word ‘disability’ was replaced by the word ‘condition’. This has been done in previous studies with the words ‘ostomy’, ‘diabetes’ and ‘Ehlers-Danlos syndrome (EDS)’ being substituted (Berglund et al, 2003; Richardson et al, 2001).

Developed and validated by Linkowski (1981) the AD Scale is based on a philosophy that recognises the subjective meaning of the disability to the individual (Linkowski, 1981; Richardson, et al, 2001). Research using the AD Scale indicates that acceptance of disability is strongly related to self-perception that ultimately affects overall adjustment (Linkowsky, 1981).

This is a valid measure for individuals with acquired disabilities and chronic illness (Cushman & Sherer, 1995). The AD Scale shows high reliability (internal consistency

coefficient, 0.93) (Linkowsky, 1981). The AD Scale consists of 50 disability related statements associated with four value areas.

1. Enlargement of scope - ability to see values other than those associated with the condition. There are many things a person with my condition is able to do (item 16).
2. Subordination of physique – ability to de-emphasise aspects of a physical condition and appearance. My condition affects those aspects of life, which I care most about (item 9).
3. Containment of disability effects – ability to restrict disability to actual physical impairment rather than spreading to other aspects of functioning self. Almost every area of life is closed to me because of my condition (item 31).
4. Transformation from comparative to asset values – ability to emphasise assets and abilities as opposed to limitations and liabilities. Though I can see that people with physical conditions are able to do well in many ways, still they can never lead normal lives (item 37).

A 6-point Likert-type scale is used, with scores ranging from 50-300. A higher score indicates a higher level of acceptance/adjustment.

Analysis

The data was analysed using the SPSS version 11.0 for Windows. To test for changes in SOC-29 scores and subscale scores across time a one-way repeated measures ANOVA was conducted with data from Time 1, Time 2, Time 3 and Time 4. This analysis was used to test the null hypothesis. The same analysis was conducted to test for changes in ADM scores using data collected at Time 2, Time 3 and Time 4.

If a significant change in scores was seen for either the SOC or ADM follow up analysis using paired samples t-tests were then conducted to determine where the change occurred. As the SF-36 was only measured twice a paired-samples t-test was conducted using data collected at Time 2 and Time 4. Data collected is for the subscales of the SF-36, as there is no total score.

Relationships between the SOC and the other measures (ADM and SF-36) were explored using the Pearson's r correlation. A significance level of 0.05 was set for all analysis.

RESULTS

120 people participated in this study, 93 (77.5 %) were female while 27 (22.5 %) were male. Their mean age was 58.5 years and ranged from 30 to 90. There was no difference in the mean age or range between males and females. As can be seen in Table 3, 82% ($n = 98$) of the participants identified themselves as NZ European, 13% as NZ Maori ($n = 15$), and 6% ($n = 7$) as other. In terms of diagnoses, - 33% ($n = 40$) were diagnosed as having fibromyalgia, 23% ($n = 27$) osteoarthritis, 16% ($n = 19$) rheumatoid arthritis, 8% ($n = 9$) back pain, and the remaining 21% ($n = 25$) as other. Among those designated as 'other' 10 had no diagnosis, 7 had various arthritic conditions, 5 were post-polio, 2 had chronic pain and 1 multiple sclerosis. Of the 116 who reported their marital status, half were married ($n = 57$) or in a defacto relationship ($n = 1$), while the other half were divorced ($n = 22$), single ($n = 20$) or widowed ($n = 16$). In terms of income, 62% ($n = 74$) of the 116 who responded to this question, were on a benefit ($n = 64$) or receiving income support from ACC ($n = 10$). The remainder were either working ($n = 24$) or reported 'other income' ($n = 18$). Of those working, nearly half (i.e. 11 of 24) were in part-time employment. When asked about their highest-level education, 79 responded and 41 did not. Of those responding, 16% ($n = 19$) had completed primary school and/or some secondary, but had not completed a secondary qualification. 13% ($n = 15$) had completed secondary school but had not gone on for further training, while 29% ($n = 35$) had taken courses and/or completed other qualifications, and 13% ($n = 10$) had a degree from university.

One hundred and twenty participants completed the questionnaires at T1. By T2 this had reduced to 112 (93%). At T3 102 (85%) participants remained in the study and by T4 there were 72 (60%). Reasons for withdrawing from the study included ill-health requiring a transfer to another facility (one participant had a stroke), participant choice (no reasons given), having clinical contact with the researcher, not completing the 3-week programme, and some participants who had completed at T1 did not appear for admission at all, or their admission was cancelled. At T4 102 questionnaire packs were sent out, 72 were returned completed and 4 were returned incomplete.

Table 3. Demographic Data

	Mean (SD)	Range	Number (%)
Gender			
Males			27 (22.5)
Females			93 (77.5)
Age (Years)			
Males	58.49 (13.87)	30 – 90	
Females	58.74 (14.43)	30 – 90	
	58.41 (13.78)	30 – 88	
Ethnicity			
European NZ			98 (73.7)
Maori			15 (11.3)
Pacific Island			1 (0.8)
Other			6 (4.5)
Diagnosis			
Fibromyalgia			40 (33.3)
Osteoarthritis			27 (22.5)
Rheumatoid Arthritis			19 (15.8)
Back Pain			9 (7.5)
Other			25 (20.8)
Marital Status			
Married			58 (48.3)
Single			58 (48.3)
Did Not Answer			4 (3.3)
Income			
Private (work part/full)			24 (20)
Public (WINZ/ACC)			74 (61.6)
Other			18 (15.0)
Did Not Answer			4 (3.3)
Education (Highest Qualification Completed)			
Primary			19 (15.8)
Secondary			15 (12.5)
Additional Training			35 (29.2)
Tertiary			10 (8.3)
Did Not Answer			41 (34.16)

SOC-29

The means and standard deviations for the SOC-29 at Times 1 through to 4 are reported in Table 4. Scores are presented for the total sample at each time point and for the 72 who completed the study. For the 72 who completed, the mean SOC-29 scores increased from 138.6 at Time 1 (pre-admission), to 139.6 at Time 2 (admission), and 144.1 at Time 3 (discharge). That score decreased slightly to 141.3 at Time 4 (6-month follow up). A one-way repeated measures ANOVA was conducted to compare scores on the SOC-29 over time. There was a significant effect for time, Wilks' Lambda = .89, $F(3,69) = 2.82$, $p = .045$.

Table 4. Means and SDs for SOC-29 over time

Time 1 Preadmission			Time 2 Admission			Time 3 Discharge			Time 4 6-month follow-up		
N	M	sd	N	M	sd	N	M	sd	N	M	sd
120	135.3	27.36	112	137.6	26.81	102	141.9	23.49	72	141.1	26.18
72	138.6	26.05	72	139.6	26.02	72	144.1	24.99	72	141.1	26.18

Wilks' Lambda = .89 $df = 3,69$ $F = 2.82$ $p = .045^*$

*significant <.05

Paired sample t-tests were conducted as a follow-up test to determine where the difference over time occurred. Significant differences were found between Time 1 and 3 ($t(101) = -3.08$, $p = 0.005$) and Time 2 and 3 ($t(101) = -1.95$, $p = .05$). The eta squared statistic indicated that the effect between Time 1 and 3 (i.e., = .08) was moderate, while that between Time 2 and 3 (i.e., = .03) was small.

Further follow-up was conducted to determine where changes occurred over time on the three subscales of the SOC-29. As can be seen in Table 5, the mean scores for comprehensibility (Wilks' Lambda = .856, $F(3,67) = 3.74$, $p = 0.015$) and meaningfulness (Wilks' Lambda = .812, $F(3,67) = 5.18$, $p = 0.003$) appeared to change over time. While the mean scores for manageability showed a very slight but progressive increase at each subsequent time point, they remained relatively stable over time (Wilks' Lambda = .967, $F(3,67) = 0.75$, $p = .535$).

Table 5. Mean and SDs of the Subscales of the SOC-29 Over Time

Subscale	Time 1			Time 2		Time 3		Time 4	
	N	M	sd	M	sd	M	sd	M	sd
Comprehensibility	72	48.9	9.96	47.4	10.13	50.4	10.22	48.8	11.36*
Manageability	72	48.9	9.99	49.4	9.21	49.9	9.40	50.1	9.66
Meaningfulness	72	40.5	8.49	41.0	8.86	43.3	7.96	41.8	7.64*

Follow-up using paired samples t-tests indicates that significant differences were found for the subscales of comprehensibility between Times 2 ($M = 47.4$, $SD = 10.13$) and 3 ($M = 50.4$, $SD = 10.22$, $t(99) = -2.54$, $p = 0.01$, eta squared = .06), and meaningfulness for both Times 1 ($M = 40.5$, $SD = 8.49$) and 3 ($M = 43.3$, $SD = 7.96$, $t(100) = -4.07$, $p = .0005$, eta squared = .14), and Times 2 ($M = 41.0$, $SD = 8.86$) and 3 ($M = 43.3$, $SD = 7.96$), $t(99) = -3.19$, $p = 0.002$, eta squared = .09) The eta squared statistics indicate moderate to large effects.

ADM

The means and standard deviations for the ADM at Times 2, 3 and 4 are presented in Table 6. Again the scores for the 72 who completed are shown with the total sample at each time point. The mean ADM score ($n = 72$) increased from 217.04 at Time 2 (admission) to 238.1 at Time 3 (discharge) and decreased to 222.9 at Time 4 (6-month follow-up). A one-way repeated measures ANOVA was conducted to compare the scores of the ADM over time. There was a significant effect for time, Wilks' Lambda = .58, $F(2,70)=25.22$, $p = .0005$.

Table 6. Means and SDs for ADM over time

Time 2 Admission			Time 3 Discharge			Time 4 6-month follow-up		
N	M	sd	N	M	sd	N	M	sd
112	215.9	35.15	102	235.7	31.78	72	222.9	40.26
72	217.4	33.76	72	238.1	31.86	72	222.9	40.26

Wilks' Lambda= .58, $df = 2,70$, $F=25.22$, $p = .0005$ *

*significant <.05

As with the SOC, paired sample t-tests were conducted as a follow-up test to determine where the difference over time occurred. A significant difference was found between Times 2 and 3 ($t(101)=-7.68$, $p = .0005$). The eta squared statistic (.37) indicated a large effect.

Additionally, a significant difference was found between Times 3 and 4 ($t(71) = 4.56$, $p = .0005$) and the eta squared statistic (.23) indicates a large effect. This indicates that ADM scores increased significantly following intervention (T3), but also dropped back significantly at the 6-month follow up (T4).

SF-36

Table 7 shows the mean scores and standard deviations for the subscales of the SF-36 on admission and at 6-month follow up. Scores are presented for both the 112 participants who completed at Time 2 and for the 72 participants who completed the study. The paired samples t-test conducted on the SF-36 data demonstrated a significant increase on all subscales ($p < 0.05$ – $p < 0.0005$) except general health ($t(71) = -1.84$, $p = 0.07$) between Time 2 (admission) and Time 4 (6-month follow up).

Table 7. Means and Standard Deviations for SF-36

	Time 2				Time 4	
	Admission				6-Month Follow Up	
	N=112		N=72		N=72	
	M	sd	M	sd	M	sd
Physical Function	30.06	9.66	29.02	8.74	33.55	10.13
Role Physical	31.30	7.79	31.30	6.52	34.93	9.36
Bodily Pain	32.16	6.30	31.69	5.77	34.95	7.80
General Health	37.93	9.83	38.53	9.47	40.55	10.89
Vitality	36.59	8.87	37.39	8.70	42.79	10.24
Social Functioning	35.02	9.89	35.70	10.18	39.64	11.80
Role Emotional	36.55	12.16	37.68	11.08	41.36	13.09
Mental Health	42.08	10.45	43.74	10.51	46.88	11.66

The most notable changes found were for physical function ($t(71) = -5.06$, $p = 0.0005$, eta squared = .26), role physical ($t(71) = -3.69$, $p = 0.0005$, eta squared = .16), vitality T2 ($t(71) = -4.58$, $p = 0.0005$, eta squared = .23), bodily pain ($t(71) = -3.54$, $p = 0.001$, eta squared = .14) and social function ($t(71) = -2.85$, $p = 0.006$, eta squared = .10). The eta square statistic for these subscales indicates a large effect. Mental health ($t(71) = -2.47$, $p = 0.02$, eta squared = .08) and role emotional ($t(71) = -2.24$, $p = 0.03$, eta squared = .06) showed moderate effects on the eta square statistic.

Relationship Between the Sense of Coherence, Adjustment and Health Status.

The relationship between the SOC (as measured by the SOC-29) and adjustment (as measured by the ADM) and the SOC and health status (as measured by the SF-36) were investigated using Pearson product-moment correlation coefficient. The analysis was conducted using data collected at Time 2 (admission). The results are presented in Table 8 and indicate that there was a medium, positive and statistically significant correlation between the SOC and adjustment (ADM, $r = .45$, $n = 112$, $p = 0.0005$). The SOC also

correlated with health status. More specifically, the SOC-29 did not correlate significantly with physical function ($r = .09$, $n = 112$, $p = .34$) but has a small to medium correlation with all other subscales of the SF-36. Correlations were positive and statistically significant ($p = 0.01 - p = 0.0005$), with the strongest correlations being between the SOC-29 and mental health ($r = .58$, $n = 112$, $p = .0005$), vitality ($r = .39$, $n = 112$, $p = .0005$), role emotional ($r = .37$, $n = 112$, $p = .0005$) and general health ($r = .36$, $n = 112$, $p = .0005$).

Table 8. Correlations between the SOC-29, the ADM and SF-36 (T2, n=112)

	1	2	3	4	5	6	7	8	9	10
1. SOC	----	.44**	.09	.25**	.23**	.36**	.39**	.28**	.37**	.58**
2. ADM	.44**	----	.06	.38**	.25**	.22**	.20*	.27**	.37**	.53**
3. Physical Function	.09	.06	----	.34**	.24*	.01	.22*	.19*	.27**	.08
4. Role Physical	.25**	.38**	.34**	----	.48**	.28**	.45**	.33**	.55**	.34**
5. Bodily Pain	.23**	.25**	.24*	.48**	----	.33**	.45**	.36**	.40**	.36**
6. General Health	.36**	.22*	.01	.28**	.33**	----	.54**	.34**	.37**	.49**
7. Vitality	.39**	.20*	.22*	.45**	.45**	.54**	----	.38**	.46**	.54**
8. Social Function	.28**	.27**	.19*	.33**	.36**	.34**	.38**	----	.47**	.45**
9. Role Emotional	.37**	.37**	.27**	.55**	.40**	.37**	.47**	.47**	----	.57**
10. Mental Health	.58**	.53**	.08	.34**	.36**	.49**	.54**	.45**	.57**	----

(* $p < 0.05$ (2-tailed), ** $p < 0.01$ (2-tailed))

Interestingly, from the matrix it would appear that there is a relationship between all of the variables with only physical function not correlating significantly with all other variables.

Malmgren-Olsson and Branholm (2002) repeated their correlation analysis following their intervention and found the relationships between the SOC-29 and the SF-36 to be stable. However, they also reported no change in the SOC-29 over time. As the SOC-29 scores in this present study did change over time, the correlation analysis was again conducted at Time 4 (6-month follow-up) to explore the stability of the relationship between the SOC-29 and the other variables.

Interestingly, the relationship between the SOC and adjustment strengthened (ADM, $r = .64$, $n = 72$, $p = .0005$). This was also the case for the SOC-29 and health status, with the relationships reported above also strengthening (except physical function). The

relationship between the SOC-29 and physical function changed from a positive (but not significant) correlation at Time 2, to a negative correlation ($r = -.003$, $n = 72$, $p = .98$) at Time 4, but again this was not significant. However, it could be argued that these changes occurred due to the change in numbers of participants from T2 ($n = 112$) to T4 ($n = 72$).

A correlation analysis was therefore conducted at Time 2 for the 72 participants who completed the study. The results were found to be very similar to those for the 112 participants reported above. The only notable exceptions are that for the group of 72 the relationship between the SOC-29 and physical function is a negative (but not significant) correlation ($r = -.01$, $n = 72$, $p = .93$). This was a positive (but not significant) correlation for the group of 112. Furthermore, there was not a significant correlation between the SOC-29 and bodily pain ($r = .19$, $n = 72$, $p = .10$), whereas again for the group of 112 this was a significant correlation ($p = 0.05$).

Pallant (2001) has suggested that relationships between variables are better understood by looking at the coefficient of determination (shared variance). This was calculated to explore the relationships between the SOC-29 and the ADM (adjustment) and the subscales of the SF-36 (health status) at both Time 2 ($n = 112$ and $n = 72$) and Time 4 ($n = 72$). The results are presented in Table 9, with the shared variance presented as a percentage.

Table 9. Shared variance (%) between the SOC-29 and the ADM and the SOC-29 and the SF-36.

	SOC T2	(N=72)	SOC T4
	(N=112)	(N=72)	(N=72)
	%	%	%
ADM	19	17	45
Physical Function	0.81	0.01	0.0009
Role Physical	6.4	10	16
Bodily Pain	5	4	8.8
General Health	12	20	31
Vitality	15	19	39
Social Function	7.7	9.7	28
Role Emotional	13	19	23
Mental Health	33	30	47

Looking at the results for the group of 72, at Time 2, the SOC-29 scores help to explain 17% of the variance in the adjustment (ADM) scores, but by Time 4 this has increased to 45%. This same pattern can be seen for the subscales of the SF-36 except bodily pain, which remains relatively the same (Time 2, 4%, Time 4, 8.8%). Most notably by Time 4 the shared variance between the SOC-29 and general health has increased by 11% (T2, 20%, T4, 31%), the SOC-29 and vitality 20% (T2, 19%, T4, 39%), the SOC-29 and social function 18.3% (T2, 9.7%, T4, 28%) and the SOC-29 and mental health 17% (T2, 30%, T4, 47%). The relationship between the SOC-29 and physical function remains a negative correlation, with the percentage of explained shared variance dropping even further from .01% at Time 2 to .0009% by Time 4.

DISCUSSION

The main aim of this study was to investigate the stability of the SOC in relation to an intervention over time. The results of the study revealed a significant change over time on the total SOC-29 score ($F = 2.82, p = .05$) with this change occurring following the intervention (T1–T3, $t = -3.08, p = .005$, T2-T3, $t = -1.95, p = .05$) and not before (T1-T2, $t = -.99, p = .32$). This supports the hypothesis that the intervention *will* have an impact on the SOC.

This same finding was also true of the ADM scores that also changed significantly over time ($F = 25.22, p = 0.0005$) with the change again occurred following the intervention (T2-T3, $t = -7.68, p = 0.0005$). The significant difference was not sustained at the 6-month follow up for either the SOC-29 or the ADM. Conversely, the SF-36 scores showed a significant improvement from admission to the 6-month follow up on all scores except general health ($t = -1.84, p = 0.07$).

As reported in earlier studies (Larsson et al, 1995; Lustig et al, 2000, Petrie & Azariah, 1990) subscale analysis (of the SOC-29) revealed that the subscales may function quite differently, giving quite a different picture than the one gained by examining the total SOC-29 score alone. The subscales of comprehensibility ($F = 3.74, p = 0.01$) and meaningfulness ($F = 5.17, p = 0.003$) changed significantly over time, but manageability ($F = 0.75, p = 0.53$) did not. As with the total SOC-29 score, the change occurred for comprehensibility between admission and discharge ($t = -2.54, p = 0.01$). For meaningfulness the change occurred between pre-admission and discharge ($t = -4.07, p = 0.0005$) and admission and discharge ($t = -3.19, p = 0.002$). Changes were not sustained at the 6-month follow up. While the manageability subscale did not show a significant difference over time ($F = 0.75, p = 0.53$) it did show a slight but steady increase, and did not drop back at the 6-month follow up.

The significant change in the SOC-29 scores (and two of the subscales) following the intervention suggests that there may be some dynamic characteristic to it and this is consistent with the emerging literature. However, due to changes not being sustained at the 6-month follow up, the result of this study provides inconclusive evidence with which to challenge the stability of the SOC.

But, the SOC-29 correlated strongly with the ADM ($p = 0.01$), with the ADM also not being sustained at the 6-month follow up it is possible that a 3-week programme is not long enough to establish a lasting change in the sense of coherence (or the acceptance of disability). This seemed too simple an explanation so a post hoc analysis was conducted to clarify a number of factors, pertinent to the research sample that may have influenced the results.

Post Hoc Analysis

With only 72 of the original 120 people remaining in the study at 6-month follow up, it was important to see if there were any significant differences between the participants who completed ($n = 72$) and those who withdrew ($n = 48$). Demographically, the groups were very similar for age, ethnicity, diagnosis, marital status and education. However, the group who withdrew had more people employed in either part-time or full time work (25% compared with 16.6%).

The only measure that all participants completed was the SOC-29 at pre-admission (T1). Prior to analysing for difference, normality was assessed in terms of distribution. Both groups appeared to have reasonably normal distributions when looking at the Kolmogorov-Smirnov statistic, which reported a non-significant result of 0.2 for both groups. The Histograms, Normal Q-Q Plots and Detrended Normal Q-Q Plots further supported this.

An independent samples t-test was then conducted to analyse the difference in SOC-29 scores for the two groups at Time 1. Those who completed the study ($n = 72$) had a mean SOC-29 score of 138.64 ($SD = 26.05$); those who withdrew ($n = 48$) had a mean SOC-29 score of 130.25 ($SD = 28.79$). However, this difference was not statistically significant ($p = 0.54$).

Low, Medium and High SOC Scores

Other studies have looked at the impact of low, medium and high SOC-29 scores (Karlsson et al, 2000). For comparison, this sample was divided into three groups Low SOC-29 scores (29-87), Medium SOC-29 scores (88-145) and High SOC-29 scores (146-203). Appendix J shows the impact of the level of SOC-29 score on drop out rate.

A Chi square was conducted, but it violated the assumptions and could not be pursued. Pearson Chi-square was not significant (.109). The percentages of participants in the groups from pre-admission (T1) to 6-month follow up (T4) did change although not drastically. The figures are presented in Appendix K.

By the 6-month follow-up (T4) only 2 were left in the Low SOC-29 scores group, so comparison for this group was pointless. However, the Medium SOC-29 scores group ($n=40$, T4) and the High SOC-29 scores group ($n=30$, T4) could be analysed. Paired samples t-tests were conducted for these two groups.

The Medium SOC-29 score group showed significant changes between SOC-29 Time 1 ($M=124.25$, $SD=14.00$) and SOC-29 Time3 ($M=132.42$, $SD=18.06$), $p=0.0005$, and SOC-29 Time 2 ($M=127.70$, $SD=18.87$) and SOC-29 Time 3 ($M=132.42$, $SD=18.06$), $p=0.03$. Also ADM Time 2 ($M=211.84$, $SD=33.18$) and ADM Time 3 ($M=230.12$, $SD=33.31$), $p=0.0005$. The significant difference was not sustained at Time 4. On the SF-36, this group showed significant improvements at Time 4 on the subscales of physical function ($p=0.0005$), role physical ($p=0.005$), bodily pain ($p=0.01$), vitality ($p=0.0005$) and social function ($p=0.03$).

The High SOC-29 score group did not show any significant improvements in their SOC-29 scores using the same analysis. However, there was a significant improvement in their ADM scores between Time 2 ($M=227.30$, $SD=33.69$) and Time 3 ($M=245.20$, $SD=28.74$), $p=0.0005$, but this was not sustained at Time 4. On the SF-36 at Time 4, the High SOC-29 scores group improved significantly on physical function ($p=0.006$), role physical ($p=0.04$), bodily pain ($p=0.02$), and vitality ($p=0.03$). The results for this group and the Medium SOC-29 score group on the SF-36 scores are consistent with the findings of Weissbecker et al (2002).

Despite the post hoc analysis the results remain inconclusive with regard to why the SOC-29 changes were not sustained. Of interest is that the High SOC-29 scores group showed no significant improvement in their SOC-29 scores but did on the ADM following the intervention. The Medium SOC-29 scores group showed significant improvement on both the SOC-29 and ADM following intervention. However, this was

not sustained at Time 4 and the reasons for this are not clear. The lack of low SOC-29 score participants makes it impossible to know what may have occurred for this group.

Antonovsky (1979) stated that he believed that the SOC could change temporarily, but that changes would occur around a stable location. This does seem to be the case with the participants in this study and on face value would lend support to Antonovsky's suggestion that the SOC is a stable trait. However, it is important to recognise that over 93% of the participants in this study had medium to high SOC-29 scores to begin with and highlights a possible reason why scores were not sustained at the 6-month follow-up.

With a mean SOC-29 score of 135.3 at Time 1, the participants in this study had SOC-29 scores comparable to those found in other studies with similar populations (see Appendix L). Furthermore, this supports the view that those with a chronic illness or disability do not automatically have low SOC-29 scores (Hawley et al, 1992). However, their ADM mean on admission (215.91) is slightly lower when compared with other studies (see Appendix M), although this is still within a moderate to high range. Of more interest though are the SF-36 scores.

Appendix N present the SF-36 scores on admission and at the 6-month follow up for the participants in this study, and the mean scores for the US general population. The norm-based score for the SF-36 subscales is $M = 50$ ($SD = 10$) (Ware, 1999). With this in mind, all mean scores presented show that the participants in this study have scores lower than the norm, and considerably lower than the US general population (McDowell & Newell, 1996). As the SF-36 measures general health status this is perhaps not surprising given the population. However, what this does indicate is that while the participants in this study may have a compromised health status, they have a reasonable level of acceptance and sense of coherence. Again this supports findings from other studies (Hawley et al, 1992, Mendal et al, 2001).

Antonovsky (1979) indicated that it was perhaps those with a moderate SOC-29 score who would demonstrate the ability to better manage the challenges they faced. He was concerned that a very high SOC-29 suggested a 'fake' sense of coherence with a low SOC-29 obviously being cause for concern. It may therefore be unreasonable to expect,

or even unnecessary, to achieve lasting changes for those who have moderate SOC-29 scores.

However, even small increases in SOC-29 scores have been noted to have an impact on health outcomes, even when this did not reach statistical significance ($p = 0.1$, Ravestloot et al, 1998). For the participants in this study ($n = 72$), their mean SOC-29 scores remained higher at Time 4 ($M = 141.1$, $SD = 26.18$) than at Time 1 ($M = 138.6$, $SD = 26.05$) ($p = 0.3$).

A robust sense of coherence is thought to help an individual mobilise generalised resistance resources (GRR's), promoting effective coping and making the difference "between salutogenic tension management and pathogenic stress" (Sullivan, 1993, p. 1774). That is, perhaps the participants in this study, due to their moderate SOC's, were able to take advantage of the rehabilitation programme to such an extent that they were able to improve their overall health status. With the majority of the participants having moderate-high SOC-29 scores, it could be argued that this may explain the significant improvement in SF-36 scores at the 6-month follow up.

Furthermore, the total SOC-29 score correlated strongly with all scales of the SF-36 except physical function. Interestingly, the relationships between the variables strengthened (by up to 20%) between Time 2 and Time 4, which differ from the results presented by Malmgren-Olsson and Branholm (2002). The reasons for this are unclear, but may indicate that a healthy sense of coherence may play a unique and different role in the achievement of improved health.

However, there were a number of limitations of this study that need to be discussed which may have influenced the results.

Limitations

First, the decrease in participant numbers across time will have reduced statistical power, which may have caused the non-significant change in the SOC-29 (and ADM) at Time 4. Follow up of those who did not return the questionnaires at the 6-month follow up would have been useful. Of the 102 that were mailed out, 76 were returned but only

72 were completed. Consequently, the results for 30 participants who completed the questionnaires at discharge (T3) are unknown.

Second, when recruiting for this study, it was the researcher's impression that many of the people who agreed to participate were coping fairly well and had the energy to engage in such a commitment (this is reflected in the SOC-29 scores). Several who declined to participate often commented that although they would like to participate they felt that they 'had enough on their plates' and could not cope with completing the questionnaires. These impressions were gained during the follow up phone call after the mailing of the information letter. The resultant sample included participants with predominantly moderate to high SOC-29 scores, with very few having low SOC-29 scores taking part. Hence, this was a self-selected biased sample. Consequently, the impact of the intervention on low SOC-29 scores is unknown.

Third, of interest is the fact that while the SF-36 still showed improvement at 6-month follow up, the SOC-29 scores and ADM scores no longer showed a significant difference. As the SF-36 was not administered on discharge there is no way of knowing what the picture may have been here, and what the relationship is.

While, it was appropriate not to administer the SF-36 on discharge (it asks questions about engaging in everyday activities (e.g. cleaning the house, shopping etc) over the last 4 weeks, which the participants in the in-patient programme did not do, it may have been useful to include an open-ended question (or questions) with the 6-month follow-up questionnaires to ascertain if there had been any noteworthy incidents since discharge. Several participants did send letters with their questionnaires reporting falls, accidents, hospitalisations and deaths in the family, but none of this information could be used in the analysis.

Recommendations for Further Research

Unfortunately, what this study was unable to show was the impact of the intervention on those with low SOC-29 Scores. Logically, it may be this group who could benefit most from having their sense of coherence enhanced. Whether enhancing low SOC-29 scores is possible remains an area for further investigation. Furthermore, the role of comprehensibility, meaningfulness and manageability also needs to be investigated

further. It is interesting that the comprehensibility and meaningfulness subscales showed significant improvement following the intervention, but that the manageability subscale did not. However, the manageability subscale showed a slow but steady increase and unlike the other two subscales did not drop back at the 6-month follow up.

Strang and Strang (2001), in a qualitative study with patients with brain tumours, identified that comprehensibility is constructed predominantly by the patient's thoughts and theories, manageability achieved by active information-seeking strategies, social support and coping (including positive reinterpretation of the situation). Meaningfulness was created by faith, hope, close relationships and work. It was also important for the patient to have a "fighting spirit" (p. 132). Interestingly, only three of the patients believed in God indicating that spirituality has different meanings for people.

While the aim of the study was not to explore the intervention as such, there may well be components of the programme that have potential to enhance the SOC and, in particular, strengthen the participant's GRRs. The QEH programme is recognised for its focus on education designed to improve self-management, which is in line with identified GRRs (see introduction). This means providing knowledge regarding different conditions, but also knowledge and training on the development of flexible and rational coping strategies.

According to Strang and Strang (2001) this is more in line with manageability, the only subscale in this study not to show significant improvement. Perhaps something else occurs during this programme that can promote health and that is of value to this population.

The philosophy of QEH has always been somewhat unique (see Methods) and this continues to be the guiding influence of programmes offered here. Fundamental to the QEH approach is a focus on identity, particularly spiritual identity and addressing issues related to adjustment and self-worth. Strang and Strang (2001) found that comprehensibility and meaningfulness appeared to be 'internally' constructed and did have a spiritual component. However, while this may explain in part the significant increase in SOC-29 scores (and more specifically the comprehensibility and

meaningfulness subscales) following the intervention, it does not explain why this was not sustained at the 6-month follow up.

Faull et al (2004) and more recently Faull (2005) found that this population defines health quite differently. Given their SF-36 scores this is perhaps not surprising. Health, to this population, seems to be less about functional ability i.e. 'doing', and more about 'being'. Furthermore it is about the development of a resilient spiritual identity that is at the core of maintaining health. This seems to be very much in line with the salutogenic view of health.

However, Faull, Kalliath and Smith (2004) have also found that organisations with such philosophies are constantly challenged by the health care system in terms of survival, despite an enduring salutogenic culture. As a consequence of maintaining economic viability, value is placed on 'functional' outcomes (Faull et al, 2004) despite this perhaps being inappropriate for this population. This may also influence the type of patients who are admitted, identifying those who have the potential to make functional or physical improvements.

Perhaps, then, it is no coincidence that the participants in this study had reasonable SOC-29 scores to begin with that would fluctuate around a stable location. They certainly made the expected functional gains. What then happens to those with low SOC-29 scores? Are they admitted to rehabilitation programmes with the same frequency as those with medium to high SOC-29 scores?

The literature indicates that those with lower SOC-29 scores cope less well and experience more secondary health problems and functional limitations than those with a higher SOC-29 score (Ravesloot et al, 1998). Clinical observations indicate that these people do not benefit from health care interventions that simply address physical and/or functional issues.

This is particularly true for those diagnosed with a condition that defies a pathogenic explanation (e.g. fibromyalgia, chronic pain). Unfortunately, when these individuals do develop secondary problems (e.g. anxiety and depression) they often find themselves under the care of Mental Health Services.

In theory those with low SOC-29 scores stand to gain the most from a salutogenic rehabilitation programme, but this can only occur if such programmes are valued and financially supported.

The World Health Organisation (WHO) (2002) has investigated health care provision for those with chronic conditions and have presented their findings and recommendations in a global report. They found that on the whole health outcomes are poor for this population and suggest that worldwide there is no plan for managing chronic conditions. Symptoms are treated when they occur, but there seems to be little other provision.

Due to their very nature, chronic conditions require management across time. Not surprisingly, when patients receive support to self-manage, with regular follow up, health outcomes are better (WHO, 2002).

WHO (2002) argues that a paradigm shift is needed away from the acute/episodic model of health care. The report states that health care costs become excessive when chronic conditions are poorly managed and they assert that “as long as the acute care model dominates health care systems, health expenditures will continue to escalate, but improvements in populations’ health status will not” (WHO, 2002, p.6). This researcher would also like to suggest that this may not be enough and a shift away from the pathogenic model is also required.

The report does allude to this and emphasises the patients’ central role and responsibility in promoting personal health. To achieve this, quality relationships with health care professionals need to be developed. The aim should be to empower patients and it is suggested that this can be achieved by providing broader, on-going support and environments that promote self-management. Furthermore, innovative care should not be based on etiology but on health promotion. They conclude by saying that there is a need for a comprehensive model of health that broadens thinking and allows for the development of interventions that produce better outcomes.

This sounds very much in line with a salutogenic model. In relation to this current study perhaps the original conclusion, that a 3-week programme is not long enough to effect a lasting change in the SOC, is valid. If the participants had received on-going support the outcomes may have been different. In our current health care system, follow up is not funded and, if anything, discouraged. Patients requiring repeat interventions are often seen as failures and accused of not self-managing. Alternatively, the programmes attended by these patients are viewed as being unsuccessful, and this can impact future funding.

The participants in this study did show a significant increase in SOC-29 scores following the intervention. Could this be maintained with appropriate follow-up support, and how would this then impact on health outcomes? In line with the WHO (2002) recommendations this would be an area worthy of research.

Conclusions

As Antonovsky (1979) argued, the pathogenic model simply does not explain the mystery of survival or indeed the experience of those with chronic illness or disability. What he suggested was the identification of factors that promote health despite illness or disability. He identified GRR's and developed the SOC-29 measure. However, he also promoted the view that the SOC was a stable personality trait.

With the growing body of evidence that the SOC plays a crucial role in the adjustment to and acceptance of chronic illness or disability, this study has sought to challenge Antonovsky's view. Establishing that the SOC has state like qualities that can be enhanced, could lead to the support for salutogenic programmes that really address the needs of this population.

As with most research, this study raised more questions than it answered. A significant change in the SOC-29 was demonstrated over time, but was not sustained. The reason for this could have been that the SOC is indeed a stable trait. However, there were other factors identified, related to the characteristics of the sample and to wider factors that could have had an impact on the outcome of this study, and these were explored. What remains unknown is the impact of the intervention on low SOC-29 scores and this requires further exploration. Furthermore, the relationship between the SOC-29 and the

other variables strengthened over time, and this is different to previous findings. The nature of this relationship and the impact this had particularly on the SF-36 scores is unknown, and another area for further investigation. Lastly, the role of on-going support and the maintenance of a healthy SOC may be the key to providing effective interventions for those with chronic conditions and investigating this possibility would be the next step for this researcher.

REFERENCES

Adams, T.B., Bezner, J.R., Drabbs, M.E., Zambarano & Steinhardt, M.A., (2000). Conceptualization and measurement of the spiritual and psychological dimensions of wellness in a college population. *Journal of American College Health*, 48, 165-173.

Antonak, R.F., & Livneh, H., (1991). A hierarchy of reactions to disability. *International Journal of Rehabilitation Research*. 14, 13-24.

Antonovsky, A., (1987). Unravelling the Mystery of Health. *How People Manage Stress and Stay Well*. Jossey-Bass, San Francisco.

Antonovsky, A., (1979). *Health Stress and Coping*. Jossey- Bass, San Francisco.

Antonovsky, A., (1993). The structure and properties of the sense of coherence scale. *Social Science Medicine*, 36, 725-733.

Antonovsky, H., & Sagy, S., (1986). The development of a sense of coherence and its impact on responses to stress situations. *The Journal of Social Psychology*, 126, 213-225.

Bengtsson-Tops, A., & Hansson, L., (2001). The validity of Antonovsky's sense of coherence measure in a sample of schizophrenic patients living in the community. *Journal of Advanced Nursing*, 33, 432-438.

Berglund, B., Mattiasson, A., & Nordstrom, G., (2003). Acceptance of disability and sense of coherence in individuals with Ehlers-Danlos syndrome. *Journal of Clinical Nursing*, 12, 770-777.

Boman, L., Bjorvall, H., Languis, A., & Cedermark, B., (1999). Two models of care as evaluated by a group of woman operated on for breast cancer with regard to their perceived well-being. *European Journal of Cancer*, 8, 87-96.

Bornman, J., (2004). The world health organisation's terminology and classification: application to severe disability. *Disability and Rehabilitation*, 26, 182-188.

Breakwell, G.M., (1983). *Threatened Identities*. John Wiley & Sons, Chichester.

Broderick, J.E., (2000). Mind-body medicine in rheumatologic disease. *Rheumatic Disease Clinics of North America*, 26, 161-176.

Buchi, S., Sensky, T., Allard, S., Stoll, T., Schnyder, U., Klaghofer, R., & Buddeberg, C., (1998). Sense of coherence – a protective factor for depression in rheumatoid arthritis. *The Journal of Rheumatology*, 25, 869-875.

Caap-Ahlgren, M., & Dehlin, O., (2004). Sense of coherence is a sensitive measure for changes in subjects with Parkinson's disease during 1 year. *Scandinavian Journal of Caring Sciences*, 18, 154-159.

Callahan, L.F., & Pincus, T., (1995). The sense of coherence scale in patients with rheumatoid arthritis. *Arthritis Care and Research*, 8, 28-35.

Campbell, D.T., & Stanley, J.C., (1963). *Experimental and Quasi- experimental Designs for Research*. Rand McNally, Chicago.

Cederfjall, C., Languis-Eklof, A., Lidman, K., & Wredling, R., (2001). Gender differences in perceived health-related quality of life among patients with HIV infection. *Aids Patient Care and STD's*, 15, 31-39.

Chapman, C.R., & Gavrin, J., (1999). Suffering: the contributions of persistent pain. *The Lancet*, 353, 2233-37.

Christopher, J.C., (1999). Situating psychological well-being: exploring the cultural roots of its theory and research. *Journal of Counselling and Development*, 77, 141-151.

Cushman, L.A., & Sherer, M.J., (1995). *Psychological Assessment in Medical Rehabilitation*. American Psychological Association, Washington, USA.

Cowley, S., & Billings, J.R., (1999). Resources revisited: salutogenesis from a lay perspective. *Journal of Advanced Nursing*, 29, 994-1004.

Delbar, V., & Benor, D.E., (2001). Impact of a nursing intervention on cancer patients' ability to cope. *Journal of Psychosocial Oncology*, 19, 57-75.

Drory, Y., Kravetz, S., & Hirschberger, G., (2002). Long-term mental health of men after a first acute myocardial infarction. *Archives of Physical Medicine and Rehabilitation*, 36, 725-33.

Faull, K., (2000). Coping with disability: the physical, cognitive, social and spiritual dimensions of self and health. *Masters Thesis*. University of Waikato.

Faull, K., (2005). Health and the spiritual self: development and application of a theory of the process of health change. *Unpublished doctoral thesis*, University of Waikato, Hamilton, New Zealand.

Faull, K., Hills, M.D., Cochrane, G., Gray, J., Hunt, M., McKenzie, C., & Winter, L., (2004). Investigation of health perspectives of those with physical disabilities: the role of spirituality as a determinant of health. *Disability and Rehabilitation*, 26, 129-144.

Faull, K., Kalliath, T., & Smith, D., (2004). Organizational culture: the dynamics of culture on organizational change within a rehabilitation centre. *Organization Development Journal*, 22, 40-55.

Feldt, T., Lesikinen, E., Kinnunen, U., & Ruoppila, I., (2003). The stability of sense of coherence: comparing two age groups in a 5-year follow-up study. *Personality and Individual Differences*, 35, 1151-1165.

Fillary, R., (2000). Acute and chronic conditions: keys to effective rehabilitation counselling. *Vision. A Journal of Nursing*, 6, 15-20.

- Flannery, R.B., Flannery, G.J., (1990). Sense of coherence, life stress, and psychological distress. A prospective methodological inquiry. *Journal of Clinical Psychology*, 46, 415-420.
- Frank, A.W., (2002). *At the Will of the Body. Reflections on Illness*. Mariner Books, Boston, New York.
- Frank, R.G., Van Vallin, P.H., & Elliot, T.R., (1987). Adjustment to spinal cord injury: a review of empirical and non-empirical studies. *Journal of Rehabilitation*. 43-48.
- Freeman, J.A., Hobart, J.C., & Thompson, A.J., (1996). Outcomes-based research in neurorehabilitation: the need for multidisciplinary team involvement. *Disability and Rehabilitation*, 18, 106-110.
- Forbes, D.A., (2001). Enhancing mastery and sense of coherence: important determinants of health in older adults. *Geriatric Nursing*, 22, 29-32.
- Fuhrer, M.J., (1994). Subjective well-being: implications for medical rehabilitation outcomes and models of disablement. *American Journal Physical and Medical Rehabilitation*. 73, 358-364.
- Gana, K., (2001). Is sense of coherence a mediator between adversity and psychological well-being in adults? *Stress and Health*, 17, 77-83.
- Germano, D., Misajon, R., & Cummins, R.A., (2001). Quality of life and sense of coherence in people with arthritis. *Journal of Clinical Psychology in Medical Settings*, 8, 253-261.
- Goleman, D., & Gurin, J., (1993). *Mind Body Medicine. How To Use Your Mind For Better Health*. New York; Consumer Reports Books.
- Hadler, N., (1992). Knee pain is the malady- not osteoarthritis. *Annals of Internal Medicine*, 116, 598-9.

Hadler, N., (1996). If you have to prove you are ill, you can't get well. *Spine*, 21, 2397-2400.

Hadler, N., (1997). Workers with disabling back pain. *The New England Journal of Medicine*, 337, 341-343.

Hall-Lord, M.L., Larsson, G., & Steen, B., (1999). Chronic pain and distress in older people: a cluster analysis. *International Journal of Nursing Practise*, 5, 78-85.

Hawley, D.J., Wolfe, F., & Cathey, M.A., (1992). The sense of coherence questionnaire in patients with rheumatic disorders. *The Journal of Rheumatology*, 19, 1912-1918.

Higginson, I.J., & Carr, A.J., (2001). Using quality of life measures in the clinical setting. *British Medical Journal*, 322, 1297-1300.

Hochstenbach, J., (2000). Rehabilitation is more than functional recovery. *Disability and Rehabilitation*, 22, 201-204.

Imrie, R., (2004). Demystifying disability: a review of the international classification of functioning, disability and health. *Sociology of Health & Illness*. 26, 287-302.

Jahnsen, R., Villien, L., Stanghelle, J.K., & Holm, I., (2002). Coping potential and disability - sense of coherence in adults with cerebral palsy. *Disability and Rehabilitation*, 24, 511-518.

Johnston, M., Stineman, M., & Velozo, C., (1997). Outcomes research in medical rehabilitation: foundations from the past and directions for the future. In M.J. Fuhrer (Ed), *Assessing Medical Rehabilitation Practices: The Promise of Outcomes Research* (pp.1-42).

Karlsson, I., Berglin, E., & Larsson, P.A., (2000). Sense of coherence: quality of life before and after coronary artery bypass surgery-a longitudinal study. *Journal of Advanced Nursing*, 31, 1383-1392.

Kivimaki, M., Feldt, T., Vahtera, J., & Nurmi, J., (2000). Sense of coherence and health: evidence from two cross-lagged longitudinal samples. *Social Science and Medicine*, 50, 583-597.

Klang, B., Bjorvell, H., & Cronqvist, A., (1996). Patients with chronic renal failure and their ability to cope. *Scandinavian Journal of Caring Science*, 10, 89-95.

Larsson, G., Johansson, I., & Hamrin, E., (1995). Sense of coherence among elderly somatic patients: predictive power regarding future care needs. *Journal of Nursing Management*, 3, 307-311.

La Grow, S., (1999). *What is this thing called rehabilitation: it's all in your perspective*. Paper presented at the New Zealand Rehabilitation Association Biennial Conference. Auckland, November 1999.

Linkowski, D.C., (1981). The acceptance of disability scale. Retrieved October 7, 2002 from World Wide Web: <http://home.gwu.edu/~dcl/ads.htm>.

Lorig, K., Stewart, A., Ritter, P., Gonzalez, V., & Lynch, J., (1996). *Outcome Measures for Health Education and other Health Care Interventions*. California, Sage Publications Inc.

Lustig, D.C., Rosenthal, D.A., Strauser, D.R., & Haynes, K., (2000). The relationship between sense of coherence and adjustment in persons with disabilities. *Rehabilitation Counselling Bulletin*, 43, 134-141.

Malmgren-Olsson, E., & Branholm, I., (2002). A comparison between, three physiotherapy approaches with regard to health-related factors in patients with non-specific musculoskeletal disorders. *Disability and Rehabilitation*, 24, 308-317.

McBurney, D.H. (2001). *Research Methods*. Wadsworth/Thomas Learning, Belmont, CA, USA.

- McDowell, I., & Newell, C., (1996). *Measuring Health*. Oxford University Press, New York.
- McWhinney, I.R., Epstein, R.M., & Freeman, T.R., (1997). Rethinking somatization. *Annals of Internal Medicine*, 126, 747-750.
- Mendal, B., Bergenius, J., & Languis, A., (2001). The sense of coherence: a tool for evaluating patients with peripheral vestibular disorder. *Clinical Otolaryngology*, 26, 19-24.
- Minichiello, V., Sullivan, G., Greenwood, K., & Axford, R., (1999). *Handbook for Research Methods in Health Sciences*. Sydney, Australia: Addison Wesley Longman Australia.
- Moore, T., (1995). *Habilitation and Rehabilitation in New Zealand*. Paper commissioned by the National Advisory Committee on Core Health and Disability Support Services.
- Nesbitt, B.J., & Heidrich, S.M., (2000). Sense of coherence and illness appraisal in older woman's quality of life. *Research in Nursing and Health*, 23, 25-34.
- Nilsson, B., Holmgren, L., & Westman, G., (2000). Sense of coherence in different stages of health and disease in northern Sweden. *Scandinavian Journal of Primary Health Care*, 18, 14-20.
- Nilsson, B., Holmgren, L., Stegmayr, G., & Westman, G., (2003). Sense of coherence - stability over time and relation to health, disease, and psychosocial changes in a general population: a longitudinal study. *Scandinavian Journal of Public Health*. 31, 297-304.
- O'Leary, V.E., (1998). Strength in the face of adversity: individual and social thriving. (Thriving: Broadening the paradigm beyond illness to health). *Journal of Social Issues*, 54, 425-449.
- Pallant, J., (2001). *SPSS Survival Manual*. Allen & Unwin, NSW, Australia.

Pallant, J.F., & Lae, L., (2002). Sense of coherence, well-being, coping and personality factors: further evaluation of the sense of coherence scale. *Personality and Individual Differences*, 33, 39-48.

Petrie, K., & Azariah, R., (1990). Health-promoting variables as predictors of response to a brief pain management program. *The Clinical Journal of Pain*, 6, 43-46.

Queen Elizabeth Hospital Website: www.gehospital.co.nz/history.htm. Retrieved from World Wide Web October 2002.

Ravesloot, C., Seekins, T., Young, Q., (1998). Health promotion for people with chronic illness and physical disabilities: the connection between health psychology and disability prevention. *Clinical Psychology and Psychotherapy*, 5, 76-85.

Rennemark, M., & Hagberg, B., (1999). What makes old people perceive symptoms of illness? The impact of psychological and social factors. *Aging and Mental Health*, 3, 79-90.

Richardson, A., Adner, N., & Nordstrom, G., (2001). Persons with insulin-dependant diabetes mellitus: acceptance and coping ability. *Journal of Advanced Nursing*, 33, 758-763.

Riley, B.B., Perna, R., Tate, D.G., Forchheimer, M., Anderson, C., & Leura, G., (1998). Types of spiritual well-being among persons with chronic illness: their relation to various forms of quality of life. *Archives of Physical and Medical Rehabilitation*, 79, 258-264.

Sanden-Eriksson, B., (2000). Coping with type-2 diabetes: the role of sense of coherence compared with active management. *Journal of Advanced Nursing*, 31, 1393-1397.

Schnyder, U., Buchi, S., Sensky, T., & Klaghofer, R., (2000). Antonovsky's sense of coherence: trait or state? *Psychotherapy and Psychosomatics*, 69, 296-302.

Seligman, M.E.P., (2002). *Authentic Happiness*. Free Press, New York.

Soderberg, S., Lundman, B., & Norberg, A., (1997). Living with Fibromyalgia: sense of coherence, perception of well-being, and stress in daily life. *Research in Nursing and Health*, 20, 495-503.

Soderfeldt, M., Soderfeldt, B., Ohlson, C., Theorell, T., & Jones, I., (2000). The impact of sense of coherence and high-demand/low-control job environment on self-reported health, burnout and psycho physiological stress indicators. *Work & Stress*, 14, 1-15.

Suominen, S., Blomberg, H., Helenius, H., & Koskenvuo, M., (1999). Sense of coherence and health - does the association depend on resistance resources? A study of 3115 adults in Finland. *Psychology & Health*, 14, 937-952.

Strang, S., & Strang, P., (2001). Spiritual thoughts, coping and 'sense of coherence' in brain tumour patients and their spouses. *Palliative Medicine*, 15, 127-134.

Sullivan, G.C., (1993). Towards clarification of convergent concepts: sense of coherence, will to meaning, locus of control, learned helplessness and hardiness. *Journal of Advanced Nursing*, 18, 1772-1778.

Taylor, W., & McPherson, K., (1999). *Measuring quality of life*. Paper presented at the New Zealand Rehabilitation Association Biennial Conference. Auckland, November, 1999.

Tennant, M., (1996). Disability in New Zealand: an historical survey. *New Zealand Journal of Disability Studies*, 3-33.

Tuomi, K., & Seitsamo, J., (1999). Stress management, aging, and disease. *Experimental Aging Research*, 25, 353-358.

Vash, C.L., (1991). More thoughts on empowerment. *Journal of Rehabilitation*, 13-16.

Ware, J.E., (1993). *SF-36 Health Survey Manual and Interpretation Guide*. Nimrod Press, Boston, Massachusetts.

Ware, Jr, J.E., (1999). SF-36 Health Survey. In Maruish, M.E.,(ed). *The Use of Psychological Testing for Treatment Planning and Outcomes Assessment*. Lawrence Erlbaum Associates, Publishers, Malway, New Jersey.

Weissbecker, I., Salmon, P., Studts, J.L., Floyd, A.R., Dedert, E.R., & Sephton, S.E., (2002). Mindfulness-based stress reduction and sense of coherence among women with Fibromyalgia. *Journal of Clinical Psychology in Medical Settings*, 9, 297-307.

Whiteneck, G.G., (1994). Measuring what matters: key rehabilitation outcomes. *Archives of Physical and Medical Rehabilitation*, 75, 1073-1076.

WHO (2002). Innovative care for chronic conditions. Global report. www.who.int/chronic_conditions/en/icccglobalreport.pdf. Retrieved from World Wide Web, October 2005.

Wolff, A.C., & Ratner, P.A., (1999). Stress, social support, and sense of coherence. *Western Journal of Nursing Research*, 21, 182-197.

APPENDIX A SOC AS A STABLE PERSONALITY TRAIT

Article	Setting	Design	Sample	Outcome Measures	Results	Conclusions
Hawley et al, 1992	Wichita Arthritis Centre, USA	As part of Longitudinal Clinical Study	N=1333, RA,N=572 OA,N=403 FMS,N=358 79% female, mean age 59 years	SOC-29, HAQ, VAS pain and global severity, AIMS	Mean SOC score Total=148.0 RA=149.9 OA=154.9 FMS=137.5. RA greater HAQ functional disability, FMS higher pain, global severity, anxiety and depression scores.	SOC strongly related to AIMS anxiety and depression. Less strongly related to clinical or demographic variables. Did not support concept of distinct variables.
Callahan & Pincus, 1995	Private practises, USA	As part of Longitudinal Clinical study	N=828 RA, 78% female, mean age 56.6 years	MHAQ, SOC-29, SOC-13, VAS pain, global health status, RAI, ADL difficulty scale	Mean SOC score=146.5, neg. correlated with all measures of clinical and psychological status (P<0.001).	SOC-29 and 13 valid for RA populations and explains variation in clinical status. Did not support distinct variables.
Larsson et al, 1995	Hospital (Surgical and Orthopaedic Departments), Sweden	Prospective study	N=53 consec. pts who had completed treatment, mean age 82.2 years (1st interview). N=42 (2nd interview) 1 month later	SOC-9 (adapted). Future care needs (return home, institutions)	At follow up 25=returned home,17=institution, 8=died. SOC (1st int.) + correlated with return home. Low SOC particularly comprehensibility subscale neg. correlated with institution. SOC meaningfulness subscale neg. correlated with those who died.	SOC has predictive value regarding future care needs. Supports distinct variables.
Klang et al, 1996	Sweden	Descriptive study	CRF N=48, dialysis N=23, predialysis N=25. Mean age 58 years	SOC-13, JCS-40, (COS, EOS, POS coping styles)	Dialysis higher scores on tot. JCS-40, and COS and POS than predialysis (P<0.05). SOC neg. correlated with EOS and POS.	SOC is significantly correlated with JCS (i.e. coping strategies used).

Article	Setting	Design	Sample	Outcome Measures	Results	Conclusions
Soderberg et al, 1997	Rehabilitation centre, Sweden	Descriptive study	N=60, FMS N=30 mean age 45.2, Healthy matched for Type A personality N=30 mean age 41.3	SOC-29, Stress-Key, Well-being Scale	Median SOC score for FMS=143.5, Healthy=147.5. Significant difference on other measures. In FMS group low SOC correlated with more stress and less wellbeing.	FMS suffers with weaker SOC may need more support.
Buchi et al, 1998	Rheumatology out-patient clinic, London	Descriptive study	N=89, RA, 73% female, mean age 61.	SOC-29, HAQ, VAS pain, RADAI, HAD.	Mean SOC score=144. SOC neg. correlated with depression + higher reported pain levels.	SOC may be a protective factor for depression for those with RA.
Hall-Lord et al, 1999	Community health care, Sweden	Descriptive study	N=42 (pts 65yrs+) living in the community with chronic pain. Mean age 80.1 years	SOC-9 (adapted) Specifically designed pain and distress questionnaire. ADL questionnaire	Cluster analysis-3 profiles pain and distress (A,B,C), not related to physical pain (intensity and duration). A-oldest, mod. SOC, favourable most scores, life had meaning + hope. B-strongest SOC, most favourable all scores, life meaningful, C-lowest SOC scores, least favourable on all scores, life no meaning. SOC correlated neg. with functional and psychological status.	Effective assessment of pain and distress needs to be individualised.
Boman et al, 1999	Karolinska Hospital, Sweden	Prospective study	Breast cancer pts, 2 groups. 1. Established care N=29 (2nd follow-up N=23) 2. Continuity care model N=115 (2nd follow-up N=100)	SOC-29 (before surgery only), Study specific questionnaire, TNM	Mean SOC score higher in group 2 than group 1 (P<0.05). Correlated + with other measures. 1 year post-surgery group 2 rated more favourably than group 1 (P<0.05).	SOC is correlated with post-surgical outcomes, and can have predictive value for care.

Article	Setting	Design	Sample	Outcome Measures	Results	Conclusions
Rennemark & Hagberg, 1999	Swedish community	Correlational study	All inhabitants of community born in 1923, sub-group N=58	SOC-29, Social Networks Measure, Zung, Symptom Checklist	SOC neg. correlation with number reported symptoms ($P<0.001$) particularly depression and tension. Strong relationship between SOC and social networks ($p<0.05$).	SOC serves as a buffer against the experience of illness. Also interacts with social context to define sickness behaviour.
Nesbitt & Heidrich, 2000	Midwestern states, USA	Cross-sectional descriptive, correlational study	Women 65+ with chronic health problems N=137. Mean age 75.8 years	SOC-29, PHL, QOL, IA	Mean SOC score=157.21, SOC and IA mod. pos correlated. SOC and IA highly + correlated with QOL, despite PHL.	SOC and IA have mediating effects between PHL and QOL.
Nilsson et al, 2000	Northern most counties, Sweden	Population-based study	Stomach trouble (ST) N=309, Identified disease (ID) N=198, Without reported symptom or disease (W) N=1212	SOC-13, ISSI subscales AVAT, AVSI	ST lower SOC than ID and W($p<0.05$). Relationship b/t low SOC scores and poor perceived health, low social support and low emotional support, particularly for woman.	SOC provides new way of perceiving health and disease. Indications for clinical practise.
Sanden-Eriksson, 2000	Primary health care centres, Sweden	Prospective study	Newly diagnosed NIDM N=88, 50 men mean age 65.4 years, 38 woman mean age 68.7	SOC-13, Study specific questionnaire, HbA1c	Mean SOC score= 72.6. No relationship b/t SOC and HbA1c. Self-assessed health strong pos relationship with SOC ($P<0.001$) and HbA1c ($P<0.02$).	A high SOC and positive self-assessment indicates better acceptance and management of NIDM.
Lustig et al, 2000	Universities in USA	Correlational study	Convenience sample of college students with disabilities, N=89	SOC-29, DIS, Scale of Psychological Well-being (adjustment)	All variables measured significantly correlated ($P<0.01$). Meaningfulness component most important.	SOC plays a significant part in adjustment to disability.
Forbes, 2001	Community, Ontario, Canada	Correlational study	People 65+ living in community. Young-old (YO) (65-79) N=2006). Old-old (OO) (80+) N=406	SOC-?, Mastery Index, Self-Esteem Rosenberg Scale, Health Utility Index	Older adults form 2 groups. SOC pos related to socio-demographic variables YO, but not OO. SOC + mastery related to health status both groups.	SOC and mastery stronger predictors of health status than socio-demographic variables.

Article	Setting	Design	Sample	Outcome Measures	Results	Conclusions
Richardson et al, 2001	Acute hospital, Stockholm, Sweden	Descriptive study	Out-patient IDDM N=107. Men=47, Women=60. Mean age 43	SOC-29, ADM, HbA1c	Mean SOC score=148. SOC neg. correlated with number of complications ($p<0.05$). Correlation between SOC and age, and age of onset. Correlation b/t SOC and ADM ($p<0.001$). SOC not correlated with HbA1c, but ADM was.	SOC is related to the acceptance of IDDM, and acceptance is related to metabolic control.
Cederfjall et al, 2001	Hospital, Stockholm, Sweden	Explorative, cross-sectional design	HIV pts N=189 + 2 healthy reference groups	SOC-29, HI, HIV symptom scale, Well-being scale, ISSI, AVSI, AVAT.	SOC significant impact on all dependant variables ($p<0.05$). HIV pts significantly lower SOC than health reference groups ($p<0.001$) and general health ($p<0.05$). SOC + correlated with social support.	SOC is the strongest predictor of HRQOL. Need for individualised approaches.
Mendal et al, 2001	Karolinska Hospital, Sweden	Correlational study	Patients with peripheral vestibular disorder (PVD) N=99, Women =63, mean age 54, Men=36, mean age 55. Healthy reference group N=268	SOC-13, HAD, Vertigo symptom scale, Somatic anxiety scale, VHQ, SIP,	PVD pts higher mean SOC score than ref group ($P<0.001$). SOC neg. correlated with self-rated handicap ($P<0.001$), emotional distress ($P<0.001$), working capacity ($P<0.05$), sleep and rest ($p<0.05$) psychosocial functioning ($p<0.001$).	SOC crucial in predicting impact of PVD and individual's ability to cope.
Bengtsson-Tops & Hansson, 2001	Out-patient clinics, Malmo, Sweden	18 month follow-up study	Schizophrenia patients living in the community N=94	SOC-29, LQOLP, mastery measure, ISSI, BPRS, GAF	Mean SOC score=129, SOC pos correlated with mastery, self-esteem, social integration. Neg. correlated with psychopathology. Changes in SOC over 18 months correlated with changes in subjective QOL etc. ($p<0.000-0.032$).	SOC has predictive validity in this population, and was significantly associated with health related factors. Possible to enhance an individual's SOC.

Article	Setting	Design	Sample	Outcome Measures	Results	Conclusions
Drory et al, 2002	Eight medical centres in Israel	Longitudinal study	Male patients with AMI, N=209, Mean age 52 years, interviewed 3 times	SOC-29, BDI, MSPSS, MHI	SOC correlated to short-term psychological well-being. Short-term related to long-term psychological well-being.	Increase in negative affect occurs immediately after AMI, which then continues over time. SOC a protective factor.
Jahnsen et al, 2002	University of Oslo, Norway	Descriptive study	Cerebral Palsy Pop. N=406. 51.5% female. Age 18-72. Mean age 34 yrs. Reference group.	Demographic questionnaire, SF-36, IQOLA, FQ. SOC adapted (3 questions)	Sample had lower SOC scores than reference group (p=0.05). SOC effected by age. High SOC scores correlated with employment. SOC neg. correlated with fatigue.	Comprehensibility domain played major role. Impact of care on meaningfulness domain, compromises development of strong SOC.
Berglund et al, 2003	Huddinge University Hospital, Sweden	Descriptive, correlational study	Ehlers-Danlos Syndrome (EDS) pts. N=77, 69 female, 8 male. Mean age 39.	Study specific questionnaire, AD Scale (modified), SOC-29, SIP	SOC pos. correlated with AD (p<0.001). SOC accounted for 38% variance in AD. SOC neg. correlated with SIP (functional + psychosocial) (p<0.05).	SOC is related to adjustment and is correlated with functional and psychosocial health status.

Key: Appendix A

AD – Adjustment to Disability Scale	ISSI – Interview Schedule of Social Interaction
ADL – Activities of Daily Living	
AIMS – Arthritis Impact Measurement Scale	IQOLA – International Quality of Life Assessment
AMI – Acute Myocardial Infarction	JCS-40 – Jalowiec Coping Scale
AVAT – Availability of Attachment	LQOLP – Lancashire Quality of Life Profile
AVSI – Availability of Social Integration	
BDI – Beck Depression Inventory	MHI – Mental Health Inventory
BPRS – Brief Psychiatric Rating Scale	MSPSS – Multidimensional Scale of Perceived Social Support
COS – Confrontational	
CRF – Chronic Renal Failure	NA – Negative Affect
DIS – Demographic Information Sheet	OA – Osteoarthritis
EOS – Emotional	PHL – Physical Health Limitations
FMS – Fibromyalgia Syndrome	POS – Palliative
FQ – Fatigue Questionnaire	QOL – Quality of Life
GAF – Global Assessment of Function Scale	RA – Rheumatoid Arthritis
HAD – Hospital Anxiety and Depression Scale	RADAI-RA – Disease Activity Index
HAQ – Stanford Health Assessment Questionnaire	RAI – Rheumatology Attitudes Index
HRQOL – Health Related Quality of Life	SIP – Sickness Impact Profile
IA – Illness Appraisal	SOC – Sense of Coherence
	SQOL – Subjective Quality of Life
	TNM – Tumour, Lymph nodes, Metastases
	VAS – Visual Analogue Scale
	VHQ – Vertigo Handicap Questionnaire

APPENDIX B SOC AS A STATE

Article	Setting	Design	Sample	Outcome Measures	Results
Schnyder et al, 2000	University Hospital, Zurich, Sweden	Longitudinal study	Study 1. Severely injured accident victims, N=96, mean age 38.4, male=71, female=25. Study 2. RA pts, N=60, mean age 61.1, male 14, female 46.	Study 1. SOC-13, ISS, SCL-90-R. Study 2. SOC-13, HADS	Study 1 – Significant decrease in mean SOC scores in first 6 months post accident. Second half of year SOC scores remained stable. Correlations between SOC and anxiety became increasingly stronger over time. Significant neg. correlations between SOC and SCL-90-R subscales depression and anxiety (P< 0.01). Study 2 – High stability of mean SOC scores and HADS over time. Highly significant correlation between SOC and HAD (p< 0.01).
Bengtsson-Tops & Hansson, 2001	Out-patient Clinics, Malmo, Sweden	18 month follow-up study	Schizophrenia patients living in the community N=94	SOC-29, LQOLP, mastery measure, ISSI, BPRS, GAF	Mean SOC score=129, SOC pos correlated with mastery, self-esteem, social integration. Neg. correlated with psychopathology. Changes in SOC over 18 months correlated with changes in subjective QOL etc. (p<0.000- 0.032) SOC has predictive validity in this population, and was significantly associated with health related factors. Possible to enhance an individual's SOC.
Nilsson, Lars, Stegmayr & Westman, 2003	Umea University, Sweden	Longitudinal	General Population, n=1254	SOC-13, ISSI, AVAT, AVSI	Significant difference in SOC scores between 1994-1999 (p<0.001). Those with identified disease and age 45-74 largest decrease. SOC only stable for those with initially high SOC scores.
Caap-Ahlgren & Dehlin, 2004	Malmo University Hospital, Sweden	Longitudinal	Patients with Parkinson's Disease, n=91	SOC-13, SF-36, GDS, Hoehn & Yahr Scale, PDQ-8, Insomnia questionnaire.	Significant decrease in SOC scores in 1 year (p<0.0001). Also Hoehn & Yahr (0.01) and PDQ-8 (0.01). No significant change in other scores.

Key: Appendix B

AVAT – Availability of Attachment

AVSI – Availability of Social Interaction

BPRS – Brief Psychiatric Rating Scale

GAF – Global Assessment of Function Scale

GDS – Geriatric Depression Scale

HADS – Hospital Anxiety and Depression Scale

ISS – Injury Severity Scale

ISSI – Interview Schedule of Social Interaction

LQOLP – Lancashire Quality of Life Profile

PDQ-8 – Parkinson's Disease Quest

RA – Rheumatoid Arthritis

SCL-90-R – The Symptom Checklist

APPENDIX C
SOC AS A FOCUS OF INTERVENTION

Article	Setting	Design	Sample	Intervention	Outcome Measures	Results
Ravesloot et al, 1998	Independent Living Centres, Montana, Kansas, Missouri, USA	Quasi-experimental treatment evaluation. Measures, pre-, post- and 6 months	N=14, convenience sample with spinal cord injury. Male=10, Female=4, Mean age 38	Health promotion intervention, "Living well with Disability". Aim: to reduce impact of secondary conditions.	SOC-29, SCSII, HCU, CES-D (depression)	Improvement in SOC (p=0.10). Sig dec in reported funct. limitation due to secondary conditions, 45% dec in use of physician services.
71 Karlsson et al, 2000	University Hospital, Goteberg, Sweden	Prospective design. Measures taken pre-op, 3, 6, 12 months post-op	Coronary artery bypass grafting (CABG) pts N=111, Male=99, 89%. Mean age 54 years	CABG	SOC-29, Visual analogue scale- emotional state, experience of chest pain (1 question)	SOC had changed (more than +/- 10%) in 41%pts, SOC also correlated with improved QOL and less chest-pain 1 year post-op.
Delbar & Benor, 2001	Israel, in patients own homes	Quasi-experimental treatment evaluation. Measures, pre-, post-.	Cancer pts who attended large medical centre. N=94 Mean age 49.87 years. Divided into control(C) N=46, intervention(I) N=48	Structured Nursing Intervention focused on case management and patient empowerment.	SOC-29, MHLC, SCA	SOC scores, MHLC increased for I group (SOC p<0.001), but decreased for C group. Correlated sig. with SCA. Pos correlated with control, neg. correlated with intensity.

Article	Setting	Design	Sample	Intervention	Outcome Measures	Results
Malmgren-Olsson & Branholm, 2002	Umea University, Umea, Sweden.	Quasi-experimental controlled comparative outcome study	Pts with non-specific musculoskeletal disorders and persistent pain syndromes. N=71. BAT group n=23 mean age 41.9, FK group n=22, mean age 45.7, TAU n= 26 mean age 43.1	3 treatment groups. BAT, FK (20 sessions over 4-5 months) and TAU (individual treatment physio. decided number of sessions).	SOC-29, SF-36, ASES	Significant correlations b/t SOC and SF-36 on all dimensions except 3 physical ($p < 0.05$ - $P < 0.01$). High SOC improved significantly on physical function ($p < 0.05$). In FK group low SOC improved on mental health ($p < 0.01$) and role emotional ($p < 0.05$). TAU group high SOC improved on body pain. Found SOC to be stable over time.
Weissbecker et al, 2002	University of Louisville, Kentucky, USA	RCT	N=91, FMS - Women. Mean age = 48.03. Immediate treatment group n=51, delayed treatment group n=40	Mindfulness based stress-reduction programme (MBSR)	SOC-29, FIQ, PSS, BDI	SOC correlated neg. with PSS ($p < .01$) and depression ($p < .01$). Participation in MBSR significant increase in SOC ($p < .01$). Wait-list controls maintained stable SOC.

Key: Appendix C

ASES – Arthritis Self-Efficacy

BAT – Body Awareness Therapy

BDI – Beck Depression Inventory

CES-D – Depression Scale

FIQ – Fibromyalgia Impact Questionnaire

SCA – Symptom Control Assessment

FK – Feldenkrais

FMS – Fibromyalgia Syndrome

HCU – Health Care Utilisation Scale

MHLC – Multi-Dimensional Health Locus of Control Scale

PSS – Perceived Stress Scale

QOL – Quality of Life

SCA – Symptom Control Assessment

SCSI – Secondary Conditions Surveillance Instrument

TAU – Treatment as Usual

APPENDIX D
INFORMATION LETTER

(Printed on Massey University letterhead)

AN INVESTIGATION OF THE STABILITY OF THE SENSE OF COHERENCE
FOR THOSE ATTENDING A 3-WEEK REHABILITATION PROGRAMME

THE SOC STUDY

Information Sheet

8 September 2003

You are invited to take part in a study approved by the Bay of Plenty Ethics Committee and The Massey University Human Ethics Committee.

INTRODUCTION

My name is Toni Hocquard: of QE Health, Rotorua, and I am undertaking this study to complete my Master in Rehabilitation qualification. The study will be conducted under the supervision of Professor Steve La Grow, Massey University and Kieren Faull, Researcher QE Health.

I have worked at QE Health (formerly Queen Elizabeth Hospital) for ten years first as a Counsellor and now as the Professional Advisor for Counselling. During this time, I have witnessed the unique holistic environment that QE Health offers to the people who come here for rehabilitation.

The research literature identifies a concept known as the Sense of Coherence (which is measured by a questionnaire) that is thought to play a part in the way people adjust to and cope with such things as chronic illness/ and or disability. It is currently seen, by most, as a stable personality trait, that is something that cannot be changed. Viewing it

this way means that those with a weaker Sense of Coherence will cope and adjust less well than those with a stronger Sense of Coherence. This seems to be the case in the literature.

I would like to challenge this theory, as I believe that rehabilitation in general (and perhaps the QE approach more specifically) has the ability to enhance people's Sense of Coherence. If this is true, then it will be possible to promote such an approach in order to really help people who are dealing with chronic illness and/or disability. Currently such approaches are seen as luxuries and are in a vulnerable position in terms of funding.

This study is therefore investigating the stability of the Sense of Coherence for people who come to QE Health.

WHY ME?

You have been selected to be invited to participate in this study as you meet the criteria for the study. That is, you are to be admitted to QE Health for a 3-week-rehabilitation programme for the first time and you are over 30. I will need 120 people to complete this study.

WHAT WILL I NEED TO DO IF I AGREE TO TAKE PART?

Within a week of receiving this Information Sheet I, as the researcher, 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. (Margaret Hall, Maori Liaison Officer, will also be available at this time and throughout the study).

If you are I will send you a consent form and two questionnaires. One questionnaire will ask some personal details, and the other will be the SOC-29, which will measure your Sense of Coherence at that time. A stamped addressed envelope will be included so that you can return these questionnaires within one week.

On admission to QE Health a package will be left for you either in your room at Compton Court, or on your bed if you are staying in the hospital. This package will contain the SOC-29, the SF-36 and the Acceptance of Disability Scale. It is estimated

that the questionnaires could take you approximately ½ - ¾ hour to complete. Members of the nursing staff will collect the questionnaires by the end of the first day.

You will be asked to complete the measures again (except the SF-36) on your last day at QE Health. The nursing staff will collect the completed questionnaires before you leave.

Six months later, I will send you out all the questionnaires again for the final time. There will be a stamped addressed envelope enclosed so that you can return the completed questionnaires within seven days.

On completion of the study I will send you a Summary Report and you will be invited to a presentation of the results.

WHO WILL KNOW IT WAS ME THAT TOOK PART?

Only myself and the nursing staff who collect the questionnaires will know that you are taking part. Your name will be removed from the questionnaires and be replaced by numbers as soon as I receive them. This information will then be stored separately within a secured environment.

YOUR RIGHTS

It is very important that you are aware of your rights for this study. You have a right not to participate at all, and this will in no way impact on your treatment or rehabilitation. Even if you do agree to participate in the study, you may withdraw at any time with no questions asked. As this study uses only questionnaires, it is also important to point out that you have the right to decline to answer any of the questions.

WHAT CAN I DO IF I WISH TO TALK TO SOMEBODY ABOUT THIS STUDY?

At anytime during the study you are welcome to contact me (Toni Hocquard) or make an appointment to discuss any issues about the study that may concern you. My contact details are listed below. The Maori Liaison Officer, Margaret Hall, will also be available to you and can be contacted on (07) 3480189.

You may also contact my supervisors Professor Steve La Grow, Head of School, School of Health Sciences, Massey University, Palmerston North, Ph (06) 350 5799 ext 2248, or Kieren Faull, Researcher, QE Health (07) 348 0189 ext 877.

This project has been reviewed and approved by the Massey University Human Ethics Committee, PN Protocol 03/72. If you have any concerns about the conduct of this project, please contact Professor Sylvia V Rumball, Chair, Massey University Campus Human Ethics Committee: Palmerston North, telephone 06 350 5249, email S.V.Rumball@massey.ac.nz.

The Health Consumer Service is available to all patients in the Midland Health Area. Any participant in this study who has concerns about treatment can contact the Health Consumer Service. The freephone number is 0800 223 238.

Thank you for your time.

Toni Hocquard
Masters Student
QE Health
PO Box 1342
Rotorua
Ph. (07) 3480189 ext 868
Email toni.hocquard@qehospital.co.nz

APPENDIX E
DEMOGRAPHIC QUESTIONNAIRE

This questionnaire will collect data about all the participants in the study for purposes of comparison, and the identification of important factors if differences occur.

Age

Gender

Male

1

Female

2

How would you describe yourself?

European NZ

3

Maori

4

Pacific Island

5

Asian

6

Other

7

What is your diagnosis?

How long have you had this condition?

When were you diagnosed?

Current Marital Status

Married

8

Single

9

Divorced

10

Defacto

11

Income

- Employed Full Time (30 - 40 hours) 12
- Employed Part Time (under 30 hours) 13
- WINZ Benefit 14
- ACC/Catalyst 15
- Other 16

What is your highest level of education?

- Primary 17
- Some Secondary 18
- Completed High School 19
- Some Additional Training 20
- Completed Undergraduate 21
- Completed Postgraduate 22

**APPENDIX F
CONSENT FORM**

(Printed on Massey University letterhead)

**AN INVESTIGATION OF THE STABILITY OF THE SENSE OF COHERENCE
FOR THOSE ATTENDING A 3-WEEK REHABILITATION PROGRAMME**

THE SOC STUDY

8 September 2003

Consent Form

This consent form will be held for a period of five (5) years.

I have read the Information Sheet and have had the details of the study explained to me.

My questions have been answered to my satisfaction and I understand that I may ask further questions at any time.

I agree to participate in this study under the conditions set out in the Information Sheet.

Signature _____ **Date** _____

Full Name – printed _____

**APPENDIX G
SENSE OF COHERENCE-29 (SOC-29)**

Here is a series of questions relating to various aspects of our lives. Each question has seven possible answers. Please mark the number, which expresses your answer, with numbers 1 and 7 being the extreme answers. If the words under 1 are right for you, circle 1, if the words under 7 are right for you, circle 7. If you feel differently, circle the number which best expresses your feeling. Please give only one answer to each question.

1. When you talk to people, do you have the feeling that they don't understand you?

1	2	3	4	5	6	7	
never have						always have	<input type="checkbox"/>
this feeling						this feeling	

2. In the past, when you had to do something, which depended upon cooperation with others, did you have the feeling that it:

1	2	3	4	5	6	7	
surely wouldn't						surely would	<input type="checkbox"/>
get done						get done	

3. Think of the people with whom you come into contact daily, aside from the ones to whom you feel closest. How well do you know most of them?

1	2	3	4	5	6	7	
you feel that						you know them	<input type="checkbox"/>
they're strangers						well	

4. Do you have the feeling that you don't really care about what goes on around you?

1	2	3	4	5	6	7	
very seldom						very often	<input type="checkbox"/>
or never							

5. Has it happened in the past that you were surprised by the behaviour of people whom you thought you knew well?

1 2 3 4 5 6 7
never always
happened happened

6. Has it happened that people whom you counted on disappointed you?

1 2 3 4 5 6 7
never always
happened happened

7. Life is:

1 2 3 4 5 6 7
full of completely
interest routine

8. Until now your life has had:

1 2 3 4 5 6 7
no clear goals or very clear goals
purpose at all and purpose

9. Do you have the feeling that you're being treated unfairly?

1 2 3 4 5 6 7
very seldom very often
or never

10. In the past ten years your life has been:

1 2 3 4 5 6 7
full of changes completely
without your consistent and
knowing what clear
will happen next

11. Most of the things you do in the future will probably be:

1 2 3 4 5 6 7
completely deadly
fascinating boring

12. Do you have the feeling that you are in an unfamiliar situation and don't know what to do?
- | | | | | | | | |
|-------------------------|---|---|---|---|---|------------|--------------------------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | |
| very seldom
or never | | | | | | very often | <input type="checkbox"/> |
13. What best describes how you see life:
- | | | | | | | | |
|---|---|---|---|---|---|---|--------------------------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | |
| one can always
find a solution
to painful things
in life | | | | | | there is no
solution to
painful things
in life | <input type="checkbox"/> |
14. When you think about your life, you very often:
- | | | | | | | | |
|------------------------------------|---|---|---|---|---|--------------------------------------|--------------------------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | |
| feel how good it
is to be alive | | | | | | ask yourself why
you exist at all | <input type="checkbox"/> |
15. When you face a difficult problem, the choice of a solution is:
- | | | | | | | | |
|--------------------------------------|---|---|---|---|---|----------------------------|--------------------------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | |
| always confusing
and hard to find | | | | | | always completely
clear | <input type="checkbox"/> |
16. Doing the things you do every day is:
- | | | | | | | | |
|--|---|---|---|---|---|---------------------------------|--------------------------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | |
| a source of deep
pleasure and
satisfaction | | | | | | a source of pain
and boredom | <input type="checkbox"/> |
17. Your life in the future will probably be:
- | | | | | | | | |
|---|---|---|---|---|---|--------------------------------------|--------------------------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | |
| full of changes
without your
knowing what
will happen next | | | | | | completely con-
sistent and clear | <input type="checkbox"/> |

18. When something unpleasant happened in the past your tendency was:
- | | | | | | | | | |
|----------------------------------|---|---|---|---|---|--|--|--------------------------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | | |
| "to eat yourself
up" about it | | | | | | to say "okay,
that's what, I
have to live with
it," and go on | | <input type="checkbox"/> |
19. Do you have very mixed-up feelings and ideas?
- | | | | | | | | | |
|-------------------------|---|---|---|---|---|------------|--|--------------------------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | | |
| very seldom
or never | | | | | | very often | | <input type="checkbox"/> |
20. When you do something that gives you a good feeling:
- | | | | | | | | | |
|---|---|---|---|---|---|---|--|--------------------------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | | |
| it's certain that
you'll go on
feeling good | | | | | | it's certain that
something will
happen to spoil
the feeling | | <input type="checkbox"/> |
21. Does it happen that you have feelings inside you that you would rather not feel?
- | | | | | | | | | |
|-------------------------|---|---|---|---|---|------------|--|--------------------------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | | |
| very seldom
or never | | | | | | very often | | <input type="checkbox"/> |
22. You anticipate that your personal life in the future will be:
- | | | | | | | | | |
|--|---|---|---|---|---|--------------------------------|--|--------------------------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | | |
| totally without
meaning or
purpose | | | | | | full of meaning
and purpose | | <input type="checkbox"/> |
23. Do you think that there will *always* be people whom you'll be able to count on in the future?
- | | | | | | | | | |
|---------------------------------|---|---|---|---|---|----------------------------|--|--------------------------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | | |
| you're certain
there will be | | | | | | you doubt
there will be | | <input type="checkbox"/> |

APPENDIX H
SF-36V2 HEALTH SURVEY

This survey asks for your views about your health. This information will help you keep track of how you feel and how well you are able to do your usual activities. Answer every question by selecting the answer as indicated. If you are unsure about how to answer a question, please give the best answer you can.

1. In general, would you say your health is: (*Tick in the circle that best describes your answer*)

Excellent	Very Good	Good	Fair	Poor
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

2. Compare to one year ago, how would you rate your health in general now?

Much better now than one year ago	Somewhat better now than one year ago	About the same as one year ago	Somewhat worse now than one year ago	Much worse now than one year ago
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

3. The follow question are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

	Yes, limited a lot	Yes, limited a little	No, not limited at all
a. Vigorous Activities, such as running, lifting heavy objects, participating in strenuous sports	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Moderate Activities, such as moving a table, pushing a vacuum cleaner, bowling or playing golf	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Lifting or carrying groceries	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Climbing several flights of stairs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. Climbing one flight of stairs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. Bending, kneeling or stooping	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g. Walking more than a mile	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
h. Walking several hundred yards	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
i. Waling one hundred yards	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
j. Bathing or dressing yourself	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

4. During the past four weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

- | | All of
the time | Most of
the time | Some of
the time | A little of
the time | None of
the time |
|---|-----------------------|-----------------------|-----------------------|-------------------------|-----------------------|
| a. Cut down on the amount of time you spent on work or other activities | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| b. Accomplished less than you would like | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| c. Were limited in the kind of work or other activities | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| d. Had difficulty performing the work or other activities (for example, it took extra effort. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

5. During the past four weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

- | | All of
the time | Most of
the time | Some of
the time | A little of
the time | None of
the time |
|---|-----------------------|-----------------------|-----------------------|-------------------------|-----------------------|
| a. Cut down on the amount of time you spent on work or other activities | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| b. Accomplished less than you would like | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| c. Did work or activities less carefully than usual | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

6. During the past four weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours or groups?

- | Not at all | Slightly | Moderately | Quite a bit | Extremely |
|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

7. How much bodily pain have you had during the past four weeks?

- | None | Very mild | Mild | Moderate | Severe | Very Severe |
|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

8. During the past four weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

- | | | | | |
|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Not at all | Slightly | Moderately | Quite a bit | Extremely |
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

9. These questions are about how you feel and how things have been with you during the past four weeks. For each question, please give the one answer that comes closest to the way you have been feeling.

How much of the time during the past four weeks...

- | | All of
the time | Most of
the time | Some of
the time | A little of
the time | None of
the time |
|---|-----------------------|-----------------------|-----------------------|-------------------------|-----------------------|
| a. Did you feel full of life? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| b. Have you been very nervous? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| c. Have you felt so down in the dumps
that nothing could cheer you up? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| d. Have you felt calm and peaceful? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| e. Did you have a lot of energy? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| f. Have you felt downhearted and
depressed? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| g. Did you feel worn out? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| h. Have you been happy? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| i. Did you feel tired? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

10. During the past four weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc)?

- | | | | | |
|-----------------------|-----------------------|-----------------------|-------------------------|-----------------------|
| All of
the time | Most of
the time | Some of
the time | A little of
the time | None of
the time |
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

11. How true or false is each of the following statements for you?

- | | Definitely
true | Mostly
true | Don't
know | Mostly
false | Definitely
false |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| a. I seem to get sick a little easier than
other people | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| b. I am as healthy as anybody I know | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| c. I expect my health to get worse | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| d. My health is excellent | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

APPENDIX I
ACCEPTANCE OF DISABILITY SCALE (MOD.)

Read each statement and put an "X" in the space indicating how much you agree or disagree with each statement.

A physical health condition may limit a person in some ways, but this does not mean he/she should give up and do nothing with his/her life.

___ I disagree very much	___ I agree a little	
___ I disagree pretty much	___ I agree pretty much	
___ I disagree a little	___ I agree very much	<input type="checkbox"/>

Because of my condition, I feel miserable much of the time.

___ I disagree very much	___ I agree a little	
___ I disagree pretty much	___ I agree pretty much	
___ I disagree a little	___ I agree very much	<input type="checkbox"/>

More than anything else, I wish I did not have this condition.

___ I disagree very much	___ I agree a little	
___ I disagree pretty much	___ I agree pretty much	
___ I disagree a little	___ I agree very much	<input type="checkbox"/>

Physical condition or not, I'm going to make good in life.

___ I disagree very much	___ I agree a little	
___ I disagree pretty much	___ I agree pretty much	
___ I disagree a little	___ I agree very much	<input type="checkbox"/>

Good physical appearance and physical ability are the most important things in life.

___ I disagree very much	___ I agree a little	
___ I disagree pretty much	___ I agree pretty much	
___ I disagree a little	___ I agree very much	<input type="checkbox"/>

My condition prevents me from doing just about everything I really want to do and from becoming the kind of person I want to be.

___ I disagree very much
___ I disagree pretty much
___ I disagree a little

___ I agree a little
___ I agree pretty much
___ I agree very much

I can see the progress I am making in rehabilitation, and it makes me feel like an adequate person in spite of the limitations of my condition.

___ I disagree very much
___ I disagree pretty much
___ I disagree a little

___ I agree a little
___ I agree pretty much
___ I agree very much

It makes me feel very bad to see all the things other people can do which I cannot.

___ I disagree very much
___ I disagree pretty much
___ I disagree a little

___ I agree a little
___ I agree pretty much
___ I agree very much

My condition affects those aspects of life, which I care most about.

___ I disagree very much
___ I disagree pretty much
___ I disagree a little

___ I agree a little
___ I agree pretty much
___ I agree very much

Though I live with this condition, my life is full.

___ I disagree very much
___ I disagree pretty much
___ I disagree a little

___ I agree a little
___ I agree pretty much
___ I agree very much

If a person is not entirely physically able, he/she is that much less a person.

___ I disagree very much
___ I disagree pretty much
___ I disagree a little

___ I agree a little
___ I agree pretty much
___ I agree very much

A person with a physical condition is restricted in certain ways, but there is still much he/she is able to do.

___ I disagree very much
___ I disagree pretty much
___ I disagree a little

___ I agree a little
___ I agree pretty much
___ I agree very much

There are many more important things in life than physical ability and appearance.

___ I disagree very much
___ I disagree pretty much
___ I disagree a little

___ I agree a little
___ I agree pretty much
___ I agree very much

There are times I completely forget that I have this condition.

___ I disagree very much
___ I disagree pretty much
___ I disagree a little

___ I agree a little
___ I agree pretty much
___ I agree very much

You need a good and whole body to have a good mind.

___ I disagree very much
___ I disagree pretty much
___ I disagree a little

___ I agree a little
___ I agree pretty much
___ I agree very much

There are many things a person with my condition is able to do.

___ I disagree very much
___ I disagree pretty much
___ I disagree a little

___ I agree a little
___ I agree pretty much
___ I agree very much

Since my condition interferes with just about everything I try to do, it is foremost in my mind practically all the time.

___ I disagree very much
___ I disagree pretty much
___ I disagree a little

___ I agree a little
___ I agree pretty much
___ I agree very much

If I did not have my condition, I think I would be a much better person.

___ I disagree very much
___ I disagree pretty much
___ I disagree a little

___ I agree a little
___ I agree pretty much
___ I agree very much

My condition, in itself, affects me more than any other characteristic about me.

- ___ I disagree very much
- ___ I disagree pretty much
- ___ I disagree a little

- ___ I agree a little
- ___ I agree pretty much
- ___ I agree very much

The kind of person I am and my accomplishments in life are less important than those of others.

- ___ I disagree very much
- ___ I disagree pretty much
- ___ I disagree a little

- ___ I agree a little
- ___ I agree pretty much
- ___ I agree very much

I know what I cannot do because of my condition, and I feel that I can live a full and normal life.

- ___ I disagree very much
- ___ I disagree pretty much
- ___ I disagree a little

- ___ I agree a little
- ___ I agree pretty much
- ___ I agree very much

Though I can see the progress I am making in rehabilitation, this is not very important since I can never be normal.

- ___ I disagree very much
- ___ I disagree pretty much
- ___ I disagree a little

- ___ I agree a little
- ___ I agree pretty much
- ___ I agree very much

In just about everything, my condition is annoying to me so that I cannot enjoy anything.

- ___ I disagree very much
- ___ I disagree pretty much
- ___ I disagree a little

- ___ I agree a little
- ___ I agree pretty much
- ___ I agree very much

How a person conducts himself or herself in life is much more important than physical appearances and ability.

- ___ I disagree very much
- ___ I disagree pretty much
- ___ I disagree a little

- ___ I agree a little
- ___ I agree pretty much
- ___ I agree very much

A person with my condition is unable to enjoy very much in life.

- ___ I disagree very much
- ___ I disagree pretty much
- ___ I disagree a little

- ___ I agree a little
- ___ I agree pretty much
- ___ I agree very much

The most important thing in this world is to be physically normal.

- ___ I disagree very much
- ___ I disagree pretty much
- ___ I disagree a little

- ___ I agree a little
- ___ I agree pretty much
- ___ I agree very much

A person with my condition finds it especially difficult to expand his/her interests and range of abilities.

- ___ I disagree very much
- ___ I disagree pretty much
- ___ I disagree a little

- ___ I agree a little
- ___ I agree pretty much
- ___ I agree very much

I believe that physical wholeness and appearance make a person what he/she is.

- ___ I disagree very much
- ___ I disagree pretty much
- ___ I disagree a little

- ___ I agree a little
- ___ I agree pretty much
- ___ I agree very much

A physical condition affects a person's mental ability.

- ___ I disagree very much
- ___ I disagree pretty much
- ___ I disagree a little

- ___ I agree a little
- ___ I agree pretty much
- ___ I agree very much

With my condition, I know just what I can and cannot do.

- ___ I disagree very much
- ___ I disagree pretty much
- ___ I disagree a little

- ___ I agree a little
- ___ I agree pretty much
- ___ I agree very much

Almost every area of life is closed to me because of my condition.

- ___ I disagree very much
- ___ I disagree pretty much
- ___ I disagree a little

- ___ I agree a little
- ___ I agree pretty much
- ___ I agree very much

Because of my condition, I have little to offer other people.

- ___ I disagree very much
- ___ I disagree pretty much
- ___ I disagree a little

- ___ I agree a little
- ___ I agree pretty much
- ___ I agree very much

Besides the many physical things I am unable to do, there are many other things I am unable to do.

- ___ I disagree very much
- ___ I disagree pretty much
- ___ I disagree a little

- ___ I agree a little
- ___ I agree pretty much
- ___ I agree very much

Personal characteristics such as honesty and a willingness to work hard are much more important than physical appearance and ability.

- ___ I disagree very much
- ___ I disagree pretty much
- ___ I disagree a little

- ___ I agree a little
- ___ I agree pretty much
- ___ I agree very much

I get very annoyed with the way some people offer to help me.

- ___ I disagree very much
- ___ I disagree pretty much
- ___ I disagree a little

- ___ I agree a little
- ___ I agree pretty much
- ___ I agree very much

With my condition, there isn't a single area of life that is not affected in some major way.

- ___ I disagree very much
- ___ I disagree pretty much
- ___ I disagree a little

- ___ I agree a little
- ___ I agree pretty much
- ___ I agree very much

Though I can see that people with physical conditions are able to do well in many ways, still they can never lead normal lives.

- ___ I disagree very much
- ___ I disagree pretty much
- ___ I disagree a little

- ___ I agree a little
- ___ I agree pretty much
- ___ I agree very much

A condition, such as mine, is the worse possible thing that can happen to a person.

- ___ I disagree very much
- ___ I disagree pretty much
- ___ I disagree a little

- ___ I agree a little
- ___ I agree pretty much
- ___ I agree very much

No matter how hard I try or what I accomplish, I could never be as good a person as one without my condition.

- ___ I disagree very much
- ___ I disagree pretty much
- ___ I disagree a little

- ___ I agree a little
- ___ I agree pretty much
- ___ I agree very much

There is practically nothing a person in my condition is able to do and really enjoy it.

- ___ I disagree very much
- ___ I disagree pretty much
- ___ I disagree a little

- ___ I agree a little
- ___ I agree pretty much
- ___ I agree very much

Because of my condition, I am unable to enjoy social relationships as much as I could if I did not have this condition.

- ___ I disagree very much
- ___ I disagree pretty much
- ___ I disagree a little

- ___ I agree a little
- ___ I agree pretty much
- ___ I agree very much

There are more important things in life than those my physical condition prevents me from doing.

- ___ I disagree very much
- ___ I disagree pretty much
- ___ I disagree a little

- ___ I agree a little
- ___ I agree pretty much
- ___ I agree very much

I want very much to do things that my condition prevents me from doing.

- ___ I disagree very much
- ___ I disagree pretty much
- ___ I disagree a little

- ___ I agree a little
- ___ I agree pretty much
- ___ I agree very much

Because of my condition, other people's lives have more meaning than my own.

- ___ I disagree very much
- ___ I disagree pretty much
- ___ I disagree a little

- ___ I agree a little
- ___ I agree pretty much
- ___ I agree very much

Often times, when I think of my condition, it makes me feel so sad and upset that I am unable to think of or do anything else.

- ___ I disagree very much
- ___ I disagree pretty much
- ___ I disagree a little

- ___ I agree a little
- ___ I agree pretty much
- ___ I agree very much

A physical condition changes one's life completely. It causes one to think differently about everything.

- ___ I disagree very much
- ___ I disagree pretty much
- ___ I disagree a little

- ___ I agree a little
- ___ I agree pretty much
- ___ I agree very much

I feel that I should be as able as the next person, even in areas where my condition prevents me.

- ___ I disagree very much
- ___ I disagree pretty much
- ___ I disagree a little

- ___ I agree a little
- ___ I agree pretty much
- ___ I agree very much

Life is full of so many things that I sometimes forget for brief periods of time that I have a physical condition.

- ___ I disagree very much
- ___ I disagree pretty much
- ___ I disagree a little

- ___ I agree a little
- ___ I agree pretty much
- ___ I agree very much

Because of my condition, I can never do most things that normal people can do.

- ___ I disagree very much
- ___ I disagree pretty much
- ___ I disagree a little

- ___ I agree a little
- ___ I agree pretty much
- ___ I agree very much

I feel satisfied with my abilities, and my condition does not bother me too much.

- ___ I disagree very much
- ___ I disagree pretty much
- ___ I disagree a little

- ___ I agree a little
- ___ I agree pretty much
- ___ I agree very much

APPENDIX J
THE IMPACT OF SOC-29 SCORES ON DROP OUT RATE

Continue	SOC Scores		
	High	Medium	Low
Yes	63.8% (n=30)	61.5% (n=40)	25% (n=2)
No	36.2% (n=17)	38.5% (n=25)	75% (n=6)

APPENDIX K
THE IMPACT OF SOC-29 SCORES T1 TO T4

	SOC Scores			
	High	Medium	Low	Total
T1	47 (39%)	65 (54%)	8 (7%)	120
T4	30 (41%)	40 (56%)	2 (3%)	72

APPENDIX L
MEANS AND SDS OF PUBLISHED STUDIES USING THE SOC SCALE

Study	SOC	
	Mean	SD
Petrie & Azariah (1990) Chronic Pain (n=107)	138.6	14.9
Hawley et al. (1992) Rheumatic disorders (n=1333)	148.0	29.66
Callahan & Pincus (1995) RA (n=828)	146.5	29.4
Buchi et al (1998) RA (n=89)	144.0	27.9

APPENDIX M
MEANS AND SDS OF PUBLISHED STUDIES USING THE ADM

Study	ADM	
	Mean	SD
Linkowski (1981) Variety of disabilities (n=46)	217	37.97
Linkowski (1981) Variety of disabilities (n=55)	254	32.01
Richardson et al (2001) Diabetes (n=107)	260	27.1
Berglund et al (2003) ED Syndrome (n=77)	240	38.0

ED- Ehlers-Danlos Syndrome

APPENDIX N
MEANS AND STANDARD DEVIATIONS FOR SF-36 AND US GENERAL
POPULATION MEANS

	Admission T2	6-Month FU T4	US General Population
	(N=112)	(N=72)	
	Mean (SD)	Mean (SD)	Mean (SD)
Physical Function	30.06 (9.66)	33.55 (10.13)	84.2 (23.3)
Role Physical	31.30 (7.79)	34.93 (9.36)	81.0 (34.0)
Bodily Pain	32.16 (6.30)	34.95 (7.80)	75.2 (23.7)
General Health	37.93 (9.83)	40.55 (10.89)	72.0 (20.3)
Vitality	36.59 (8.87)	42.79 (10.24)	60.9 (21.0)
Social Functioning	35.02 (9.89)	39.64 (11.80)	83.3 (22.7)
Role Emotional	36.55 (12.16)	41.36 (13.09)	81.3 (33.0)
Mental Health	42.08 (10.45)	46.88 (11.66)	74.4 (18.1)

APPENDIX O

MASSEY UNIVERSITY ETHICS COMMITTEE APPROVAL

Massey University Campus Human Ethics Committee: Palmerston North (HEC: PN)
Old Main Building, Turitea Fax: 64 6 350 5622 <http://www.massey.ac.nz/~muhec>

Professor Sylvia V Rumball, Chair Secretary
Telephone: 64 6 350 5249 Telephone: 64 6 350 5799 extn 7773
Email: S.V.Rumball@massey.ac.nz Email:



Private Bag 11 222,
Palmerston North,
New Zealand
Telephone: 64 6 356 9099

12 August 2003

Ms Toni Hocquard
130 Pakuhangi Road
ROTORUA

Dear Toni

**Re: HEC: PN Protocol – 03/72
An investigation of the stability of the Sense of Coherence for those
attending an intensive rehabilitation programme**

Thank you for your letter dated 04 August 2003 and the amended protocol.

The amendments you have made now meet the requirements of the Massey University Human Ethics Committee and the ethics of your protocol are approved. Approval is for three years. If this project has not been completed within three years from the date of this letter, a new application must be submitted at that time.

Any departure from the approved protocol will require the researcher to return this project to the Massey University Campus Human Ethics Committee: Palmerston North for further consideration and approval.

A reminder to include the following statement on all public documents "This project has been reviewed and approved by the Massey University Human Ethics Committee, PN Protocol 03/72. If you have any concerns about the conduct of this research, please contact Professor Sylvia V Rumball, Chair, Massey University Campus Human Ethics Committee: Palmerston North, telephone 06 350 5249, email humanethicspn@massey.ac.nz"

Yours sincerely

Professor Sylvia V Rumball, Chair
Massey University Campus Human Ethics Committee: Palmerston North

cc Professor Steve La Grow
School of Health Sciences
TURITEA PN351

Massey University Human Ethics Committee
Accredited by the Health Research Council

Te Kunenga ki Pūrehuroa

Inception to Infinity: Massey University's commitment to learning as a life-long journey

APPENDIX P

BAY OF PLENTY ETHICS COMMITTEE APPROVAL

Bay of Plenty Ethics Committee

144-146 The Strand
P.O. Box 134
Whakatane
Phone (07) 308 5030
Fax (07) 308 5033
Email: adcam@ihug.co.nz

8 September, 2003

Toni Jacqueline Hocquard
130 Pukehangi Road
ROTORUA

Re: An Investigation of the stability of "The sense of Coherence" for those attending an intensive Rehabilitation Programme.
Investigator: Toni Jacqueline Hocquard
Site/Area: **BOP/03/08/038 Site specific**

Thank you for your letter dated 18 August 2003 and the study submission.

The Bay of Plenty Ethics Committee considered the application at its meeting of the 2 September and advises that ethical approval is granted for the above study. The committee suggested that you would need to change the starting/finishing dates in line with the approval date of 8th September 2003.

Approved Documents

Information Sheet and consent form (Not dated)
Toni Hocquard of: Queen Elizabeth Hospital, Rotorua

Certification: Not Applicable

Accreditation

This Committee by the Health Research Council and is constituted and operates in accordance with the Operational Standard for Ethics Committees, March 2002.

Progress Reports

The study is approved until 8th September 2004. The Committee will review the approved application annually. A progress report is required for this study on 8th September 2004. You will be sent a form requesting this information. Please note that failure to complete and return this form may result in the withdrawal of ethical approval. A final report is also required at the conclusion of the study.

Requirements for SAE Reporting.

Please advise the Committee as soon as possible of the following:

- any study in another country that has stopped due to serious or unexpected adverse events
- withdrawal of Investigational product from continued development
- withdrawal from the market for any reason
- all serious adverse events which result in the investigator or sponsor breaking the blinding code at the time of the SAE or which result in hospitalisation or death.

Accredited by Health Research Council

Amendments:

All amendments to the study must be advised to the Committee prior to their implementation, except in the case where immediate implementations is required for reasons of safety. In such cases the Committee must be notified as soon as possible of the change.

General

It should be noted that Ethics Committee approval does not imply any resource commitment of administrative facilitation by any healthcare provider within whose facility the research is to be carried out. Where applicable, authority for this must be obtained separately from the appropriate manager within the organisation.

Please quote the above ethics committee reference number in all correspondence.

Yours faithfully,

pp *C. Campbell*
.....
Barry Smith.
CHAIRPERSON

APPENDIX Q

KUINI RIRIPETI KAUNIHERA LETTER OF SUPPORT

Kuini Riripeti Kaunihera

C/- Queen Elizabeth Hospital
PO Box 1342
ROTORUA

Telephone: 07 348 0189

MH:JAS
14 May 2003

Toni Hocquard
Counsellor
Queen Elizabeth Hospital
ROTORUA

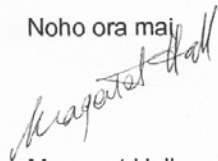
Tena koe Toni

Thank you for inviting the Kaunihera to have input into your interesting study - An investigation into the Stability of the Sense of Coherence for Those Attending an Intensive Rehabilitation Programme. We all enjoyed reading the study and would like to suggest a couple of improvements.

- 1 That an interpreter be offered if required for the consent.
- 2 That the Maori Liaison Officer be available if you require help with the interpretation of the questionnaires or information sheets.
- 3 You add the ethnicity box to the demographic questionnaire.

Please feel free to use any of the Kaunihera at any time to help you with your study.

Noho ora mai



Margaret Hall
Maori Liaison Officer

APPENDIX R
QUEEN ELIZABETH HOSPITAL COMMUNITY TRUST
LETTER OF SUPPORT



QUEEN ELIZABETH HOSPITAL
COMMUNITY TRUST

1 May 2003

Elizabeth Harding
Research Coordinator
Queen Elizabeth Hospital
ROTORUA

Dear Elizabeth

Thank you for your application for funding, on behalf of Toni Hocquard, for her research project titled "An Investigation of the Stability of the Sense of Coherence of Those Attending an Intensive Rehabilitation Programme".

It was discussed at our meeting of 24 April. The trustees had been sent a copy of the proposal with the agenda of the meeting, so they had plenty of time to familiarise themselves with the contents prior to the discussion. Would you please thank Toni for her offer of availability. We did not feel the need to do this.

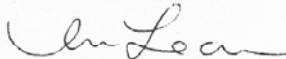
The trustees were very supportive of the study, and as Peter Jones pointed out, it ties into the work that Kieren Faulk has done. As you know, the Trust gave Kieren some financial support.

It was agreed to award \$4500.00 as a grant in aid of the research project. The intention is to cover the full direct costs of the project but not the study leave/salary or course costs.

We would like to take this opportunity to wish Toni every success with her study and it is a pleasure for the Trust to be able to support Research projects.

If further applications from other sources are not successful for the remainder of the funding, the Trust would consider a re-application for the outstanding amount.

Yours sincerely



Mary Lean
Secretary

Chairperson David Freyne : Secretary / Treasurer Mary Lean
Queen Elizabeth Hospital Community Trust