

# **Quality of Life and Sense of Coherence in People with Arthritis**

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Project Title Quality of Life and Sense of Coherence in People With Arthritis

We the undersigned declare that the above-named research project has been completed as described in the Application for Ethics Approval and in accordance with the ethics guidelines of Deakin University.

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## ABSTRACT

The current study investigated the physical and psychological impact of arthritis on people's quality of life. A range of variables were examined in a sample of 375 participants who comprised three groups: people with arthritis receiving a support based service from the Arthritis Foundation of Victoria, people with arthritis receiving standard medical treatment, and a group of people from the general population. The variables under investigation included functional impairment, social support, social activity, mood, pain, negative affect, positive affect, and Sense of Coherence - a personality dimension hypothesized to facilitate the ability to cope with stress and overall well-being. Composed of three sub-scales, comprehensibility, meaningfulness, and manageability, the 13 item short form version of the Sense of Coherence was used to determine its factor structure. The concept of separate subscales was not supported. The results showed that the two arthritis groups reported a significantly higher level of functional impairment, pain and negative affectivity, and lowered mood, positive affect, and SOC, compared to the general population group. They also reported lower levels of satisfaction on various life domains. After statistically controlling for pain, group differences were eliminated on all variables except for functional impairment and for all satisfaction domains except health. Hierarchical multiple regression analysis indicated that social support, social activity, mood and positive affect were significant predictors of Subjective quality of life for people with arthritis. SOC was not a significant predictor of Subjective well-being. The findings show that people with arthritis experience well-being substantially below that of people in the general population largely because of the negative influence of pain. The study outcome demonstrates that, unlike various life conditions, people do not adapt to pain. The implications of this are discussed in relation to feelings of loss of control and its consequences.

Arthritis is the most prevalent single cause of disability in Australia. According to the Australian Bureau of Statistics it affects 12.4% of the population (ABS, 1990). It is common in all age groups, although its incidence increases with age. Of persons aged 70 years or more, 45% are affected by some type of arthritis (ABS, 1990). There are more than 150 different forms of the disease, which include rheumatoid arthritis, osteoarthritis, systemic lupus erythematosus, fibromyalgia, scleroderma, and gout. Sadly its cause is still unknown and a cure has not been found. Individuals forced to contend with this condition are thus faced with an unpredictable and painful future. In view of its profound consequences the related effects of arthritis on quality of life (QOL) are important areas for research.

QOL is an elusive, multidimensional concept that has generated a great deal of research, controversy and debate during the last two decades. It has been operationally defined in very different ways by different investigators. Initially, measures to assess QOL were derived from objective indices of living conditions. These included social indicators such as economic prosperity, income, health, welfare, housing, education, savings and employment. They represented concrete items that were readily observable and relatively easy to measure (Campbell, 1976).

The scope of measurement, however, broadened when it was found that objective well-being by itself is an inadequate index of QOL since it ignored the views of the individual (Campbell & Converse, 1972; Abbey & Andrews, 1985). It was recognized that defining and measuring life quality needs to incorporate the individual's judgement because different people value different things. Subjective indicators of well-being were thus developed (Andrews & Withey, 1976; Campbell, Converse & Rodgers, 1976). They assess the experience of life directly by studying people's subjective reactions to their experiences. As QOL subsumes many aspects of an individual's life, researchers took into account specific domains as a valid assessment. Cummins (1993) proposes a list of seven domains relevant to Subjective QOL as: material well-being, health, productivity, intimacy, safety, place in society and emotional well-being.



Although the literature on QOL is copious, it is replete with the use of different measurement procedures which severely limits the interpretation of data pertaining to subjective well-being. In order to arrive at a life-satisfaction 'gold standard', Cummins (1995) has formulated a common statistic, "Percentage of Scale Maximum", to enable comparison between studies. This expresses any Likert scale score as a percentage of the maximum scale score ranging from 0 to 100. Comparing normative data, using diverse sample sizes and widely differing methodologies conducted in Western countries, the combination of data yielded a mean of 74.90%SM and a standard deviation of just 2.81. This has been simplified to  $75 \pm 2.5\%$  SM and a normal range of life satisfaction equals 70 - 80% SM.

Previous studies have found that arthritis is associated with decreased QOL (Burckhardt, 1985; Bradbury, 1989; Shaul, 1995; Downe-Wamboldt & Melanson, 1995). It leads to diminished independence and reduced involvement in family, work and social roles (Meenan et al., 1981; Reisine, Goodenow & Grady, 1987; Revenson, Schiaffino, Majerovitz & Gibofsky, 1991), economic deprivation (Newman et al., 1989), and a decreased ability to engage in physical and leisure activities (Liang et al., 1984). Furthermore, people with arthritis experience sexual problems (Elst et al., 1984), stress (Lerman, 1987), poor self-esteem (Earle et al., 1979; Affleck et al., 1987), lowered psychological well-being (Achterberg-Lawlis, 1982; Laborde & Powers, 1980; Anderson et al., 1985), and depression (Baker, 1982; Burckhardt, 1985; Frank et al., 1988).

Pain is one of the major stressors of arthritis impacting on quality of life (VanLankveld et al., 1994; Lambert, 1985) together with subsequent functional impairment in activities of daily living (VanLankveld et al., 1993). Indeed, pain has been significantly related to both anxiety and depression (Hawley & Wolfe, 1988; Revenson et al., 1991; Kraaimaat et al., 1995). Those with more severe forms of arthritis often suffer from more depressed affect (Mindham et al., 1981; Kazis et al., 1983; Blalock et al., 1988; Bendtsen & Homquist, 1994; Revenson & Feiton, 1989) and increased negative affectivity (Dekker et al., 1992; Summers et al., 1988; Dekker et al., 1993) than those with less severe forms of the illness. Negative affect may be

induced by chronic pain and then influences subjective well-being. However, a different point of view has been put forward by Smith et al., (1995), who found that 'disease impact', an index that was comprised of five measures of impairment and four of pain, significantly and negatively related to life satisfaction even after the influence of negative affect was partialled out. According to the authors, negative affectivity operates as a trait rather than a state measure, and arthritis related outcomes such as pain and impairment can impact on life satisfaction irrespective of negative affectivity.

It is important to distinguish between positive affective states and negative affective states in studies of health and life satisfaction, since both are independent feeling states and offer separate information about subjective QOL (Bradburn, 1969; Watson & Clark, 1992). Negative affect is a general dimension of subjective distress, whereas positive affect reflects one's level of energy, excitement and enthusiasm (Watson & Pennebaker, 1989). It has been shown that patients with arthritis experiencing pain and activity limitation experienced more negative affect and reduced positive affect (Zautra et al., 1995). Pain is thus likely to lead to increased negative affect, and its effect can lower positive affect when people are deprived of positive experiences and engagement in role activities are lost.

Social support, as a vehicle for expressions of affect, affirmation and assistance, can enhance positive well-being. In fact, it can be considered to play an important role in reducing stress and disease (Krol et al., 1993), and as contributing to positive adjustment (Larson, 1993) and improved life quality (Abbey et al., 1985; Abbey & Andrews, 1985). People can thus use social support as a means of coping to buffer the negative effects of stress on affect and health.

Social support may play a major role in determining the perceived QOL of persons with arthritis (Patrick et al., 1986; Weinberger et al., 1990; Affleck et al., 1988; Fitzpatrick et al., 1988; Goodenow et al., 1990; Burckhardt, 1985; Lambert et al., 1989; Revenson et al., 1991). Arthritis patients who report a higher degree of social support have more positive mood, higher self-esteem, better psychological well-being and less depression than those with lesser levels of support (Anderson et al.,

1985; Affleck et al., 1988; Brown et al., 1989; Manne & Zautra, 1989; Kerns et al., 1990; Kraaimaak et al., 1995). Social activity has also been found to have a substantial positive influence on subjective well-being in people with arthritis (Zimmer et al., 1995).

However, it should be emphasized that objective measures of social support do not relate consistently to Subjective QOL, since the influence of support is dependent upon the social and psychological processes through which it takes place. If the degree, quality and type of social support provided does not match the perceived needs of the individual, positive well-being may not ensue (Patrick, et al., 1986; Goodenow et al., 1990).

The current study explores the Sense of Coherence (SOC), a personality characteristic proposed by Antonovsky (1979, 1987) which refers to a disposition to look at life and its problems in a manner which makes coping easier. 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 environment's in the course of living are structured, predictable and explicable; (2) the resources are available to one to meet the demands posed by stimuli; and (3) these demands are challenges, worthy of investment and engagement (Antonovsky, 1987, p19)

The three elements of the SOC described in this definition correspond to (a) comprehensibility, (b) manageability, and (c) meaningfulness of one's life. Antonovsky (1987) operationalized SOC in the Orientation to Life Questionnaire which comprises 3 subscales to measure these components.

The SOC takes a "salutogenic" theoretical orientation, which seeks to explain why people stay healthy, as opposed to a "pathogenic" model, which focuses on what makes people ill (Antonovsky, 1992). The core of the salutogenic paradigm is the focus on successful coping through the selection of realistic coping strategies

(Antonovsky, 1984). SOC emerges from generalized resistance resources, which are posited to be major psychosocial resources such as ego strength, social support, cultural stability, wealth, a stable system of values, and beliefs derived from one's philosophy or religion, and many other things that are effective in avoiding and combatting a wide range of stressors (Antonovsky, 1979).

Based on the salutogenic orientation of the SOC, Antonovsky (1987) suggests that a positive, but not directly causal, relationship exists between the SOC and well-being. There are several studies which have supported this notion. A significant association between SOC and life satisfaction has been found in Israeli refugees (Sagy & Antonovsky, 1990), university academics (Ryland & Greenfield, 1991), patients recovering from joint replacement surgery (Chamberlain et al., 1992), elderly people (Stolar et al., 1992), young children (Margalit, 1985), caregivers (Gallagher et al., 1994), and people from the general population (Kalimno & Vuori, 1990).

However, no studies have focused on the relationship between SOC and QOL in people with arthritis. In fact, there are only two published studies that have investigated this topic. In a sample of 828 patients with rheumatoid arthritis (RA), Callahan and Pincus (1995) found that higher scores on SOC were significantly associated with better clinical status for activities of daily living, pain, global health status, and perceived learned helplessness.

A second cross-sectional study conducted by Hawley et al. (1992) analyzed the SOC in 1033 patients, including 572 with RA, 403 with osteoarthritis (OA), and 358 with fibromyalgia. Those with osteoarthritis had the highest scores on the total SOC score, and patients with fibromyalgia the lowest. However, when separate analyses were undertaken to statistically control for age, pain, functional disability, severity, anxiety, and depression, the significant differences on SOC between those with OA and RA were removed. Adjustment for age and depression eliminated any difference on SOC between those with fibromyalgia and the other two groups. Interestingly, SOC was found to be strongly correlated to anxiety.

A strong negative correlation between SOC and trait anxiety has also been reported in non-arthritic samples (Flannery & Flannery, 1990; Carmel & Bernstein, 1989; Kravetz et al., 1993; Antonovsky and Sagy, 1986; Frenz et al., 1993). This raises the possibility that SOC is confounded by components of trait anxiety. It may also be consonant with the notion that individual's scoring high on the SOC scale are low in negative affectivity. If so, SOC may thus contain items which partially overlap with the construct of negative affectivity.

Concern also exists as to whether the three components of the SOC should be viewed unidimensionally or as consisting of one global factor. Results from several studies have indicated that the three components of the scale are not separable (Flannery & Flannery, 1990; Hawley et al., 1992; Frenz et al., 1993; Callahan & Pincus, 1995). In contrast, Flannery et al (1994) found that the three subscales emerged as unique factors. These few available data regarding its factor structure raise measurement concerns about the composition of the SOC construct.

The purpose of this study is to investigate the physical and psychological effects of arthritis on people's QOL. It will examine the extent to which a number of factors influence and predict QOL in three separate groups of people: individuals with arthritis receiving a support based service from the Arthritis Foundation of Victoria (AFV), individuals with arthritis receiving standard medical treatment, and a group of individuals from the general population. The study will compare differences between these population groups in relation to severity of impairment, mood, pain, social support, social activity, positive affect, and negative affect. The investigation of a number of factors is warranted since the impact of arthritis on people's QOL is clearly not a unitary process. This investigation also seeks to explore the relationship of SOC to Subjective QOL and negative affect, and to determine whether the three subscales emerge as unique factors or as a single core factor in both an arthritis and general population sample. Finally, this study will seek to investigate the effects of pain on psychological well-being. It will examine whether differences between arthritis and non-arthritis sufferers on the above variables exist after statistically controlling for pain. The following hypotheses are to be tested:

- 1) People with arthritis will report increased functional impairment, pain, and negative affect, and decreased subjective well-being, SOC, mood, and positive affect.
- 2) The effects of arthritis on impairment and well-being can be primarily attributed to pain.
- 3) Social support will ameliorate the influence of arthritis on impairment.

## **METHOD**

### **Subjects**

A total of 375 participants took part in this study. The distribution between the three groups is as follows.

Group 1 (AFV) consisted of 116 people with arthritis receiving support through the Phone Link Service of the Arthritis Foundation of Victoria ( 88.8% female, mean age  $57.10 \pm 15$  years).

Group 2 (A) comprised 93 individuals with arthritis not obtaining any support service or treatment from the Arthritis Association of Victoria, but who received medical treatment from a medical practitioner (65.5% female, mean age  $61.47 \pm 13.6$  years).

Group 3 (N) consisted of 166 individuals from the general population ( 65.1% female, mean age  $47.31 \pm 15.2$  years).

People from the AFV, A, and N groups respectively reported suffering from the following types of arthritis: rheumatoid arthritis (43.1%, 44.1%, 7.8%); osteoarthritis (48.3%, 62.4%, 12.7%); systemic lupus erythematosus (6.6%, 2.2%, 0.0%); fibromyalgia (19%, 12.9%, 0.6%); scleroderma (1.7%, 1.1%, 0.0%); psoriatic arthritis (7.8%, 1.1%, 0.6%); reiter's syndrome (1.7%, 1.1%, 0.0%); gout (5.2%, 6.5%, 1.8%); low back pain (40.5%, 53.8%, 19.3%); tendonitis/bursitis (12.1%, 8.6%, 4.8%); osteoporosis (19.8%, 16.1%, 1.8%); sjoren's syndrome (5.2%, 0.0%, 0.0%).

81% of individuals in the AFV group took medication for their arthritis, compared to 67.7% in the A group and 11.4% in the N group. The 11.4% reported incidence of severe arthritis in the general population group is consistent with the normal population incidence of 12.4% (ABS, 1990). Within the AFV group 65.5% took other forms of medication, compared to 65.6% in the A and 26.5% in the N.

Duration of arthritic illness for each of the three groups is as follows: AFV, 2.7 to 65 years; N, 2.3 to 60 years; A, 0 to 40 years. 34.9% of individuals in the N group reported having some form of arthritis.

The distribution of ethnic background for the AFV, A, and N groups respectively was as follows: British (93.9%, 65.2%, 86.7%); Italian (2.6%, 12%, 3.6%); Greek (2.6%, 5.4%, 3%); Northern Europe (0.9 %, 3.3%, 4.8%); Croatian (0.0%, 10.9%, 0.6%); Jewish (0.0% 2.2%, 0.6 %); Asian (0.0%, 1.1%, 0.6%). Current living arrangements was as follows: lived alone (20%, 23.7%, 9.1%); lived with their partner or significant other (68.1%, 65.6%, 72.1%); resided in a shared household (6.9%, 7.5%, 18.2%); lived in a retirement village (2.6%, 2.2%, 6.6%); lived in a hostel (1.7%, 1.1%, 0.0%).

Fortnightly income for the AFV ranged from \$100 to \$7,500 (median income, \$540), for the A group from \$180 to \$15,000 (median income, \$405), and for the N group from \$100 to \$10,000 (median income, \$1200). Notably, there is a substantial difference in median income between the two arthritis groups (AFV and A) and the normal population group.

## **Measures**

- 1) Arthritis Impact Measurement Scales 2 (AIMS 2) (Meenan et al., 1992): The AIMS 2 is a revised and expanded version of the Arthritis Impact Measurement Scales (Meenan et al., 1980). It is an arthritis-specific measure of health status widely used in arthritis research. It produces scores on three dimensions: physical disability, psychological disability and pain. Seven of the twelve scales were used as follows:
  - (i-iii) Hand and finger function, arm function, and self-care tasks: The scores from three scales were combined to assess functional impairment. The alpha reliability was .93.
  - (iv) Social activities: This assesses the extent of the respondents' interactions with friends and family members during the previous month (alpha. 74).
  - (v) Social support: This scale assessed the perceived availability of support from family and friends during the previous month (alpha. 87).
  - (vi) Mood: This scale assesses the respondents' mood during the past month (alpha .88). A higher score indicates more negative mood. The actual items used pertain to: i) how often people enjoyed the things they do; ii) how often they have been in low or very low spirits; iii) how often they feel nothing turned out the way they wanted it to; iv) how often they felt that others would be better off if they were dead; v) how often they felt so down in the dumps that nothing would cheer them up.
  - (vii) Arthritis Pain: This scale assesses the amount of pain experienced during the previous month. In this sample this scale demonstrated an alpha reliability of .93.



All AIMS 2 scales contain 4 or 5 items and each is rated from 1 to 5. One of the five items from the pain scale was not included in the questionnaire. The item "how often did your morning stiffness last more than one hour from the time you woke up" was excluded following deliberations with the AFV, who did not consider it to an appropriate indicator of pain due to variations in people's medication usage. Although all 4 items from the social support scale were included in the questionnaire, only 3 items were used in the statistical analysis. It was decided not to incorporate the question "did you feel that your family or friends understood the effects of your arthritis" in the analyses since the word "arthritis" resulted in the majority of participants from the N group not providing a response. Scale scores represent the aggregate of item scores. Items from the self-care, pain and mood scales were recoded to ensure that a low score indicates a high health status. A higher score on any of the AIMS 2 scales thus indicates worse status.

The reliability, validity and scaling properties of the AIMS and AIMS 2 have been found to be adequate ( Meenan et al., 1980; Meenan et al., 1982; Potts & Brandt, 1987; Meenan et al., 1992).

Additional items from the AIMS 2 that do not form part of the scales were also included. These identify the type and duration of arthritis and provide an estimate of medication usage. In addition, a question about participants' level of fear was devised and included: "How often have you felt a fear of being unloved because of your arthritis". This question was devised to ascertain whether people with arthritis feel more emotionally vulnerable because of their illness. A lower score indicates a greater fear of being unloved.

2) Subjective Quality of Life (SQOL): Subjective well-being was measured with the Subjective Quality of Life Dimension of the Comprehensive Quality of Life Scale (Com Qol-4), (Cummins, 1993). It assesses SQOL within seven life domains: Material Well-Being, Health, Productivity, Intimacy, Safety, Place in Society, and Emotional Well-Being. It contains an importance subscale and a satisfaction subscale for each domain. The importance and satisfaction scores within each domain can be

analysed separately, or summed to provide a weighted measure of SQOL for each domain.

ComQol-4 has proven to be psychometrically satisfactory in regard to reliability and validity (Cummins, in press). Concerning the SQOL dimension, Cronbach's alpha for the importance subscale has been shown to be 0.65, and for the satisfaction subscale 0.73 (Cummins, McCabe, Romeo & Gullone, 1994). In this sample the SQOL scale demonstrated an internal consistency (alpha) of .82.

3) Sense of Coherence (Antonovsky, 1979; 1987): The short-form of the SOC was used in this study (Antonovsky, 1987). This 13 item version includes items measuring each of the three dimensions of SOC. The scale consists of five Comprehensibility items, four Manageability items, and four Meaningfulness items. Each item is presented on a 7-point Likert scale. Five of the items are negatively stated and reversed in scoring, so that a high score always indicates a stronger SOC. Antonovsky (1987;1993) reports the short-form SOC to be reliable and reasonably valid. Sixteen reports using the SOC-13 include alpha reliabilities between 0.74 and 0.91 (Antonovsky, 1993). The alpha reliability in this current study was .89.

4) Positive and Negative Affect Schedule (PANAS): Positive Affectivity (PA) and Negative Affectivity (NA) was assessed using the trait version of the PANAS (Watson, Clark & Tellegen, 1988). This scale assesses the independent dimensions of positive and negative affect. It contains a 10-item NA subscale and a 10-item PA subscale. Respondents are asked to rate on a 5 point scale, ranging from very slightly to extremely, how they "generally feel" for each of the mood states listed. The 10 positively valenced affective states are: interested, excited, strong, enthusiastic, proud, alert, inspired, determined, attentive and active. The negative affect items include: distressed, upset, guilty, scared, hostile, irritable, ashamed, nervous, jittery and afraid. The PANAS scales are brief and easy to administer. They have been found to be a reliable measure of positive and negative affect, and discriminant and convergent validity have been demonstrated (Watson, Clark & Tellegen, 1988). In this sample the

NA subscale demonstrated an alpha reliability of .92, and the PA subscale demonstrated an alpha reliability of .85.

5) Sociodemographic data: Data were collected on: date of birth, gender, ethnicity, living arrangements, household income, and whether participants received any form of treatment or support from the AFV.

### **Procedure**

The study design was cross sectional: each participant was required to complete four questionnaires, which formed part of a questionnaire booklet. This also contained an informed consent sheet, a plain language statement on University letterhead and a reply-paid envelope. The study was explained through a plain language statement which contained details of the research and assured participants of anonymity. The questionnaires took approximately thirty-five minutes to complete.

Collection of data did not involve personal contacts with participants unless they requested this. Their names appeared only on the consent form which was detached on receipt.

Participants in the AFV group were recruited through the Arthritis Foundation of Victoria. To ensure that participant anonymity would be preserved, the AFV posted the questionnaire packets to prospective participants, which included a covering letter confirming their endorsement of the study, while also making it clear that non-participation would in no way jeopardize access to Arthritis Foundation of Victoria services. This group of subjects mailed their completed questionnaires to the AFV. They were then forwarded to Deakin University with the questionnaires detached from the signed consent form. Of the 285 questionnaire packets that were mailed to Phone Link participants, 116 were returned indicating a 41% response rate.

Participants in the A group were recruited through three sources of treatment for patients suffering from some form of arthritis: ( i ) predominantly from General

Practitioners in private practice; ( ii ) a community health clinic; ( iii ) a pain management clinic. Securing the cooperation of General Practitioners entailed prior negotiations with each Project Officer from six Divisions of General Practice, who agreed to assist in enlisting the support of General Practitioners from their respective division. The questionnaires were distributed to arthritic patients by participating General Practitioners and other health workers. Since the number of questionnaires that were distributed is unknown, the response rate cannot be determined. Furthermore, other interventions that patients were receiving is also not known.

The N group comprised a non-clinical sample of people who had previously formed part of a longitudinal study on quality of life at the School of Psychology. Details of prospective participants were obtained through the Co-Ordinator of the study. Of the 270 people who were sent questionnaires, 166 were returned indicating a 61% return rate.

## **RESULTS**

Analysis of the data was carried out on an IBM compatible computer using SPSS for MS Windows. Before proceeding to test the hypotheses, two factor analysis procedures were executed to determine whether the three subscales comprising the SOC proposed by Antonovsky could be demonstrated in an arthritic sample and a normal population sample, Descriptive statistics are also provided. Following this, the hypotheses of the current study are tested using Multivariate Analysis of Variance (MANOVA), Hierarchical Regression, and Correlational Analysis.

A factor analysis with oblimin rotation was undertaken to determine if the three subscales proposed by Antonovsky could be identified in both an arthritic disease sample (Group 1 and Group 2) and a normal population sample (Group 3). As there are insufficient reports from studies of essentially healthy populations or clinical populations confirming the three subscales, the theoretical basis for a 3 factor model was insufficient for confirmatory factor analysis. Therefore, a factor analysis for an initial exploration was carried out for both sample groups.

Prior to execution, a reliability analysis of the 13 SOC indicated the item total correlation was between .2 and .8 for each variable, which is adequate for the purpose of reliability. An examination of the correlation matrix indicated that all items correlated with at least one other item  $> .4$ .

In view of the acceptable reliability, the factor analyses were accompanied by rotation in order to improve interpretability. Oblique rotation using direct oblimin is one of the best rotation methods currently available because it offers a continuous range of correlations between factors (Tabachnick & Fidell, 1989).

Using a criterion of eigenvalues greater than one (Norusis, 1988) three factors were identified. For ease of interpretation, the factor pattern matrix has been reported. According to Tabachnick & Fidell (1989), interpretation of factors through the pattern matrix rather than the structure matrix is recommended as the difference between high and low loadings is more apparent in the former.

The results of the factor pattern matrix for the arthritic sample (AFV and A) and the normal sample (N) are shown in Table 1. It shows for each factor its eigenvalue and percent of variance. Variables that had factor loadings of .40 or greater were selected to represent that factor. Where a variable loaded highly on more than one factor, it was reported as a complex variable within the table. This occurred for Question 3 and Question 1 in the normal population sample.

**Table 1. Pattern matrix of unique correlation between factors and the variables for the arthritis and normal population sample.**

<u>Arthritis sample</u>				<u>Normal population sample</u>			
Item	Factor 1	Factor 2	Factor 3	Item	Factor 1	Factor 2	Factor 3
Q8	.85			Q13	.79		
Q9	.84			Q10	.79		
Q6	.79			Q6	.72		
Q13	.62			Q9	.71		
Q5	.62			Q8	.66		
Q12	.51			Q5	.56		
Q2		.94		Q2		.80	
Q3		.89		Q3	.48	.70	
Q1		.47					
Q10		.46					
Q11			.85	Q1		.40	.76
Q4			.76	Q7			.74
				Q4			.68
				Q12			.65
Q7				Q11			
Eigen values	5.75	1.33	1.18		5.45	1.31	1.09
Percent of variance	44.2%	10.3%	9.1%		42.0%	10.1%	8.4%

In the arthritic disease sample only two variables loaded on Factor 3, while in the normal population sample two variables loaded on Factor 2. Interpretation of factors defined by only two variables remains cautious, under even the most exploratory factor analysis (Tabachnick & Fidell, 1989). Thus two core factors emerged for each of the two sample groups. Furthermore, within both sample groups the content of the factors could not be sorted into separate meaningful constructs in terms of the putative sub-scales of comprehensibility, manageability and meaningfulness.

Descriptive statistics for the SQOL scale are provided in Table 2.

**Table 2. Domain scores for Importance, Satisfaction and Subjective QOL.**

Domain	AFV Group		A Group		N Group	
	Mean $\pm$ s.d	% SM	mean $\pm$ s.d	% SM	means $\pm$ s.d	% SM
<b>IMPORTANCE</b>						
Material	3.40 $\pm$ 0.89	60.0	3.45 $\pm$ 0.89	61.2	3.46 $\pm$ 0.71	61.5
Health	4.25 $\pm$ 0.70	81.2	4.40 $\pm$ 0.69	85.0	4.25 $\pm$ 0.67	81.2
Productivity	3.64 $\pm$ 0.72	66.0	3.51 $\pm$ 0.95	62.7	3.77 $\pm$ 0.70	69.2
Intimacy	4.31 $\pm$ 0.70	82.7	4.40 $\pm$ 0.59	85.0	4.33 $\pm$ 0.68	83.2
Safety	3.99 $\pm$ 0.79	74.7	3.81 $\pm$ 0.92	70.25	3.88 $\pm$ 0.81	72.0
Community	3.37 $\pm$ 0.98	59.2	3.26 $\pm$ 1.00	59.0	3.30 $\pm$ 0.74	57.5
Emotion	3.93 $\pm$ 0.80	73.25	3.96 $\pm$ 0.74	74.0	4.02 $\pm$ 0.66	75.5
Total	26.88 $\pm$ 3.17	71.00	26.80 $\pm$ 3.42	70.50	27.04 $\pm$ 3.17	71.25
<b>SATISFACTION</b>						
Material	5.55 $\pm$ 1.03	75.8	5.50 $\pm$ 1.03	74.9	5.65 $\pm$ 0.83	77.4
Health	3.69 $\pm$ 1.42	44.8	4.19 $\pm$ 1.49	53.1	5.40 $\pm$ 1.01	73.3
Productivity	4.64 $\pm$ 1.42	60.6	5.03 $\pm$ 1.10	67.6	5.42 $\pm$ 1.03	73.6
Intimacy	5.29 $\pm$ 1.42	71.4	5.53 $\pm$ 1.17	75.4	5.71 $\pm$ 1.12	78.4
Safety	5.06 $\pm$ 1.29	67.6	5.22 $\pm$ 1.07	70.30	5.61 $\pm$ 0.83	76.8
Community	4.92 $\pm$ 1.42	65.3	5.21 $\pm$ 1.11	70.13	5.26 $\pm$ 0.86	70.9
Emotion	4.71 $\pm$ 1.57	61.8	4.93 $\pm$ 1.37	65.4	5.45 $\pm$ 1.05	74.1
Total	33.68 $\pm$ 7.08	63.80	33.59 $\pm$ 6.60	68.80	38.53 $\pm$ 4.96	75.0
<b>SUBJECTIVE (IMP*SAT)</b>						
Material	8.50 $\pm$ 4.95	69.7	8.38 $\pm$ 5.31	69.4	9.24 $\pm$ 4.02	71.6
Health	-0.68 $\pm$ 10.2	49.9	2.89 $\pm$ 10.3	54.9	10.1 $\pm$ 5.8	73.9
Productivity	5.20 $\pm$ 7.69	61.0	6.86 $\pm$ 5.64	65.4	9.04 $\pm$ 5.67	71.1
Intimacy	9.75 $\pm$ 8.06	72.9	10.95 $\pm$ 7.05	76.1	11.87 $\pm$ 6.56	78.5
Safety	7.48 $\pm$ 7.43	67.0	7.86 $\pm$ 6.14	68.0	10.06 $\pm$ 4.76	73.8
Community	6.17 $\pm$ 7.32	63.5	7.12 $\pm$ 5.89	66.0	7.59 $\pm$ 4.33	67.3
Emotional	5.67 $\pm$ 9.10	62.2	6.67 $\pm$ 8.51	64.9	9.76 $\pm$ 5.76	73.0
Total	41.79 $\pm$ 39.30	63.04	51.13 $\pm$ 35.34	66.7	67.75 $\pm$ 26.70	72.85

\*Note, the maximum score possible for the importance subscale is 5 and for the satisfaction subscale is 7. Overall subjective scores for each life domain were calculated by multiplying scores on subjective importance with scores on subjective satisfaction. The percent of scale maximum (%SM) represents the score achieved in each subscale as if the scoring was on a scale from 0 to 100.

Table 2 indicates that little difference exists between the three groups on domain scores for QOL-Importance. In contrast, there are marked group differences in relation to both QOL-Satisfaction and subjective QOL, with the two arthritis groups

showing lower %SM scores on the various domains in comparison to the general population group. The AFV group generally emerge with the lowest scores. Scores for the other arthritis group are comparable in some domains, but slightly higher in others. %SM scores for both arthritis groups on the domains of health, productivity, safety and emotional well-being are nevertheless strikingly lower than the general population group.

Descriptive statistics for QOL-importance, QOL-satisfaction, functional impairment, social activity, social support, pain, mood, fear, positive affectivity, negative affectivity, and SOC according to each group are provided in Table 3.

**Table 3. Descriptive statistics for dependent variables by Group.**

	AFV mean $\pm$ sd	A mean $\pm$ sd	N mean $\pm$ sd
Functional impairment	26.64 $\pm$ 11.23	24.65 $\pm$ 9.15	14.92 $\pm$ 2.86
Social activity	16.41 $\pm$ 3.40	15.91 $\pm$ 3.30	15.66 $\pm$ 3.04
Social support	7.09 $\pm$ 2.98	6.31 $\pm$ 2.74	6.04 $\pm$ 2.60
Mood	12.51 $\pm$ 4.63	12.19 $\pm$ 4.08	9.75 $\pm$ 3.20
Pain	13.42 $\pm$ 3.86	12.99 $\pm$ 4.11	5.40 $\pm$ 2.91
Fear	3.68 $\pm$ 1.28	4.04 $\pm$ 1.29	4.90 $\pm$ 0.48
Negative affect	22.40 $\pm$ 9.82	21.99 $\pm$ 9.05	17.16 $\pm$ 6.09
Positive affect	32.72 $\pm$ 7.03	32.40 $\pm$ 7.48	34.88 $\pm$ 6.14
SOC	60.25 $\pm$ 17.40	62.91 $\pm$ 15.50	67.14 $\pm$ 13.05

A comparison of the three groups was performed through a multivariate analysis of variance (MANOVA). This incorporated the nine dependent variables in Table 3 together with Importance and Satisfaction. The total of 375 cases was reduced to 344 due to missing data. Examining all possible combinations, the bivariate scatterplot revealed no outliers. As many of the variables were found to be skewed or kurtosized initial transformation of variables was undertaken but made little difference to the distributions. It was thus decided not to proceed with transformations. In the case of grouped data with large samples, transformation of variables is less imperative and may threaten interpretation (Tabachnick & Fidell, 1989).



Univariate tests of homogeneity of variance (Cochran's C) revealed non-significant values for social activity, positive affect, importance, and social support ( $p > .05$ ). Significant values were obtained for functional impairment, mood, negative affect, pain, satisfaction, and SOC ( $p < .05$ ). However, MANOVA is robust to variations in normality if the violation is created by skewness (Tabachnick & Fidell, 1989). As previously stated, the variables could not be transformed to attained normality. The multivariate test for homogeneity, Box's M, was significant (Box's  $M = 637.2$ ,  $p < .05$ ). However, Box's M test is a notoriously sensitive test of homogeneity of variance-covariance matrices available through SPSS MANOVA (Tabachnick & Fidell, 1989).

The multivariate test of significance of main effects and interactions using Pillai's criterion was significant:  $F(22, 674) = 14.39$ ,  $p < .001$ . Pillai's criterion was used as it is considered more robust than the other three criteria (Tabachnick & Fidell, 1989). The results of the eleven Univariate F-tests for significance together with differences between groups are presented in Table 4. All univariate tests were significant except for social activity and QOL-Importance.

**Table 4. Univariate tests of significance for dependent variables.**

Variable	F-value	p<	AFV<A<N	AFV&A<N	AFV&A>N	AFV>A&N
Functional status	88.79	.001			*	
Social activity	1.47	NS				
Social support	4.78	.01				*
Mood	19.18	.001			*	
Pain	219.67	.001			*	
Fear	55.79	.001	*			
Negative affect	16.19	.001		*		
Positive affect	4.78	.01		*		
QOL-Importance	.196	NS				
QOL-Satisfaction	23.23	.001		*		
SOC	6.89	.001		*		

\* A higher score on functional impairment, social activity, social support, pain, mood, and negative affect means worse status.

\* A lower score on fear, positive affect, satisfaction, and SOC means worse status.

In order to determine whether differences between groups remain while using pain as a covariate, a multivariate analysis of covariance (MANCOVA) was performed on the same dependent variables. With the use of Pillais' criterion, the combined dependent variables were significantly related to the covariate, approximate  $F(20, 674) = 2.03$ ,  $p < .05$ . Effects of group membership on the dependent variables after adjustment for the covariate were investigated in univariate analyses, which revealed that a reliable difference between the three groups was present for only functional impairment and fear. Those in AFV (adjusted mean = 23.57) and A (22.24) showed greater functional impairment than N (20.44). In regard to fear, AFV (3.97) felt a greater fear of being unloved than A (4.32), who had an increased level of fear than N (4.30).

Since significant differences between groups was found for satisfaction, a MANOVA was also performed on the seven domains of Satisfaction as the dependent variables. The analysis and evaluation of assumptions were conducted using the same procedures as described in the first two analysis. The total of 375 cases were reduced to 369 due to missing data. There were no univariate or multivariate within cell outliers at  $\alpha = .05$ .

With the use of Pillai's criterion, the combined dependent variables were significantly affected by group membership  $F(14, 722) = 9.42$ ,  $p < .05$ . The results of the seven Univariate F-tests for significance together with differences between groups are presented in Table 5. All univariate tests were significant except for material well-being.

**Table 5. Univariate tests of significance for AFV, A, and N groups according to Satisfaction domains.**

Variable	F-Value	p<	AFV<A & N	AFV & A<N
Material	0.74	NS		
Health	67.08	.001	*	
Productivity	15.35	.001		*
Intimacy	3.39	.05		*
Safety	9.51	.001		*
Community	3.61	.05	*	
Emotion	11.48	.001		*

As before, a MANCOVA was performed on the seven domains of satisfaction using pain as a covariate. There were no univariate or multivariate within cell outliers. The total of 375 cases was reduced to 367 due to missing data. With the use of Pillais' criterion, the combined dependent variables were significantly related to the covariate, approximate  $F(14, 716) = 2.49, p < .05$ . Univariate analysis revealed a significant difference between AFV, A, and N groups for the domain of health only ( $F = 5.90, p < 0.01$ ). Those in AFV showed a lower level of satisfaction with their health after adjustment for the covariate (adjusted mean health = 4.08) than A (4.56) and N (4.65).

A Pearson correlation was executed to investigate whether SOC will be negatively related to NA in the combined arthritis groups (AFV and A) and general population group (N). A strong negative correlation was found between SOC and NA for both the arthritis sample (Pearson  $r = -.69, p < .001$ ) and the general population sample (Pearson  $r = -.73, p < .001$ ). A series of Pearson's correlation analyses were carried out in order to examine whether social support and social activity will be significantly related to subjective QOL in both groups. For the purpose of interpretation, it should be explained that higher scores indicate less social support and social activity but increased Subjective QOL. Significant correlations were found in the arthritis sample (Pearson  $r = -.47, p < .001$ ) and the general population sample (Pearson  $r = -.48, p < .001$ ). Similarly, there were significant correlations between social activity and subjective QOL for the arthritis group (Pearson  $r = -.57, p < .001$ ) and the normal group (Pearson  $r = -.35, p < .001$ ). The combined arthritic sample also



impairment, negative affectivity, positive affectivity, SOC, and social support added to prediction of Subjective QOL,  $R^2 = .67$  (adjusted  $R^2 = .66$ ). Addition of these seven variables to the equation did reliably improve  $R^2$ . Only four of the independent variables, mood, social activity, social support and positive affectivity contributed significantly to the prediction of the dependent variable, "Subjective QOL".

Concerning the normal population group, two cases had missing data,  $N = 164$ . Table 7 displays correlations between the variables, the unstandardized regression coefficients ( $B$ ) and intercept, the standardized regression coefficients ( $b$ ), the semipartial correlations ( $sr^2$ ), and  $R$ ,  $R^2$ , and adjusted  $R^2$  after entry of nine independent variables.  $R$  was significantly different from zero at the end of each step. With all independent variables in the equation,  $R = .73$ ,  $F(9,154) = 19.31$ ,  $p < .001$ .

**Table 7. Hierarchical regression of variables on Subjective QOL for the normal population group.**

Variables	SQOL (DV)	1	2	3	4	5	6	7	8	9	Step	B	b	Sr2	Sig F Change
1. Pain	-.14										1	-1.73	-.18	.02	.067
2. Mood	-.57	.12									2	-2.19	-.26	.33	.000
3. Activity	-.34	.01	.26								3	-.60	-.06	.53	.000
4. Fear	-.05	-.38	-.06	.07							3	-5.15	-.09		
5. Func	-.00	.68	.09	.01	-.35						3	1.43	.15		
6. NA	-.45	.11	.60	.17	-.10	-.01					3	.25	.05		
7. PA	.52	-.03	-.54	-.25	-.00	.04	-.41				3	.99	.22		
8. SOC	.58	-.09	-.69	-.33	-.01	-.01	-.72	.56			3	.34	.16		
9. Support	-.47	.16	.29	.35	-.06	.14	-.39	-.20	-.40		3	-2.87	-.27		
Intercept = 67.28															
Means	67.87	5.41	9.77	15.68	4.89	14.92	17/15	34.88	67.09	6.08					
Sd	26.81	2.92	3.20	3.04	0.47	2.87	6.09	6.17	13.07	2.59					
$R^2 = .53$															
Adjusted $R^2 = .50$															
$R = .72^{**}$															

\*\*  $p < .01$

After Step 1, with pain in the equation,  $R^2 = .02$ ,  $F(1,154) = 3.40$ . After Step 2, with mood added to prediction of Subjective QOL,  $R^2 = .33$ ,  $F(2,154) = 8.66$ ,  $p < .001$ . Addition of mood to the equation does result in a significant increment in  $R^2$ . After Step 3, with the remaining seven variables added to prediction of Subjective QOL,  $R^2 = .53$  (adjusted  $R^2 = .50$ ). Addition of the remaining seven variables did reliably improve  $R^2$ . Four of the independent variables, mood, pain, positive affect, and social support contributed significantly to the prediction of the dependent variable, "Subjective QOL".

## DISCUSSION

This study has demonstrated that individuals with arthritis experience a poorer Subjective QOL than people in the general population. The %SM for QOL satisfaction was 63.80% for the AFV group, 68.80% for the A group, and 75% for the N group. The %SM scores for the two arthritis groups are thus below the hypothesised gold standard range of 70-80%SM (Cummins, 1995). Indeed, the two arthritis groups report lower %SM scores on all domains for QOL-satisfaction except for material well-being. They especially feel a lower level of satisfaction with their health (44.8%SM for the AFV group and 53.1%SM for the A group) compared to the normal population group (73.3%SM). Subjective QOL (importance x satisfaction) scores yield similar findings. People with arthritis report lower %SM scores on all subjective QOL domains. Again, %SM scores for the health domain are drastically lower in the two arthritis groups (49.9%SM for the AFV group and 54.9%SM for the A Group) compared to the general population group (73.9%SM).

These results demonstrate the severe impact of this disease on subjective well-being. They are consistent with previous research (Burckhardt, 1985; Lerman, 1987) which has shown that arthritis is associated with a decreased quality of life. Furthermore, the data concur with Cummins' (1995) assertion that people with a chronic medical condition will have a level of life satisfaction below the normative %SM range.

This study has also revealed significant differences between people with arthritis and those in the general population on a range of other physical and psychological variables. Persons with arthritis, in general, reported being more functionally impaired and suffering more pain. They also reported a greater fear of being unloved, lowered mood, higher levels of negative affect, and lower levels of positive affect. Their SOC scores were also lower than the general population group.

The findings further indicate that pain is the major variable which accounts for significant differences between the groups in relation to a broad range of psychological variables. After statistically controlling for pain, inter-group differences are removed on all variables except for functional impairment and fear, and for all satisfaction domains except health. Functional impairment, like pain, is a disease related-variable which may lead people to focus on what they cannot do. Together they evoke fears connected with threats to self-image and an overall dissatisfaction with their health that makes adaptation more difficult.

Previous studies have shown that people adapt to various life conditions, including spinal-cord injury (Schulz & Decker, 1985), intellectual disability (Barlow & Kirby, 1991), cancer (Muthney et al., 1990), or paraplegia (Brickman et al., 1978), such that their level of subjective well-being is not much different to that of the general population. In contrast, this study demonstrates that people do not adapt to pain. Their level of subjective well-being remains below that of the general population due to this negative influence.

Loss of control could be implicated in the connection between pain and decreased well-being. The power of pain lies in its capacity to take away people's control over their health and erodes any power to make themselves well. Heckhausen and Schultz (1995) distinguish between primary control, which refers to behaviours directed at controlling the external environment, and secondary control, which is targeted at internal processes to minimize losses in, maintain, and expand existing levels of primary control. They contend that the experience of control is intrinsically rewarding, leading to feelings of well-being. Thus, in the case of arthritic patients, it may be that the dual failure of primary and secondary control, due to the unrelenting nature of pain, denies the experience of positive affect. Decreased control thus induces decreased mood.

These feelings of despair and lowered mood in turn may lead to lowered subjective well-being. In this context, chronic arthritis sufferers may hold beliefs that neither they nor anybody else can help to control their pain. Consistent with this 25

interpretation, it has been shown that negative cognitions and feelings of perceived helplessness mediate the relationship between disease severity and depression (Smith et al., 1988; Smith, Peck and Ward, 1990).

The moderate positive association between pain and mood which emerged in this study is also consistent with previous studies which have found a deterioration in mood with increasing severity of arthritis (Brown, Nicassio & Wallston, 1989; Bendsten & Hornquist, 1994; Revenson & Felton, 1989; Kraaimaat et al., 1995). In addition, mood and positive affect were found to be significant predictors of Subjective QOL in both the arthritic and general population samples. The path to increased subjective well-being should focus on enhancing positive affect, which may help in regaining a sense of control.

In this regard, social support can have a substantial impact on positive well-being through its capacity to engender intimacy and close, supportive relationships with others. The findings from this study show that individuals who have family and friends to rely on for physical help, advice and social activity perceive a higher level of subjective well-being. They add to the growing body of evidence that social support may help to reduce the adverse consequences of this illness (Pow, 1987; Fitzpatrick et al., 1988; Manne & Zautra, 1989; Brown, et al., 1989). Clearly, social support holds enormous potential to positively impact on subjective QOL through its capacity to counteract loss of control.

It should be noted that differences emerged between the two arthritis patient samples in regard to perceived level of social support from family and friends and their perception of being loved by others. The AFV sample reported receiving less social support and feeling less loved, which perhaps explains their need to tap into a support based service. Since this group seems to comprise individuals with more severe arthritis, their medical problems may be accompanied by threats to self-image which serves to heighten their emotional insecurity. Their need for various forms of support may hence be greater.



In relation to the SOC, a number of interesting findings emerged. Firstly, the three separate sub-scales of the SOC questionnaire were not demonstrated in either sample. Only two factors emerged in both analyses, and the item content of the factors did not specifically match that of the three constructs. These data show that the concept of separate subscales within the SOC cannot be supported, and are consistent with previous findings which showed that three separate factors did not emerge in a normal population sample (Flannery & Flannery, 1990), a clinical group (Frenz et al., 1993), and in people with arthritis (Hawley et al., 1992; Callahan & Pincus, 1995). It would seem that the SOC subscales might all be measuring the same concept rather than three separate parts. This raises concerns about the validity of the subscales.

Secondly, SOC was not found to be a significant predictor of subjective QOL in either people with arthritis or people in the general population. Chamberlain and Zika (1992) similarly found SOC to have a relatively small influence on well-being in two different samples consisting of mothers with young children and elderly persons. Thus, the current finding does not lend support to Antonovsky's (1987) suggestion that SOC may have positive consequences for subjective well-being.

A strong negative relationship between SOC and negative affectivity was clearly demonstrated for both sample groups. This raises the interesting question of whether SOC simply reflects aspects of negative affect. It has previously been proposed that the SOC instrument is more a measure of emotionality than SOC (Korotkov, 1993). Previous research has also shown significant correlations between SOC and measures of anxiety (Bernstein & Carmel, 1987; Carmel & Bernstein; Carrnel & Bernstein, 1990; McSherry & Holm, 1994; Kravetz et al., 1993). The discriminant validity of the measure can thus be questioned, more so when one takes into account that group differences on SOC were removed when statistically controlling for pain.

There are several implications of these findings. Arthritic pain is a complex phenomenon that is crucial to our understanding of people's experience to this illness. It induces negative affect that results in lowered well-being. Psychological treatment

strategies thus have an important role to play in helping to reduce the physical discomfort of pain and psychological distress. Interventions that focus on the adoption of effective styles of coping to specifically deal with the stresses of arthritis can enhance psychological well-being (Vanlankveld et al., 1994) and decrease the level of pain and depression experienced by arthritis sufferers (Brown, Nicassio & Wallston, 1989; Revenson & Felton, 1989).

Several methodological limitations to this study should be mentioned. Firstly, as the data were cross-sectional, causal interpretations cannot be made. Longitudinal data are required to further enhance our understanding of the impact of arthritis on subjective QOL, especially the capacity of control enhancing interventions to raise life satisfaction through their enhancement of positive affect.

Several limitations pertain to the sample. Due to the selective-voluntary nature of the subjects, these data may not include the people most adversely affected by their arthritis. Since most of the subjects were of Anglo-Saxon origin, these findings may not be generalizable to non-english speaking populations. Studies with samples tapping different cultures and ethnic backgrounds are required to determine whether people with arthritis from non-english speaking backgrounds perceive their subjective QOL to be different, and if so, identifying the mechanisms accounting for this. Finally, the sample comprised mainly women. More intensive study to explore gender differences in relation to quality of life among people with arthritis is needed.

This study has clearly shown that people with arthritis endure a quality of life well below that of people in the general population, and that their capacity for adaptation is markedly diminished due to pain. It has been proposed that the consequences of pain are far reaching, particularly in its capacity to lower positive affect through loss of control. Emotional distress, insecurity and feelings of helplessness may all ensue. Individuals' perception of control over their illness thus has a potentially important role to play in more fully understanding how to improve life quality, as does the benefit of social support. The challenge lies in tailoring

interventions and support programs which incorporate regaining a sense of control, thus enhancing positive affect, in order to improve quality of life for people suffering from this illness.

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APPENDIX A  
Ethics Approval

# Deakin University

Faculty of Health & Behavioural Sciences  
Burwood Campus

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## Memorandum

**To:** Dr. R.A. Cummins  
School of Psychology

**From:** Secretary  
Faculty Ethics Subcommittee

**Date:** November 8, 1995

**Project**                    **THE QUALITY OF LIFE AND SENSE OF COHERENCE IN**  
**EC- H 95/95**                **PEOPLE WITH ARTHRITIS**

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Thank you for your response to my memo.

The project is **recommended for approval** and the application is now proceeding to the Deakin University Ethics Committee for ratification and, in the absence of any further advice, the project may commence.

As supervisor you are responsible for secure storage and retention of all data pertaining to this project for the minimum of **two** years after completion. You are requested to comply with this requirement.

**Shelley Maher**

APPENDIX B

Arthritis Impact Measurement Scales 2

**INSTRUCTIONS:**

Please answer the following questions about your health. Most questions ask about your health during the past month. There are no right or wrong answers to the questions and most can be answered with a simple (✓). Please answer every question.

**These questions relate to how you feel on your usual treatment.**

These questions refer to ***HAND AND FINGER FUNCTION***

During the **PAST MONTH . . . .**

1. Could you easily write with a pen or pencil?

all days	most days	some days	few days	no days
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2. Could you easily button a shirt or blouse?

all days	most days	some days	few days	no days
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3. Could you easily rum a key in a lock?

all days	most days	some days	few days	no days
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4. Could you easily tie a knot or a bow?

all days	most days	some days	few days	no days
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

5. Could you easily open a new jar of food?

all days	most days	some days	few days	no days
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

These questions refer to ***ARM FUNCTION***

During the **PAST MONTH ....**

6. Could you easily wipe your mouth with a napkin?

all days	most days	some days	few days	no days
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

7. Could you easily put on a pullover/sweater?

all days

most days

some days

few days

no days

8. Could you easily comb or brush your hair?

all days

most days

some days

few days

no days

9. Could you easily scratch your lower back with your hand?

all days

most days

some days

few days

no days

10. Could you easily reach shelves that were above your head?

all days

most days

some days

few days

no days

These questions refer to ***SELF-CAFE TASKS***

During the **PAST MONTH . . . .**

11. Did you need help to take a bath or shower?

always

very often

sometimes

almost never

never

12. Did you need help to get dressed?

always

very often

sometimes

almost never

never

13. Did you need help to use the toilet?

always

very often

sometimes

almost never

never



14. Did you need help to get in or out of bed?

always

very often

sometimes

almost never

never

These questions refer to ***SOCIAL ACTIVITY***

During the **PAST MONTH . . . .**

15. How often did you get together with friends or relatives?

all days

most days

some days

few days

no days

16. How often did you have friends or relatives over to your home?

all days

most days

some days

few days

no days

17. How often did you visit friends or relatives at their homes?

all days

most days

some days

few days

no days

18. How often were you on the telephone with close friends or relatives?

all days

most days

some days

few days

no days

19. How often did you go to a meeting of a church, club, team or other group?

all days

most days

some days

few days

no days

These questions refer to ***SUPPORT FROM FAMILY AND FRIENDS***

During the **PAST MONTH . . . .**

20. Did you feel that your family or friends would be around if you needed assistance?

always                  very often                  sometimes                  almost never                  never  
                                                                       

21. Did you feel that your family or friends were sensitive to your personal needs?

always                  very often                  sometimes                  almost never                  never  
                                                                       

22. Did you feel that your family or friends were interested in helping you solve problems?

always                  very often                  sometimes                  almost never                  never  
                                                                       

23. Did you feel that your family or friends understood the effects of your arthritis?

always                  very often                  sometimes                  almost never                  never  
                                                                       

These questions refer to ***ARTHRITIS PAIN***

During the **PAST MONTH . . . .**

24. How would you describe the arthritis pain you usually had?

severe                  moderate                  mild                  very mild                  none  
                                                                       

25. How often do you have severe pain from your arthritis?

all days                  most days                  some days                  few days                  no days  
                                                                       

26. How often did your morning stiffness last more than one hour from the time you woke up?

all days                  most days                  some days                  few days                  no days

27. How often did your pain make it difficult for you to sleep?

all days

most days

some days

few days

no days

This question refers to **LEVEL OF FEAR**

During the **PAST MONTH . . . .**

28. How often have you felt a fear of being unloved because of your arthritis?

always

very often

sometimes

almost never

never

These questions refer to **MOOD**

During the **PAST MONTH . . . .**

29. How often have you enjoyed the things you do?

always

very often

sometimes

almost never

never

30. How often have you been in low or very low spirits?

always

very often

sometimes

almost never

never

31. How often did you feel that nothing turned out the way you wanted it to?

always

very often

sometimes

almost never

never

32. How often did you feel that others would be better off if you were dead?

always

very often

sometimes

almost never

never

33. How often did you feel so down in the dumps that nothing would cheer you up?

always                      very often                      sometimes                      almost never                      never  
                                                                                       

Please check (✓) the most appropriate answer for each question. These questions refer to your ***CURRENT AND FUTURE HEALTH***

34. In general would you say that your **HEALTH** now is excellent, good, fair or poor?

excellent                      good                      fair                      poor  
                                                                 

35. In general do you expect that your **HEALTH 10 YEARS FROM NOW** will be excellent, good, fair or poor?

excellent                      good                      fair                      poor  
                                                                 

36. How big a problem do you expect your arthritis to be 10 YEARS FROM NOW?

no problem at all                      minor problem                      moderate problem                      major problem  
                                                                 

This question refers to ***OVERALL ARTHRITIS IMPACT***

37. Considering **ALL THE WAYS THAT YOUR ARTHRITIS AFFECTS YOU**, how well are you doing compared to other people your age?

very well                      well                      fair                      poor                      very poorly

38. What are the main kinds of arthritis that you have?

- |                                       |                          |
|---------------------------------------|--------------------------|
| Rheumatoid Arthritis                  | <input type="checkbox"/> |
| Osteoarthritis/Degenerative Arthritis | <input type="checkbox"/> |
| Systemic Lupus Erythematosus          | <input type="checkbox"/> |
| Fibromyalgia                          | <input type="checkbox"/> |
| Scleroderma                           | <input type="checkbox"/> |
| Psoriatic Arthritis                   | <input type="checkbox"/> |
| Reiter's Syndrome                     | <input type="checkbox"/> |
| Gout                                  | <input type="checkbox"/> |
| Low Back Pain                         | <input type="checkbox"/> |
| Tendonitis/Bursitis                   | <input type="checkbox"/> |
| Osteoporosis                          | <input type="checkbox"/> |

Other -----

(Please specify) -----

39. How many years have you had arthritis? -----

40. Do you take medication for your arthritis?      YES       NO

Please check (✓) for each question.

41. Is your health currently affected by any of the following medical problems?

- |                                | YES                      | NO                       |
|--------------------------------|--------------------------|--------------------------|
| High Blood Pressure            | <input type="checkbox"/> | <input type="checkbox"/> |
| Heart Disease                  | <input type="checkbox"/> | <input type="checkbox"/> |
| Mental Illness                 | <input type="checkbox"/> | <input type="checkbox"/> |
| Diabetes                       | <input type="checkbox"/> | <input type="checkbox"/> |
| Cancer                         | <input type="checkbox"/> | <input type="checkbox"/> |
| Alcohol or Drug Use            | <input type="checkbox"/> | <input type="checkbox"/> |
| Lung Disease                   | <input type="checkbox"/> | <input type="checkbox"/> |
| Kidney Disease                 | <input type="checkbox"/> | <input type="checkbox"/> |
| Liver Disease                  | <input type="checkbox"/> | <input type="checkbox"/> |
| Ulcer or other Stomach Disease | <input type="checkbox"/> | <input type="checkbox"/> |
| Anemia or other Blood Disease  | <input type="checkbox"/> | <input type="checkbox"/> |

Other (Please list) -----

-----

42. Do you take medicine every day for any problem than your arthritis?

YES

NO

**Please provide the following information about yourself:**

43. What is your date of birth? -----

44. What is your sex? MALE

FEMALE

45. What culture/race do you identify with?

British

Italian

Vietnamese

Jewish

Other -----  
(Please specify)

46. What are your current living arrangements?

Alone

Partner/Significant Other

Shared Household

Retirement Village

Hostel

Nursing Home

47. What is your personal or household (whichever is most relevant to you) fortnightly or monthly income before tax?

Fortnightly Income -----

Monthly Income -----

48. Do you receive any form of treatment or support from the Arthritis Foundation of Victoria?

YES

NO

If so what? -----  
-----

APPENDIX C

Comprehensive Quality of Life Scale (COMQOL-4)

## How **IMPORTANT** are each of the following life areas to you?

Please answer by placing a (✓) in the appropriate box for each question.

There are no right or wrong answers. Please choose the box that best describes how **important each area is to you**. Do not spend too much time on any one question.

1. How **Important** to you ARE THE THINGS YOU OWN?

could not be  
more  
important

very  
important

somewhat  
important

slightly  
important

not  
important  
at all

2. How **Important** to you is YOUR HEALTH?

could not be  
more  
important

very  
important

somewhat  
important

slightly  
important

not  
important  
at all

3. How **Important** to you is WHAT YOU ACHIEVE IN LIFE?

could not be  
more  
important

very  
important

somewhat  
important

slightly  
important

not  
important  
at all

4. How **Important** to you are CLOSE RELATIONSHIPS WITH YOUR FAMILY OR FRIENDS?

could not be  
more  
important

very  
important

somewhat  
important

slightly  
important

not  
important  
at all



5. How **Important** to you is HOW SAFE YOU FEEL?

could not be  
more  
important

very  
important

somewhat  
important

slightly  
important

not  
important  
at all

6. How **Important** to you is DOING THINGS WITH PEOPLE OUTSIDE YOUR HOME?

could not be  
more  
important

very  
important

somewhat  
important

slightly  
important

not  
important  
at all

7. How **Important** to you is YOUR OWN HAPPINESS?

could not be  
more  
important

very  
important

somewhat  
important

slightly  
important

not  
important  
at all





APPENDIX D

Orientation to Life Questionnaire (SOC)

## ORIENTATION TO LIFE QUESTIONNAIRE

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. 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 or never						very often

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

1	2	3	4	5	6	7
never happened						always happened

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

1	2	3	4	5	6	7
never happened						always happened

4. Until now your life has had:

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

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

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

6. 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 often						very seldom or never

7. 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

8. Do you have very mixed-up feelings and ideas?

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

9. Does it happen that you have feelings inside you would rather not feel?

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

10. Many people - even those with a strong character - sometimes feel like sad sacks (losers) in certain situations. How often have you felt this way in the past?

1	2	3	4	5	6	7
never						very often

11. When something happened, have you generally found that:

1	2	3	4	5	6	7
you overestimated or underestimated its importance						you saw things in the right proportion

12. How often do you have the feeling that there's little meaning in the things you do in daily life?

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

13. How often do you have feelings that you're not sure you can keep under control?

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

APPENDIX E

Positive and Negative Affect Schedule

## PANAS

The following questions ask you about different feelings. Read each of the following items and place a (✓) in the box next to the words which best describe the way you generally feel.

There are no right or wrong answers. Do not spend too much time on any one item.

1. Interested . . . . .

**very slightly**

**a little**

**moderately**

**quite a bit**

**extremely**

2. Distressed . . . . .

**very slightly**

**a little**

**moderately**

**quite a bit**

**extremely**

3. Excited . . . . .

**very slightly**

**a little**

**moderately**

**quite a bit**

**extremely**

4. Upset . . . . .

**very slightly**

**a little**

**moderately**

**quite a bit**

**extremely**

5. Strong . . . . .

**very slightly**

**a little**

**moderately**

**quite a bit**

**extremely**

6. Guilty . . . . .

**very slightly**

**a little**

**moderately**

**quite a bit**

**extremely**



7. Scared . . . . .

**very slightly****a little****moderately****quite a bit****extremely**

8. Hostile . . . . .

**very slightly****a little****moderately****quite a bit****extremely**

9. Enthusiastic . . . . .

**very slightly****a little****moderately****quite a bit****extremely**

10. Proud . . . . .

**very slightly****a little****moderately****quite a bit****extremely**

11. Irritable . . . . .

**very slightly****a little****moderately****quite a bit****extremely**

12. Alert . . . . .

**very slightly****a little****moderately****quite a bit****extremely**

13. Ashamed . . . . .

**very slightly****a little****moderately****quite a bit****extremely**

14. Inspired . . . . .

**very slightly****a little****moderately****quite a bit****extremely**

15. Nervous . . . . .

**very slightly****a little****moderately****quite a bit****extremely**

16. Determined . . . . .

**very slightly****a little****moderately****quite a bit****extremely**

17. Attentive . . . . .

**very slightly****a little****moderately****quite a bit****extremely**

18. Jittery . . . . .

**very slightly****a little****moderately****quite a bit****extremely**

19. Active . . . . .

**very slightly****a little****moderately****quite a bit****extremely**

20. Afraid . . . . .

**very slightly****a little****moderately****quite a bit****extremely**

APPENDIX F

Plain language statement and informed consent form  
for the Arthritis Foundation of Victoria group

## Faculty of Health and Behavioural Sciences

School of Psychology

Burwood, Telephone (03) 9244 6859 Facsimile (03) 9244 6858



Dear Prospective Participant

I would like to invite you to participate in a research project that I am undertaking for a Master of Clinical Psychology at Deakin University, Burwood Campus. My name is Dominic Germane, and the name of my supervisor is Dr Robert A Cummins, who is Reader in Psychology at the Burwood Campus.

The aim of my project is to measure how people with arthritis feel about their lives and whether the phone-link service affects feelings of well-being. In order to explore these issues, I am asking you to take part in my research by completing the four enclosed questionnaires that relate to quality of life, health status, coping and emotional well-being. Some examples of the kind of questions asked are:

Did you feel that your family or friends were sensitive to your personal needs?

How important to you is your health?

How satisfied are you with your health?

How often do you have the feeling that there's little meaning in the things you do in your daily life?

If you agree to be involved in this study, please complete the questionnaires in private and return them in the pre-paid envelope provided. Your name is not required on any of the four questionnaires for the purposes of this research. In order to maintain confidentiality, please do not put your name on any of the questionnaires.

The questionnaires should take approximately 35 minutes to complete. You can complete them all at once if you like or you may like to complete them over a few days. Please be sure to answer every question and put the first answer that comes to mind. You may, of course, withdraw from the study at any time.

All the information that is collected will be securely stored at the School of Psychology, Deakin University, Burwood. Confidentiality is guaranteed as the questionnaires will not have your names attached and they will be stored separately from the consent forms.

If you would like to know more about this study or are interested in its progress and outcome, then please do not hesitate to contact me on 9244 6859 as I am more than willing to be of assistance. You may also contact Dr Cummins on 9244 6845. If you would like more information about your condition and its management, then please contact the Arthritis Foundation of Victoria on 9530 0255.

I thank you for your time and cooperation

Dominic Germano

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Burwood 221 Burwood Highway Burwood Victoria Australia 3125 Telephone (03) 244 6100 Facsimile (03) 808 9497	Geelong Geelong Victoria Australia 3217 Telex DUNIV AA35625 Telephone (052) 27 1100 Facsimile (052) 27 2001	Rusden 662 Blackburn Road Clayton Victoria Australia 3168 Telephone (03) 244 7100 Facsimile (03) 244 7134	Toorak 336 Glenferrie Road Malvern Victoria Australia 3144 Telephone (03) 244 5100 Facsimile (03) 244 5478	Warrnambool PO Box Warrnambool Victoria Australia 3280 Telephone (055) 63 3100 Facsimile (055) 63 3531
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I, \_\_\_\_\_ of \_\_\_\_\_

**Hereby consent** to be a subject of a human research study to be undertaken

by Dominic Germano

and I understand that the purpose of the research is to measure how people with arthritis feel about their lives.

**I acknowledge**

1. Upon receipt, my questionnaire will be coded and my name and address kept separately from it.
2. Any information that I provide will not be made public in any forms that could reveal my identity to an outside party i.e. that I will remain fully anonymous.
3. I understand that aggregated results will be used for research purposes and may be reported in scientific journals.
4. Individual results **will not** be released to any person except at my request and on my authorisation.
5. That I am free to withdraw my consent at any time during the study in which event my participation in the research study will immediately cease and any information obtained from me will not be used.

Signature:

Date:

APPENDIX G

Plain language statement and informed consent form  
for the General Practitioner Arthritis group

## Faculty of Health and Behavioural Sciences

School of Psychology

Burwood, Telephone (03) 9244 6859 Facsimile (03) 9244 6858



Dear Prospective Participant

I would like to invite you to participate in a research project that I am undertaking for a Master of Clinical Psychology at Deakin University, Burwood Campus. My name is Dominic Germano, and the name of my supervisor is Dr Robert A Cummins, who is Reader in Psychology at the Burwood Campus.

The aim of my project is to measure how people with arthritis feel about their lives in general. I also want to know whether the way people approach their problems affects their feelings of well-being. In order to explore these issues, I am asking you to take part in my research by completing the four enclosed questionnaires that relate to quality of life, health status, coping and emotional well-being. Some examples of the kind of questions asked are:

Did you feel that your family or friends were sensitive to your personal needs?

How important to you is your health?

How satisfied are you with your health?

How often do you have the feeling that there's little meaning in the things you do in your daily life?

If you agree to be involved in this study, please complete the questionnaires in private and return them in the pre-paid envelope provided. Your name is not required on any of the four questionnaires for the purposes of this research. In order to maintain confidentiality, please do not put your name on any of the questionnaires.

The questionnaires should take approximately 35 minutes to complete. Please be sure to answer every question and put the first answer that comes to mind. You may, of course, withdraw from the study at any time.

All the information that is collected will be securely stored at the School of Psychology, Deakin University, Burwood. Confidentiality is guaranteed as the questionnaires will not have your names attached and they will be stored separately from the consent forms.

If you would like to know more about this study or are interested in its progress and outcome, then please do not hesitate to contact me on 9244 6859 as I am more than willing to be of assistance. You may also contact Dr Cummins on 9244 6845. If you would like more information about your condition and its management, then please contact your Doctor and/or the Arthritis Foundation of Victoria on 9530 0255.

I thank you for your time and cooperation

Dominic Germano

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I, \_\_\_\_\_ of \_\_\_\_\_

**Hereby consent** to be a subject of a human research study to be undertaken

by Dominic Germano

and I understand that the purpose of the research is to measure how people with arthritis feel about their lives.

**I acknowledge**

1. Upon receipt, my questionnaire will be coded and my name and address kept separately from it.
2. Any information that I provide will not be made public in any forms that could reveal my identity to an outside party i.e. that I will remain fully anonymous.
3. I understand that aggregated results will be used for research purposes and may be reported in scientific journals.
4. Individual results **will not** be released to any person except at my request and on my authorisation.
5. That I am free to withdraw my consent at any time during the study in which event my participation in the research study will immediately cease and any information obtained from me will not be used.

Signature:

Date:



APPENDIX H

Plain language statement and informed consent form  
for the National Population group

## Faculty of Health and Behavioural Sciences

School of Psychology

Burwood, Telephone (03) 9244 6859 Facsimile (03) 9244 6858



Dear Prospective Participant

I would like to invite you to participate in a research project that I am undertaking for a Master of Clinical Psychology at Deakin University, Burwood Campus. My name is Dominic Germano, and the name of my supervisor is Dr Robert A Cummins, who is Reader in Psychology at the Burwood Campus.

The aim of my project is to measure how people feel about their lives in general. I also want to know whether the way people approach their problems affects their feelings of well-being. In order to explore these issues, I am asking you to take part in my research by completing the four enclosed questionnaires that relate to quality of life, health status, coping and emotional well-being. Some examples of the kind of questions asked are:

Did you feel that your family or friends were sensitive to your personal needs?

How important to you is your health?

How satisfied are you with your health?

How often do you have the feeling that there's little meaning in the things you do in your daily life?

If you agree to be involved in this study, please complete the questionnaires in private and return them in the pre-paid envelope provided. Your name is not required on any of the four questionnaires for the purposes of this research. In order to maintain confidentiality, please do not put your name on any of the questionnaires.

The questionnaires should take approximately 35 minutes to complete. Please be sure to answer every question and put the first answer that comes to mind. You may, of course, withdraw from the study at any time.

All the information that is collected will be securely stored at the School of Psychology, Deakin University, Burwood. Confidentiality is guaranteed as the questionnaires will not have your names attached and they will be stored separately from the consent forms.

If you would like to know more about this study or are interested in its progress and outcome, then please do not hesitate to contact me on 9244 6859 as I am more than willing to be of assistance. You may also contact Dr Cummins on 9244 6845.

I thank you for your time and cooperation

### Dominic Germano

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I, \_\_\_\_\_ of \_\_\_\_\_

**Hereby consent** to be a subject of a human research study to be undertaken

by Dominic Germano

and I understand that the purpose of the research is to measure how people with arthritis feel about their lives.

**I acknowledge**

1. Upon receipt, my questionnaire will be coded and my name and address kept separately from it.
2. Any information that I provide will not be made public in any forms that could reveal my identity to an outside party i.e. that I will remain fully anonymous.
3. I understand that aggregated results will be used for research purposes and may be reported in scientific journals.
4. Individual results **will not** be released to any person except at my request and on my authorisation.
5. That I am free to withdraw my consent at any time during the study in which event my participation in the research study will immediately cease and any information obtained from me will not be used.

Signature:

Date: