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**A Study of the Impact of Psychodynamic Counselling on
Disease Activity in Early Rheumatoid Arthritis**

M.Sc. Dissertation

Submitted by

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Details	Page
List of Tables	4
List of Figures	5
Acknowledgements	6
Summary	7
Introduction	9
Epidemiology of Rheumatoid Arthritis	11
Socio-economic status	13
Literature Review	14
Methodology	30
Research Design	30
Sample Selection	30
Characteristics of Study Population	31
Intervention	32
Assessment of Disease Activity	32
Assessment of Disease/Health status	33
Assessment of Psychological Morbidity	34
Counselling Intervention	35
Education / Control Group	35
Data Analysis and Results	36
Psychodynamic Counselling	43

Case Histories	3
Case History A	45
Case History B	47
Case History C	47
Case History D	48
Case History E	49
Case History F	50
Case History G	51
Case History H	51
Case History I	52
Case History Summary	53
Discussion	55
Measurement	56
Implications For Practice	64
Conclusion	66
Patient / Individual Development	66
Counselling Service Development	67
Doctor / Patient Development	67
Bibliography	68
Appendices	77
Consent Form	78
Health Assessment Questionnaire	79
Hospital Anxiety and Depression Score	80
Arthritis Impact Measurement Score 2	83
Eular Core Data Set	95

List of Tables

4

Table		Page
	Two Sample t-tests and 95% Confidence Intervals for all tables	
Table 1	Mean Change in Modified Disease Activity Score (DAS) between Week 0 and Week 10.	39
Table 2	Mean Change in Number of Swollen Joints, Tender Joints, between Week 0 and Week10.	39
Table 3	Mean Change in Erythrocyte Sedimentation Rate and C-reactive Protein between Week 0 and Week10.	39
Table 4	Mean Change in Early Morning Stiffness and Pain between Week 0 and Week10.	40
Table 5	Mean Change in Hospital Anxiety Depression Score between Week 0 and Week10.	40
Table 6	Mean Change in AIMS2 for Social and Physical components between Week 0 and Week10.	41
Table 7	Mean Change in Health Assessment Questionnaire between Week 0 and Week10.	41
Table 8	Mean Change in Erythrocyte Sedimentation Rate and Swollen Joints between Week 0 and Week 5.	41
Table 9	Mean Change in C-reactive Protein and Pain between Week 5 and Week10.	42
Table 10	Mean Change in Erythrocyte Sedimentation Rate and Swollen Joints between Week 0 and Week 5.	42
Table 11	Mean Change in C-reactive Protein and Pain between Week 5 and Week10.	42

List of Figures

5

Figure 1.	Boxplot of repeated measures for modified disease activity score for counselled patients.	37
Figure 2.	Boxplot of repeated measures for modified disease activity score for controls.	37
Figure 3.	Repeated measures plot for modified disease activity score for counselled patients.	38
Figure 4.	Repeated measures plot for modified disease activity score for controls.	38

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Title

A study of the impact of psychodynamic counselling on disease activity in early rheumatoid arthritis.

Design: Prospective randomised controlled trial.

Setting: Physiotherapy Department, Glasgow Royal Infirmary.

Subjects: 22 female patients with disease duration of less than three years.

Intervention: Individual counselling on a weekly basis of up to ten weeks, each session lasting fifty minutes. Control group received five early education talks on the subject of rheumatoid arthritis from various health professionals, each session lasting ninety minutes.

Methods: Patients randomly allocated into either a counselling group (group 1: n=13) or an education group (group 2 ; n=9). Every patient was assessed during the ten week period at Week 0, 5, and 10.

Disease activity was measured using the modified disease activity score (DAS) based on the Eular Core Data Set. The Disease Activity Score is a combined index used to assess disease activity in Rheumatoid Arthritis. A change of 1.08. is assumed to signify a significant improvement or deterioration. (Appendix 2).

Main Results

There was no significant difference between the groups at baseline and no significant difference was found in disease activity between the groups.

In terms of changes over the ten weeks there was a trend towards improvement in the counselled group for the following subjective variables:- early morning stiffness, number of swollen joints, number of tender joints and pain as reported on a visual analogue scale.

Quality of life was measured using the Arthritis Impact Score 2 (AIMS2), Hospital Anxiety and Depression Score (HAD) and the Health Assessment Questionnaire (HAQ). No statistical significance was found between the groups for any of the quality of life measures.

Conclusions

This limited pilot study suggests that psychodynamic counselling over a ten week period does not provide a significantly large improvement in ameliorating disease activity when compared to early education talks. There is however a suggestion of a moderate effect in the counselled group.

Implications for The NHS

It is difficult to make any definitive statement about the implications of the study for the NHS. Counselling may need to be made available to patients at times when they perceive there to be a need. The brief nature of the intervention may also be a factor to be considered, with each individual having different requirements with respect to the numbers of sessions offered. The fact that individuals self-select when considering counselling, needs to be taken into account when carrying out a randomised trial.

This study does, however, highlight the importance of the doctor-patient relationship in terms of helping the patient to deal with the on-going difficulties of negotiating the independent and dependent self.

Rheumatoid arthritis (RA) is a chronic inflammatory disease that is known to cause pain, disability, joint destruction and consequently psychological distress. R.A. is one of a range of rheumatic and musculoskeletal disorders that includes osteoarthritis, ankylosing spondylitis, various conditions resulting in back pain, arthritis, fibromyalgia, and lupus erythematosus. The diagnostic criteria of the American College of Rheumatology are currently used. However clinicians are not confined to these criteria. The criteria for diagnosis involve clinical signs of disease activity in the joints, together with the evidence from X-rays and the presence of rheumatoid factor from serum.

Rheumatoid factor is a form of antibody to Type II collagen. The presence of this factor has been considered an important diagnostic variable. Recent studies have shown that as many as 72 per cent of those who have a positive test for rheumatoid factor may not have the disease, Shmerling and De Blanco (1992) .

Criteria for the classification of rheumatoid arthritis;

Four or more of the following should be present:

Morning stiffness.

Arthritis of three or more joint areas.

Arthritis of hand joints.

Symmetrical arthritis.

Rheumatoid nodules.

Serum rheumatoid factor.

Radiographic changes.

Source: Arnett et al (1987).

This research seeks to investigate the impact of psychodynamic counselling on the disease activity in the early stages of the disease process. Support in the form of counselling early on in the disease was investigated to see whether this would have some impact in alleviating the psychological distress precipitated by the diagnosis and onset of symptoms. In addition, an early exploration of events prior to the onset of the disease was considered worthy of attention in terms of linking the two events. Previous research has speculated about the possible events triggering the decrease in immunological tolerance prior to the onset of the disease. The research draws on various health related areas to investigate the underlying processes taking place in the individual which may or may not have existed in the pre-morbid state.

Literature based on the latest findings in the field of psychoneuroimmunology is utilised to support the link between the immune system and psychological well-being. Findings from psychobiology and early developmental studies have also been used. In addition the contemporary findings in psychoanalytic psychosomatic theories have been incorporated. An attempt has been made, drawing on all these different sources, to interlink the ideas presented, in order to explain the complex processes taking place in the individual. Previously these areas of research have been looked at in isolation.

The counselling or therapeutic process is examined and discussed in the light of these different areas of focus. Aitken (1987) stresses the significance of a psychosomatic approach in chronic diseases where no effective cures have yet been found. There is growing recognition that most diseases are influenced by social and psychic mechanisms, in their onset, as well as in their development and maintenance, Poulsen (1991). The presence of services related to the issues of body / mind are not always recognised. According to Poulsen (1991) greater resources are utilised in supporting individuals facing death than

sustaining those patients who are struggling with the consequences of a painful and unpredictable disease such as rheumatoid arthritis. The appreciation of this fact is evident in the prevalence of patient education programmes as an integral part of treatment.

Mcfarlane (1990), emphasises the need for psychological therapies, stating that patient outcome in severe rheumatoid arthritis is still relatively poor with forty percent of patients being significantly disabled after twenty years of disease. This is in spite of the use of powerful immuno-suppressive drugs. The use of counselling and these other therapies may assist the situation, leading to a better outcome for patients with this crippling disease.

This research looks at the impact of psychodynamic counselling on disease activity in the early stages of the disease. It looks at both quantitative and qualitative outcomes to assess the response. This is an attempt to bridge the gap between these two approaches. It also brings together ideas from different disciplines which have, until recently, been regarded as separate, that is: psychoneuroimmunology, psychoanalytic theories and psychobiology.

This research takes a broad based look at the factors influencing the processes involved between the psyche and the soma and attempts to form an hypothesis based on the findings from this study and these related areas.

Epidemiology of R.A.

Arthritis and Rheumatism as a whole are the biggest single source of disability in UK and North American populations. Figures for the prevalence of RA range from 1 per cent to 3 per cent of the population with lower estimates obtained when data and medical examination, Verbrugge et al (1991). A prevalence rate between 0.8 per cent and 1.0 per cent has been shown in surveys using more rigorous definitions of RA, Wood and Badley (1986).

There is some evidence of geographical variation in the prevalence of RA. For example some Chinese and African populations have a lower prevalence than is found in European or American populations.

The rate of new cases of RA in the population has shown to increase with age in all studies. The association of RA with older age is two-fold; the risk of onset increases with ageing and the disability associated with the disease, increases over time, Scott and Huskisson, (1992).

There is some evidence from the US and the UK that the incidence of RA has begun to decline among women but not among men, Spector (1991). Changes in the nature of the disease have also been observed. Anderson et al (1990), noted that over time the number of patients in severe classes of the disease has declined. It has been suggested that changes in the character of the disease are consistent with a viral aetiology. Spector (1991).

RA is far more common in women. The reasons for this are not well understood. The most commonly agreed estimate is of a female/male ratio of 3:1. It has also been observed that the overall pattern of a much higher prevalence in women is due to an earlier age of onset in women typically 45-64 and a more severe course, Da Silva and Hall (1992). Much of the evidence supports the view that women experience RA in a more severe form than men, but it is not all consistent. In this study it has been found from radiological evidence that women had more severe damage in the hands from RA than did men, but there were no differences for large joints, Carvalho et al (1980).

Differences in the personal impact of the disease need to be considered. A number of studies have examined gender differences by means of the Health Assessment Questionnaire Fries et al (1982). The majority of studies indicate

greater disability for women, Ekdaahl et al (1988). A number of explanations have been offered to account for gender differences in disability resulting from RA. One is that women experience more disability because of the more severe aggressive form of the disease that they experience.

Socio-economic status

The influence of social class on health is unequivocal. The effects of class have been clearly demonstrated in relation to a range of social variables including occupation, income, education and housing, Davey, Smith and Egger (1993). However, in general, evidence for an association between social class and both the occurrence and outcome of musculoskeletal disorders is patchy. When adopting a broader definition of outcome than typical clinical epidemiological studies, RA does appear to be more disabling for working class than for middle class people, Laing et al (1981). Systematic attempts to explore the relationship between social class and RA are scarce. There are puzzling differences in the pattern of RA by gender and social background.

In spite of extensive research the aetiology of rheumatoid arthritis remains unknown. Most evidence supports the concept that the pathology of rheumatoid arthritis (R.A) has its basis in an inflammatory response involving the immune system. There is some evidence that auto-immune mechanisms play a role. It is a chronic inflammatory disease affecting the synovium and other tissues. Both the humoral and cellular components of the immune system are intimately involved throughout the disease, Firestone and Zvaifler (1987). Many questions and uncertainties remain about the initiation and maintenance of the auto-immune process in this disease. The triggers for this process are unknown although a variety of viral agents and non-viral organisms have been considered as a possibility. Some research evidence supports the view that a virus such as Epstein-Barr may be involved in the initial triggering of the auto-immune response that leads to R.A. It is also possible that the onset of the virus is secondary to the onset of R.A. Sewell and Trentham (1993). It appears clear that triggered, T-cells which are normally part of the body's adaptive immune system and which normally respond against foreign bodies, are induced to attack individual's joints, Harris (1990).

Epidemiological evidence points to the prevalence of rheumatoid factor in people who do not have the clinical or radiological features of rheumatoid arthritis, Weiner (1977). This suggests that breakdown of immunological tolerance is not sufficient in itself to lead to the development of rheumatoid arthritis. This points to the relative importance of other factors, including psychological ones, that might influence the loss of immunological tolerance. Other humoral and cellular processes may also be involved in the initiation of acute inflammation. A high concentration of antibody and a low concentration of antigen leads to the production of intermediate sized complexes which are highly immunogenic, Blalock (1989). Any state therefore that effects the relative

intensity of the immune response, such as bereavement and depression, may influence whether immune complexes are formed, promoting further antibody production.

It is important to emphasise that the role of immunological variables in the onset and course of R.A. is complex and poorly understood. In addition it is a disease which is heterogeneous. Therefore any exploration of the psychoimmunological factors in rheumatoid disease must be speculative.

Rheumatoid arthritis has a prevalence rate of between 1% and 2% of the population in several countries with the peak age of onset in the fifth decade, Currey and Hull (1987). This may be an underestimate, according to the authors, with X-ray surveys showing that a number of people have asymptomatic rheumatoid changes in their joints.

The response of patients to the disease varies, Newman and Revenson (1993). Some patients with severe disease when measured by X-rays or other clinical assessments do not evidence much disability. In contrast some may appear to be severely disabled with seemingly mild disease. These facts are apparent to rheumatologists and this phenomenon is not restricted to rheumatoid arthritis. The poor correlation between measures of disease activity and progression underline the problem in rheumatoid arthritis. Laboratory and clinical measures assess different phenomena and do not necessarily correlate.

Rheumatoid arthritis is a major source of disability, Newman and Revenson (1993). A third of patients progress to persistent disabling disease with about 10% becoming so disabled that they require a wheelchair. Efforts to abate the negative impact of the disease are important.

Psychologists have been involved for many years in research related to the onset and course of arthritis, Anderson et al (1985). Knowledge about psychological processes in the early stages of the disease holds considerable promise for designing intervention to serve the dual goals of preventing maladjustment and enhancing quality of life, Newman and Revenson (1993). They highlight the need to pay more attention to the development of coping strategies in early rheumatoid arthritis, with the maintenance of psychological well-being and the prevention of depression and helplessness.

The possibility that psychological factors play a significant role in the aetiology and course of rheumatoid arthritis has been investigated for many years, McFarlane and Brooks (1990). According to the authors evidence suggests that there is an increase in the number of adverse life events in the period which immediately precedes the onset of the disease. The importance of taking recent life events into account as well as the impact of the disease is also emphasised by Brewerton and Baker (1981). In this controlled study, findings suggested the possibility that emotional stress in the months before onset of the disease may be one of the precipitating factors in the disease process. However further investigation of psychosomatic factors in R.A. was recommended to enable a greater understanding of the complex processes at work in any disease process.

Anderson et al (1985) critically reviewed current research on the psychological aspects of R.A.. They outlined the need for future research to establish more objective criteria for determining stressful events and disease onset as well as the use of adequate control groups. The dearth of randomised controlled studies in this field illustrates this point.

The concept of an arthritic personality is an old one. Possible influences of psychological factors was noted in 1909, Jones (1909). Psychosomatic theorists have listed R.A. amongst the classical diseases. This however is an outmoded notion with most of the work related to studies done in the 1960's with very few randomised controlled trials. Researchers described a variety of personality traits thought to be specific to R.A. patients. Arthritic personality prior to onset of the disease was thought to predispose certain individuals to occurrence. Most studies in the 60's tended not to be randomised controlled trials. Rheumatoid arthritis patients were described as dependent, depressed, conscientious and perfectionistic. Also restricted in emotional expression and unable to express feelings of anger.

Most reviewers agree that methodological weaknesses seem to be a major impediment to advancing knowledge regarding the role of psychosocial variables in the aetiology of R.A., McFarlane and Brooks (1990). This raises the issue as to whether the reporting of stressful life events and the identified personality traits are a response to the development and experience of the illness rather than preceding the onset.

Research relating to precipitating factors in the onset of the disease may be found in the emerging field of psychoneuroimmunology. This field offers an opportunity to investigate the possible psychophysiological mechanisms involved in the onset and course of R.A.. The relevance of this field in understanding the mechanisms between a psychological event and the pathological process has been recognised for a period of time, Solomon (1970).

Possible links with immune function and life stressors have also recently come to the fore with the spread of HIV infection, Kemeny (1994). Research studies in

the area of psychoneuroimmunology support a relationship between exposure to stressful life experiences and the immune system in healthy individuals Kiecolt-Glaser (1988). For example bereavement has been found to be associated with a decrease in the proliferative response to mitogens, Schleifer (1983). Kiecolt-Glaser et al (1993) further supports the link between personal relationships and immune function and cites it as one of the robust findings in psychoneuroimmunology. Relatively little is known, he states, about the underlying biopsychosocial mechanisms. Cacioppo (1994) states that it is now clear that the immune system is influenced by central nervous system processes that are shaped by social psychological factors.

The growing field of psychoneuroimmunology highlights the link between the immune system and psychological well-being. However, in order to investigate the role that psychological factors may play in influencing immune functioning in rheumatoid arthritis, the difficulties of methodological problems need to be addressed. This link may provide answers to the longstanding uncertainties about the role of psychosomatic factors in this disease, McFarlane and Brooks (1990).

R.A. patients form a very heterogeneous population with inter-individual and intra-individual variation. It is therefore not surprising that there is little consistency in the findings across studies investigating the influence of psychological factors. It is suggested that future studies should be prospective, include multiple sampling techniques and comparisons within patient groups in order to obtain accurate information about psychoneuroimmunological factors in R.A.

Studies in the 1980's and 1990's (Edgcumbe (1984); Ciompi (1991);Lachmann (1988), seem to use the relationship between biological and psychological to

view the person as an integrative system where the psyche and the soma work together. Taylor (1993) has proposed a biopsychosocial dysregulation model of illness. Previously psychosomatic theorists have focussed on a Freudian drive conflict model of disease i.e. the psyche conceptualised as the origin of conflicts that might produce prolonged states of arousal with pathogenic effects on the body, Hofer (1984). Researchers are now moving away from this towards a relational model and have devised a new integrative model which conceptualises many illnesses and diseases as disorders of psychobiological regulation Taylor (1985). This dysregulatory model of illness integrates findings from psychoanalytic object relations theory with findings from developmental biology and the biomedical sciences. Essentially Taylor, believes that relationships can act as external regulators of biological as well as psychological processes. Illness and disease may occur within this self-regulating system when there is a withdrawal of these regulatory processes in early life thereby altering an individual's homeostatic organisation and influence susceptibility to medical and psychiatric disorder in later life, Taylor (1992).

Early mother and baby studies show that infant and mother are connected at the level of biological symbiosis as well as by emotional bonds Lachman (1995). Hofer (1984) discusses the evidence that the presence of human social relationships can modify physiologic responses in individuals and have important effects on health outcome. Variations in the doctor-patient relationship can have more intense effects on physiologic responses than the medications given by the doctor. Very many clinicians today do not choose to treat somatically ill patients. This may be due to the poor outcomes generally found with these patients. However, clinicians in the past have failed to take account of the revisions to the psychoanalytic understanding of psychosomatic illness by failing to integrate the concepts with advances in the biomedical sciences,

Taylor (1994). Several psychoanalysts have proposed useful revisions to the psychoanalytic understanding of psychosomatic disease (Nemiah and Sifneos,1970; McDougall, 1974;Krystal, 1993), with a move away from the Freudian based theories.

Earlier models were applied to the classical psychosomatic diseases i.e. bronchial asthma, ulcerative colitis, rheumatoid arthritis. These models were derived largely from instinct theory and Freud's conceptualisation of psychoneurotic symptom formation i.e. the existence of unconscious drive-related conflicts. The dysregulation model is derived from general systems theory and findings from developmental biology and the biomedical sciences (Hofer,1984,Pert et al,1985). The model has been expanded by Taylor (1992) to incorporate findings from infant-observational studies in particular those associated with affects, object relations and the development of the self.

The new model, views each person as being comprised of a hierarchy of sub-systems that interface via the brain with the larger social system. The psyche is seen as part of this system within the hierarchical arrangement of reciprocally regulating subsystems. Disturbances can occur at any level in the system, cellular or sub cellular and to the psychological and social level. These disturbances may in turn lead to the expression of somatic symptoms. This model provides an interesting parallel with the advances made in the field of psychoneuroimmunology which recognises the link between the emotions and the neuroendocrine system. The dysregulation model emphasises a psychoanalytic approach aimed at overcoming psychological deficits, involving affect regulation and the maintenance of a stable self. However Lachmann (1996) would argue that it is these deficits which have actually prevented disintegration and have thus served some purpose for the individual during development. These deficits are linked to early developmental deficiencies

which are reflected in the patient's inner self and object representations and therefore in the quality of their personal relationships. According to the model, psychoanalytic / psychodynamic interventions may favourably influence health by enhancing the regulatory capacities of the patient's psyche and modifying the reciprocal feedback which it has with other subsystems.

Taylor (1995), Taerk and Gnam (1994), discuss the effects of intensive psychoanalytic psychotherapy on Chronic Fatigue Syndrome (CFS), in two patients. The authors have developed a working model for CFS based on the dysregulatory model of disease. They propose that both a psychological and physiological vulnerability exists in CFS patients as a result of problems in early object relations. It is also proposed that this vulnerability results from a poorly developed capacity for regulating internal states in response to certain stressors, namely, disturbances in object relations. Through a psychotherapeutic technique informed by the psychology of the self and object relations theory, this vulnerability diminishes through an internalization of the tension-regulating components of the therapeutic relationship, thereby affecting the course of the illness.

Very few studies have measured the effect of psychodynamic interventions quantitatively to confirm the validity of these hypotheses although the reduction in symptoms of those patients with CFS (Taerk & Gnam 1994), would constitute a quantitative outcome measure. Most studies carried out have been single case studies over lengthy periods. Some studies have involved the use of other interventions such as creative writing and relaxation to assess the impact on the immune system. Few studies have endeavoured to adequately measure the impact of the therapeutic relationship between therapist and client on the physiological system. Fonagy (1991) suggests that the way forward for this type

of research is to select a readily definable group who tend to respond poorly to less intensive treatments provided there are clinically relevant outcome variables which are robust to contamination from the treatment process. This, he says, will help to bridge the gap between the wider scientific community and the psychoanalytic group. The issue of empirical measurement in this field is important in the present climate of clinical efficacy.

Poulsen (1991) in a randomised controlled trial investigating the effect of psychodynamic group therapy in rheumatic disease found there to be a positive effect in R.A. patients and that this effect was lasting but slightly decreasing over time. A decrease in alexithymic features was found in the intervention group. Group therapy promotes and facilitates the ability to put thoughts and feelings into words and share experiences. This leads to a decrease in alexithymic features. The concept of alexithymia refers to a cognitive-affective style that affects the way individuals experience and express their emotions, Bagby (1988). Therefore alexithymia implies a deficiency in the capacity for getting in contact with or expressing one's emotions, a deficiency said to exist in patients with rheumatoid arthritis. Alexithymia is a controversial concept. Its essential features include difficulties in describing and/or differentiating emotions, a tendency to somatise distress, externally oriented thinking and an impoverished fantasy life. Erskine (1994), McDougall (1989), stresses its origin in pre-oedipal developmental difficulties, in particular the failure to internalise a benign, care-taking maternal object. An inner sense of deadness is typical. Patients may present with superficially adjusted behaviour patterns together with somatic symptoms and concealed disturbance. Research shows (Taylor, Parker and Bagby, 1990) that alexithymia is not confined to 'psychosomatic' patients and is common to all patient and non-patient groups. It is not an all or nothing concept but can fluctuate in severity and consistency.

Poulsen (1991) states that most programs of patient education focus on imparting information to encourage insight into the disease. However the widespread difficulties among R.A. patients suggest that many patients are experiencing recurrent psychological crises. These crises require appropriate help providing there is a certain "psychological-mindedness" on the part of the individual. Poulsen based her research on the outcome of previous work regarding the effectiveness of multidisciplinary group advice. The outcome was positive with regard to increased knowledge but superficially dealt with the psychic difficulties. The effect of group psychotherapy was therefore investigated and found to be beneficial in terms of reduced alexithymic features.

This study used qualitative measurements i.e. The Toronto Alexithymia Scale (TAS) and Yalom's Curative Factors Q-Sort. The findings of this study confirm the view of psychoanalytically-oriented analysts that group therapy has a number of advantages compared to individual therapy regarding physically ill patients (ref). The chronic physically ill patient tends to somatise their intrapsychic conflicts (Taylor) therefore the group allows for an exchange of common experiences which engenders a sense of "group cohesiveness" which fosters social integration and relieves isolation, Foulkes (1975). Hofer (1984) highlights the importance of social relationships in modulating physiologic responses and consequently having important effects on health outcome. This again links with McFarlane's (1990) view that psychological responses can lead to changes in immune function through a variety of mechanisms.

A fundamental problem with much of the research evidence available showing benefits in counselling, is the poor methodology; no control group; intervention and assessment conducted by the same researcher; inappropriate statistics or a sample too small for formal statistics, Fallowfield (1993). This paper lists a number of scientific evaluation studies done in a variety of NHS settings showing positive outcomes.

Fallowfield (1993) states that it is vitally important that more good methodologically sound studies are funded to examine the putative benefits of counselling. In a randomised study investigating psychological support for patients undergoing breast cancer surgery it was found that support from the breast care nurse compared with other types of support, including counselling, significantly reduced psychological morbidity as measured by self-rating scales. McArdle et al (1996). The patients in this case primarily sought information about the disease and not for psychic difficulties. This emphasises the need to distinguish between information giving and counselling.

There is evidence that counselling is still misunderstood by many professionals working within the health service Fallowfield (1993). Gruen (1975), in a randomised controlled trial, looked at the effects of brief psychotherapy during the hospitalisation period on the recovery process in heart attacks. Quantitative and qualitative measures were used to show the benefits of the intervention. There was a decrease in the development of supraventricular arrhythmias and congestive heart failure alongside a decrease in the number of days in intensive care. A controlled trial of psychological treatment for irritable bowel syndrome, Guthrie et al (1991), demonstrated that psychological treatment is feasible and effective in the majority of those patients treated in the study who did not respond to standard medical treatment. Quantitative measures were also used in this study i.e. decrease in bowel symptoms, Waydenfield (1980).

The association between personal relationships and immune function is one of the most robust psychoneuroimmunology findings, Kiecolt-Glaser (1992). For example lonelier medical students were found to have poorer immune function than their less lonely contemporaries Kiecolt-Glaser (1984). Marital disruption has been associated with poorer immune function. There is solid evidence that

the use of mental health services is associated with lower utilisation of medical services Jones and Vischi (1980). It would seem that the personal relationship involved in these interactions is of paramount importance in the modulation of the immune system. It is certainly possible that interventions such as counselling or psychotherapy which primarily focus on the quality of the relationship can have some effect on the physiological systems of the individual.

De Vellis and Blalock (1993) suggest that psychotherapeutic interventions are used less frequently to treat arthritis than cognitive-behavioural treatments and have been subjected to less systematic scrutiny. Various psychotherapeutic techniques are presumed to be of value in treating certain sequelae of arthritis because they seem effective in treating similar problems when they arise from causes other than arthritis. Many patients who experience life adjustment difficulties marital strains or depression as a result of arthritis may seek help from psychotherapists. The authors suggest that given the small number of published studies concerning efficacy of psychotherapeutic procedures these methods should not be the first to be chosen to relieve distress stemming from arthritis. In contrast Erskine (1995) expresses concern that those suffering from illness or body-image disturbance should be able to access counselling or psychotherapy alongside good medical care. This should be tailored to patient's needs i.e. some may need brief supportive counselling to enhance coping strategies or others cognitive behavioural interventions. Psychoanalytical counselling or psychotherapy may be appropriate when the individual is prepared to look at their inner world and past life.

In addition, Scott et al (1987), states that despite all the efforts with powerful immuno-suppressive agents, patient outcome in severe rheumatoid arthritis is still relatively poor with over 40 percent of patients being significantly disabled

after twenty years of disease. Adjunctive therapies such as psychological interventions may assist this situation and lead to a better outcome for patients with rheumatoid arthritis McFarlane and Brooks (1990).

Measurement.

It is important to measure quality of life as well as physical functioning levels in rheumatological conditions. The experience of loss of independence, being a burden on others, the difficulties involved in asking for help and consequently, the importance of being able to maintain independence and normal social roles. The closest to any consensus of definition of quality of life is that it is an umbrella concept encompassing health states as well as satisfaction with a broader range of domains such as environment, economic resources, relationships, work and leisure time, Burckhardt et al (1989).

The W.H.O. (1980) made a distinction between physical status (impairment), physical functioning (disability) and social functioning (handicap) but most activities of daily living and health status measures, incorporate aspects of all three dimensions and not all of them clearly distinguish between them. It needs to be clarified whether the aim is to measure impairment, disability and/or handicap. It should also be ensured that instruments measuring functional ability also include items on the effects of the condition on social roles and activities. The cyclical nature of rheumatoid arthritis needs to be taken into account when administering measurement scales (Isaccson et al. 1987). The inclusion of meaningful activity ought not to be forgotten when measuring well-being.

Assessment of functioning in everyday social roles is important in measuring the outcome of joint disorders. Several of the generic health-related quality of life scales (health status scales) have been used to assess outcome in

rheumatology. Some of these include The Nottingham Health Profile, McMaster Health Index Questionnaire and The Index of Well-Being.

Researchers have found the Health Assessment Questionnaire to be sensitive to outcome. This is an important finding in view of its simplicity and brevity.

An important dimension in addition to physical functioning is psychological well-being. Depression is regarded as a consequence of the disability suffered by patients with rheumatoid arthritis, (Creed and Ash 1992) although the measurement of mood after years of experiencing disabling chronic illness is complex and causality is difficult to assess. Commonly used scales of anxiety and /or depression in rheumatology include the Beck Depression Inventory (Beck et al. 1961) and the Hospital Anxiety and Depression Scale (Zigmond and Snaith 1983). The Hospital Anxiety Depression Scale was designed by Zigmond and Snaith (1983) specifically to exclude somatic items. Depression scores have been positively associated with pain, duration of morning stiffness and functional ability. Murphy et al (1988) also reported that grip strength and HAQ score were significantly associated with depression. The Beck Depression Inventory (BDI), Beck et al. (1961) has been found to correlate with increased depression at times of acute flare-ups leading to hospital admission. Creed and Ash (1992) have recommended the use of the HAD in diagnostic assessments of RA patients.

It is suggested that personality assessments should be avoided in outcome assessment although personality can influence response to illness. The authors state that if personality is to be assessed the instrument of choice is Eysenck's Personality Questionnaire (Eysenck and Eysenck 1985).

Scales of physical functioning have been superseded by newer disease-

specific functional ability scales including the Functional Status Index (Jette 1980), the Arthritis Impact Measurement Scales (AIMS) Meenan et al (1982) and the Health Assessment Questionnaire (HAQ), Fries et al (1980). The older scales tend to be limited and insensitive in relation to the greater degrees of information needed about functional disability.

The HAQ is an arthritis-specific scale that measures difficulties in performing activities of daily living (ADL), the need for equipment and physical assistance to perform tasks. The framework used for the development of the HAQ was based on the belief that a patient desires to be alive, free of pain, functioning normally, experiencing minimal treatment toxicity, and financially solvent. HAQ used in this study does not include the last two sections. Functional ability is measured by nine components: dressing and grooming, rising, eating, walking, hygiene, reach, grip, outside activity and sexual activity. The HAQ is self-administered and takes 5-10 min to complete. The HAQ is a good measure of function and has been tested for reliability and validity. It is concise, sensitive to change, can be self- or interviewer administered and is suitable to change.

The revised AIMS2 is a 78-item questionnaire. The first 57 items form 12 scales: mobility level, walking and bending, hand and finger function, arm function, self care tasks, household tasks, social activity, social support, pain from arthritis, work, level of tension, and mood. The remaining items relate to satisfaction, with health status in each of these areas in which the respondent would most like to see improvement. Most questions refer to problems experienced within the last month. The AIMS-2 is self-administered and takes approximately 20 min to complete. No major problems with AIMS has emerged with comprehension or administration. AIMS has good measurement properties, has been tested for validity and the sections explain the majority of illness impact estimated by patients.

An evaluation of disease activity by single variables leads to methodologic problems, Prevo et al (1995) . Several indices consisting of more than one variable have been developed. One of these indices is the Disease Activity Score (DAS) which has been developed and validated in patients with recent onset RA. The DAS includes 2 comprehensive joint counts, i.e. the Ritchie Articular Index (RAI) and the total number of swollen joints plus the erythrocyte sedimentation rate (ESR), and a general health assessment scored on a visual analog scale (VAS).

Research Design

The study was designed to evaluate the impact of psychodynamic counselling on disease activity in early rheumatoid arthritis. The subjects were randomly allocated to a control (education) group or a counselling group. Both groups were tested and re-tested at week 0, week 5, and week 10.

Sample Selection

Twenty-two female patients aged 47.8 yrs, mean, participated in the study. The criteria for inclusion were that each patient had disease duration of less than three years and was female. This last criterion was motivated by the need to control variables and keep the group as homogenous as possible with respect to gender. The diagnostic criteria of The American College of Rheumatology was used. The criteria for diagnosis involved clinical signs of disease activity in the joints, together with the evidence from X-rays and the presence of rheumatoid factor from serum. However clinicians are not confined to these criteria. For example there may not be the presence of rheumatoid factor.

Those patients with pre-existing co-morbid conditions such as chronic lung disease, cardiac disease, renal disease, diabetes were excluded. These exclusions were necessitated since the focus of the counselling was not on the depression/anxiety precipitated by the presence of a chronic illness. The project was designed to look at patients in the early stages of the disease prior to the onset of psychopathology such as depression or anxiety. All such patients were asked to take part in a study to examine the benefits of giving support early on in the disease process and that the two approaches were being compared i.e. counselling and early education. The study was explained by the counsellor or

medical staff clinic personnel. The study was approved by the hospital ethics committee. Thereafter the patient was consented (Appendix1) and randomised into the project.

Patients were referred from a variety of sources. Out-patient rheumatology clinic; Physiotherapy dept; Rheumatology ward at Glasgow Royal Infirmary, other hospitals and G.P. surgeries. Patients were randomly allocated into either a counselling group (group 1; n=13) or an education group (group 2; n=9). Every patient was assessed during a ten week period at Week 0, 5, and 10.

Through randomisation the population was divided into an experimental group and a control group (education group).

The demographic characteristics of the study population are shown.

Characteristics of study population

Number of patients 22

Age, years mean 47.8 years

Age span, years 23-76 yrs

Quantative and qualitative data were collected. The number of patients taking part in the study did not meet the expectation of the original proposal i.e. forty patients. Approximately seventy patients were identified as being suitable but only twenty-two were allocated to the study. Recruitment proved to be extremely problematic .This had not been envisaged.(See discussion) In total twenty G.P. practices were contacted, with only one reply. Five other hospitals were also approached with one patient available for allocation. All other patients were recruited from the Centre for Rheumatic Diseases, Glasgow Royal Infirmary.

Individual psychodynamic counselling on a weekly basis of up to ten weeks, each session lasting fifty minutes.

The control group received five early education talks on the subject of rheumatoid arthritis from various health professionals, each session lasting ninety minutes. These sessions included talks from the following professionals; podiatrist, physiotherapist, occupational therapist, ward sister, social worker, rheumatologist, dietitian, pharmacist, and a representative from 'Young Arthritis Care'. Talks were delivered in the Physiotherapy Department. The general atmosphere was informal. Patients were encouraged to ask questions. Those attending tended to discuss issues informally with each other.

The talks took place at the same time each week and in the same place.

The education group was organised by a nurse practitioner and was not exclusively for the project i.e. there were other group members not belonging to the study and with disease duration of greater than three years, although in general the group consisted of patients diagnosed within five years.

Assessment of disease activity

Every patient was assessed during the ten week period at Week 0, 5, 10.

Measurements were carried out by the metrologist from the Rheumatology Clinic who was not aware of which group each patient belonged to. The metrologist was experienced in carrying out the measurements. These consisted of those measurements outlined in the Euler Core Data Set. They are Measurement of pain on a visual analogue scale; number of swollen joints;

number of tender joints; patient's global assessment of disease activity; assessor's assessment of disease activity and acute phase response measure (ESR or C-reactive protein). These measurements are also recommended by the American College of Rheumatology as a core set of measures for use in clinical trials.

Disease activity was measured using the modified disease activity score (DAS) based on The Eular Core Data Set as validated by The Eular Standing Committee for International Clinical Studies including Therapeutic Trials.

Recent studies have indicated that joint counts consisting of 28 joints are as valid and reliable as more comprehensive joint counts. Prevoo et al (1995). Therefore the Modified DAS has been developed that includes different 28-joint counts, measuring tenderness, swelling or both.

The Disease Activity Score is a combined index used to assess disease activity in Rheumatoid Arthritis. A change of 1.08 is assumed to signify a significant improvement or deterioration. See Appendix 2 for nomogram.

Assessment of Disease/Health status

Assessment of disease-specific disability was measured using the Arthritis Impact Score 2 (AIMS2) Appendix 3 and the Health Assessment Questionnaire (HAQ). Appendix 4 . A simple questionnaire designed for use in osteoarthritis and Rheumatoid Arthritis. It provides an overall Disability Index from 0 (no disability)-3.0 (complete dependence on others). The AIMS 2 instrument is designed to measure the health status component of outcome in a multidimensional fashion using specific scales. A low value indicates a high health status.

Psychological morbidity was measured with the Hospital Anxiety Depression Score (HAD). Appendix 5. This measure was designed specifically for hospital patients and scores range from 0 to 21 for both anxiety and depression. The Hospital Anxiety and Depression Scale, a self-assessment scale, has been developed and found to be a reliable instrument for detecting states of depression and anxiety in the setting of an hospital medical outpatient clinic. The anxiety and depressive subscales are also valid measures of severity of the emotional disorder; Zigmond and Snaith (1983). The assessment consists of two sub-scales, one relating to depression and the other to anxiety. Each sub-scale contains eight items. For the depression subscale a score of 7 or less was found for non-cases, scores of 8-10 for doubtful cases and scores of 11 or more for definite cases. The same score ranges for the anxiety subscale. Assessment of the overall severity of anxiety and depression are rated on a five-point (0-4) scale.

The American College of Rheumatology has recommended the following core set of disease activity and functional ability measures for clinical trials in rheumatoid arthritis: tender joint count and swollen count; patient's assessment of current pain (using a 10cm VAS) ; patient's assessment of his or her overall progress e.g. the Arthritis Impact Measurement Scale (Meenan and Mason 1990), the Stanford Health Assessment Questionnaire (Fries et al, 1982) and laboratory evaluation of acute-phase reactant (Westergren erythrocyte sedimentation rate or C-reactive protein level) (Felson et al. 1993). These measures were selected on the basis of literature reviews, as providing the best coverage of the broad range of improvement in R.A. and are moderately sensitive to change.

All patients were receiving standard medical treatment.

Active treatment involved up to ten fifty minute counselling sessions on an individual basis using the psychodynamic model. The sessions took place in the Physiotherapy Department of the hospital. All patients were aware of the fact that the counsellor was also a physiotherapist. The purpose of the study was explained at the initial session and this session was treated as an assessment. During the session suitability for counselling was assessed . A brief family history was taken and information about onset of the disease was obtained. After the initial session patients were invited to talk about anything that they felt to be important . If patients required information about the disease itself then access to this information was made available via another source. Thereafter the emotional issues surrounding these concerns would sometimes become the focus of the sessions. In general patients were given the opportunity to discuss any psychic and / or emotional difficulties which were concerning them.

Education / Control Group

Patients in the control group were seen for assessment . The metrologist did not engage in any discussion with any of the patients about emotional problems. The patients attended the education group which also took place in the Physiotherapy Department. The talks consisted of discussions on the subject of rheumatoid arthritis given by the physiotherapist, occupational therapist, dietitian, pharmacist, podiatrist, rheumatologist, social worker, nurse practitioner and a member of Arthritis Care. The approach was didactic but patients did have an opportunity to ask questions.

Twenty-two patients were allocated to the study but it was not possible to complete measurements on this number since some began the study but never completed or attended for final measuring. Hence the small sample size.

Patients did not tend to return questionnaires to the department. The number of different questionnaires given to be completed, i.e. three, may have deterred patients attending from completing them. The average time for completion was approximately forty minutes.

The attendance in the education group was particularly poor with only two patients attending for all five talks. This was perhaps due to the length of each session. In comparison there was greater compliance of the counselled patients perhaps due to the individual attention given. Eight out of thirteen patients in the counselled group attended more than five counselling sessions in contrast to only four out of nine patients attending three or more education talks.

Data Analysis and Results

Quantitative and qualitative data were collected.

Figures 1 and 2 show the boxplots for the modified disease activity scores for both groups, over the ten week period. There is suggestion of a trend towards improvement for the scores in the counselled group.

Figures 3 and 4 show the modified disease activity score for both groups over the ten week period. There is a greater trend towards improvement in the counselled group. However, the poor attendance of those taking part in the education group made it difficult to collate any complete data. In comparison the counselling data is more complete. The data on the modified disease activity score were summarised using the two sample t-test. There was no statistical significance between the groups at baseline. The data were analysed at the three assessment points. P values are reported.

The confidence interval in Table 1 shows a greater trend towards improvement in the counselled group for the modified disease activity score between Week 0 and Week 10.

Repeated Measures boxplot
for Counselling Patients

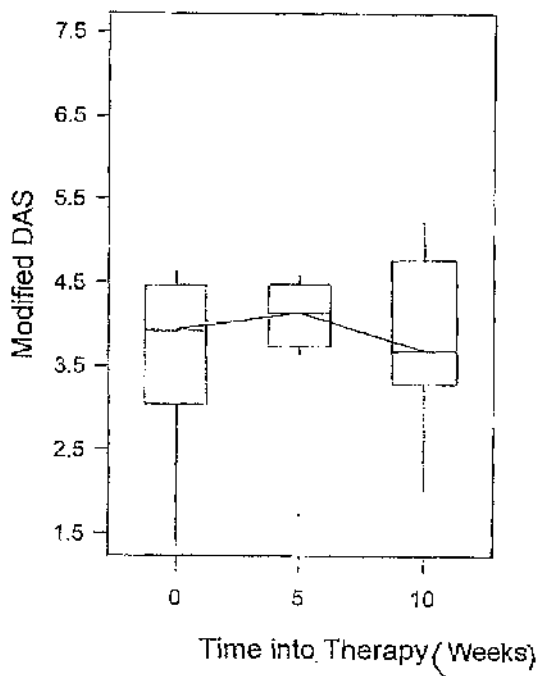


Figure 1

Repeated Measures boxplot
for Controls

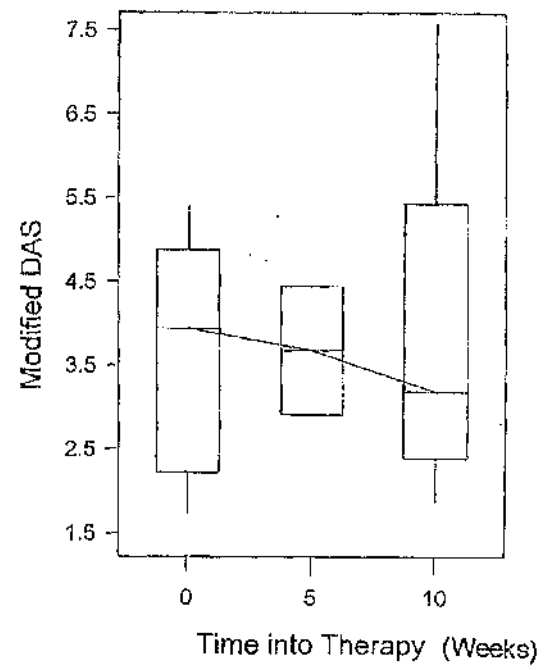


Figure 2

Figure 1 and Figure 2 show the interquartile ranges for changes in the modified disease activity score in both groups over the ten week period.

Repeated Measures plot
for Counsellled Patients

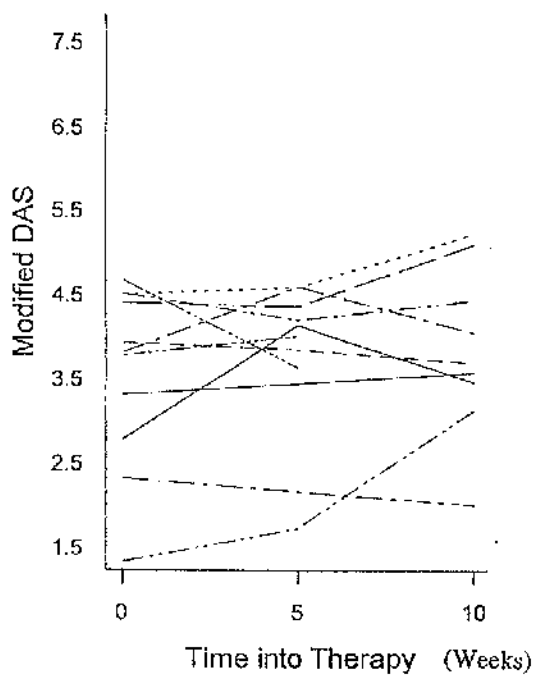


Figure3

Repeated Measures plot
for Controls

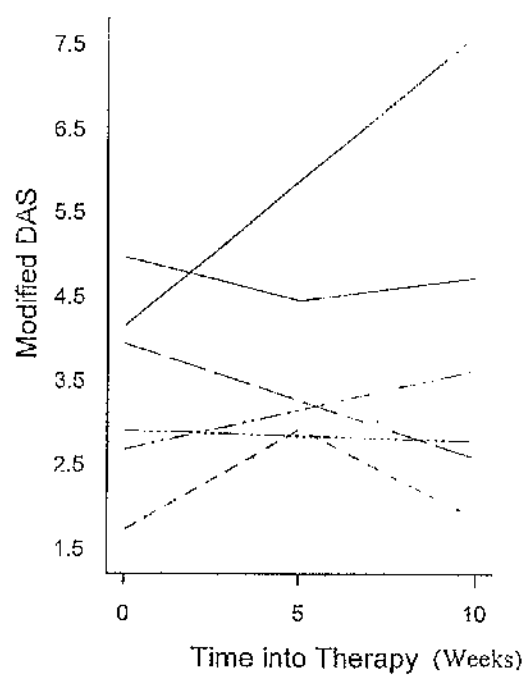


Figure4

Figure 3 and Figure 4 show repeated measures for individual patients over the ten week period.

Table 1 Mean Change (SD) in Modified Disease Activity Score (DAS) between Week 0 and Week 10.

Group	Mean Change	SD	P Value	95% C.I.
1 (n=9)	0.42	0.66	0.94	(-1.78,1.67)
2 (n=6)	0.47	1.64		

n = patients who attended for assessment at Week 0, Week 5 and Week 10.

Table 2 Mean change (SD) in number of swollen joints (SJ), Tender Joints (TJ), between Week 0 and Week 10.

Group	Mean Change	SD	P Value	95% C.I.
SJ 1 (n=10)	3.2	2.44	0.20	(-2.0,7.70)
2 (n=6)	0.3	4.46		
TJ 1 (n=10)	0.50	2.42	0.84	(-7.20,8.53)
2 (n=6)	-0.17	7.25		

Table 3 Mean Change (SD) in Erythrocyte Sedimentation Rate (ESR), and C-Reactive Protein (CRP) between Week 0 and Week 10.

Group	Mean Change	SD	P Value	95% C.I.
ESR 1 (n=9)	2.4	14.1	0.28	(-110,39.9)
2 (n=6)	37.7	70.6		
CRP 1 (n=10)	-1.50	19.58	0.86	(-15.5,13.2)
2 (n=6)	2.67	4.4		

Table 4 Mean Change (SD) in Early Morning Stiffness (EMS), and Pain (Visual Analogue Scale) between Week 0 and Week 10.

Group	Mean Change	SD	P Value	95% C.I.
EMS(mins)1(n=9)	56.7	115.7	0.35	(-54,141.1)
2 (n=6)	13.5	53.5		
Pain(cms)1(n=10)	1.42	3.11	0.57	(-2.90,4.91)
2 (n=6)	0.40	3.46		

Tables 1-4 show the results of the change over the ten week period for different variables. The data were summarised using the two sample t-test. There tended to be a trend towards improvement in the counselled group for the following variables:- early morning stiffness, swollen joints, tender joints and pain as reported on a visual analogue scale. See Table 2 and Table 4.

N.B. ESR mean change in Table 3 for control group is 37.0, due to one patient coming off all drugs during the project.

The two sample t-tests all proved non-significant mainly due to small sample sizes having insufficient power to detect moderate improvements. Non-parametric tests would effectively have shown similar overall conclusions. The five week changes are not reported for similar reasons. The changes between Week 0 and Week 10 are representative of the overall change.

Quality of life assessment

Table 5 Mean Change (SD) in Hospital Anxiety Depression Score, between Week 0 and Week 10.

Group	Mean Change	SD	P Value	95% C.I.
Anxiety 1(n=9)	0.11	4.31	0.71	(-17.0,13.9)
2 (n=3)	1.67	5.69		
Depression1(n=9)	1.11	2.37	0.75	(-28.2,26.43)
2 (n=2)	2.00	2.83		

Table 6 Mean Change (SD) in AIMS 2 for Social and Physical components between Week 0 and Week 10.

Group	Mean Change	SD	P Value	95% C.I.
Social 1 (n=7)	0.31	1.05	0.64	(-14.3,12.98)
2 (n=2)	1.00	1.41		
Physical 1 (n=7)	-0.80	2.10	0.71	(-3.93,3.03)
2 (n=2)	-0.35	1.06		

Table 7 Mean Change (SD) in Health Assessment Questionnaire (HAQ) between Week 0 and Week 10.

Group	Mean Change	SD	P Value	95% C.I.
HAQ 1(n=4)	-3.00	2.58	0.41	(-79.3,64.3)
2 (n=2)	4.50	7.78		

There was no statistically significant difference for any of the changes in the quality of life assessments between the groups. This is mainly due to the incomplete data.

Table 8 Mean change (SD) in C-reactive protein (CRP) and Pain (Visual analogue scale) between week 0 and week 5.

Group	Mean Change	SD	P Value	95% C.I.
CRP 1 (n=8)	12.3	26.2	0.67	(-24.6,35.1)
2 (n=2)	7.00	9.90		
PAIN 1 (n=8)	-1.96	2.32	0.06	(-3.94,0.12)
2 (n=2)	-0.05	0.35		

Table 9 Mean change (SD) in Swollen Joints (SJ) and Erythrocyte Sedimentation Rate (ESR) between week 0 and week 5.

Group	Mean Change	SD	P Value	95% C.I.
SJ 1 (n=8)	-0.87	3.56	0.34	(-4.58,1.8)
2 (n=2)	0.57	0.71		
ESR 1 (n=7)	3.40	18.0	0.86	(-17.6,20.8)
2 (n=2)	2.00	5.66		

Table 10 Mean change (SD) in swollen joints (SJ) and erythrocyte sedimentation rate (ESR) between week 5 and week 10.

Group	Mean Change	SD	P Value	95% C.I.
SJ 1 (n=9)	1.22	3.83	0.66	(-27.65,18.6)
2 (n=2)	2.50	4.95		
ESR 1 (n=9)	-8.00	13.8	0.94	(-127.5,129.5)
2 (n=2)	-9.00	12.7		

Table 11 Mean change (SD) in C-reactive protein (CRP) and pain (Visual analogue scale) between week 5 and week 10.

Group	Mean Change	SD	P Value	95% C.I.
CRP 1 (n=8)	-5.00	27.6	0.66	(-27.65,18.6)
2 (n=2)	-0.50	0.71		
PAIN 1 (n=8)	-0.87	1.89	0.86	(-21.2,20.48)
2 (n=2)	-0.50	2.12		

Tables 8-9 show the mean changes between week 0 and week 5 for ESR Pain,

Swollen joints and C-reactive protein. There is a greater trend towards improvement in the counselled group for ESR and CRP.

Tables 10 and Table 11. There is a greater trend towards improvement in the counselled group for ESR only. However only certain variables could be shown due to the incomplete nature of the data. Hence the small sample size.

Psychodynamic Counselling

The intervention involved weekly individual counselling sessions on a psychodynamic model. Each session lasted fifty minutes in accordance with the "therapeutic hour". Patients were offered up to ten sessions. Some only came for one session whilst others completed all ten.

The first session involved an assessment of the patient. Usually when patient's opt to come for counselling the question which is uppermost in the counsellor's mind is; what has brought the person here at this point in time? This question becomes somewhat distorted when the person has been invited to take part in a randomised controlled trial. During the first session it was explained that the counselling would provide the opportunity to discuss feelings or issues arising from having had a diagnosis, such as rheumatoid arthritis.

This research is not concerned with discussing various counselling approaches but it is worthwhile outlining the basic premises behind the psychodynamic approach.

The word psychodynamic links psychotherapy and counselling with psychoanalysis. Psychodynamic refers to the way in which the psyche is seen as active and not static. The "healthy" personality is a dynamic system, changing continuously as the individual relates to himself, to others, and to the

events in his life. He has a variety of mechanisms to help maintain a degree of equilibrium in order to cope with evolving circumstances. When the equilibrium cannot be maintained because the mechanisms are not effective the disturbance becomes noticeable and consequently a problem.

The term psychodynamic is linked primarily with the Object Relations School embodied in the work of Klein, Winnicott and Guntrip. There is a shift in emphasis away from the Freudian drive-conflict model towards the importance of personal relationships. The following statements outline the basic premises of psychodynamic theory.

'Each individual is the product and author of his own particular history: how he is now is a direct consequence of his earlier experience with others and his environment. Subsequent experience confirms or modifies that early experience, for better or worse. He is not, however passive in his history, but contributes to its shape.'

'He lives simultaneously in his external and internal worlds: the former he is mostly aware of, but the latter is primarily unconscious.'

'All behaviour, no matter how apparently irrational and senseless, is logical and purposeful according to some personal system.' Noonan (1983).

The counsellor tries to be aware of these processes within the client and within him/herself. During the sessions the counsellor endeavours to work with the material the client brings, in an attempt to make some understanding of the process. The counsellor can be seen to be a witness to all that is said and done in the therapeutic encounter. This in itself is therapeutic, especially for clients who are accustomed to having themselves or their words ignored or rendered meaningless. It is the relationship which is critical. People seek and find for

themselves, their significance in a relationship with another. The counsellor is able to maintain a safe psychological 'container' for the wealth of difficult thoughts and emotions that are brought to the session and in turn this can promote the creation of a safe therapeutic environment.

'The environment facilitating growth and personal discovery is created and preserved by the counsellor's ability to keep the external, everyday world at bay but not denied; to maintain a helpful distance between herself and the client; and to keep the internal and external worlds in perspective.' Noonan (1983).

The following case histories outline the similar and different issues which arose in the counselling sessions for different individuals. These help to illustrate the process. Seven different cases are discussed.

Case Histories

Case A

47yr old woman. Diagnosed within the past three years although remembers having some symptoms twelve years previously. Married with two sons 27yrs and 24yrs. Eldest son still living at home. Husband unemployed. Youngest of nine children. "Father's only child". Mother re-married. Mother died aged 10. Father aged 22.

A. looked after father, following mother's death. Problematic relationship with mother. Good relationship with father. A. felt a special relationship with him, since she was his only child. Only discovered this fact when she had to make her first Holy Communion and parents were not married.

Main concern at initial sessions was of what was going to happen in the future.

Would the disease become so bad that she would be in a wheel chair and become completely dependent on others? She was looking for some guarantee that this would not happen .

A. felt good that she was helping me by taking part in a project. It was difficult for her to hold on to the fact that this was a support for her. She had a family history of helping others in the family, like a 'family connector' (patient's word). Symptoms had the effect of beginning to make functional tasks difficult for her.

A. expressed concern about coming for counselling as if "taking the lid off things", would result in not being able to cope. Others had told her that counselling would make her become depressed.

There was an increase in somatisation as the sessions progressed, coinciding with an anger that was expressed concerning the nature of the disease.

It emerged that A. had been a very active and independent person prior to the onset of the disease and very much resented the fact that she now had to ask for help. She also resented the fact that others could not recognise how much pain she was in and that she had to verbalise her distress. This was an on-going process throughout the sessions, moving from somatising to verbalising.

Initially there was very little mention of her husband. She expressed irritation towards her husband because he was always at home and not working. She gradually admitted how dependent she was on her husband and the difficulty she had in asking him for help. The sessions ended with the realisation of her need for others but also her ability to be independent and develop things for herself. She started to consider activities that she could again take up for herself.

Case B.

A 29yr old woman. Diagnosed 18 months previously. Married. Husband employed. No children. Youngest of two. Older brother (5 years difference). Mother living. Father died of alcoholism aged 36, physically abusive . Sense of B. looking after mother and brother at an early age. Mother re-married. B had a good relationship with step-father.

B looks after brother's son. Feels as if he's her child and that she has looked after him since he was born. Biological mother not present. Nephew now five. B lives near her own mother .

History of endometriosis. Infertility problem developed at the same time her nephew was born. R.A. symptoms developed when her nephew started school. She has now given up work due to endometriosis and was previously very independent and active. Husband was not mentioned initially and then she gradually talked about a lack of help from him and feelings of having to look after him. There was a difficulty in asking for her needs to be met.

Sessions were interspersed with somatisation and increase in symptoms. There were some cancelled sessions.

During the ending of sessions B. felt a benefit from looking at how to continue to express what she wanted in a healthy way. .

Case C.

A 50yr old woman. Married, two children, with a son 20 yrs. Daughter 14 yrs. Both living at home. Discovered that nephew, aged 9, also lives with C.

She was the youngest of five and lived at home until her parents died, when

she was 30 yrs . Her son leaving home became the main focus of sessions. He had started to have a relationship and B. was not willing to tolerate him staying with the girlfriend and coming back to "use" home when he felt like it. She asked her son to leave.

This created a great deal of anxiety on her part. She wanted time for herself and wanted not to be used by the family but at the same time she did not want to lose her son.

She had previously been very dynamic, spontaneous and lively but now felt embarrassed and frustrated that she was unable to do the basic activities of daily life. She had difficulty verbalising her need for help. She began to talk about a sense of loss at not being able to do the things she used to although now finding other ways to do them.

There was a break in sessions due to her holiday. Somatising occurred after the break.

During the final session her awareness was raised of the benefit of the sessions and she reported that she had arranged to go to a self-help group. She made the effort to come to the last session. There was an emotional ending with a sense of connection acknowledged between the counsellor and the patient.

Case D

50 yr old woman. Separated 18 yrs. Has a partner. Two sons 29yrs and 27yrs. Youngest lives at home. 2nd youngest of eight.

R.A. for two years. Works seven days / week as a domestic. Very active until the onset of symptoms. She had a problematic relationship with her mother. She

had to look after her mother at an early age. She always had a relative or a baby at home to look after.

D. wanted to continue working but she was finding it difficult. She was also finding it difficult to give up work. She feared that this would be the 'slippery slope' to complete dependency. It was difficult to balance the need for independence and dependence. She expressed this difficulty by asking others for help .

During the course of the sessions D. was able to take time off work but only because the symptoms became difficult to manage. There was a sense of using the counsellor to try to balance these two parts. A sense of holding these two parts for her.

The main focus of sessions was trying to let go of some of the domestic work in order to gain a greater sense of balance. Somatising increasing during sessions as D. struggled with the difficulty of having own needs met. She realised her dependency on her partner and the difficulty of asking for help.

The sessions ended with D. being able to develop a sufficient sense of self in order to re-negotiate her working life.

In the following cases, each person had suffered a bereavement which coincided with the onset of symptoms .

Case E.

50 yr old woman. Married. Three girls 27yrs, 23yrs ,17yrs.

Middle daughter and child living at home. R.A. for one year. Developed symptoms one month after mother died. Older brother. Seven years older.

Brother also diagnosed with R.A. at same time. Busy independent woman prior to onset of symptoms.

E. made a connection between the onset of symptoms and the death of her mother. She felt that she had not been able to express her grief. This was all related in the first session.

2nd Session. E. was reluctant to move back into that space and felt that she did not want to continue with the sessions. She felt that there was no point in crying about her mother's death since she would just be crying for herself. It was as if she was not allowed to express emotions for herself.

There was a strong sense from her that to remain in this space would be too difficult. There was no other way than to express her feelings through the body.

Case F

61 yr old woman. Widowed 20 years previous. Two daughters 39yrs and 35yrs. Diagnosed with R.A. two years previous. Developed symptoms at the same time her mother developed signs of dementia. Mother had died one year previously. F. had a close relationship with her mother. She has an older brother.

F. was a very independent woman prior to the onset of symptoms and expressed a difficulty in asking for help. She felt as if she 'had to drag this other woman around with her.' (patient's words).

There was not much mention of her husband. She had to bring the children up independently. F. had a difficulty in expressing her grief about her mother and decided not to continue after four sessions.

Case G.

60 yr old woman. Married 2nd oldest of four .Three children 33yrs, 32yrs., 28yrs. Father had died in the previous year. G. had a close relationship with her father.The bereavement period came after the diagnosis of R.A. G. was able to attend for ten sessions. Diagnosed for three years.

G. was a retired nurse and had been a mature entrant in her forties. She was currently childminding her son's daughter. She was a determined woman and with difficulty allowed her family to help. G. had an early history of looking after the home at aged ten, due to her mother being admitted to hospital. She had always played a key supportive role in the family. Father's death had highlighted mother's vulnerability and manipulative personality. G. realised that family dynamics had now changed and that she was asked to adopt a care-taking role for her mother. This was not overtly expressed by her mother.

G's husband was unhappy about having to look after her. Previously G. had looked after everything at home. She was able to express anger about her domestic situation. There was a subsequent increase in symptoms resulting in G. having to ask her husband for help.

There was a decrease in symptoms towards the end of the sessions.

Case H

30 yr old woman. Married with two boys aged 4 and 20 months. One year history of Rheumatoid Arthritis.

Developed symptoms gradually, shortly after the baby was born.

Family History. Seventh in a family of eight. Parents separated when she was ten. She described her father as a quiet down- to- earth man. Her mother as outspoken and assertive. Her mother lives nearby in fact directly opposite H's house.

The main focus of the sessions was H's desire to have another baby before it was too late i.e. too difficult for her to manage.

The work involved exploring this desire and the impact of another child whilst experiencing a very painful disease. There was a certain amount of denial of her disability and its future.

H. gradually came to accept her own need for help and the difficulties which may have been experienced with the birth of another child.

In the initial sessions her partner was not mentioned and only on questioning in later sessions was information forthcoming about him and their relationship.

With this realisation came the recognition of her need for help from her husband and her ability to verbalise this need.

Case I

31 yr old woman. Single parent looks after 9yr old daughter. Three month history of Rheumatoid arthritis. I. currently at college as a mature student.

Family History

Middle child of three. Two brothers one five years older and eight years younger. Mother and father separated when she was a baby. Mother re-married when she was five. Initially I. did not like him but this changed over the years.

I. took on a caretaking role in the family by looking after the boys, doing most of the domestic duties at home. Independent, capable, efficient woman

I.'s mother lives nearby and I. still tends to look after her when required.

Main focus of the sessions was around her previous relationship with her child's father who had an addiction problem with addiction. I. had some contact with him but was trying to establish an appropriate boundary between him and herself in order to establish a healthy pattern of relating for the future.

I. also explored the difficulties of developing relationships now, since her

daughter tended to sabotage any possibilities of this happening.

I. displayed a certain amount of insight in to her problems and was given the opportunity to pursue the work with another counsellor.

Case History Summary

There are certain similarities in all these cases. Each woman tended to be fiercely independent and active prior to the onset of their symptoms. There tended to be a strong resistance to expressing their need for others which seemed to exist pre-morbidly.

There were also similarities in the family histories .Each patient was often the youngest in the family and performed some caretaking role for the parent. They often portrayed themselves as the connector in the family and the sibling who had to contain certain feelings for the family.

The common feature seemed to be the early caretaking role, with their own unexpressed dependency needs which had become subjugated at an early age.

In later life there appears to be a common theme of difficulty in separation from the parent and a continued caretaking role of the partner, offspring or sometimes parent.

With the onset of a disease such as Rheumatoid Arthritis a situation exists where the most basic of daily functions requires help. In the sessions anger was frequently expressed at the fact that others were not able to recognise their need. There was also a reluctance to verbalise these needs.

In general most of the women expressed anger towards their partner with respect to the care-taking aspect of the relationship. It was only after this expression that they were able to begin to look at ways of asking for help from their partner.

In general, the work, albeit short term, allowed the patients to move forward in a small way towards a tentative recognition of their dependent self. This resulted in a move away from somatising to a verbalising of their needs, which led to a recognition of their own needs and the need for others.

In the two cases where there had been a recent bereavement, coinciding with the onset of the disease, each patient opted not to continue with the sessions.

Interestingly in Case G. where the bereavement had occurred after the onset of the disease the patient was able to take part in all ten sessions. However in her case there seemed to be an increase in symptoms with the change in family dynamics after the bereavement.

In the other two cases where bereavement had occurred (E.&F.) it may be speculated that the disease was paradoxically providing the person with a way of dealing with the grieving process in the absence of being able to express themselves verbally.

The counsellor provided a sufficiently containing presence, where the struggle between the independent and dependent self could be held until the patient was able to contain it within herself. The counter-transference often felt difficult and manifested itself within the counsellor as a feeling of redundancy or at times helplessness . At other times the need for complete support was felt. Gradually as the patient was able to contain both aspects within herself the counter-transference dissipated. To the counsellor the counter-transference indicated the degree of inner conflict / struggle going on within the client

Discussion

This limited pilot study suggests that psychodynamic counselling over a ten week period does not provide a significantly large improvement in ameliorating disease activity when compared to early education talks. There is however a suggestion of a moderate effect in the counselled group. The results may not have shown a statistical significance between the groups which was primarily due to the small sample size. However there was a suggestion of a moderate effect in the counselled group. One of the main reasons for the small sample size was the difficulties with recruitment which proved to be extremely problematic. This was perhaps due to a number of reasons;

1. The nature of the intervention i.e. counselling deterred some from embarking on the project. Participation in the intervention usually assumes a certain psychological-mindedness on the part of the individual. Individuals in counselling settings therefore tend to be self-selecting.
2. The Centre for Rheumatic Diseases, Glasgow Royal Infirmary, is a Regional Centre which means that patients often travel distances to come for assessment and therefore were unable to take part
3. Some patients were in employment and not available during the day.
4. A number of other research programmes were running concurrently, therefore limiting access to patients with early rheumatoid arthritis.
5. Personnel in the Rheumatology Department were not always able to remember to pass information on to the appropriate patients and it was not always feasible to be present at each clinic.

Measurement

It was not possible to collate complete sets of measurements, both qualitatively and quantitatively. Some subjects having only attended for less than two sessions did not return for assessment. The return of the qualitative data was particularly poor. Patients not returning questionnaires presented a problem in terms of collating data. Patients were allowed to take the questionnaires home to complete if they chose to. This was primarily because of the nature of the disease i.e. some found it difficult to write, due to pain or stiffness and wanted to take time filling out the questions. In addition the quality of life measures may not have been sensitive enough to any perceived change. It is difficult to measure benefits of an intervention such as counselling objectively.

A satisfaction questionnaire may have been more appropriate in providing feedback with less quality of life measures used.

It proved difficult to find an appropriate quality of life measure which would be sensitive to or reflect any change relating to shifts in internal relationships. This may have been due to an inability to locate suitable measures or the fact there are not any available. These measures may have proved to be more sensitive. It may also have been appropriate to have had a three month follow-up to ascertain any long-term benefits of the intervention.

The Education Group was run separately from the counselling and the counsellor was not involved in its setting up. The group only ran at certain times in the year which meant waiting to allocate control subjects at specific times. This also became logistically difficult and in retrospect involving the controls in something different would have produced a more consistent outcome.

The attendance in the education group was very poor. It is difficult to say why since the subjects were attending as controls and not for a comparative study. There was therefore no analysis of the education group or a review of the content of the programme.

Measuring the impact of counselling in terms of the disease activity was problematic in that some of the patients changed medication during intervention or had begun therapy prior to the study. It is difficult to control for this variable which will always affect outcome. Some patient's drugs regimes changed during the project, potentially influencing the results although all were receiving counselling which was a consistent factor. Most were receiving second-line therapy which would tend to have some impact on the immune system.

It is difficult to draw conclusions from the study due to the small sample size. In drawing any conclusions it may be necessary to look at what the lack of compliance and interest illustrates about the difficulties of performing a randomised controlled trial looking at the impact of counselling.

A fundamental problem with much of the research evidence surrounding the benefits of counselling seems to be poor research methodology, Fallowfield (1993). Very few randomised trials exist within the literature. This randomised trial looking at the benefits of counselling presented certain problems. The nature of the intervention in the form of counselling was affected by the process of randomisation. This meant the randomisation was artificially imposed on what would normally have been a self-selecting group of people. This confined the patient's choice and in doing so, resulted in limited numbers of people taking part, thus influencing the results of the study.

The study in a way, assumed a certain psychological-mindedness on the part of the patient which would influence participation in the project.

Patients with a relatively recent diagnosis did not tend to identify specific issues relating to the disease which would have benefitted from psychological input. The aim of the counselling had therefore to be explained. For instance the opportunity to explore issues surrounding the impact of such a diagnosis and its relevance for relationships in the patient's life. Not necessarily specifics connected to the disease but what the underlying fears behind these thoughts might be. This proved to be a difficult process for the patient's to initially engage in. There was a tendency to revert back to the comfort of discussing the facts about the disease and the counsellor who also had a medical background was at times tempted to collude in this safe environment. There was a relatively strong defence against the very overwhelming feelings of anxiety, fear and powerlessness in the face of a disease for which there is no definitive factor in its onset. These anxieties were often expressed as concern about how it would be in the future. What would they be like? Would they be wheelchair-bound? and the consequent dependency on others, which tended not to be overtly expressed. Sometimes these feelings were projected into the counsellor with a desire to search for some answer or definitive statement to assuage these fears. The majority of the work centred around the issue of how to integrate the independent and dependent parts of oneself.

Initially it was suggested that the provision of support in the form of counselling during the first year post-diagnosis may enable an exploration of recent life events prior to the onset of disease thus modifying the patient's coping styles early on and potentially affecting the disease process, Newman and Revenson (1993).

In general those patients coming, tended not to identify any recent life events with the exception of two who had recent bereavements and interestingly only came for less than four sessions. Most did not talk specifically about the disease

itself but tended to explore issues surrounding their relationships which the onset of the disease may or may not have precipitated. The common theme of unexpressed dependency needs and the attempt to integrate their dependent and independent self proved to be ever present in the work, to varying degrees, for each person. It is not clear whether this was due to the gradual realisation of the impact this disease has on the ability to perform very basic activities of daily life such as opening a jar or turning a door-handle and the inevitable need for others to help or whether this was part of a pre-morbid personality. This aspect of the disease tended to impact on each patient's relationships by "forcing" the issue of dependency.

Lomas (1994) asks the question; How dependent should we be on each other and in what way? Should there be a striving for self-sufficiency, stoically enduring anxieties or an openness about vulnerabilities and a turning to others for help?

There are dangers in limiting ourselves to one strategy. The resolution of the conflict of dependence is a life long struggle and presents itself in a very immediate way with the onset of rheumatoid arthritis.

It may also be beneficial to offer counselling to those who have experienced problems as a result of the crippling disease process, addressing the mental health issues which may arise as a consequence.

The logistics of this project proved to be rather difficult. The counselling took part in the Physiotherapy department and the counsellor was part of this department. Each client was aware of the fact that the counsellor was a physiotherapist since it would have been too contrived to disguise the fact. Patients did at times try to engage the counsellor in a discussion about various

issues related to the disease. The counsellor tended to try to look at the anxiety behind these queries rather than focusing on them. If further information was required the individual was directed to the appropriate professional.

In hindsight it would have been easier to conduct the sessions outwith the department and explanations of what was taking place would not have been required for those working in the physiotherapy department.

Those coming for counselling found it difficult to engage in the therapeutic process. This could have been for reasons previously outlined i.e. the artificiality of the process and the difficulty in identifying any specific issue. However the attendance in this group was reasonable indicating that some kind of process was going on at some level. Patients consistently used the opportunity to express how they felt about their relationships in general.

The problems identified in the relationships seemed to centre around a difficulty in asking for help, specifically and generally. Rheumatoid arthritis paradoxically is a disease which quite powerfully makes one confront the issue of dependency on others. The women coming for counselling tended to be fairly independent in their life-styles with a general tendency to have cared for others throughout their lives, even from an early age.

The difficulties the counsellor felt in the therapeutic process seemed to be mirroring the difficulty in the inner world of the client. The lack of engagement could perhaps be linked to the strong defence against the dependency on the counsellor. The sessions tended to form a pattern of "holding" the client in a space where she could feel contained enough to express her dependent self but at the same time "hold on to" the independent self. The struggle seemed to be towards a more integrated sense of these parts within the self.

The counsellor at times felt passively cast in the role of being redundant and merely providing the physical presence of another. Some patients had to struggle with the reality of having to give up physically demanding work and the fear that everything would disintegrate as a result, as if their work was preventing this from happening. The expression of need was felt to herald the end of independence and the complete dependence on others. Most of the sessions focussed on the issues and beliefs surrounding this.

Auto-immune disorders may be looked upon metaphorically as being a process of fighting against oneself; of the body fighting against itself. This is reflected in the process of negotiating some path through to an integrated self where there is some sense of healthy interdependency. In relating this theoretically to the dysregulatory model of disease or the theories of psychobiology, the counsellor it can be hypothesised in being physically and emotionally present provides an opportunity for the individual to regulate their physiologic processes thereby moving away from the need to express oneself somatically as opposed to verbally.

Hofer (1984) discusses the evidence that the presence of human social relationships can modify physiologic responses in individuals and have important effects on health outcome. Variations in the doctor-patient relationship can have more intense effects on physiologic responses than the medications given by the doctor. Therefore, reducing the alexythymic tendency, as Poulsen (1991) found, linking the person with their inner life .

The original proposal which was centred around providing support to those with significant life events prior to onset had to be revised since most did not identify any such event.

Interestingly the two patients who had suffered a bereavement only attended for two sessions. It could perhaps be hypothesised that the on-going process of grieving was connected with the onset of the disease and that the manifestation of symptoms was linked with this and therefore provided some kind of function. These patients were reluctant to engage in the counselling process. It is interesting that the initial proposal for the project was concerned with exactly this, the presence of life events prior to onset of symptoms and the provision of support in the form of counselling during this period. It would seem that in these cases the actual disease was providing a necessary defence against the grieving process and providing a protective function for the individual in that the expression of distress was through the body and not expressed verbally. In these cases the issue of separation was extremely significant. McFarlane(1990) discusses the fact that depression is known to lower the effect on the immune system and paradoxically would, in theory, dampen the effects of an auto-immune disorder. There are other specific implications in this study regarding the issue of separation anxiety and its link with the disease process specifically related to unexpressed dependency needs in patients with rheumatoid arthritis. Those coming for counselling had similar issues relating to separation in their family histories. Baker and Brewerton (1981) found that those newly diagnosed women who reported a difficult relationship with their mother's in childhood were more vulnerable.

In the other cases the issue of separation was apparent from taking the case histories. Most identified significant life events surrounding separation. In later life the issue of separation remained apparent with some having older children still at home or continuing to live with or close to parents or offspring. Separation and dependency would appear to be closely related. The acknowledgement of the dependency on another helps to ease the process of separation in that if the individual is able to sufficiently internalise the notion of

Kohut's "good caretaking figure", Kohut (1983) or Winnicott's "maternalising breast", Winnicott (1957), then through this acknowledgement there can be some move forward to the integration of the independent and dependent self

Perhaps in the previous separations experienced in the early life of these patients there has been difficulty in negotiating this issue. Separation and dependency needs would appear to be intimately related. There may also have been a recurring familial problem with separation and this may account for the familial pattern seen in Rheumatoid Arthritis. The issue of separation is clearly an important one in the negotiation of dependence/ independence.

What then is possible in terms of short-term psychodynamic work ? The benefits of negotiating the integration of the two parts through counselling would seem like a worthwhile endeavour if the outcome were to be an improved relationship with one's inner world. This would be especially so if the long term effects can influence the disease activity. However the benefits in terms of being able to negotiate the difficulties encountered at a later stage in the disease process would in itself make the counselling worthwhile. It would also seem that only a certain percentage of the population would be amenable to this treatment which is the case in most treatments. Looking globally, the wider issue of how the institution itself reflects the inner process of the patient may be worth looking at in providing some clues as to what processes may be taking place on both sides of the doctor-patient relationship.

The nature of the disease rheumatoid arthritis means that the doctor generally relies on very powerful drugs to arrest the progression of the disease. This inevitably and unavoidably engenders a philosophy of dependency on the doctor and the drugs .The doctor tends not to engage the patient in a dialogue concerning the drugs, since the body of knowledge remains with the doctor,

thus reinforcing the dependent self. The independent part of the process seems to be encouraged by the paramedical staff with input from occupational and physiotherapy staff trying to engage the patient in a process of remaining as independent as possible for as long as possible. Both approaches still do not acknowledge or address the difficulties of integrating the independent and dependent self.

It may be useful for each profession to look at these difficulties from their own perspectives. It is interesting that the issues which appear to manifest themselves in individuals who have rheumatoid arthritis are reflected in the external world. It may be useful to look at the inter-relationship of the external and internal worlds. Is this prevalent generally throughout the NHS? Is this the "schizoid" nature of the NHS where things tend to become split in order to cope with the uncomfortable feelings which tend to get defended against and the cycle of disease perpetuated. Menzies-Lyth (1997) discusses how the institution acts as a defence against anxiety, by using rigid practises, to defend against these uncomfortable feelings.

This is an area, however, which requires separate attention and is outwith the scope of this project.

Implications for practice

The implications for practice are wide reaching. The difficulty of finding a balance between independence and dependence cannot be underestimated with efforts made at most turns to thwart the process of accepting inter-dependency.

In specifically relating this work to rheumatoid arthritis it may be beneficial to

focus on the issue of separateness and attachment since there may be difficulty in acknowledging these two positions. The work being done was not at the level of personality restructuring but short-term focussed. The main focus which dealt with the issue of independent/dependent self, appears to be fundamental to these patients.

The establishment of self-help management programmes, is a step towards the acknowledgement of the independent self with the idea that perceived locus of control is beneficial. However studies have not shown long term benefits.

Generally some combined approach i.e. self-management programmes with some short-term group therapy may be beneficial, as advocated by Poulsen (1991). This would allow the individual to develop a perceived locus of control, while at the same time allowing the space for the individual to express themselves psychologically. Thereby mobilising the independent and dependent self.

The implications of this project then would seem to be that the quality of presence one with another - in relationship - has the potential to inform, enhance and develop practice. This quality of presence and attention allows one to hear and perceive what is being communicated which benefits both patient and therapist.

It enables the patient to become a more active participant in the therapeutic process and also allows the therapist to make a more informed assessment of the nature of the interplay between the physical and psychological conditions. This may have an impact on the therapist being able to address the issues of inter-dependency within him/herself. The therapist may have to address the issues of inter-dependency within him, herself in order to fully take part in this process.

An integrative approach, tailored to individual's needs is the way forward. An approach that addresses the physical, psychological and emotional needs of the individual who happens to have Rheumatoid Arthritis.

"One ought, then to treat the soul first and foremost if the head and the rest of the body were to be well. He said the soul was treated with certain charms and that these charms were beautiful words. As a result of such words, self-control came into being in souls. When it came into being it was then easy to secure health both for the head and for the rest of the body ". (Plato: Early Socratic Dialogues)

Conclusion

The research highlighted a number of areas for potential development. These fall into three categories.

- 1.The patient/individual**
- 2.Counselling service**
- 3.Doctor/patient relationship**

1.The patient/Individual

The research indicated that the provision of psychological insight leads to the relief of psychic distress in the individual . There was a raised awareness about the individual's perceived locus of control, engendered through a greater sense of a more integrated self. It also highlighted that it is possible for the patient to become a more active participant in the therapeutic process.

The patient was able to gain a greater sense of inter-dependency through psychological insight which in turn led to a healthier approach to the overall management of the disease.

2. Counselling service

The research has emphasised the need for psychological support as part of or underpinning the management of patients with rheumatoid conditions. There are, however, implications for the existence of a counselling service within this environment. Counselling, generally, is either ignored or at best neglected within a hospital setting. The general ethos in this setting tends not to support this aspect of care, as borne out by the recruitment difficulties in the project.

3. Doctor/patient relationship

Doctor is used in this context to refer to any medical personnel. The hoped for outcome of this work may be greater empowerment for patient and doctor with a more mature and realistic partnership. This was indicated through the importance of the presence of the counsellor for the client in enabling him/her to gain insight into their part in the process. The relationship is important here and given a greater awareness of this, the doctor's role can be to support a more integrated sense of self rather than a dependent one.

Dependency as referred to earlier is fostered through the need for powerful immuno-suppressive drugs which can become the main focus of treatment. Medical personnel need to be aware of the dependency this generates.

With the ever increasing demand on ever decreasing resources it may be of value to address this fundamental area especially when chronicity is concerned. How these issues may be addressed is up for debate or discussion. Initially undergraduate training should begin to look at this process. In established environments this may prove to be more difficult with personnel and patients needing more time and training to take on board this potential for growth. The patients charter and the call for evidence-based practise are steps towards this, albeit from their specific standpoints.

Addendum Page 20 para 2.

Psychoanalytic psychosomaticists of the 1940's and 1950's applied Freud's 'drive-conflict' model of psychopathology to patient's suffering from bronchial asthma, essential hypertension, peptic ulcer, ulcerative colitis, thyrotoxicosis, rheumatoid arthritis and neurodermatitis. These seven diseases came to be known as the 'classical' psychosomatic diseases (Taylor 1992).

Addendum Page 23 para. 2, line 5.

Omitted reference is (Poulsen 1991).

Addendum Page 56 para. 1, line 1.

Delete the words 'both qualitatively and quantitatively'.

Addendum Page 56 para. 1, line 3.

Delete 'qualitative data' and replace with 'quality of life measures'.

Addendum to Conclusion Page 66 to 67.

1. The patient/ individual

The counsellor subjectively reports her impression that the provision of psychological insight leads to the relief of psychic distress in the individual. The actual quantitative results did not indicate this change and the reasons for this have been outlined in the discussion e.g. methodological flaws.

2. Counselling service

As the research stands it would appear that the counselling offered was in low demand and of questionable benefit. However, evidence from the results indicated a need for further research on a greater scale to fully assess the benefits of counselling.

3. Doctor/patient relationship

It has been assumed that the presence of the counsellor enables the patient to gain insight into their part in the doctor/patient relationship. There is no quantitative evidence from the project to support this and the counsellor is proffering a subjective opinion which future research may or may not be able to substantiate.

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Appendices

Statistical Analysis

In order to answer the key question, does the intervention have an effect on the counselled patients compared to the controls, two-sample t-tests and 95% confidence intervals were used on the changes in each of the variables from before and after the intervention (i.e. Week 10 minus Week 0 values were used).

The two sample t-test is used where there are two groups of matched subjects, who do one condition each and the results from the two conditions are compared to see if there are differences between them. The two sample t-test was used since this project had a matched subject design. This test was also selected because it is especially suitable for "before and after", type designs when comparing the effects of a treatment on one group of subjects.

Title: A study of the impact of counselling on disease activity in early rheumatoid arthritis.

We would like to invite you to take part in a study to determine the possible health-related benefits of counselling in early rheumatoid arthritis. If you wish to take part in the study you will be randomly selected into two different groups as follows:

- (1) 10 weeks of once weekly 50 minute counselling.
- (2) Early education group who will participate in ten weekly talks given by various health professionals.

Measurements will be taken before ,during and after the ten week period. The tests are as follows.

- (a) Three questionnaires
- (b) Swollen and tender joint measurement
- (c) Blood test to measure inflammation
- (d) Measurement of pain on a visual scale

If you do not wish to take part in the study or if at any time you wish to stop taking part in the study you may do so. The care you are receiving will not be affected in any way. If you do agree to take part ,your own G.P. will be informed about any care which you are to receive.

It should be noted that your participation in this study may not be of any direct benefit to you but the results may help other patients in the future.

Consent

I,(Name).....of(Address).....
.....

agree to take part in the research project/study programme as described above.

Dr/Mr.....has explained to me what I have to do, how it might affect me and the purpose of the research project/study programme.

Signed.....Date.....

Witness.....Date.....

HEALTH ASSESSMENT QUESTIONNAIRE

Name Date

We are interested in learning how your illness affects your ability to function in daily life.
Please feel free to add any comments at the end of this form.

PLEASE TICK THE ONE RESPONSE WHICH BEST DESCRIBES YOUR USUAL ABILITIES
OVER THE PAST WEEK:

	Without ANY difficulty	With SOME difficulty	With MUCH difficulty	Unat- to do
1. DRESSING AND GROOMING				
Are you able to:				
- Dress yourself, including tying shoelaces and doing buttons?
- Shampoo your hair?
2. RISING				
Are you able to:				
- Stand up from an armless straight chair?
- Get in and out of bed?
3. EATING				
Are you able to:				
- Cut your meat?
- Lift a full cup or glass to your mouth?
- Open a new can of milk (or soap powder)?
4. WALKING				
Are you able to:				
- Walk outdoors on flat ground?
- Climb up five steps?

PLEASE TICK ANY AIDS OR DEVICES THAT YOU USUALLY USE FOR ANY OF THESE ACTIVITIES:

- | | |
|-----------------------------|--|
| Cane | Devices used for dressing (button hook, zipper pull, long hand
shoe horn, etc.) |
| Walking frame | Built-up or special utensils |
| Crutches | Special or built-up chair |
| Wheelchair | |
| Other (specify) | |

PLEASE TICK ANY CATEGORIES FOR WHICH YOU USUALLY NEED HELP FROM ANOTHER PERSON:

- | | |
|--------------------------------|---------------|
| Dressing and
Grooming | Eating |
| Rising | Walking |

Please Complete

PLEASE TICK THE ONE RESPONSE WHICH BEST DESCRIBES YOUR USUAL ABILITIES OVER THE PAST WEEK

	Without ANY difficulty	With SOME difficulty	With MUCH difficulty	Unable to do
5. HYGIENE				
Are you able to:				
- Wash and dry your entire body?
- Take a bath?
- Get on and off the toilet?
3. REACH				
Are you able to:				
- Reach and get down a 5lb object (e.g. a bag of potatoes) from just above your head?
- Bend down to pick up clothing from the floor?
7. GRIP				
Are you able to:				
- Open car doors?
- Open jars which have been previously opened?
- Turn taps on and off?
3. ACTIVITIES				
Are you able to:				
- Run errands and shop?
- Get in and out of a car?
- Do chores such as vacuuming, housework or light gardening?

PLEASE TICK ANY AIDS OR DEVICES THAT YOU USUALLY USE FOR ANY OF THESE ACTIVITIES:

- | | |
|---|---|
| Raised toilet seat | Bath rail |
| Bath seat | Long handled appliances for reach |
| Jar opener (for jars previously opened) | Other (specify) |

PLEASE TICK ANY CATEGORIES FOR WHICH YOU USUALLY NEED HELP FROM ANOTHER PERSON:

- | | |
|---------------|-----------------------------------|
| Hygiene | Gripping and opening things |
| Reach | Errands and housework |

Doctors are aware that emotions play an important part in most illnesses. If your doctor knows about these feelings he will be able to help you more.

This questionnaire is designed to help your doctor to know how you feel.

80

Read each item and underline the reply which comes closest to how you have been feeling in the past week.

Don't take too long over your replies: your immediate reaction to each item will probably be more accurate than a long thought out response.

I feel tense or 'wound up':

Most of the time

A lot of the time

From time to time occasionally

Not at all

I still enjoy the things I used to enjoy:

Definitely as much

Not quite so much

Only a little

Hardly at all

I get a sort of frightened feeling as if some thing awful is about to happen:

Very definitely and quite badly

Yes but not too badly

A little but it does'nt worry me

Not at all

I can laugh and see the funny side of things:

As much as I always could

Not quite so much now

Definitely not so much now

Not at all

Worrying thoughts go through my mind

A great deal of the time

A lot of the time

From time to time but not too often

Only occasionally

I feel cheerful :

Not at all

Not often

Sometimes

Most of the time

I can sit at ease and feel relaxed:

Definitely
Usually
Not often
Not at all

I feel as if I am slowed down:

Nearly all the time
Very often
Sometimes
Not at all

I get a sort of frightened feeling like 'butterflies' in the stomach

Not at all
Occasionally
Quite often
Very often

I have lost interest in my appearance:

Definitely
I don't take so much care as I should
I may not take quite as much care
I take just as much care as ever

I feel restless as if I have to be on the move:

Very much indeed
Quite a lot
Not very much
Not at all

I look forward with enjoyment to things:

As much as ever I did
Rather less than I used to
Definitely less than I used to
Hardly at all

I get sudden feelings of panic:

Very often indeed

Quite often

Not very often

Not at all

I can enjoy a good book or radio or TV programme:

Often

Sometimes

Not often

Very seldom

Now check you have answered all the questions

Please check (X) the most appropriate answer for each question.

These questions refer to MOBILITY LEVEL

	All Days (1)	Most Days (2)	Some Days (3)	Few Days (4)	No Days (5)	
DURING THE PAST MONTH...						
1. How often were you physically able to drive a car or use public transportation?	_____	_____	_____	_____	_____	8/
2. How often were you out of the house for at least part of the day?	_____	_____	_____	_____	_____	9/
3. How often were you able to do errands in the neighborhood?	_____	_____	_____	_____	_____	10/
4. How often did someone have to assist you to get around outside your home?	_____	_____	_____	_____	_____	11/
5. How often were you in a bed or chair for most or all of the day?	_____	_____	_____	_____	_____	12/

AIMS

These questions refer to WALKING AND BENDING.

	All Days (1)	Most Days (2)	Some Days (3)	Few Days (4)	No Days (5)	
DURING THE PAST MONTH...						
6. Did you have trouble doing vigorous activities such as running, lifting heavy objects, or participating in strenuous sports?	_____	_____	_____	_____	_____	13/
7. Did you have trouble either walking several blocks or climbing a few flights of stairs?	_____	_____	_____	_____	_____	14/
8. Did you have trouble bending, lifting or stooping?	_____	_____	_____	_____	_____	15/
9. Did you have trouble either walking one block or climbing one flight of stairs?	_____	_____	_____	_____	_____	16/
10. Were you unable to walk unless assisted by another person or by a cane, crutches, or walker?	_____	_____	_____	_____	_____	17/

Please check (X) the most appropriate answer for each question.

These questions refer to SELF-CARE TASKS.

DURING THE PAST MONTH...	Always (1)	Very Often (2)	Sometimes (3)	Almost Never (4)	Never (5)	
21. Did you need help to take a bath or shower?	_____	_____	_____	_____	_____	28/
22. Did you need help to get dressed?	_____	_____	_____	_____	_____	29/
23. Did you need help to use the toilet?	_____	_____	_____	_____	_____	30/
24. Did you need help to get in or out of bed?	_____	_____	_____	_____	_____	31/

..... AIMS

These questions refer to HOUSEHOLD TASKS.

DURING THE PAST MONTH...	Always (1)	Very Often (2)	Sometimes (3)	Almost Never (4)	Never (5)	
25. If you had the necessary transportation, could you go shopping for groceries without help?	_____	_____	_____	_____	_____	32/
26. If you had kitchen facilities, could you prepare your own meals without help?	_____	_____	_____	_____	_____	33/
27. If you had household tools and appliances, could you do your own housework without help?	_____	_____	_____	_____	_____	34/
28. If you had laundry facilities, could you do your own laundry without help?	_____	_____	_____	_____	_____	35/

Please check (X) the most appropriate answer for each question.

These questions refer to ARTHRITIS PAIN.

DURING THE PAST MONTH...	Severe (1)	Moderate (2)	Mild (3)	Very Mild (4)	None (5)
38. How would you describe the arthritis pain you usually had?	_____	_____	_____	_____	_____
	All Days (1)	Most Days (2)	Some Days (3)	Few Days (4)	No Days (5)
39. How often did you have severe pain from your arthritis?	_____	_____	_____	_____	_____
40. How often did you have pain in two or more joints at the same time?	_____	_____	_____	_____	_____
41. How often did your morning stiffness last more than one hour from the time you woke up?	_____	_____	_____	_____	_____
42. How often did your pain make it difficult for you to sleep?	_____	_____	_____	_____	_____

These questions refer to WORK.

DURING THE PAST MONTH...	Paid work (1)	House work (2)	School work (3)	Unemployed (4)	Disabled (5)	Retired (6)
43. What has been your main form of work?	_____	_____	_____	_____	_____	_____

If you answered unemployed, disabled or retired, please skip the next four questions and go to the next page.

DURING THE PAST MONTH...	All Days (1)	Most Days (2)	Some Days (3)	Few Days (4)	No Days (5)
44. How often were you unable to do any paid work, house work or school work?	_____	_____	_____	_____	_____
45. On the days that you did work, how often did you have to work a shorter day?	_____	_____	_____	_____	_____
46. On the days that you did work, how often were you unable to do your work as carefully and accurately as you would like?	_____	_____	_____	_____	_____
47. On the days that you did work, how often did you have to change the way your paid work, house work or school work is usually done?	_____	_____	_____	_____	_____

Please check (X) the most appropriate answer for each question.

These questions refer to LEVEL OF TENSION.

DURING THE PAST MONTH...	Always (1)	Very Often (2)	Sometimes (3)	Almost Never (4)	Never (5)
48. How often have you felt tense or high strung?	_____	_____	_____	_____	_____
49. How often have you been bothered by nervousness or your nerves?	_____	_____	_____	_____	_____
50. How often were you able to relax without difficulty?	_____	_____	_____	_____	_____
51. How often have you felt relaxed and free of tension?	_____	_____	_____	_____	_____
52. How often have you felt calm and peaceful?	_____	_____	_____	_____	_____

AIMS

These questions refer to MOOD

DURING THE PAST MONTH...	Always (1)	Very Often (2)	Sometimes (3)	Almost Never (4)	Never (5)
3. How often have you enjoyed the things you do?	_____	_____	_____	_____	_____
4. How often have you been in low or very low spirits?	_____	_____	_____	_____	_____
5. How often did you feel that nothing turned out the way you wanted it to?	_____	_____	_____	_____	_____
6. How often did you feel that others would be better off if you were dead?	_____	_____	_____	_____	_____
7. How often did you feel so down in the dumps that nothing would cheer you up?	_____	_____	_____	_____	_____

Please check (X) the most appropriate answer for each question.

These questions refer to satisfaction with each health area.

DURING THE PAST MONTH...	Very Satisfied (1)	Somewhat Satisfied (2)	Neither Satisfied Nor Dissatisfied (3)	Somewhat Dissatisfied (4)	Very Dissatisfied (5)
58. How satisfied have you been with each of these areas of your health?					
MOBILITY LEVEL (example: do errands)	---	---	---	---	---
WALKING AND BENDING (example: climb stairs)	---	---	---	---	---
HAND AND FINGER FUNCTION (example: tie a bow)	---	---	---	---	---
ARM FUNCTION (example: comb hair)	---	---	---	---	---
SELF-CARE (example: take bath)	---	---	---	---	---
HOUSEHOLD TASKS (example: housework)	---	---	---	---	---
SOCIAL ACTIVITY (example: visit friends)	---	---	---	---	---
SUPPORT FROM FAMILY (example: help with problems)	---	---	---	---	---
ARTHRITIS PAIN (example: joint pain)	---	---	---	---	---
WORK (example: reduce hours)	---	---	---	---	---
LEVEL OF TENSION (example: felt tense)	---	---	---	---	---
MOOD (example: down in dumps)	---	---	---	---	---

AIMS

You have now answered questions about different AREAS OF YOUR HEALTH. These areas are listed below. Please check (x) up to THREE AREAS in which you would MOST LIKE TO SEE IMPROVEMENT. Please read all 12 areas of health choices before making your decision:

check =
blank =

60. AREAS OF HEALTH

THREE AREAS FOR IMPROVEMENT

MOBILITY LEVEL (example: do errands)	_____	20/
WALKING AND BENDING (example: climb stairs)	_____	21/
HAND AND FINGER FUNCTION (example: tie a bow)	_____	22/
ARM FUNCTION (example: comb hair)	_____	23/
SELF-CARE (example: take bath)	_____	24/
HOUSEHOLD TASKS (example: housework)	_____	25/
SOCIAL ACTIVITY (example: visit friends)	_____	26/
SUPPORT FROM FAMILY (example: help with problems)	_____	27/
ARTHRITIS PAIN (example: joint pain)	_____	28/
WORK (example: reduce hours)	_____	29/
LEVEL OF TENSION (example: felt tense)	_____	30/
MOOD (example: down in dumps)	_____	31/

Please make sure that you have checked no more than THREE AREAS for improvement.

Please check (X) the most appropriate answer for each question.

These questions refer to your CURRENT and FUTURE HEALTH.

	Excellent (1)	Good (2)	Fair (3)	Poor (4)
61. In general would you say that your HEALTH NOW is excellent, good, fair or poor?	_____	_____	_____	_____

	Very Satisfied (1)	Somewhat Satisfied (2)	Neither Satisfied Nor Dissatisfied (3)	Somewhat Dissatisfied (4)	Very Dissatisfied (5)
62. How satisfied are you with your HEALTH NOW?	_____	_____	_____	_____	_____

	Not a Problem For Me (0)	Due Entirely To Other Causes (1)	Due Largely To Other Causes (2)	Due Partly to Arthritis and Partly To Other Causes (3)	Due Largely To My Arthritis (4)	Due Entirely To My Arthritis (5)
63. How much of your problem with your HEALTH NOW is due to your arthritis?	_____	_____	_____	_____	_____	_____

	Excellent (1)	Good (2)	Fair (3)	Poor (4)
64. In general do you expect that your HEALTH 10 YEARS FROM NOW will be excellent, good, fair or poor?	_____	_____	_____	_____

	No Problem At All (1)	Minor Problem (2)	Moderate Problem (3)	Major Problem (4)
65. How big a problem do you expect your arthritis to be 10 YEARS FROM NOW?	_____	_____	_____	_____

AIMS

Please check (X) the most appropriate answer for each question.

This question refers to OVERALL ARTHRITIS IMPACT.

	Very Well (1)	Well (2)	Fair (3)	Poor (4)	Very Poorly (5)	
66. CONSIDERING ALL THE WAYS THAT YOUR ARTHRITIS AFFECTS YOU, how well are you doing compared to other people your age?	_____	_____	_____	_____	_____	3

AIMS

67. What is the main kind of arthritis that you have?	check -	blank -	
Rheumatoid Arthritis	_____	_____	38
Osteoarthritis/Degenerative Arthritis	_____	_____	39
Systemic Lupus Erythematosus	_____	_____	40
Fibromyalgia	_____	_____	41
Scleroderma	_____	_____	42
Psoriatic Arthritis	_____	_____	43
Reiter's Syndrome	_____	_____	44
Gout	_____	_____	45
Low Back Pain	_____	_____	46
Tendonitis/Bursitis	_____	_____	47
Osteoporosis	_____	_____	48
Other	_____	_____	49

68. How many years have you had arthritis? _____ 50-51,

DURING THE PAST MONTH...	All Days (1)	Most Days (2)	Some Days (3)	Few Days (4)	No Days (5)	
69. How often have you had to take MEDICATION for your arthritis?	_____	_____	_____	_____	_____	52,

Please check (X) yes or no for each question.

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

	Yes (1)	No (2)	
High blood pressure_____	_____	_____	53/
Heart disease_____	_____	_____	54/
Mental illness_____	_____	_____	55/
Diabetes_____	_____	_____	56/
Cancer_____	_____	_____	57/
Alcohol or drug use_____	_____	_____	58/
Lung disease_____	_____	_____	59/
Kidney disease_____	_____	_____	60/
Liver disease_____	_____	_____	61/
Ulcer or other stomach disease_____	_____	_____	62/
Anemia or other blood disease_____	_____	_____	63/

Yes
(1)

No
(2)

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

64/

Yes
(1)

No
(2)

72. Did you see a doctor more than three times last year for any problem other than arthritis?

65/

David L. Scott
Piet L. van Riel
Désirée van der Heijde
Andrea Studnicka Benke

On behalf of:
The EULAR Standing Committee
for International Clinical Studies
including Therapeutic Trials - ESCISIT
(Chairman: Josef S. Smolen)

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THE EULAR CORE DATA SET

After detailed review, EULAR have recommended the following measures to assess the activity and outcome of rheumatoid arthritis:

- Number of swollen joints (28 joint count)
- Number of tender joints (28 joint count)
- Joint pain (on visual analogue scale)
- Patient's global assessment of disease activity (on visual analogue)
- Assessor's global assessment of disease activity (on 5 point scale)
- Acute phase response measure (ESR or C-reactive protein)
- Functional assessment (HAQ)
- Radiological assessment (Larsen)

EULAR core data

PAIN

No pain _____

Pain as bad as it could be

Swollen Joints

Number

Tender joints

Number

ESR mm/hr

C-reactive protein g/l

PATIENT'S GLOBAL ASSESSMENT OF DISEASE ACTIVITY

Not active
at all

Extremely active

ASSESSOR'S GLOBAL ASSESSMENT OF DISEASE ACTIVITY

(1-5): 1 = asymptomatic; 2 = mild; 3 = moderate; 4 = severe; 5 = very severe.

COMBINED INDICES

The Disease Activity Score (DAS) is a combined index to assess disease activity in rheumatoid arthritis. The index can be calculated with three or four variables. The DAS can be used to compare groups of patients but also to determine response of a single patient. A change of 1.08 is a significant improvement or deterioration.

The original DAS was defined with the Ritchie index and the 44 swollen joint count. A modification with the replacement by the 28 tender joint count and the 28 swollen joint count has been defined also.

	DAS four variables	DAS three variables	DAS modification
Ritchie index	+	+	-
Swollen joint count (44 joints)	+	+	-
ESR (mm after 1 hr)	+	+	+
Patient's global assessment VAS	+	-	+
Tender joint count (28 joints)	-	-	+
Swollen joint count (28 joints)	-	-	+

The formulae to calculate the DAS are:

four variables:
$$\text{DAS} = 0.54 \cdot \sqrt{(\text{Ritchie index})} + 0.065 (\text{swollen joint count}) + 0.33 \cdot \ln (\text{ESR}) + 0.007 \cdot (\text{patient's global assessment})$$

three variables:
$$\text{DAS} = 0.54 \cdot \sqrt{(\text{Ritchie index})} + 0.065 (\text{swollen joint count}) + 0.33 \cdot \ln (\text{ESR}) + 0.224$$

modified:
$$\text{DAS} = 0.555 \sqrt{(28 \text{ tender joints})} + 0.284 \sqrt{(28 \text{ swollen joints})} + 0.70 \ln (\text{ESR}) + 0.0142 (\text{patient's global assessment})$$

A nomogram to determine the DAS with three variables is available.