

EVALUATING JOINT PROTECTION EDUCATION FOR PEOPLE WITH
RHEUMATOID ARTHRITIS.

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Thesis submitted to the University of Nottingham
for the degree of Doctor of Philosophy, May 1994.

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ABSTRACT

Joint Protection (JP) education is considered an essential component of therapeutic programmes for Rheumatoid Arthritis (RA) patients. The main emphasis is teaching alternate patterns of movement at affected joints to reduce joint stress, particularly in the hands and wrists (Hand JP). Little has been published investigating patients' knowledge of, attitudes towards and adherence to Hand JP following education.

Assessments were developed to evaluate these constructs. Reliability and validity were established. A pretest-posttest trial was conducted with RA patients attending a 4 x 2 hour arthritis education programme, including 2.5 hours of JP over 2 sessions (n = 21). Teaching techniques typical of those current in the UK were used. Adherence was evaluated using the Joint Protection Behaviour Assessment. Subjects were videorecorded performing a standardised kitchen activity (making a hot drink and snack) in their own homes. Hand movements during 20 tasks within this (eg. turning a tap) were analyzed and scored as Correct (5%), Partial (2.5%) or Incorrect (0%) Hand JP behaviours. Maximum score = 100%. A significant score increase was determined as 20%. Subjects were kept blind to trial aims.

There was no significant behaviour change in the pre-education control phase (median score at assessment 1 = 18.40%, IQR 10.25 - 35.55%). No significant increase occurred at 6 and 12 week follow-ups. Mean score change was +4.01% (SD 10.59%; p = 0.14). No significant knowledge increase occurred. Post-education interviews identified a number of barriers to behavioural change.

A cognitive-behavioural JP education programme was developed, using motor learning, recall and adherence enhancement strategies, of 4 x 2 hours, with an optional home visit. A crossover trial was conducted (n = 35). There was no significant difference between treatment phase first (T1, median 15.00%, IQR 5.15 - 25.60%) and control phase first (C1, median 8.75%, IQR 4.38 - 26.25%; p = 0.47) groups' scores pre-education. Both groups' scores rose significantly at 6 weeks post-education, which was sustained at 18 weeks (T1: median 52.50%, IQR 31.75 - 65.00%; p = 0.00) (C1: median 41.25%, IQR 30.00 - 60.23%; p = 0.00). A significant increase in knowledge occurred. Factors most associated with behaviour change were: hours of education (8 or more); regular home practice; weaker grip, poorer hand range of movement and less hand pain.

These results suggest: current JP education methods are ineffective; and this cognitive-behavioural programme significantly increases Hand JP at 4.5 month follow-up. Having demonstrated adherence can be achieved, it is essential to demonstrate whether any therapeutic benefit results before advocating the widespread use of this approach in practice.

ACKNOWLEDGEMENTS

Primarily, I would like to thank my supervisor, Dr. N. Lincoln, for her invaluable advice and interest throughout this study and Dr. R. Stevens (second supervisor).

I would also like to thank the Arthritis and Rheumatism Council, which has generously largely funded this research, and the additional financial support kindly provided by the Constance Owens Trust and Lord Byers Memorial Fund.

I am grateful to the following: Southern Derbyshire Health Authority and the University of Derby for granting me study time to conduct this research; staff and students at the School of Occupational Therapy, University of Derby for volunteering to participate in studies developing the Joint Protection Behaviour Assessment and the Joint Protection Knowledge Assessment and, in particular, the critical comments of Avril Drummond, Avril Bagshaw, Marg Foster and Irene Ilott; Ms. Anne Allen (Senior O.T.) and Ms. Kate Gadsby (Rheumatology Nurse) for their invaluable assistance and running the arthritis education programme at the Derby Royal Infirmary (DRI) for over a year; Ms. Glenys Crookes, Head O.T. (DRI) for her permission to use Occupational Therapy department facilities; Dr. Murray-Leslie, Dr. Summers and Dr. Williams, Consultant Rheumatologist, (DRI) for their interest and permission to approach their patients; Mrs. Wendy Lockley and Ms. Judie Briggs, Head Occupational Therapists at Nottingham City Hospital (NCH) for their kind permission to use Occupational Therapy department facilities; Dr. Doherty, Dr. Swannell and Dr. Bossingham, Consultant Rheumatologists (NCH), for their support and permission to approach patients; Ms. Lyn Sutcliffe, Stroke Research Unit, (NCH) for her extremely thorough and reliable assistance in data collection; the patients who gave of their time and interest to this study; and to JB.

1. INTRODUCTION.

1.1. FOREWORD.

Rheumatoid Arthritis (RA) affects approximately one and a half million people in the United Kingdom, 500,000 of whom are appreciably affected (Hickling and Golding, 1984). Generally prolonged monitoring and management by health services and self-management by the patient is required. Patients must learn to live with symptoms such as pain, stiffness, weakness and fatigue which can make routine everyday activities difficult to perform.

RA cannot be cured. Therapeutic interventions aim to reduce symptoms, maximise function and maintain independence. The patient is frequently asked to adhere to complex, changing treatment regimens of uncertain benefit (Belcon, Haynes and Tugwell, 1984). Patient education is considered an essential aspect of RA management, teaching self-management techniques and encouraging adherence to therapies (Gerber, 1988; Hess, 1988). Joint Protection (JP) is commonly cited in rheumatology texts as an essential self-management technique (section 1.3).

Cordery (1965b) originally proposed JP theory as a means of preventing the development of deformities. More recently, aims of JP have been revised to "reducing the risk of deformity," rather than prevention, through reducing pain, inflammation and internal and external joint stresses (Brattstrom, 1987; Melvin, 1989).

Early referral to Occupational Therapy (OT) for JP education is strongly recommended and it is also a common component of arthritis education programmes (AEPs). As the commonest and earliest joints affected by RA are the hands and wrists, much JP education focuses on care of these joints, particularly through changing movement patterns. This aspect of JP will be referred to as Hand JP throughout.

Treatments may be ineffective either because the treatment itself does not work or the patient does not adhere to the treatment regimen sufficiently (Foa and Emmelkamp, 1983). There is little objective evidence that Hand JP achieves the aims cited above or that patients adhere to using Hand JP techniques during daily life (sections 1.3.3.v., 1.4.1. and 1.5.3). An earlier pilot study (Hammond, 1988) identified no significant increase in Hand JP behaviour occurred following traditional JP education (ie. that normally provided by OT).

This study was planned to investigate further the effectiveness of traditional JP education. If limited adherence again resulted, to explore further why this was so and to develop an alternative education programme using techniques proven to enhance adherence and evaluate its' effectiveness in changing patients' Hand JP behaviour. Once adherence with using these techniques can be demonstrated, it will be possible in future to evaluate the efficacy of Hand JP. If not, the value of Hand JP as a component of RA management should be questioned.

1.2. RHEUMATOID ARTHRITIS.

RA is a systemic connective tissue disorder, more appropriately termed "rheumatic disease." It is the commonest chronic inflammatory disease of synovial joints (Dieppe, Doherty, McFarlane and Maddison, 1985).

It is generally the most disabling of arthropathies, affecting more joints and being more destructive than others (Wood and Badley, 1983). It is the underlying cause of disability in 10% of severely disabled people in the U.K. (Wood, 1978) and in women it causes more incapacity than any other rheumatic disease (Lawrence, 1977).

Any treatment technique successfully reducing pain, deformity and maintaining function, as JP claims to do, has the potential to reduce

future levels of disability.

1.2.1. EPIDEMIOLOGY.

Between one to two percent of the UK's adult population are affected by RA (Binder, 1992), with an incidence of 0.02% per annum (Wood, 1978). More women than men are affected in a ratio of 3:1, ie. 5% of women and 2% of men (Barnes, 1980; Hochberg, 1988). Peak age of onset is 25 to 50 years, with prevalence increasing with age in both sexes, rising to 16% of women over 65 years (Masi and Medsger, 1979). There is recent evidence to suggest the incidence of RA is declining in women but its prevalence has been increasing in both sexes in the last decade (Hochberg, 1990).

1.2.2. AETIOLOGY AND PATHOLOGY.

The aetiology of RA is unknown but current theories suggest genetically predisposed people encounter a triggering factor (eg. bacterial, viral or environmental) producing joint inflammation.

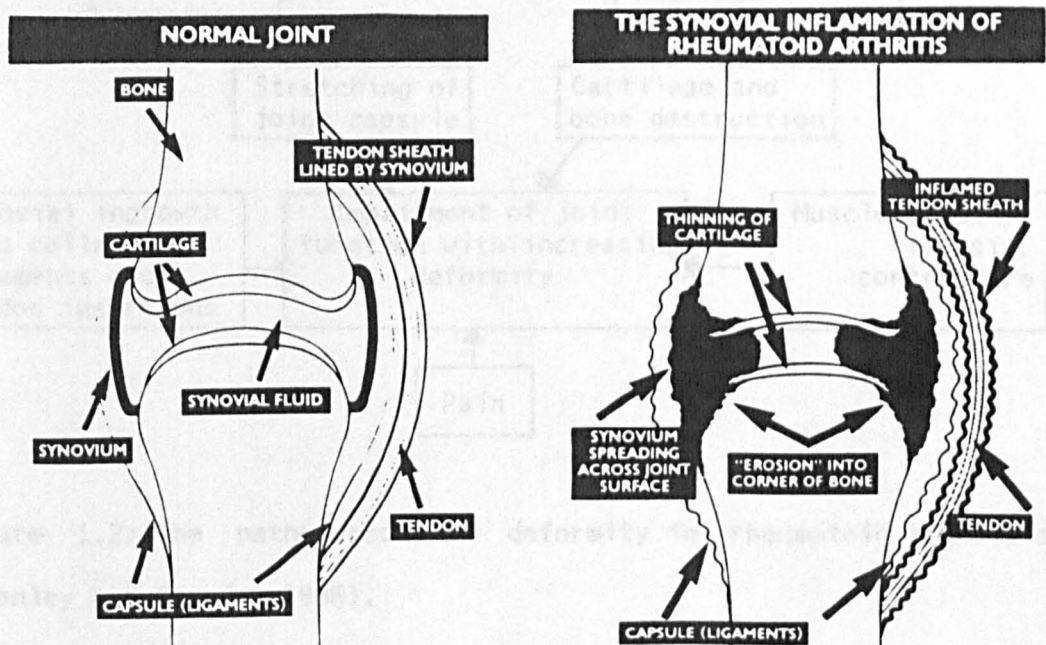


Figure 1.1: Normal joint structure and pathological features of rheumatoid synovitis (Arthritis and Rheumatism Council, 1991a).

Normal cellular and humoral immune mechanisms then become self-perpetuating, resulting in chronic inflammation long after the initial trigger has disappeared (Bhardwaj and Paget, 1992; Dieppe et al, 1985).

The main pathological feature is synovitis, ie. inflammation of the synovial lining of diarthrodial joints, tendon sheaths and bursae (Figure 1.1). Cartilage, bone, ligaments and tendons are eroded. Fibrosis and adhesions develop, resulting in stiffness.

These changes, combined with the mechanical stresses of weightbearing and muscular forces, produce the characteristic deformities of RA (Figure 1.2). Common deformities in the rheumatoid hand are described in section 1.2.4.

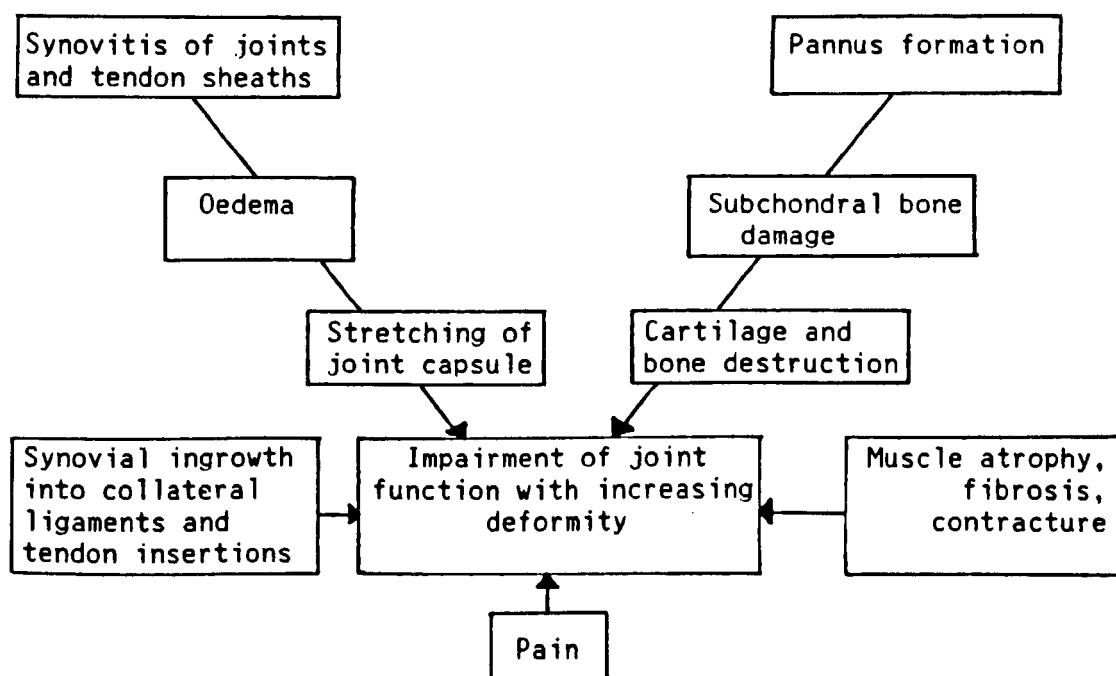


Figure 1.2: The pathogenesis of deformity in rheumatoid arthritis (Stanley and Norris, 1988).

1.2.3. CLINICAL FEATURES.

Disease onset may be sudden or insidious. Eberhardt (in Svensson, 1988) reported 25% of patients could recall the day of onset and 50% the month. The disease is initially intermittent but becomes more

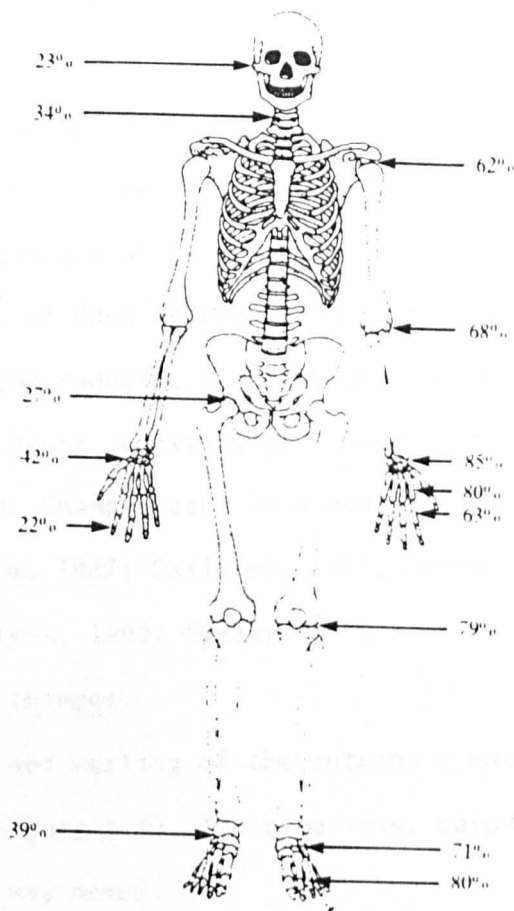


Figure 1.3: Distribution of joint involvement in RA (Dieppe et al, 1985).

sustained over time. Onset is polyarticular, symmetrical and in the hands in over 50% of patients (Eberhardt, Rydgren, Petersson and Wollheim, 1990; Svensson, 1988; Zvaifler, 1984). The wrists, metacarpophalangeal (MCP), proximal interphalangeal (PIP) and metatarsal (MTP) joints are the commonest initial sites of damage. It may then spread to larger, central joints (Figure 1.3).

Swelling, pain and stiffness are the commonest articular symptoms. Muscle weakness, loss of range of movement (ROM) and soft tissue contractures are early secondary complications. Systemic features include vague ill-health, low grade fever, poor appetite, weight loss, undue fatigue, decreased stamina, and transient muscle pain. Other body systems can also be affected, eg. heart, lungs, eyes.

Diagnosis is on the basis of presenting symptoms, radiological evidence and laboratory tests (Appendix 1).

1.2.4. THE RHEUMATOID HAND.

Hand involvement in RA is common, with up to 90% of patients experiencing hand and wrist problems (McKenna and Wright, 1985). The major emphasis of much JP education is maintenance or improvement of hand function and reducing the risk of hand deformities. Flatt (1983) describes that every constituent tissue of the hand can be affected by the disease. Changes can be summarised as (Agnew, 1982; Agnew, 1983; Brattstrom, 1987; Cailliet, 1975; Cordery, 1965a; Melvin, 1989; Stanley and Norris, 1988; Swezey, 1971):

a) Soft tissue changes.

Joint swelling and wasting of the intrinsic muscles is apparent at an early stage (Figure 1.4). Tenosynovitis, carpal tunnel syndrome and tendon rupture may occur.

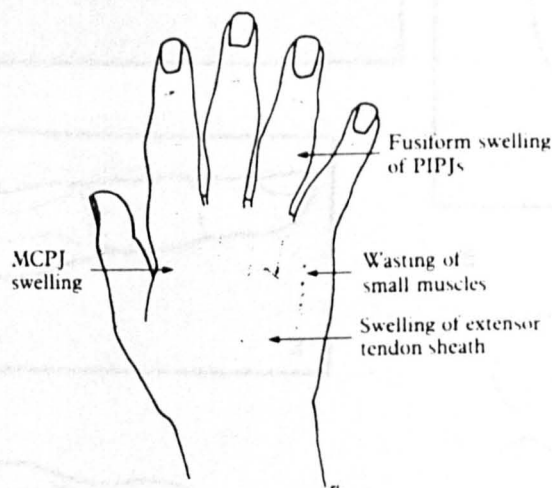


Figure 1.4: The early rheumatoid hand (Dieppe et al, 1985).

b) Wrist deformities.

Inflammation weakens the wrist and radio-ulnar ligaments, extensor carpi ulnaris tendon and disrupts the wrist's articular disc. Anterior subluxation and radial deviation result (Figure 1.5).

c) Metacarpophalangeal joint deformities.

Ulnar deviation and anterior subluxation occur in almost half of RA patients within five years of onset (Bishop, Hench, Lacroix, Millender and Opitz, 1991). Contributory factors include: wrist radial deviation, MCP ligament laxity, finger tendon sheath swelling, protective flexion responses of the interossei and lumbricals and strong pinch and pulp grip actions (Figure 1.5).

d) Finger and thumb joint deformities.

These include swan-neck, boutonniere and mallet finger and Z-thumb deformities (Figure 1.5).

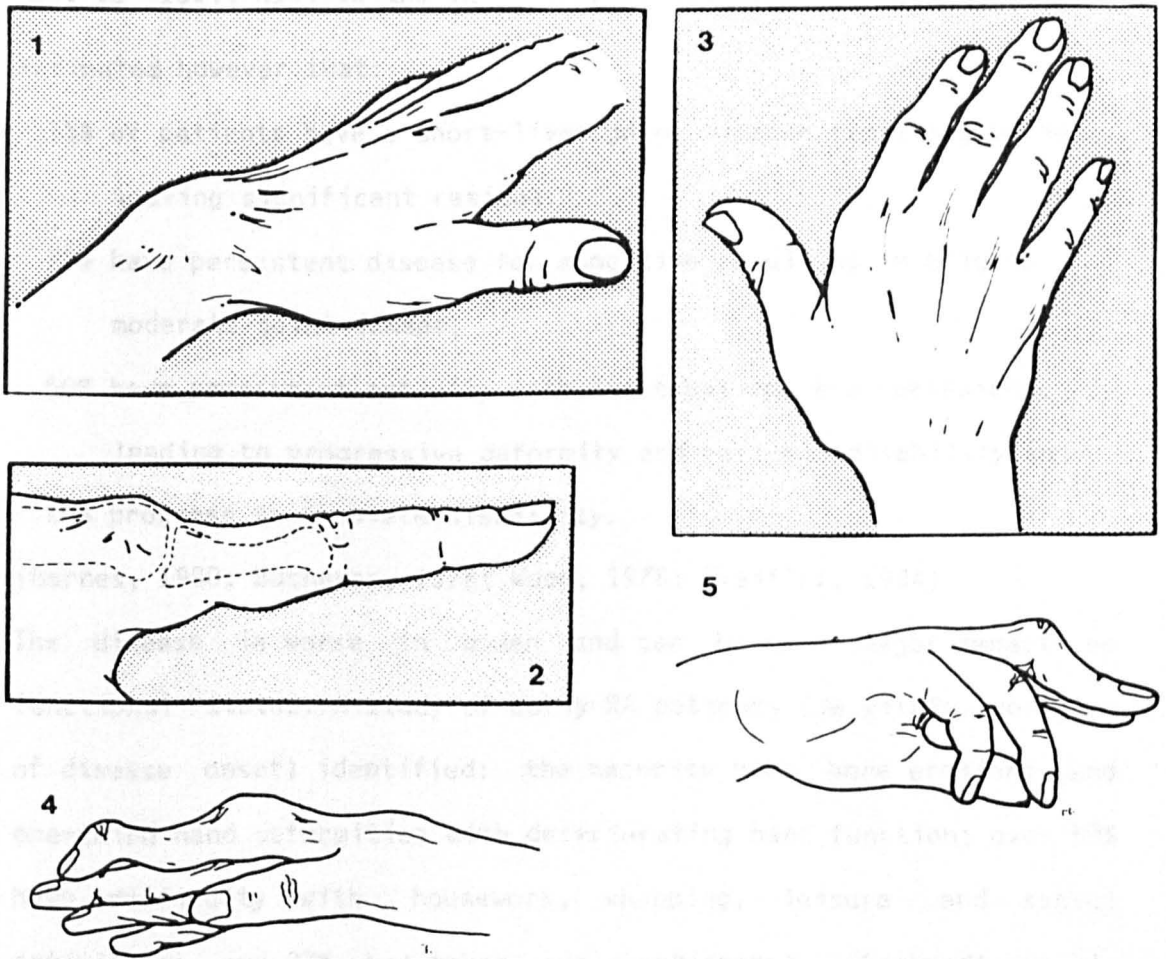


Figure 1.5: Common hand deformities (Dieppe et al, 1985; Melvin 1989). 1. Wrist anterior subluxation. 2. MCP anterior subluxation. 3. MCP ulnar deviation. 4. Swan-neck finger 5. Boutonniere finger.

Swelling, tenderness and radiographic changes (joint space narrowing and erosions) are significantly more severe, with deformity tending to be worse, in dominant hands (Boonsaner, Louthenroo, Meyer and Schumacher, 1992; Mody, Myers and Reinach, 1989; Owsianik, Kundi, Whitehead, Kraag and Goldsmith, 1980). This is commonly attributed to the dominant hand being used more frequently, skilfully and under greater joint stress than the non-dominant. Jones et al (1991) have demonstrated grip strength, manual dexterity and hand function are significantly reduced in RA patients.

1.2.5. PROGNOSIS.

This is still unclear due to a lack of longitudinal studies. It is estimated however that:

15% of patients have a short-lived joint disease remitting without leaving significant residua,

25% have persistent disease for some time resulting in mild to moderate joint damage,

50% have persistent activity with exacerbations and remissions, leading to progressive deformity and variable disability and

10% progress to complete disability.

(Barnes, 1980; Buchanan, 1978; Wood, 1978; Zvaifler, 1984).

The disease is worse in women and can have a major impact on functional status. A study of early RA patients (ie. within two years of disease onset) identified: the majority have bone erosions and one-third hand deformities with deteriorating hand function; over 50% have difficulty with housework, shopping, leisure and social activities; and 37% had taken early retirement (Eberhardt et al, 1990). In women with RA of on average 10 years duration: 89% had restricted leisure and hobby activities; 88% had difficulty with housework; 66% with shopping; 53% with work; 42% with cooking; and 42% with maintaining family and social roles (Reisine, Goodenow and

Grady, 1987). Most patients experience declining functional status (Pincus and Callahan, 1992).

1.2.6. MANAGEMENT.

It is not the intention to describe medical and rehabilitation management in detail here. Overall treatment aims include: education of the patient in the disease, its treatment and self-management techniques; relief of symptoms and prevention of disease progression, through drug therapy, rest, splinting and surgery; maintaining optimal joint function, through exercise, other physiotherapeutic modalities and joint protection; and modifying the environment to suit patients' needs, eg. by provision of aids and adaptations (Dieppe et al, 1985; Ehrlich, 1986; Liang and Logigian, 1992; Swezey, 1978).

Symptomatic improvement is achieved with drug therapy, eg. aspirin, paracetamol and non-steroidal anti-inflammatories (NSAIDs). By reducing pain, inflammation and stiffness, laxity of peri-articular structures should be reduced and muscle activity maintained promoting joint integrity. Disease modifying drugs, eg. gold, methotrexate and penicillamine, are used early to prevent or reduce erosive effects (Binder, 1992). Kushner (1989) concluded such treatment results in substantial improvement in the first years of use, but long-term outcome does not appear affected, because of poor long-term adherence in taking these. Multi-disciplinary team management is seen as essential by rheumatologists to complement drug therapy. Other treatments are also dogged by the problem of adherence. Belcon et al (1984) estimated at least 50% of RA patients are non-adherent, irrespective of intervention.

Comprehensive team care in both in- and out-patient programmes, including OT, has been shown to improve functional status of RA patients (Ahlmen, Sullivan and Bjelle, 1988; Feinberg and Brandt,

1984; Spiegel, Spiegel and Ward, 1987) as have comprehensive home OT programmes (Helewa et al, 1991). Many patients are not referred to rheumatology clinics (and therefore to such programmes) until five years or more post-diagnosis (Recht, Brattstrom and Lithman, 1989; Wood and Badley, 1983), by which time disease effects are usually well-established. Neither do patients commonly receive community care. A rheumatic disablement survey in one UK Health District identified only one in thirty people with ADL difficulties had received OT to assist with these (Tennant and Badley, 1992).

Many RA patients are unable to benefit from team care and OT at an early disease stage, particularly preventative self-management techniques such as JP. Yet the figures describing outcome in RA (section 1.2.5) suggest 60% to 85% of RA patients could benefit from receiving and implementing JP advice.

1.2.7. THE ROLE OF OCCUPATIONAL THERAPY.

Caruso and Cordery (1986) describe that the major emphasis of OT with rheumatic disease patients is teaching patients and their families self-management techniques, ie. joint protection, energy conservation and stress management, at an early stage of the disease. This is supported by training in alternate methods of ADL, provision of adaptive equipment, environmental and task modification, splinting, therapeutic activity and exercise programmes as appropriate. The OT's role is to improve a person's ability to perform daily tasks, facilitate successful adaptation to disruptions in lifestyle and prevent loss of function (Arthritis Health Professionals Association Practice Committee, 1992).

1.3. JOINT PROTECTION.

The aims of JP are to reduce pain, inflammation and internal and external joint stresses in order to preserve the integrity of joint structures and reduce the risk of deformities developing (Agnew,

1987; Brattstrom, 1987; Melvin, 1989). Principles are listed in Appendix 2.

1.3.1. COMPONENTS OF JP.

JP can be conceptualised under five main strategies or self-management techniques:

1. Exercise - providing full ranging of joints daily.
2. Splinting - the use of working and/ or resting splints to support joints in correct alignment and restrict joint motion.
3. Rest - to reduce pain and fatigue by: stopping and resting if pain and/or fatigue are acute or persevering; resting for longer during the day and at night; and taking regular rest periods.
4. Energy Conservation (EC) - to reduce pain and fatigue by: using work simplification, good posture and body mechanics, balancing rest and work, prioritising and pre-planning activities, eliminating unnecessary tasks, avoiding rushing and using unnecessary movements and having an ergonomic work area.
5. Altering Movement Patterns - of affected joints by: distributing load over more joints; avoiding positions of deformity; reducing effort through the use of technical aids, labour saving devices and avoiding lifting; using joints in stable positions; using stronger, larger joints. (Correct methods can be found illustrated in Appendix 3).

Much emphasis is placed on teaching altering movement patterns by OTs, particularly in relation to the hand and wrist joints (Hand JP). Using all these JP strategies in daily life would require a restructuring of time use to include: a daily exercise period, a daily rest period, regular short rests, allowing more time to perform tasks and allowing planning time to restructure, prioritise and decide which tasks to eliminate. Patterns of movement used to carry out a wide range of physically stressful work, leisure and daily living

activities need alteration. This may be combined with splint and technical aid use.

1.3.2. BIOMECHANICAL BASIS OF JP.

Inflamed synovium produces effusion stretching joint capsules and ligaments and interfering with surrounding muscles' function. This causes joint instability and promotes deformity, which is further aggravated by cartilage and bone erosion (Chamberlain, Ellis and Hughes, 1984). Whilst JP cannot effect the underlying disease cause and pathology, it can theoretically limit the effects of these processes by:

- a) reducing joint stress resulting from normal daily activities by reducing the force or effort necessary to perform these (both:
 - i) internal, ie. reducing muscular compressive forces during strong grip actions, eg. by using technical aids applying leverage, distributing load over two hands and;
 - ii) external ie. avoiding excess loading from heavy weights and resistive activities, eg. by avoiding lifting and positions of deformity) and therefore;
- b) reducing secondary inflammation, resulting from continuing irritation of inflamed synovium during normal activity and from forcing hands to do actions when painful and/or stiff. This leads to co-contraction of antagonistic muscle groups, aggravating the inflammatory response and further stretching peri-articular structures if not avoided;
- c) reducing excess physical stretch on peri-articular structures during activity and so limiting the development of capsular laxity;
- d) reducing pain, resulting from:
 - i) excess stretch and compression of inflamed capsules, thus reducing protective flexion responses in muscles and avoiding reduction in joint RoM from this cause, and from

ii) chronic muscle tension and joint overuse. Unstable joints under stress require greater muscular activity to maintain positioning, resulting in muscle fatigue and diffuse aching round joints and muscles;

e) reducing fatigue, as less muscular activity and thus less energy is used;

f) limiting further damage to articular cartilage. Cartilage, ligaments and sub-chondral bone are normally protected from absorbing the full shock of compressive forces during activity by "the attenuation of shock by joint motion combined with lengthening muscles under tension" (Radin, 1975). Where muscles are insufficiently strong or their actions insufficiently co-ordinated (eg. due to fatigue or pain limiting speed of reaction) to do this, loading on cartilage and sub-chondral bone increases promoting osteoarthritic changes (McCloy, 1982). Maintaining muscle action through exercise and ligamentous stability through reduction of stress should assist maintaining the normal shock absorbing process;

g) promoting correct alignment of joints, thus assisting maintenance of a correct balance of extrinsic and intrinsic muscle action, maintaining joint stability and reducing excess force resulting from using hands in "trick" or compensatory positions.

(Bishop et al, 1991; Brattstrom, 1987; Chamberlain et al, 1984; Cordery, 1965b; Liang and Logigian, 1992; McCloy, 1982; Melvin, 1989; Philips, 1989a and 1989b).

Joint Protection is widely held by rheumatologists to be an essential component of treatment programmes for RA patients (eg. Barnes, 1980; Bird, le Gallez and Hill, 1985; Birnbaum, Gerber and Panush, 1989; Bishop et al, 1991; Brattstrom, 1987; Chamberlain et al, 1984; Ehrlich, 1986; Flatt, 1983; Huskisson, 1983; Swezey 1978). Much has been published describing the principles and application of JP,

particularly Hand JP and EC (eg. Baginski, 1989; Brattstrom, 1987; Gruen, Medsger and White, 1980; McKnight, 1988; Melvin, 1989; Philips, 1989a and 1989b; Rossky, 1980; Still, 1983). However, there is relatively little evidence for the effectiveness of JP in achieving these aims.

1.3.3. REVIEW OF JP EFFICACY.

a) Exercise.

Exercise is necessary to maintain both muscle power for joint stability and joint RoM and is of proven benefit in RA. Partial and non-weightbearing aerobic exercise (eg. cycling and swimming) can improve general fitness and reduce fatigue (Harkcom, Lampman, Banwell and Castor, 1985) and aerobic training reduce the number of swollen joints (Lyndberg, Danneskiold-Samsøe and Halskov, 1988). Isometric and joint ranging exercise programmes, commonly provided for patients to follow at home, can maintain joint RoM and muscle strength (McCubbin, 1990). Regularly using hand exercise programmes reduces loss of joint RoM and maintains or increases grip strength (Brighton, Lubbe and van der Merwe, 1993), improves dominant hand joint count and dexterity (Hoenig, Groff, Pratt, Goldberg and Franck, 1993) and reduces pain with non-resisted motion, joint stiffness and flexion deficits (Dellhag, Wollersjö and Bjelle, 1992). However, long-term maintenance of exercise regimes is problematic (Minor and Brown, 1993).

b) Splinting.

Splinting theoretically supports the joint, reduces stress to the capsule, allows muscles to relax, eliminates pain due to motion and therefore results in decreased inflammation (Melvin, 1989). Relatively few studies have been conducted evaluating effectiveness, with the majority of studies having small sample sizes.

i) Hand Resting Splints.

These are recommended to be worn almost continually during acute exacerbations of the disease and at night when synovitis is present. Gault and Spyker (1969) and Partridge and Duthie (1963) have demonstrated significant reduction in disease activity (ie.reduced inflammation and increased wrist RoM) in patients wearing resting splints (immobilising the hand and wrist) continually during in-patient admissions of three weeks, in comparison to non-splinted patients. This was only of short-term benefit as deterioration was noted one week after the end of treatment.

A 17 month follow-up study of seven patients wearing a night resting splint regularly on one hand only, demonstrated the majority reported nocturnal pain relief but there was no significant difference in the progression of ulnar deviation in splinted and non-splinted hands (Malcus-Johnson, Sandkvist, Eberhardt, Liang and Herrlin, 1992). Feinberg and Brandt (1981) concluded resting splints had no effect on RoM or stiffness. If patients do not report nocturnal pain relief, night splinting apparently is of no benefit.

ii) Wrist Working Splints.

Wrist working splints (immobilising or partially immobilising the wrist during activity, depending on the splint's structure) have been shown to reduce pain and increase grip strength (Backman, 1988; Biddulph, 1981; Nordenskiold, 1990). Grip strength is increased in those with moderate to severe but not mild involvement (Sharma, Von Feldt, Imonite and Schumacher, 1991). Certain styles of wrist splint restrict dexterity and slow hand function meaning patients may perceive these as an encumbrance and only wear them for specific activities or not at all (Carlson and Trombley, 1983; Stern, 1991). Agnew and Maas (1990) in a two year follow-up of subjects wearing elastic wrist splints showed no significant difference in progression

of deformity on X-ray analysis in comparison to a control group.

Wrist splints are of most value to those with moderate to severe involvement for pain relief and to improve function.

iii) MCP Splints.

Although a variety of splint designs are used to provide pain relief, increase function and prevent or reduce progression of ulnar deviation and anterior subluxation at the MCP joints, no studies could be identified evaluating these.

iv) Finger Splints.

Palchik et al, (1990) evaluated the effectiveness of a 6 week programme of splinting (in complete immobilization) and individualized Hand JP education with three patients with a boutonniere deformity in comparison to five control subjects. At six weeks, splinted subjects had no evidence of deformity whilst control subjects' fingers were unchanged. Splinted subjects had some recurrence between three to six months post-treatment. One continued nightly splint use for one year with no recurrence. Control subjects' deformities remained the same or progressed. Although taught Hand JP, the resolution of deformity in the patient using a night splint suggests splinting, rather than Hand JP, was the most effective component.

Adherence to splint-wearing is also problematic (Feinberg, 1992).

c) Rest.

Acutely inflamed and painful joints should be rested. Complete bed rest for two to three weeks has been shown of short-term effectiveness in reducing inflammation in some studies (eg. Scott and Wolman, 1992) but not others (Alexander, Hortas and Bacon, 1983; Mills, Pinals and Ropes, 1971).

Patients are recommended to rest for 10 to 12 hours per day, including one to two hours during the day to assist natural recovery

processes, improve overall endurance for activity and enhance muscle function (Melvin, 1989). Both Cordery (1965b) and Melvin (1989) stress the necessity of respecting pain, by reducing activity and resting in response to pain lasting more than one hour post-activity. Higher pain levels are related to greater joint swelling (Hagglund, Haley, Reville and Alarcon, 1989), suggesting that if rest reduces inflammation, pain will also reduce. However, there appears to be no objective evidence that increasing daily rest duration and resting in response to pain can affect inflammation or pain levels, nor is there objective evidence of patients' adherence to this advice.

d) Energy Conservation.

Only one study has been identified evaluating EC efficacy. Using EC methods of regular rest periods throughout activity to prevent fatigue increases patients' duration of daily physical activity (Gerber et al, 1987), although no significant difference in self-reported pain, functional disability or fatigue, nor in articular index, walk time or grip strength occurred following EC education. However, the authors highlight that the follow-up period was short (three months) and sample size small, providing insufficient data for conclusive results.

e) Altering Movement Patterns and Hand JP.

Joint stress is reduced by altering normal movement patterns through applying the JP principles of:

- i) Distributing load. The entire palmar surface and/ or two hands should be used when lifting to reduce external stress on individual joints;
- ii) Using stronger, larger joints. A given amount of stress is tolerated better by a larger joint;
- iii) Using joints in stable positions. This reduces excess stretch on ligaments and allows muscles to be used to the best mechanical

advantage;

- iv) Reducing effort by using technical aids, labour-saving devices and avoiding lifting. Less muscular effort reduces internal joint stress and;
- v) Avoiding positions of deformity. Tight gripping actions at the MCPs promote anterior subluxation and finger twisting actions promote ulnar deviation. Joints should be used in correct alignment and less force applied during activity.

(Brattstrom, 1987; Cordery, 1965b; Melvin, 1989; Liang and Logigian, 1992).

Anecdotally, using different movement patterns to perform painful tasks, eg. lifting heavy saucepans, can immediately reduce pain on activity and, with continued use, can reduce joint stress and inflammation over a several day period (Melvin, 1989). Only two studies have been identified evaluating pain and reduction of joint stress, both of which were pilot studies proposing methods for evaluating outcome. Campbell and Schkade (1991 and personal communication) utilised the McGill Pain Scale before and after two RA subjects lifted a heavy container using a normal grip versus a JP method. Only one patient reported less pain, with the other reporting greater pain. Agnew (1987) tested five normal subjects applying normal and JP methods (including use of technical aids) for five common activities taught during JP education. Muscle activity in Extensor Carpi Ulnaris was measured using electromyography. This muscle was selected as it is under constant stress in all hand activities as a prime mover, stabiliser or antagonist and thus indicative of the degree of wrist joint stress. For only one subject did JP methods result in reduced muscle activity in all five tasks. Muscle activity was increased with some JP methods and in some subjects.

There is also evidence that use of some technical aids (eg. electric can openers and easy vegetable peelers) reduce pain (Bradshaw, 1981; Bradshaw, 1986). Technical aids are more commonly prescribed for patients with rheumatoid and osteoarthritis than for any other chronic disease, but usage rates are highly variable (Rogers and Holm, 1992).

1.3.4. POTENTIAL PSYCHOLOGICAL EFFECTS OF JP.

JP education is often claimed by clinicians to assist patients in adjusting to the disease. Deformities and functional limitations impact on independence, personal relationships and psychological state. The main problem reported by RA patients in a dutch survey was the frustration of being unable to do things they used to do and of dependency on others (Cornelissen, Rasker and Valkenburg, 1988). Difficulties in performing homemaking tasks (cooking, cleaning, shopping, family care) can give rise to feelings of guilt, a sense of loss at the inability to perform activities central to social roles (eg. mother/carer, homemaker), reduced autonomy and concerns about restricting other family members lives (Williams, 1987). Many women perceive their hands as inherently unattractive compared to before developing RA, even without visible deformities (Vamos, 1990). Body image, independence and ability to fulfil normal roles contribute to self-esteem. Any means by which deformities and functional deficits can be avoided or limited could maintain the individual's independence, role activities and psychological well-being.

There appears to be a relationship between psychological variables and functional status. Patients using active coping strategies and with less anxiety and depression, have lower levels of functional impairment (Hagglund et al, 1989). Whether this relationship is causal is unknown.

JP is an active coping strategy. By enhancing patients' belief in

their ability to control disease symptoms (but not to eliminate the disease) through utilising JP strategies, locus of control (LOC) could be enhanced, ie. "the degree to which individuals perceive events in their lives as being a consequence of their own actions, and thereby controllable (internal control) or as being unrelated to their own behaviour, and therefore beyond personal control (external control)" (Lefcourt, 1976). Thompson (1981) suggests that internal LOC reduces emotional stress through:

i) informational control - knowing about factors indicating the onset of negative events provides some predictive ability. In JP education, patients should be taught to recognise the symptoms of inflammation and evaluate disease activity through monitoring levels of synovitis and fatigue (Sliwa, 1986). Monitoring should enable some prediction of symptom worsening due to overuse or exacerbation.

ii) behavioural control - believing a behaviour will regulate a negative event provides the assurance this event will not become completely unmanageable. Early application of JP, once increasing synovitis has been monitored, should theoretically prevent or diminish ensuing symptoms.

iii) a sense of control reflects positively on the self. A lack of control can lead to learned helplessness, ie. a person may learn they have no personal control over what happens to them in certain situations as, in the past, efforts to change these were ineffective. Consequently, actions to change the situation are not used as believed ineffective, and new, effective responses are not learnt. Learned helplessness can lead to lower self-esteem and depression (Lau, 1988). Demonstrating JP can lead to reduced pain and fatigue by asking patients to apply techniques (eg. Hand JP for commonly painful tasks) may assist them in perceiving actions are effective, enhance control and reduce learned helplessness.

Anxiety and depression increase pain perceptions (Hagglund et al, 1989). Through reducing these, by teaching active coping strategies to enhance locus of control, pain perceptions may be reduced. No studies have evaluated whether JP education affects locus of control, learned helplessness or other psychological variables. Parker et al (1984) evaluated an AEP predominantly teaching JP, EC and coping with psychosocial stresses. Patients reported significantly more pain and physical impairment following education than controls receiving standard care. It was suggested JP could be heightening patients' sense of vulnerability as they were assuming too strong a relationship between movement and joint damage. Presumably the JP education was ineffective in enhancing beliefs that JP limits joint damage. This finding has not been reported in other AEP evaluations.

1.3.5. SUMMARY.

There is some evidence to support claims of the effectiveness of some JP strategies. Hand pain can be reduced by regular hand exercises and splinting; inflammation can be reduced by prolonged bed rest and prolonged splinting; deformity has only been shown to be reducible in boutonniere fingers by splinting.

No research was identified to demonstrate the efficacy of EC, altering movement patterns and Hand JP nor was there evidence that JP strategies reduce joint stress, preserve joint structures and reduce the risk of deformities.

1.4. PATIENT ADHERENCE.

Foa and Emmelkamp (1983) reported that treatment failure may be due to two factors: the treatment methods are ineffective or the client fails to adhere sufficiently to the methods. Non- or limited adherence to prescribed and recommended treatments is widespread amongst RA patients.

The term adherence rather than compliance is used throughout. Agras

(1989) states:

"Compliance...denotes following a regimen prescribed by a physician, indicating a relatively passive role for the patient. Adherence, on the other hand, suggests a more equitable role in which the patient participates in goal setting and in determining the particular manner in which the goals will be reached, with shared responsibility for the outcome. The more complex ... the more long-term the health problem to be addressed, the more desirable it is that the second, more participatory, model be followed."

As adopting JP requires multiple changes in task performance and time use, adherence is a more appropriate term.

1.4.1. ADHERENCE TO JP BEHAVIOURS.

Few studies have investigated how commonly JP behaviours are used by RA patients, apart from exercise and splints. Melvin (1989) noted "widespread long-term compliance difficulties" with JP.

Surveys evaluating the proportion of exercise adherence range from 39% to 65% of patients (Ferguson and Bole, 1979 (40%); Kroshus and Abbott, 1988 (55%); O'Carroll and Hendriks, 1989 (53%); Parker and Bender, 1957 (39%); Treusch and Krusen, 1943 (65%)).

Reported use of splints varies between 25% and 65% (Feinberg and Brandt, 1981 (62%); Ferguson and Bole, 1979 (25%); Moon, Moon and Black, 1976 (28%); Nicholas, Gruen, Weiner, Crawshaw and Taylor, 1982 (50%); Oakes, Ward, Gray, Klauber and Moody, 1970 (65%); O'Carroll and Hendriks, 1989 (36%)). Spoorenberg and Boers (1991) reported wrist working splints were more commonly used than resting splints by patients prescribed both.

RA patients often comment they alter some movement patterns and use some Hand JP and EC methods naturally in response to pain. This natural use is little documented. Conn (1990) surveyed self-care

practices of 53 older adults, with self-reported "joint problems." Rest was cited as a method of pain relief by 11% and Joint Protection by 2%. Work simplification and use of aids were not cited at all. Hampson et al (1993) surveyed self-management practices of 61 Osteoarthritis (not RA) patients identifying 75% rested (EC) and 25% used JP methods (excluding exercise and splints). Tack (1990) identified pacing and recovery periods to aid fatigue but did not state the frequency these were used. Use of technical aids is variable, with a substantial proportion not used. Hollings and Haworth (1978) identified 21% of aids prescribed to RA patients were not used one-year later. Most studies have been with multidagnostic groups and a variety of aids. Disuse rates are between 18% and 59% (Bynum and Rogers, 1987 (18%); Finlayson and Havixbeck, 1992 (25%); Haworth, 1983 (59%)). Patients' use of Hand JP significantly correlates with self-reported hand pain on activity (Hammond, 1988). Adherence to many JP practices is either poor or unknown. The reasons why patients do not adhere to treatment are multiple and complex.

1.4.2. FACTORS AFFECTING ADHERENCE.

Factors affecting adherence include:

- i) Health beliefs - individuals do not act unless they perceive their illness leads to serious organic or social repercussion (ie. perceived threat); they have confidence in the diagnosis, the clinician and the recommended treatment (ie. belief in benefit of treatment) (Becker, 1976); and they believe they can carry out the treatment regimen (ie. self-efficacy) (Meichenbaum and Turk, 1987; Rosenstock, 1988).
- ii) Degree of patient satisfaction - with Health Care Professionals (HCPs), eg. poor patient - clinician interaction (Haynes, 1976); and with the treatment regimen. Satisfaction is closely related to the degree to which patients' beliefs and expectations have been met, eg.

the extent to which the treatment "fits in" to their explanatory model of illness (Meichenbaum and Turk, 1987).

iii) Poor communication of instructions - eg. when and how to use the treatment (Ley, 1977).

iv) Poor recall - the more complex the instructions, the more likely they are to be forgotten (Agras, 1989).

v) Duration of treatment - the longer the treatment, the greater the probability of life events, eg. illness, change of job, interfering with daily routines making treatments requiring life-style changes (eg. JP) more difficult to implement (Agras, 1989).

vi) Degree of behavioural change required of the patient - the greater, the less co-operation (Haynes, 1976; Meichenbaum and Turk, 1987).

vii) Immediacy of treatment effects - immediate, observable effects promote greater adherence than delayed or hidden effects (Agras, 1989)

viii) Organisational factors - poor degree of supervision, eg. irregular appointments with clinicians (Haynes, 1976); poor continuity of care; poor communication between health care professionals and poor role delineation (Agras, 1989); the health care professional or clinic do not teach or use strategies to facilitate adherence (Meichenbaum and Turk, 1987); poor physical facilities, eg. limited parking (Agras, 1989); insufficient appointment reminders, block rather than individual appointments and long waiting times (Agras, 1989).

ix) Socio-economic factors - limiting accessibility to health care, eg. work and family commitments (Thompson, 1984).

x) Social support - lack of family and spouse support reduces adherence (Sallis and Nader, 1988).

1.4.3. HEALTH BEHAVIOUR MODELS.

A number of models have been proposed to explain the relative importance of different factors in adherence or non-adherence to health behaviours. The most frequently used theories are outlined below.

a) The Health Belief Model (HBM).

This model explains health behaviours from the perspective of the individual decision-maker (Salazar, 1991). The individual's beliefs are seen as primary influential factors, predominantly: having sufficient concern to perceive the health behaviour as relevant; a belief that one is susceptible to an illness or its consequences; and that the behaviour will be sufficiently beneficial at reducing the illness or its consequences at an acceptable cost (Rosenstock, Strecher and Becker, 1988). "Cost" refers to the barriers (outlined in section 1.4.2) which restrict adoption of behaviours. Even though an action may be seen as beneficial, if it is too inconvenient, unpleasant or expensive it will not be utilised. These factors influence the person's likelihood of carrying out the behaviour (Figure 1.6).

The HBM is a psychosocial model explaining behaviour in terms of attitudes and beliefs. Janz and Becker (1984) highlighted deficiencies in the model: health is considered as a highly valued goal for most people, where this is not the case, the HBM is unlikely to explain behaviour; health behaviours may be undertaken for non-health reasons, eg. to gain social approval. A patient may decide to use a splint or walking stick as a "badge" showing their disability to others in order to gain assistance or attention, not as a JP strategy; economic and environmental factors may prevent behaviours being used, eg. a patient may be unable to afford the cost of technical aids to reduce joint stress; and some behaviours are

habitual. meaning that even though a conscious decision is made that performing an alternative behaviour is beneficial, it is difficult to overcome present habits and institute change.

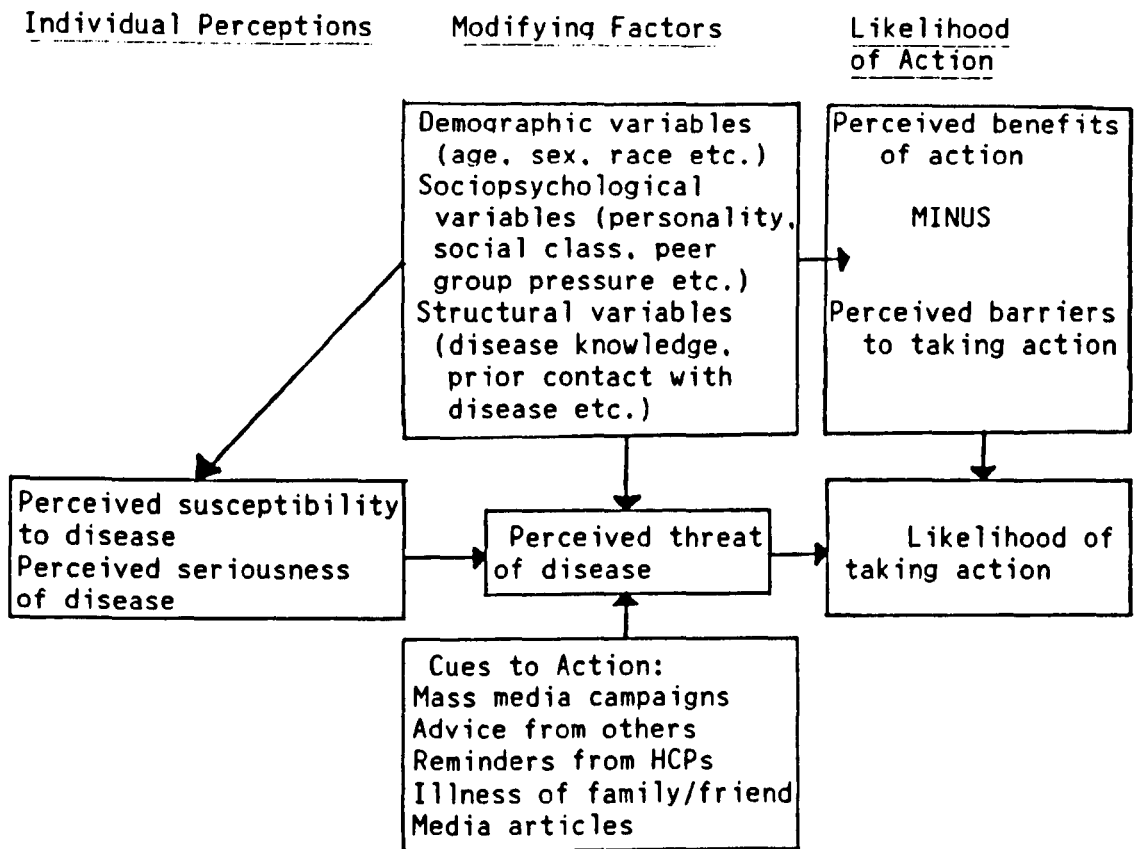


Figure 1.6: The Health Belief Model (in Rosenstock, 1974).

Janz and Becker (1984) and Rosenstock, Strecher and Becker (1988) have therefore suggested elements of other theories should be integrated into the model or utilised in association with it to explain health behaviour, particularly social learning theory and self-efficacy.

b) Self-Efficacy Theory (SE).

Bandura (1977) proposed that behavioural change is a function of self-efficacy (a construct from social learning theory) which has two major components: efficacy expectations, ie. the belief one can perform the activity; and outcome expectations, ie. the belief the effect of the behaviour will be desirable, a similar concept to

perceived benefits in the HBM (Rosenstock, Strecher and Becker 1988).

Figure 1.7 illustrates this relationship.

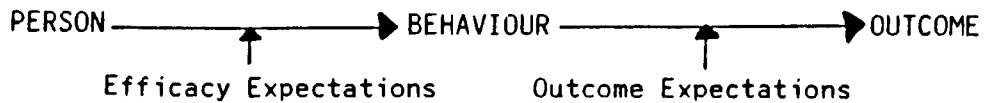


Figure 1.7: Self-Efficacy Theory (Bandura, 1977).

For a person to adopt JP methods (behaviour) to improve disease symptoms (outcome), they must believe JP will improve health status (outcome expectancy) and that they are capable of making sufficient changes in their time use and in daily activities (efficacy expectancies). Self-efficacy has been shown to be a major predictor of behaviour (Rosenstock, 1988).

c) Theory of Reasoned Action (TRA).

Fishbein and Ajzen's Theory of Reasoned Action (1975) is based on the belief that people act rationally, contemplating their actions before deciding whether or not to do them. It assumes one's intention to act is a major predictor of behaviour. Two major influencing factors on intention to act are: attitude towards the behaviour, ie. whether the person perceives the behaviour as beneficial or not and whether the behaviour is perceived to be important to them personally; and perceptions of social pressures (from family, friends and those seen as important, eg. health care professionals) to perform or not the behaviour and the motivation to conform to these pressures (Salazar, 1991; Mullen, Hersey and Iverson, 1987) (Figure 1.8).

This theory however, presupposes behaviour is under complete volitional control and that the intention to act results in the behaviour. Self-efficacy theory has also influenced the development

of this model, which has been expanded to include the concept of perceived behavioural control as additionally influencing intention. This construct includes: the belief about the ease with which the behaviour can be performed (similar to efficacy expectation); and barriers to performing this (similar to perceived barriers) (Ajzen and Madden, 1986). These three factors are seen as the most influential and therefore no other modifying variables, such as age and educational status, are included in the revised model, the Theory of Planned Behaviour (Ajzen, 1985).

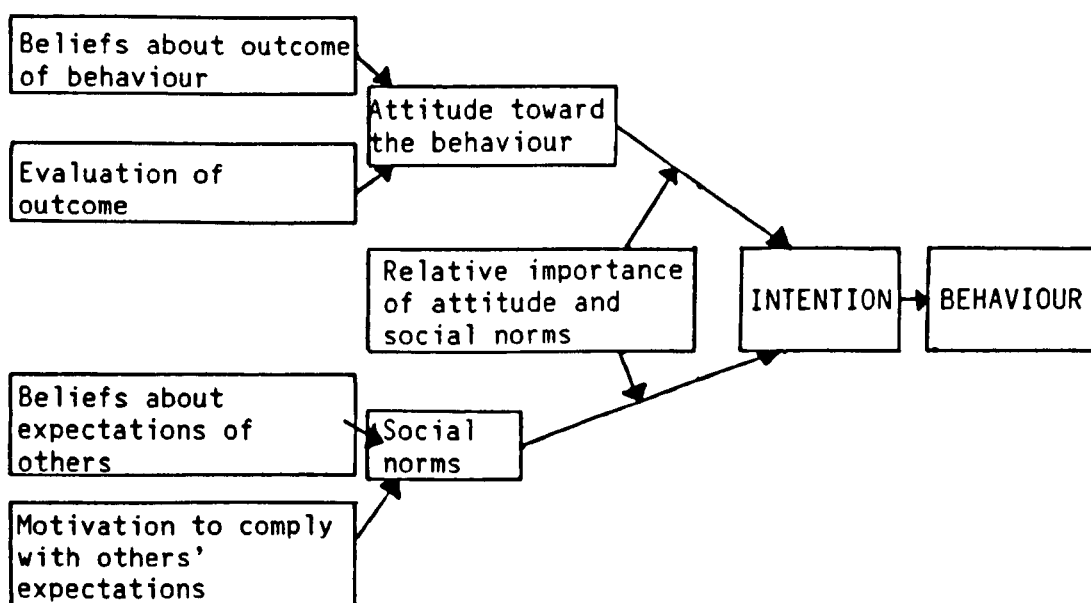


Figure 1.8: Theory of Reasoned Action (after Salazar, 1991; Young, Lierman, Powell-Cope, Kasprzyk and Benoliel, 1991).

Young et al (1991) identified problems with this model in practice, primarily in evaluating attitudes reliably, eg.: when a person does not believe in the benefit of the behaviour in question; measuring attitudes acontextually, as in some instances not performing a behaviour may be bad, but mitigating factors for non-performance mean this may be acceptable; and subjects' difficulty distinguishing between the concepts evaluated and frustration with apparently

reiterative questions.

d) PRECEDE.

PRECEDE (ie. Predisposing, Reinforcing and Enabling Constructs in Educational Diagnosis and Evaluation, Green, Kreuter, Deeds and Partridge, 1988) was developed for the evaluation of health education programmes. Mullen et al (1987) describe that this integrates many of the concepts of the HBM, SE theory and TRA and can also be utilised to explain health behaviour. The three major components are: Predisposing factors, eg. a person's prior knowledge, attitudes, belief and experience; Enabling factors, eg. characteristics of the individual, community and environment; and Reinforcing factors, eg. social support. Mullen et al (1987) suggest that its benefit is that the Reinforcing factors component addresses why behaviours may or may not be maintained over time but its drawback is the large number of variables included and lengthy interview required to investigate it.

1.4.4. THE HEALTH BELIEF MODEL AND SELF-EFFICACY THEORY.

The HBM is the most widely evaluated model and Mullen et al (1987) have recommended this has advantages over the PRECEDE and TRA models for evaluating adherence, in terms of acceptability to respondents (when used as a basis for constructing interview questions), parsimony (ie. requires less questions) and specificity of questions. It has therefore been used as the theoretical framework for this study.

The Health Belief Model and Self-Efficacy Theory are derived from similar theoretical roots and have been coalesced (Rosenstock, Strecher and Becker, 1988). This revised model suggests the likelihood of a person adopting a behaviour is influenced by many factors:

a) Perceived threat of the disease.

This will be influenced by individual perceptions of:

i) perceived susceptibility to the disease. For patients already diagnosed with a condition, this refers to a person's belief in the accuracy of the diagnosis and the likelihood of disease recurrence.

ii) perceived severity of the disease, ie. the person's subjective perception that serious organic and/or social repercussions will result;

and by modifying variables, eg:

iii) demographic variables such as age, sex and race,

iv) sociopsychological variables, such as personality, social class, peer and reference group pressure,

v) structural variables, such as knowledge about the disease, prior contact with it, knowledge of required health behaviours and how to correctly perform these,

vi) cues to action. These may be:

- external, eg. advice from others, articles in the media, specialist information booklets, education campaigns or

- internal, eg. the person's perception of their bodily state.

b) Perceived benefits of the behaviour.

This is the extent to which a person believes the behaviour/s will be beneficial and is similar to the concept of outcome expectancy in self-efficacy theory, ie. the outcome expected from executing the behaviour. The stronger the belief in beneficial outcomes, the more likely the person is to be motivated to change.

c) Perceived barriers to performing the behaviour.

The likelihood of a behaviour change will be decreased by perceived barriers to carrying out the behaviour, eg.; cost, extent to which it must be adopted (particularly if there are many new behaviours at once and/or the person has social, family or work pressures), and it's complexity and duration.

d) Self-efficacy expectancy.

This is the degree to which one believes one can successfully perform the behaviour. This influences how much effort a person expends on a behaviour and how persistent in the face of obstacles. Feelings of self-efficacy can vary from one situation to another.

A review of Health Belief Model research (Janz and Becker, 1984) concludes that perceived severity, benefits of treatment, barriers and susceptibility (in that order) are the most influential factors in adherence with treatment advice in those with a medical diagnosis. Self-efficacy is also highly rated as an influential factor where behavioural changes are long-term (Rosenstock, 1988).

Social Learning theory emphasises that adequate reinforcement (incentive) and level of skill are needed to perform the behaviour.

1.5. PATIENT EDUCATION.

Health education has been defined as "any combination of learning experiences designed to facilitate voluntary adaptations of behaviours conducive to health" (Green et al, 1988). Patient education is the process by which patients learn to participate in their own management. It empowers patients to take control of their condition and enhances co-operation between the health care professional and patient in order to reduce ill-health and enhance positive health (Downie, Fyfe and Tannahill, 1990). It therefore goes beyond providing information and must include strategies to assist patients in making behavioural changes in order to adhere to recommended treatments. Bower (1985) and Redman (1993) classify goals of patient education in three domains:

- i) Cognitive change - an adequate understanding of the treatment is required: what they are required to do and why, how and when it should be done and what equipment may be needed.
- ii) Attitudinal change - is required: a belief in the benefit of

treatment (perceived benefit or outcome expectancy), health locus of control (ie. a belief in one's general ability to influence the disease through one's own actions), efficacy expectation (ie. a belief that one is able to perform the behaviour being taught), acceptance or emotional adjustment to the illness, the willingness to use self-management techniques and the intention to adhere to the various requirements of the treatment.

iii) Behavioural change - ie. the adoption and maintenance of the desired behaviours at an appropriate frequency level, which requires an appropriate level of psychomotor skill.

It is presumed behavioural change then results in improved health status but Holman and Lorig (1987) cast doubt on this, suggesting other psychological attributes, specifically self-efficacy, may be another mediating factor.

There is not necessarily a causal relationship between the three factors above, although knowledge and attitudinal change are thought necessary before behavioural change can occur. Barriers to behavioural change were cited above (sections 1.4.2 and 1.4.4).

1.5.1. PATIENT EDUCATION IN ARTHRITIS MANAGEMENT.

Patient education is considered a foundation to arthritis management (Ehrlich, 1986; Riggs and Gall, 1984). Arthritis education programmes (AEPs) have become increasingly common in North America, Europe and Australia, in community as well as health care settings. In the UK, AEPs are predominantly run in Rheumatology centres.

A review of arthritis education research concluded that patient education can increase knowledge, change attitudes (eg. improve mood/morale: stated as including acceptance and hopefulness, coping ability and self-efficacy) and increase some health behaviours (exercise, relaxation, sleep duration) (Lorig, Konkol and Gonzalez, 1987). They reported 61% of the health status measures utilised

within the reviewed articles showed improvement (ie. pain, disability, painful joint count, depression and quality of life), and concluded the effect of AEPs could be potentially similar to that of other arthritis treatments, such as NSAIDs.

1.5.2. PATIENT EDUCATION APPROACHES.

Bartlett (1982) broadly defined two approaches to patient education:

a) the Information Dissemination model associated with eg. teaching (lectures), instructional aids (written, visual), demonstration, counselling and, increasingly, multimedia programmes. This didactic approach is mainly oriented towards increasing knowledge and to a lesser extent attitudes and skills and,

b) the Behaviour Change model, based on behavioural diagnosis, ie. prior needs assessment and identification of barriers, motivation, beliefs, habits, skills and environmental factors influencing behaviour. This utilises a range of strategies, including teaching, demonstration, instructional aids and counselling, and additionally eg. peer group discussion, behaviour modification, simplifying the regimen, social support and community organization.

Behavioural change approaches include a range of cognitive-behavioural therapies (CBT), which arose from a fusion of cognitive and behavioural therapy. Cognitive therapy was initially developed by Beck (1976) working with depressed clients, using an information-processing model, to aid clients identify, modify and evaluate dysfunctional thought patterns. Strategies include problem-solving, imagining and planning to alter negative cognitions of self and events. Behavioural therapy is based on classical and operant conditioning positing people as essentially passive, with behaviour altered by modifications in the environment (Scott, 1989). Social Learning theory (Bandura, 1977a) emphasised other important influences are from observing the behaviour of others and its

consequences. Strategies used in this approach include modelling, behaviour modification and reinforcement schedules. CBT is jointly concerned with both the mechanics of training (eg. practice, feedback and reinforcement) and clients' readiness to learn (eg. outcome expectancies, values, understanding of causes and consequences of actions), ie. not only overt motor acts but clients' thoughts and beliefs (Karoly, 1982). It utilises additionally such techniques as covert modelling, guided imagery and role-play. Teaching is generally time-limited (eg. six to twelve weeks) and many programmes run effectively as groups. Scott (1989) warns of the danger these may be taught mechanically. Strategies must be adapted to individual members' needs and for the therapist to convey empathy, warmth and positive regard.

Essentially CBT is a psycho-educational approach (Scott, 1989) and it is these approaches applied in AEPs which are most successful in improving behaviour and health outcomes (eg. Lorig, Lubeck, Kraines, Seleznick and Holman, 1985; O'Leary, Shoor, Lorig and Holman, 1988). Hall (1980) reported that whilst many CBT/ self-management programmes have been shown to be more effective than other therapies, there are still unknowns about long-term effectiveness, but generally relapse rates are slower although overall remain high. Only one AEP (Lorig et al, 1985) has been followed up long-term to evaluate whether behaviour change and health status remain improved. Exercise and pain levels were significantly improved in comparison to controls at four months, but, although still significantly improved, were considerably attenuated at eight and 20 months, with reinforcement schedules being ineffective (Lorig and Holman, 1989). At four years, pain remained significantly lower in the treatment in comparison to control groups, although disability continued to increase (Lorig, Mazonson and Holman, 1993). Self-management behaviours were not reported.

Mazzuca (1982) reviewed the effectiveness of didactic programmes conveying information in a standard manner in comparison to programmes additionally incorporating behavioural measures emphasising patients' responsibility for self-management. Behavioural programmes were consistently more effective in improving behavioural and health status outcomes. Similarly Tucker and Kirwan (1991), reviewing AEPs, concluded those most successful in improving health status emphasised problem-solving, self-management activities, coping and self-efficacy.

1.5.3. JOINT PROTECTION EDUCATION.

JP education is considered essential by both health care professionals (HCPs) and patients (Birnbaum, Gerber and Panush, 1989; Caruso and Cordery, 1986; Chamberlain et al, 1984; Melvin, 1989; Wade, Brown and Wasner, 1982). To evaluate whether JP is an effective treatment, ie. reduces pain, inflammation and risk of deformity as claimed, RA patients' adherence to JP must first be evaluated. Does traditional JP education (ie. that normally provided by OTs) lead to behavioural change?

A literature review (Bowell and Ashmore, 1992; Furst, Gerber and Smith, 1987; Lorig, 1986a; Melvin, 1989; Pigg, Ambrose and Casper, 1981; Reeks et al, 1990; Sliwa, 1986; Smith, McGee and Whitworth, 1990; Unsworth, 1990; Watkins and Robinson, 1974) and a survey of JP programmes run at four hospital OT departments (Royal Devonshire Hospital, Buxton; Nottingham City Hospital; Derby Royal Infirmary and Odstock Hospital, Salisbury) established common JP education content as:

- a) the possible causes of RA,
- b) definition of the disease,
- c) normal joint structure (using a diagram of the joint and explaining terminology),

- d) how joint structure is disrupted by the disease process,
- e) physical stresses on joints during daily activities as contributory factors in the development of typical rheumatoid deformities,
- f) JP and Energy Conservation (EC) principles (Appendix 2) followed by;
- g) demonstration of everyday activities (usually kitchen, occasionally household and gardening, tasks) using;
- i) normal methods, illustrating how joint stress contributes to deformity,
- ii) JP methods (eg. altering movement patterns, Hand JP and use of technical aids), explaining the application of JP principles,
- h) return demonstration by the patient,
- i) provision of leaflets reinforcing the information given and containing further JP methods in a range of Activities of Daily Living (ADL).

Optionally education may also include:

- j) a problem-solving exercise applying taught principles to individuals' ADL problems, constructing a range of possible solutions
- k) discussion of patients' daily schedules and specific use of EC methods in planning and pacing activities.

Duration of JP programmes ranged between one and 12 hours (median two hours). Some authors (Cordery, 1965b; Lorig and Fries, 1983; Lorig, 1986a; Melvin, 1989; Shapiro-Slonaker, 1984; Sliwa, 1978) stress the importance of teaching patients principles to provide them with the tools to problem-solve difficulties arising, rather than a standardised list of do's and don'ts. The four programmes surveyed all used this problem-solving approach, followed by one practice of some methods required to make a hot drink. Group JP programmes have only relatively recently developed in Rheumatology Centres in the UK.

A pilot survey of the duration of and teaching techniques used in individual and group JP education in five Rheumatology centres in Trent Regional Health Authority identified this lasted between 10 to 65 minutes. The majority of disease, JP principles and methods information was provided in both verbal and written forms. A few of the nine JP principles taught were demonstrated through mime actions but most were infrequently demonstrated with return demonstrations by patients. Three of the five centres related some principles to individual patient's problems. None followed up patients unless re-referred (Nee, 1992). This suggests much of JP education in the UK is currently being provided didactically on mainly one occasion, ie. uses the Information Dissemination model rather than Behaviour Change model of patient education.

1.5.4. REVIEW OF JP EDUCATION STUDIES.

There has been little published evaluating outcomes of JP education, although it has been a regular part of OT with rheumatology patients for over 25 years. Does it lead to an increase in knowledge, attitudinal improvements (eg. whether patients believe it is beneficial and a means of control over their lives) and behavioural change, over and above that which occurs naturally, as patient education intends? Is this sufficient to potentially impact on disease status?

There is little evidence to show patients have learnt more about JP following education. Studies have incorporated JP measures in questionnaires evaluating arthritis education programmes (AEPs), but none reported on this item specifically, only concluding overall knowledge levels rose (eg. Berg, Alt, Himmel and Judd, 1985; Goeppinger, Arthur, Baglioni, Brunk and Brunner, 1989; Kaplan and Kozin, 1981; Lorish, Parker and Brown, 1985; Oehrmann, Doyle, Clark, Rivers and Rose, 1986).

The majority of studies have used self-report to identify whether behavioural change following AEPs occurred. Several included JP education in their AEP but did not report changes in JP/EC behaviours specifically, only that self-care behaviours increased (eg. Goeppinger, Brunk, Arthur and Riedessis, 1987). Knudson, Spiegel and Furst (1981), Lorig et al (1985) and Cohen, van Houten Sauter, DeVellis and DeVellis (1986) have shown AEPs can significantly increase the use of exercise programmes and rest. Furst, Gerber, Smith, Fisher and Shulman (1987) evaluated a six session JP/EC "behavioural" programme versus a "traditional" JP/EC programme. An activity record of rest and work periods and type of work (heavy/light) was used to evaluate if patients balanced rest and work (EC) better post-education. This showed positive, but not significant, improvement in comparison to "traditional" EC education, leading them to question the efficacy of the latter. Other JP principles were not evaluated. Lindroth, Bauman, Barnes, McCredie and Brooks (1989) evaluated subjects attending a six session AEP covering eight topics, one of which was work simplification (EC) and JP, in comparison to a control group receiving no education. Increased, but not significant, use of work simplification practices resulted.

In some studies, it is difficult to identify what aspects of JP were being measured. Kaye and Hammond (1978) had a 50% response rate in a retrospective study of an AEP consisting of an audio-visual presentation, consultation with a health educator, setting of behaviour change goals and information booklets. Subjects were asked "how much attention do you pay to not abusing joints?" A positive change was reported by 63%, but no pre-test was included in this study. Wetstone, Sheehan, Votaw, Peterson and Rothfield (1985) developed a computer-based AEP with 10 major topic areas, one of which was JP. Subjects worked through topics at their own speed with

information reinforced with intermittent multiple choice questions. Subjects were interviewed pre-education regarding their adherence behaviour and post-education on their self-perceived changes in "care taken to protect joints." Most (65%) reported no change and 35% (6/17) an increase. Bowell and Ashmore (1992) evaluated a two hour AEP, including disease information, exercise, relaxation and JP. Six months post-education, 84% reported "altering the way they had tackled everyday activities" with examples being: regulate speed of work, adapt equipment, JP techniques, exercise, ask for help, delegate tasks, use splints. Again, no pre-test was included nor was the extent of behaviour use measured. In all of these studies, the type of joint care is unspecified.

Self-report can be prone to bias and reactivity effects, meaning behavioural observation is preferable (Haynes, 1978; Kazdin, 1981; Meichenbaum and Turk, 1987). Only two studies have used behavioural measures to identify change. Tucker and Kirwan (1989) developed a six session AEP, including one JP lecture and practical session. Subjects were asked pre- and post-education to demonstrate correct methods of turning a tap, resulting in a significant increase in ability to do so. To what extent this reflects learning of other JP methods was not evaluated. Neuberger, Smith, Black and Hassanein (1993) also demonstrated a significant increase in ability to demonstrate JP practices. Subjects were asked to perform six ADL tasks between three and 16 weeks after having worked through a four unit self-instructional AEP, one of which was on JP and EC (25 minutes duration). Although content was based on that normally provided, this approach differed from traditional JP education as it used individualised instruction methods. Subjects demonstrated a mean of 3.3 behaviours pre- and 5.25 behaviours post-education. A control group receiving teaching from their health care professional

(traditional education) made no such gain.

Use of return demonstrations may evaluate practical learning, but does not necessarily indicate whether JP is implemented regularly in daily life. Neuberger et al (1993) asked subjects to report frequency of using JP at home. Regular use rose significantly (from four to five behaviours) in comparison to the control group. These results confirm patients adopt JP practices naturally to some extent pre-education. Yet JP is meant to be effective as a result of making widespread changes in patterns of affected joint use. Only one additional behaviour was reported as adopted on average. Although showing significant improvement, this study did not sufficiently evaluate the extent to which JP is used or generalised to other activities.

An earlier pilot study (Hammond, 1988) concluded Hand JP behaviour did not significantly increase following "traditional" JP education of three hours duration over two sessions, forming part of a six session AEP of 12 hours duration (the SPIRE programme, Unsworth, 1990). Four of the nine subjects increased JP behaviour in one to three tasks, ie. none reached the pre-determined significant increase of performing four correct behaviours out of 15 ADL tasks observed in a naturalistic setting. However, this was a small study, using an assessment with limited validity, meaning results were inconclusive.

1.6. AIMS OF THE STUDY.

Research to date does not prove that JP education leads to RA patients changing their behaviour in accordance with JP principles.

The aims of the study were:

- i) to develop valid, reliable assessments evaluating JP knowledge, attitudes towards the benefit of these and behaviour (chapter 2);
- ii) to use these to evaluate the effectiveness of traditional JP education in improving knowledge, changing attitudes and increasing

JP behaviours, particularly Hand JP (chapter 3);

iii) to explore reasons for patients adhering or not adhering to JP recommendations, using the Health Belief Model and Self-Efficacy theory as a theoretical framework (chapter 3);

iv) to identify if disease factors (eg. pain) influence the natural adoption of Hand JP (chapter 3);

v) to develop a cognitive-behavioural JP programme to improve Hand JP by incorporating adherence enhancement strategies targeted at those factors identified as contributing to non-adherence from the previous stage, if non-adherence again results (chapter 4);

vi) to evaluate the effectiveness of this programme in altering Hand JP behaviour (chapter 5).

2. DEVELOPMENT OF ASSESSMENTS EVALUATING JP EDUCATION.

2.1. INTRODUCTION.

Patient Education should increase a person's knowledge of, attitude towards, adoption and frequency of carrying out desired behaviours, in order to reduce ill-health and enhance positive health (Downie, Fyfe and Tannahill, 1990; Green, Kreuter, Deeds and Partridge, 1988). No assessments have been published evaluating JP education. The aim of this study was to develop assessments, based on a review of JP education content (section 1.5.2) and using the Health Belief Model as a theoretical framework. These were to evaluate:

- a) knowledge of RA, JP principles and methods,
- b) attitudes towards and beliefs regarding the efficacy of JP,
- c) self-reported use of JP behaviours,
- d) Hand JP behaviour, using direct observation,
- e) factors influencing adherence or non-adherence with JP behaviours and finally:
- f) evaluate disease and functional status, as changes in some disease measures (eg. hand pain on activity) may influence the use of Hand JP methods (Hammond, 1988).

Earlier work (Hammond, 1988) included the development of an observational assessment of Hand JP behaviour applying four JP principles. This assessment was reviewed and expanded (section 2.2. Joint Protection Behaviour Assessment). An interview procedure was developed to measure: knowledge of disease, JP principles and methods; self-perceived JP behaviour; and factors influencing attitude and behaviour change (section 2.3). Additionally, a knowledge questionnaire of JP methods was constructed (section 2.4). Disease measures selected are described in section 2.5.

2.2.DEVELOPMENT OF THE JOINT PROTECTION BEHAVIOUR ASSESSMENT.

2.2.1. INTRODUCTION.

This was developed as part of a MSc in Rehabilitation Studies (Hammond, 1988) to evaluate Hand JP behaviour. In the original assessment, RA patients' hand movement patterns during 15 selected tasks involved in making a hot drink and snack meal were analyzed. Movements were scored as either Correct, Borderline (ie. partially correct) or Incorrect Hand JP behaviours, evaluating the degree to which four JP principles, related to altering movement patterns, were applied to reduce joint stress. Principles assessed were:

1. Distributing load over several joints,
2. Reducing effort, through the use of aids, labour saving devices and avoiding lifting,
3. Using joints in stable positions and
4. Avoiding positions of deformity.

Behaviour codes and score categories were developed through literature review and videotape analysis of non-RA and RA subjects performing these standardised kitchen tasks. Three Rheumatology OTs reviewed the assessment to check for face validity. A training tape was developed demonstrating the behaviour codes and a "blind" observer trained in the assessment, who then independently assessed 12 videorecorded assessments. Inter-rater reliability was 93.5% with the researcher. Assessments were videorecorded for ease of analysis. Direct observation was originally chosen rather than self-report of behaviours through questionnaire, interview or daily logging of occurrence, as these can be prone to memory decay, error, social desirability bias and reactivity effects (Dunbar, Dunning and Dwyer, 1989; Haynes, 1978; Kazdin, 1981). Self-report is utilised in the interview (section 2.3) to compare subjects' perceived with their actual Hand JP behaviour.

2.2.2. PROCEDURES.

The assessment required improvement for use in further research as information on validity and reliability were limited.

The original process of development was reviewed and extended, ie.;

1. Identifying target subjects,
2. Selecting an appropriate sampling strategy,
3. Establishing target behaviours for assessment,
4. Selecting appropriate conditions for assessment (eg. natural or clinic setting, obtrusive or unobtrusive, audio or video recording) and minimising subject reactivity,
5. Precise definition and coding of target behaviours, to reduce the possibility of observer bias,
6. Checking validity,
7. Checking test-retest reliability and
8. Checking inter-observer reliability

(Barlow, Haynes and Nelson, 1983; Haynes, 1978; Kazdin, 1981).

2.2.2.1 IDENTIFYING TARGET SUBJECTS.

JP is considered appropriate for a range of rheumatic conditions (Brattstrom, 1987; Cordery, 1965b; Ehrlich, 1986; Lorig, 1986a; Melvin, 1989). JP advice varies depending on patterns of joint involvement and the nature of the disease process. RA subjects were selected as this is the largest diagnostic group receiving JP from OTs.

Which and when RA patients should receive JP education is infrequently discussed in the literature. Chamberlain et al (1984) state "all must be taught methods of joint protection." Caruso and Cordery (1986) state it should be taught in the early stages of the disease, to those at risk of losing function. Birnbaum, Gerber and Panush (1989) state those with moderate to severe disease soon after diagnosis and Shapiro-Slonaker (1984) those with active disease

and/or lax peri-articular structures. Brattstrom (1987) considers those in ARA functional grade I (ie. "coping with daily life with no limitations") should have knowledge of JP methods, but clarifies those in functional grade II ("capable of normal activities, possibly with minor adjustments in spite of pain and some limitations of movement") should apply JP in everyday life. ARA functional grades have since been reclassified (Appendix 1), therefore patients for whom it is most appropriate to implement JP are those;

- classified as ARA functional grade III (ie. with functional limitations in vocational activities such as work and homemaking) and
- active inflammation and/or soft tissue changes (eg. lax peri-articular structures) and/or deformities.

Advice should be given soon after diagnosis but is still appropriate for those who have had the disease some years, as disease duration does not necessarily relate to disease severity.

2.2.2.2. SELECTING AN APPROPRIATE SAMPLING STRATEGY.

Discrete categorisation was selected, ie. observing specified, clearly defined tasks. The observation period needed to be short as RA subjects tire easily. This sampling method is used if there are limited opportunities for targeted responses and allows for rating the degree to which behaviours occur. Other methods (eg. interval, duration and frequency) require the degree of Hand JP behaviour for all movements observed to be defined, a more extensive job than categorising selected tasks only.

2.2.2.3. ESTABLISHING TARGET BEHAVIOURS.

The original JPBA assessed whether subjects changed hand movement patterns during a standardised sequence of kitchen activities to adhere to the four principles cited above (2.2.1). The reasons for this choice were:

- a) the hands are the commonest, earliest joints affected in RA,

b) JP education assists patients to apply JP principles to everyday activities. Asking subjects to demonstrate tasks separately (eg. turning a tap, opening a jar) may elicit JP behaviours recalled from JP education but is not necessarily indicative of their use in everyday life. Observing a normal sequence of familiar daily activities in as naturalistic setting as possible is more likely to be representative of "true" behaviour.

c) kitchen activities were selected because clinical experience indicated these were the commonest and earliest functional problems.

d) basic kitchen tasks involved in making a hot drink and simple snack meal were selected as being; quick to perform so avoiding fatigue; familiar to both men and women; commonly targeted for change during JP education; they require many hand movements within a short time span; and these (or similar) are performed daily by most people providing many opportunities for subjects post-education to practice JP methods for the assessed tasks.

The principles and tasks assessed in the JPBA were reviewed:

a) JP principles.

A review of the eight JP principles not previously assessed in the JPBA (Appendix 2) was conducted to evaluate if more could be included. If not, these would be assessed through self-report in the interview.

i) Respect for pain.

Patients should carry out activities only up to the point of discomfort, before pain occurs (Melvin, 1989). Pain behaviour frequency (eg. rubbing hand joints, stretching fingers repetitively, shaking hands out) could be recorded but diurnal variations in pain levels and the limited association between pain behaviour and the subjective experience of pain could be confounding variables.

McDaniel et al (1986) developed an observation assessment of RA

patients' pain behaviour during a 10 minute period of lying, sitting, standing and walking, and assessed frequency of these. However, this is mainly indicative of pain in larger joints. The authors state "the method shows promise for... OTs.. making reliable observations of pain behaviours during specific tasks to aid in the determination of types of training or assistive devices patients require to perform their daily living activities with the minimum of pain." However, it was not feasible to devise and test a further assessment and therefore self-report was chosen. This could be a potential topic for future research.

ii) Balance between rest and work.

This has two components; increasing the daily duration of rest to 10 to 12 hours and taking short five to 10 minute rests during activities. The first element would require observation throughout the day and the second at least several hours observation. This would be time-consuming so a simpler self-report measure was incorporated into the interview procedure.

iii) Use of Energy Conservation techniques.

This incorporates a number of concepts (section 1.3.1), some of which, eg. speed and efficiency of movements, could be analyzed from JPBA videorecordings. However, during development (section 2.2.2.6.2) the majority of non-RA subjects reported they were self-conscious about being videorecorded and therefore less organised and efficient. This principle is more amenable to unobtrusive observation or self-report.

iv) Avoiding activities that cannot be stopped.

Activities should be stopped if they become too stressful, ie. cause sudden or severe pain, such as carrying a package a long distance and;

v) Avoidance of staying in one position for too long

Patients should change position or stretch about every 20 minutes to avoid pain and stiffness (Melvin, 1989).

For both these principles, it was considered unethical to expose subjects to assessment procedures specifically constructed to cause pain and stiffness in order to assess if these were avoided. Subjects may force themselves to complete or sustain tasks in the belief they are being of assistance. Self-report or unobtrusive observation is more appropriate.

vi) Maintenance of muscle strength and joint range of motion through exercise and full ranging during daily activities.

Adherence to exercise programmes cannot be assessed during ADL tasks. A more appropriate method is self-report. Full-ranging during tasks more applicably assesses elbow and shoulder movements (eg. reaching to high or low cupboards). Assessing full ranging in hand and wrist joints was not feasible due to the time required, although could be a potential research topic in future.

vii) Use of splinting.

Use of wrist splints during the JPBA could be recorded but not all patients are prescribed splints and they are not always available in a clinic setting. Self-report was therefore selected.

viii) Use of the strongest, largest joint to perform the task.

This was not previously assessed but a review of kitchen activities demonstrated such tasks could be easily incorporated into the assessment procedure (Appendix 4).

The JPBA was expanded to assessing five principles, all of which are concerned with altering hand and wrist joint movement patterns during daily activities. Other principles are assessed using self-report in the interview.

b) Review of JPBA tasks.

JP literature was reviewed to identify kitchen tasks recommended for change which apply the five selected JP principles (Appendix 4). The JPBA was extended to incorporate tasks related to use of stronger, larger joints and to increase examples applying the other four. A range of tasks were identified as feasibly being added to the 15 item original assessment. Tasks to be included in the JPBA were selected, following activity analysis, by:

- i) constructing tasks to be weighty enough or offer sufficient resistance to require a JP response (Appendix 3 - JPBA manual, pages 6-7, final 20 tasks described only). Two potential tasks were omitted, "turning a knob" and "stirring" as these would not require change by patients with mild disease,
- ii) ensuring tasks required a minimal amount of explanation/instruction to be performed (Appendix 3 - pages 5, 7-8),
- iii) contriving the situation to ensure certain tasks had to be performed (eg. leaving the kettle unplugged and empty ensures tasks 2 to 6 must be completed, ie. filling and switching on the kettle),
- iv) eliminating tasks inappropriate for all subjects to perform due to differing equipment designs in different assessment settings. A third potential task "closing a drawer" was eliminated as during pilot studies many subjects had new fitted kitchens with easy-glide drawers, requiring minimal effort to close,
- v) eliminating repetitive tasks,
- vi) avoiding tasks which would unduly lengthen the assessment procedure,
- vii) including tasks usually performed on a regular daily basis by the majority of people, or if not, being representative of other frequent movement patterns,
- viii) including tasks in which JP behaviour represents a departure

from the range of normal behaviours used to complete the tasks as otherwise these would not reliably indicate whether change had occurred.

Twenty five tasks were considered for inclusion (Appendix 5).

2.2.2.4. SELECTING APPROPRIATE CONDITIONS FOR ASSESSMENT.

The original JPBA was designed for use in a standardised setting (an OT kitchen), ie. using the same equipment for all subjects. This reduced travel costs to patients' homes and portable video equipment was not available. However, behaviour in a clinic setting using unfamiliar equipment may not be representative of patients' own homes. The JPBA was redesigned to be suitable for use in both OT departments and patients' homes. This necessitated defining a wider range of behaviour codes as a greater variety of equipment might be used.

Behaviour was originally videorecorded because;

- i) no loss of data occurs as there is a permanent record,
- ii) repeated analyses are possible,
- iii) reliability of observations can be checked by trained "blind" observers,
- iv) other subsets of data can be extracted later if required.

The main disadvantage is potential subject reactivity. Studies indicate that subjects, after initial embarrassment, readily participate and are not unduly conscious of the equipment (Barnes, 1969; Goldberg, 1983). Modern portable cam- and palmcorders also mean videorecording is less obtrusive.

Minimising subject reactivity is essential to ensure subjects' behaviour during the JPBA represents normal activity and not their perceptions of expected behaviour. This can be achieved by;

- i) keeping subjects' blind to the purpose of the assessment,
- ii) not informing subjects of the specific tasks assessed or scoring

method used,

- iii) not recording sound and including hand movements only, to reduce embarrassment and maintain confidentiality,
- iv) maintaining "light" conversation during the assessment to put subjects at ease and act as a distraction to reduce subjects' conscious attention to hand movements during a contrived situation. This is more likely to promote normal, habitual movement patterns,
- v) using an independent assessor, ie. not associated with education provision, and
- vi) avoiding discussion of the assessment procedure during treatment sessions.

2.2.2.5. DEFINITION AND SCORING OF TARGET BEHAVIOURS.

The method used in the earlier (Hammond, 1988) study was expanded. Definitions of hand behaviours for the JPBA tasks were obtained from:

i) Literature review of normal and JP methods. For all selected tasks, normal hand movement patterns described are considered stressful to affected joints and are therefore Incorrect JP behaviours.

ii) Analysis of videotapes of 24 non-RA and 20 RA subjects, participating in the JPBA revision study (section 2.2.2.6.2.) and test-retest reliability study (section 2.2.2.7.1). Non-RA subjects performed tasks similarly to each other and to that described as normal in JP literature, whilst RA subjects showed a wider and more idiosyncratic range of behaviours.

These behaviour definitions or codes were reviewed by three OTs to ensure comprehensibility and unambiguity. Behaviours difficult to define precisely in writing or using different types of equipment were further clarified by a photograph. Between three and ten different behaviours were defined for each task.

The original Correct, Borderline, Incorrect scoring system was

reviewed, as the Borderline (partially correct) option includes behaviours with varying degrees of JP benefit. Expanding the categories used to five could better reflect more subtle changes in behaviour but a pilot study with three OTs showed this to be time-consuming, with greater disagreement. The former three categories were therefore retained. To reduce completion time content experts were asked to rate relevance to the five principles in general and not specifically.

The original guidelines for scoring behaviours as correct, borderline or incorrect were extended and reviewed by six "expert" Rheumatology OTs (see section 2.2.2.6.3.) and a consensus obtained (Appendix 3 - JPBA manual, page 15). Scoring instructions clarified that the assessment is concerned with JP behaviour of hands and wrists only. A content validity study was then carried out to allocate behaviour codes to the three score categories (section 2.2.2.6.3).

2.2.2.6. CHECKING VALIDITY.

2.2.2.6.1. FACE VALIDITY.

JP literature was reviewed to identify which JP principles are being applied during which Correct JPBA codes (Appendix 5), demonstrating all five principles were represented in the selected tasks. Several principles can be appropriate to each task as different Correct methods are based on different principles. For example, in task 2 "turning on a tap" using; a tap turner applies "reducing effort, use an aid"; the forearm to turn a lever tap or turner applies "use of strongest, largest joint"; a cylinder grip applies "using joints in stable positions"; and all apply "avoiding positions of deformity" as ulnar deviation at the MCPs is avoided.

2.2.2.6.2. CONSTRUCT VALIDITY BY EXTREME GROUPS.

a) Introduction.

The JPBA must discriminate between normal and JP behaviours, ie. JP

must represent a deviation from normal, or subjects could obtain high scores without any behaviour change having occurred.

Streiner and Norman (1989) describe assessing the construct validity of scales by using extreme groups, in which two groups, with and without the trait, should score significantly differently. This method was used to determine;

- i) that tasks selected for inclusion in the JPBA are all performed by non-RA subjects in an Incorrect JP manner and
- ii) that there is a significant difference between non-RA and RA subjects JP behaviour.

b) Method.

Thirty members of staff and students at Derby School of OT were asked if they would participate. Entry criteria were; no history of arthritis or any condition affecting hand function.

Data from RA subjects participating in the JPBA test-retest reliability study were used for the second group (see section 2.2.2.7.1 for details of subject recruitment).

All subjects were assessed using the same procedures (Appendix 3, JPBA manual, pages 4-8). Non-RA subjects were all assessed in the same OT kitchen.

c) Results.

i) Non-RA subject group.

Twenty four subjects volunteered: 20 women and 4 men, mean age 40.54 years (SD 7.85 years), with a range of 30 to 58 years. Six declined to participate as they were unwilling to be videorecorded.

ii) Review of tasks included in the JPBA.

Videorecordings of the 24 non-RA subjects performing the 25 potential JPBA tasks were analyzed and behaviours scored as Correct, Borderline or Incorrect using the outcome of the content validity study.

In 17/25 tasks, all subjects used an Incorrect method. "Close box"

and "wash up" were eliminated as normal subjects frequently performed these using a JP method. Three tasks ("turning a knob," "stirring a pan" and "closing a drawer") were eliminated as these were considered either insufficiently stressful or equipment design would make the task too easy to require a JP response from RA subjects. Twenty tasks were retained in the JPBA.

A numerical score is assigned to the three categories (Correct = 5%, Borderline = 2.5% and Incorrect 0%; maximum score = 100%) indicating the extent to which Hand JP methods are used in the assessed tasks.

iii) Non-RA and RA subjects' scores.

A review of non-RA subjects' JPBA scores showed those seven scoring a correct or borderline did so in one task only.

Median JPBA score of the non-RA group was 0% (IQR 0 - 0%, max. score 5%).

Median JPBA score of the RA group was 23.10% (IQR 6.48 - 31.88%).

A Mann-Whitney test showed there was a significant difference between the two groups' behaviour ($U = 175$, $p < 0.0001$).

d) Discussion.

The non-RA group were younger (mean difference 16.66 years) than the RA group, although all were within the band for typical age of RA onset (Dieppe et al, 1985). There was a significant difference between non-RA and RA subjects behaviour demonstrating non-RA subjects rarely use JP behaviours normally in tasks included in the JPBA. The maximum non-RA subject's score was 5% ($n=2$), indicating that for RA subjects a score (or score change) of 5% would not indicate changing behaviour.

2.2.2.6.3 ESTABLISHING CONTENT VALIDITY.

a) Introduction.

Discussion with Rheumatology OTs highlighted discrepancies between each other and the literature as to what constitutes JP. A content

validity study was therefore conducted, ie. the "systematic examination of the test content to determine whether it covers a representative sample of the behaviour domain to be studied" (Anastasi, 1982).

b) Method.

Eight "expert" OTs were contacted. Introductory material, scoring instructions and behaviour codes for each of the 20 JPBA tasks were mailed out. Codes were presented in random order for each task (ie. Correct, Borderline and Incorrect behaviour codes were not grouped together) and photographs provided to illustrate some of these. Instructions stated there were not necessarily equal numbers of codes for each score category and all three categories may not be represented (Appendix 6 - sample page).

The experts were asked to review the material independently and score each code (124 in total) as Correct, Borderline or Incorrect, using the previously agreed guidelines of category definition.

c) Results.

Six OTs agreed to participate. All were members of the OT Special Interest Group in Rheumatology, Senior I or Head III grade, with between two and 18 years rheumatology experience (mean 7.66 years, SD. 5.98 years) and had been involved in developing and running arthritis education programmes (Appendix 7).

The six experts' and the researcher's scores were compared for the 124 codes included in the JPBA and percentage agreement calculated (Table 2.1). Full agreement was obtained in scoring 41% of codes, although in 15%, four or less OTs agreed. Percentage agreement does not allow for agreement occurring by chance. Overall inter-rater agreement was therefore further analyzed using the weighted kappa statistic within each of the 20 tasks and for the whole JPBA.

Table 2.1: Percentage agreement for JPBA tasks scores.

No. of experts agreeing on same score category.	No. of codes (n = 124) at this level of agreement.	% of codes at this level of agreement.
7/7	51	41.13
6/7	36	29.03
5/7	18	14.52
less than 5	19	15.32

Table 2.2: JPBA Content validity agreement.

Task no.	Task description	Agreement level (k)
1	Carry tray	1.00
2	Turn on tap	0.54
3	Fill kettle	0.55
4	Turn off tap	0.51
5	Carry full kettle	0.60
6	Plug in	0.72
7	Open jar	0.49
8	Close jar	0.50
9	Carry shopping bag	0.49
10	Open tin	0.65
11	Carry pan	0.5
12	Lift plastic box	0.86
13	Lift grill pan	0.46
14	Empty pan contents	0.47
15	Carry plate	0.66
16	Pour kettle	0.58
17	Hold milk bottle/carton	0.55
18	Carry mug	0.48
19	Wipe surfaces	1.00
20	Squeeze cloth	0.57

For all items, $p < 0.001$ level.

i) Within task agreement.

In the final 20 task JPBA (Table 2.2), 14 tasks were within the range $k = 0.4 - 0.59$, ie "fair" agreement; three were within the range $k = 0.6 - 0.74$, ie "moderate" agreement; and three were within the range $k = 0.75 - 1$, ie "excellent" agreement.

ii) Overall JPBA agreement.

Inter-rater agreement was $k = 0.6$, ie. significant agreement was achieved.

d) Discussion.

Following analysis of percentage agreement, it was decided codes would be assigned to that score category to which a minimum of five OTs agreed. If this agreement level was not reached, codes would be scored Borderline. This occurred in 19/124 codes (15.3%).

Some interesting discrepancies were noted between experts' scores and the literature. For example, for the code "opening a jar - using the palm of the hand pressing down on the lid, fingers extended, ie. not included in grip" there was a 2:3:2 division of opinion. The code was originally taken from Melvin (1982, p. 357-8), who defines this as a Correct JP method. This was categorised as Borderline due to insufficient agreement. Reasons given by OTs for not assigning a Correct were that, although the method avoids ulnar deviation at the MCPs and distributes load over more joints, it can also cause stress and pain to the wrist joint.

For 70% of codes six or all seven experts agreed. Inter-rater agreement was "fair" for the majority of tasks, although significant for all 20 finally selected tasks. This reflects the variation between OTs in both defining and recommending JP behaviour, which varies with individual patient's differing severity and patterns of joint involvement, making standard recommendations difficult. For this reason, experts were specifically asked to categorise codes

considering the effect on hand and wrist joints only. If they considered a method, eg. moved stress off the hand joints but onto another joint (eg. elbow or hip) they should presume this joint was unaffected.

e) Conclusion.

From these validity studies, the JPBA was revised to 20 items and an assessment manual developed (Appendix 3). For each task, behaviour codes were scored as Correct, Borderline or Incorrect and photographs included to clarify some codes. Assessment procedures, scoring instructions and an assessment form are included in the JPBA manual. In addition, a 45 minute training videotape was developed. This includes introductory information on JP, scoring instructions and demonstrates each of the 124 behaviours described in the assessment. Two sample assessments are included for training assessors in scoring the JPBA correctly. Answers are provided in the JPBA manual.

2.2.2.7. CHECKING RELIABILITY.

2.2.2.7.1. TEST-RETEST RELIABILITY.

a) Introduction.

This measures the degree of behavioural stability, without which it would be impossible to assess if any behaviour changes occurring are due to intervention or natural variation.

Two hypotheses were tested in this study;

i) RA patients do not significantly change Hand JP behaviour over several months and

ii) there is no significant change in behaviour between subjects' own homes and a standardised, naturalistic setting (an OT kitchen).

This latter is of interest because if behaviour alters with different settings, the JPBA could not be used reliably for clinic and home assessments.

b) Method.

RA subjects were selected to participate in test-retest studies for all the assessments developed. Subjects' names were obtained from the previous three years (1988 to 1990) Derby Royal Infirmary OT patient records. Subject selection criteria were; OT records showed a diagnosis of RA with hand and wrist involvement; ADL assessments indicated kitchen tasks as the main problem; and not currently receiving OT. It was intended to select patients who had not received JP education, however records were insufficiently completed to determine whether this had occurred.

Subjects were kept blind to the purpose of the assessment and informed the aim was to observe hand movement patterns used by people with RA in daily activities, in comparison to people without RA, in order to assist the development of an OT hand assessment. They were not informed JP behaviour was assessed or the specific tasks analyzed. It was stressed whatever degree of hand involvement they had was relevant, as the study aimed to obtain a representative range of methods used. This was to avoid subjects with mild hand involvement self-selecting themselves out.

Subjects were also informed that videorecordings would;

- i) exclude their faces and sound to maintain confidentiality and reduce embarrassment,
- ii) be identified only by subjects' trial numbers, not names,
- ii) be viewed only by those involved in the study and used for no other purpose unless specific consent was obtained and
- iv) be wiped on completion of the study.

A number of disease and demographic measures were recorded (section 2.5).

All subjects were seen in their own homes for test 1. Half were assessed in their own homes again for test 2 (Group A) and half in an

OT kitchen (Group B). Group B subjects were those able to attend for assessment during normal working hours. All subjects were assessed at a time to suit their convenience in afternoons or early evenings, to reduce the possibility of hand behaviour being affected by early morning stiffness. All were asked to perform activities "just as they normally would everyday."

The same assessment procedure was used with all subjects (Appendix 3, JPBA manual, pages 4-8).

c) Results.

Forty eight subjects were contacted and 28 agreed to participate. Eight were eliminated as they preferred not to participate in all three test-retest studies or their condition had deteriorated since last seen in OT resulting in difficulty in adequately completing the JPBA. Of the 20 remaining, 13 were women and seven men. Mean age was 57.2 years (SD 9.9 years) and average disease duration 9.9 years (SD 10.2 years), although 10 had RA for five years or less (minimum five months). Four subjects had early stage RA, three moderate and 13 severe (ARA classification, Steinbrocker, Traeger and Batterman, 1949). Functional ability was measured using the Health Assessment Questionnaire (HAQ, Fries, Spitz, Kraines and Holman, 1980). Median score was 1.69 (IQR 0.78 - 1.88), ie. moderate disability. Seven scored in the slight disability range, 10 moderate and three severe on test 1. Overall pain was measured using the HAQ Pain Scale (Callahan, Brooks, Sumney and Pincus, 1987), median score was 1.25 (IQR 0.50 - 1.85). Subjects also completed a Visual Analogue Scale (VAS) of hand pain on activity during a moderately strenuous household task. Median score was 61 (IQR 20 - 71.75), range 12 to 86. The assessments took place on average 58.25 days (8.3 weeks) apart (SD = 42.77, range 12-182 days).

Group A's average age was 61 years (SD = 7.6 years), disease duration

9.1 years (SD 6.73) and median HAQ score at Test 1 of 1.25 (IQR 0.5 - 1.88). Group B's average age was 53.7 years (SD 11.02), disease duration 11.76 years (SD 12.74) and median HAQ score at Test 1 of 1.75 (IQR 1.13 - 1.88).

A Wilcoxon test showed no significant change in JP behaviour over the test period (Table 2.3).

Table 2.3: JPBA test-retest reliability results.

	Median score	IQR.	Range	Comparison
Test 1	23.10%	6.48 - 31.88%	0 - 62.5%	$z = -0.42$
Test 2	20.00%	10.63 - 33.48%	0 - 70%	$p = 0.67$

Four subjects scored more than 40% on test 1 (ie. more than one standard deviation above the mean score).

The mean score change was +0.79% (SD = 10.01%). Nineteen subjects' test 2 scores fell within a range of -7.5% to +8% of test 1 scores, ie. within one standard deviation of the mean score change.

A significant score change for the JPBA was determined as being either more or less than two standard deviations from the mean score change, ie. + or - 20.02% (or 20%).

Subjects' scores were analyzed to establish whether subjects were achieving the same score for each task on test 2. Results are shown in Table 2.4.

Table 2.4: Agreement of score category on Tests 1 and 2.

		Incorrect	Test 1 Borderline	Correct	% complete agreement
Test 2	Incorrect	238	15	11	59.5
	Borderline	15	22	6	5.5
	Correct	18	4	49	<u>12.25</u>
					77.25

During either test 1, 2 or both, 22 tasks were accidentally not

recorded (ie. 5.5% of tasks). Subjects changed score category in 69/400 tasks observed (17.25% of tasks). Agreement between test 1 and 2 scores occurred in 77.25% of tasks assessed, $k = 0.59$, ie. moderate agreement. Subjects changing score category did so between one and 10 times each, mean 3.45 tasks ($SD = 2.42$), with direction of change equally distributed within subjects, ie. half improved and half reduced JP behaviours. There was no significant correlation of time intervals between tests and score changes ($r(s) = 0.27$; $p = 0.25$). The setting in which assessments took place did not influence behaviour. Group A were assessed twice in their own homes. The Wilcoxon test showed no significant difference in JPBA scores occurred (Table 2.5).

Table 2.5: Group A JPBA scores (home - home), n=10

	Median score	IQR.	Range	Comparison
Test 1	15%	5 - 25%	0 - 62.5%	$T+ = 20$
Test 2	13.75%	10.5 - 28.9%	0 - 55%	$p > 0.05$

Group B were assessed once at home and once in an OT kitchen. No significant difference in JPBA scores occurred (Table 2.6).

Table 2.6: Group B JPBA scores (home - OT) n=10)

	Median score	IQR.	Range	Comparison
Test 1	25.65%	13.80 - 32.50%	5 - 57.9%	$T+ = 11.5$
Test 2	21.75%	19.40 - 36.80%	7.5- 70%	$p > 0.05$

Group A had a lower mean score than Group B on both tests. However, the Mann-Whitney test showed no significant difference between Groups A and B scores on either test (Test 1, $U = 87.5$, $p = 0.19$; Test 2, U

= 91, $p = 0.32$).

d) Discussion.

The results demonstrate there was no significant difference over on average a two month period or between home and OT kitchen settings. The JPBA is therefore a reliable assessment over time and in different settings.

Scores for Group B's Test 2 (OT kitchen) were slightly higher than Test 1, indicating the assessment instructions to select similar equipment and technical aids in the OT kitchen to subjects' own homes provides reliability.

Group B scored slightly higher than Group A. This group had more functional problems than group A, causing a number to give up work and meaning they were available for day-time assessments.

Overall agreement between tests was moderate, with 17.5% of tasks performed differently on test 2, although direction of behaviour change was equally divided.

2.2.2.7.2. INTER-OBSERVER AGREEMENT.

a) Introduction.

An inter-observer agreement study was carried out to ensure different observers could reliably score the JPBA.

b) Method.

Four OT's, with no recent Rheumatology experience, were asked to read the JPBA manual (Appendix 3, omitting section 1, assessment procedures), view the training videotape and analyze the two sample assessments. When complete agreement with the sample results in the JPBA manual was obtained, they assessed between seven and 11 randomly selected videotapes of test-retest subjects. Observers were requested to consult the assessment material regularly and to complete analysis within three sittings, to reduce observer drift.

c) Results.

Observers reported it took approximately two hours to become familiar with the assessment and complete the sample assessments. Only one observer raised queries regarding analysing two tasks. Results from the researcher's and the four observers' videotape analyses were compared and inter-observer agreement calculated using weighted Kappa. Results are shown in Table 2.7.

Table 2.7: JPBA inter-observer agreement (observers with researcher).

<u>Observer</u>	<u>% agreement</u>	<u>Kappa</u>
1	94.1%	0.88 "very good"
2	92.14%	0.8 "very good"
3	87.5%	0.71 "good"
4	81.6%	0.68 "good"

For all observers, significant agreement resulted ($p < 0.01$).

d) Discussion.

Inter-observer agreements were either good or very good, ie. significant agreement. Time taken to become familiar with the JPBA was relatively short at two hours.

This indicates OTs and researchers could become familiar with the JPBA with regular referral to the assessment booklet to avoid observer drift or bias.

2.2.3.CONCLUSION.

The JPBA is a valid, reliable assessment over time and in different assessment settings, with good inter-observer agreement.

2.3.DEVELOPMENT OF THE INTERVIEW SCHEDULE.

2.3.1. INTRODUCTION.

The interview schedule was designed, based on the content of typical JP education and the Health Belief Model, to obtain information on subjects':

- a) Knowledge of RA, JP principles and methods (structural variables).
- b) Perceived susceptibility to RA.
- c) Perceived severity, ie. how much RA affects them physically.
- d) Cues to action:
 - external, ie. previous sources of information about the disease and self-management methods and
 - internal, ie. physical and/ or psychological factors prompting the use of JP behaviours.
- e) Perceived benefits, ie. beliefs regarding the usefulness of exercise, rest, wearing splints, respecting pain, energy conservation methods, changing methods of performing tasks by altering patterns of joint movement and using technical aids.
- f) Perceived barriers to changing behaviour, ie. difficulties encountered applying JP behaviours.
- g) Self-efficacy - the degree to which the person believes they can successfully control their disease through self-management behaviours.
- h) Strategies used by patients to adopt JP methods into their daily routine.
- i) Self-perceived JP behaviours.

2.3.2. PROCEDURES.

A semi-structured interview format was chosen to facilitate analysis and reduce duration of assessment sessions. Questions were constructed through literature review and discussion with

Rheumatology OTs to determine content, followed by pilot interviews with RA subjects to determine appropriate utilisation of open and closed questions and options to be included in the latter.

Six RA subjects were identified from OT records at the Derby Royal Infirmary as having received JP education and willing to participate in a pilot study of the assessment procedures.

During the pilot all questions were asked open-endedly and tape-recorded to assist in development of closed questions. Response option cards were constructed for many questions prior to piloting to prompt replies if necessary and evaluate which format was most effective.

Questions were constructed to explore each area above (2.3.1).

2.3.2.1. QUESTION CONSTRUCTION.

a) Knowledge of the disease.

Understanding of RA was included to indicate subjects' understanding of the underlying rationale for adopting JP in daily life.

Questions included:

- i) whether information had been received on the disease and source/s of this, to identify if they had received this cue to action,
- ii) knowledge of the cause and effects of the disease. During the pilot, all six subjects found this difficult to answer. Replies included personal beliefs about causes as distinct from knowledge based on information received. The question was therefore re-phrased to ask " what they understood from information received about what RA is,"
- iii) knowledge of joint structure. A diagram of a typical joint (Figure 1.1) was used, with five structures to be identified. All pilot subjects recognised having seen such a diagram before, although there was some difficulty in perceiving it did not include skin and muscles. This verbal instruction was therefore included in the

interview,

iv) knowledge of how the disease process alters joint structure. During the pilot, subjects were asked to explain in their own words and draw, if possible, how joints are affected by the disease, as OTs use diagrams to demonstrate such changes and these are commonly included in information booklets. None of the subjects were able to explain diagrammatically and replies were brief and often unsure. A closed question was therefore constructed to facilitate response, using answers provided in the pilot and the correct answer "lining of joint swelling" incorporated. The question was simplified to ask what initial effect RA has on joint structure as several options could prove correct at different stages of the disease.

b) Perceived self-efficacy

Lorig, Chastain, Ung, Shoor and Holman (1989) define perceived self-efficacy (SE) as the belief that one can achieve a behaviour or state of mind, not an actual measure of accomplishment, ie. it is distinct from self-reported or observed behaviour. Using the same question structure in the Arthritis Self-Efficacy Scale (Lorig, Chastain et al, 1989) subjects were asked "How certain are you that you can...." A general statement was used "control the effects of your disease through your own actions" to investigate subjects' belief in ability to control disease symptoms by using self-management techniques. Following the pilot, an additional question was inserted "what comes to mind when you think about what actions you take." This was to determine what strategies subjects themselves consider most useful and whether JP methods are spontaneously cited.

c) Perceived benefits and self-perceived behaviour.

Questions related to JP principles (Appendix 2) were developed to ascertain subjects' belief in the benefits of, their self-perceived use and frequency of the following behaviours; exercise, rest,

wearing splints, use of technical aids, respect for pain, balancing rest and work (EC), changing work methods (ie. task performance) and reducing stress on joints.

1) Exercise, rest, splint-wearing and use of technical aids:

Following pilot interviews a number of changes were made:

i) further clarification of the meaning of terms used was necessary. Exercise was specified as Physiotherapy exercise regimes as distinct from general exercise, such as walking, swimming and yoga, as the latter do not necessarily result in full-ranging of joints. It was also necessary to determine if subjects had received such exercise programmes. Splint-wearing was defined as "working wrist splints" and subjects asked if they had been prescribed these. Rest was clarified as "for one or more hours during the day" in accordance with JP principles.

ii) Additional open-ended questions asked reasons for non-use of methods to establish if this was due to perceived barriers (eg. lack of time), lack of knowledge or beliefs as to why these were not beneficial.

iii) Frequency was defined as "on average in the last three months," as several subjects stated it varied depending on whether they were in exacerbation or remission. A three month period was selected as this was the planned follow-up period in the proposed trials.

2) Respect for pain, balancing rest and work (EC) and changing work methods.

These questions were asked specifically in relation to hand and wrist problems as the JPBA observes wrist and hand movements only.

In the first pilot, one open-ended question was initially asked "when your wrists and hands are painful or aching, what do you believe are the best things to do to manage this?" Open-ended replies were difficult to obtain and included some statements opposite to JP

principles, eg. working through the pain, keeping active for as long as possible. Subjects were then shown a response card with 11 options relating to JP principles eg. "stop and take a short rest" (respect for pain), "alter heavy and light jobs and rest during the day" (balance rest and work), "lift items with two hands" (distribute load). Most subjects agreed they believed most options useful, even though contradicting their previous statements. Several subjects stated they seemed a "good idea," indicating options were leading questions.

A second pilot restructured questions to ask about each principle separately with a correct and incorrect statement, eg "If your hands are aching and painful, should you: a) stop and give them a short rest or b) carry on as usual and work through the pain (respect for pain). Subjects were asked firstly which they believed the best action and secondly, which they actually did.

A number of changes were made in this section:

- i) subjects' responded it was not always possible to do what one thought best because of factors like pressure of work. Self-perceived behaviour was therefore qualified as "most of the time,"
- ii) the eleven questions were not easily accepted by subjects, as most encountered problems in thinking about everyday activities in detail.

Three questions were finally selected related to respect for pain, a broadly phrased question related to changing work methods and EC beliefs and behaviour were assessed using only one question (balancing rest and work) as this is the main EC principle taught in JP education.

3) Reducing stress on joints.

Questions on beliefs and behaviours related to altering movement patterns, ie. the five principles assessed in the JPBA, were assessed

using the term "reducing stress on joints." These questions specifically referred to hand joints to facilitate comparisons between beliefs, self-perceived and observed behaviours in the JPBA. Questions included the degree to which subjects believed reducing stress on hand joints was important (perceived benefit) and to what extent they had altered tasks to reduce stress (self-perceived behaviour). Following pilot studies, a number of changes were made:

- i) self-perceived stress-reducing behaviour was clarified as being "during household/ kitchen tasks" as pilot subjects differentiated between their ability to reduce stress at home and work because of the differing amount of control they had over these situations and
- ii) the rating scale for behaviour frequencies was additionally defined by using percentages (ie. "a lot" = over 50% of tasks, "some" 25 to 50%, "a little" under 25%, and none 0%. A category for over 75% of tasks was omitted as subjects had difficulty distinguishing between "a lot" and "most" tasks).

Subjects were also asked to cite examples of kitchen and household tasks they had changed, to facilitate direct comparison between self-perceived and observed behaviour in the JPBA.

Two questions were incorporated in this section from the two studies previously identified as evaluating JP behaviour following education. These were: "How much attention do you pay to not abusing joints?" (Kaye and Hammond, 1978). This was slightly rephrased to clarify "hand" joints. During the pilot, some difficulty was expressed by subjects in understanding the term "abusing" and this was altered to "stressing" to be similar to wording used in other questions. The second question was "Has the care taken to protect your joints altered in the last three months?" (Wetstone et al, 1985) to determine whether subjects involved in subsequent trials perceive a change in behaviour post-education.

d) Perceived barriers, cues to action and strategies for behavioural change.

Questions were constructed to identify whether difficulty is encountered in making behavioural changes, the degree of difficulty and why, to establish what practical and psychological barriers are perceived to limit ability to reduce joint stress. Subjects were also asked "How did you go about changing the way you do everyday tasks?" This led to two types of responses in the pilot - what precipitated any changes (cues to action) and the process of change. Two separate questions were therefore developed to explore both constructs.

e) Knowledge of JP and use of JP methods.

JP knowledge was evaluated by asking;

- i) understanding of the term Joint Protection,
- ii) specific "principles or guidelines" recalled from education,
- iii) knowledge of JP methods. This was initially asked in open-ended questions, eg. "what do you think would be a less strenuous way of lifting a hot dish out of the oven?" Subjects experienced great difficulty answering such questions and commonly attempted to do so by imagining how to do the action, miming or going to the kitchen and practically attempting tasks. Subjects' actual behaviour was therefore being described, rather than knowledge of correct methods. This was time-consuming and focused too much attention on tasks videorecorded during the JPBA. These items were therefore developed as a self-administered questionnaire (the JPKA, section 2.4).

Questions were incorporated asking for descriptions of methods taught during JP education and frequency of practice, to distinguish between naturally adopted behaviours.

f) Perceived severity and susceptibility to the disease.

Subjects' perceptions of current disease severity were rated in four categories of "no effects" to "very severe." In the pilot, severity

of overall pain and fatigue were also included as possible internal cues to action. These were eliminated as replies corresponded to the broader question of disease severity. The question on perceived susceptibility was obtained from an interview schedule developed by DeVellis, Blalock, Hahn, DeVellis and Hochbaum (1988).

g) Follow-up questions.

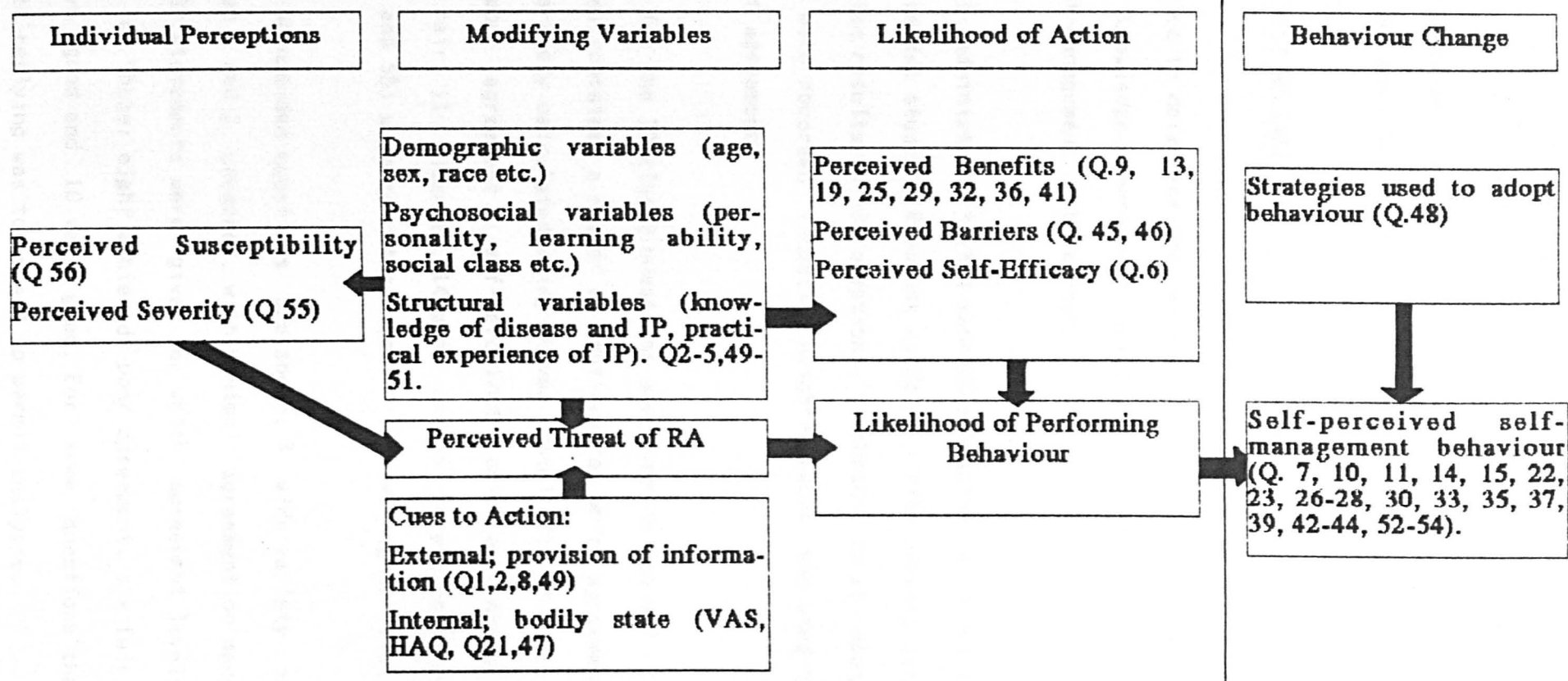
Three follow-up questions were included, to establish:

- i) whether subjects considered being in the study had influenced their behaviour,
- ii) whether they considered their behaviour during the JPBA was normal and
- ii) a final question was added for use in subsequent trials to ascertain subjects' attitudes towards attending the education groups.

2.3.2.2. INTERVIEW SEQUENCE.

A funnel sequence of questions was used (Nachmias and Nachmias, 1981). Factual information on sources of information and understanding of RA were placed first to allow answering of relatively familiar questions and to put subjects at ease. These were followed by opinion questions on beliefs and self-perceived behaviour of self-management methods. Questions on JP knowledge and methods, using the term "Joint Protection" specifically, were asked only after broader questions on beliefs, self-perceived behaviour and citations of specific behavioural changes related to "stress reducing techniques," in order to avoid alerting subjects to providing "socially desirable" answers. Information on disease severity and susceptibility were placed last, to be followed by distribution of questionnaires, to allow some distraction from discussing JP methods before videorecording the JPBA in initial assessments.

Figure 2.1: Interview Face Validity: the relationship between questions and the Health Belief Model and Self-Efficacy Theory (after Salazar, 1991).



2.3.2.3. FACE VALIDITY.

The relationship between questions in the interview schedule and the Health Belief Model and other variables discussed in section 2.3.1 is shown in Figure 2.1.

2.3.2.4. TEST-RETEST RELIABILITY.

a) Introduction.

This was conducted to determine whether the interview was sensitive to changes in knowledge, perceived benefits and self-perceived frequency of self-management JP behaviours.

b) Method.

The interview was administered to the same 20 subjects recruited to the other test-retest studies. Response cards or Yes/No answers were used to categorise results in 38 questions. Responses to 21 open-ended questions were recorded verbatim. Weighted kappa was used to analyse levels of agreement.

c) Results.

Kappa agreements for the 38 closed questions are shown in Table 2. 8. Several questions contained a number of options for which agreement levels were separately calculated using kappa (total 47). Of these; two achieved poor agreement (self-perceived pain and disease severity), four fair, 11 moderate, 14 good and 16 very good. Two questions (Q. 6 and 55) were re-categorised to achieve higher levels of agreement.

Results for the open-ended questions are shown. A wide variety of responses in test 1 and 2 occurred, with minimal agreement on many items. Overall 39 statements were given for which agreement levels were calculated. Of these: eight achieved poor agreement, six fair, 10 moderate, five good and 10 very good. For some questions the number of subjects replying was too small to permit analysis.

Table 2. 8: Interview schedule and results of Test-Retest reliability study.

Name.....

Date.....

Subject No:.....

First / Second (Third / Fourth) Interview

I am interested in what people with arthritis know about their disease, the methods they use to manage the symptoms they may experience (for instance, pain, swelling, tiredness) and whether they feel they have had to make any changes in their everyday lives, for instance in doing day to day household jobs. The questions I am going to ask are about these topics.

KNOWLEDGE ABOUT THE DISEASE.

1. Have you ever had any information explaining what arthritis is, either from hospital or medical staff or from reading?

		<u>Test 2</u>		
		Yes	No	
<u>Test 1</u>	Yes	11	1	Kappa = 0.9
	No	0	8	

2. Who / where was this information from?

	<u>Test 1</u>		<u>Test 2</u>		<u>Kappa</u>
		Yes	No		
Books/leaflets	Yes	9	1	0.70	
	No	2	8		
Nursing staff	Yes	7	1	0.50	
	No	3	9		

	<u>Test 1</u>	<u>Test 2</u>		<u>Kappa</u>
Medical staff	Yes	8	0	1.00
	No	0	12	
Occupational Therapist				
	Yes	4	0	1.00
	No	0	16	
1 hr. OT/PT education group				
	Yes	2	1	0.77
	No	0	17	
Physiotherapist	Yes	2	0	0.77
	No	1	17	

3. What did you understand from this about what rheumatoid arthritis is?

<u>Words used to explain RA</u>	<u>Test 1</u>	<u>Test 2</u>		<u>Kappa</u>
		<u>S</u>	<u>NS</u>	
Inflammation or swelling	S	5	0	0.58
	NS	4	11	
Wearing away of bone	S	1	2	0.32
	NS	1	16	
Auto-immunity/ body	S	2	0	0.77
tissue attacking itself	NS	1	17	
Weakens/attacks joints	S	2	0	1.00
	NS	0	18	
Travels in blood	S	2	0	1.00
	NS	0	18	
Pain (due to swelling)	S	0	1	-0.07
	NS	2	17	

	<u>Test 1</u>	<u>Test 2</u>		<u>Kappa</u>
		<u>S</u>	<u>NS</u>	
Wearing away of cartilage	S	1	0	1.00
	NS	0	19	
Weakening tendons	S	0	1	0.00
	NS	0	19	
Crystallization in joints	S	1	0	1.00
	NS	0	19	
To do with the genes	S	1	0	1.00
	NS	0	19	
Causes depression	S	0	1	0.00
	NS	0	19	
Too much fluid pressing	S	1	0	1.00
on bone and killing it	NS	0	19	
Unable to give an	S	9	3	0.71
explanation	NS	0	8	

Key: S = Stated, NS = Not Stated.

Thirteen subjects (65%) stated the same explanation or gave none on both tests. Four (20%) gave an explanation on test 2, who were unable to on test 1. Three (15%) gave a different explanation on test 2.

Agreement on ability to give an explanation or not on both tests was k = 0.71 (good agreement).

4. Can you label the five different structures on this diagram of a joint? (This does not include muscles and skin).

	<u>Test 1</u>	<u>Test 2</u>	<u>Kappa</u>
		<u>Yes No</u>	
1. Bone	Yes	10 0	0.80
	No	2 8	
2. Cartilage	Yes	7 2	0.79
	No	0 11	
3. Synovial fluid/joint space	Yes	4 2	0.52
	No	2 12	
4. Synovial membrane/ lining	Yes	3 1	0.69
	No	1 15	
5. Joint capsule	Yes	1 1	0.32
	No	2 16	

5. What is the initial effect that RA has on joints? ie. What is the first thing that starts to go wrong?

<u>Test 1</u>	<u>Test 2</u>				
	<u>a</u>	<u>b</u>	<u>c</u>	<u>d</u>	<u>e</u>
a. Lack of fluid in joint	3	-	-	1	1
b. Bones turn thinner/chalky	-	1	-	-	-
c. Muscles stiffen up	-	1	-	1	-
d. Cartilage and bone wear away	1	-	1	-	1
e. Joint lining swelling up	1	-	-	-	8
	<u>Kappa = 0.42</u>				

Twelve (60%) subjects gave the same answer on both tests.

PERCEIVED SELF-EFFICACY

6. How certain are you that you can control the effects of your disease through your own actions? That is to control your pain, tiredness and other symptoms but not to get rid of the disease.

<u>Test 1</u>	<u>Test 2</u>			
	<u>a</u>	<u>b</u>	<u>c</u>	<u>d</u>
a. Definitely Yes	5	5	1	-
b. Probably Yes	5	3	-	-
c. Probably No	-	-	1	-
d. Definitely No	-	-	-	-

Ten subjects altered their degree of response on test 2 giving poor agreement ($\kappa = 0.02$). By re-categorising to a Yes/No response, agreement increases to $\kappa = 0.64$).

		<u>Test 2</u>	
		Yes	No
<u>Test 1</u>	Yes	18	1
	No	0	1

7. What comes to mind when you think about what actions you can take?:

	<u>Test 1</u>	<u>Test 2</u>		<u>Kappa</u>
		<u>S</u>	<u>NS</u>	
JP/EC statements*	S	5	3	0.47
	NS	2	10	
Positive attitude**	S	3	3	0.21
	NS	4	10	
Exercise	S	3	1	0.83
	NS	0	16	
Change diet	S	1	2	0.46
	NS	0	17	
Heat/ massage	S	1	0	0.46
	NS	2	17	

JP/EC* statements included for instance, "stop if it hurts," "do a little and rest," "use gadgets." Positive attitude** statements included for instance, "not letting be beaten," "keeping going," "being positive."

BELIEFS ABOUT BENEFITS OF AND SELF-PERCEIVED SELF-MANAGEMENT BEHAVIOURS.

In the following questions, I am interested in whether you believe any of the following methods are beneficial to you and whether you do these. Sometimes there is a difference in what we think we should do and what we actually do for many reasons, such as other commitments, lack of time etc.

Exercise

8. Have you ever been provided with an exercise regime by a physiotherapist? Yes / No

		<u>Test 2</u>		
		<u>Yes</u>	<u>No</u>	
Test 1	Yes	16	0	Kappa = 1.00
	No	0	4	

9. Do you believe doing exercise regimes provided by the physiotherapist is beneficial? Yes / No

		<u>Test 2</u>		
		<u>Yes</u>	<u>No</u>	
Test 1	Yes	19	0	Kappa = 1.00
	No	0	1	

10. Do you do these exercises now? Yes / No

		<u>Test 2</u>		
		<u>Yes</u>	<u>No</u>	
Test 1	Yes	12	0	Kappa = 1.00
	No	0	8	

11. How often do you do these?

	<u>Test 1</u>	<u>Test 2</u>					
		a	b	c	d	e	f
a. Daily		7	-	-	-	-	-
b. 5-6x/week		1	-	-	-	-	-
c. 3-4x/week		1	-	-	-	-	-
d. 1-2x/week		-	-	1	2	-	-
e. Less than 1x/week		-	-	-	-	-	-
f. No at all		-	-	-	-	-	8

Kappa = 0.77

12. If no, and has had exercise advice;

Why do you prefer not to exercise? (n=8)

	<u>Test 1</u>		<u>Test 2</u>		Kappa
			S	NS	
Plenty of exercise in daily life/job	S	4	1		0.47
	NS	1	2		

Other reasons stated included: got worse following exercise (1), and boring/ no time (2).

Rest

13. Do you believe resting for an hour or more during the day is beneficial? Yes/No

	<u>Test 2</u>		Kappa = 0.88
	Yes	No	
Test 1 Yes	14	0	Kappa = 0.88
No	1	5	

14. Do you rest for an hour or more during the day?

Test 2

Yes No

Test 1 Yes 14 0 Kappa = 0.74

No 2 4

15. How often do you rest for an hour or more?

Test 1

Test 2

Have you seen providers who:

a. Daily	12	-	-	-	-	-
----------	----	---	---	---	---	---

b. 6x/week 100% - - - - - -

c. 3-4x/week

d. 1-2x/week

e. Less than 1x/week

f. Not at all Yes - 2 - - - 1 4

Kappa = 0.71

16. If does not rest for an hour:

Do you rest at all during the day? (n=6)

Test 2

Yes No

Test 1: Yes 2 0 1 Kappa = 0.33

No. 1 2

17. If yes, how long for?

Four subjects rested for between 15 to 30 minutes. Two did not rest.

18. Why do you prefer not to rest for an hour? (n = 6)

None of the reasons given were stated on both tests; not helpful (2), feels like giving in (1), too busy (1), not stated (2).

Splints.

19. Do you believe that wearing splints whilst doing activities during the day is beneficial? Yes/No

Test 2

Yes No

Test 1 Yes 13 0

No 1 6

Kappa = 0.89

20. Have you been provided with splints to wear during the day at all?

Test 2

Yes No

Test 1 Yes 12 0

Kappa = 1.00

No 0 8

21. Do you currently have wrist pain/weakness? Yes/No

Test 2

Yes No

Test 1 Yes 9 6

Kappa = 0.16

No 2 3

22. If yes, do you wear these splints during the day?

Test 2

Yes No

Test 1 Yes 10 0

Kappa = 0.90

No 1 9

23. How often do you wear these splints?

Test 1

Test 2:

a b c d e f

a. Daily

4 - - - - -

b. 6x/week

- - - 1 1 -

c. 3-4x/week

- - - 3 - -

d. 1-2x/week

- - - - - -

e. Less than 1x/week

- - - - - -

f. No at all

1 - - - - 10

Kappa = 0.56

24. If not wearing these splints at present; why do you prefer not to wear these splints?

Two subjects on test 1, and one on test 2 who had splints were not wearing them. Reasons given were no longer necessary (1), and uncomfortable (1).

Use of technical aids.

25. Do you believe using aids or gadgets is beneficial?

Yes/ No Test 2

Yes No

Test 1 Yes 19 0 Kappa = 1.00

No 0 1

26. Do you use aids or gadgets? Yes / No

Test 2

Yes No

Test 1 Yes 14 1 Kappa = 0.73

No 1 4

27. How often do you use these?

Test 1

Test 2: a b c d e f

a. Daily for Pain. 13 - - - - 1

b. 6x/week - - - - - -

c. 3-4x/week - - - - - -

d. 1-2x/week - - 1 - - -

e. Less than 1x/week - - - - - -

f. Not at all Test 2 1 - - - - 4

Kappa = 0.78

28. What aids do you use?

Eight types of aid were mentioned by 11 subjects.

	<u>Test 1</u>	<u>Test 2</u>		<u>Kappa</u>
		<u>S</u>	<u>NS</u>	
Jar aids	S	3	3	0.58
	NS	0	14	
Electric can opener	S	2	1	0.48
	NS	2	15	
Adapted taps & tapturners	S	2	1	0.61
	NS	1	16	

Other aids: vegetable peelers, knob turners, adapted plugs and kettle tippers were mentioned on one test only by one or two subjects.

In the following questions I am interested again in what you believe is the best way to manage everyday tasks, particularly if your hands are aching or painful, or you find you are more tired than usual. Again I am asking about what you believe and then if you do this.

Respect for Pain.

29. If your hands are aching or painful when working, which do you believe is the best thing to do?

- Stop and give your hands a short rest
- Carry on and work through the pain

		<u>Test 2</u>		
		<u>Stop</u>	<u>Carry on</u>	
Test 1	Stop	16	0	
	Carry on	0	4	Kappa = 1.00

30. Which do you actually do MOST of the time?

		<u>Test 2</u>		
		Stop	Carry on	
Test 1	Stop	6	0	Kappa = 1.00
	Carry on	0	14	

31. Why do you think this is the best thing to do?

	Test 1	Test 2		Kappa
		S	NS	
"Stoppers" (n=6):				
It hurts more otherwise	S	4	0	0.57
	NS	1	1	
More time to stop now	S	2	0	1.00
	NS	0	4	
"Carry-oners" (n=14):				
Should stop and don't	S	4	1	0.55
	NS	2	7	
Not giving in	S	1	2	0.44
	NS	0	11	
Hope pain goes away	S	0	2	-0.17
	NS	2	10	

Changing methods

32. If your hands are aching or painful when working, do you believe it is best to:

- Carry on doing tasks in your usual way
- Change the way you do the task

		<u>Test 2</u>		
		Carry on	Change	
Test 1	Carry on	14	1	Kappa = 0.39
	Change	3	2	

33. Which do you actually do most of the time?

		Test 2		Kappa = 0.66
		Carry on	Change	
Test 1				
	Carry on	12	1	
	Change	2	5	

34. Why do you think this?

<u>Test 1</u>	<u>Test 2</u>		<u>Kappa</u>
"Changers" (n = 14)	<u>S</u>	<u>NS</u>	
Fatigue too great	S 2	4	-0.16
	NS 4	4	

"Carry-oners" (n=6):

Hard to change (1), obstinate (3), not stated (2). Reasons were not repeated on both tests.

35. In what way do you change the tasks?

Subjects gave a wide variety of answers (eg. reduce pressure/stress on joints, leave to the next day, use different equipment) and all stated something different on test 2.

Balancing rest and work/ Energy conservation

36. When you are doing everyday jobs, do you believe it is best to;

a. Alternate doing heavy and light jobs, resting regularly during the day

b. Do jobs just as they need doing

		<u>Test 2</u>		Kappa = 0.35
		<u>Alter</u>	<u>Same</u>	
Test 1				
	Alter	10	4	
	Same	2	4	

37. Which do you actually do most of the time?

		<u>Test 2</u>		Kappa = 0.60
Test 1		<u>Alter</u>	<u>Same</u>	
	Alter	9	2	
	Same	2	7	

38. Why do you think this?

	<u>Test 1</u>		<u>Test 2</u>		Kappa
	S	NS	S	NS	
To avoid strain/	S	4	1		
heavy jobs/ pain	NS	0	15		0.86

39. How do you pace yourself?

	<u>Test 1</u>		<u>Test 2</u>		Kappa
	S	NS	S	NS	
Pace/plan ahead more	S	4	4		0.35
	NS	2	10		
Do as I feel like	S	5	3		0.38
	NS	3	12		

Joint Protection - reducing stress on joints.

Key: a lot - over 50% of tasks

some - 25 - 50%

a little - under 25%

not at all - 0%

40. How much attention do you pay to not stressing hand joints when doing everyday tasks?

	<u>Test 1</u>				<u>Test 2</u>				
	3	2	1	0	3	2	1	0	
3. A lot	9	2	0	0					
2. Some	1	1	0	0					
1. A little	0	2	3	0					
0. Not at all	0	0	2	0					Kappa = 0.45

41. How important do you believe it is to reduce stress/ strain on hand joints during daily tasks?

	<u>Test 1</u>	<u>Test 2</u>			
		<u>3</u>	<u>2</u>	<u>1</u>	<u>0</u>
3. A lot	14	0	0	0	
2. Some	0	2	1	0	
1. A little	0	2	0	0	
0. Not at all	0	0	1	0	Kappa = 0.57

42. Have you altered how you do kitchen/household tasks in any way to reduce stress/ strain on your hands?

	<u>Test 1</u>	<u>Test 2</u>			
		<u>3</u>	<u>2</u>	<u>1</u>	<u>0</u>
3. A lot	9	0	0	0	
2. Some	1	2	0	0	
1. A little	1	4	2	0	
0. Not at all	0	0	0	1	Kappa = 0.55

43. Has the care you take to protect your joints altered in the last three months?

	<u>Test 1</u>	<u>Test 2</u>		
		<u>2</u>	<u>1</u>	<u>0</u>
2. Increased	4	1	0	
1. Not changed	3	9	0	
0. Decreased	0	1	2	Kappa = 0.56

44. Can you give some practical examples of tasks you have altered?
On test 1, 69 examples were given by the 20 subjects (mean per subject 3.45, SD 1.7) and on test 2, 76 statements, (mean per subject 3.8, SD 1.58). Thirteen subjects gave mainly the same examples on both tests (ie. two or more statements agreed). Seven subjects gave

mainly different examples (ie. one or no statements agreed).

45. Has it been difficult to change how you do tasks?

	<u>Test 1</u>	<u>Test 2</u>			
		<u>3</u>	<u>2</u>	<u>1</u>	<u>0</u>
3. A lot		6	0	0	0
2. Some		1	2	2	1
1. A little		0	1	0	1
0. Not at all		0	0	0	6
Kappa = 0.58					

46. Why was this?

		<u>Test 1</u>		<u>Test 2</u>		<u>Kappa</u>
				<u>S</u>	<u>NS</u>	
Natural to change	S			5	0	1.00
	NS			0	15	
Attitude/frustration at changing	S			12	2	0.66
	NS			1	5	
Too time consuming to change	S			1	3	0.35
	NS			0	16	

47. What made you change the way you do everyday tasks? (n=19)

		<u>Test 1</u>		<u>Test 2</u>		<u>Kappa</u>
				<u>S</u>	<u>NS</u>	
Pain/poor grip	S	10	4			-0.09
	NS	4	1			

48. How did you go about changing the way you did things?

(n=19)

	<u>Test 1</u>	<u>Test 2</u>		<u>Kappa</u>
		<u>S</u>	<u>NS</u>	
Trial and error	S	2	3	0.19
	NS	3	11	
OT advice/books	S	4	2	0.62
	NS	1	12	
Thought through solutions	S	5	0	1.00
	NS	0	14	

49. Have you ever received any advice written or verbal about Joint Protection? Yes / No

		<u>Test 2</u>		
		<u>Yes</u>	<u>No</u>	
Test 1	Yes	5	0	
	No	0	15	Kappa = 1.00

For Interview 1: Add "or reducing strain on joints" after the term Joint Protection.

50. What do you understand by the term Joint Protection?

	<u>Test 1</u>	<u>Test 2</u>		<u>Kappa</u>
		<u>S</u>	<u>NS</u>	
Avoid strain/sprain	S	2	1	0.31
	NS	4	13	
Wearing splints	S	0	3	-0.08
	NS	1	16	

Ten subjects were unable to give an explanation on either test.

If yes: has received education: (n = 5)

51. Can you state any general principles or guidelines of Joint Protection?

One subject was able to give the same explanation on both tests, four gave an explanation on one test only.

52. Have you used any of the Joint Protection methods you were shown or read about to reduce stress on hand joints? Yes/ No (n = 5)

		<u>Test 2</u>		
		<u>Yes</u>	<u>No</u>	
<u>Test 1</u>	Yes	2	0	Kappa = 1.00
	No	0	3	

53. How often have you used these? (n = 5)

	<u>Test 1</u>	<u>Test 2</u>					
		<u>a</u>	<u>b</u>	<u>c</u>	<u>d</u>	<u>e</u>	<u>f</u>
a. Daily		1	-	-	-	-	-
b. 5-6x/week		-	-	-	-	-	-
c. 3-4x/week		-	-	-	-	-	-
d. 1-2x/week		-	-	-	-	-	-
e. Less than 1x/week		-	-	-	-	-	-
f. Not at all		1	-	-	-	-	3

Kappa = 0.55

54. Can you give examples of methods you are using to protect your joints that you learnt from reading or advice given?

Two gave the same examples (one or two given) on both tests, three gave different examples.

PERCEIVED SEVERITY OF THE DISEASE.

55. To what extent do you think your arthritis is affecting you at the moment?

	<u>Test 1</u>		<u>Test 2</u>	
	<u>Mild Moderate Severe</u>			
Mild	1	1	0	Kappa = 0.17
Moderate	3	8	3	
Severe	0	2	2	

PERCEIVED SUSCEPTIBILITY TO THE DISEASE.

56. In 5 years time, do you think your arthritis will be better the same or worse?

	<u>Test 1</u>		<u>Test 2</u>	
	<u>Better Same Worse</u>			
Better	6	3	0	Kappa = 0.62
Same	1	5	0	
Worse	1	0	4	

Follow-up questions:

57. Do you think participating in the study (ie. being videorecorded, doing the questionnaire and interview) has influenced how you do everyday tasks?

All 20 subjects stated No on Test 2.

58. Do you think you used your hands as you usually do when you were being videorecorded?

All 20 subjects stated Yes on test 2.

59. Lastly, how did you feel about attending the education group at the hospital?

Thankyou for answering these questions.

d) Discussion.

Results from the majority of closed questions demonstrated acceptable levels of agreement, apart from the two questions on self-perceived pain and disease severity, which would naturally fluctuate over time. However, results from many of the open-ended questions must be interpreted with caution in future trials as indicators of whether change has occurred. There was limited agreement on statements made between tests and between subjects for many questions. Despite the low kappa values resulting, particularly in questions where there was a high frequency of zeros in the tables, these open-ended questions were still retained in the interview schedule. Statements made may give insight into why subjects hold certain attitudes and how and what behaviours they carry out. However, only closed questions (apart from pain and disease severity) can be analysed statistically and used to evaluate change, although some of these results should still be viewed in the light of test-retest reliability scores.

2.3.3. CONCLUSION.

The interview schedule has face validity, and moderate test-retest reliability overall in the closed questions, but replies from open-ended questions must be interpreted with caution.

2.4.DEVELOPMENT OF THE JOINT PROTECTION KNOWLEDGE ASSESSMENT.

2.4.1. INTRODUCTION.

One predisposing factor providing the rationale for a health behaviour to occur, is the person's current knowledge of the behaviour (Green et al, 1988). A literature review identified no assessments testing JP knowledge. Some questionnaires, eg. Hill, Bird, Hopkins, Lawton and Wright (1991) have included items on JP but not in sufficient breadth or depth for the purposes of this study.

JP education includes teaching of both general principles and selected methods for a range of common ADL problems encountered by patients. During the accompanying interview, information on subjects' understanding of the term JP and knowledge of JP principles is obtained. Pilot interviews demonstrated subjects had difficulty in expressing what stress-reducing methods they could employ during daily tasks, tending instead to describe their normal methods. As a result, a questionnaire with options to facilitate responses was constructed (the Joint Protection Knowledge Assessment or JPKA). Questions using JP terminology were unlikely to be understood at pre-test. Questions therefore described daily tasks, rather than, eg. to cite or select a method illustrative of JP principles such as "distributing load." Discussion with RA patients during JP education often leads to comments such as "it's common sense to do it that way." For subjects having received little or no JP education formally or informally (eg. through information booklets), questions avoiding JP terminology are more relevant as assessing their ability to apply this "common sense" referred to.

The aim of this assessment is therefore to:

a) establish what RA subjects know about joint stress-reducing

methods and

b) assess if subjects learn more about JP methods from an education programme.

2.4.2. PROCEDURES.

2.4.2.1. INITIAL DEVELOPMENT.

A list of everyday tasks considered stressful enough to require changing was drawn up. Twenty five tasks were selected for consideration (Appendix 8). This allowed for a loss of five tasks if insufficient agreement was obtained in the inter-rater agreement and content validity studies (section 2.4.2.3) on some questions. Seven of the final 20 item JPKA are tasks included in the observation assessment (JPBA).

Multiple choice questions were devised, requiring subjects to select the option they considered least stressful. As with other assessments, questions mainly relate to JP methods for the hand and wrist joints. Three options, ie. stress-reducing (JP), intermediate (partially JP) and stressful (usually equating to normal behaviour of non-arthritic people) methods, were developed for each question. Options were based on descriptions in JP literature, from behaviours defined in the JPBA or descriptions devised by the researcher of normal (ie. stressful) methods of task completion. These were scored, or ranked, as 2,1 or 0, ie. stress-reducing, intermediate and stressful methods respectively. The rank order of options within questions did not follow a repetitive pattern to avoid a response set, and orders were equally distributed through the JPKA. Twenty items were included to be comparable in length to the JPBA.

The questionnaire is completed after the interview and mailed back to allow subjects time to use problem-solving skills at their own speed and to reduce subject reactivity in the JPBA.

The questionnaire was piloted with three OTs for comprehensibility

and appropriateness of options and changes made accordingly. Following this, face validity, content validity, inter-rater agreement and test-retest reliability studies were carried out.

2.4.2.2. FACE VALIDITY.

JP methods of performing the selected JPKA tasks were considered in terms of which JP principles (Appendix 2) were being applied, to ensure each JP principle is represented in the JPKA. Some JP methods apply to several JP principles, eg. avoiding positions of deformity occurs as a natural consequence of using joints in stable positions. The five principles assessed in the JPBA are more strongly represented, to enable assessment of the relationship between knowledge of JP methods and observed behaviour. Overall, JP principles were considered applicable 54 times in the final 20 item JPKA (Appendix 9a).

2.4.2.3. INTER-RATER AGREEMENT AND CONTENT VALIDITY STUDIES.

a) Introduction.

The process of development of the JPKA required verification, ie. that options were appropriately selected and ranked in terms of stress-reducing, intermediate and stressful methods (inter-rater agreement study) and that selected items adequately represented the domain of JP being evaluated (content validity study).

b) Method.

Thirty five OTs working in Rheumatology, identified from the OT Special Interest Group in Rheumatology, were mailed the JPKA and asked if they were willing to participate in the inter-rater agreement and content validity studies.

OTs were asked to:

- i) rank options given for each item as 2,1 or 0, ie. from least to most stressful method, and
- ii) to explain which JP principle/s they considered their "least

stressful" option applied, taking into consideration that the JPKA would be used with subjects with hand and wrist involvement. This latter instruction was included following a pilot study demonstrating difficulty obtaining agreement between OT's as one option may be least stressful for RA patients with hand/ elbow/ shoulder problems but more stressful for those with to hand/knee problems.

A further 20 OTs, identified from an attendance list at a College of OT validated Rheumatology course, were also asked to participate in the inter-rater agreement study only.

c) Results.

i) Inter-rater agreement study.

Thirty one of the 55 OTs replied (56.4% response rate). Difficulties in understanding wording of options in two questions meant replies from 11 OTs for these questions had to be eliminated from analysis, and not all questions were answered appropriately in the ranked format requested. Each question therefore had between 20 and 31 useable replies, with an average of 25 replies per question.

Kendall's coefficient of concordance (W) was used to measure agreement overall within each question. All questions achieved significant agreement ($p < 0.01$), except one (mop designs), which was eliminated from the final JPKA (Table 2.9).

Table 2.9: Inter-rater agreement of the JPKA.

Question		no.OTs	Kendall W	% agreement option
No.	JPBA Task	replying		a / b / c
1	Carry dish**	27	0.9	100.0/ 88.8 / 88.8
2	Clean windows	27	0.73	77.7/ 85.2 / 88.8
3.	Carry washing	27	0.85	92.5/ 85.2 / 92.6
4.	Writing	19	1.00	100.0/100.0 /100.0
5.	Vacuuming	27	0.90	96.7/ 90.3 / 93.5
6.	Ironing	30	0.79	93.3/ 86.6 / 83.3
7.	Housework	26	0.81	73.0/100.0 / 73.0
*	Cutting cheese	20	0.79	70.0/100.0 / 70.0
*	Mop design	25	0.21	60.0/ 64.0 / 64.0
8.	Carry shopping	27	0.80	77.7/ 92.6 / 85.2
9.	Peeling	27	0.81	96.3/ 85.2 / 85.2
10.	Turning tap**	27	0.97	96.3/ 96.3 /100.0
11.	Empty pan**	25	0.93	92.0/100.0 / 92.0
12.	Close drawer	26	0.96	96.2/100.0 / 96.2
13.	Carry bag**	30	0.79	70.0/ 70.0 /100.0
*	Washing up	26	0.67	73.0/ 73.0 / 92.3
*	Opening tin(**)	29	0.65	48.3/100.0 / 51.7
14.	Carry tray**	24	0.93	100.0/ 92.0 / 92.0
15.	Open jar**	25	0.93	92.0/ 92.0 /100.0
16.	Carry pan**	25	0.88	92.0/ 96.0 / 88.0
*	Carry mug(**)	29	0.76	58.6/ 58.6 /100.0
17.	Hold book	27	0.93	92.6/ 92.6 /100.0
18.	Respect pain	27	1.00	100.0/100.0 /100.0
19.	Organise meal	27	1.00	100.0/100.0 /100.0
20.	Rest	25	0.66	76.0/ 96.0 / 80.0

Key to Table 9: Inter-rater agreement JPKA.

- * questions eliminated from the final 20 item JPKA as insufficient agreement.
- ** questions/tasks observed in the JPBA.
- (**) questions/tasks observed in the JPBA, but eliminated.
- a,b,c JPKA options (Appendix 8).

For Kendall's coefficient(W), a mean rank is assigned to each option. These were used to determine the least and most stressful options for each question. Mean ranks were transposed to the nearest whole number to facilitate scoring. An example is given in Table 2.10.

Table 2.10: Example of ranks assigned to JPKA questions.

1. Taking a hot dish from oven Mean rank Final rank

to serve:

option a) grip sides and carry	0	0
option b) slide, lift to top	1.88	2
option c) slide and carry	1.11	1

In this example, the difference between the mean ranks was large facilitating allocation to the nearest whole rank. In other cases the differences were minimal, even though a significant level of agreement within the item was achieved. The five questions with the smallest differences between mean ranks were eliminated (Table 2.9). The JPKA is scored out of 100%. Selection of the least stressful option (2) is awarded 5%, the intermediate option (1) 2.5% and most stressful option (0) 0%.

ii) Content validity study.

Eighteen of the 35 OTs asked to participate replied (51.4% response rate). The frequency with which OTs cited each JP principle (Appendix

9b) was charted using the same format as the Face Validity study (Appendix 9a). Difficulties were encountered in interpreting these results (see Discussion) and in consequence the results were not subjected to detailed analysis.

For four principles cited in the face validity study, no OTs agreed with their relevance and for a further four only one OT agreed. These are shown in () or [] respectively in Appendix 9a. The frequency with which each principle was cited is shown in Table 2.11.

Table 2.11: JPKA Content Validity Study :frequency of JP principle citation by OTs (n = 18).

<u>JP Principle</u>	<u>Frequency cited (max = 360).</u>
1. Respect for pain	11
2. Balance rest and work	54
3. Use of energy conservation	53
4. Avoid activities that can't be stopped	0
5. Avoid holding one position	9
6. Reduce effort a) using aids	20
b) avoiding lifting/carrying	36
7. Distribute load	106
8. Use joints in stable positions	8
9. Use stronger joints	28
10. Avoid positions of deformity	58

Each principle was cited 34.8 (SD 31.2) times on average. However, principle 4 was not cited at all and principles 5 and 8 infrequently.

d) Discussion.

i) Inter-rater agreement.

Respondents indicated it took some 15 to 20 minutes to rank the questions. Those questions with insufficient agreement resulted

because:

- 1) the intermediate method proposed from literature or the JPBA were equally considered as the least stressful (JP) option by respondents,
- 2) the question was ambiguously worded,
- 3) there was professional disagreement about the least stressful method.

The numbers of respondents replying to each question varied as some omitted questions, stating ranking would depend on the pattern of joint involvement experienced by individual patients. The instructions had requested however, that a pattern of hand/wrist involvement only was considered, as this response problem was highlighted during the pilot phase.

ii) Content validity study.

Difficulty was encountered in carrying this out systematically for a number of reasons;

- 1) some respondents gave answers not related to the JP principles listed in the instructions provided but eg. "safer method," "minimises stress on joints," "best JP technique." These comments could not be related to specific JP principles.
- 2) Some answers did not use JP principle wording as requested but required "translating." For example, in question 10 "turning off a tap," one answer was "the tap turner requires a lever action which can be done by the forearm, so no grip is required." This was recorded as "reduce effort - use aids" and "use of strongest, largest joint."
- 3) Some respondents stated that although ranking options was quick, stating reasons for the choice required several hours. Replies reduced in quality towards the end, using broader phrases, as presumably the task became time consuming.
- 4) The original JP principles listed in the content validity study

instructions came from Melvin (1989, first published 1977), a classic reference work in the field. The researcher, incorrectly, assumed that this would be the same set of JP principles other Rheumatology OTs would be implementing. However, other "JP" principles were also cited, such as "encourages the person to problem-solve" which were not listed, but are part of the broad concept of JP education. These statements again proved difficult to record.

Although JP principles were listed in the instructions, respondents were asked to write appropriate principles in a box. This increased the potential for subjects to deviate from instructions and multiple-choice boxes should have been provided. Considerable agreement between the face validity and content validity study was apparent.

e) Conclusion.

The JPKA has significant inter-rater agreement, with options correctly ranked from least to most stressful methods. Content validity is acceptable for nine of the 10 JP principles evaluated in this study. However, the JP principle of "avoiding activities that cannot be stopped" was not cited by OTs. This either indicates: the JPKA is not fully representative of the domain of JP; OTs rarely consider this principle in JP education; or difficulties in interpreting the wide range of responses given by OTs led to its' omission.

2.4.2.4. PILOT STUDIES WITH RA SUBJECTS.

Pilot studies were carried out to establish the best method of obtaining replies from subjects and to clarify instructions.

The final JPKA was piloted with six RA subjects by post, as originally it was planned to mail out questionnaires for completion. Subjects were asked to rank options given from least to most stressful (2 to 0).

Five replies were received. Only one subject replied using rankings

for each option as requested. One ranked tasks they were able to do, but omitted tasks they had to ask someone else to perform. Three replies ticked or ringed the option they actually used. As a result, the written instructions were clarified: to emphasise replies should be what subjects THINK would be least stressful as opposed to the actual method used; to more simply tick the least stressful option only; and an example was provided.

A further pilot was carried out, giving these instructions verbally and working through the explanatory example, to be returned in a stamped addressed envelope (SAE) provided. All five JPKAs were returned appropriately completed.

2.4.2.5. TEST-RETEST RELIABILITY STUDY.

a) Introduction.

This was carried out to ensure subjects were able to give consistent replies over time.

b) Method.

Subjects were provided with the questionnaire, given verbal instructions as above and asked to complete and return these in the SAE provided within one week. The second test took place on average 58 days after the first.

c) Results.

Test results are shown in Table 2.12.

Table 2.12: JPKA Test-retest reliability (n=20).

	<u>Median score</u>	<u>IQR.</u>	<u>Comparison</u>
Test 1	78.75%	61.88 - 89.38%	$z = 1.39$
Test 2	85.00%	63.75 - 91.88%	$p = 0.16$

The Wilcoxon test showed no significant difference in test scores between the two occasions. The mean score change was +1.89% (SD 6.22%). A significant score change for the JPKA was determined as

either more or less than two standard deviations from the mean score change (ie. + or - 12.4%).

d) Discussion.

Although the JPKA was demonstrated to have test-retest reliability, it is questionable whether it can be considered a clinically useful tool for measuring change in knowledge of JP methods post-education. Ten subjects scored 80% or more on test 1, and 12 80% or more on test 2, there is thus little scope for a significant score increase for most subjects.

The stated aims of the JPKA were to assess subjects' abilities to:

i) problem solve using their knowledge of JP principles to determine appropriate JP methods. The majority of subjects had not received JP education, but achieved high scores despite lack of knowledge of JP principles,

ii) recall JP methods described in information booklets or by rheumatology staff. Twelve of the subjects stated they had read information booklets and most had also received advice from a variety of team members, all of which could have been sources of information on stress-reducing methods. High scores may have been obtained from recall of this advice therefore, although only five could recall having received, or knew such advice as being "Joint Protection,"

iii) problem solve using "common sense." As only five subjects had received JP advice previously, problem-solving using common-sense seems the most likely explanation for the high scores.

Questions may have been too easy, although options were limited by these having to describe practical methods of completing everyday tasks. A number of OTs participating in the validity study commented they thought patients would find difficulty distinguishing between least and intermediate stressful options in the JPKA. This proved not

to be the case.

These results would seem to support the statement of many RA patients that JP education is just common-sense. However, it could be that given options in the JPKA (thus heightening awareness of alternatives) and given time (between 15 to 30 minutes at a time chosen by the subject), subjects could problem solve the best methods, when they might experience difficulty in coming up with solutions for themselves unprompted. Pilot interviews demonstrated the latter is likely, as subjects were unable to answer similar questions at short notice without the prompt of options. A number of subjects indicated at the end of the test 2 interview that completing the questionnaire had made them think more about how they performed tasks, indicating the JPKA heightened their awareness of these behaviours.

The JPKA is therefore unlikely to prove of use in detecting changes in knowledge post-education. Several OTs participating in the validity study stated they used the JPKA with patients to check agreement with their (the OTs) reply, and found it a useful teaching tool as it encouraged patients to think more about JP methods. It could prove of use in developing patients problem-solving skills and this is an area for future enquiry.

2.4.3. CONCLUSION.

The JPKA is a valid and reliable tool. However, its usefulness as an outcome measure of changes in JP knowledge is questionable, although it could potentially be of value as a teaching tool.

The JPKA has still been incorporated within ensuing trials in order to assess the relationship between subjects' knowledge of JP methods and their actual behaviour as observed in the JPBA.

2.5. DISEASE MEASURES.

2.5.1. INTRODUCTION.

It was noted during JP education that patients stated they already used JP methods. Reasons given for this natural adoption of JP included: functional difficulties; pain; weak grip and deformity.

In the earlier (Hammond, 1988) pilot study, it was hypothesised subjects could already achieve a score on the JPBA prior to education due to disease effects and a significant correlation between JP scores and hand joint count of pain/tenderness was identified.

Disease measures were collected to identify:

- i) whether any relationship between these and JPBA scores exists prior to education,
- ii) whether any JPBA score changes could be due to disease status fluctuations (eg. an arthritis flare-up or drug induced remission) rather than the intervening education.

Disease measures were selected to evaluate which factors influence initial level of or changes in JP behaviour, ie. act as internal cues to action. JP theorists claim it can reduce the effects of inflammation (tenderness and swelling) and pain, preserve joint integrity (reduce the likelihood of deformity occurring) and increase mobility and function (Melvin, 1989). These claims, and the factors cited by patients above, influenced the choice of measures. Within the three month follow-up period planned, and given it was not possible to control the medication or other treatment patients received in this period, it was considered unlikely any changes in disease measures could be attributed to the use of JP methods. Therefore these measures are not being utilised as JP outcome measures.

Assessments were selected as being quick to administer and record and having good reliability, given the number of assessments already

used.

2.5.2. DISEASE MEASURES SELECTED.

a) Disease classification.

Progression of RA (severity) was recorded using ARA criteria of early, moderate and severe RA (Steinbrocker, Traeger and Batterman, 1949: Appendix 1).

b) Disease duration.

Recorded in months since diagnosis (patients' report).

c) Degree of Hand Involvement.

As a major focus of the study is Hand JP, disease involvement in the hands/wrists was recorded.

i) Inflammation:

Standard clinical assessments estimate the total "amount" of active joint inflammation in the whole body. Joint Count measures of both tenderness and swelling were collected using the ARA Co-operating Clinics Articular Index (cited in McCarty, 1979) for the wrist, MCP and PIP joints only. This Index uses a 4 point weighted summation, the scaling system only was used (ie. 0=none, 3=severe). As 11 joints per hand were recorded (ie. those included in the Hand JAM scale - see below), the potential maximum score was 33/hand, 66 bilateral score. Both pain/tenderness and swelling counts were recorded during the test-retest study. However, as significant correlations were obtained ($p < 0.05$) between hand pain/tenderness and swelling scores, pain/tenderness (or Hand Joint Count, HJC) only was recorded in ensuing trials. Spiegel, Spiegel and Paulus (1987) and Lorish, Abraham, Austin, Bradley and Alarcon (1991) also reported strong correlations between total joint tenderness and swelling.

ii) Mobility and Deformity:

As Spiegel et al (1987) point out, articular indices measure pain/tenderness and swelling which may or may not be associated with joint

deformity. Patients may have no current evidence of synovitis but have the permanent sequelae of this, ie. reduced RoM and deformity. Methods of evaluating preservation of joint integrity and mobility, could include detailed tracings of the hand and fingers, accompanied by goniometer measures as described by MacBain (1970) in the RA Hand Assessment; radiographic analysis; and the Hand Evaluation of joint structure and function described by Treuhaft, Lewis and McCarty (1971). These were considered too time consuming. The Joint Alignment and Motion scale (JAM scale, Spiegel, Spiegel and Paulus 1987) was selected, measuring percentage limitations in range of motion and deformity. This correlates significantly with both radiological grading methods and ARA functional class (Parker, Harrell and Alarcon 1988; Parker et al, 1989). Wrist, MCP and PIP joints only were recorded, using a shortened version of the form developed by Parker, Harrell and Alarcon (1988). This scale is similarly scored 0-4, giving a maximum potential score of 44/hand, 88 bilaterally. As the JAM scale correlates significantly with grip strength measures (Spiegel et al, 1987) this latter measure was not included. This hand measure is referred to as the Hand JAM (HJAM) scale throughout.

iii) Hand Pain on Activity.

Pain on activity was measured, as well as joint tenderness scores, as patients experience differing degrees of pain at rest and on activity (Papageorgiou and Badley, 1989). Scott and Huskisson (1976) concluded Visual Analogue Pain Scales are readily used by patients with no previous experience and are most effective with the terms "severe, moderate and slight" equally distributed along the scale. Subjects were asked to rate : degree of dominant hand pain (ie. wrist and hand), as individual joint pain can vary from overall pain levels (Badley and Papageorgiou, 1989); during a "moderate daily activity, eg cooking, housework, gardening." Donovan, Blake and Fleming (1989)

reported that patients discuss pain within the context of daily life and suggested it would cause difficulty completing VAS if they were "out of context."

d) Pain.

Pain experienced throughout the body during activity was also recorded using the Health Assessment Questionnaire Pain Scale (Callahan, Brooks, Sumney and Pincus, 1987), as an indicator of disease severity.

e) Functional assessment.

Functional ability was recorded using the Health Assessment Questionnaire (Fries et al, 1980), to identify whether there is any relationship between degree of functional impairment and usage of Hand JP. This includes upper limb activities: Dressing, Grooming (item 2), Eating (items 1,2,3), Hygiene (item 1), Reach (item 1), Grip (items 1,2,3). As scores on these sections have been shown to correlate with a hand and upper limb function test (the Signals of Functional Impairment Test, Eberhardt, Svensson and Moritz, 1988), a specific hand function test was not included.

f) Psychological factors.

The interview (section 2.3) aimed to explore why subjects do or do not adopt JP methods. Nicassio, Wallston, Callahan, Herbert and Pincus (1985) postulated that Learned Helplessness theory could explain why RA patients adopt health maintenance behaviours. It was theorised that people who develop feelings of personal helplessness, passive resignation and inappropriate coping behaviours (ie. "loss of control with arthritis") are less likely to adopt or develop health maintenance or problem-solving behaviours, and the Arthritis Helplessness Index (AHI) was developed to evaluate this (Nicassio et al, 1985). This has significant correlation with health locus of control, self-esteem and depression measures. A subsequent study by

Stein, Wallston, Nicassio and Castner (1988) also demonstrated a significant correlation between the AHI and levels of adherence with recommended levels of medication, exercise and rest, ie. higher helplessness led to greater noncompliance. This measure was incorporated to identify whether degree of loss of control with arthritis correlates with use of Hand JP methods.

2.5.3. OTHER VARIABLES.

a) Living arrangement.

This was recorded as Living Alone; With Partner (significant other); and in a Family (ie. with/without partner and with child/children).

b) Hand dominance.

That used for writing was recorded as the dominant hand.

2.6. ASSESSMENT PROCEDURE.

During pilot studies it was considered preferable to videorecord the JPBA prior to asking detailed questions on behaviour to reduce subject reactivity. However, this was inappropriate on initial assessments, when the assessor was unknown to subjects. The sequence was determined as: collection of demographic and clinical data, interview, instructions on completion of self-administered questionnaires (HAQ, HAQ Pain, AHI, JPKA) and videorecording the JPBA. On subsequent visits the JPBA was recorded before the interview.

3. EVALUATION OF "TRADITIONAL" JOINT PROTECTION EDUCATION.

3.1. INTRODUCTION.

Research has not demonstrated that "traditional" JP education improves JP knowledge, changes attitudes or causes behavioural change.

Clinical experience and the earlier pilot study (Hammond, 1988; Hammond, 1994) suggested education leads to some cognitive and attitudinal changes. Patients correctly understood the aims of JP and believed it beneficial and relevant for them to incorporate JP and Hand JP into daily life. Despite expressing these positive beliefs, Hand JP did not increase. Patients self-reported they were doing so but for the majority of behaviours cited as used, either these were not observed or were already being performed prior to education in the JPBA. This indicated patients became more aware of their behaviour, rather than change occurring. Altering the frequent, automatic patterns of performing everyday activities is a mammoth task. To what extent "traditional" JP education facilitates RA patients making the widespread changes commonly recommended is relatively unexplored.

The aim of the study was therefore to:

- i) use the assessments described in chapter 2 to evaluate the efficacy of "traditional" JP education in improving knowledge, changing attitudes and increasing the use of JP behaviours,
- ii) identify if disease factors (eg. pain) act as internal cues to action, influencing the natural adoption of Hand JP,
- iii) investigate whether discrepancies between beliefs in the benefit of JP behaviours and adherence with these exists,
- iv) investigate patients' strategies for changing behaviour and
- v) identify factors facilitating or limiting adherence with JP.

3.2. METHOD.

3.2.1 NULL HYPOTHESES.

It was hypothesised that:

- i) there is no difference between RA patients' knowledge of, attitudes towards and use of eight JP behaviours before and after attending a "traditional" JP programme,
- ii) there is no relationship between attitudes towards the benefit of these and self-perceived and observed JP behaviours,
- iii) there is no relationship between the use of Hand JP behaviours and the disease's impact.

3.2.2. EDUCATION PROGRAMME DEVELOPMENT.

JP education is provided to both in- and out-patients, either individually or in groups. Evaluating an out-patient programme ensures subjects have the opportunity to practice taught methods at home between assessments. Individual education varies in both content and duration because of eg.:

- i) the patient's level of interest in attending. Patients may be referred with little knowledge why and what will happen,
- ii) how frequently they are willing and able to attend,
- iii) which joints are painful and what functional difficulties they have,
- iv) staff availability,
- v) staff experience in JP and patient education techniques and,
- vi) the patient's educational level, physical and psychological state.

Evaluating group, rather than individual, education programmes ensures subjects receive similar advice and information. Staff are regularly committed to teaching these, ensuring continuity and that programmes have standard contents and duration. Patients selected to attend are considered as sufficiently stable physically and

psychologically to participate in group interactions. Patients also choose to make the commitment to attend, increasing the likelihood of attending all sessions and adhering to the advice given. The Outpatient group format is only one method of providing "traditional" JP education, but that which is more likely to have positive effects. Enquiries to Rheumatology units in the locality (Buxton, Chesterfield, Derby, Nottingham and Sheffield) identified two ran group programmes. Other units expressed interest in these, but were unable to provide them due to staffing problems.

i) Buxton Rheumatology unit ran an in-patient AEP on: disease information, exercise, JP, diet, medication and benefits. However, many patients have severe RA with restricted function, limiting their ability to adopt JP, and as this is a regional unit, follow-up assessments would be difficult.

ii) Derby Royal Infirmary (DRI)- ran a 1.5 hour out-patient education group on disease information, exercise and JP. This was offered to interested patients following attending OT or PT.

The Rheumatology team (three consultants, two out-patient rheumatology nurses, one PT and one OT) were interested in extending the programme content, with wider availability. Following review of the research protocol, the team enthusiastically agreed to assist developing a programme and to refer to the trial. Ethical approval was then obtained.

A rheumatology nurse, OT, PT and the researcher developed a programme based on: RA patients commonly expressed information needs (Buckley, Vacek and Cooper, 1990; Kay and Punchak, 1988; Silvers, Hovell, Weisman and Mueller, 1985); and AEPs used in the UK and USA (Rehabilitation through Learning, Furst, Gerber and Smith, 1987; the Arthritis Self-Management course, Lorig, 1986a; Columbia Hospital Program for Patients with Rheumatic Disease, Pigg, Ambrose and

Casper, 1981; the SPIRE programme, Unsworth, 1990; Joint Preservation techniques for patients with rheumatoid arthritis, Watkins and Robinson, 1974).

A 4 x 2 hour programme was finalised (Figure 3.1 and Appendix 10), using teaching methods and including topics common in AEPs. Teaching plans for each session were developed by individual team members and reviewed by the group for appropriateness of content. All staff involved in the programme reviewed and discussed these to ensure all agreed with the content and mode of delivery. The teaching style adopted by staff was not discussed with or influenced by the researcher as the aim of the trial was to evaluate "traditional" or normal methods of arthritis and JP education. All the staff in the team had previously been involved in providing arthritis patient education (for a minimum of three years) to individuals and the OT and PT also to groups.

Role play teaching sessions were run by team members with each other (excluding consultants who had insufficient time to participate) to increase confidence in running and teaching groups, as only the OT was experienced in group skills. Feedback was provided on teaching techniques, audio-visual aid presentation and group interaction skills by the team and researcher.

Topics lasted between 45 and 55 minutes and were delivered as short talks (20 to 30 minutes) supported by flip-chart or poster visual aids of the main points, followed by questions and discussion. Arthritis and Rheumatism Council (ARC) and other booklets on RA and JP were provided to reinforce information given ("Rheumatoid Arthritis - a handbook for patients," ARC, 1991a; "Rheumatoid Arthritis - helping yourself" Reeks et al, 1990; "Your Home and Your Rheumatism" Ansell and Lawton, undated). Relaxation sessions were mainly practical, using a variety of methods (Guided imagery,

Jacobsen's and Benson's methods). The exercise and JP sessions were half lecture/demonstration and half return demonstration by patients. The group was held in the OT department, with access to the OT kitchen to practice JP. Comfortable high chairs in a horseshoe seating arrangement were provided to ensure correct sitting positions and allow the speakers and visual aids to be easily viewed whilst allowing ready eye-contact between group members. A 15 to 20 minute break was included to facilitate informal discussion and questioning and allow position changes to prevent discomfort and stiffness. Staff were available for questions at the end of each session.

Figure 3.1: "Traditional" arthritis education programme contents.

Session	Topic	Staff
1	a. Disease education	Rheumatology
	- causes, definition, joint structure and changes	nurse
	b. Disease management and drug therapy	Rheumatologist
2	a. Alternative therapies and diets	Rheumatology
		nurse
	b. Rest and relaxation / practice	OT
3	a. Introduction to Joint Protection	OT
	- joint structure and disease changes, development of deformities, JP and EC principles, demonstration of ADL tasks using normal and JP methods, Problem-solving task.	
	b. Exercise and positioning / practice	PT
	Pain control.	
	c. Relaxation practice	OT
4	a. Joint Protection	OT
	- problem-solving task, JP and EC principles,	

demonstration and practice of kitchen
ADL tasks, aids available and practice.

Energy Conservation	PT/OT
b. Relaxation practice	OT
c. Questions/ discussion	Team

Referrals to the group were made by team members in clinic or individual treatment sessions, once entry criteria were met (see 3.2.5). Group size was planned as four to eight patients.

The programme was co-ordinated by the OT, sending out invitation letters and trial information, teaching other topics when staff were unavailable, attending each session, welcoming patients and using group skills to encourage interaction and discussion during sessions.

3.2.3. JOINT PROTECTION EDUCATION SESSIONS.

The JP component of the programme was planned to last for 2.5 hours over the last two sessions of the AEP. Content and teaching methods were based on literature review and the survey of OT JP programmes, described in section 1.5.3, and was designed to be representative of "traditional" or typical current JP education provided by OTs (Figure 3.1 and Appendix 10). One hour of demonstration and return demonstrations by patients was included. The survey also identified 2.5 hours education as the maximum generally provided for patients. Other studies of JP education include two 1.5 hour sessions (Furst, Gerber, Smith, Fisher and Shulman, 1987; Lindroth and Brattstrom, 1991), one of two hours (Bowell and Ashmore, 1992), one of one hour (Byrne, Campbell, Hunt and Hough, 1992; Lorig, 1986a) and two of 30 minutes (Tucker and Kirwan, 1989) indicating the selected duration was appropriate.

JP methods for hand and wrist problems were emphasised during the demonstrations and the practice component being of kitchen tasks (at

the request of the researcher), to ensure the taught content was appropriate to the developed assessment procedure (the JPBA).

All sessions in the AEP were observed by the researcher on at least two occasions during the trial. Content and mode of delivery were similar to other AEP and JP programmes previously observed at other centres by the researcher. Descriptions of this AEP and the JP component have also been considered as similar to their normal clinical practice by four other rheumatology OTs.

Clinically, JP education is also provided by other rheumatology team members but does not normally include practical elements due to lack of access to ADL facilities and is usually shorter. This programme is therefore representative of OT JP education.

3.2.4. TRIAL DESIGN.

Trial participation was optional. The trial was planned to last 12 to 18 months, depending on recruitment and staff agreed to run the programme without changes for this period. The team planned to review and make alterations as appropriate following this. A one-group pretest-posttest design was selected as:

- a) primarily team members (apart from rheumatologists) were unwilling to have patients act as controls, either not receiving treatment or waiting several months as a control group in a crossover design. Nursing and therapy staff all had a strong belief in the importance of educating patients at an early stage and had not previously assisted in research trials nor had any research training, meaning the concept of control was unfamiliar to them. As the study was occurring within their department it was not possible to insist on a crossover or randomised controlled trial being run;
- b) subject numbers were difficult to estimate and sufficient numbers for control and treatment groups might not be available;
- c) the earlier test-retest studies demonstrated assessments had good

reliability over a two month period, indicating temporal effects are minimal;

d) the aim was to measure individual's knowledge, attitudes and behaviour over time, meaning a design with subjects acting as their own controls was appropriate.

The weaknesses of a one-group pretest-posttest design are:

a) temporal effects - changes may occur naturally with the passage of time. The lack of a control group means any treatment effects would not be distinguishable from temporal effects, although the test-retest study indicated behaviour is stable over on average a two month period. A control period of six weeks was therefore included.

b) attention effects - change may occur as a result of additional attention irrespective of treatment content. The control phase thus spanned the first two sessions of the AEP to assess if this increased attention could lead to increased JP behaviours.

c) learning effects - behaviour may increase as a result of repeated testing, not treatment. The lack of a control group (in which such learning would also therefore occur) means if this effect occurs it could be interpreted incorrectly as a treatment effect.

Using this design, should change occur it would be impossible to attribute this to the education programme. However, if it does not, this will support the hypothesis that traditional JP education methods are ineffective in changing behaviour.

Criticisms received of the earlier (Hammond, 1988) pilot study were that follow-up phases at two and six weeks were inadequate. Assessment intervals were therefore extended to six weeks each.

The control phase pre-education was originally planned as six weeks. This was shortened to four weeks, as problems arose with group and trial information letters being sent out at agreed dates by staff. Follow-up was at six weeks post-education, to indicate the short-term

impact of taught behaviours and at three months, to evaluate longer-term recall and behavioural change. The design is shown in Figure 3.2.

Figure 3.2: Trial design.

Weeks:

1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18
0		X	X	0	X	X					0						0

0 = assessment X = education sessions

Subjects were kept "blind" to the purpose of the study. It was described as a survey of: what information people with arthritis have been given about their disease and its management; how their disease affects performing everyday household activities and how they manage these; and the development of an OT assessment evaluating hand movements of RA patients during normal daily activities.

Care was taken to avoid discussion with patients during either group sessions or assessments linking the trial aims, assessments and JP advice being given. The researcher was not involved in the education group. Maintaining subject "blindness" to the trial aims was essential to prevent reactivity during video assessments.

3.2.5. PILOT STUDY.

The programme was piloted twice to improve staff confidence in teaching the material and running groups, alter timings and make final adjustments to content.

These included: a reduction in lecture content to allow more time for patients to ask questions; a wider display of leaflets; a display of small kitchen aids and the opportunity for patients to purchase these.

All assessments were intended to be carried out in subjects' homes,

at times convenient to them. Difficulties arose arranging the second assessment in the week between sessions two and three, as subjects were not always available. The second assessment was therefore conducted in the OT department kitchen, using equipment as similar as possible to the subject's, either immediately before or after session two. A pilot was conducted to ensure this did not inconvenience the education programme, appropriate equipment was available and make minor alterations to the OT kitchen layout to facilitate videorecording.

3.2.6. SUBJECT SELECTION.

a) Sample size

Using STPLAN software (Brown et al, 1990) a minimum sample size of 14 was required (ie. based on a pre-test mean estimated at 23% and standard deviation of 18% (see test-retest reliability data, Table 2.3), a significant increase of 20% required, power of 0.8 and significance level of 0.05).

b) Criteria for referral:

- i) adult patients with a firm diagnosis of RA,
- ii) identified by a member of the rheumatology team as likely to benefit from group education. Factors influencing this decision included: the patient's expressed interest in learning about the disease and its management; considered likely to contribute positively to a group - those patients who are overly talkative or dwelling on their disease problems are offered individual education; concentration not impaired by pain; physically well enough to attend; physically able to implement the advice given - patients with severe disability were excluded,
- iii) patients choose to attend the group and are willing to commit themselves to attending for four weeks.

Referred patients usually had less than a five year history but those

with a longer disease duration were considered. There was no upper age limit, provided the patient has no cognitive impairment.

Additionally, trial entry criteria were:

iv) wrist and/ or MCP involvement (either inflammation and/ or deformity), to ensure JP education is applicable to their disease symptoms;

v) no other medical condition affecting hand function.

c) Patient consent

Trial information letters and reply forms were forwarded out with education group invitation letters by the OT. These outlined the nature of the trial involvement and emphasised that, as the trial was separate to the education group, non-participation would not affect their attendance at this in any way. Names and addresses of those patients agreeing to participate were forwarded to the researcher.

These patients were contacted by telephone to confirm they met the trial entry criteria and arrange the initial assessment. A verbal explanation of their involvement was given, ie. four assessments over a four to five month period at times convenient to them, when they would be videorecorded making a hot drink and snack meal taking 10 to 15 minutes and on the first and final of these, they would also be interviewed and asked to complete and return several questionnaires.

At the initial assessment patients were supplied with a further verbal and written explanation of the trial. The confidentiality of the videorecordings, interview and questionnaire information was emphasised. To allay embarrassment about being videorecorded, subjects were assured sound was not recorded and the camera focused on their hands. Patients signed a consent form, stating they were free to withdraw from the study at any time. General Practitioners were informed of their patients' consent.

3.2.7. ASSESSMENT PROCEDURES.

Assessments were conducted at intervals described above. As the test battery takes 1.5 hours to complete, it was decided the JPBA would be conducted at each assessment (as the main aim of the study is to identify Hand JP behavioural change), with other measures at the initial and final assessments only as: subjects could find repeated testing time-consuming and boring; disease measures are unlikely to show variations over six week periods; and repeated testing with the interview and questionnaire could cause contamination from learning effects.

Age, disease duration and hand dominance were recorded at the first assessment. Disease class was obtained from patients' records. The JPBA was videorecorded at all four assessments, using the instructions described in Appendix 3. The JPKA, interview and other disease measures (Hand Joint Count (HJC), Hand Joint Alignment and Motion scale (HJAM), 100mm. Visual Analogue Scale (VAS) of hand pain on activity, Health Assessment Questionnaire (HAQ), HAQ Pain scale and Arthritis Helplessness Index (AHI)) were obtained at the first and final assessments, using the methods described in sections 2.3, 2.4 and 2.5.

3.2.8. STATISTICAL ANALYSIS.

Non-parametric statistics were used throughout as data was not normally distributed. The Wilcoxon test (T+) was used to assess differences in JPKA, HAQ, HAQPAIN, AHI, VAS, HJC and HJAM measures pre- and post-education. Friedman's two-way ANOVA (F(r)) tested for changes in JPBA scores (obtained on all four assessments). Mann-Whitney (U) and Wilcoxon (Z) tests were used when comparing data from between and within sub-groups of subjects, due to the small sample sizes resulting. Relationships between these variables were assessed using Spearman's rank correlation coefficient. For interview data,

the McNemar and Wilcoxon tests were used to assess changes in categorical and ordinal data respectively obtained pre-and post-education, with Spearman's and Cramer's coefficient to assess relationships.

3.3. RESULTS

Results cited are at four weeks pre- and 12 weeks post-education unless otherwise stated.

3.3.1. SUBJECT RECRUITMENT.

The trial ran between October 1990 and October 1991. The OT co-ordinating and running the JP education sessions left and her replacement did not adhere to the planned JP education, so the trial prematurely ceased.

Eight groups ran during this period. Trial information letters were accidentally not sent by staff to one group from which no recruitment occurred. Ten to 15 patients were invited to participate in each group (94 in total). Between three to seven attended each (43 in total, ie. a 46% response rate).

Twenty-five subjects agreed to participate in the trial. However four withdrew because they no longer wished to continue with the assessment procedures, two of whom had ceased attending the education group after one session. Data from these four subjects was excluded from analysis, giving a sample of 21.

3.3.2. SUBJECT SAMPLE.

a) Demographic characteristics.

See Table 3.1.

b) Disease duration.

This ranged from five months to 24 years, mean duration was 6.43 years (SD 7.6 years). Thirteen had the disease for less than five years (10 of these less than two years).

c) ARA classification of disease progression.

Eight were classified as early, seven moderate and six severe (Appendix 1). Those six subjects in the severe category had already developed hand deformities, such as wrist subluxation, ulnar deviation, boutonniere or swan-neck fingers.

Table 3.1: Demographic characteristics of RA subjects (n = 21).

Age (years)	Mean	48.95
	SD	12.54
	Range	22 - 70
Sex	Women	17
	Men	4
Race	Caucasian	21
Living Arrangement	Alone	3
	With partner	11
	With family	7
Hand dominance	Right	20
	Left	1

d) ARA functional grade.

All subjects were ARA functional grade III (Appendix 1).

3.3.3. DISEASE MEASURES.

3.3.3.1. PHYSICAL MEASURES.

a) Hand involvement (HJC and HJAM).

The degree and distribution of HJC and HJAM involvement pre-education are shown in Table 3.2.

Table 3.2: Degree and distribution of HJC and HJAM involvement.

HJAM: Degree of Involvement	Unilateral	Bilateral	HJAM No. subjects
Mild	0 - 14	0 - 29	14
Moderate	15 - 29	30 - 59	6
Severe	30 - 44	60 - 88	1
<u>HJC:</u>			
Mild	0 - 11	0 - 22	13
Moderate	12 - 22	23 - 44	7
Severe	23 - 33	45 - 66	1

There were no significant differences in HJC and HJAM scores pre- to post-education (Table 3.3).

Table 3.3: HJC and JAM scores pre- and post-education (n= 21).

	Right Median & IQR	Left Median & IQR	Bilateral Median & IQR
<u>HJC</u> pre-ed:	8.00 (2.00 - 15.00)	8.00 (1.50 - 15.00)	16.00 (4.00 - 30.00)
post-ed:	6.00 (0.50 - 20.00)	6.00 (1.50 - 14.50)	12.00 (2.50 - 31.50)
z =	0.28	0.46	0.48
p =	0.77	0.64	0.63
<u>HJAM</u> pre-ed:	10.00 (1.00 - 23.50)	8.00 (1.00 - 23.00)	20.00 (2.00 - 46.00)
post-ed:	12.00 (2.50 - 19.50)	10.00 (2.00 - 21.50)	26.00 (7.00 - 41.00)
z =	0.37	1.71	1.24
p =	0.71	0.88	0.21

b) Hand pain on activity.

Seven subjects had mild (scores 0 - 33), 11 moderate (scores 34 - 66) and three severe (67 - 100) pain pre-education, with eight mild and 13 moderate pain post-education. There was no significant difference

in VAS scores post-education ($z = 1.06$; $p = 0.29$) (Table 3.4).

c) Functional disability.

Pre-education, six subjects had mild (scores of 0 - 1), 12 moderate (scores 1.1 - 2) and three severe (scores of 2.1 - 3) functional disability. Post-education five had mild, 11 moderate and five severe functional disability. There was no significant difference in HAQ scores ($z = 0.70$; $p = 0.49$) (Table 3.4).

Table 3.4: VAS, HAQ, HAQPAIN and AHI scores pre-and post-education (n = 21).

	Pre-education		Post-education	
	Median	IQR	Median	IQR
VAS	51.00	31.50 - 60.50	55.00	37.00 - 77.00
HAQ	1.38	1.00 - 1.81	1.38	1.00 - 2.00
HAQPAIN	1.00	0.69 - 1.69	1.13	0.50 - 2.00
AHI	34.00	32.00 - 36.50	34.00	32.00 - 37.50

Twenty subjects reported difficulty with grip (18 in opening jars and 13 with taps), suggesting JP methods were appropriate for most subjects.

d) Pain on functional activity scores (HAQPAIN).

There was no significant score change pre- to post-education ($z = 0.33$; $p = 0.74$) (Table 3.4).

3.3.3.2. PSYCHOLOGICAL MEASURES

a) Learned helplessness (AHI) scores.

Pre-education, one subject had low (scores of 15 - 20) and 20 moderate (scores of 31 - 45) perceived helplessness (AHI). Post-education, three had low and 18 moderate perceived helplessness, ie. there was no significant difference ($z = 0.16$; $p = 0.87$) (Table 3.4).

b) Perceived severity.

Pre-education, 15 subjects considered they had severe disease, five

moderate and one mild. Post-education, there was no significant change ($Z = 0.26; p = 0.79$) with 16 severe, three moderate and two mild disease.

c) Perceived susceptibility.

There was no significant change in perceived susceptibility ($Z = 0; p = 1.0$) with nine subjects considering they would be better in five years time, six the same and six worse.

d) Perceived self-efficacy.

There was no significant change in subjects belief in their ability to control their disease symptoms post-education ($Z = 0.91; p = 0.36$), with all considering they could to some degree. Replies summarising strategies used are shown in Table 3.5.

The commonest methods were related to joint care (JP) and pacing (EC), with eight subjects before and 12 after education citing these: eg. "use joints depending on pain," "don't push joints too far"; and "pace yourself," "stop and rest when need to" (EC).

Table 3.5: Coping strategies for controlling RA symptoms (n = 21).

	<u>Pre-education</u>	<u>Post-education</u>
Don't know	5	4
Joint Care	5	8
Balancing Rest and Work/Pacing	5	6
Positive attitude	5	2
Rest/relaxation	3	7
Exercise	2	6
Taking medication	1	1
Diet	1	0
Reflexology	0	1
Fight it/work through pain	3	0

3.3.4. OUTCOME OF TRADITIONAL JP EDUCATION.

3.3.4.1. HAND JP BEHAVIOUR.

Seven subjects could recall receiving some advice from a health professional on care of joints (three from an OT) prior to attending the programme. This group's median score (27.5%, IQR 10.50 - 42.50%) was not significantly different to those who had not received such advice ($n = 14$: 14.1%, IQR 10.00 - 35.00: $U = 34.5$; $p = 0.28$).

Median JPBA scores pre- and post-education are shown in Table 3.6.

Table 3.6: JPBA scores pre- and post-education ($n = 21$).

	<u>Median</u>	<u>IQR</u>
4 weeks pre-	18.40	10.25 - 35.55
1 week pre-	23.70	11.90 - 34.30
6 weeks post-	22.50	14.40 - 38.15
12 weeks post-	23.70	15.35 - 37.45

No significant change in scores occurred during the pre-education control phase ($z = 0.78$; $p = 0.43$), demonstrating neither the extra attention from attending the first two education sessions, time nor the different assessment locations (home and OT department) altered behaviour.

There was no significant difference in JPBA scores before and after education ($F(r) = 1.64$, $df = 3$; $p = 0.65$). No significant score differences occurred between any assessments using the Wilcoxon test. The mean score change from four weeks pre- to 12 weeks post-education was +4.01% (SD 10.59).

3.3.4.2. FREQUENCY OF JP BEHAVIOURS.

There was no significant change in the frequency with which JPBA tasks were performed Correctly, Borderline or Incorrectly by subjects over the four assessment periods. Proportions of JP score categories

are shown in Table 3.7. Each task was observed a maximum of 84 times (ie. 21 subjects observed on four occasions each).

Filling and Carrying a Kettle were the commonest tasks performed correctly, with Squeezing a Cloth and Closing Jars least often.

Twenty subjects considered they had used their hands as they would normally whilst being videorecorded, and one that she took "a little more care because of the camera."

Table 3.7: Proportions of JPBA tasks scored Correct, Borderline and Incorrect.

Task	Percentage: Correct	Borderline	Incorrect
Fill Kettle	57.3	2.44	40.24
Carry Full Kettle	45.2	10.7	45.2
Wipe Surfaces	33.8	5.2	61.0
Carry Shop bag	26.5	4.82	68.7
Carry Plate	25.3	3.6	71.1
Open Tin	23.8	29.8	46.4
Push in Electric Plug	21.3	2.5	76.25
Lift Box from Bag	20.2	40.5	39.3
Hold Milk Bottle	20.0	5.0	75.0
Turn on Tap	19.3	6.02	74.69
Empty Pan Contents	17.9	2.4	79.8
Lift Grill Pan	15.7	37.1	47.2
Carry Mug	15.6	4.9	79.3
Turn Off Tap	15.6	6.02	78.5
Pour Kettle	11.9	16.6	71.4
Open Jar	10.9	10.7	78.6
Carry Pan to Cooker	7.1	15.5	77.4
Carry Tray	4.8	20.2	75.0
Squeeze Cloth	3.8	1.3	94.9
Close Jar	1.2	8.3	90.5

3.3.4.3. CORRELATION BETWEEN HAND JP BEHAVIOUR, DISEASE AND DEMOGRAPHIC MEASURES.

Pre-education, there was a significant correlation of JPBA with HAQ scores and a moderate correlation with HJC ($p = 0.1$) and HJAM scores ($p = 0.12$). None of these variables were significantly correlated at 12 weeks post-education, although HAQ scores were moderately ($p = 0.15$). Pre- and post-education, there were no other significant correlations (Table 3.8).

Changes in JPBA scores from four weeks pre- to 12 weeks post-education were significantly related with changes in HJC (hand joint pain) ($r(s) = 0.48$; $p = 0.03$) and disease duration ($r(s) = 0.49$; $p = 0.03$) and moderately with HJC changes ($r(s) = 0.39$; $p = 0.08$). No other significant correlation with changes in other measures listed above was found.

Table 3.8: Relation between JPBA scores and demographic variables (n = 21).

	Pre-education	Post-education
	<u>r(s)</u>	<u>r(s)</u>
HAQ	0.49*	0.33
ARA disease class	0.40	-0.04
Hand Joint Count (bilateral)	0.36	-0.01
Hand JAM (bilateral)	0.35	-0.02
AHI	-0.27	0.03
VAS hand pain on activity	0.27	-0.08
HAQPAIN	0.25	0.31
Perceived disease severity	0.21	-0.22
Disease duration	0.11	0.15
Perceived future susceptibility	0.08	0.21

* $p \leq 0.05$, one-tailed.

3.3.4.4. ATTITUDE TOWARDS, OBSERVED AND SELF-REPORTED HAND JP BEHAVIOUR.

Most subjects believed it was "very important" to reduce stress on hand joints pre- and post-education (17 and 15 respectively), a non-significant change ($Z = 0.91$; $p = 0.36$).

There was no significant change in the amount of self-reported Hand JP behaviour ($Z = -0.22$; $p = 0.82$, Figure 3.3). There was no significant change in attention to care of joints reported ($Z = 0.28$; $p = 0.77$).

Pre-education, seven reported practising using JP methods (all of whom had previously received JP advice). Post-education, nine reported doing so (a non-significant increase: $p = 0.63$); four pre- and seven post did this daily (a non-significant change, $Z = 0.67$; $p = 0.5$).

Twelve stated they were already increasing care of joints in the last three months pre-education, and 11 post-education, a non-significant increase ($Z = 0.46$; $p = 0.65$).

There was a significant correlation between JPBA scores and self-reported Hand JP behaviour pre-education, but not post-education (Table 3.9). There was no significant association between the degree of belief in the importance of reducing joint stress and amount of self-reported JP behaviour pre- or post-education (pre-: Cramer's $V = 0.18$; $p > 0.9$). Post-education: Cramer's $V = 0.55$; $p > 0.7$), nor with JPBA scores, with subjects' attaching greater importance to their belief in reducing joint stress than their behaviour demonstrated. Neither did changes in JPBA scores correlate with self-perceived alteration in amount of care taken to protect joints post-education ($r(s) = 0.07$; $p = 0.8$).

Table 3.9: Relationship between observed, self-reported and belief in benefit of Hand JP behaviour (n = 21).

	JPBA scores Pre- education r(s)	JPBA scores Post-education r(s)
Self-reported Hand JP behaviour	0.49*	0.23
Belief in importance of reducing joint stress	-0.01	0.24

* $p < 0.05$.

3.3.4.5. SELF-REPORTED HAND JP METHODS.

Subjects had difficulty stating Hand JP methods used but most examples were methods observed in the JPBA (Appendix 11).

Pre-education, 40 Hand JP methods were cited, 28 of which were JPBA tasks. Only 13/28 (46%) were observed performed correctly or borderline in the JPBA. Post-education, 51 methods were cited, 39 of which were JPBA tasks. Only 17/39 (44%) were observed. The majority of these (13) were observed being performed pre-education.

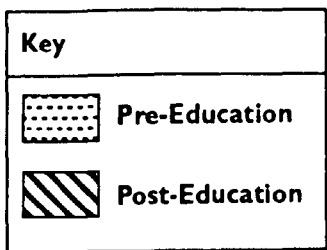
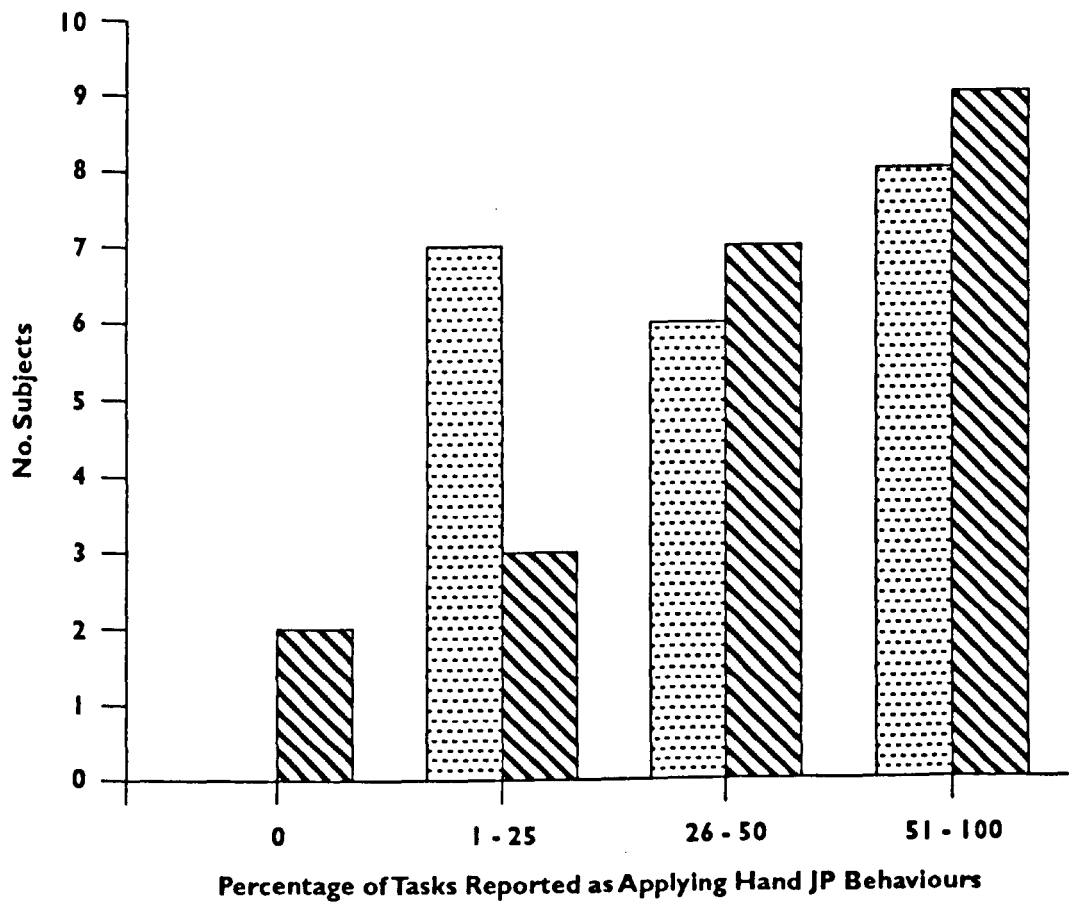
3.3.4.6. USE OF HAND JP METHODS - SUBJECTS' COMMENTS.

Post-education, of the seven who had previously received joint care advice, six stated they now used additional Hand JP methods taught in the education programme (one considered previous advice was sufficient). Three additional subjects reported using Hand JP methods.

Of these nine: two stated it soon became habitual; two that they were "much more conscious of it now"; four that they used some methods sometimes "on bad days," "I do it more when in pain..when I'm better I tend to be forgetful of it," "I'm often too busy.. it's easier to change by changing equipment than method..it's remembering to do it" and "I've done these.. as a last resort ... but if the disease had gone away I would have reverted back to normal."

Of the 12 stating they did not use the Hand JP methods taught: five

Figure 3.3
Self-reported Frequency of Hand JP Behaviours Pre - and Post-Education (n = 21)



could not recall any, five considered it was inapplicable to them as they were "not that bad" and one stated "I know the correct methods but I'm not using them." Any changes they had made were those they had found for themselves, "if you've got RA you know you can't do these things. It comes natural.. automatically, if hurting yourself more," although one subject stated "it was helpful as it confirmed what I was doing was right." Nine (of the 12) already used some technical aids, eg. electric can openers or jar aids and all reported pre-education using their hands differently, commonly using two hands to lift.

There was no significant difference at 12 weeks post-education between the JPBA scores of subjects stating they had practised JP methods taught ($n = 9$; median 23.70%, IQR 12.85 - 36.25%) and those who had not ($n = 12$; median 26.25%, IQR 17.95 - 37.45%: $U = 0.49$; $p = 0.75$). Neither did the scores of those self-reporting practising JP increase ($T+ = 53$; $p = 0.97$).

3.3.4.7. SELF-REPORTED HAND JOINT STRESS REDUCTION STRATEGIES.

Subjects were asked to give examples of how they practically altered everyday tasks to reduce hand joint stress (Table 3.10). Changes were not analyzed as the test-retest study indicated limited reliability on this question, with a third of subjects giving different answers on test 2. Overall there was little increase in the number of strategies cited, with the greatest increase being "avoiding lifting/reducing weight of tasks" and "doing tasks less often."

Table 3.10 : Self-reported strategies for reducing hand joint stress.

	<u>Pre-ed.</u>	<u>Post-ed.</u>
Use technical aids, electrical gadgets or labour-saving devices.	17	14
Lift differently eg. use 2 hands, forearms.	16	17
Ask for help/delegate	14	9
Avoid lifting/ reduce weight of objects lifting.	7	13
Use joints in stable, deformity avoiding positions, eg. flat of hand, wrists straight	5	2
Do tasks more slowly/for shorter periods/ rest between	5	8
Leave tasks/ do less often	4	11
Reorganise tasks/ work areas	2	5
Enlarge grip of equipment	1	1
Distribute work through week	<u>1</u>	<u>0</u>
	72	80

3.3.4.8. SELF-REPORTED DIFFICULTY IN CHANGING BEHAVIOUR.

Post-education, five subjects reported having changed less than 25% of tasks; four had little or no difficulty making these few changes. One found change very difficult.

Most subjects (16) post-education, continued reporting changing 25% or more of tasks. Pre-education, 11 reported change was difficult, the main reason being "frustration," eg. "difficulty accepting having to change," "losing your sense of independence and achievement... when you've done it all your life" (10) and four also stated "difficulty in remembering" and "forming new habits." Five reported little difficulty changing, these had "come naturally." Although initially four of them had found it frustrating, they now accepted

change as necessary.

Post-education, 11/16 reporting changes stated these were less difficult, an almost significant change ($Z = 1.85; p = 0.06$).

Of the three subjects achieving significant score increases at some stage none found making changes frustrating and had no difficulty changing and all made positive comments about helping oneself, eg "its important to do something to fight back."

3.3.4.9. REASONS FOR AND METHODS OF CHANGING.

Both pre- and post-education, 20 subjects stated the main reason for changing a task was either it became too painful or their grip was too weak to do it normally; eg. "forced to by the pain," "not physically possible."

Strategies used to find alternate methods are shown in Table 3.11. Half of the group pre-education cited they had no strategy (ie. unconscious or automatic changes), with little change in their strategy use post-education. The other half (11) cited greater use post-education of conscious strategies eg. "thinking through" (problem-solving) and use of ideas from the JP group.

Median JPBA score of "unconscious strategy" users ($n = 10$) post-education was 17.95% (IQR 12.50 - 31.60%) and of "conscious strategy" users ($n = 11$) 35.00% (IQR 20.00 - 37.50%), an almost significant difference ($U = 28.5; p = 0.06$).

Table 3.11: Strategies used to change work methods.

	<u>Pre-ed</u>	<u>Post-ed</u>
Unconscious/ automatic change	10	10
Trial and error	5	3
Thinking through/ planning	4	8
Ideas from OT/ education group	3	9

3.3.4.10. COMPARISON OF HIGH AND LOW JPBA SCORERS.

Subjects were divided into post-education low JPBA scorers (ie. less than 30%, median = 17.5%, IQR 10.5 - 20%, n = 11) and high scorers (30% or more, median = 37.45%, IQR 31.60 - 40.00%, n = 10). There were no significant differences in any variables between high and low scorers ($p > 0.1$), apart from a tendency for low scorers to be older. Pre-education, seven low scorers stated change was difficult, nine that changing "simple everyday tasks" was frustrating or they did not like doing so and nine used "unconscious" strategies. Of the high scorers, four found the problem was remembering and "getting used to new methods," six that, although change was frustrating in the past, they were now more accepting of RA and prepared to change and all cited using conscious strategies.

Post-education, low scorers made less comments related to frustration but most continued reporting having no conscious strategy for change. Amongst high scorers, less difficulty was also reported, but developing new habits and routines was commonly problematic. Using conscious strategies were cited twice as frequently.

3.3.4.11. ATTITUDES TOWARDS JP EDUCATION.

Eighteen subjects stated the JP advice was relevant for them at present and three that it was not. Fifteen considered it psychologically supportive attending the education group, particularly talking to others with RA and eg. finding out how they had learned to cope and their practical ideas.

3.3.5. OUTCOME OF EDUCATION - EFFECT ON DISEASE KNOWLEDGE.

a). Source and type of disease information.

Pre-education, 6/21 (28.5%) subjects considered they had never received any information about the disease previously from any source. Three considered their only source was books or leaflets they had obtained themselves, whilst 12/21 (57.1%) had received

information from health care staff.

Asked what disease information this was: 10 stated how joints are affected by the disease; five on the cause of RA.

Of the 12 who had been given advice by staff: three received advice on drugs, two on exercise, one on diet and seven on "looking after joints."

The six subjects who had not received advice expressed dissatisfaction at this, as did five others who considered they had received insufficient.

Following education, all had received information about the disease cause and process, and advice from all four professions.

b) Disease Knowledge.

There was no significant increase in ability to identify five structures in a diagram of a typical joint. The median score was 1.00 (IQR 0 - 3.00) pre- and 2.00 (IQR 0.50 - 3.00) post-education, ($Z = 0.67; p = 0.51$).

There was also no significant increase in ability to correctly identify the initial effect RA has on joints ("joint lining swelling up"). Ten identified this pre- and 11 post-education ($X = 7.91; p = 0.25$).

When asked pre-education what their understanding of RA was, 12 subjects gave no explanation (ten had received some but were unable to explain it), two were incorrect and seven gave brief correct descriptions.

Post-education, seven were unable to give an explanation and fourteen gave some correct description.

3.3.6. OUTCOME OF EDUCATION - EFFECT ON JP KNOWLEDGE.

a) JPKA results.

Median JPKA score pre-education was 82.50% (IQR 77.50 - 90.00%) and post-education, 90.00% (IQR 82.50 - 93.75%). A significant score

difference occurred (mean +5.14 (SD 9.91%: $Z = 2.5$; $p = 0.01$). A significant score change for this assessment was determined as + or - 12.4% (section 2.4.2.5). Only four subjects achieved such an increase.

b) Understanding of the term Joint Protection.

The terms used to explain the term "Joint Protection" are shown in Table 3.12.

Pre-education: all seven who had already received JP advice gave an appropriate explanation; seven made appropriate comments; and seven gave no explanation.

Post-education, all were able to give some explanation, "reducing strain/damage to joints" being the commonest.

Table 3.12: Joint Protection explanations.

	<u>Pre-ed.</u>	<u>Post-ed.</u>
Don't know	7	0
Reduce damage/ pressure/ strain	11	12
Protecting/ caring for/ not injuring joints	2	6
Do things less often/ give up tasks	2	0
Alternative methods	2	0
Not overdoing things	1	4
Rest	1	2
Wearing splints	1	2
Using gadgets	0	1
Asking others	0	1

c) Ability to state JP principles.

JP principles stated pre- and post-education are shown in Table 3.13. The mean number of principles cited was 0.8 principles pre- and 1.2 principles post-education. Principles stated are applied to the five principles (underlined in the table) emphasised by the OT during the JP education. A marked increase in ability to state principles

occurred post-education, with 11 additional subjects being able to.

Table 3.13: JP Principles cited.

	<u>Pre- ed.</u>	<u>Post-ed.</u>
None	15	4
<u>1. Distribute weight over joints</u>	0	7
<u>2. Avoid unnecessary joint stress.</u>		
Keeping weight/ pressure off joints	3	3
Avoid lifting	2	0
Use gadgets/ aids	2	2
Avoid certain positions	0	1
Ask for help	0	2
Total:	7	6
<u>3. Achieve a balance of rest and work.</u>		
Resting and relaxing more	2	6
Avoid doing activities for too long	2	2
Total:	4	8
<u>4. Use joints in stable/straighter positions</u>	2	5
<u>5. Avoid staying in one position for too long.</u>	0	0
<u>Others.</u>		
Wear splints	2	0
Respect for pain	1	0
TOTAL:	16	28

3.3.7. RELATIONSHIP BETWEEN JPKA AND JPBA SCORES.

There was a significant difference between JPBA and JPKA scores. Pre-education JPKA scores were on average 59.9% (SD 11.4%) higher than JPBA scores ($Z = 4.01; p = 0.0001$). Post-education, JPKA scores were 61.1% (SD 16.97%) higher ($Z = 4.01; p = 0.0001$). There was a significant relationship between JPBA and JPKA scores pre-education

($r(s) = 0.55$; $p = 0.01$) but not post-education ($r(s) = 0.37$; $p = 0.09$).

3.3.8. ATTITUDES TOWARDS AND SELF-REPORTED USE OF JP BEHAVIOURS.

Most subjects initially believed exercise, rest, using technical aids, respect for pain and changing work methods were beneficial. Half considered splinting and balancing rest and work (EC) non-beneficial. There was no significant increase ($p > 0.1$) in belief in benefit of any of these JP behaviours following education (Figure 3.4).

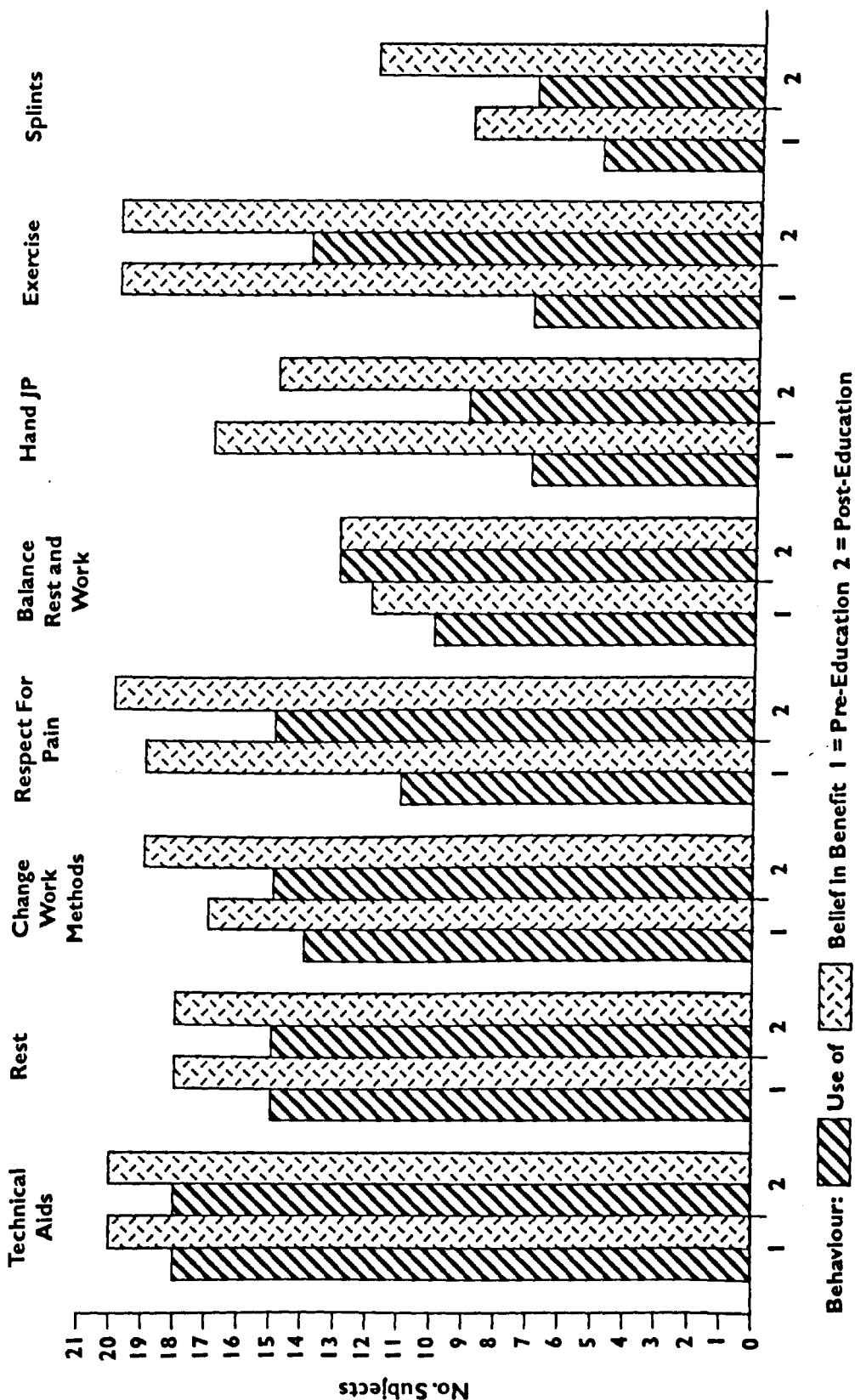
The mean number of behaviours adhered to pre-education ($n = 7$, splinting excluded as not all subjects had received splints) was 3.9 (SD 1.6) and post-education, 4.7 (SD 1.8), a mean increase of 0.8 behaviours (SD 1.4, range -1 to +3) per subject.

The commonest JP behaviours pre-education were use of technical aids, rest, respect for pain and changing work methods, by over 50% of subjects. There was no significant increase in subjects using any behaviours post-education ($p > 0.1$) apart from exercise ($p = 0.03$). No significant increase in the frequency of using splints, technical aids or resting was reported ($p > 0.1$), although a significant increase in exercise frequency occurred ($Z = 2.1$; $p = 0.04$).

There was a significant relationship between belief in and reported use of most JP behaviours ($p < 0.01$) pre- and post-education, apart from exercise, rest and changing work methods post-education ($p > 0.1$).

There was little relationship between disease measures and frequency of exercise, rest, use of splints or technical aids, apart from: splint use correlating significantly with HJC scores post-education; rest with HAQPAIN scores post-education; and technical aids use and HAQ scores pre- and post-education (to be expected as HAQ scores are influenced by reported use of aids).

Figure 3.4
 Belief in Benefit of and Self-Reported Use of JP Behaviours (n = 21)



3.4. DISCUSSION.

The trial was designed to test the hypotheses that:

- i) "traditional" JP education does not lead to an increase in knowledge of JP principles and methods, change attitudes towards the benefit of these or increase the use of JP behaviours, particularly Hand JP,
- ii) there is no relationship between belief in the benefit of JP behaviours and use of these and
- iii) there is no relationship between use of hand JP behaviours and the disease's impact on the person.

The strategies RA patients use to change JP behaviours and what factors facilitate or limit adherence with these were also investigated.

3.4.1. TRIAL DESIGN.

The main drawbacks of the study were:

- i) the lack of a control group - as team members preferred education not to be withheld or delayed (eg. as necessary in a crossover trial),
- ii) the control phase was not the same duration as the follow-up phase (12 weeks) - as team members preferred patients did not wait three months for education.
- iii) the four rather than six week pre-education control phase - due to difficulties in trial information being forwarded at agreed times,
- iv) a sufficient (21), but small, sample size, although the necessary sample size was predetermined as 14. It was originally intended to recruit at least 30 subjects. However, the departure of the OT and subsequent alteration in JP education prevented this.

Collaborative research with the rheumatology team had many benefits, primarily the permanent adoption of the AEP to the treatment package offered to RA patients, as well as staff increasing abilities in

patient education methods and in seeking new approaches based on research findings of this and other studies. However, nursing and therapy staff's priorities were to provide education as soon and to as many patients as possible, which caused difficulties ensuring adequate control.

This could be resolved by ensuring control of the education organisation, ie. the researcher having direct responsibility for subject recruitment and education provision and patients' attendance being dependent on trial participation.

The major weaknesses of pretest-posttest designs would have meant that if a significant behaviour change had occurred, this could have been due to temporal, attention and/or learning effects and not the education programme. No change did occur however, which again supports the findings of the test-retest reliability study that Hand JP is relatively stable (over an 18 week period) and neither does repeated testing or additional attention influence JPBA scores.

3.4.2. SUBJECT SAMPLE.

Subjects' average age was 49 and most were women, reflective of the general RA population. Many had the disease for less than five years and all were in ARA functional class III, ie. meeting the criteria for patients to know and use JP methods (Brattstrom, 1987).

From clinical experience, the sample were similar to those normally referred for JP. This group differed however, in having made the commitment to attend for four sessions. Less than half of those invited did so (following assessment by rheumatology team members as being appropriate and willing to attend), suggesting attenders may have been more interested in patient education and self-management techniques and more likely to implement these than many patients normally referred for JP education. The lack of significant change in disease measures was as expected, as most had mild to moderate

disease involvement.

3.4.3. EFFECT ON ATTITUDES OF THE JP EDUCATION PROGRAMME.

3.4.3.1. BENEFIT FROM ATTENDING THE PROGRAMME.

Prior to education, over half considered they had received insufficient information from the rheumatology team, corresponding to other findings that most patients want more information (Knudson, Spiegel and Furst, 1981; Silvers et al, 1985). Most considered they learnt more and it was psychologically supportive. Meeting other RA patients, finding similar personal and practical difficulties, discussing solutions, as well as the education confirming changes already implemented were the right thing to do, were common themes as to why this was so.

Surveys have identified between 65 and 70% of patients consider EC and JP education important (Buckley et al, 1990; Silvers et al, 1985). This study supported these findings, with most considering the JP education relevant to their needs and JP and EC cited most as preferred methods for controlling disease symptoms.

3.4.3.2. BELIEF IN THE BENEFIT OF JP BEHAVIOURS.

Most believed JP behaviours beneficial pre-education and no change in belief in benefit (attitudes) occurred post-education. It is difficult to evaluate if JP education could influence attitudes as most already held positive ones. However, the lack of attitudinal change regarding splinting and balancing rest and work (EC) suggests it may not.

Felton and Revenson (1984) identified those RA patients with greater positive adjustment used "Information Seeking" as a coping strategy. Parker, McRae et al (1988) define this as "searching for advice and information about the illness with reliance on active, instrumental approaches to problems." As most already perceived active self-management methods beneficial, it seems the programme attracted

Information Seekers, already adopting or wanting to adopt proactive, problem-solving strategies, such as exercise, JP and EC. The interview findings support this as all believed they could control disease symptoms through their own actions, suggesting the study sample may be representative of a sub-group of RA patients, more likely to adhere to treatment than usual. Both Felton and Revenson (1984) and Parker, McRae et al (1988) reported RA patients more commonly use passive, avoidant coping strategies than active, problem-focused ones.

3.4.3.3. ATTITUDES TOWARDS THE DISEASE.

Subjects' attitudes of perceived severity and susceptibility were not altered by the AEP. Although most thought they had severe disease, most believed they would get better or stay the same. The AHI scores supported this as most had moderate to low helplessness, ie. believed they were in control of their disease and this did not change. Lindroth et al (1989) similarly found no change in a locus of control measure following a six session AEP including JP and EC.

3.4.4. EFFECT ON KNOWLEDGE OF THE EDUCATION PROGRAMME.

3.4.4.1. DISEASE KNOWLEDGE.

Knowledge of the disease process is considered an essential element in arthritis education by both health care professionals and patients (Hill, 1990; Silvers et al, 1985; Wade, Brown and Wasner, 1982).

Post-education, subjects were no more able to identify joint structures than before. Almost half considered this helpful information, even if unable to recall structures, as it helped "to understand about straining joints." However, over a third considered it of no help as "it doesn't stop you hurting," "it's more important to know what to do." A group AEP of necessity provides the same information to all patients, whether they consider it personally relevant or not. Over a third finding this unnecessary suggests staff

giving individual education should question patients' views of its relevance and omit it if appropriate. Mazzuca (1982) considered "patients need to know less about the pathophysiology of their disease and more about integrating new demands into their daily routine," which accords with this sub-group's views.

Neither were subjects more able to correctly identify the disease's initial effects on joints. This limited level of understanding supports Ley's (1980) findings that "53 to 89% of lay people cannot understand what [medical advice] they are told." Often subjects gave answers because "that it was it feels like to me." Donovan, Blake and Fleming (1989) identified that patients lay beliefs influence acceptance or otherwise of advice and suggested didactic education does not necessarily change these. Lay beliefs should first be identified, then discussed and modified using interactive education. Williams and Wood (1986) suggest this may be a difficult task and "errors are not simply open to correction: they form part of a valued framework which helps patients to cope with the consequences of chronic illness" and that a greater tolerance of common-sense beliefs leads to more satisfactory interaction.

Post-education, twice as many gave some verbal explanation of the disease process, showing some degree of learning and understanding had occurred, although only a quarter could provide a more detailed, correct description.

Over half forgot the disease information (at least half of whom thought it relevant), reflecting the findings of Anderson, Dodman, Kopelman and Fleming (1979) that rheumatology patients only recalled some 40% of information provided at clinic appointments. This suggests teaching methods need altering to aid recall.

Studies have shown significant improvements in knowledge after education programmes can occur (eg. Cohen et al, 1986; Kaye and

Hammond, 1978; Lorig et al, 1986; Parker et al, 1984; Potts and Brandt, 1983; Spiegel, Knutzen and Spiegel, 1987; Vignos, Parker and Thompson, 1976). The majority of these used leaders trained in patient education techniques. This study aimed to evaluate "traditional" education, with staff receiving minimal training in patient teaching, over and above their already existing skills. The lack of disease knowledge gain suggests staff regularly teaching patients may need extra training in patient education.

Cartlidge, Higson and Stent (1984) reported a discrepancy in knowledge and attitudes in a pilot evaluation of an audio-visual AEP. Although knowledge showed a significant increase on a multiple choice questionnaire, subjects' perceptions of disease comprehension were of insufficient understanding. Donovan et al (1989) suggest questionnaires test ability to fill in checklists but not understanding. Interviewing patients in this study may have given a truer picture of patients' limited degree of understanding or alternately embarrassment or uncertainty about using technical terms limited its' assessment.

3.4.4.2. JOINT PROTECTION KNOWLEDGE.

a) JP PRINCIPLES.

Ability to define JP improved post-education, as did knowledge of JP principles. Greater awareness of some, eg. "distributing weight more" and "using joints in stable positions" occurred, but not others eg. "avoiding staying in one position for too long." This suggests those cited most should be emphasised during education as being more pertinent or comprehensible to patients.

JP authors (Lorig, 1986a and b; Melvin, 1989; Shapiro-Slonaker, 1984) emphasise teaching principles, followed by problem-solving discussions (as occurred in this programme), to aid patients find solutions to their own problems in future. However, the low level of

principle recall suggests patients would have difficulty doing this. Almost half stated they continued to have no conscious strategy for identifying Hand JP behaviours post-education, supporting this view.

b) JP METHODS.

Although a significant increase in JPKA scores occurred (knowledge of JP methods), this was small. Few increased scores by more than the pre-determined significant score change indicating JP knowledge did not clinically significantly rise. Pre-education scores were already high suggesting subjects were problem-solving using "common-sense," perhaps aided by recall of specific methods taught and prompted by the options given, rather than poorly recalled principles. Further input is recommended to improve principle recall and problem-solving ability.

3.4.5. JOINT PROTECTION BEHAVIOURS.

3.4.5.1. RESPECT FOR PAIN.

Activities and exercise should be carried out only to the point of fatigue or discomfort (Melvin, 1989), with pain respected and used as a signal to moderate activities. Lorig, Cox, Cuevas, Kraines and Britton (1984) and Potts, Mazzuca and Brandt (1986) identified pain as the major concern of RA patients and many AEPs stress the importance of respecting pain as an integral principle to all JP behaviours (eg. Althoff and Nordenskiold, 1985; Lorig, 1986a; Unsworth, 1990).

Education did not lead to a significant increase in the number of subjects reporting stopping and resting in response to hand pain on activity. Those who carried on despite pain commonly wanted to "fight the disease." Donovan et al (1989) identified a similar sub-group in their study of RA patients' coping strategies, wanting to "fight the arthritis... to suffer not inconsiderable amounts of pain in order to keep going." Non-pain respecters used less self-management behaviours

than pain respecters both pre- and post-education. Although willing to seek information, they were less willing to use these pre-education, although adopting a similar amount of new behaviours to pain-respecters following education. They believed they should do so, yet did not, suggesting education should include strategies to aid overcoming this discrepancy between belief and actions.

3.4.5.2. CHANGING WORK METHODS.

Education led to little increase in the number of strategies cited to change work methods to reduce joint stress. Many considered they already did so, as an automatic response to pain and/or poor grip strength. These natural changes included: using technical aids; lifting differently, eg. with two hands, avoiding lifting and avoiding deformity positions; asking for help; doing tasks less often; and slowing down and putting less effort into tasks. These responses were similar to those identified as behavioural coping strategies by Blalock, DeVellis, Holt and Hahn (1993) of: Material resources; Modification; Instrumental Social Support; Decreasing Activity; and Carefulness respectively.

Few studies have evaluated the use of these JP strategies pre- or post-education. Kaye and Hammond (1979) reported a similar extent of "not abusing joints" (63%), although this study lacked a pre-test, meaning it is impossible to evaluate if subjects were already doing this naturally or as a result of education.

3.4.5.3. BALANCE OF REST AND WORK.

Furst, Gerber, Smith, Fisher et al (1987) reported patients receiving traditional JP/EC education did not significantly improve resting during physical activity behaviour. The findings of this study were similar. Over half already balanced activities pre-education. Tack (1990) identified pacing as a natural coping strategy to fatigue, but that some patients, even though having RA for many years, found this

difficult and overworked when feeling better. This was a common theme amongst non-pacers in this study. Although tasks were left if "feeling bad," they often overdid it when better and regretted this later. For some this gave them a greater feeling of achievement and control, that they were still able to do heavy tasks despite RA. Pacers indicated they had learnt the consequences of overworking and additionally delegated tasks to others or did them infrequently and considered they were only harming themselves further by "obstinacy." This suggests education should include components designed to aid patients change cognitive processes related to managing fatigue.

3.4.5.4. REST.

Patients are commonly recommended to take more rest, including a one to two hour rest during the day (Furst, Gerber and Smith, 1987; Melvin, 1989). Most already rested for an hour or more regularly and education did not lead to any increase. Furst, Gerber, Smith, Fisher et al (1987) similarly identified no significant increase amongst those receiving traditional or behavioural JP/EC education. Tack (1990) reported a common fatigue strategy amongst RA patients as "time-outs," ie. recovery periods, suggesting subjects in this study already adopted this behaviour as a natural response.

3.4.5.5. EXERCISE.

JP recommends RA patients range affected joints fully daily. A significant increase in use of the taught exercise regime and frequency of exercising occurred post-education, although a third still did not exercise.

This level of adherence is comparable to other studies of exercise taught using similar methods (ie. one or two sessions, with written reinforcement but no follow-up), ranging from 39 to 65% (section 1.4.1). Reasons for non-adherence include: the effort required to incorporate exercise into a daily routine and solitary exercising at

home lacking motivational stimulus (Ferguson and Bole, 1979; O'Carroll and Hendriks, 1989); and primarily a lack of belief in the benefit of exercise (Ferguson and Bole, 1979; O'Carroll and Hendriks, 1989; Terpstra, deWitte and Diederiks, 1992). Post-education, similarly non-adherers considered either their daily activities were sufficient exercise (lack of belief in benefit) or could not develop an exercise habit.

Studies achieving high adherence rates (Cohen et al, 1986; Lorig et al, 1985; Terpstra et al, 1992) used either daily training with a physiotherapist or weekly group sessions with contracting to continue exercise daily at home, supported by written, diagrammatic and/or audiotape instructions. This suggests such methods should be adopted when teaching exercise to increase motivation and habit development at home.

3.4.5.6. USE OF SPLINTS.

Adherence with wearing wrist working splints was generally poor. Adherence measures in splint studies have varied: Ferguson and Bole (1979) considered this as three times a week or more; O'Carroll and Hendriks (1989) as "with therapists instructions"; and Feinberg and Brandt (1981) as more than 50% of the time. Splint usage in this study in comparison to any of these criteria would appear poor. Most splint studies have evaluated adherence with night resting splints or not specified the type. Further research is needed to identify reasons for non-adherence and of adherence levels with wrist-working splints, as both pre-fabricated and custom-made splints are widely provided.

Over half did not consider splints beneficial, with a common belief being that splints would make hands worse, encouraging wrists to stiffen. The other main reason was discomfort and restrictiveness. This suggests education should include clearer explanations of how

and why splints aid RA, discussion of patients' beliefs on their efficacy, clearer instructions on their appropriate use and more follow-up to check for comfort. Feinberg (1992) has demonstrated using adherence enhancement strategies does significantly increase resting splint use. Splint-wearing adherence could be increased if appropriately trained rheumatology staff fitted, educated and followed-up patients.

3.4.5.7. USE OF TECHNICAL AIDS.

Most subjects stated they already used technical aids pre-education, mostly kitchen aids. JP education did not increase reported or observed kitchen aids use. A comparison of self-reported and observed kitchen aids use (Appendix 11) showed less than half were used in the JPBA. This was a similar range to the conclusions of Rogers and Holm's (1992) review of aids compliance studies, which suggested self-reported aids use does not reflect actual use.

The commonest aids cited were jar openers, most of which were not used. Rogers and Holm (1992) suggest factors predicting aids use include disease severity, pain, functional ability and level of skill using the aid. In this study, most had moderate hand pain and functional ability, and those observed using jar openers often struggled with these (which were usually kept in drawers, not easily to hand). The commonest aids observed in use were usually in view in the work area, prompting their ready use.

3.4.6. HAND JP BEHAVIOUR.

These subjects scored similarly to the test-retest group (22.43% and 23.01% respectively) initially, supporting the clinical impression and subjects' self-reports that RA patients naturally begin to make some changes in hand movement patterns during daily activities. However JP education did not lead to any further increase in Hand JP behaviour.

Most stated any changes they had made were in response to pain or lack of grip strength. JPBA scores correlated significantly with functional disability (HAQ) scores and Hand JAM scores (which have been shown to correlate significantly with grip strength (Spiegel, Spiegel and Paulus, 1987)) and almost significantly with Hand JC (pain) scores pre-education. Post-education, JPBA score changes correlated significantly with Hand JC score changes. This suggests Hand JP does alter in response to fluctuating levels of hand pain and grip strength, ie. these are internal cues to action as subjects state.

A number reported "you get used to the pain" and they now noticed it less whilst working. This ability to reduce pain perceptions effectively reduces the natural prompt to change behaviour. This was supported by the results related to the principle of Respect for Pain. Although most believed one should stop if hands become painful, only half pre-education did this and most only as a result of the pain getting "so bad," ie. becoming unbearable. If pain is the main prompt to change, therapists should encourage patients to become more aware of the pain and aching they experience whilst trying to change behaviours, to act as a prompt.

Most believed it "very important" to reduce joint stress and considered JP education relevant for them. Potts, Weinberger and Brandt (1984) similarly found "learning how to protect joints from stressful motion" was ranked highly by patients. Despite this, few increased self-reported or observed Hand JP behaviour post-education. There was no significant increase in the amount of self-reported Hand JP used although subjects cited using specific Hand JP methods more. On comparing these statements with what was observed in the JPBA, it was identified these were either not used (suggesting they had not become habits) or were already used pre-education (suggesting

subjects had become more aware of their behaviour). Those patients reporting using Hand JP did not have significantly higher scores than those reporting not doing so.

The commonest tasks performed correctly or partially correctly were: Filling and Carrying a Kettle, Opening a Tin, Lifting a Box and Lifting a Grill Pan. The commonest strategies for reducing joint stress cited post-education were: using aids, lifting differently and avoiding lifting, which are the strategies being applied to perform these five tasks in a JP method. These would therefore seem to be the strategies most naturally adopted to reduce joint stress.

Another common theme was "frustration," at experiencing difficulties in ADL and with having to accept making changes. This was particularly noticeable amongst those with lower JPBA scores. Williams and Wood (1988) similarly reported frustration as a common response in patients perceiving symptoms intruding into daily life, with a sense of incompetence and failure (ie. poor self-efficacy for ADL) and loss of perceived control seeming to occur in such patients. High JPBA scorers in comparison, seemed to adopt a more pragmatic attitude "it's a matter of accepting...and then life improves. It took a long time...at first I didn't want to accept..then you have to come to terms...and then you're finally prepared to be sensible and do things differently."

Frustration was reported less frequently by low scorers post-education, suggesting education aided the attitudinal change that had already occurred in the high scoring group. However, they continued to report having no or few conscious strategies for change. High scorers found their main problem was developing new habits and routines, but considered they used conscious change strategies more frequently.

The high scorer and conscious strategy user groups were almost

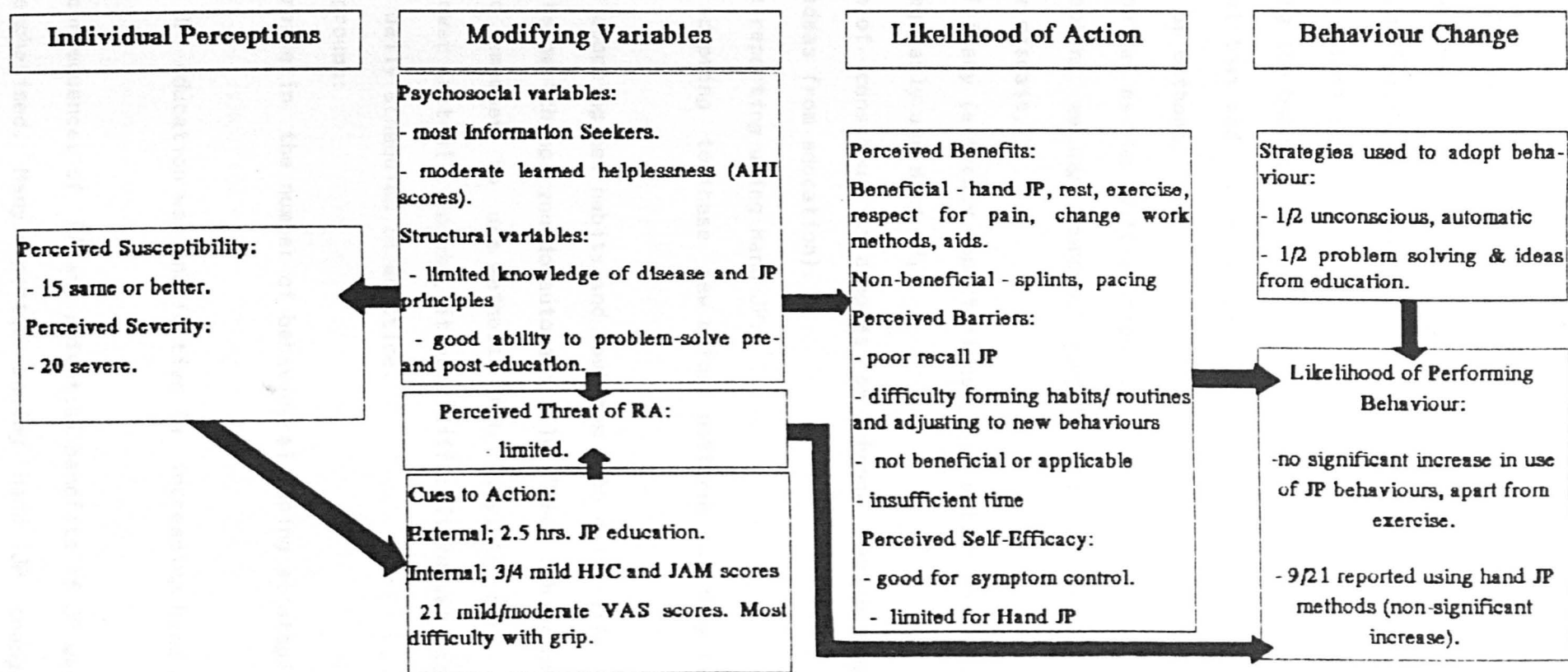
identical, suggesting problem-solving does aid greater use of Hand JP, although the education had no additional effect on this group, apart from reporting less frustration at accepting change. Schiaffino, Revenson and Gibofsky (1991) suggest problem-solving coping is moderately associated with positive disease adjustment.

The three subjects achieving a significant score change at some stage had no marked changes in any disease measures to account for this but did have lower AHI scores (less perceived helplessness), expressed strong feelings of being independent and accepted change without frustration. There were no significant differences between high and low scorer groups on any measures. This suggests patients' attitude to accepting their disease, the need to make changes in how they do everyday tasks and believing they are able to do so (ie. self-efficacy for using Hand JP) as well as internal cues to action, may be factors influencing the natural adoption of some Hand JP.

3.4.7. POSSIBLE REASONS FOR LACK OF CHANGE.

The Health Belief Model and Self-Efficacy theory (section 1.4.4) suggest the most influential factors for changing behaviour are perceived threat (severity and susceptibility), benefits of treatment, barriers and self-efficacy (Janz and Becker, 1984; Rosenstock, 1988). Figure 3.5 summarises the main findings of this study in relation to these factors. Although most subjects perceived their disease as severe, most believed they would be the same or better in five years time (limited perceived susceptibility). Most had mild/moderate pain scores (limited internal cues to action), suggesting they were not unduly threatened by their RA. Most believed they could adequately control their disease symptoms through their own actions (good self-efficacy for symptom control) pre-education and already used half of the eight JP behaviours. This suggests subjects may not have viewed adding behaviours to their

Figure 3.5: Possible reasons for lack of change following traditional JP education, based on the Health Belief Model and Self-Efficacy Theory.



current repertoire, apart from exercise, as necessary. Although most behaviours were seen as beneficial, many barriers were reported to adhering to these. For Hand JP limiting factors were:

1. Amongst those reporting not using Hand JP:

- i) not perceiving the behaviour currently as beneficial or applicable as they "were not that bad," (limited perceived benefits and threat),
- ii) poor recall of methods,
- iii) frustration at having difficulties with performing ADL and difficulty accepting making changes, suggesting a difficulty in adjusting to the disease,
- iv) poor self-efficacy (efficacy expectations), ie. a limited belief in ability to regularly use Hand JP,
- v) limited use of conscious strategies for change (eg. problem-solving, using ideas from education).

2. Amongst those reporting using Hand JP:

- vi) difficulty adapting to these new motor patterns as they felt "awkward,"
- vii) difficulty adopting new habits and routines into daily life: as it was hard to change "things you do automatically" "the habits of a lifetime" and to remember to use methods when busy. As Hand JP methods were slower initially to use, it was difficult to set aside time out of busy daily schedules to practice.

3. Amongst both groups:

- viii) little increase in the number of behavioural coping strategies cited as used.

Reasons why the JP education was ineffective in increasing Hand JP could be:

- i) The possible consequences of RA and potential benefits of JP were insufficiently emphasised. Many reported making Hand JP changes (naturally or following education) only when pain and poor grip

strength meant it was too difficult to continue normally. They started using many behaviours automatically, which then stopped when pain reduced again. Yet JP is intended as a preventative technique. Kanfer and Gaelick (1989) state an essential precursor to change using the self-management approach is creating the motivation for change. Education should therefore aim to increase awareness of internal cues to action (pain), which appears to be a prime motivator, and emphasise how using JP reduces this.

2. Although JP information was supported by provision of two relevant booklets, one third had poor recall, highlighting greater input is needed to teach JP principles and methods.

3. Strategies for adopting these new motor patterns were not included. Patients were encouraged to use problem-solving techniques and given verbal instructions in Hand JP, supported by a demonstration and return demonstration, but then expected to transfer these into daily life, without any input on how this should be attained. Poole (1991) states that although OTs teach motor skills, most are not trained extensively in motor skill acquisition strategies and few OT texts, apart from Mosey (1986) and Trombly (1989) devote space to this. Motor learning principles have been applied successfully to functional rehabilitation of CVA patients (Carr and Shepherd, 1987), training patients to re-learn previously automatic behaviours. This approach shows potential in the re-training of RA patients from previous to new automatic behaviours.

4. Strategies for incorporating new routines into daily life were not included. Reviews of AEPs show those most successful in increasing behaviour use cognitive-behavioural techniques (Holman and Lorig, 1987; Lorig, Konkol and Gonzalez, 1987; Mazzuca, 1982) rather than a more didactic approach as used in the traditional JP education.

5. Psychological strategies to increase adherence were not

incorporated (eg. to enhance self-efficacy and perceived control) which have been shown to be effective (O'Leary et al, 1988; Wallston, Wallston, Smith and Dobbins, 1987).

6. Psychological strategies to enhance adjustment to RA were not included. Coping style is seen as an important determinant of this (Smith and Wallston, 1992). Influencing cognitive and behavioural responses to RA may increase arthritis health behaviours.

3.5. CONCLUSION.

JP aims to reduce pain, inflammation and the risk of deformities developing through regular rest, exercise, use of EC and making widespread changes in patterns of affected joint use. The results of this study indicate "traditional" JP education led to:

i) No significant objective increase in knowledge of RA or JP methods, although subjects were generally more able to give explanations of the disease process, the meaning of JP and cite JP principles on questioning.

No significant increase in belief in the benefit of using JP behaviours. Some attitudinal change occurred, primarily subjects were more accepting of making changes in Hand JP behaviour and, in those who had already reached this stage pre-education, problem-solving and ideas from education were cited more commonly post-education to make changes.

No significant increase in the use of any JP behaviours, apart from exercise by significantly more subjects with greater frequency. There was no significant increase in the use of observed or self-reported Hand JP, the main focus of the 2.5 hours of JP education.

ii) Most believed Hand JP, exercise, rest and changing work methods to be beneficial, but there was no significant relationship between subjects' belief in the benefit of these and their use post-

education. There was a significant relationship between the degree of belief in benefit and self-reported use of other JP behaviours.

iii) Hand JP behaviour was significantly correlated with functional disability (HAQ scores) pre-education and Hand JP behavioural changes during the trial were significantly correlated with hand pain (HJC) changes, supporting patients' frequent comments that pain and physical difficulty performing a task are the main reasons for adopting Hand JP.

3.6. RECOMMENDATIONS.

3.6.1. "TRADITIONAL" JP EDUCATION.

The College of Occupational Therapists (1987) advised OT managers "in the light of current financial stringencies and restrictions" (which still continue) that "education, eg. joint preservation" should be a low priority in departments' workloads.

Occupational Therapists should question whether the therapist contact time spent on "traditional" JP education (between one to two and a half hours per patient in individual education) is cost-effective if some cognitive and attitudinal but not behavioural change is occurring. Both Cartlidge et al (1984) and Wetstone et al (1985) have shown significant increases in knowledge can occur from audio-visual and computer AEPs. Costs could be reduced by using audio-visual materials and supporting literature (both commercially available) to convey this information, which patients can view within the department and/ or take home, supported by individual ADL assessment if necessary.

Cohen et al (1986) demonstrated there were no significant differences in outcome between AEPs led by professional instructors and trained lay instructors, implying JP education could be equally effective if provided by either specially trained support staff or RA patients,

but at less cost.

Clinically, some therapists argue that, even if behavioural change is not occurring, the psychological benefits of traditional JP education mean it is worth continuing. These claims are:

i) patients' can be aided to feel more in control of their disease. No research has been conducted on this for JP education specifically and in this trial no significant improvement in learned helplessness (AHI scores) or in perceived self-efficacy for controlling disease symptoms occurred.

ii) patients' self-efficacy increases, ie. belief in ability to perform functional tasks improves. This claim is supported by referring to the findings of Lorig, Seleznick et al (1989), Lenker, Lorig and Gallagher (1984) and Holman, Mazonson and Lorig (1989), although these programmes used behavioural not traditional teaching techniques. As no research demonstrates "traditional" JP education leads to improvements in self-efficacy as claimed, this is a possible future area for research.

This prompted inclusion of a self-efficacy measure (Lorig, Chastain et al, 1989) in the subsequent trial to explore the effects of education on this construct further.

3.6.2. ACHIEVING BEHAVIOURAL CHANGE.

As "traditional" JP education does not lead to behavioural change, alternative educational approaches need to be developed and evaluated. Recommendations to improve the effectiveness of JP education include:

a) Attitudinal Change.

Subjects found the most psychologically supportive aspect of the programme was discussion with other patients, although a number stated there was insufficient time due to the structured nature of sessions. Increased opportunities to discuss problems with other RA

patients could aid peer modelling ie. seeing others have successfully made changes and found JP beneficial, to increase acceptance of making changes.

Creating motivation for change may be aided by increasing patients' perceived threat and by self-monitoring pain/ discomfort levels during activities targeted for change. Self-efficacy enhancement strategies have also been shown to be effective (Lorig et al, 1985).

b) Knowledge Change.

Recall can be aided by eg. simplification, repetition and categorisation (Hilton, 1992; Ley, 1980). This should be coupled with using appropriate teaching strategies for adult learners. Training in problem-solving strategies, with practice in these, is needed to encourage adoption of conscious strategies for change.

Motor learning also needs to occur. Fitts and Posner (1967) defined three stages in this process: cognitive, associative and autonomous or automatic. In the cognitive stage, the learner needs to understand what is involved in the motor task, through clear oral, visual, written and kinaesthetic instructions (Maring, 1990; Poole, 1991; Rosenbaum, 1991).

c) Behavioural Change.

The associative and automatic stages of motor learning, in which habit development occurs, are improved by regular feedback and practice (Lee, Swanson and Hall, 1991; Poole, 1991; Rosenbaum, 1991). Most JP education programmes allow inadequate time for this to occur. Poole (1991) states learning most effectively occurs in the actual environment in which the skill is to be performed. Whilst home training is possible, for many hospital and social services OTs repeated home visits to provide sufficient practice is not feasible. Hospital or other community centre based education programmes need to encourage patients to maximise practice between sessions in their own

homes. Cognitive-behavioural education has been shown to be most effective at increasing some JP behaviours (eg. Gerber et al, 1987 - energy conservation; Lorig et al, 1985 - exercise).

4. DEVELOPMENT OF A COGNITIVE-BEHAVIOURAL JP PROGRAMME.

According to the Health Belief Model perceived threat, benefits, barriers and self-efficacy are the factors most influencing adherence of those with diagnosed medical conditions (Janz and Becker, 1984; Rosenstock, 1988).

As "traditional" JP education did not lead to behavioural change, an alternative programme was designed to increase adherence with Hand JP by influencing those barriers identified from the previous trial, ie.: limited perceived threat; limited perceived benefits of Hand JP; poor recall of Hand JP methods; difficulty adapting to new motor patterns; changing habits and routines; limited psychological adaptation, such as frustration at difficulties performing daily tasks, accepting the need for change and limited self-efficacy for adopting Hand JP.

A group, rather than individual, programme was developed as being more cost-effective and standardising the JP education provided.

The following strategies were used:

4.1. TO INCREASE PERCEIVED SEVERITY, SUSCEPTIBILITY AND PERCEIVED BENEFITS.

Studies designed to increase perceived severity and susceptibility lead to greater adherence (Becker and Rosenstock, 1984; Kirscht, 1974), if followed by reassurance that treatment can be effective. The higher the threat, the more effectively is adherence achieved. Disease information was tailored to increase threat by: emphasising deformities develop through insidious joint stress during daily activities and pain is a sign of potential joint damage; showing diagrams of joint deformities; describing the functional difficulties that result from hand deformities; highlighting that statistically over half of RA patients will develop some kind of hand deformity; discussing the functional, family and social problems subjects have

experienced because of pain, reduced grip, RoM and fatigue; discussing how much hands are used for all aspects of daily life, their use in communication, physical interactions and subjects' feelings about their hands' appearance; subjects identifying their own RoM limitations and deformities; the researcher highlighting these to them and others in the group and emphasising the need to halt or slow the process in specific joints.

Common concerns of RA patients are pain, loss of functional independence and becoming a burden on families (Lorig, 1986b; Williams and Wood, 1988). Frustration experienced in coming to terms with making changes in daily activities, scheduling and negotiating others performing tasks was a common feeling amongst subjects in the previous trial. Some had come to accept this and others not, seeing change as a loss of control and a threat to their self-esteem. To increase perceived benefits, JP was immediately introduced as a process they could utilise (in addition to their medication necessary to control inflammation), to prevent or reduce pain, fatigue and deformity, maintain their ability to do everyday activities, work (if still in employment), their family and social roles. The efficacy of JP was emphasised and that it was not "giving in" but "outwitting" arthritis. Although there is no research to prove JP is effective, the therapist's belief in treatment efficacy can influence adherence (Meichenbaum and Turk, 1987). The researcher's usual equivocal stance was avoided throughout. It was stressed that people who cope best, are those making changes. A video "Help is at Hand" (Arthritis and Rheumatism Council (ARC), 1991b) was shown, which includes interviews with four people with different degrees of and limitations caused by their RA and how they cope with these to live a normal life, both practically (ie. use of JP methods), emotionally, socially and their acceptance of making changes as an essential aspect of "getting on

with life." This was followed by a discussion of subjects' coping methods, Hand JP already used and the benefits experienced from these, to promote group support for making changes. JP was described as a naturally occurring process to some extent, but it can take many years to adopt this habitually and the programme was designed to enable rapid changes to act preventatively now rather than when it is too late. Coping, practically and emotionally, was used as a recurrent discussion theme throughout the programme.

4.2. TO AID LEARNING AND RECALL.

Knowledge is not the sole determinant of adherence but is a necessary prerequisite, not necessarily resulting in adherence (Becker and Maiman, 1980; Bower, 1985).

a) Learning Principles.

Adult learning principles were employed (Knowles, 1980):

i) adults are independent learners - patients and therapists should collaborate in decision-making about educational objectives and presentation (Gessner, 1989). This was not possible as a standardised programme was necessary for the purposes of the clinical trial. However, Padberg and Padberg (1990) recommend sharing of full information, doubts and concerns, avoiding settings reminding of passive "school" experiences by expecting and enabling active involvement. The programme and its' accompanying workbook emphasised subjects choosing which tasks and methods they would target for change.

ii) adults' past experiences are resources for learning - prior to disease information being given in the first session, subjects were asked to explain briefly what they already understood about the causes and effects of the disease in their own words to identify prior levels of knowledge. In a group situation, it is not possible to wholly tailor teaching content to individual's knowledge but

subjects' prior knowledge was referred to, eg. "the point you made about something in the joints ties in here with how the supports round the joints start to lose their elasticity." Subjects were also asked to contribute practical ideas for making ADL easier and positive reinforcement was provided.

iii) adult learning is task or problem-oriented and information should be useful immediately:

- over half of the sessions were practical. Problem-solving processes were taught to encourage utilising planned strategies for change and problem-solving activities were based on problems contributed by subjects.

- controlling the disease long term may not be as interesting initially (Gessner, 1989), nor indeed possible. The immediate benefits of reducing pain and increasing functional ability were therefore emphasised.

b) Programme structure.

Subjects were provided with pre-reading (the ARC booklet "Rheumatoid Arthritis") to act as an advance organiser, introducing some of the main contents of the first session, ie, disease information and JP, to aid subjects in creating cognitive links with their already existing knowledge and to provide a framework on which to add later information (Ausubel, Novak and Hanesian, 1978).

During teaching, strategies recommended by Entwistle (1988) were included: a lively, interesting manner of presentation; pauses to allow information to be coded into long-term memory; voice modulation to draw attention to important points; questions and audio-visual aids to maintain attention, reinforce main points and stimulate active processing. Overloading of information was avoided by using many short (between 10 and 20 minutes) rather than long teaching sessions, interspersed with practical activities and short breaks

(Bartlett, 1988; Feinberg, 1988). As different people have differing desires for levels of information and excessive amounts can hinder learning for some, only essential information about disease effects was given and this was repeated again in the following session.

Providing written information allows its content to be more carefully thought through, and, if constructed properly, enables learning and recall and can be used for future reference (Ley, 1989). Material was reinforced by including the main points of talks in the programme workbook (Appendix 13) with sections to be read each week, avoiding medical jargon, including specific examples and visual material, limiting the number of pages required to be read each week (four maximum) for those with lower reading ability and providing supplemental reading material ("Coping with Rheumatoid Arthritis" Unsworth, 1986) for those wishing more (Weinman, 1990). The workbook was designed using readability strategies, eg. appropriate vocabulary, using shorter words and sentences, using action verbs (Ley, 1989; McCabe, Tysinger, Kreger and Curwin, 1989) and was reviewed by two rheumatology OTs for appropriateness of content and comprehensibility, and piloted with three RA patients for readability.

The teaching environment was designed to be informal, using a horseshoe seating arrangement to facilitate eye-contact amongst the group, whilst allowing audiovisual aids to be clearly seen.

c) Teaching methods to aid recall.

Methods to improve learning and recall included were (Hilton, 1992; Ley, 1980; Ley, 1989; Meichenbaum and Turk, 1987):

- i) simplification - technical terms were avoided, or if used, explained and further definitions were supplied in the accompanying workbook,
- ii) explicit categorisation - the overall contents, aims and

objectives were explained initially, each session was introduced with an outline of content and each change of topic highlighted, with aims and objectives explained,

iii) repetition - each session included a resume of the previous week, with the main points summarised in the workbook,

iv) asking patients to repeat back - patients were asked to explain what they understood about the disease, recall JP principles, explain the rationale for performing JP methods in terms of the disease and JP principles throughout the course,

v) giving specific advice - initially subjects were asked to practice a set number of tasks a set number of times per week, which changed to subjects writing their own goals.

4.3. TO INCREASE PSYCHOLOGICAL ADAPTATION.

A number of psychological constructs have been postulated as affecting the adoption and maintenance of health behaviours. These include self-efficacy, locus of control, perceived control, learned helplessness and coping, which are seen as inter-related. Strategies to improve these should therefore increase adherence and health outcomes and were therefore included.

4.3.1. SELF-EFFICACY.

Self-efficacy was proposed by Bandura (1977b) as a mechanism influencing coping behaviour. Self-efficacy affects the acquisition of new behaviours, the amount of effort expended in using these, the length of time persisting in these in the face of obstacles and emotional reactions affecting performance (O'Leary, 1985). Changing behaviour is seen as a function of cognitive processes. The motivation for change, activating and enabling persistence in behaviours, comes from beliefs that certain behaviours will lead to certain outcomes or outcome expectancies. The acquisition and maintenance of new behaviours is then influenced by efficacy

expectations, ie. the conviction one can successfully perform the behaviour required to produce that outcome. This is largely learnt through evaluation of personal experience and observation of others. A number of studies support the role of self-efficacy in influencing behaviour and health outcomes. Ewart (1989) and Ewart, Stewart, Gillian et al (1986) demonstrated self-efficacy is more predictive of adherence to exercise prescriptions than mood, personality or functional evaluations. Research into smoking cessation and weight control programmes likewise show higher levels of self-efficacy amongst those electing to join such programmes than non-joiners (Brod and Hall, 1984) and predictive of initiation and maintenance of health behaviours taught (Jeffrey et al, 1984; Pechacek and Danaher, 1979). Kaplan, Atkins and Reinsch (1984) demonstrated greater practice and feedback on treadmill walking increased Walking Self Efficacy of patients with chronic obstructive pulmonary disease, as well as increasing their everyday walking behaviour.

Lenker, Lorig and Gallagher (1984) and Lorig, Seleznick et al (1989) identified although an AEP (the Arthritis Self-Management programme) led to a significant increase in the use of health behaviours and significant improvement in health status outcomes (pain and disability), these were not significantly correlated. Those patients achieving a positive outcome attributed this to a greater sense of control over their disease and ability to effect change in their symptoms (ie. self-efficacy). Shoor and Holman (1985) and Lorig, Chastain et al (1989) demonstrated there was a strong correlation between arthritis subjects' self-efficacy and both their current and future pain and disability levels (health status outcomes), ie. the stronger self-efficacy, the less their pain and functional disability.

O'Leary, Shoor, Lorig and Holman (1988) and Lenker et al (1984)

demonstrated adding self-efficacy enhancement techniques (into a pain management programme and the Arthritis Self-Management course respectively), eg. individual goal-setting, specific instruction and practice, contracting, modelling and reinterpretation of physiological symptoms, led to increased self-efficacy, increased self-reported use of health behaviours taught and improvement in health status outcomes amongst RA subjects. O'Leary et al (1988) also identified greater self-efficacy for managing arthritis pain was correlated with greater numbers of suppressor/cytotoxic T cells post-treatment, but recommended these results be viewed with caution because of the large number of statistical tests performed.

Self-efficacy is not a trait but relates to specific behaviours in specific situations and so varies from one situation to another. It also varies along dimensions of strength (ie. degree of certainty of performing the behaviour, generally measured on a 100 point scale) and generality (ie. the degree of satisfaction with the behaviour).

Higher levels of satisfaction with abilities (generality of self-efficacy) in home management activities, leisure and pain control are associated with improved psychological well-being amongst those who perceive these activities as important (Blalock et al, 1992).

Lorig, Chastain et al (1989) developed an instrument specifically measuring self-efficacy for pain control, function (ADL) and control of "other symptoms" (eg. fatigue), demonstrating these three subscales significantly correlate with each other and the total self-efficacy scale. A generality scale of satisfaction for function (ADL) and pain control accompanies these. As this cognitive-behavioural JP programme included self-efficacy enhancement strategies, this self-efficacy scale was added to the assessment procedure.

4.3.1.1. STRATEGIES TO INCREASE SELF-EFFICACY.

To increase self-efficacy, education was planned to increase:

a) Outcome expectations - ie. beliefs that a given behaviour will lead to a given outcome. Strecher, deVellis, Becker and Rosenstock (1986) state that perceived susceptibility and beliefs in the benefit of using health behaviours can both be considered as outcome expectancies. Strategies to increase these (section 4.1) should help create the initial motivation for change. However, Jensen, Turner and Romano (1991) evaluating adjustment to chronic pain, identified outcome expectancies as less predictive of adopting coping strategies (eg. exercise, relaxation, rest) than efficacy expectations and recommended less time be spent teaching their benefits and more training performance. This approach was therefore used.

b) Efficacy expectations - ie. how capable one is of performing behaviours leading to those outcomes. Bandura (1977b) states Self-efficacy expectations are learnt from four major sources:

i) Performance accomplishments

ie. personal experience in achieving mastery over the task or event. This is considered especially influential, with a major source being Participant Modelling, ie. providing the subject with opportunities to practice under supervision, with much positive feedback enabling refining and perfecting of skills to ensure successful task achievement. Over half of the programme was therefore devoted to practice under supervision. This was gradually withdrawn over the four sessions, as subjects had greater self-directed experience, practising methods increasingly at home. Strecher et al (1986) recommend target behaviours are broken down into relatively easily managed components serially arranged, with initial tasks easier than subsequent, as Self-efficacy will be stronger if performance is achieved with relative ease. ADL tasks, mainly food and drink preparation, were taught separately initially, eg. carrying a plate, mug, kettle and pan, using the same JP principle of distributing load

over more joints (lifting with two hands with palms in full contact). This principle was emphasised first as it was one of the strategies most commonly naturally adopted by subjects in the previous trial. (Avoid lifting and use of technical aids were also emphasised early for the same reason). Subjects were encouraged to generalise this movement pattern to lifting other objects. Tasks applying other JP principles were then introduced and practised, with the length and complexity of activities increased during sessions.

ii) Vicarious experience

ie. observation of events or people (modelling). The ARC video "Help is at Hand" was shown. During this, four people with RA demonstrate their practical (JP) methods of coping with everyday problems. Live modelling was also used with the well-practised researcher demonstrating tasks. Strecher et al (1986) recommend that modelling is more effective in increasing Self-efficacy if: the model is similar in characteristics (such as age and sex); viewed as overcoming difficulties through determined effort rather than with ease; and, preferably, by observing more than one person. During practical sessions, subjects were therefore asked to work in pairs or threes (of similar age and same sex where possible) and observe each other in turn performing tasks.

iii) Verbal persuasion

ie. exhorting the person to change. This is probably the commonest method used by health care professionals. Subjects were regularly encouraged to practice methods during sessions and correctly repeat those performed wrongly. Positive verbal reinforcement was given and encouragement to try more the following week. Strecher et al (1986) recommended regular encouragement to demonstrate subjects' progress towards the target. Each week subjects set goals for home practice and progress achieving these was reviewed weekly at the beginning and

during each practical session. Successful partial or correct performances of JP methods were highlighted.

iv) Physiological state.

High physiological arousal usually impedes performance. Therefore sessions were designed to be informal, with opportunities for group interaction "built in," by avoiding timetabling sessions fully. Observing in pairs or threes (with whom subjects consistently practised) was designed to be less threatening than being observed by the whole group. Incorrect performances were not criticised, but used as opportunities for analysis and correction by providing further demonstration, repeat performance and additional feedback.

4.3.2. PERCEIVED CONTROL.

a) Locus of control.

Locus of control (LOC) is a construct from Social Learning Theory related to self-efficacy, referring to individuals' beliefs that events are determined by internal factors (ie. under his/her own control) or external factors (ie. affected by chance, fate, luck or the behaviour of powerful others) (Rotter, 1966). There is a relationship between belief in internal control and physical well-being. Those with a higher (internal) Health LOC (Wallston, Kaplan and Maides, 1976) exhibit greater: information-seeking (Wallston, Maides and Wallston, 1976); knowledge of health and disease, willingness to be involved in treatment and adherence (research reviewed in Maas, deJonge and McKenna, 1988); and make the greatest progress in rehabilitation (Norman and Norman, 1991).

Strecher et al (1986) differentiate between Health Locus of Control and Self-Efficacy by defining Health Locus of Control as the perception of control of an outcome (ie. outcome expectancy of health) whereas Self-efficacy (efficacy expectation) is the belief in ability to perform behaviours which may or may not lead to that

outcome.

b) Perceived control.

Self-efficacy and Locus of Control are related constructs contributing to perceived control (Wallston, 1991), with Self-efficacy being more predictive of behaviour (Nicassio, Brown, Wallston, Abraham and Wallston, 1987). A study by Chambliss and Murray (1979) identified a significant interaction between these, with those internal Locus of Control subjects receiving Self-efficacy interventions experiencing greater weight loss than: external Locus of Control subjects receiving Self-efficacy interventions; and those not receiving these, whether having internal or external Locus of Control.

Perceived control is defined by Wallston, Wallston, Smith and Dobbins (1987) as "the belief that one can determine one's own internal states and behaviour, influence one's environment and/or bring about the desired outcomes." Affleck, Tennen, Pfeiffer and Fifield (1987) identified patients with RA who had greater perceived personal control:

- i) over symptoms and the disease course - perceived their illness as more predictable;
- ii) over symptoms - had greater positive mood (amongst those with moderate to severe RA) but
- iii) over the disease course - had greater negative mood (amongst those with severe RA). Believing one can control severe disease that cannot be controlled through one's own efforts increases learned helplessness and is maladaptive. Aiming to improve perceived control of symptoms through education would be beneficial (eg. to improve pain, maintain or improve functional ability and hand status) but aiming to improve perceived control over the disease course (eg. to prevent exacerbations) is not.

iv) treatment processes - was positively correlated with mood, whereas believing health care professionals were in greater control correlated with negative mood. This emphasises the importance of patients' active partnership in both designing and executing their treatment programme.

Johnston, Gilbert, Partridge and Collins (1992) demonstrated physiotherapy patients (diagnoses including pain, fractures and osteoarthritis) receiving an experimental letter designed to increase perceived control over recovery during rehabilitation, had greater internal control and satisfaction with information received than did control subjects at three week follow-up. Longer term effects of this intervention are unknown.

Greater perceived control is associated with improved health outcomes, eg. using preventative health behaviours (Wallston et al, 1987), for spinal injury patients (Shadish, Hickman and Arrick, 1981) and faster recovery in patients with strokes or wrist fractures (Partridge and Johnston, 1989). The mechanisms by which perceived control improves health status are unknown, but Wallston et al (1987) suggest this is mainly the effect on changing health behaviour. Both Skevington (1990) and Wallston (1991) have since suggested beliefs about Self-efficacy and Locus of Control may have a direct physiological effect and be as important in affecting health status outcomes as performing health behaviours.

4.3.2.1. STRATEGIES TO INCREASE PERCEIVED CONTROL.

To increase perceived control subjects were sent an information sheet almost identical to that described by Johnston et al (1992), emphasising they would be shown how to control their symptoms as quickly and effectively as possible, the participative nature of the group, the need to follow the accompanying home programme and the more effort they expended the quicker results would be achieved

(Appendix 14).

4.3.3. LEARNED HELPLESSNESS.

The Arthritis Helplessness Index (AHI) measures patients' perceptions of an aspect of control, that of loss of control with arthritis (Nicassio et al, 1985) and this was developed using the learned helplessness model. Learned Helplessness occurs in situations where uncontrollability is the antecedent (Peterson, 1982), such as the largely unpredictable nature of RA (Nicassio et al, 1985), and is situation specific, with generalizability dependent on the person's attributions of causality, which is influenced by Locus of Control among other factors (Miller and Norman, 1979). A person may come to expect that whatever they do they cannot control their situation. People attributing failure (eg. in controlling disease symptoms) to an internal cause (eg. failing to use taught self-management techniques) are more likely to experience negative affect (helplessness) than those attributing to an external cause (eg. insufficient therapy at the hospital) and have less perceived control of their arthritis in future.

Learned Helplessness studies illustrate this point. Subjects attributing failure to insufficient effort, task or situational factors, rather than a personal inability to do the task have less Learned Helplessness (Miller and Norman, 1979). For example, in Tennen and Eller's (1977) study, subjects informed presented tasks would be successively more difficult attributed their failure to task difficulty, whereas those informed tasks would get easier, attributed failure to their lack of ability and consequently had greater Learned Helplessness.

Those with greater perceived helplessness have been found to have greater depression and anxiety, lower self-esteem, greater limitations and pain in performing ADL and a belief that behaviour

did not contribute to their health status and vice versa (Nicassio et al. 1985). They suggested further study could be conducted to identify whether perceived helplessness predicts deficits in RA patients' behaviour such as self-care and adherence and that it could be a useful screening tool for patients attending psychosocial interventions, as well as physiotherapy and educational programmes.

4.3.3.1. STRATEGIES TO AVOID LEARNED HELPLESSNESS.

Subjects were informed changing behaviour can be difficult. They should not expect observing and practising JP methods a few times in the programme to change their hand movements all the time at home. If they failed to use a method or did not change as rapidly as expected, they should not see this as a personal failure but rather that remembering to change previously normal, automatic movement patterns is a difficult task, requiring time and regular effort.

4.3.4. COPING.

Coping is defined as "the behavioural and cognitive responses to stressful events (in this case RA) taxing a person's ability to adjust" (Folkman and Lazarus, 1980) and can be thought of as the behaviour occurring as a function of self-efficacy beliefs (Schiaffino, Revenson and Gibofsky, 1991). Coping style is an important determinant of adjustment to RA, which is primarily determined by the person's appraisals of the disease and its limitations (Smith and Wallston, 1992). These appraisals are determined by three general factors:

- i) current health status (eg. levels of pain and functional disability),
- ii) beliefs regarding one's own abilities and other internal resources (eg. Self-efficacy, Health Locus of Control and helplessness) and
- iii) perceived availability of external resources (eg. social

support).

Lazarus and Folkman (1984) argued coping is not a stable trait influencing the person's reactions in different situations, but varies depending on different problems and the flexibility of the individual. Coping research in arthritis has focused on:

i) Coping with the illness in general

- through the use of problem- and emotion-focused coping strategies. Felton and Revenson (1984), Parker et al (1988) and Manne and Zautra (1992) identified Information-Seeking and Cognitive Restructuring (ie. redefining the illness as an opportunity for growth and seeking positive aspects of the situation) responses as being more associated with positive affect than Wish-fulfilling Fantasy and Self-Blame. Cognitive Restructuring is associated with better functional status.

ii) Coping with pain.

Brown and Nicassio (1987) identified two strategies, Active and Passive Coping. Passive Coping (eg. taking to bed and restricting social activities) is considered to result in poorer long-term adaptation, whilst Active Coping results in better (eg. continuing to function despite pain, staying busy and attempting to ignore pain). Those using Active Coping have less depression and greater Self-efficacy and vice versa (Brown and Nicassio, 1987). Smith and Wallston (1992) note there are constraints to the effectiveness of Active Coping as denying the realities and limitations imposed by RA could be injurious. Some Active Coping strategies are contradictory to JP theory, eg. continuing to function despite pain could lead to further secondary inflammation, muscle fatigue, promote ligamentous laxity and contribute to deformities developing. Cognitive and behavioural Active Coping strategies have been identified. RA subjects with greater perceived ability to decrease pain have lower pain levels than those who do not (Keefe et al, 1991).

iii) Coping strategies for daily activity, leisure, work and social relations problems

Behavioural strategies are commonly used to deal with daily living problems. Those with more flexible coping responses have been found to have greater psychological adjustment (Blalock et al, 1993).

Strategies identified in this study were:

- i) Carefulness, ie. doing things in a careful way or pacing activities (63.5%),
- ii) Modification, ie. changing something about the situation, eg. the way the activity is performed (57.6%),
- iii) Perseverance, ie. attempting to continue despite the problem (56.5%),
- iv) Using material resources, ie. special equipment or devices (50.6%),
- v) Stopping the activity (40%),
- vi) Decreasing the activity, ie. reducing frequency of performing problematic activity (30.6%),
- vii) Relaxation, ie. rest, sleep, take naps (15.3%).

These strategies were all reported by subjects in the previous trial as coping methods (chapter 3).

Morgan and Spiegel (1987) identified greater use of problem-focused coping strategies was associated with less pain, anxiety and depression and recommended treatment should emphasise problem-focused skills training. Blalock et al (1993) concluded cognitive-behavioural interventions teaching a wide variety of coping strategies should be more effective in promoting flexibility, which is associated with better psychological adjustment.

4.3.4.1 STRATEGIES TO INCREASE COPING SKILLS AND FLEXIBILITY.

The programme had a practical, problem-focused approach throughout. The main strategies emphasised and practised were altering patterns

of movement, using technical aids and restructuring tasks to avoid lifting (ie. those identified in the previous trial as most naturally adopted). Other behavioural strategies were also presented: energy conservation, eg. work simplification, pacing activities, regular rest periods; respect for pain, stopping activities and resting when pain or aching occurs; decreasing frequency of performing activities; delegation of tasks to others; giving up an activity when necessary; wearing a splint; and the use of hand exercises to maintain muscle strength and support of joint structures. These strategies are all described in "Coping with Rheumatoid Arthritis" (Unsworth, 1986), provided to all subjects in the accompanying programme information pack.

Problem-solving strategies were taught, discussed and practised, emphasising the potential application of all these approaches to finding solutions to ADL, work and leisure difficulties.

4.4. TO INCREASE MOTOR SKILLS.

Adopting Hand JP behaviours requires patients to change from using normal automatic movement patterns, used for decades, to developing skills in "abnormal" patterns. Perceptual motor skill acquisition is defined by Fitts and Posner (1967) as occurring in three stages, cognitive, associative and automatic. As a major barrier to change identified in the previous study was adopting new motor habits, this theory was explained to enable subjects' understanding of the rationale for teaching strategies used in the programme (Appendix 12 and 13).

a) Cognitive stage:

The person must understand what is involved in the motor task. Robb (1972) described this as forming an "overall picture" of the skill. Developing this correctly can be aided through:

i) Visual instructions.

Demonstrations were given prior to each practice session to the group, and to individuals during practice as necessary, to enable subjects to develop this mental image against which to compare their performance, both temporally and sequentially. Eaton and Davis (1987) emphasised demonstrations must be smooth, skilled and accompanied by clear instructions for learners to develop a correct perceptual trace. Observation of fellow group members also provided opportunities to analyze others' movement patterns and evaluate these with their own perceptual trace. This concept is similar to that of vicarious modelling (Bandura, 1977b). Adams (1986) demonstrated subjects watching unskilled models, especially if they also received the model's knowledge of results (see "intrinsic and extrinsic feedback" below), had better task performance than subjects learning solely through demonstration by a skilled model. Lee, Swanson and Hall (1991) postulate this provides greater opportunities for problem-solving to correct errors.

Photographs were also provided in the accompanying workbook of JP methods for all 20 JPBA tasks to remind subjects of joint positioning and appropriate equipment to use at home.

ii) Verbal instructions.

Higgins (1991) warns against teaching wholly through demonstration, as mimicry can train skills successfully, but does not equip the learner to generalise solutions to other motor problems. Gentile (1987) describes that the early stage of motor learning involves a high degree of cognitive-conscious involvement. The learner engages in task analysis, both to understand the movement(s) required and the problem-solving strategy involved, enabling them to develop their "mental image" and self-refer back to this when monitoring performance. Both task analysis and problem-solving processes were

taught in short lectures.

Theoretical explanations of JP movements were discussed initially as separate tasks were demonstrated, to enable subjects to understand the strategies used. For example, when lifting heavy objects such as pans and kettles, JP principles were emphasised: to ensure wrists were in extension (or neutral if this was impossible) to maintain a stable, functional position and maximise grip strength; and to avoid a position of deformity by avoiding lifting with a flexed wrist, as this can contribute to anterior subluxation. Gonnella, Hale, Ionta and Perry (1981) recommended therapists avoid information overload whilst demonstrating motor skills. Thus verbal instructions were minimised during demonstration and practice sessions, focusing on essential aspects and perceptual cues, eg. "keep the wrist up, in extension," to allow subjects to attend selectively to movements taught.

iii) Kinaesthetic instruction.

Manual guidance can also assist in providing sensory and proprioceptive feedback on correct joint alignment. This should not be excessive as the learner then moves passively with the therapist, which is less effective (Carr and Shepherd, 1987; Schwartz, 1982). This approach is generally not as effective as visual instruction when teaching upper limb skills.

b) Associative or Fixative stage -

In this stage, the skill becomes more efficient, co-ordinated and less variable. Feedback and practice are essential for skill development.

Both Adams (1971) and Kottke, Halpern, Easton, Ozel and Burrill (1978) proposed motor learning occurs through the refinement of perceptual-motor feedback loops (closed loop theory). Skills are learnt by forming rigidly engrained habits, or engrams, requiring

precise practice and feedback to be developed (Kottke et al, 1978). Error-free practice is advocated to allow correct perceptual traces or engrams to develop (Adams, 1971; Kottke, 1980). However, Lee, Swanson and Hall (1991) point out this does not account for those skills successfully performed without practice. Schmidt (1988) alternatively theorised learners form schemas from perceptual-motor feedback to build motor memory. Rather than an engram for each skill, generalised programmes (schemas) contain abstract codes of classes of movements. New skills develop through modification of the parameters of existing, similar movement schemas. Thus subjects allowed to make errors whilst learning a task perform better than those learning in errorless situations (Edwards and Lea, 1985).

i) Intrinsic feedback:

This comes from visual and auditory systems as well as proprioceptive and skin receptors. Information is compared with the mental image and evaluated, eg. as to whether joints are in correct alignment or excessive muscle force is being used, and movements subsequently corrected and re-corrected until congruent with this.

Adams (1971) identified subjects frequently give themselves self-instructions, ie. use self-talk to monitor performance, detect errors, form hypotheses why these occurred, (eg. "I need to keep my palm, not fingers on top of jar") and then correct these. Self-talk may be both knowledge of results (KR) ie. feedback concerning the movement's outcome or knowledge of performance (KP), ie. feedback concerning the movement itself (Gentile, 1972). Subjects were therefore encouraged to become more aware of self-talk as a means of consciously monitoring performance.

ii) Extrinsic feedback

The therapist can also provide knowledge of results and knowledge of performance. Learning can occur without either (Rosenbaum, 1991), but

it is more efficient with. Feedback should be slightly delayed, up to five seconds (Weinberg, Guy and Tupper, 1964) to allow subjects time to process intrinsic feedback and facilitate comparison with extrinsic feedback. Gentile (1987) believes therapists have placed insufficient emphasis on providing verbal feedback for knowledge of performance and visual feedback for knowledge of results. An example of knowledge of performance given in the programme was "you need to keep as much of the surface of your hands in contact to distribute strain evenly over joints." Knowledge of results was emphasised using visual feedback by giving a repeat demonstration with essential cues, particularly during earlier sessions, accompanied by knowledge of performance on how subjects' performances differed. The more specific the feedback, the better performance (Goodgold-Edwards, 1984; Singer, 1980). Movements were further corrected using manual guidance if necessary. Working in pairs or threes increased opportunities for subjects to observe additional demonstrations and hear others' knowledge of results. Magill (1986) further emphasises positive, specific feedback should be given when movements are performed correctly (eg. "you got turning the tap just right"), to aid learners identify where to look for errors.

Lee et al (1991) reviewed research demonstrating blocked-order (ie. consistent) knowledge of results of segments of a motor task led to better initial skill accuracy in these. However, random-order knowledge of results led to more accurate and consistent performance of the entire task long-term. They suggest this required fuller advance planning of the entire action and so encouraged learning each segment in the context of others. Knowledge of results and knowledge of performance were therefore provided randomly for different segments of tasks practised. For instance, making a hot drink involves: turning on a tap, lifting and carrying a kettle, opening

and closing a jar etc. Feedback was provided at varying intervals to different members of pairs or threes for different tasks.

iii) Amount of Practice.

Motor improvement results from repetition (Lee et al, 1991), although practice alone does not make perfect (Singer, 1980). The person must be motivated to perform the skill and be knowledgeable of the correct movements or errors may be perpetuated. Overlearning results in better retention, although "drill" can become boring to the learner and take time from learning other skills (Singer, 1980). JP methods for all 20 JPBA tasks were therefore demonstrated and practised at least twice in at least three sessions. A variety of other JP methods commonly included in JP education were also demonstrated and practised. The programme of four weekly two hour sessions was unlikely to provide sufficient practice for fixation to occur, although the cognitive stage would be achieved. Practice in the home setting was therefore essential.

iv) Part, blocked versus whole, varied practice.

Part practice, ie. practising components of an activity, such as opening a jar or lifting a kettle, aids learning sequences of tasks more efficiently initially (Singer, 1980). Shea and Morgan (1979) identified subjects receiving blocked practice, ie. practising one task repetitively before moving onto another, were both quicker and more accurate than those learning using random order practice. However, greater retention and skills transfer occurred at 10 days in those receiving random-order practice. Subjects were therefore taught using part, blocked practice whilst teaching the rationale behind adopting JP techniques. Subjects practised specific tasks for selected principles, eg.: turning on and off a tap and opening and closing a jar, using the same movement pattern and were asked to suggest other activities to which these could be applied to aid in

generalising these.

However, whole practice (making a hot drink and / or snack meal in their entirety) was used from then on. Kottke (1980) recommended that if the learner has the prerequisite skills to master the task in its entirety, then whole practice is superior as most learning is related to integrating force, speed and timing components. Varied sequences of kitchen activities, with increasing numbers of sub-tasks in differing order each week were then practised, eg. meal preparation included soup, cheese on toast, spaghetti neapolitan or stew and potatoes.

v) Practice setting

Stallings (1982) recommends practice must simulate real-life settings as closely as possible for transfer of skills to home and other similar motor skills to occur. The programme was therefore conducted in an OT kitchen, with gas, electric and microwave cooking facilities and a variety of models of kettles, can openers and other commonly used food preparation equipment, to allow subjects to select equipment similar to those at home. Any differences in facilities and equipment causing difficulties applying the movements learnt at home were then discussed and alternative movement patterns practised. The programme was followed up with a home visit to enable supervised practice in subjects' own environments.

vi) Mental practice

As well as physical practice, mental practice has been well-documented as effective in skill acquisition (Richardson, 1967a and b), particularly in sports science (reviewed in Warner and McNeill, 1988). Weinberg (1982) reviewed studies combining both physical and mental practice, concluding these produce the greatest gains in performance although the most effective combination of the two is unclear. Mental practice involves the symbolic rehearsal of a

physical activity without gross muscular movement. Subjects were therefore asked to pay conscious attention to the "feel" of performing one activity (making a hot drink) during practice sessions, to produce a stronger visual image (Weinberg, 1982). These movements were then mentally rehearsed in the group on two occasions, eg. "imagine making a hot drink and imagine performing each hand movement correctly," followed by prompts for each task. Subjects were then asked to regularly repeat this at home. The rationale for using this strategy was explained and it was emphasised this method required regular practice for it to contribute to habit development. Warner and McNeill (1988) recommend a minimum of five sessions on separate days as necessary. Subjects were asked to set goals for mental rehearsal and asked to feedback to the group on practice frequency and effectiveness, to promote its continued use. This method also has the advantage of enabling RA patients to acquire sufficient practice even if fatigue reduces the opportunities to physically practice at home. However, Denis and Carfantan (1985) found a third of subjects following education rejected the idea of mental practice aiding skill learning and discontinued its use before benefits were experienced. This approach is not therefore likely to be of benefit to all patients.

c) Automatic stage.

In this final stage, the skill is executed sub-consciously, despite distracting stimuli (ie. it has become a habit). This requires continuing practice, with extrinsic knowledge of results and knowledge of performance no longer necessary, to develop smooth, co-ordinated speedier movement sequences.

This degree of practice cannot cost-effectively be provided under therapist supervision and neither is this necessary once the subject is able to use their own intrinsic knowledge of results and knowledge

of performance effectively to correct themselves, although continued motivation to practice is required. To encourage this degree of practice at home behavioural strategies were incorporated.

4.5 TO ENABLE ADOPTION OF NEW HABITS AND ROUTINES.

Cognitive-behavioural programmes have been demonstrated to improve RA patients' JP behaviours: exercise and relaxation (Lorig, Lubeck et al, 1985); self-care practices (Goeppinger et al, 1989); and resting during activity (Gerber et al, 1987), indicating this approach is more effective than traditional education.

Many sequences of ADL (such as meal preparation) are associated with well-learned repertoires stored in long-term memory, use automatic cognitive processing to be accomplished and are difficult to change because so well engrained. For these to be altered, self-regulation using controlled processing, ie. focused attention and continuous decision-making is necessary. Previous habitual behaviour must be "deautomatized," self-regulation applied and new behaviours "reautomatized." Strategies used to do so are temporary techniques to aid change, progressively abandoned as new behaviours become habitual (Kanfer and Gaelick, 1989).

Self-management behavioural approaches (Kanfer, 1979), including self-regulation, are normally utilised for altering maladaptive behaviours. Here the process has been adapted for changing automatic behaviours. The stages include (Kanfer and Grimm, 1980):

a) Creating a working relationship

Enhancing the person's perceived control over problems and the change process is a goal of self-management approaches. The client-therapist relationship is an important component of achieving this, which should be one of mutual participation (Meichenbaum and Turk, 1987). Whitcher-Alagna (1983) reported patients are more satisfied, liking of the clinician and adherent if they receive sufficient information

in a caring, co-operative encounter. Garrity (1981) proposed four aspects of the client-therapist relationship which can be structured to enhance adherence.

i) Pedagogical techniques

Learning principles should be applied to facilitate understanding and recall (section 4.2). Feinberg (1988) reviewed research suggesting patients receiving an adequate explanation of the nature of their disease are more likely to be adherent, although this should not be excessively detailed as the more information given, the higher the proportion not recalled. Following introductory disease information, subjects were given the opportunity to ask questions and this opportunity was repeated in subsequent sessions and the home visit.

ii) Sharing of expectations

The therapist should be aware of the expectations of the client (Feinberg, 1988) by asking about their: expectations of the programme and what they hope to achieve; explanatory model of illness; worries and concerns about their illness; perceptions of the costs and benefits of the treatment; existing health knowledge, skills and practices; and degree of adaptation to the disease. These points were therefore discussed in the programme. (Strategies for eliciting information are discussed in Meichenbaum and Turk, 1987).

iii) Patient's assumption of responsibility.

Self-management utilises a participant model in which the person takes responsibility for behaviour change. Prior to the programme, telephone or face-to-face contact was made to describe its' aims, benefits in controlling symptoms and emphasise its' self-help approach in which their suggestions would be valued. The expectation they would practice activities and home programmes was conveyed early on (section 4.3.3). Patients must be involved in treatment planning and goal-setting (section 4.5c) and discussion concerning the

benefits and barriers to adherence was included during sessions.

iv) Affective tone.

The following therapist qualities increase adherence and were adopted: a clear introduction of oneself; be welcoming and approachable; show positive regard for the client; be willing to listen and explore patients' worries, goals and expectations; establish a relaxed atmosphere allowing patients to ask questions freely; answer all questions and check understanding; inspire confidence by demonstrating a belief in the effectiveness of the treatment and be knowledgeable in its use, its effects and about the disease; discuss the pro's and con's of different treatments; be friendly and engage in some non-therapy talk with some self-disclosure; make regular eye-contact; sit at the same level; and the patient must not perceive the therapist as imposing goals and methods or "preaching" (Feinberg, 1988; Feinberg, 1992; Meichenbaum and Turk, 1987; Tunks and Bellissimo, 1991).

b) Creating/ maintaining motivation for change.

The person must want to make changes initially, thus Self-management programmes must be attended voluntarily (as was the case). The therapist's role is to enhance motivation and aid its maintenance through:

i) Goal and value clarification.

Explanation for the rationale of JP and discussion of its therapeutic goals aids motivation by increasing perceived benefits (section 4.1).

ii) Self-monitoring.

The initial stage of the self-regulation process is self-monitoring, ie. paying deliberate attention to the behaviour under consideration and comparing this with performance standards (ie. the rules by which a person judges their own behaviour), which are influenced by social

and personal experiences (Kanfer and Gaelick, 1989). The disease, deformity and JP information provided initially intended JP methods to be seen as desirable performance standards.

Initially, following disease education, subjects observed the researcher performing normal movements contributing to joint stress (eg. opening a tight jar, lifting a heavy kettle), were asked to identify positions of deformity adopted, repeat the movements, observe their own hand positioning and be aware of any discomfort or weakness occurring. Tasks selected were deliberately resistive to promote difficulty or discomfort in task performance. This self-monitoring aimed to increase awareness of pain or discomfort, as a motivator to initiate change (temporarily), as pain was identified in the previous study as the major prompt for behavioural change, although subjects reported being able to suppress it.

The second stage of self-regulation is self-evaluation. Performance is matched against what one ought to be doing, ie. JP performance standards. As part of the home programme, subjects were asked:

- to self-monitor (at least once in the following week) hand positioning and joint strain whilst making a hot drink, record actions pushing hand and wrist joints sideways or downwards (ie. ulnar deviation and flexion) and causing discomfort or strain, in order to evaluate discrepancies with JP performance standards;
- observe a friend or relative performing the same task and compare this with their own performance, in order to identify what changes in hand behaviour they had already made (ie. what JP standards were met);
- and identify specific ADL causing pain or aching during the week, in order to identify behaviours requiring change.

Subjects were asked to choose times to self-monitor, rather than to become generally more aware of their movements, as focusing attention

excessively on automatic behaviours can be too disruptive of daily life and act as a negative reinforcement. Subjects could then perceive changing tasks as too enormous a challenge.

The third stage is self-reinforcement, ie. the individual's reactions to this self-evaluation of whether they are satisfied or dissatisfied with the amount of discrepancy. If dissatisfied, this should motivate them to practice JP methods and develop new habits. If not, they are likely to either cease attending the programme or practice methods insufficiently. Subjects were asked to feedback to the group on their self-monitoring, whether they thought JP beneficial for them and what tasks needed changing, in order to identify individuals' degree of motivation for change. This also enabled the researcher to identify those subjects needing greater encouragement subsequently to self-monitor, additional input on JP benefits and greater positive reinforcement on progress. Self-regulation does not necessarily lead to commitment to change or use of new behaviours. Factors contributing to making commitment easier include:

- the presence of others making promises. All subjects were therefore asked to verbalize goals, ie. which methods and amount of weekly practice at the end of each session and discuss progress achieving these at the beginning of the next;
- promise-making leads to social approval. Positive verbal reinforcement for achieving goals was given, which was generally supported by group members;
- and the behaviour to be changed cannot be easily checked. Whether subjects practised methods between sessions was their choice (Kanfer and Gaelick, 1989).

c) Developing and executing a behavioural change programme.

Where possible the person should have control over the treatment programme in order to increase perceived control. The constraints of

evaluating a programme using a group trial, rather than single case design, meant subjects must receive the same treatment. Tasks targeted for change in the programme were selected as being the commonest problems experienced by RA patients (kitchen ADL). Subjects were given some decisional control by selecting which tasks (four out of six) and which method (out of two or three) they would select to practice each week from the workbook (Appendix 13) and how much practice they would do at home. In addition, subjects were also encouraged to target and change other ADL they identified as problematic.

Tunks and Bellissimo (1991) stress the importance of ensuring components of a complex regimen are introduced gradually. In session one six tasks were practised, in session two a dozen, in session three over twenty and by session four over thirty.

Homework assignments, goal setting and reinforcement programmes are essential components of self-management programmes and why these are effective strategies was explained to subjects.

Homework tasks should be graded in difficulty as the person increasingly takes responsibility for change, assisting in continuity between the programme and everyday life. They should reflect the short and long term goals subjects are trying to attain and highlight further areas of potential change to subjects as well as providing increased practice of skills. For homework assignments to be effective, four stages are needed (Kanfer and Gaelick, 1989):

i) The information stage.

This includes instruction in methods, the minimum practice necessary for change to occur and identifying how practice can be fitted into subjects' daily routines realistically (Tunks and Bellissimo, 1991). Discussion with subjects identified periods in the day or week which allowed sufficient time for practice completion, as JP methods

initially take longer than normal because of the greater attention required.

ii) Prerehearsal.

ie. through part and whole practice of JP methods in the programme. Initially the therapist should provide regular feedback and guidance, reducing this over time and emphasise encouragement and reinforcement (section 4.4.6.).

iii) Use in natural settings.

ie. practice in the home environment. Initially assignments were set by the researcher but by session three subjects set their own short-term practice goals. Assignments were given verbally at the end of each session and also written in the workbook. Written instructions lead to significantly better recall and adherence to homework as they: structure assignments into discrete tasks making them easier to follow; increase perceived importance of homework; and act as a prompt in the natural environment (Cox, Tisdell and Culbert, 1988). Manageable amounts of homework must be given (Shelton, 1979) so this was limited initially to requesting at least one practice session at home of four tasks. To monitor practice frequency, subjects were asked to record in their workbook when practising a specific JP method or sequence of tasks. This can further enhance motivation as progress towards goals is readily observed and provides reinforcement through satisfaction with progress. It was recommended the workbook be kept to hand in the kitchen (or the pages with photos of JP methods torn out and displayed prominently) both to act as a reminder and enable recording to occur at time of practice as delay can weaken the motivating effects of self-monitoring (Kanfer and Gaelick, 1989; Tunks and Bellissimo, 1991).

iv) Review.

Feedback was requested each week as to whether practice was completed

and the problems and benefits identified. Discussion should promote self-efficacy and negative feedback be avoided if homework is not completed, particularly when this may have been beyond the person's control, eg. a family member's illness, additional pressures at work. Kanfer and Gaelick (1989) also suggest records should be brought in to sessions and frequencies monitored.

For homework to be effective, clear objectives are needed (Shelton, 1979). Subjects were asked to set their own homework towards the end of the programme in order to facilitate its continuing review and resetting after the programme ended and support ceased. Teaching and practice in how to set homework was therefore provided by explaining goal-setting procedures (based on the method used in the Pain Management Course (O'Leary et al, 1988)). Goals must be realistic to minimise the possibility of failure and maximise self-efficacy through successfully achieving these (Tunks and Bellissimo, 1991). Subjects were therefore asked to set goals once they had the experience of what could be realistically achieved through following the earlier pre-set goals.

Self-reinforcement schedules promote attaining goals by giving strong incentives (Kanfer and Gaelick, 1989). Subjects were encouraged to use self-rewards when achieving goals, following discussion of what they personally found most effective:

- i) material reinforcers, eg. a rest, chocolate bar, buy a special treat and,

- ii) verbal-symbolic rewards eg. "I did that well."

Manipulating the physical environment through stimulus control can also assist the person in not commencing undesired behaviours. This concept was applied by encouraging use of some technical aids to obviate the need for certain movements to occur, although in general few aids were recommended because of cost and the likely barrier this

would present for many subjects.

Problem-solving is a common cognitive-behavioural treatment strategy for improving transfer effects which educate the person to use conscious cognitive strategies to identify potential solutions (Kanfer, 1979). The procedure taught was that used in the Arthritis Self-Management course (Lorig, 1986a).

d) Providing support.

Social support refers to the personal contacts available to an individual and can be tangible, emotional and informational. It can be both positive, providing a sense of belonging, a source of aid, information, encouragement and feelings of success, as well as negative, undermining adjustment through criticism, causing focusing on negative aspects of the situation and encouraging non-adherence. Positive social support can be provided in several ways (Meichenbaum and Turk, 1987):

i) Verbal reinforcement

- of the client's efforts and successes by the therapist,

ii) Involving family members or friends in the programme.

Manne and Zautra (1989) identified people with RA who perceived their spouse as supportive engaged in more adaptive coping than those with critical spouses. Subjects were asked to encourage a significant other to read the booklet sent prior to the programme, to attend the group if possible and to read the information provided in the accompanying book "Coping with Rheumatoid Arthritis" (Unsworth, 1986) and workbook. Family or friends attending were also asked to self-monitor and practice JP methods, to realise the difficulties of changing automatic behaviours and assist the subject in changing through; providing feedback on performance, at practice times agreed with the subject, to avoid this being perceived as "nagging" which could prove an obstacle to change; assisting the subject in

scheduling practice times during the week; engaging in problem-solving with the subject; assisting in identifying and obtaining (now or in the future) those technical aids and labour-saving devices which proved most beneficial during the programme; providing encouragement to continue goal-setting and practice after completion of the programme.

iii) Peer group discussion.

This allows sharing of common experiences. Subjects in the previous trial commonly reported the group had been supportive psychologically and practically, but there was insufficient time for discussion. Time was purposefully allowed for spontaneous discussion of common problems and reactions of both subjects and significant others during talks, practicals and in breaks.

iv) Home visits.

A follow-up visit within two weeks of the programme ending was planned to enable: further practice in the home environment; monitoring of goal-setting and practice; and discussion of problems identified by both subjects and families. If family members were unable to attend the programme, subjects were asked if they would like the visit to occur when the family could be present to enable discussion.

4.6. COGNITIVE-BEHAVIOURAL JP PROGRAMME OUTLINE.

Previous feedback from Derby AEP subjects recommended four sessions (ie. 8 hours) to be optimal. The programme developed is summarised below and described in Appendix 12. A workbook accompanied the programme (Appendix 13), as part of an information pack containing:

- i) "Rheumatoid Arthritis - a handbook for patients" (ARC, 1991a),
- ii) "Your Home and Your Rheumatism" (Ansell and Lawton, undated),
- iii) "Coping with Rheumatoid Arthritis" (Unsworth, 1986),
- iv) and a selection of technical aids brochures to assist patients in

purchasing those identified as beneficial.

"Managing Your Arthritis," a cognitive-behavioural JP programme.

Session 1.

1. Introduction - aims of group, format, self-help basis, the Four P's, distribution of information packs.
2. Disease information - definition of RA, outcomes, normal and diseased joint structure.
3. Development of common hand deformities - identification of deformities and/or loss of RoM of group members.
4. Making changes - attitudes to change, "Help is at Hand" (ARC video).
5. Break - discussion of video (problems caused by RA and coping).
6. Joint Protection - the four P's.
7. Practical - normal and JP methods of six common activities, self-monitoring.
8. Home programme.

Session 2.

1. Review of home programme.
2. Review previous session - the 4 P's, common deformities and their development, contributory stresses.
3. Joint Protection principles.
4. Practical - applying principles to common everyday tasks, demonstration and return demonstration.
5. Practical - making a hot drink, working in pairs or threes.
Observation and feedback. Relatives practice if numbers allow.
6. Break - discussion of group members alternative working methods.
7. Developing new habits - motor learning theory, self-talk, mental rehearsal.
8. Practical - making a hot drink and snack (eg. spaghetti on toast).
9. Home programme.

Session 3.

1. Review of home programme.
2. Review of previous session - JP principles, motor learning theory.
3. Practical - making a hot drink.
4. Task analysis - tasks involved in making snack meal, analysis of normal movements and stressful components, application of JP principles, JP methods.
5. Practical - making a snack meal (soup and cheese on toast), a hot drink, washing up and clearing away.
6. Break -
7. Mental rehearsal.
8. Setting goals - barriers and rewards.
9. Home programme.

Session 4.

1. Review of home programme.
2. Review of previous session - JP principles, examples of methods, goal setting, rewards.
3. Practical - making a meal (eg. spaghetti neapolitan, stew and potatoes or home-made soup), hot drink and clearing up.
4. Break -
5. Problem-solving - process and application to a common ADL problem (eg. ironing).
6. Discussion of common problems and possible solutions.
7. Home programme.
8. Further information sources - information leaflets and books, national and local interest groups, local facilities.
9. Arrange Home Visits.
10. Close group.

Session 5 - optional Home Visit.

Kitchen and homemaking ADL difficulties. Practice hot drink.

5. EVALUATION OF THE COGNITIVE-BEHAVIOURAL JP EDUCATION PROGRAMME.

5.1. INTRODUCTION.

The final stage of the research was to evaluate the effectiveness of the cognitive-behavioural JP programme described in the previous chapter.

The aims of the study were to identify:

i) whether a cognitive-behavioural JP programme, using motor learning, adult education, adherence and recall enhancement and behavioural principles:

- increases knowledge of RA, JP principles and Hand JP methods,
- changes attitudes towards the benefit of adopting JP,
- and increases use of Hand JP.

ii) what factors are associated with a significant increase in Hand JP and

iii) what pre-education factors predict significant increases in Hand JP to assist in identifying which subjects are more likely to benefit from education.

5.2. METHOD.

5.2.1. NULL HYPOTHESIS.

It was hypothesised that:

i) there is no significant difference between RA patients' knowledge of, attitudes towards and use of Hand JP behaviour before and after attending a cognitive-behavioural JP programme.

5.2.2. TRIAL PLANNING.

a) Trial location.

Following review of the research protocol, Nottingham Rheumatology and OT services agreed to the trial occurring. Ethical approval was obtained.

b) Trial design.

Recommendations from the previous trial were adopted: ie. the researcher provided the education programme to ensure standardisation of content over time and organised subject recruitment and group allocation. A research assistant was employed to conduct assessments independently.

The researcher's work commitments, cost containment for a research assistant post and the need to ensure an assistant would remain in post throughout the trial, led to a design choice minimising subject numbers and duration. A crossover design was selected, with 12 week assessment intervals (Fig.5.1). Group T1 received education first, whilst C1 acted as a control group, receiving education following T1's first post-education assessment.

Figure 5.1: Cognitive-behavioural JP programme - trial design.

Assessment no.:

1	2	3	4
<u>Weeks:</u>			
1	12	24	36
T1 0 XXXX(HV)	0	0	
C1 0	0 XXXX(HV)	0	0

0 = assessments, X = education sessions, (HV) = Follow-up home visit.

T1 = education first group, C1 = control phase first group.

The education programme lasted over a six week period, ie. four weekly group meetings and a home visit within two weeks of the programme ending. Assessments were conducted at 12 week intervals, ie. at one week pre- and six and 18 weeks post-education. A six week post-education, rather than an immediate follow-up, was planned to allow time for subjects to consolidate information, practice JP

methods and develop new habits. As the JPBA assesses habitual movement patterns by distracting the subject, an immediate post-education assessment would be less likely to show change as subjects would still need to consciously practice movements. The 18 week assessment was included to evaluate if behaviours were sustained. C1 were additionally assessed 12 weeks pre-education to control for the effects of time.

The trial was planned to last 10 months, with eight education groups run during a six month period and final follow-up completed within the next four months.

c) Sample size.

A minimum of 26 subjects was required. Using the method described in Daly, Bourke and McGilvray (1991) to detect the predetermined significant difference of 20% in subjects' JPBA scores (section 2.2.2.7.1. results), with:

$$\alpha = 0.05, \beta = 0.2, \sigma = 18$$

a sample size of 13 is required in each group. (As standard deviations in the test-retest study were 17.45% and 18.07% (Table 2.3, section 2.2.2.7.1.), σ was set at 18).

Group size was planned at four to six subjects, meaning a maximum of 48 places were available, to ensure sufficient subject numbers in case of drop-outs.

d) Research Assistant Training.

Initial training was provided in conducting all assessment procedures. The research assistant was experienced in interviewing techniques but did not have a therapy/rheumatology background and therefore education on the disease and its management was provided, as well as training in identification of hand deformities and assessing joint ROM (for completion of the HJAM scale).

Previous studies (Stewart, Palmer and Knight, 1990; Legerton,

Callahan, Marcum, Brooks and Pincus, 1991; Mason et al, 1992; Abraham et al, 1993) have shown RA patients can reliably self-report joint counts. Subjects were therefore asked to self-report HJCs, using the same 0 to 3 scale, to the research assistant. Training was followed by observation of three assessment visits conducted by the researcher and three assessments conducted under supervision.

A copy of the JPBA booklet and training videotape was supplied. On successful completion of the sample JPBA's in this, an inter-rater reliability study was conducted.

e) Assessment procedures and blind conditions.

At each assessment, the interview, JPBA, JPKA, AHI, functional status, disease, pain and hand measures were recorded.

Two other measures were added:

1) a self-efficacy measure (Lorig, Chastain et al, 1989, see section 4.3.1.) of:

i) degree to which subjects are certain they can perform specified ADL, control pain and other symptoms, and

ii) generality of self-efficacy, ie. satisfaction with ability to perform ADL (SATADL) and control pain (SATPAIN).

2) A grip strength measure to explore the influence of grip on Hand JP. The Smith and Nephew Rolyan Digital Dynamometer was used. Solgaard, Kristiansen and Jensen (1984) have shown this instrument to be as sensitive and reliable as the Martin vigorimeter. The mean of three readings for both right and left hands was recorded.

The same procedures to keep subjects' "blind" to the aims of the study were used as in the previous trial. The research assistant was not informed of the trial design and given minimal information on aims. Video analysis was conducted by both researcher and research assistant, with most of that by the researcher done after education was completed, apart from assessments included in the inter-rater

reliability study.

f) Education group venue.

A location was chosen which met the following requirements:

- i) a room large enough to seat a group up to eight people (subjects and relatives or friends) with audio-visual aids in use and appropriate comfortable seating for RA patients,
- ii) sufficient kitchen facilities (same room or adjacent) for up to six patients to work simultaneously,
- iii) available for both afternoon and evening sessions, to maximise the opportunities for patients with children or at work to attend,
- iv) on regular public transport routes, with adequate car and disabled parking within a short walking distance (and lift access if not ground floor) - to maximise access.

The OT department, Health Care of the Elderly, Nottingham City Hospital (NCH) agreed to provide such a location. Afternoon sessions were organised to fit into normal department routines with minimal disruption and evening security arrangements negotiated. Health Authority food preparation regulations were followed.

5.2.3. SUBJECT SELECTION.

a) Trial entry criteria.

These were as in the previous trial (section 3.2.6), apart from "identified by a member of the rheumatology team as likely to benefit from JP education." This was the case in sources iii) and iv) below. Otherwise subjects were identified by the researcher.

A list of potential subjects meeting these criteria was drawn up from four sources:

- i) review of the previous three years of Rheumatology OT records,
- ii) review of one rheumatology consultant's record system,
- iii) referral from one rheumatology consultant's out-patient clinics and

iv) identified by one rheumatology consultant from record system.

b) Patient consent procedure.

i) Education group and trial information was forwarded to patients meeting entry criteria, along with a reply form to be returned within three weeks. This emphasised the practical, positive, self-help nature of the group, described content, outlined trial involvement, confidentiality and that non-participation would not affect normal treatment. The trial purpose was explained as previously.

ii) Patients replying positively were contacted by telephone to confirm they met entry criteria, provide a further explanation of trial participation, confirm they were willing to agree to this and provide further information on group times and venue. Patients were informed groups would commence in two months time, with a waiting list of up to six months, but the person conducting the trial would be contacting them in the near future.

iii) A short questionnaire to aid in group planning was forwarded to subjects requesting: age, disease duration, affected joints, any difficulties in work, ADL or leisure activities, whether they wished to bring a friend or relative, if afternoon or evening sessions were preferred and if there was anything they additionally wanted included in the programme.

iv) Patients were randomly allocated to either group T1 or C1. Four education groups were run for each.

v) Information from the questionnaire was used to allocate subjects to specific education groups according to: times preferred, age groupings, male subjects paired in groups, with maximum group size (including friends or relatives) of eight.

vi) Patients were telephoned to confirm dates and times were convenient and a reminder letter and map of the venue forwarded. C1 subjects (waiting four to six months) were telephoned one month prior

and sent reminders two weeks prior to the group.

vii) The research assistant was provided with the subject/group list and 10 month assessment schedule, who then contacted subjects to arrange assessment appointments at times convenient to them in their own homes. A further verbal and written explanation of the study was provided by the research assistant at this first assessment and written consent obtained.

5.2.4. PILOT STUDY.

Five patients agreed to participate in a pilot study of the group programme. Two withdrew due to ill-health and three attended. The pilot aimed to evaluate: timing of session contents; adjust the content as necessary following feedback from subjects on sessions, the workbook and other information provided; necessary equipment was available; short-term effectiveness (at two and six weeks) in improving Hand JP behaviour.

Assessments were conducted by the research assistant for additional practice before trial commencement.

Two of the three subjects increased JPBA scores significantly (ie. more than 20%) post-education. All three attended all four sessions, with two agreeing to a home visit.

Changes made as a result of the pilot were:

i) reduction in the duration of taught content to increase time available:

- for patient interaction, as the ARC video "Help is at Hand" in session one prompted considerable discussion from both patients and relatives on practical and emotional problems of coping with arthritis and

- to ensure sufficient time for demonstration, return demonstration and practice of targeted tasks each session;

ii) reduction in disease and joint structure information with

increased emphasis on identifying deformities and that JP can reduce risk of these worsening, even if they already exist;

iii) additional encouragement in sessions one and two to ensure patients performed all tasks completely. There was some initial embarrassment at practising kitchen ADL tasks differently;

iv) subjects were reticent to provide feedback to each other initially, meaning additional verbal feedback and manual guidance was provided by the researcher and encouragement needed;

v) in the latter sessions, patient interaction required controlling to ensure adequate practice and feedback occurred;

vi) the term "homework" was changed to "home programme" as subjects considered this reminded them of school. Asking subjects to show and discuss their workbooks with practice frequency boxes and goals sheets completed was also omitted for the same reason;

vii) an increased range of information leaflets, books and technical aids was provided at the last session for subjects to view, along with a reference list and information on the local Disabled Living Centre, OT services and commercial outlets for purchase of technical aids;

viii) the home visit of necessity became optional, as not all considered this necessary;

ix) home visits led to additional ADL problems being identified and arrangements were made with the OT department for referral;

x) alterations to wording in the workbook reported as unclear.

The programme is described in Appendix 12.

5.2.5. STATISTICAL ANALYSIS.

Non-parametric statistics were used throughout as normal plots identified data was not normally distributed.

Mann-Whitney tests were used to assess differences between T1 and C1 groups at each assessment stage (continuous and ordinal variables)

and Chi-square tests for categorical variables. Friedman two-way ANOVA was used to test for changes within groups for continuous and ordinal variables and the Cochran Q test for dichotomous categorical variables. Relationships between variables were assessed using Spearman's rank correlation coefficient. Backward multiple regression was used to identify factors significantly associated with and predicting JPBA score changes.

5.3. RESULTS.

5.3.1. JPBA INTER-RATER RELIABILITY STUDY.

Seventeen assessments were evaluated by both the researcher and research assistant prior to assessment coding. Of the 340 tasks observed, 92.6% were scored identically, Kappa = 0.79, ie. "good" agreement.

5.3.2. SUBJECT RECRUITMENT.

The trial commenced in September 1992, with education groups ceasing in March 1993 and follow-up assessments completed by August 1993. Eight groups ran during this period.

Subjects meeting entry criteria were recruited from four sources, shown in Table 5.1.

Table 5.1: Referral sources and numbers of subjects agreeing to participate.

<u>Referral source</u>	<u>No. contacted</u>	<u>No. agreeing</u>	<u>Percentage</u>
OT records	71	19	27%
Review of 1 consultant's records	60	16	26.6%
1 Consultant's Out-patient clinics (1 month period)	33	11	33%
Consultant's review of records	11	4	36%
	175	50	Mean = 30.65%

Replies were received from 46% of patients contacted, 29 replying negatively (16%). Recruitment rates were similar from each source at approximately one-third of patients.

Three subjects attended the pilot group. Of the remaining 47, 23 were randomly allocated to T1 and 24 to C1 groups.

Before trial commencement three subjects were re-diagnosed with different rheumatological conditions and no longer met entry criteria and nine withdrew due to ill-health, work or family commitments. Group T1 consisted of 17 and C1 of 18 subjects.

In total, 24/35 subjects attended more than two sessions (more than the "traditional" JP education lasting two sessions) and were deemed education Completers. Eleven were Non-completers. Three stopped attending after one session, not considering it of further benefit and withdrew from the trial. One had her transport stolen and withdrew. Seven ceased attending after one or two sessions due to ill-health, four of whom were unavailable for follow-up. Data from eight subjects was therefore incomplete. The results presented in the following sections have post-education data for these eight missing. An intention to treat analysis is presented in section 5.3.5.3, in which post-education data for these eight was presumed not to have changed.

Three assessments were conducted with group T1 and four with C1.

5.3.3. SUBJECT SAMPLE.

a) Demographic characteristics.

are shown in Table 5.2.

There was no significant difference between T1 and C1 on any of these, apart from Living Arrangement (Age: $U = 123.5$; $p = 0.33$. Sex: $X = 0.01$, $df = 1$; $p = 0.94$. Living arrangement: $X = 9.95$, $df = 2$; $p = 0.01$). More subjects in T1 lived in a family (T1 = 9, C1 = 2), whilst more in C1 lived with a partner (C1 = 12, T1 = 3).

Table 5.2: Demographic characteristics of RA subjects (n = 35).

Age (years)	Mean	55.17
	SD	9.39
	Range	33 - 69
Sex	Female	29
	Male	6
Race	Caucasian	35
Living arrangement	Alone	9
	With partner	15
	With family	11
Hand dominance	Right	35

b) Disease duration.

At time of trial entry, this ranged from 3 months to 28 years, mean duration was 9.83 years (SD 8.06). Fourteen had the disease less than five years. There was no significant difference between groups T1 and C1 ($U = 137$; $p = 0.59$).

c) ARA classification of disease progression.

There was no significant difference between groups ($U = 142$; $p = 0.69$). Seven had early, 15 moderate and 13 severe disease.

d) ARA functional grade.

All subjects were ARA functional grade III.

5.3.4. DISEASE MEASURES.

5.3.4.1. PHYSICAL MEASURES.

a) Degree of hand involvement.

There was no significant difference within group's bilateral HJAM scores (T1: $F(r) = 3.84$, $df = 2$; $p = 0.15$. C1: ($F(r) = 4.71$, $df = 3$; $p = 0.19$), nor between groups at any assessment (Assessment 1: $U = 133.5$; $p = 0.52$. 2: $U = 125$; $p = 0.72$. 3: $U = 67.5$; $p = 0.25$).

There was no significant difference within C1 bilateral HJC scores

($F(r) = 0.45$, $df = 3$; $p = 0.93$), but there was a significant increase within T1 between assessments 2 and 3 ($F(r) = 6.27$, $df = 2$; $p = 0.04$). There was no significant difference between groups' HJC scores at assessments 1 and 2 (Assessment 1: $U = 126.5$; $p = 0.38$. 2: $U = 102$; $p = 0.23$), but there was at assessment 3 ($U = 36$; $p = 0.008$), with T1 being higher. See Table 5.3.

b) Degree of hand pain on activity.

There was no significant difference in VAS scores within groups (T1: $F(r) = 4.5$, $df = 2$; $p = 0.11$. C1: $F(r) = 1.56$, $df = 3$; $p = 0.67$).

There was however between groups at assessments 1 and 3 (Assessment 1: $U = 89.5$; $p = 0.04$. 2: $U = 95$; $p = 0.15$. 3: ($U = 45$; $p = 0.03$), with T1 being higher. See Table 5.3.

c) Grip scores.

There was no significant difference within or between T1 and C1 dominant hand (ie. right) grip strength (T1: $F(r) = 0.34$, $df = 2$; $p = 0.12$. C1: $F(r) = 3.8$, $df = 3$; $p = 0.28$) (Assessment 1: $U = 127.5$; $p = 0.39$. 2: $U = 105.5$; $p = 0.28$. 3: $U = 61$; $p = 0.15$). See Table 5.3.

d) Functional disability.

There was no significant difference within C1 HAQ scores ($F(r) = 2.31$, $df = 3$; $p = 0.51$) but there was a significant increase in T1 ($F(r) = 7.53$, $df = 2$; $p = 0.02$) between assessments 2 and 3. There was no significant difference between groups at any assessment (Assessment 1: $U = 110.5$; $p = 0.37$. 2: $U = 115.5$; $p = 0.69$. 3: $U = 63.5$; $p = 0.18$).). See Table 5.3.

e) Pain on functional activity scores.

There was no significant difference within or between T1 and C1 HAQPAIN scores (T1: $F(r) = 3.5$, $df = 2$; $p = 0.17$. C1: $F(r) = 1.05$, $df = 3$; $p = 0.78$) (Assessment 1: $U = 93$; $p = 0.13$. 2: $U = 93.5$; $p = 0.22$. 3: $U = 60.5$; $p = 0.14$). Mean scores are shown in Table 5.3.

Table 5.3: Physical disease measures scores pre- and post-education.

Median(IQR) scores. Assessment no.:				
1 (n = 35)	2 (n = 33)	3 (n = 27)	4 (n = 14)	Change within.
<u>BILATERAL HJAM:</u>				
T1	37.00 (29.00-49.00)	46.00 (31.00-49.00)	47.00 (38.00-52.50)	-
C1	34.00 (23.75-48.25)	42.50 (29.75-50.25)	45.00 (33.75-48.75)	42.50 (36.00-47.00)
Diff. between:				
<u>BILATERAL HJC:</u>				
T1	40.00 (15.00-59.50)	36.00 (18.00-50.00)	55.00 (45.50-60.50)	*
C1	25.00 (15.50-39.25)	24.50 (5.50-49.50)	20.00 (8.00-42.50)	22.50 (14.75-39.75)
Diff. between:				
<u>VAS:</u>				
T1	41.00 (32.00-63.50)	37.00 (30.00-57.00)	62.00 (40.50-72.50)	
C1	30.00 (10.75-41.75)	28.00 (4.75-41.00)	24.00 (4.50-54.25)	22.00 (8.00-53.75)
Diff. between: *				
<u>RIGHT HAND GRIP STRENGTH:</u>				
T1	4.60 (1.65-8.45)	5.30 (1.60-6.50)	4.30 (2.10-9.45)	
C1	4.80 (3.35-9.53)	5.30 (2.53-8.38)	6.90 (4.52-10.38)	6.00 (3.90-10.25)
Diff. between:				
<u>HAQ:</u>				
T1	1.63 (0.88-2.00)	1.44 (1.09-1.91)	1.75 (1.25-2.19)	*
C1	1.50 (0.75-1.63)	1.50 (0.78-1.81)	1.13 (0.81-2.03)	1.50 (0.50-1.91)
Diff. between:				
<u>HAQPAIN:</u>				
T1	1.25 (0.88-2.00)	1.38 (0.56-1.78)	1.50 (0.88-2.06)	
C1	0.88 (0.50-1.38)	0.75 (0.38-1.34)	0.94 (0.44-1.53)	0.75 (0.50-1.41)
Diff. between:				
<u>KEY:</u> Change within = * significant score change within group.				

Diff. between = * significant score difference between groups.

f) Summary.

There were no significant differences between T1 and C1 scores at assessment one, apart from T1 having higher hand pain on activity (VAS) scores. At assessment two, there were no significant differences, but at assessment three there were in hand pain (ie. HJC and VAS) scores, with T1 again being higher.

5.3.4.2. PSYCHOLOGICAL MEASURES.

a) Degree of helplessness scores (AHI).

There was no significant difference within or between T1 and C1 AHI scores (T1: $F(r) = 0.35, df = 2; p = 0.84$. C1: $F(r) = 1.56, df = 3; p = 0.67$) (Assessment 1: $U = 82; p = 0.06$. 2: $U = 106.5; p = 0.46$. 3: $U = 73; p = 0.38$). See Table 5.4.

b) Perceived severity.

There was no significant difference within T1 and C1 perceived severity scores (T1: $F(r) = 0.73, df = 2; p = 0.69$. C1: $F(r) = 2.23, df = 3; p = 0.52$), but there was between groups at assessments 1 and 3, with T1 reporting moderate disease more commonly (ie. higher perceived severity) (Assessment 1: $U = 95; p = 0.03$. 2: $U = 105; p = 0.25$. 3: $U = 51; p = 0.03$). Pre-education, of the T1 group: four reported mild, 11 moderate and two severe disease. In C1 group: 11 reported mild, six moderate and one severe disease.

c) Perceived susceptibility.

There was no significant difference within or between T1 and C1 perceived susceptibility scores (T1: $F(r) = 0.46, df=2; p = 0.79$. C1 $F(r) = 1.97, df = 3; p 0.58$) (Assessment 1: $U = 149; p = 0.88$. 2: $U = 107; p = 0.27$. 3: $U = 87.5; p = 0.86$). Pre-education, of the T1 group: six considered they would be better, three the same and eight worse in five years time. Of the C1 group: 14 considered they would be the same and four worse.

Table 5.4: Psychological disease measures scores pre- and post-education.

	Median (IQR) scores. Assessment no.:			
	1 (n = 35)	2 (n = 33)	3 (n = 27)	4 (n = 14)
<u>AHI:</u>				
T1	37.00 (34.00-39.00)	37.50 (31.75-41.00)	37.00 (32.00-38.50)	-
C1	35.00 (32.00-37.00)	35.00 (32.75-38.50)	34.00 (31.75-39.00)	33.00 (30.25-36.00)
<u>SELF-EFFICACY:</u>				
T1	53.00 (34.00-62.00)	54.00 (36.25-67.00)	46.00 (37.50-55.00)	-
C1	64.50 (42.75-71.25)	55.00 (41.00-75.50)	58.00 (42.25-72.00)	60.50 (44.75-77.25)
<u>SATADL:</u>				
T1	50.00 (30.00-70.00)	50.00 (30.00-72.50)	50.00 (45.00-55.00)	-
C1	55.00 (50.00-82.50)	55.00 (40.00-90.00)	60.00 (50.00-75.00)	75.00 (35.00-82.50)
<u>SATPAIN:</u>				
T1	40.00 (20.00-50.00)	55.00 (30.00-72.50)	50.00 (40.00-60.00)	-
C1	50.00 (40.00-60.00)	45.00 (30.00-60.00)	50.00 (40.00-62.50)	35.00 (27.50-72.50)

d) Perceived self-efficacy.

There was no significant difference within or between T1 and C1 self-efficacy scores (T1: $F(r) = 4.19$, $df = 2$; $p = 0.12$. C1: $F(r) = 0.94$, $df = 3$; $p = 0.82$) (Assessment 1: $U = 85.5$; $p = 0.07$. 2: $U = 112$; $p = 0.59$. 3: $U = 63$; $p = 0.17$). See Table 5.4.

The commonest methods reported by subjects pre-education to control disease symptoms were rest, medication and exercise. At six and 18 weeks post-education joint care was more frequently mentioned (Table 5.5).

Table 5.5: Coping strategies for controlling RA symptoms (n = 27).

	Pre-education	6 weeks	18 weeks
None	3	2	4
Joint Care	3	14	17
Rest	13	14	14
Pacing /EC	6	6	6
Medication	8	1	3
Exercise	5	0	0
Relaxation/stress control	2	2	0
Diet	2	1	0
Alternative medicine	2	0	0
Fight it	2	0	0
Positive attitude	1	0	0

e) Perceived satisfaction with ADL performance (SATADL).

There was no significant difference within (T1: $F(r) = 0.15, df = 2; p = 0.93$. C1: $F(r) = 0.75, df = 3; p = 0.69$) or between groups' satisfaction in their ADL performance (Assessment 1: $U = 84; p = 0.06$. 2: $U = 103; p = 0.38$. 3: $U = 61; p = 0.13$). See Table 5.4.

f) Perceived satisfaction with ability to control arthritis pain (SATPAIN).

There was no significant difference within (T1: $F(r) = 3.12, df = 2; p = 0.21$. C1: $F(r) = 0.11, df = 3; p = 0.95$) or between groups' satisfaction with their ability to control pain (Assessment 1: $U = 94; p = 0.13$. 2: $U = 108.5; p = 0.5$. 3: $U = 77.5; p = 0.5$). See Table 5.4.

g) Summary.

There were no significant differences within or between T1 and C1 psychological measures, apart from T1 reporting higher perceived severity at assessments 1 and 3.

5.3.5. OUTCOME OF COGNITIVE-BEHAVIOURAL JP EDUCATION.

5.3.5.1. HOURS OF EDUCATION RECEIVED.

Mean hours of education received was 5.97 (SD 3.07), ie. almost 3 sessions attended on average, with a median of 8 hours. Eleven attended four hours or less, three 6 hours and 21 8 to 10 hours.

5.3.5.2. HAND JP BEHAVIOUR.

Mean JPBA scores pre- and post-education for T1 and C1 are shown in Table 5.6.

Table 5.6: JPBA scores pre- and post-education.

Assessment no.:				
	1	2	3	4
	n = 35	n = 33	n = 27	n = 14
	Median (IQR)	Median (IQR)	Median (IQR)	Median (IQR)
T1	15.00 (5.15-25.60)	40.00 (25.00-50.00)	52.50 (31.75-65.00)	-
C1	8.75 (4.38-26.25)	10.00 (5.00-22.50)	46.25 (30.63-53.75)	41.25 (30.00-60.63)

There was no significant difference between T1 and C1 scores at assessment 1 ($U = 117.5; p = 0.24$). There was a significant difference at assessment 2 ($U = 46.5; p = 0.001$) with T1's median score being 30% higher than C1. At assessment 3, there was no longer a significant difference ($U = 72.5; p = 0.37$).

A significant increase within both groups' scores occurred (T1: $F(r) = 16.42, df = 2; p = 0.0003$. C1: $F(r) = 20.83, df = 3; p = 0.0001$) at the six week follow-up stage which was maintained at 18 weeks.

The overall median JPBA score increase ($n = 27$) was +30.00% (IQR 16.00-42.50%). The mean number of JPBA tasks in which behaviour improved was +7.22 (SD 4.97, range -2 to +16).

Pre-education, eight subjects recalled receiving advice on joint protection from a health professional (ie. traditional education). This group's median score (8.90%, IQR 5.00-17.90%) did not differ

significantly from those 27 who did not received this (12.50%, IQR 5.00-27.50%; $U = 95$; $p = 0.61$).

5.3.5.3. INTENTION TO TREAT ANALYSIS.

The previous analysis does not evaluate non-completers data and is therefore not representative of clinical practice. For those subjects' with missing data ($n = 8$) JPBA scores were presumed not to have changed since subjects' last assessment and an intention to treat analysis performed (Table 5.7).

Table 5.7: JPBA scores pre- and post-education ($n = 35$).

Assessment no.:				
	1	2	3	4
	Median (IQR)	Median (IQR)	Median (IQR)	Median (IQR)
T1	15.00 (5.15-25.60)	32.50 (18.75-50.00)	45.00 (13.75-61.25)	-
C1	8.75 (4.38-26.25)	10.00 (5.00-22.50)	41.25 (24.00-52.50)	31.25 (24.38-58.13)

There was no significant difference between groups' scores at assessment 1 ($U = 117.5$; $p = 0.24$). There was a significant difference at assessment 2 ($U = 6.15$; $p = 0.003$) with T1 scoring on average 20.75% higher than C1. At assessment 3, there was no longer a significant difference ($U = 143.5$; $p = 0.75$).

A significant increase in both groups' scores occurred (T1: $F(r) = 8.85$, $df = 2$; $p = 0.01$. C1: $F(r) = 20.96$, $df = 3$; $p = 0.0001$) at the six week follow-up stage which was maintained at 18 weeks. The overall median JPBA score increase ($n=35$) was 22.50% (IQR 5.00-40.00%).

There was no significant difference in Hand JP score increases between men and women ($U = 39$; $p = 0.32$), those receiving ($n = 8$) and not receiving a home visit ($n = 27$; $U = 63$; $p = 0.69$) and those

bringing a "significant other" to the group (n = 11) or not (n = 24: U = 87.5;p = 0.98).

5.3.5.4. FREQUENCY OF JP BEHAVIOURS.

The frequency with which the JPBA tasks were performed Borderline and Correct (for 27 subjects for whom all data was available) at one week pre- and 18 weeks post-education are shown in Table 5.8. The number of sessions in which tasks were both demonstrated and practised are also shown.

Table 5.8: Correct/Borderline JPBA Behaviours observed pre-education and changed post-education.

<u>Task</u>	<u>No. Sessions</u>	<u>% observed pre-ed.</u>	<u>% change post-ed</u>
Carry Tray	4	7.5	+ 59.1
Carry Full Kettle	4	18.5	+ 55.6
Open Jar	4	3.7	+ 55.6
Carry Bag	4	3.7	+ 51.8
Carry Plate	3	3.7	+ 48.1
Push in Plug	4	11.1	+ 44.5
Carry Pan	3	14.8	+ 44.2
Fill Kettle	4	44.4	+ 40.5
Lift Box	3	37.0	+ 37.0
Close Jar	4	0.0	+ 37.0
Turn On Tap	4	22.2	+ 37.0
Carry Mug	4	14.8	+ 33.4
Empty Pan	3	14.8	+ 33.1
Pour Kettle	4	25.9	+ 29.5
Wipe surfaces	3	11.1	+ 25.9
Turn Off Tap	4	25.5	+ 25.9
Squeeze Cloth	3	3.7	+ 22.3
Pour Milk	4	22.2	+ 18.5
Open Tin	3	44.4	+ 18.5
Lift Grill Pan	3	55.5	- 11.1

In eight tasks more than 40% (ie. 11 to 16 subjects) of subjects changed to JP behaviours and in a further eight, 25 to 40% changed. In the four tasks where least change occurred, two were performed using JP by over 40% of subjects pre-education. A decrease in JP behaviour occurred in one task only.

At the final interview, all but one subject considered they used their hands as they would normally everyday, whilst being videorecorded. One considered it different (using less JP methods).

5.3.5.5. RELATIONSHIP BETWEEN HAND JP BEHAVIOUR, DISEASE AND DEMOGRAPHIC MEASURES.

At one week pre-education, JPBA scores correlated significantly ($p \leq 0.05$) with VAS, HJC, HAQ, GRIP right hand, HAQPAIN and self-efficacy scores.

Table 5.9: Relation between JPBA scores and demographic variables pre- and post-education.

	1 week pre- (n = 35) r(s)	6 weeks post- (n = 28) r(s)	18 weeks post- (n = 27) r(s)
Grip strength (right)	-0.54**	- 0.03	-0.33
VAS hand pain on activity	0.49**	-0.18	0.17
HJC	0.44**	-0.04	0.34
HAQPAIN	0.38*	-0.12	0.10
Self-efficacy	0.35*	0.11	0.10
HAQ	0.34*	0.02	-0.05
Disease duration	0.31	0.00	-0.17
AHI	0.31	-0.34	0.02
Hand JAM	0.26	-0.19	0.00
SATADL	-0.17	0.24	0.10
SATPAIN	-0.16	0.11	0.13
Perceived disease severity	0.17	-0.27	0.13
Perceived susceptibility	0.09	0.18	0.37

Key: * $p \leq 0.05$, ** $p \leq 0.01$.

At six and 18 weeks post-education, no significant correlation between JPBA scores and any disease or demographic measures occurred (Table 5.9), although at 18 weeks JPBA scores were moderately correlated with disease susceptibility ($p = 0.06$), HJC ($p = 0.08$), Grip ($p = 0.09$).

5.3.5.6. FACTORS PREDICTING HAND JP BEHAVIOUR CHANGES POST-EDUCATION.

Multiple regression was used as an exploratory technique to identify factors potentially predicting or associated with behavioural change. Backward stepwise regression was selected as this allows all variables potentially considered as important explanatory variables to be included in the analysis (Altman, 1991). The variables included were: age, disease duration, hours of education received, HAQ, HAQPAIN, AHI, VAS, bilateral HJAM and HJC, dominant hand grip strength, self-efficacy and self-reported practice of Hand JP scores. Altman (1991) recommends that no more than $n/10$ variables are included and thus results from these analyses should be viewed with caution but may provide some insight into what factors influenced behavioural change. JPBA score changes, rather than levels, were analyzed. Analysing levels is less helpful as some subjects already had high scores pre-education, through naturally adopting behaviours. These high levels sustained post-education could therefore interfere with identifying predictive and associative factors.

Backward multiple regression was used to identify those factors at one week pre-education predicting JPBA score changes from pre-education to 18 weeks post-education (Table 5.10).

Higher JPBA and hand pain (HJC) and lower JPBA, helplessness (AHI) and HJAM (ie. better ranges of movement/less deformity) scores pre-education were significantly predictive of JPBA score changes from pre-education to 18 weeks post-education, explaining 37% of the variance of these.

Table 5.10. Regression model of pre-education variables predicting JPBA score changes (n = 27).

Variable	Coefficient	Standard Error	t	p
	b	se(b)		
Constant	47.21	46.33		
JPKA	0.93	0.37	2.93	0.02
Bilateral HJC	0.61	0.26	2.33	0.03
AHI	-2.08	0.93	-2.23	0.04
JPBA	-0.61	0.3	-2.04	0.05
Bilateral Hand JAM	-0.78	0.39	-2.02	0.06

Analysis of variance:

	DF	Sum of squares	Mean squares	F	P
Regression	5	6207.31	1241.47	4.08	0.01
Residual	21	6383.37	303.97		

Adjusted r squared = 0.37

5.3.5.7. FACTORS ASSOCIATED WITH HAND JP CHANGES POST-EDUCATION.

Backward multiple regression was used to identify which variable changes were significantly associated with JPBA score changes pre-education to 18 weeks post-education (Table 5.11).

Greater amounts of education, more frequent JP practice at home, as well as changes in degree of hand involvement (less hand pain on activity but decreasing grip strength and hand RoM) and younger age were associated with increased Hand JP behaviour, explaining 64% of the variance in JPBA score changes.

Table 5.11: Regression model of variables associated with JPBA score changes (n = 27).

Variable	Coefficient b	Standard Error se(b)	t	p
Constant	-14.49	22.72		
Hours of education	5.08	1.6	3.18	0.005
Change in grip dominant hand	-3.73	1.21	-3.09	0.006
Change in bilateral HJAM	0.94	0.31	3.06	0.007
Self-reported frequency of practising JP	5.35	2.07	2.58	0.02
Age	-0.83	0.35	-2.4	0.03
Change in VAS	-0.32	0.14	-2.36	0.03

Analysis of variance:

	DF	Sum of squares	Mean squares	F	P
Regression	8	9427.45	1178.43	6.71	0.0004
Residual	18	3163.23	175.74		

Adjusted r squared = 0.64

5.3.5.8. COMPARISON OF CHANGERS AND NON-CHANGERS RESULTS.

Nineteen subjects significantly increased Hand JP behaviour (ie. by more than 20%) at 18 weeks (Changers). Changers median JPBA score increases were +37.50% (IQR 30.00 - 57.40%) in comparison to Non-changers (n = 8) of +3.75% (IQR -5.00 - 13.00%). The mean number of JPBA tasks Changers increased behaviour in was 9.74 (SD 3.36). They did not have significantly different disease, physical, psychological, demographic, JPBA, knowledge or attitudinal measures pre-education in comparison to those not significantly increasing behaviour (Non-Changers, n = 8), apart from: Changers having higher JPBA scores (U = 32.5;p = 0.02) and lower AHI scores (U = 72;p = 0.03).

Changers received significantly more education than Non-Changers (median 8 hours (IQR 8 - 8) and 4.50 (IQR 3 - 8) respectively, $U = 28.5; p = 0.003$). Significant JPBA score increases occurred amongst those subjects receiving five to 10 hours of education (Completers) in comparison to those receiving less than this (Non-completers) ($U = 3.5; p = 0.004$).

At 18 weeks post-education, Changers had significantly: lower helplessness (AHI) scores ($U = 75.5; p = 0.04$); reported practising Hand JP methods more frequently ($U = 63.5; p = 0.003$); higher satisfaction with ADL ability ($U = 36.5; p = 0.03$); higher satisfaction with pain control ability ($U = 67.5; p = 0.02$); lower perceived susceptibility ($U = 40; p = 0.04$); and were more likely to live in a nuclear family setting than with a partner ($X = 6.02, df = 2; p = 0.05$). They also tended to have higher self-efficacy scores ($U = 83.5; p = 0.07$). There were no other significant differences in disease, disease duration, physical, psychological, knowledge and attitudinal variables ($p > 0.1$) post-education.

5.3.5.9. ATTITUDES TOWARDS, OBSERVED AND SELF-REPORTED HAND JP BEHAVIOUR.

Most subjects (27/35) believed it was "very important" to reduce joint stress pre- and at six and 18 weeks post-education. There was no significant difference in degree of belief either within groups ($T1: F(r) = 1.5, df = 2; p = 0.47$. $C1: F(r) = 1.03, df = 3; p = 0.79$) or between groups at any assessment (Assessment 1: $U = 137.5; p = 0.61$. 2: $U = 150.5; p = 0.94$. 3: $U = 150; p = 0.94$).

Pre-education, 22/35 considered they had changed hand behaviour in more than 25% of tasks. There was no significant difference in the amount of self-reported hand JP behaviour within groups ($T1: F(r) = 2.35, df = 2; p = 0.31$. $C1: F(r) = 2.21, df = 3; p = 0.53$) or between groups (Assessment 1: $U = 150.5; p = 0.94$. 2: $U = 141; p = 0.71$. 3: $U = 112.5; p = 0.18$).

Of the eight who could recall receiving JP advice pre-education, three used some of the methods taught, two of these daily. At 18 weeks post-education, 25/27 for whom data was available reported using methods, ie. a significant increase ($Z = -4.2; p = 0$) .

Initially, there was no difference between groups' self-reported frequency of practising Hand JP ($U = 144; p = 0.54$). Frequency rose significantly within both T1 and C1 groups following education (T1: $F(r) = 15.27, df = 2; p = 0.0005$. C1: $F(r) = 22.86, df = 3; p = 0.0$), with T1 reporting significantly more frequent use at 6 weeks post-education in comparison to C1 ($U = 36; p = 0.0$). Twenty subjects reported practising methods daily at both six and 18 weeks post-education.

Both groups reported taking significantly more care of hand joints post-education (T1: $F(r) = 8.77, df = 2; p = 0.01$. C1: $F(r) = 10.18, df = 3; p = 0.02$).

There was a significant association between the amount of self-reported and observed Hand JP behaviour pre-education, but not post-education (Table 5.12). There was no significant association between degree of belief in benefit in reducing joint stress with observed (Table 5.12) or self-reported Hand JP behaviour (pre: Cramer's $V = 0.3; p = 1.0$; 6 weeks post-: Cramer's $V = 0.2; p = 1.0$).

Table 5.12: Relation between attitude towards, observed and self-reported Hand JP behaviour.

	Pre-education (1 week, n = 35)	Post-education (6 weeks, n = 27)
	JPBA scores r(s)	JPBA scores r(s)
Belief in importance of reducing joint stress	0.25	0.12
Self-reported JP behaviour	0.44*	0.23

Key: * $p < 0.01$

5.3.5.10. CHANGERS AND NON-CHANGERS SELF-REPORTED MEASURES.

There was no significant difference between Changers and Non-Changers scores for the above measures ($p > 0.1$), apart from Non-Changers reporting taking significantly more care of joints pre-education than Changers ($U = 49; p = 0.03$).

5.3.5.11. SELF-REPORTED JOINT STRESS REDUCTION STRATEGIES.

The commonest strategies used to reduce hand joint stress pre-education were: using technical aids and gadgets, asking others for help and using two hands. Post-education, these remained common, apart from "asking others," which was reported less often. Those strategies cited more were: using joints in stable and deformity avoiding positions and larger, stronger joints (Table 5.13).

Table 5.13: Self-reported strategies for reducing hand joint stress

<u>(n = 27).</u>	<u>Pre-education 1 week</u>	<u>Post-education</u>	
		<u>6 weeks</u>	<u>18 weeks</u>
Use technical aids, electrical gadgets or labour-saving devices.	21	26	25
Ask for help/ delegate	16	6	7
Use 2 hands	13	17	17
Avoid lifting/ reduce weight of objects	13	14	14
Do tasks more slowly/ for shorter periods/ rest between	3	0	1
Leave tasks/ do less often	3	2	1
Use joints, in stable deformity avoiding positions, eg. flat of hand, wrists straight, avoid twisting fingers	2	17	15
Reorganise tasks/ work areas	2	1	3
Larger joints, eg. forearms, hips.	2	9	7
None	<u>1</u>	<u>0</u>	<u>0</u>
	76	92	90

5.3.5.12. REASONS FOR AND METHODS OF CHANGING.

There was no significant difference in reported difficulty in changing behaviour within (T1: $F(r) = 0.12, df = 2; p = 0.94$. C1: $F(r) = 4.56, df = 3; p = 0.21$) or between groups (Assessment 1: $U = 119; p = 0.22$. 2: $U = 90; p = 0.08$. 3: $U = 85; p = 0.76$).

To reduce pain and increase independence were the main reasons cited pre-education for making changes. Post-education, 19/27 (70%) attributed change mainly to having attended the education group (Table 5.14).

Table 5.14: Reasons for changing hand behaviour (n = 27).

Reason	Pre-education (1 week).	Post-education (18 weeks).
Pain	15	11
Make task easier/ increase independence	10	6
Weak grip	5	1
Protect joints	3	7
No change	3	0
JP education	1	19

Strategies used to change work methods are shown in Table 5.15. The main differences were: nine subjects had no conscious strategy pre-education but only one post-education (who attended only one session); and 16 changed to more planned strategies, three adopting problem-solving and 13 using ideas from and regular practice of techniques demonstrated in the education programme. Examples of comments made are:

"It was done very gradually concentrating on trying to change a couple of tasks a week. You can't try and take it on board all at once...When that comes more or less automatically you can move on to something else. At first I tried to do it all and I ended up nearly

walking up the wall!"

"It was through listening to what she said, one example spreads to everything, so taking the weight of a cup applies to other things."

"I tried to look at what I was doing, tried to picture the right way and then had to practice it, then it should become a habit. I tried to concentrate on one or two things then the others."

Table 5.15: Strategies used to change work methods (n = 27).

	<u>Pre-education (1 wk.)</u>	<u>Post-education (18 wks.)</u>
Trial and error	11	9
Problem-solving	10	13
Unconscious/automatic	9	1
Practising methods shown in JP education	1	14

5.3.6. OUTCOME OF EDUCATION - EFFECT ON DISEASE KNOWLEDGE.

a) Previous sources of information.

Twenty-five subjects had obtained some disease information previously and ten none. Sources were: books/information leaflets (24); doctors (7); OT (3); PT(3); nurses (2). Post-education, all had received education about RA.

b) Disease knowledge.

A significant increase in ability to identify correctly five structures in a diagram of a typical joint occurred (T1: $F(r) = 8.35, df = 2; p = 0.02$. C1: $F(r) = 7.69, df = 3; p = 0.05$) (Table 5.16).

Table 5.16: Number of joint structures identified.

	Assessment no:			
	1	2	3	4
<u>Joint structures</u> <u>(max. score = 5)</u> <u>median and IQR.</u>				
T1	0 (0 - 0.50)	1.00 (0 - 2.00)	2.00 (1.00-4.00)	-
C1	1.00 (0 - 1.25)	1.00 (0 - 2.00)	2.00 (0.75-3.00)	2.00 (1.00-4.00)

There was no significant difference in either group's ability to correctly identify the initial effects of the disease on joints (T1: $F(r) = 16.7$, $df = 4$; $p = 0.06$. C1: $F(r) = 0.88$, $df = 4$; $p = 0.90$).

5.3.7. OUTCOME OF EDUCATION - EFFECT ON JP KNOWLEDGE.

There was no significant increase in JPKA scores within T1 ($F(r) = 1.5$, $df = 2$; $p = 0.47$) although there was in C1 ($F(r) = 12.92$, $df = 3$; $p = 0.005$). There was no significant difference between groups (Assessment 1: $U = 114.5$; $p = 0.46$. 2: $U = 81.5$; $p = 0.08$. 3: $U = 68.5$; $p = 0.27$) (Table 5.17).

Table 5.17: JPKA scores pre- and post-education.

	Assessment no.:			
	1 n = 35 Median (IQR)	2 n = 33 Median (IQR)	3 n = 27 Median (IQR)	4 n = 14 Median (IQR)
T1	80.00 (75.00-87.50)	90.00 (77.50-95.00)	87.50 (82.50-95.00)	-
C1	81.25 (68.75-85.63)	81.25 (69.38-90.00)	85.00 (82.50-90.00)	88.75 (85.63-93.13)

Post-education, there was a marked increase in subjects' abilities to state JP principles (Table 5.18).

Table 5.18: JP principles cited (n = 27).

	<u>Pre-education (1 wk)</u>	<u>Post-education (18 wks)</u>
Principles not cited	20	2
<u>Hand JP Principles taught:</u>		
Reduce effort	2	18
Distribute weight over joints	0	11
Avoid positions of deformity	1	10
Use stronger, larger joints	0	10
<u>Others:</u>		
Rest	0	8
Pace	2	7
Plan ahead	2	3
Delegate tasks more	1	3
Wear splints when working	2	1

5.3.8. ATTITUDES TOWARDS AND SELF-REPORTED USE OF OTHER JP BEHAVIOURS.

There was no significant difference in belief in or self-reported use of most JP behaviours, as most subjects already believed these beneficial and reported using these, apart from splints and pacing which were less common (Table 5.19).

Table 5.19: Attitudes towards and self-reported use of other JP behaviours (n = 27).

JP behaviour.	1 week pre-ed.	6 weeks post-ed.	18 weeks post-ed.	Q (df = 2)	p
<u>Exercise</u>					
Belief in	18	22	21	2.88	0.24
Exercise ed.	12	27	27	40.0	0
Use	5	12	8	9.25	0.01**
Frequency- daily	4	6	5	3.13*	0.21
2-6x/wk.	3	6	3		
<u>Rest</u>					
Belief in	27	26	27	2.0	0.37
Use	18	20	23	3.8	0.15
Frequency- daily	24	21	23	1.06*	0.59
<u>Splints</u>					
Wrist pain	24	22	25	2.8	0.25
Belief in	23	24	21	3.5	0.17
No. with splint	15	16	16	2.0	0.37
Use	9	10	9	0.5	0.78
Frequency-daily	4	3	4	0.29*	0.86
-2-6x/wk.	3	6	3		

Key: *Friedman's ANOVA. ** significant at $p \leq 0.05$.

Table 5.19 cont.: Attitudes towards and self-reported use of other JP behaviours (n = 27).

JP behaviour.	1 week pre-ed.	6 weeks post-ed.	18 weeks post-ed.	Q (df = 2)	p
<u>Technical aids</u>					
Belief in	27	27	27	0	1
Use	19	25	25	6.88	0.03**
Frequency-daily	18	19	19	3.17*	0.21
-2-6x/wk.	1	5	4		
<u>Respect for pain</u>					
Belief in	26	27	27	2.0	0.37
Use	20	22	22	1.0	0.61
<u>Change work methods</u>					
Belief in	24	27	27	6.0	0.05**
Use	22	26	26	6.4	0.04**
<u>Pacing</u>					
Belief in	17	24	20	6.17	0.05**
Use	14	18	14	2.66	0.26

Key: * Friedman's ANOVA. ** significant at $p \leq 0.05$.

A significant increase did occur in: exercise and technical aids use, a belief in benefit and use of changing work methods and a belief in benefit of pacing.

5.3.9. COMPARISON OF COMPLETERS AND NON-COMPLETERS RESULTS.

The Completers group (n = 24) consisted of all 19 Changers and five Non-changers. Pre-education, there was no significant difference ($p > 0.1$) between Completers and Non-completers (n = 11) for most disease, physical, psychological, demographic, knowledge and JP attitude measures, apart from Completers having significantly: lower learned helplessness (AHI), lower JPBA scores, greater self-efficacy,

greater satisfaction with their ability to control pain (SATPAIN) and perform ADL (SATADL). There was a tendency for Non-completers to have had a shorter disease duration (Table 5.20).

There was also no significant difference ($p > 0.2$) between Completers and Non-Completers degree of belief in the importance of reducing joint stress, amount of self-reported Hand JP, difficulty changing behaviour or having previously received JP education. Non-completers reported taking significantly more care of joints than Completers ($U = 86; p = 0.01$).

Table 5.20: Significant differences between Completers and Non-completers disease, demographic and JPBA scores pre-education.

Variable	Median (IQR) Completers	Median (IQR) Non-completers.	p
AHI	35.00 (33.00-37.00)	38.00 (37.00-40.50)	0.01
JPBA	8.75 (5.00-19.15)	20.00 (10.00-37.50)	0.03
Self-efficacy	57.00 (42.00-75.00)	38.00 (34.50-49.00)	0.04
Satisfaction ability to perform ADL	60.00 (40.00-85.00)	40.00 (20.00-55.00)	0.04
Satisfaction ability to control pain	50.00 (30.00-60.00)	30.00 (25.00-75.00)	0.05
Disease duration(yrs)	9.54 (4.92-17.00)	4.33 (3.08- 6.00)	0.08

At 18 weeks post-education, Completers significantly increased JPBA scores (median 32.50%, IQR 21.00 - 56.30%) in comparison to Non-completers (median 0%, IQR 0 - 0%: $U = 3.5; p = 0.004$). Nineteen of the 24 Completers (79.2%) achieved more than the previously determined significant increase of 20% (range 20 to 65%). The remaining seven had score changes between -5 to +17.5%. Two of these had achieved a significant score increase at six weeks (40% and 25%)

which reduced by 18 weeks (to 17.5% and 5% respectively). The mean number of tasks Completers changed to or improved Hand JP behaviour in was 8.13 (SD 4.46, range 0 to 16). Completers continued to have significantly: lower helplessness (AHI, $U = 44.5; p = 0.01$); greater self-efficacy ($U = 37; p = 0.003$); greater satisfaction with pain control ability (SATPAIN: $U = 38.5; p = 0.004$); greater satisfaction with ADL performance ability (SATADL: $U = 27.5; p = 0.0005$), in comparison to Non-completers. There were no other significant differences.

There was no significant difference in ability to correctly identify joint structures (1 week pre-: $U = 119; p = 0.62$. 6 weeks post-: $U = 89; p = 0.11$. 18 weeks post- education: $U = 91.5; p = 0.14$), although Completers tended to get slightly higher scores. There was no significant difference in ability to correctly state the initial effects of RA on joints at 1 week pre- ($X = 2.45, df = 3; p = 0.48$) or 6 weeks post-education ($X = 7.18, df = 4; p = 0.13$). At 18 weeks, Completers were significantly more able to get this correct ($X = 12.14, df = 3; p = 0.007$). There was no significant difference in JPKA scores (1 week pre-: $U = 87.5; p = 0.41$. 6 weeks post-: $U = 66.5; p = 0.09$. 18 weeks post-education: $U = 72; p = 0.14$), although Completers tended to get higher scores.

5.3.10. ATTITUDES TOWARDS JP EDUCATION.

Subjects were asked their opinions of the education programme at the end of the final interview. Twenty six ($n = 27$) made positive comments about the group: 18 that it was enjoyable; 12 that it was informative; three that it was beneficial meeting others; three that it was good for partners. One subject found it too tiring as it was too far away and so the group was "too much for me."

Four subjects also tempered these with some reservations: three that it was "a bit late for them" and one of these that it had added guilt feelings she had caused her deformities (all three significantly

increased behaviour); and one that identifying deformities was worrying but she had been reassured.

5.3.11. JP PROGRAMME COSTS.

Based on six patients attending a group, costs were:

Table 5.21: JP programme costs.

Information packs	£ 42.00 (6 @ £7.00 each)
Groceries	£ 7.50
Therapist's time*	<u>£ 114.30</u>
TOTAL: £ 163.80	
ie. £27.30 per patient.	

* Therapist's time was based on 8 hours programme time and 2 hours preparation time (eg. contacting patients, preparing room/information/ equipment). Costed at the top of Senior I OT scale (£18,370) plus 16.5% oncosts, as such groups are most likely to be run by experienced therapists. Home Visit costs are not included.

Initial investment would include: purchase of ARC video "Help is at Hand" (£5.00), and any additional kitchen equipment (eg. different kettle models, pans, etc) and technical aids (eg. jar openers, electric can openers, Stirex knives) to have sufficient choice and quantity for six patients to use. However, many departments would already have much of this. Loan of a video player and TV is needed for session one.

5.4. DISCUSSION.

This trial was designed to test the hypothesis that:

i) there is no significant difference in RA patients' knowledge of, attitudes towards and use of Hand JP behaviour following attending a cognitive-behavioural JP programme.

5.4.1. TRIAL DESIGN AND SUBJECT SAMPLE.

The problems occurring in the previous trial (chapter 3) were overcome by recruiting a sufficient sample prior to trial commencement, enabling random allocation to a three month control phase. The sample, from clinical experience, can be considered as an average cross-section of patients normally referred for JP education. Pre-education, there were no significant difference between the two groups on any measures, apart from two which may have been due to chance as cross comparisons were performed.

Although the sample size achieved was sufficient, a larger sample was intended, but exacerbation of RA was the main cause preventing subjects either entering the trial or completing as planned. More than 50 patients should therefore originally have been recruited.

5.4.2 OUTCOME OF THE COGNITIVE-BEHAVIOURAL JP PROGRAMME.

5.4.2.1. ATTITUDES TOWARDS AND ATTENDANCE AT THE PROGRAMME.

The majority of subjects found the programme enjoyable, informative and attendance was good. Those subjects expressing some reservations about the education (eg. that it was a "bit late" as they had already developed some deformity) still achieved significant or almost significant JPBA score increases.

Approximately one-third of patients contacted initially were interested in attending this practical education programme. Silvers et al (1985) similarly found that 45% of patients considered planned education groups an important means of receiving arthritis education and 29% considered these appropriate for OT topics. Only three

subjects stopped attending because they did not see the programme as beneficial, with the disease information provided meeting their needs. The main reason for subjects dropping out before or during assessments was exacerbation of their RA. Most wished to attend at a later date, but this was not possible because of the assessment schedule. In a clinical setting, later attendance would be feasible, meaning a lower overall drop-out rate from the programme would be expected.

5.4.2.2. EFFECT ON KNOWLEDGE.

Subjects demonstrated a significant increase in ability to identify joint structures and, amongst Completers there was a significant increase in ability to identify correctly the disease's initial effects. There was no significant increase in JPKA scores overall. In the JPKA test-retest reliability study (2.4.2.5) it was noted that subjects' initially gained high scores, indicating this may not be a useful measure as there is little scope for scores to improve. There was a marked increase in ability to cite JP principles, particularly those related to Hand JP specifically taught in the programme. The recall enhancement strategies were therefore effective in increasing disease and JP knowledge.

5.4.2.3. ATTITUDE AND PSYCHOLOGICAL MEASURES.

Most subjects already believed reducing stress on hand joints and other JP behaviours were beneficial pre-education, suggesting those self-selecting to attend the programme were Information Seekers, as in the previous trial (chapter 3).

Holman and Lorig (1987) suggested potential adverse consequences of AEPs could be patients' "developing a misplaced designation of personal responsibility for disability and deterioration." This programme, unusually, deliberately aimed to heighten subjects' awareness of disease effects to increase perceived threat and aid

understanding the benefits of JP. No detrimental effects of doing so were identified as perceived severity, susceptibility and helplessness (AHI) did not significantly change. Additionally, a significant increase in belief in the benefit of changing work methods to reduce joint stress, rest and pacing (ie. Energy Conservation) occurred. Emphasising these aspects of JP during the programme appeared effective in increasing perceived benefits.

Blalock et al (1993) identified those with flexible coping responses have greater psychological adjustment to RA and clinicians claim JP can assist patients adjust to the disease. It was hypothesised that forwarding a letter emphasising the programme's effectiveness and patients' responsibilities in adhering to advice given as well as teaching active coping strategies would increase perceived control and the range and flexibility of behavioural coping strategies used. The increase in the number of strategies reported used post-education suggests education may be effective at improving coping and potentially therefore disease adjustment (although this was not evaluated).

Strategies to avoid learned helplessness were included, ie. by emphasising failing to achieve weekly goals was not a personal failure but rather the process of changing habits is difficult. Twice as many subjects post-education attributed any difficulties experienced to changing the habits of a lifetime, suggesting this emphasis was effective. The AHI, a measure of learned helplessness and perceived control of arthritis did not significantly improve, suggesting the programme, whilst not having detrimental effects, did not influence this. The AHI has been refined to two sub-scales; of Internality (belief in ability to control arthritis symptoms) and Helplessness. Although both are significantly correlated with the total AHI scale, the Helplessness sub-scale is deemed more clinically

useful (Stein, Wallston and Nicassio, 1988). Using the two scales, rather than the total AHI, may have been more sensitive in evaluating the programme's effectiveness. Higher scores on the Helplessness sub-scale are associated with greater difficulty in adjusting to RA, non-adherence, pain and functional impairment (Stein, Wallston and Nicassio, 1988). Non-adherent subjects in this trial (ie. Non-Changers) had significantly higher AHI scores.

Self-efficacy did not improve despite the incorporation of many self-efficacy enhancing strategies, in contrast to other programmes using such strategies (Lenker et al, 1984; O'Leary et al, 1988). Neither was self-efficacy influential in the adoption of Hand JP, in contrast to the findings of eg. Brod and Hall (1984), Ewart (1989), Ewart et al (1986) and Kaplan et al (1984,; section 4.3.1a). Either these strategies were ineffective or the measure used was insufficiently sensitive. Perceived self-efficacy is behaviour specific and not generalized (Lorig, Chastain et al, 1989). The Arthritis Self-Efficacy scale measures perceptions of ability to perform a wide range of ADL (eg. walking, undoing buttons), pain control (eg. during activities, at night, relaxation) and control of other symptoms (eg. fatigue, depression). Not all of these were appropriate to Hand JP and EC behaviours targeted in the programme, suggesting the scale may be insufficiently sensitive to measure such changes. This problem was considered pre-trial and a Hand JP self-efficacy scale constructed. However, as there was insufficient time for reliability and validity studies to be conducted, the Arthritis Self-efficacy measure was used. For future research, this scale could be developed and used to evaluate programme effectiveness on JP self-efficacy.

5.4.2.4. JP BEHAVIOURS.

Eight JP behaviours were assessed and some information provided on

all of these in the programme. Hand JP, use of technical aids and changing work methods were specifically targeted for change using behavioural and motor learning strategies. Self-reported increases in behaviour occurred in these but not others, apart from exercise. These strategies are therefore effective in changing observed and/or self-reported behaviour. Lorig et al (1985) similarly identified that self-management behaviours targeted for change using behavioural strategies (exercise and relaxation) significantly increased in comparison to those not targeted (use of heat). Exercising was emphasised in the JP programme, but practice and goal-setting for this were not. The accompanying book (Unsworth, 1986) described a general exercise programme, which subjects were regularly encouraged to use. Exercising increased significantly at six but not 18 weeks. Exercise behaviour also increased in the previous trial, suggesting exercise is readily perceived as beneficial by RA patients and adopted in the short-term, but that behavioural strategies can assist in its longer-term maintenance.

5.4.2.5. EFFECT ON HAND JP.

A significant improvement in JPBA scores occurred in both groups (even taking into account non-completers presumed lack of change) at six weeks and 4.5 months, demonstrating this cognitive-behavioural programme, incorporating adherence enhancement strategies, was effective, at a relatively low cost (£27.30 per patient) for eight hours treatment).

Pre-education, JPBA scores correlated significantly with higher hand pain (VAS and HJC), poorer grip strength and difficulties in functional activities (HAQ) scores, as in the previous trial. Natural adoption of Hand JP is therefore influenced by these internal cues to action. At six week there were no longer such significant relationships but by 18 weeks pain and grip strength were moderately

correlated.

Changers were more likely to be those pre-education who: used fewer Hand JP methods (lower JPBA scores), had higher JP knowledge scores (JPKA), higher hand pain but lower HJAM scores (ie. better range of movement and less deformity) and had lower perceived helplessness. This latter supports the findings of Lenker et al (1984) and Lorig, Chastain et al (1989) that those benefitting most from an AEP begin with a more optimistic outlook and higher sense of ability to influence the consequences of their disease than those who do not. Hand pain again appears to be the most important internal cue to action, particularly amongst those with less hand impairment. This suggests the programme effectively emphasised the preventative potential of Hand JP and can improve adherence amongst early RA patients for whom change could be most beneficial.

Non-changers were only significantly different pre-education to Changers in having less JP knowledge, higher AHI scores (ie. greater loss of control with arthritis) and self-reporting taking greater care of joints. Possibly they thought change unnecessary as they were already using Hand JP sufficiently or they did not believe further change would have any impact on their disease. Multiple regression analysis only predicted a third of the variance in JPBA score changes occurring. It is difficult therefore to identify what factors can aid appropriate selection of patients to attend, although AHI scores could be investigated further. Most completing the programme changed behaviour. Most Non-completers would have liked to attend but were prevented by ill-health. This suggests that self-selection is a suitable recruitment strategy.

Minor and Brown (1993) suggested behaviour research should not only explore relationships between baseline measures and subsequent behaviour but also what programmatic factors and changes in the

subject during the programme might be predictive of subsequent change. Post-education, the most noticeable difference between Changers and Non-changers was that Changers attended for significantly longer (eight hours of education on average) and reported significantly higher levels of practice at home, indicating that treatment duration and the motor learning and behavioural strategies incorporated were the most influential factors. Subjects also clearly attributed change to attending the group (as well as pain), which did not occur in the previous trial. Both T1 and C1 had similar average score increases despite C1 having significantly lower hand pain and perceived severity scores than T1. This also indicates that the programme, rather than internal cues to action, was the most influential factor. Other factors were that Changers tended to be younger (a similar finding to the previous trial) and change was associated with their hand pain on activity improving whilst their grip strength and range of movement decreased. These disease measures were originally included to assess their influence, not as outcome measures. Whether these hand changes influenced change or were a result of Hand JP change is unclear. If a result, this would verify that Hand JP can assist in reducing pain but imply that grip strength and RoM are reduced. Potentially this could be because by avoiding lifting, making tasks lighter, doing them less often and in different ways muscles are not exercised and joints not ranged as much as during normal activity. If this is so, this emphasises the need to teach Hand exercises during education to prevent this occurring. This is recommended by Melvin (1989) and these are effective in increasing grip strength and RoM (Brighton et al, 1993; Hoenig et al, 1993). Although subjects were encouraged to do these in the programme (hand exercises are described in the accompanying book, Unsworth, 1986), these were not targeted for change using behavioural

techniques. This was because the more behaviours one asks patients to adopt in a given period of time, the less likely they are to adhere (Meichenbaum and Turk, 1987). There were no significant differences between Changers and Non-changers hand pain, grip and HJAM. The only disease variables changing were: in C1 a significant worsening of hand RoM/alignment and in T1 in hand pain (HJC) and functional disability (HAQ) occurred, although combining both groups' scores on these variables there was no significant change. This suggests using Hand JP does not have deleterious effects. However, setting goals to practice hand exercises incrementally through the programme may in future be a beneficial addition. A significant worsening of HAQ scores could be attributed to an increased use of technical aids (ie. a JP strategy) as within this assessment higher scores are allocated if these are used to complete a task independently. This latter suggests the HAQ assessment would be a questionable outcome measure in any future trials evaluating the effectiveness of Hand JP.

Change was not influenced by receiving a home visit, suggesting subjects were able to transfer methods used in the OT department to home and this may be an unnecessary element of the programme. Neither did having a relative or significant other attend have a noticeable influence. Changers were more likely to live in a family than just with a partner. Possibly the demands of a family mean subjects cannot avoid doing home management tasks and so perceive a greater necessity to change, whilst living with a partner means he/she may more easily take over tasks causing pain.

Post-education, Changers had significantly higher satisfaction with performing ADL than Non-Changers. This indicates that adopting Hand JP improves generality of self-efficacy for ADL (ie. satisfaction). Blalock et al (1992) identified higher levels of satisfaction with home management activities are associated with improved psychological

well-being amongst those who see these activities as important. This suggests using Hand JP may therefore be of psychological benefit.

The behavioural coping strategies reported used most commonly pre-education (using technical aids, using two hands and avoiding lifting) were the same as those cited in the previous trial, indicating these are the commonest naturally adopted strategies. Post-education there was an increase in the number of strategies reported used, with the most obvious change being using larger, stronger joints and using joints in stable and deformity avoiding positions. This did not occur in the traditional JP education trial, suggesting the emphasis on making patients more aware of how hand deformities develop and of their hand status led to this increase.

There was also a marked increase in the number of subjects stating they used conscious change strategies suggesting the repeated emphasis on setting and fulfilling Hand JP practice goals as well as problem-solving were major influences for change.

Bradley (1989), reviewing arthritis adherence literature, reported how little this has been examined for many treatments, apart from medication, as is still the case. One criticism levelled at adherence studies was that self-reported frequency but not quality of behaviour was reported. This study has evaluated both quality and self-reported frequency. Subjects improved Hand JP behaviour in more tasks than their JPBA scores might indicate (on average seven tasks in comparison to the four that the average 22% score increase could be interpreted as). Although Correct methods were emphasised in the programme as best, Borderline methods were also presented as possible alternatives to aid individualisation of the programme. In a number of tasks subjects reported being unable to perform the Correct method, eg Carrying a Tray with both palms upwards underneath proved impossible for those unable to fully supinate and one hand underneath

with the other gripping the tray edge (Borderline) was preferred. This indicates a need for further research to evaluate which JP methods are identified as preferable and achievable by RA patients themselves, as to date, many of the ideas in JP literature are apparently based on what therapists consider biomechanically less stressful methods.

Feinberg (1992) and Bradley (1989) have highlighted that few studies have evaluated adherence-enhancing interventions with arthritis patients in a controlled manner. These have included: an automatic electronic counter to a hand exercise device (Waggoner and LeLievre, 1981); an individualised problem-solving intervention based on Leventhal, Zimmerman and Gutmann's (1984) self-regulation model to increase exercise behaviours or medication use (DeVellis, Blalock, Hahn, DeVellis and Hochbaum, 1988); therapist's use of positive tone and behaviour, learning principles and emphasis of the patient's responsibility, to increase resting splint wear (Feinberg, 1992); cognitive-behavioural methods to increase exercise and relaxation (Lorig, Lubeck et al, 1985 - the Arthritis Self-Management course); and rest during activity (Gerber et al, 1987). This study has demonstrated that adherence-enhancement strategies are also effective in increasing Hand JP behaviours. It differs to the above in changing multiple normal, automatic behaviours throughout the day, whereas these others have added one or two behaviours to the patients' daily regime, predominantly necessitating a restructuring of time use. How much the JP principles taught were generalised to other, similar hand movement patterns during the day is unknown and an area for further study. However, this suggests these adherence enhancement approaches are also effective for more complex health behavioural changes.

Longer term maintenance of these Hand JP changes was not evaluated. Follow-up assessments of these subjects are needed to identify

whether this is sustained for a sufficient period of time for it to potentially have a beneficial impact on hand status and whether follow-up appointments (in clinic or home visits) or short "top-up" courses aid patients to maintain or increase behaviour further. A number of subjects stated they would like to attend a further programme directed at using JP in other joints and in other ADL.

Cameron and Best (1987) reviewed research on adherence interventions recommending there was a need for:

a) a comprehensive theoretical model to be used when designing intervention strategies (eg. self-efficacy and social learning theory), as much research had been eclectic to date. The Health Belief Model and social learning theory were used in this study, targeting interventions at those barriers identified from the previous trial as inhibiting patients from adopting Hand JP.

b) standardisation of interventions that would:

i) permit replication studies. This programme has a standard curriculum (Appendices 12 and 13) enabling replication and
ii) permit manipulation of specific adherence measures within this to identify which elements are most effective. Different elements could be systematically omitted in a series of trials to identify these, aiding other health professionals to determine which adherence-enhancement strategies could be most effective in other treatments.

5.5. CONCLUSION.

The results of this study demonstrated that a cognitive-behavioural JP programme, using motor learning, adult education, behavioural, recall and adherence enhancement strategies did:

i) increase disease and JP knowledge,
ii) not increase attitudes towards the benefit of JP, as those self-selecting to attend already believed this,
iii) significantly increase use of Hand JP and self-reported use of

technical aids, changing work methods and exercise.

Those increasing Hand JP behaviour were most influenced by greater amounts of education and home practice, and having decreasing grip strength and hand RoM, explaining two-thirds of the variance in JPBA score changes. Factors pre-education predictive of change were using less Hand JP and having less learned helplessness, better hand RoM and more JP knowledge, although these factors explained only one-third of the variance in JPBA score changes.

As stated earlier, treatment is either ineffective because the treatment is of no use or the patient does not sufficiently adhere (Foa and Emmelkamp, 1983). This study has proven for the first time that significant adherence with Hand JP can be achieved. As yet, the longer-term adherence with Hand JP is unknown, as the follow-up period was of four and a half months duration. If long-term adherence can be proven, it is then possible to evaluate whether Hand JP is an effective treatment and research can be directed at evaluating the long-term benefits of Hand JP in reducing pain, inflammation, internal and external joint stress and reducing the risk of deformity.

6. TRADITIONAL VERSUS COGNITIVE-BEHAVIOURAL JP EDUCATION PROGRAMMES.

The CB-JP programme clearly led to a significant improvement in Hand JP whilst the traditional programme did not. The traditional JP trial identified the main barriers to subjects changing behaviour were believing JP was inapplicable for them currently (although believing it to be beneficial), recalling methods and developing new habits. It became questionable whether Hand JP could be improved following this trial, particularly if subjects did not experience hand pain during everyday activities, as a number reported (despite knowing about JP methods) using Hand JP only when in pain and automatically reverting to normal movements when this reduced or ceased. As these barriers were partly motivational and partly practical in origin, multiple strategies were incorporated to attempt to change behaviour in the CB-JP programme.

The Health Belief Model (HBM, incorporating self-efficacy theory as an explanatory variable) was selected as a framework for its development (section 1.4.3); ie. through increasing perceived threat of the disease, perceived benefit of Hand JP and self-efficacy. The HBM's major drawback, however, is that health behaviours are viewed as under volitional control, with change consequential to sufficient motivation developing to overcome barriers. Yet there is evidence that if a health behaviour requires changing habitual behaviours, however motivated a person, change does not result (Janz and Becker, 1984). Other strategies were therefore incorporated to aid changing habits, ie. motor learning to teach correct JP movement skills and self-management behavioural approaches to de-automatise old habits and re-automatise new.

Other health behaviour models also include similar constructs to the HBM:

i) the Theory of Reasoned Action (TRA, Fishbein and Ajzen, 1975) considers self-efficacy and the degree of social pressure as being primary influences on the intention to act;

ii) and Protection Motivation theory (Prentice-Dunn and Rogers, 1986) similarly proposes behaviour is influenced by perceived threat, susceptibility, self-efficacy, outcome expectancy and cost-benefit analyses, which stimulate specific coping responses.

These three theories are termed value expectancy theories, ie. cognitive theories which hold that action is determined by expectations (Padilla and Bulcavage, 1991). If the initial motivation exists, behavioural change is likely to occur.

Many subjects self-selecting to attend for both programmes already had positive scores for perceived control of arthritis/ learned helplessness, self-efficacy, perceived severity and susceptibility to the disease and believed JP behaviours beneficial pre-education. In both trials, more than three-quarters of the subjects already believed it "very important" to reduce joint stress and two-thirds that they had changed more than a quarter of everyday tasks in order to do so. As previously discussed, this suggests self-selectors to both programmes were Information Seekers, already having the initial motivation to change and a degree of behavioural change had already occurred pre-education (as the median JPBA scores and self-reports indicate).

These psychological and belief measures did not alter in either trial, suggesting strategies incorporated in the CB-JP programme specifically to influence motivation, self-efficacy and perceived control, based on HBM theory, were unnecessary with these subjects. The HBM would appear to have been an inappropriate theoretical framework on which to base the development of the CB-JP programme, although as noted in the previous discussion, assessments selected

may have been insufficiently sensitive to measure psychological changes. It was, however, a useful theory for identifying factors aiding or hindering subjects' Hand JP behaviour following the traditional JP/AEP trial.

The TRA additionally suggests that social pressures influence change. Social support in the CB-JP trial was only measured in terms of whether subjects' spouses/ significant others attended the programme or not, but this was not an influential factor, again suggesting the TRA to be an inappropriate explanatory model. The HBM and other value-expectancy models appear not to explain why behavioural change occurred in the CB-JP and not the traditional AEP, given both sets of subjects were similarly motivated pre-education and no significant difference in psychological and belief measures occurred in either. This supports the contention of Janz and Becker (1984) that the HBM does not explain why health behaviours are not adopted when behaviours requiring change are habitual.

One psychological difference post-education between subjects attending the two programmes was that the self-reported range of behavioural coping strategies used increased in the CB-JP but not the traditional. However, subjects' abilities to self-report behaviours may be unreliable, as demonstrated by the difference in subjects' self-reported and observed Hand JP behaviours in the traditional AEP/JP trial (Appendix 10), and lower test-retest reliability in open questions in the interview, meaning these findings are inconclusive. Problem-solving was incorporated in both programmes to increase flexibility of coping responses and as recommended by JP theorists (section 1.5.3) but in both only a few subjects additionally stated consciously using this strategy to change behaviour post-education. Subjects' in both programmes obtained similarly high scores on the JPKA pre- and post-education, suggesting they already had a

reasonable ability to identify less stressful methods of performing ADL using "common-sense" and that, if not an artefact of self-report, there is another causal factor. Increasing subjects' repertoire of behavioural coping strategies results in greater psychological adjustment (Blalock et al, 1993). Further investigation of the effects of JP education on coping may be of value, to objectively identify whether increased use of coping strategies and disease adjustment does occur as a result (eg. using The London Coping with Rheumatoid Arthritis Questionnaire and The Acceptance of Illness Scale, Newman and Revenson, 1993).

Change seems not therefore to have occurred because of the psychological components. Multiple regression analysis identified hours of education, self-reported frequency of practising Hand JP, as well as changes in hand RoM, pain and grip, as explaining two-thirds of the variance in JPBA score changes. Hours of education received particularly appears an important factor for behavioural change as those attending for less than eight hours did not do so. The educational, motor learning and behavioural strategies seem more likely factors influencing Hand JP. Alternately, simply extending the JP education component of the traditional AEP, allowing increased opportunity for demonstration and practice, could have led to the same degree of change.

The disease and JP knowledge content of both programmes were similar. The major difference was the structured presentation of teaching and repetition of material in the CB-JP programme. The limited knowledge increases following the traditional AEP could have been because of:

- i) insufficient time. Both disease and JP information were given twice (one hour disease information in session one, one hour disease and JP information in session three and a half hour on JP and EC in session 4) with supporting booklets and leaflets provided. However,

this was comparable with the total amount of time spent on these topics in the cognitive-behavioural programme.

ii) poor teaching skills of the staff involved. None had received specific training in patient education methods, in common with the majority of therapists and nurses, although all had several years experience in teaching patients similar content to the AEP in a one-to-one setting. Although given some practical assistance in the structuring of the programme by the researcher, the education team designed the presentation of the material as they deemed most appropriate, as the intention was this programme should be representative of normal practice. Observation of sessions and review of the teaching notes showed the format and presentation to be similar to other AEPs observed by the researcher elsewhere. In comparison, the researcher (running the cognitive-behavioural programme) had previous experience of developing and running AEPs, four years experience of higher education teaching and included verbal, visual and written strategies to increase recall. The traditional AEP/JP programme could potentially be equally effective in increasing knowledge if staff were trained in the use of appropriate patient education techniques to aid learning and recall (section 4.2).

The JP behaviours taught in both programmes were also similar. Fourteen JPBA tasks were demonstrated and practised once in the traditional AEP. Generally, only one JP method for each task was presented. For those finding a method difficult, no alternative was presented due to limited teaching time, although the accompanying booklet contained some alternative ideas. The therapist provided additional individual instruction, particularly in using technical aids if difficulties were noted. In contrast, all twenty JPBA tasks were demonstrated and practised a minimum of three times, many four

to six times in the CB-JP programme, with a home programme of practice.

In the traditional AEP, subjects were only requested to try using these methods at home. At follow-up, many stated they had difficulty recalling correct methods, few reported practising these and only two achieved a significant increase in behaviour. In contrast, the majority of those completing the CB-JP programme increased behaviour, implying the motor learning strategies employed enabled subjects to learn and perform the movement patterns required correctly and the behavioural strategies the implementation of these. Arguably, simply increasing the JP practice time from one hour (as in the traditional AEP) to five (as in the CB-JP programme) without altering the motor skill teaching methods used or incorporating behavioural strategies could lead to a similar degree of change.

Whether the motor learning strategies used would be any more effective than the therapist's normal skill teaching approach, given the same time being available, is unclear as therapists would normally utilise many of these strategies, although in a less systematic way. However, the research reviewed in section 4.4. indicates improved skill teaching is effective. As Poole (1991) states, whilst OTs teach motor skills, most are not trained extensively in motor skill acquisition. Relatively little of undergraduate courses and standard undergraduate texts are assigned to motor learning and teaching, suggesting OTs knowledge of these strategies and their systematic application could be improved.

Most CB-JP subjects attributed change to following the homework programme of regular weekly practice, commencing with a few tasks and building these up as recommended, suggesting behavioural strategies were the most influential factor. These strategies are taught in undergraduate OT programmes and commonly used in mental health OT,

although less so in physical rehabilitation, apart from with clients with cognitive deficits.

Daltroy and Liang (1988) identified that "diffusion and maintenance of patient education skills among practitioners is one of the most important and least studied areas affecting arthritis patient education" and Webber (1990) that a major problem in patient education is the poor preparation of educators in teaching. The results from the traditional AEP trial suggest this continues to be a need in the UK.

Which subjects are more likely to change behaviour was unclear from these studies. Multiple regression analysis identified pre-education JP knowledge, Hand JP behaviour, helplessness, hand pain and RoM as predictive, but these only explained a third of the variance in JPBA score changes. Self-selection following invitation therefore appears an appropriate method of recruiting to AEPs as other measures were inconclusive in identifying suitable subjects.

The implications of these two studies are that, amongst patients self-selecting to attend for arthritis education, the most effective methods for increasing Hand JP are motor learning and behavioural strategies and the use of value expectancy models to develop JP programmes for such patients are unnecessary.

An alternate theory for programme development is the PRECEDE model which encompasses a wider range of influential variables (predisposing, reinforcing and enabling). This emphasises educationally diagnosing the relative importance of these for the specific group of patients participating in a planned programme and developing it accordingly (Green et al, 1988). Unlike value-expectancy models, the process of enabling change to occur through administrative diagnosis is then emphasised. PRECEDE recommends that for complex, widespread, frequent, long-term, psychomotor changes

(which Hand JP is), the most relevant strategies are: skill development, peer group discussion, modelling and behaviour modification, ie. the strategies incorporated in the CB-JP programme. Utilising this model may therefore have been an appropriate theoretical underpinning, allowing a more accurate educational diagnosis (identifying most subjects were already predisposed to change) and thus focusing planning more on the process of change and less on psychological factors. Alternately, given that the major objective of the CB-JP programme was to increase Hand JP behaviour amongst subjects self-selecting to attend and thus likely to be motivated to change, educational diagnosis may also have been an unnecessary step. However, using a structured approach to JP programme development was clearly more effective than that normally adopted in clinical practice.

Group programmes are not suitable for all patients. The take-up for both programmes was less than a half of patients invited. Further research is needed to identify why many did not wish to attend. This may have been due to:

- i) practical reasons, such as timing, transport, work or family commitments, which organisational changes in programme timing and venue may be able to overcome;
- ii) concerns that other patients attending an AEP may focus on negative aspects of their disease, which would be depressing. This could be reduced by effective marketing and telephone contact by the group leader to emphasise the self-help nature of AEPs;
- iii) psychological factors, such as poor perceived control, lack of perceived threat or denial, leading patients to believe AEPs to be unnecessary and inappropriate for them. In this case, a theoretical framework such as the HBM or PRECEDE may assist in the development of individualised education programmes, designed to motivate patients to

use health behaviours prior to referral to a cognitive-behavioural AEP to assist them in the process of change.

7. RECOMMENDATIONS FOR FUTURE RESEARCH AND IMPLICATIONS FOR PRACTICE.

7.1. FUTURE RESEARCH

Research needs to be directed at the following:

1. Long-term follow-up of subjects attending the CB-JP programme to identify if Hand JP behaviour is maintained.
2. Whether further education in either group or individual sessions can aid maintenance or further increases of Hand JP.
3. Replication of the CB-JP study, using improved measurement techniques (eg. the Rheumatology Attitudes Index, a cognitive and behavioural coping strategies scale (eg. the London Coping with Rheumatoid Arthritis Questionnaire), a Hand JP self-efficacy scale, a disease adjustment measure (eg. the Acceptance of Illness Scale)) to evaluate if any beneficial psychological effects result.
4. Follow-up of those patients in the CB-JP trial for whom data was incomplete because of ill-health (but who wished to continue attending) to identify whether they used the workbook independently and if change occurred.
5. What factors influence patients choosing to attend an AEP or not.
6. Whether the CB-JP programme can be used as a self-instructional programme entirely, or with introductory and follow-up sessions to promote adherence, thus reducing costs and making it more accessible for those with limited ability to regularly commit to attending a four session programme.
7. Whether an individualised education programme based on the HBM or another health behaviour change model, can improve patients' motivation to adopt health behaviours amongst those not selecting to attend AEPs.

8. To what extent Hand JP behaviours taught in the CB-JP programme are generalised to other daily living and work activities.
9. The amount of training in running the CB-JP programme and previous experience required for therapists to achieve similar results to the researcher.
10. Evaluation of which JP methods for which everyday tasks are preferred by RA patients and why, as current JP advice is largely based on biomechanical theoretical assumptions by therapists.
11. Evaluation of JP methods using reliable, valid measures of pain and joint stress to identify which methods do achieve the aims of JP.
12. Evaluation of the long-term benefits of Hand JP in reducing pain, inflammation, internal and external joint stress and reducing the risks of deformity.

7.2. IMPLICATIONS FOR PRACTICE.

The results of the traditional AEP highlighted the need for rheumatology health professionals to be trained in patient education and behavioural techniques. A shared role amongst these practitioners is to facilitate patients in adjusting their lifestyle to manage the effects of their disease. This, and other studies reviewed earlier (section 1.5.2), have demonstrated that using these approaches is the most effective method of enabling patients to adopt arthritis health behaviours.

Patient non-adherence is a major issue in health care, resulting in inefficient use of health services (Sackett and Snow, 1979). Half of RA patients appear to be non-adherent with some or all of their recommended treatment meaning patients cannot be obtaining maximum benefit from the treatment programmes prescribed by their doctor and rheumatology team, resulting in poorer health. Adherence-enhancing strategies have been shown to be effective in changing behaviour in this, and other studies, and so should be more widely adopted in

health care.

The low test-retest reliability of subjects' responses to many of the open-ended questions in the interview (section 2.3.2) and discrepancy between self-reported and observed Hand JP behaviours (Appendix 10) highlights that clinicians should be cautious in interpreting subjects' replies to follow-up enquiries of use of health behaviours. Currently, this is the main method employed in clinical practice to evaluate adherence. There is a clear need to use objective measures of behaviour, such as the JPBA, to evaluate adherence. Where behaviours are not amenable to direct observation, there is a need to develop reliable, valid measures of self-report.

Disease outcome is thought to be related to the use of many treatments, eg. drug therapy, exercise, joint protection, splints. Adherence to all these aspects would affect treatment outcome to a greater degree than any single component (Feinberg, 1992). Ahlmen, Sullivan and Bjelle (1988) and Feinberg and Brandt (1984) have demonstrated that co-ordinated team care, with regular follow-up, results in better outcome than the more normal pattern of referral to team members when problems are noted at clinic visits. The CB-JP programme purposefully only targeted one treatment (Hand JP) as the more complex the treatment regime, the poorer the adherence. The only AEP that has been subjected to detailed long-term evaluation is the Arthritis Self-Management programme (Lorig, 1986a), with predominantly osteoarthritis and a minority of rheumatoid arthritis patients. This is a six session programme including disease and drug therapy information, pain therapy (heat, cold, massage), psychosocial effects of arthritis, joint protection, nutrition, evaluating non-traditional treatments, improving relationships with doctors, stress management, relaxation and exercise. Behavioural methods were used to change the last two behaviours and only these significantly

increased. This programme has been shown to have beneficial long-term effects over a four year period in increasing physical activity, reducing pain, number of doctors' visits and health care costs, although disability was unchanged (Lorig, Mazonson and Holman, 1993). If these individual arthritis treatments are effective at improving health status long-term, these beneficial effects could be further enhanced by developing an AEP using a modular approach over a year or more to increase adherence with a range of treatments. An introductory short module (one or two sessions) of disease, drug therapy, non-traditional treatment and therapies' effectiveness information could be followed by modules targeting specific behaviours, eg. exercise, Hand JP, energy conservation, relaxation and pain management, each lasting two to four sessions, which utilise a cognitive-behavioural approach to promote change. Patients then select modules to attend in priority order as and when they are able to over a period of time. This would enable patients to slowly adopt new behaviours and consolidate these into new habits and routines before trying to add further behaviours to their repertoire. This approach could potentially achieve not only the beneficial psychological effects of the Arthritis Self-Management programme, but also improve health status further through increasing adherence to a range of treatments.

8. CONCLUSION

Finally, this study has clearly demonstrated that traditional JP education was ineffective. None of the attitudinal, knowledge, behaviour or psychological factors measured altered significantly, apart from short-term self-reported use of exercise. As subjects ability to reliably self-report was questionable, this latter finding may be doubtful. Although the design of this trial was weak, criticisms for insufficient or lack of control for temporal,

attention and learning effects are applicable primarily if change had occurred.

This method of JP and arthritis education is widely used by OTs, PTs, rheumatology nurses and doctors in clinical practice in the UK. JP education is often provided for less time and with less practical content than was included in this AEP. Doubt must therefore be cast on the efficacy of current practice and whether resources are being cost-effectively used.

Further research is needed to evaluate to what extent individual traditional JP education is effective in achieving behavioural change. However, it is likely to be similarly as ineffective as the group traditional JP programme, as contact hours are frequently less than that included in the AEP. It is recommended that OT and other rheumatology health professionals providing JP education review current practice. Alternatives are to limit time allocated to individual JP education (eg. to half an hour) or change to providing audio-visual programmes, supported by written information, eg. a standard Hand JP video of similar duration to much of the individual treatment currently provided (three-quarters to one hour) with an accompanying booklet. This approach would provide sufficient input to allow patients to self-select attending a CB-JP programme. Apart from initial production costs, loaning or supplying an audio-visual programme would be cheaper than therapist's time in teaching JP to individuals. Up to a third of a rheumatology OT's working week may be taken up by this activity. This would then allow resources to be redistributed away from providing ineffective individual JP education to group CB-JP programmes, for which patients have self-selected to attend, ie. to patients who are more likely to change behaviour.

For the first time it has been objectively demonstrated that Hand JP behaviour can be changed, by utilising a cognitive-behavioural

approach during a four two hour session programme. The design of this trial, in comparison to the traditional AEP, controlled for temporal and learning effects, increasing the reliability of these findings. This study also further demonstrates the effectiveness of using educational, motor learning and behavioural strategies in changing behaviour and the importance of incorporating these into AEPs. Whilst long-term adherence is unknown, it is now feasible to evaluate whether Hand JP is an effective treatment in reducing pain, inflammation and the risk of deformities developing and if this has any beneficial psychological effects. Current clinical practice should then be reviewed and altered in the light of these findings. If effective, CB-JP programmes should become the standard method of JP education and if ineffective, resources should be directed away from providing JP education to other self-management behaviours proven to improve health status and/ or well-being.

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APPENDIX 1: DIAGNOSTIC AND CLASSIFICATION CRITERIA FOR RHEUMATOID ARTHRITIS.

A. 1987 REVISED AMERICAN RHEUMATISM ASSOCIATION (ARA) CRITERIA FOR THE DIAGNOSIS OF RA (Arnett et al, 1987).

Four or more criteria must be present to diagnose RA. Criteria 1 - 4 must be present for at least six weeks.

1. Morning stiffness for at least one hour and present for at least six weeks.
2. Swelling of three or more joints for at least six weeks.
3. Swelling of wrist, MCP or PIP joints for six or more weeks.
4. Symmetric joint swellings.
5. Hand roentgenogram changes typical of RA that must include erosions or unequivocal bony decalcification.
6. Rheumatoid nodules.
7. Serum rheumatoid factor by a method positive in less than 5% of normals.

B. ARA CRITERIA FOR PROGRESSION OF RA (Steinbrocker, Traeger and Batterman, 1949).

Stage I, Early:

1. No destructive changes on roentgenographic examination.*
2. Roentgenologic evidence of osteoporosis may be present.

Stage II, Moderate:

1. Roentgenologic evidence of osteoporosis with or without slight subchondral bone destruction; slight cartilage destruction may be present.*
2. No joint deformities, although limitation of joint mobility may be present.*
3. Adjacent muscle atrophy.

4. Extra-articular soft tissue lesions, such as nodules and tenosynovitis may be present.

Stage III, Severe:

1. Roentgenologic evidence of cartilage and bone destruction, in addition to osteoporosis.*
2. Joint deformity, such as subluxation, ulnar deviation or hyperextension, without fibrous or bony ankylosis. *
3. Extensive muscle atrophy.
4. Extra-articular soft tissue lesions, such as nodules and tenosynovitis may be present.

Stage IV, Terminal:

1. Fibrous or bony ankylosis.*
2. Criteria of stage III.

* Criteria must be present for classification in this stage.

C. ARA CLASSIFICATION OF FUNCTIONAL STATUS IN RA* (Hochberg, Chang, Dwosh, Lindsey, Pincus and Wolfe, 1992).

Class I: Completely able to perform usual activities of daily living (self-care, vocational and avocational).

Class II: Able to perform usual self-care and vocational activities, but limited in avocational activities.

Class III: Able to perform usual self-care activities, but limited in vocational and avocational activities.

Class IV: Limited in ability to perform usual self-care, vocational and avocational activities.

* Usual self-care activities include dressing, feeding, bathing, grooming, and toileting. Avocational (recreational and /or leisure) and vocational (work, school, homemaking) activities are patient-desired and age- and sex-specific.

APPENDIX 2 - JOINT PROTECTION PRINCIPLES.

1. Respect for pain.
2. Balance between rest and work.
3. Use of energy conservation techniques (eg. work simplification, use of good body mechanics, eliminating unnecessary tasks).
4. Avoiding activities that cannot be stopped.
5. Avoidance of staying in one position for prolonged periods.
6. Reduction of effort by:
 - a) using adaptive devices,
 - b) avoiding lifting and carrying.
7. Distributing load over several joints.
8. Using each joint in its' most stable and functional position.
9. Use of the strongest, largest joint to perform a task.
10. Avoiding positions leading to possible joint deformities.
11. Maintenance of muscle strength and joint range of movement through exercise and full ranging during daily activities.
12. Use of splinting.

(Cordery, 1965b; Unsworth, 1986; Lorig and Fries, 1983; Brattstrom, 1987; Melvin, 1989; Sandles, 1990).

**JOINT PROTECTION
BEHAVIOUR ASSESSMENT**

Alison Hammond

THE JOINT PROTECTION BEHAVIOUR ASSESSMENT.

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Further copies of the Joint Protection Behaviour Assessment (JPBA) booklet, score sheets and the accompanying training tape can be obtained from the author.

1992 prices:

Assessment book and tape	5.50 (UK and Europe)
	9.00 (other countries)

Payment must be in UK funds.
(Payment covers the cost of the videotape, postage and packing).

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Illustrations: R. Chester Photography. Ilkeston, Derbyshire.

file: jpbinf1

ACKNOWLEDGEMENTS

The author gratefully acknowledges the assistance of the following:

- in establishing the content validity of the assessment:

Marion Ferguson, Senior OT, St. Albans City Hospital.

Paula Jeffreson, Senior OT, Robert Jones and Agnes Hunt Orthopaedic Hospital, Oswestry.

Valerie Kulkarni. Senior OT. Cookridge Hospital. Leeds.

Anne McGee, Senior OT, Derby Royal Infirmary.

Jane Purser, Head OT. West Suffolk Hospital. Bury St. Edmunds.

Heather Unsworth. Research OT. Odstock Hospital. Salisbury.

- Dr. N. Lincoln (research supervisor, Nottingham Stroke Research Unit). Avril Bagshaw. Avril Drummond. Margaret Foster and Irene Ilott (Derby School of OT) for reviewing the assessment.

- staff and students at Derby School of OT and RA patients at the Derby Royal Infirmary for agreeing to be videorecorded for the reliability and validity studies.

- the Arthritis and Rheumatism Council, Lord Byers Memorial Fund and Constance Owens Trust for funding this research.

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INTRODUCTION

The aim of this assessment is to establish if subjects with Rheumatoid Arthritis are using patterns of hand movements that can be defined as Joint Protection techniques.

Section I - details how to set up the assessment procedure.

Section II - outlines the scoring procedure and completing the assessment form.

Section III- details the scoring of the twenty kitchen tasks which are observed in the assessment procedure - making a hot drink, snack meal and clearing up. Each task title is followed by a series of descriptions of different methods of performing the task, classified as either: Correct, Borderline or Incorrect. Some of these descriptions are illustrated with a photograph.

Section IV - provides answers to the practice assessments included in the accompanying training tape.

The JPBA training tape includes:

1. Introduction
2. Demonstration of correct, borderline and incorrect methods for each of the 20 tasks in the assessment.
3. Practice assessments.

JOINT PROTECTION METHODS FOR THE HAND AND WRIST JOINTS ONLY ARE ANALYSED IN THIS ASSESSMENT.

The particular Joint Protection principles being assessed are;

1. Use of strongest, largest joint to perform a task.
2. Distributing load over several joints
3. Use of each joint in it's most stable, functional anatomical position.
4. Reducing effort to perform tasks by a) use of assistive devices, b) avoiding lifting/ carrying or c) employing leverage.
5. Avoiding positions leading to potential joint deformity, eg. pushing fingers into ulnar deviation, pressing against the backs of fingers, using tight grips, holding with flexed wrists.

The 20 tasks included in the assessment were selected because:

- i) these are commonly targetted in joint protection education as requiring change.
- ii) these are common, early ADL problems experienced by people with RA
- iii) they are designed to be sufficiently stressful to require a change in motor behaviour
- iv) they require the application of 1 or more of the 5 joint protection principles listed.

SECTION I

ASSESSMENT PROCEDURES.

USING THE ASSESSMENT IN CLINICAL OR RESEARCH SETTINGS.

The assessment can be used in both department and home settings with equal reliability. Assessments should be videorecorded, as the assessment is too detailed to recall accurately to assess 'in vivo.' A portable video camera is preferable as it allows the subject to move more naturally around the kitchen, without being concerned they are blocking your view as you record. Using a tripod-mounted camera requires careful planning to ensure all tasks can be adequately observed.

Recording behaviour accurately.

Two difficulties need to be overcome when videorecording subjects:

- i) subjects' behaving as they know you want them to behave (subject reactivity) - in this case, using joint protection methods during the assessment when normally they have not been doing so.
- ii) subjects' embarrassment

To avoid these problems:

- i) keep subjects unaware, if possible, of the purpose of the assessment, ie. do not inform them you are assessing if they use joint protection methods or not. (For research uses, this point should be made clear when seeking ethical approval). Use vaguer terms such as 'to see how you normally do these tasks.'
- ii) do not inform subjects of the 20 specific tasks you are assessing or the scoring methods being used. Do not use the assessment booklet as a teaching tool.
- iii) Emphasise to subjects to use their normal everyday methods of doing tasks.
- iv) Keep up 'light' conversation to put subjects at their ease and to purposefully distract them from consciously attending to their hand movements. This is more likely to encourage 'automatic,' normal hand actions, including joint protection behaviours if they have become habitual.
- v) change the topic of conversation if subjects begin to discuss how they are using their hands during the assessment.
- vi) recording should preferably not be done by the person providing joint protection education.
- vii) to reduce embarrassment - inform subjects you are focussing the camera on their hands not their face. Do not record sound and inform subjects of this.

Suitable subjects

The assessment was originally devised with adult RA patients.

Note: Subjects with marked, fixed hand deformities are physically unable to achieve some of the 'correct'

behaviours described in the assessment (eg. task 19) and can therefore not gain the maximum score.

Timing of Assessments.

It is recommended the assessment is carried out in afternoons, to reduce the possibility of subjects' hand behaviour being affected by morning stiffness.

Standardising assessment conditions.

In the assessment procedure, subjects are asked to make a hot drink, snack meal and to wash and clear up. Please view the practice assessments in the training tape to clarify how the assessment is carried out and equipment used.

The following equipment should be provided by the assessor and used in both home and clinic assessments:

- tray
- saucepan (minimum weight 0.8kg)
- jar of instant coffee (100gram - kept full)
- sugar (full jar of, weight approx. 100grams)
- pottery mug
- dinner plate
- tupperware box (approx. 245 x 160 x 110 mm) - containing sliced bread
- shopping bag (type illustrated in task 9, section III).
- 225 gram can of baked beans (or similar).

All these items will store in the bag easily.

In home assessments:

All other equipment is that normally used by the subject. No prompts should be given regarding use of aids/equipment.

In clinic assessments:

Commence by asking:

"Do you normally use:

- a jug or similar to fill your kettle at home?
- a tap turner or adapted taps?
- a jar opener?
- a kettle tipper? (if yes, put kettle on tipper)
- an adapted plug on kettle?
- an electric can opener?"

Ensure any relevant aids are placed in clear view on worktops. Do not prompt subject to use aid during assessment.

Request subjects to use equipment and aids that are most similar to the models they use at home, eg. sink with lever or non-lever taps, gas or electric cooker, jug, travel or 'traditional' style kettle.

Give subjects time to familiarise themselves with the kitchen layout.

Tasks in home and clinic assessments should be standardised before assessing to ensure they are weighty enough or offer sufficient resistance to require a joint protection response from subjects:

Task 1 - Carry tray

Wooden tray, jar of coffee, pottery mug, jar of sugar, plate. Total weight approx. 1.38kg.

Subject asked to 'carry tray across room.' Distance - minimum 3 metres. Ask to carry tray from adjacent room if small kitchen.

Task 2 - Turn tap

Finger tighten prior to assessment to ensure resistance offered to fingers.

In clinic: provide tap turner if subject states would normally use.

Task 3,5,16 - Fill, carry, pour kettle

Kettle emptied and unplugged at start. Request subject to fill kettle sufficiently to make two mugs of hot drink. (Minimum amount required is 0.5 litres, although subjects frequently fill with a larger amount, increasing weight further).

Plastic jug kettle + 0.5 litres water = 1.32 kg approx.

Metal kettle + 0.5 litres water = 1.62 kg. approx.

In clinic: if a jug (or other similar container) normally used to avoid carrying kettle, place next to kettle prior to start. If kettle tipper used, place under kettle.

Task 6 - Push in wall plug

Assess pushing in the kettle plug. Ensure kettle unplugged prior to start. If subject normally does not unplug kettle, request them to push in another plug at end of assessment. (Subject may push in a plug during assessment if has an electric can opener, thus avoiding need to request this).

In clinic: ensure kettle lead with adapted plug available as an alternative if normally uses this at home. If not available, request subject to push in an adapted plug into socket at end of assessment.

Task 7 - Open jar.

Finger tighten prior to start to ensure resistance.

In clinic: place jar aid in clear view.

Task 9 - Carry bag.

Shopping bag (illustrated in section 3) to contain: saucepan, minimum 4 225g cans of baked beans, tupperware box containing bread.

Total weight approx. 2.9kg.

Minimum carrying distance 3 metres. If subjects kitchen too small, place bag in adjacent hallway or room.

Task 10 - Open tin.

In clinic: provide variety of wing and blade tin openers and ask subject to select model most like the one they use at home. If normally uses electric or wall can opener, provide.

Task 11 - Carry pan to cooker

Saucepan (0.8kg) within bag at start of assessment, necessitating lifting pan to cooker.

Task 12 - Lift box from bag.

Box plus bread inside approx. 0.75kg min.

Task 13 - Lift grill pan

Weight varies with model, usually approx. 1.3kg.

Ask subject to make toast under grill not using toaster. (Even if subject does not normally use grill for toasting, would do so for other cooking tasks). Remove grill pan from rack at start of assessment to ensure subject required to lift it into place. If subject states would never normally remove grill pan apart from cleaning purposes leave in situ.

Some cooker models have grill pans that cannot be removed, mark as 'not seen' on assessment.

Task 15 - Carry plate

Use a dinner plate. Assess carrying plate with snack meal on. Weight approx. 0.77kg.

Task 17 - Hold milk

Weight 0.5 to 0.8kg approx. Ensure milk bottle/carton available in home assessments full.

In clinic: supply with full (half litre) milk bottle/carton.

Task 18 - Carry mug

Provide pottery mug, weight approx. 0.5kg when full.

Task 19,20 - Wipe surface and squeeze cloth

In clinic: provide range of sponges/cloths and ask subjects to select what would normally use at home.

Instructions at start of assessment:

Prior to all assessments (home or clinic), ask subject:

"Does someone normally assist you in any stage of making a drink and snack?" - If yes, ask subject to request assessor to perform task during the videorecording.

Remind subjects no sound recorded so they can talk during assessment and that video pointed at hands and not face should they have any embarrassment.

All subjects are given the same instructions throughout:

"I would like you to make a cup of coffee (adding milk) and beans on toast. You can take your time, there is no need to rush and you can do it in any order you like. I am interested in how you would normally do these, so please do it just as you usually would. Could you start by carrying the tray, with the jars, mug and plate on and then the bag across the room. There is bread in a tupperware box, a tin of beans and a saucepan in the bag for you to use. Would you use the grill rather than the toaster to make the

toast. At the end, could you carry the mug of coffee and the plate of beans on toast back across the room separately, not on the tray and then wash up and wipe the work surface. If you forget any of this, I am not recording sound so you can check and ask or I will remind you. If you would wait just a moment, I will label your video and get ready to record."

Each video assessment is identified by recording a card with the subject's trial or record number and date.

Duration of assessment

Setting up the assessment takes 5 minutes maximum.

Clinic assessments: allow extra time for subjects to become familiar with layout, storage, cooker controls etc.

Home assessments: it may take slightly longer to set up to politely request subjects' permission/co-operation in setting up tasks (eg. unplugging kettle etc).

Subjects may take between 8 - 20 minutes to complete the task, dependent on how talkative they are.

Total time: 20 - 30 minutes.

SECTION II

ASSESSMENT SCORING INSTRUCTIONS

SCORING INSTRUCTIONS

Read through this section and view the JPBA training tape to familiarise yourself with the assessment scoring procedure and task descriptions. Test your knowledge by assessing the practice videos at the end of the tape. Check your results with the answer sheets. If there are any discrepancies, go back over the practice videos and check with the booklet again, until scores are correct, before assessing patients.

Assessing the videos:

Write your name, the subject's trial or record number and date of assessment/video number at the top of the JPBA form.

Assess each task by ticking the appropriate column (C, B, or I) on the assessment form.

For each task, read through the Scoring Instructions and task descriptions to make your decision.

PLEASE NOTE: Tasks must be assessed as defined in this assessment and not according to your own opinion if this differs from the JPBA (as this would invalidate the results). The task descriptions are scored as correct, borderline or incorrect as a result of a content validity study with a panel of 7 Occupational Therapists, with between 2 - 18 years experience in Rheumatology (average 8 years).

You may need to 'still' and review tasks a number of times to make your decision. You may wish to use the 'fast search' facility on the video player to move on more quickly between tasks as you become used to the assessment procedure.

NB.

Subjects may perform a task several times whilst making the hot drink and snack meal.

Assess the FIRST time you see the task being performed ONLY.

Ensure you are assessing the task specified on the JPBA form:

eg. a subject may carry the empty mug across the room to the kettle, then carry the full mug back. Assess 'carrying a full mug.'

If a task is not seen as described, assess its nearest equivalent:

eg. carry plate - with meal on it. However if not seen, assess carrying empty plate across room or taking plate out of cupboard.

'NOTES' COLUMN

Please record:

- use of an aid ('Aid')
- which joint protection method used (eg as Ca. Bc (see task descriptions)
- if performed by someone else during the assessment ('Help')

If a task is not seen (eg. because accidentally omitted during assessment), write 'N/S'

BUT please check through the video again, as some tasks are performed in quick succession and you may have missed this.

If you cannot code a task because there seems no appropriate description, write 'no code.'

JOINT PROTECTION BEHAVIOUR ASSESSMENT

Assessor Name. A. Smith Subject No. 123 Video. AX ... 1 [] [] []
5 []

	C	B	I	Notes	Score
1. Carry tray	[]	[✓]	[]		7[1]
2. Turn on tap	[✓]	[]	[]	+ Aid	9[2]
3. Fill kettle	[]	[]	[✓]		11[0]
4. Turn off tap	[✓]	[]	[]	+ Aid	13[2]
5. Carry full kettle	[]	[✓]	[]		15[1]
6. Push in wall plug	[]	[]	[✓]		17[0]
7. Open jar	[]	[✓]	[]		19[1]
8. Close jar	[]	[]	[✓]		21[0]
9. Carry shop bag	[]	[]	[✓]		23[0]
10. Open tin	[]	[✓]	[]	+ Help	25[1]
11. Carry pan to cooker	[]	[]	[✓]		27[0]
12. Lift box from bag	[]	[]	[✓]		29[0]
13. Lift grill pan	[]	[]	[✓]		31[0]
14. Empty pan contents	[✓]	[]	[]		33[2]
15. Carry plate	[✓]	[]	[]		35[2]
16. Pour kettle	[]	[]	[✓]		37[0]
17. Hold milk	[]	[]	[✓]		39[0]
18. Carry mug	[✓]	[]	[]		41[2]
19. Wipe surfaces	[]	[]	[✓]		43[0]
20. Squeeze cloth	[]	[]	[✓]		45[0]

Score.... 14/40

35%

47[1][4]

SCORING THE JPBA

Correct = 2 (or 5%)
Borderline = 1 (or 2.5%)
Incorrect = 0 (0%)

Maximum score for the 20 tasks observed is 40 (or 100%).

In the sample JPBA score sheet, total score is 14/40 or 35%.

If any tasks are recorded as 'not seen.' the total possible score should be reduced accordingly.

ie. if one task 'not seen' total maximum score would be 38.

if two tasks 'not seen' total maximum score would be 36.

This score should then be converted to percentages to allow comparison across and between subjects.

eg 14/38 = 36.8%

14/36 = 38.8%

SIGNIFICANT SCORE INCREASE

A test-retest reliability study has established that a significant score increase between assessments is at least 8/40 or 20%.

SECTION III

SCORING DEFINITIONS AND TASK DESCRIPTIONS.

SCORING DEFINITIONS:

CORRECT:

a) Methods reducing stress on hand/ wrist joints as described in this assessment.

BORDERLINE:

a) Methods partly reducing stress on hand/ wrist joints as described in this assessment.

b) Any task started incorrectly but then quickly altered and completed correctly.

c) Two-handed tasks where one hand is performing correct action and other hand incorrect.

d) Action performed by another person as subject was unable to do.

INCORRECT:

a) Methods causing stress on hand/ wrist joints as described in this assessment.

b) Any task started correctly but then completed incorrectly.

c) Any task started incorrectly, and finally corrected only after struggling to perform it incorrectly.

SUMMARY - IF PERSON ALTERS METHOD DURING TASK:

<u>Starts:</u>	<u>Changes to</u>	<u>Score as</u>
Correct	Borderline	Borderline
Correct	Incorrect	Incorrect
Borderline	Correct	Borderline
Borderline	Incorrect	Incorrect
Incorrect QUICKLY	Correct	Borderline
Incorrect STRUGGLES	Correct	Incorrect
Incorrect	Borderline	Incorrect

TASK DESCRIPTIONS FOR JPBA

1) Carry tray.

Correct:-

- a) Slide tray onto palms/forearms and carry tray on both equally.

Borderline:-

- a) One hand gripping tray edge with 'plate' grip, ie. between thumb and side of fingers, other supporting tray weight on palm/forearm.

Incorrect:-

- a) Both hands gripping edges of tray - between thumb and sides of fingers.

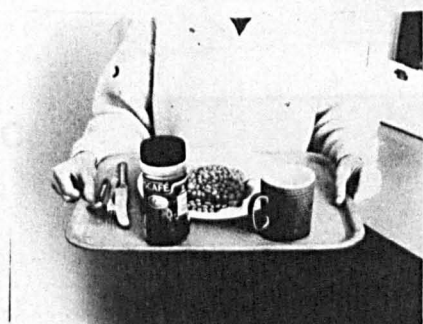
Ca



Ba



1a



2) Turn on tap.

Correct:-

- a) Use heel/ palm of hand - fingers not involved in grip - pressing down on top of tap. (May use piece of dycem matting to improve purchase).
- b) Use both hands gripping tap between palms to turn.
- c) Use tap turner (any design).
- d) Use lever tap (any design)

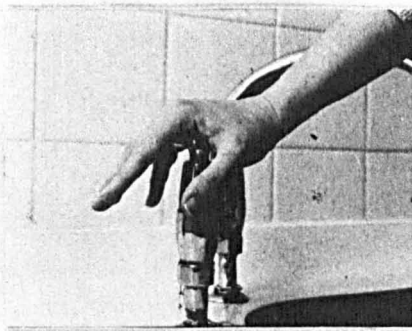
Borderline:-

- a) Using cylinder grip one handed - holding side of tap (eg. crystal tap style or horizontal mixer taps)
- b) Using tap turner to slightly loosen tap, completing movement with fingers.
- c) Use correct grip (ie. heel/ palm or both hands gripping between palms) to slightly loosen tap, completing movement with deviating fingers.

Incorrect:-

- a) Turning one-handed using fingers.

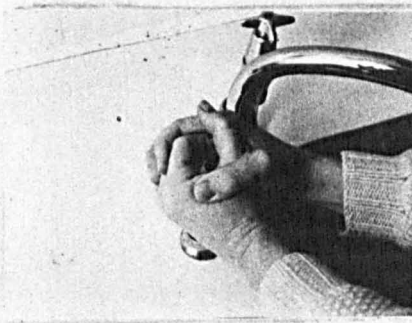
Ca



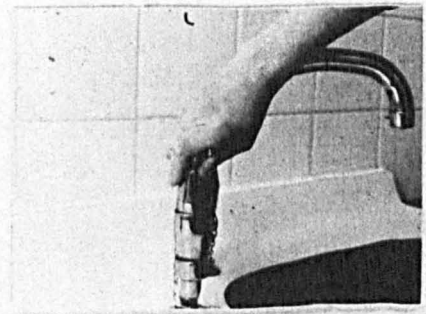
Ba



Cb



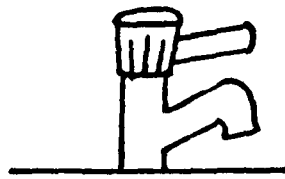
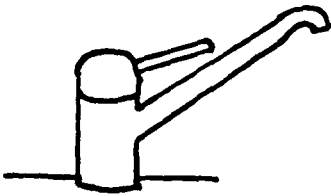
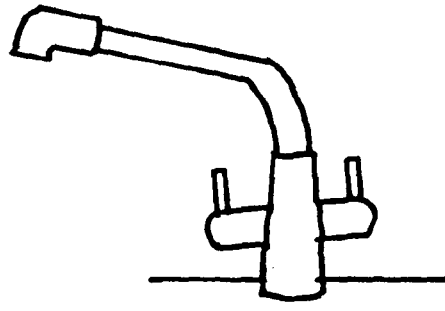
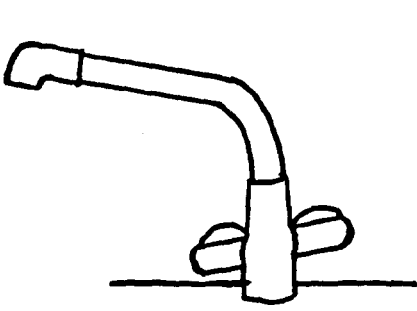
la



Cc



LEVER TAP DESIGNS:



3) Filling kettle (traditional or jug style).

Correct:-

- a) Use jug/milk bottle/mug to fill kettle, so avoiding lifting.
- b) Kettle sitting in sink or resting on sink edge whilst filling - ie. with weight obviously not being taken on hands.
- c) Use small lightweight travel kettle and fill with small amount.

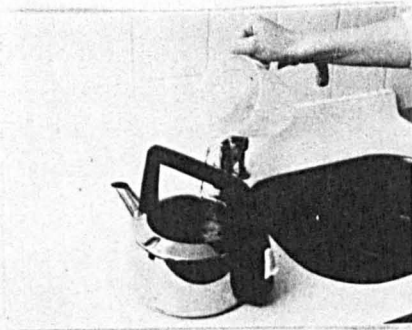
Borderline:-

- a) Holding kettle with two hands whilst filling (one on handle, one underneath).

Incorrect:-

- a) Holding kettle one-handed under tap whilst filling - whatever grip used (ie. holding over, under or side of handle).
- b) Holding kettle with two hands whilst filling (both on handle).

Ca



Cb



1a



1b



4) Turn off tap.

Correct:-

- a) Use heel/ palm of hand - fingers not involved - pressing down on top of tap.
- b) Use both hands gripping tap between palms to turn.
- c) Use tap turner (any design).
- d) Use lever tap (any design)

Borderline:-

- a) Use cylinder grip, holding side of tap.

Incorrect:-

- a) Turning one-handed gripping with fingers.
- b) Using tap turner to initially turn tap, remove aid and finally tighten with fingers.
- c) Use correct grip (ie.heel/ palm of hand, both hands gripping between palms) to initially turn tap, completing movement by tightening with fingers.

5) Carry full kettle.

Correct:-

- a) Avoid carrying by using jug to fill.
- b) Sliding along work surface as much as practicable.

Borderline:-

- a) Use two hands on handle -both wrists in extension and firmly gripping.
- b) One hand on handle, wrist in extension, second hand supporting weight from beneath on palm of hand.

Incorrect:-

- a) Holding one-handed - wrist flexed, on traditional kettle.
- b) Holding one-handed - wrist extended, on traditional kettle.
- c) Holding one- handed - jug style kettle.
- d) Using two hands on handle, but with wrists flexed/ deviated .
- e) One hand holding handle and other pressed against side of kettle.
- f) One hand holding handle and other with fingers, not palm, only in contact.

Cb



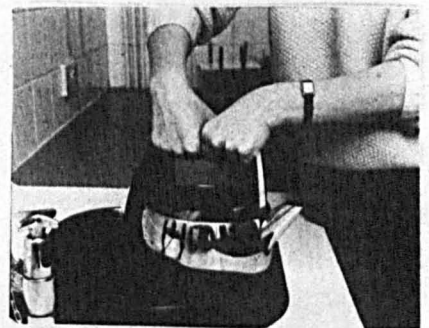
Bb



la



ld



lf



6) Push in Electric Wall Plug.

Correct:-

- a) Use palm / heel of hand, ie. fingers not included to push in (nb. fingertip grip may be used whilst lining up pins with socket).
- b) Use adapted plug.
- c) Use forearm (if plug accessible).

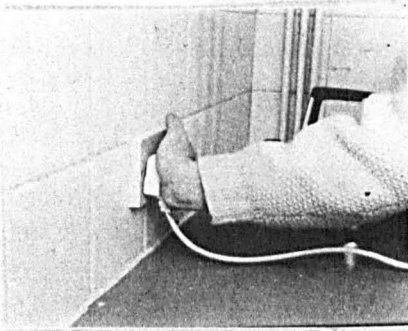
Borderline:-

- a) Pushing with fist.

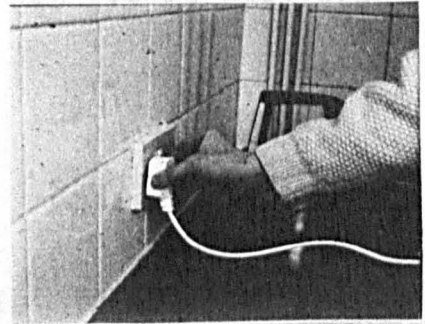
Incorrect:-

- a) Gripping with fingers/ thumb as push in.
- b) Pushing in with thumb/s.
- c) Pushing in with fingertips.
- d) Pushing in with backs of fingers.

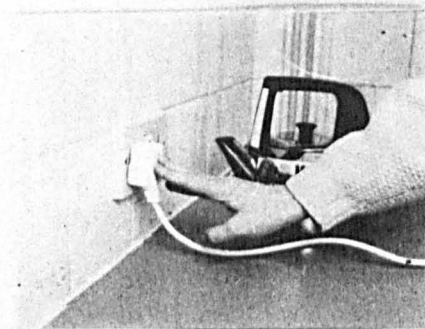
Ca



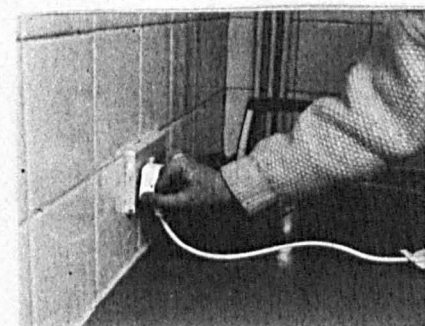
la



lc



ld



7) Open jar.

Correct:-

a) Use jar opener - any design.

b) Hold jar lid still by pressing down with heel/ palm of hand, fingers not involved in grip, and turn jar with other hand to unscrew.

Borderline:

a) Tests tightness of lid briefly with fingers, then uses jar aid to loosen.

b) Use palm of hand pressing down on lid, fingers extended (ie. not included in grip).

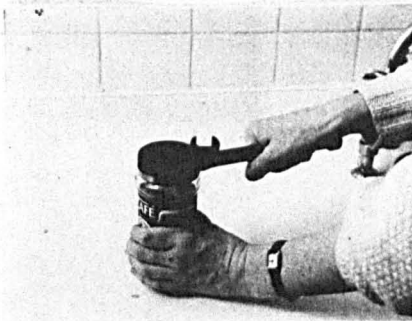
c) Gripping side of jar lid with index/middle fingers, palm and thumb in contact.

Incorrect:-

a) Twisting off cap, using fingers.

b) Struggle to remove and only then use aid to complete.

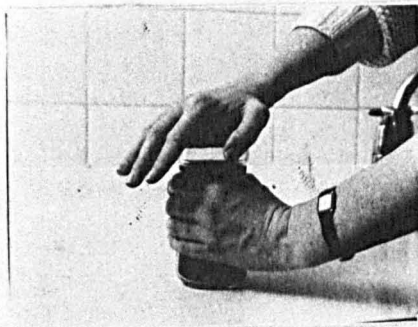
Ca



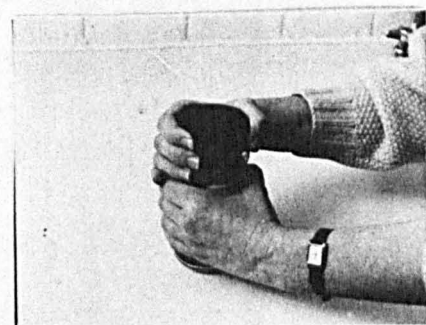
la



Bb



Bc



8) Close jar.

Correct:-

- a) Use jar aid any design.
- b) Place lid on jar, hold lid still by pressing with heel/palm of hand (fingers not involved in grip) and turn jar with other hand.

Borderline:-

- a) Use palm of hand, fingers not involved in grip.

Incorrect:-

- a) Screw on lid with fingers.
- b) Uses aid but completes task by finally tightening lid with fingers.
- c) Uses heel/palm of hand then completes task by finally tightening lid with fingers.

9). Carry shopping bag

Correct:-

- a) Carry in arms close to body
- b) Carry over forearm (can pick up with hook grip one-handed initially to put on forearm).

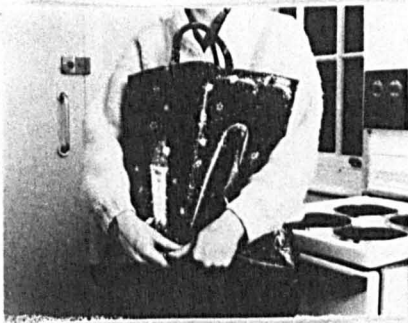
Borderline:-

- a) Use hook grip two hands, fingers in alignment.
- b) Pick up with hook grip and start crossing room, then change to forearm
- c) Take items out to reduce weight of bag, then carry using hook grip one or two handed.

Incorrect:-

- a) Use hook grip one-handed.
- b) Use 'hook' grip two-handed with deviated fingers.
- c) Lift and carry using fingertips only.

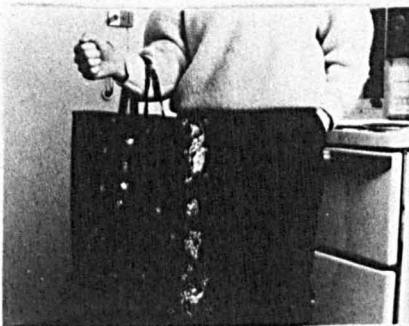
Ca



Ba



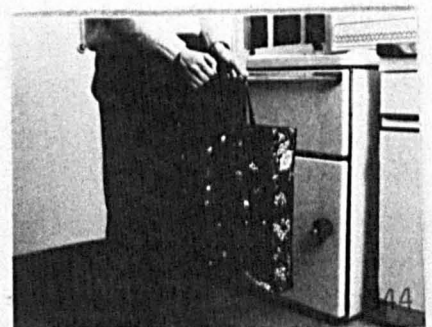
Cb



la



lb



10) Open tin.

Correct:-

a) Use electric can opener - table top model.

Borderline:-

a) Use wall can opener.

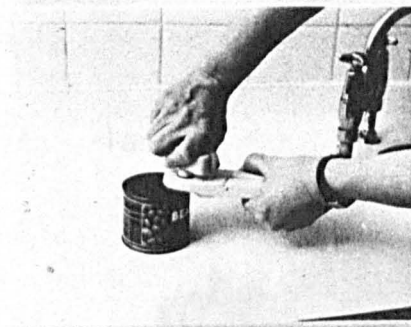
b) Use electric can opener - hand held model.

Incorrect:-

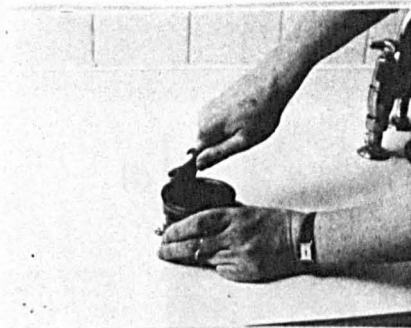
a) Using 'butterfly/ wing' style openers, turning with thumb and index/middle fingers.

b) Use tin opener with blade, ie. requiring lid be stabbed/ pierced to initially open.

1a



1b



11) Carry pan to cooker.

(Pan weighs 850g or 1lb. 10 oz.)

Correct:-

- a) Using one hand on handle, other supporting base with palm of hand.

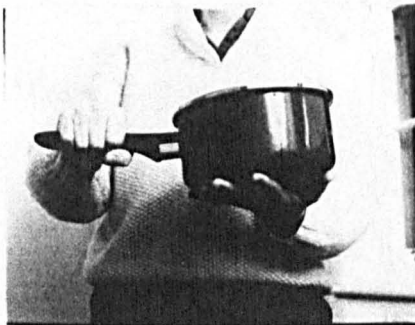
Borderline:-

- a) Using 2 hands on handle.

Incorrect:-

- a) Using one hand - wrist extended or flexed.
- b) Using two-hands - one however obviously not taking weight but only guiding (eg.fingertips of one hand in contact only with handle or at side of pan).
- c) Carrying part-way one-handed and completing two-handed.
- d) Carrying part-way two-handed and completing one-handed.

Ca



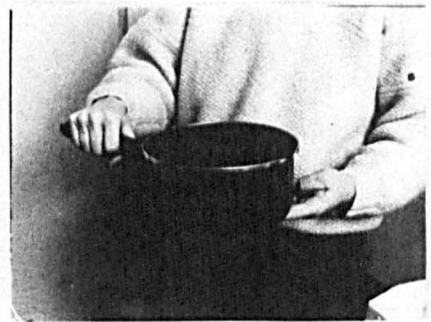
1a



Ba



1b



12) Lift out large tupperware box from bag

(Weight approx. 850g)

Correct:

a) Use two hands, box held between palms.

Borderline:

a) Use two hands, box gripped between thumb and fingers on each hand

Incorrect:

a) Lifting one-handed, between thumb and fingers.

13) Lift grill pan into place

Correct:-

- a) Using 2 hands - one on handle other obviously supporting weight of grill on palm of hand (use cloth if hot).
- b) Avoid lifting grill pan by putting bread on rack and removing with fingers or tongs/fork etc.

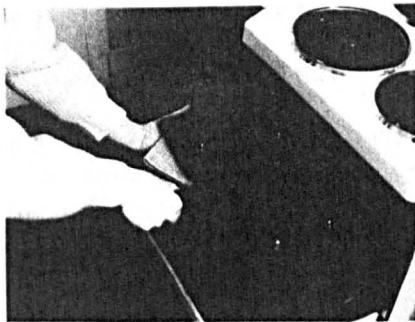
Borderline:-

- a) Using 2 hands on handle.
- b) Using two-handled grill.

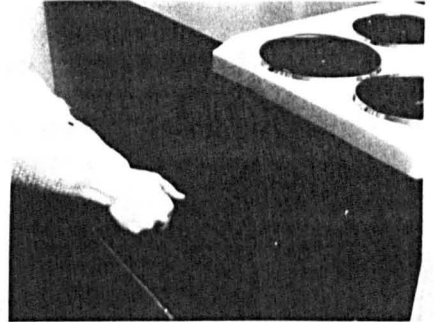
Incorrect:-

- a) Using 1 hand on handle.
- b) Using two hands - one on handle but second obviously only guiding pan into place by gripping grill edge with fingers/thumb (ie. not supporting weight).

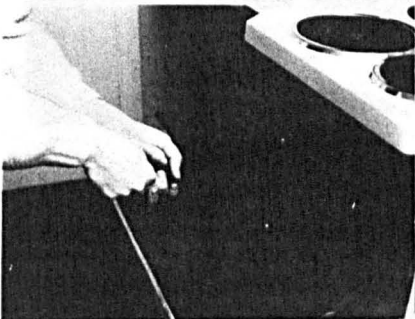
Ca



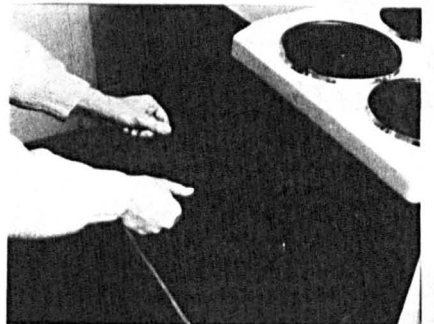
1a



Ba



1b



14) Emptying contents of pan.

Correct:-

- a) Using 2 hands - one on handle, other supporting base (using ovencloth), allowing contents to pour out.
- b) Leave pan sitting or resting tipped on surface (ie. weight not taken on hands) and spooning contents out.

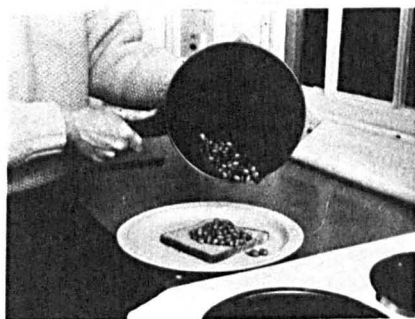
Borderline:-

- a) Using two hands on handle to pick up and hold as contents pouring out.

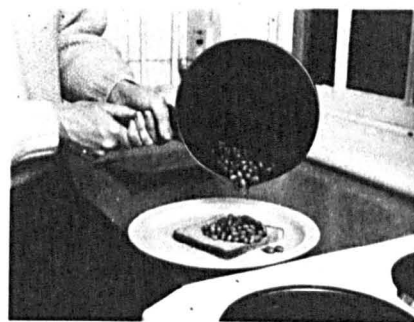
Incorrect:-

- a) Using one hand to hold pan whilst pouring/spooning out. Handle held horizontally.
- b) Picks up pan one-handed, shakes vigorously, then grips 2 handed.
- c) Lifting two handed but shaking pan vigorously before or whilst emptying.
- d) Picks up pan one-handed initially and time lapse (5secs. plus) until correct method used.
- e) Picks up pan two-handed but completes one-handed.
- f) Uses one-handed cylinder grip holding pan handle down vertically and slightly tilted whilst pours out contents.

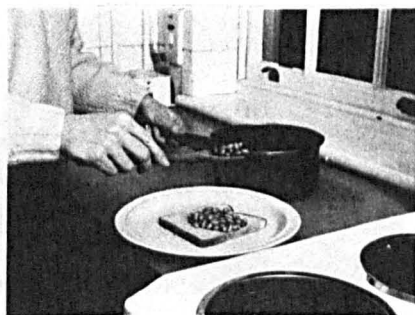
Ca



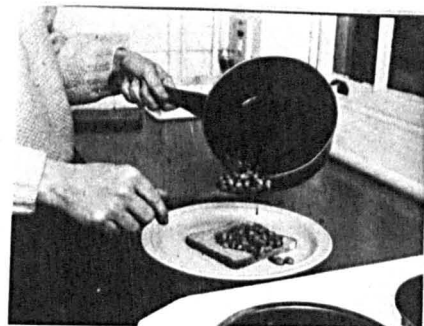
Ba



Cb



la



15). Carry plate

Correct:-

a) Hold with two hands, weight distributed over palms.

Incorrect:-

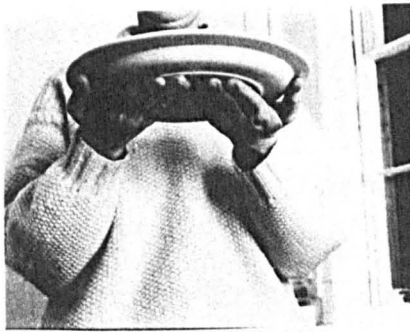
a) Gripping edge of plate one-handed, with thumb and side of index/middle fingers.

b) Gripping edge of plate two-handed, with thumb and side of index/middle fingers.

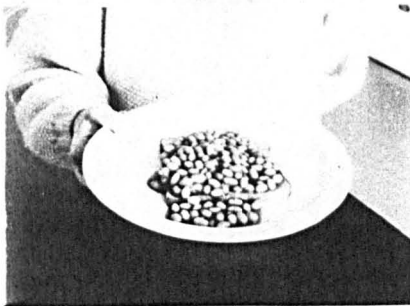
c) Hold with two hands, supporting on fingers only.

d) Gripping plate two-handed, one with fingers and thumb, other fingertips only.

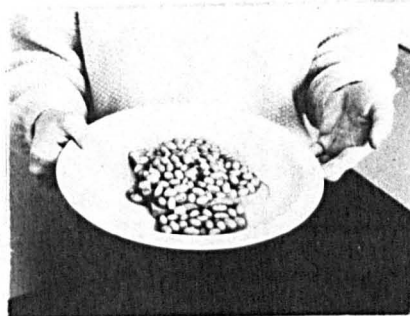
Ca



1a



1d



16) Pour kettle.

Correct:-

a) Use 2 hands - one wrist extended holding handle, other supporting weight of kettle at base (using cloth to protect from heat).

b) Use kettle tipper

c) Tip kettle (weight not held) pouring to mug - at lower level if necessary.

Borderline:-

a) Firmly gripping handle two-handed - wrists extended.

Incorrect:-

a) Holding one handed.

b) Holding two-handed but one hand obviously not supporting weight, eg. fingertips only in contact.

c) Holding two-handed - wrists flexed.

Ca



la



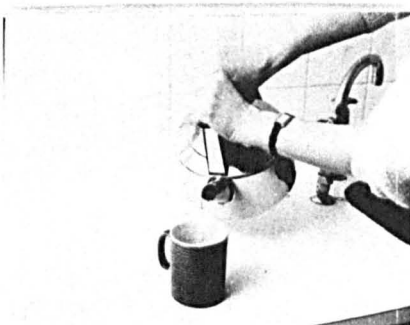
Cb



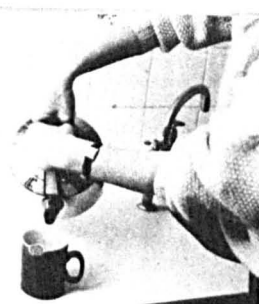
lb



Ba



lc



17) Holding full milk bottle/carton.

Correct:-

- a) Use 2 hands - one on base of bottle supporting weight, other wrapped round body of bottle.
- b) Use 2 hands - both on body of bottle.
- c) Use light milk jug.

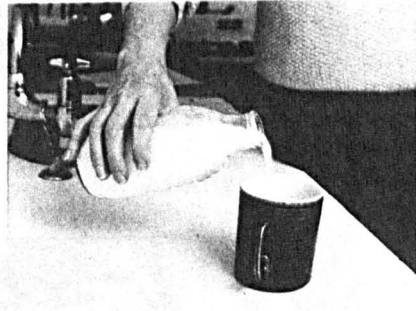
Incorrect:-

- a) Gripping body of bottle one-handed.
- b) Gripping top of bottle with fingertips.

Ca



1a



18) Carry full mug to table.

Correct:-

a) Two-handed - one on handle, other supporting weight of mug at base on palm of hand.

b) Two-handed - one on handle, other firmly wrapped round side of mug with palm and all fingers in contact.

Borderline:-

a) One-handed, with thumb hooked through handle and palm/fingers wrapped round mug.

Incorrect:-

a) Holding mug by handle only one-handed.

b) Using 2 hands - one on handle, other obviously only guiding, eg. only fingers/ fingertips in contact at side or base of mug.

c) Using 2 hands - but weight resting on side of fingers at base (fingers ulnar deviated).

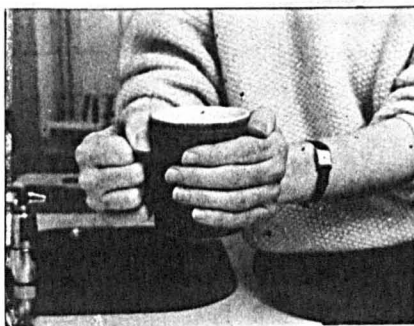
Ca



la



Cb



lc



19). Wipe surfaces

Correct:-

a) Wiping with cloth/ sponge held under flat of hand (thumb in extension at side), using waving, stroking or circular movements.

Incorrect:-

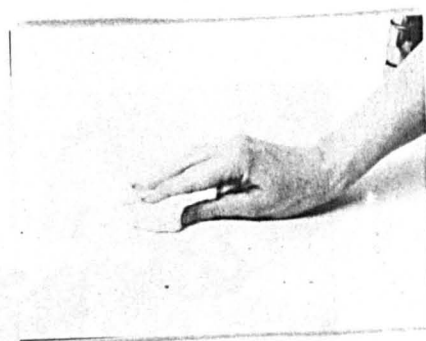
a) Hold cloth/ sponge in fingertips/thumb pressing down onto surface.

b) Cloth/ sponge held under hand but with thumb tucked under palm, ie pressure from fingers and not from palm of hand.

Ca



lb



20). Squeeze out cloth/sponge

Correct:-

a) Press out cloth/ sponge on sink surface with palm of hand.

b) Press out cloth/ sponge between palms of hands, fingers in extension.

Borderline:-

a) Wrap cloth round taps to squeeze out excess water.

Incorrect:-

a) Use two hands in twisting/ wringing/squeezing movement.

b) Squeeze out in fist of one hand.

Ca



Ja



Ba



Ib



SECTION IV

PRACTICE ASSESSMENT ANSWERS.

DO NOT look at these answers until you have assessed the practice assessments at the end of the training tape.

If your assessments disagree with the answers given here, go back and review the tape and booklet until you are sure why the answer sheet is right.

Please contact Alison Hammond if any difficulties.

JOINT PROTECTION BEHAVIOUR ASSESSMENT - TRAINING TAPE.

Approximate running times (mins.):

Introduction	0.00
Task 1	8.00
Task 2	9.00
Task 3	11.00
Task 4	13.08
Task 5	15.00
Task 6	17.10
Task 7	18.25
Task 8	19.50
Task 9	20.55
Task 10	22.15
Task 11	23.10
Task 12	24.30
Task 13	25.20
Task 14	26.40
Task 15	28.40
Task 16	29.25
Task 17	31.00
Task 18	31.45
Task 19	33.35
Task 20	34.25

Practice assessment introduction:
35.35

Practice 1	36.30
Practice 2	41.20

End tape 46.40

JOINT PROTECTION BEHAVIOUR ASSESSMENT

Assessor Name.....A.H..... Subject No. J... Video..7....1[] [] []

5[]

	C	B	I	Notes	Score
1. Carry tray	[]	[✓]	[]	1 HAND C, OTHER I = B.	7[]
2. Turn on tap	[]	[✓]	[]	CYLINDER GRIP = B	9[]
3. Fill kettle	[✓]	[]	[]	KETTLE SITTING IN SINK = C	11[]
4. Turn off tap	[]	[]	[✓]	TURN WITH FINGERS = I	13[]
5. Carry full kettle	[]	[✓]	[]	2 HANDS, WRISTS EXTENDED = B	15[]
6. Push in wall plug	[]	[]	[✓]	PUSH WITH THUMB = I	17[]
7. Open jar	[✓]	[]	[]	HOLD LID WITH PALM + TURN JAR = C	19[]
8. Close jar	[]	[]	[✓]	SCREW LID ON WITH FINGERS = I	21[]
9. Carry shop bag	[]	[✓]	[]	HOOK GRIP CROSS ROOM, CHANGE TO FOREARM = B	23[]
10. Open tin	[]	[]	[✓]	BUTTERFLY CAN OPENER = I	25[]
11. Carry pan to cooker	[]	[]	[✓]	ONE HAND ON HANDLE, OTHER ONLY GUIDING = I	27[]
12. Lift box from bag	[]	[✓]	[]	2 HANDS GRIPPING THUMB/ FINGERS = B	29[]
13. Lift grill pan	[]	[]	[✓]	1 HAND ON HANDLE, OTHER GUIDING = I	31[]
14. Empty pan contents	[]	[]	[✓]	VERTICAL CYLINDER GRIP = I	33[]
15. Carry plate	[]	[✓]	[]	1 HAND ON PALM = B	35[]
16. Pour kettle	[]	[]	[✓]	1 HAND ON HANDLE, OTHER FINGERS ONLY IN CONTACT = I	37[]
17. milk	[✓]	[]	[]	2 HANDS ON BODY OF BOTTLE = C	39[]
18. Carry mug	[]	[✓]	[]	1 HAND THUMB HOOKED THROUGH WITH FINGERS ROUND = B	41[]
19. Wipe surfaces	[]	[]	[✓]	*	43[]
20. Squeeze cloth	[]	[]	[✓]	SQUEEZE 1 FIST = I CHANGE TO 2 FISTS = I	45[]

19.* CLOTH HELD WITH THUMB UNDER = I, CHANGE TO HAND FLAT = B, BUT CHANGING TO FINGER/THUMB GRIP = I

Score...13/40..

47[] []

32.5%

JOINT PROTECTION BEHAVIOUR ASSESSMENT

Assessor Name.....AH..... Subject No. 2. Video...X...1[] [] []

5[]

	C	B	I	Notes	Score
1. Carry tray	[]	[]	[✓]	2 HANDS ON EDGES = I, CHANGE TO 1 HAND UNDER BUT WEIGHT ON PALM ONLY NOT FOREARM ∴ = I	7[]
2. Turn on tap	[]	[✓]	[]	PALM OF HAND TO LOOSEN, COMPLETING MOVEMENT WITH FINGERS = B (C) PAGE 18.	9[]
3. Fill kettle	[]	[]	[✓]	1 HAND HANDLE + 1 UNDER = C, BUT CHANGING TO 1 HAND ONLY = I	11[]
4. Turn off tap	[]	[]	[✓]	FINGERS TO TURN = I	13[]
5. Carry full kettle	[]	[]	[✓]	START WITH 1 HAND, ^I HALFWAY CHANGE TO 2, BUT WRISTS FLEXED =:	15[]
6. Push in wall plug	[✓]	[]	[]	LINE UP WITH FINGERS, PUSH IN WITH PALM = C	17[]
7. Open jar	[]	[]	[✓]	STRUGGLE TO OPEN + FINALLY USES AID = I	19[]
8. Close jar	[]	[]	[✓]	USE PALM, (C) CHANGE TO FINGERS = I	21[]
9. Carry shop bag	[]	[]	[✓]	HOOK GRIP 2 HANDS AS LIFT UP FINGERS → ULNAR DEVIATION = I	23[]
10. Open tin	[]	[✓]	[]	HAND HELD ELECTRIC NOSE = B	25[]
11. Carry pan to cooker	[]	[]	[✓]	START WITH 1 HAND PARTWAY, COMPLETING 2 HANDED = I (C), PAGE 27.	27[]
12. Lift box from bag	[]	[]	[✓]	LIFT OUT WITH 1 HAND = I	29[]
13. Lift grill pan	[]	[]	[✓]	LIFT WITH 2 HANDS = C, BUT COMPLETE WITH 1 = I ∴ = I	31[]
14. Empty pan contents	[]	[]	[✓]	START 1 HAND (I) CHANGE TO REST ON SURFACE (C) CHANGE TO 1 HAND = I	33[]
15. Carry plate	[]	[]	[✓]	2 HANDS ON EDGES = I	35[]
16. Pour kettle	[]	[]	[✓]	START 1 HAND (I) CHANGE TO 2 HANDS WRISTS FLEXED (I)	37[]
17. Hold milk	[]	[✓]	[]	LIFT OUT 1 HAND (I) CHANGE TO 2 HANDS (C) ∴ = B	39[]
18. Carry mug	[]	[]	[✓]	1 ON HANDLE, 1 UNDER BUT WITH DEVIATED FINGERS = I	41[]
19. Wipe surfaces	[]	[]	[✓]	HELD FINGERS/THUMB = I	43[]
20. Squeeze cloth	[]	[]	[✓]	FIST OF 1 HAND = I.	45[]

Score...5/40..

12.5%

47[] [] []

The JPBA score sheet on the following page may be freely photocopied.

JOINT PROTECTION BEHAVIOUR ASSESSMENT

Assessor Name..... Subject No.... Video.....1[][][]
5[]

	C	B	I	Notes	Score
1. Carry tray	[]	[]	[]		7[]
2. Turn on tap	[]	[]	[]		9[]
3. Fill kettle	[]	[]	[]		11[]
4. Turn off tap	[]	[]	[]		13[]
5. Carry full kettle	[]	[]	[]		15[]
6. Push in wall plug	[]	[]	[]		17[]
7. Open jar	[]	[]	[]		19[]
8. Close jar	[]	[]	[]		21[]
9. Carry shop bag	[]	[]	[]		23[]
10. Open tin	[]	[]	[]		25[]
11. Carry pan to cooker	[]	[]	[]		27[]
12. Lift box from bag	[]	[]	[]		29[]
13. Lift grill pan	[]	[]	[]		31[]
14. Empty pan contents	[]	[]	[]		33[]
15. Carry plate	[]	[]	[]		35[]
16. Pour kettle	[]	[]	[]		37[]
17. Hold milk	[]	[]	[]		39[]
18. Carry mug	[]	[]	[]		41[]
19. Wipe surfaces	[]	[]	[]		43[]
20. Squeeze cloth	[]	[]	[]		45[]

Score..... % 47[][]

If you have any queries, difficulties or require information on the content validity, test re-test reliability and inter-observer reliability studies carried out in the development of this assessment please contact the author.

APPENDIX 4 - KITCHEN ACTIVITIES RELEVANT TO THE FIVE JP PRINCIPLES
ASSESSED IN THE JPBA.

1. Reducing effort required to perform tasks by:

a) Use of technical aids.

Labour-saving equipment, eg. food processors, dishwashing machines.

Aids to daily living, eg. wide grip peelers, jar opener, tap turner, easy grip scissors, kettle tipper, adapted plug.

b) Avoiding lifting/carrying.

Sliding objects along surfaces as much as possible.

Using wheels to assist, eg. trolley to transport rather than carry.

Tipping to empty kettle or pan contents.

Using a spoon/ladle to empty pan contents and avoiding lifting and pouring out.

2. Distributing load over several joints.

Closing drawer with both palms, wrists in neutral, rather than fingers.

Carrying plates on both palms rather than gripping edges.

Carrying a tray on both palms and forearms.

Carrying with two hands, eg. mug, pan.

Stirring holding spoon with two hands.

3. Use each joint in its' most stable, functional position.

Avoiding performing activities in wrist flexion, eg. lifting pans, kettles etc. with extended wrists.

Wringing out cloths by wrapping round taps or squeezing out flat (avoid wringing).

Holding a spoon for stirring/ wash-up brush/knife for cutting in a dagger rather than pen grip, ensuring wrist flexion avoided.

4. Use of strongest, largest joint.

Closing drawer with foot, hip, knee or elbow, not fingers.

Closing plastic storage box with elbow.

Use strap through door handles, pulling open with forearm.

Lift packages with forearms.

Carry bags over shoulder/forearm, not hands.

5. Avoiding positions of possible joint deformity.

a) Avoid pressure against the dorsum, sides and pads of fingers.

eg. avoid:

Pressing spray buttons with fingertips.

Using butterfly style can openers.

Tight key grips.

Cleaning pans etc. by holding wash-up sponge/cloth in fingertips tightly.

Stirring/mixing with spoon in pen grip.

Cutting hard objects and peeling vegetables with knife held pushing MCPs into ulnar deviation.

Opening jars/ turning taps with fingers in ulnar deviation.

Pushing in plugs/ closing drawers with fingertips.

Lifting items with fingers in ulnar deviation, eg. mugs, jugs, bottles, teapot, kettles, pans.

Gripping tray/ plate edges.

Opening packets with fingers.

Using scissors to cut thick items.

Lifting heavy objects, eg. pans, kettles, one-handed. Avoid cylinder grip where fingers pushed into ulnar deviation.

Straining or emptying pan contents one-handed.

b) Avoid tight grips and keep the hands open.

Avoid tight grips on kitchen knives, cutlery - use built up handles.

Avoid holding ends of rolling pin, roll with palms.

Use a mitt-style wash-up cloth, avoid holding with fingertips.

Avoid wringing cloths, use a sponge and press out.

Avoid holding vegetables when peeling, use a spikeboard.

Secure objects with wedges, clamps or non-slip matting, rather than having to hold steady.

Sources: Brattstrom, 1987; Chamberlain, Ellis and Hughes, 1984; Cordery, 1965b; Feinberg, undated; Furst, Gerber and Smith, 1987; Gruen, Medsger and White, 1980; Haviland, Kamil-Miller and Sliwa, 1978; Lorig and Fries, 1983; Melvin, 1989; Reeks et al, 1990; Rossky, 1980; Sandles, 1990; Smith, McGee and Whitworth, undated; Swezey, 1978; Unsworth, 1986; Watkins and Robinson, 1974; Wiggins, Freeman and Collier, undated.

Appendix 5:
Face Validity of the JPBA

JPBA TASKS	HAND JP PRINCIPLE				
	Reduce effort	Distribute load over several joints	Use joints in stable positions	Use strongest, largest joint	Avoid positions of possible deformity
1 Carry tray		●	●	●	●
2 Turn on tap	●	●	●	●	●
3 Fill kettle	●	(●)			●
4 Turn off tap	●	●	●	●	●
5 Carry full kettle	●	(●)			●
6 Push in plug	●			●	●
7 Open jar	●	●			●
8 Close jar	●	●			●
9 Carry shop bag	●	(●)		●	●
10 Open tin	●				●
11 Carry pan to cooker		●	●		●
12 Lift box from bag		●	●		●
13 Lift grill pan	●	●	●		●
14 Empty pan contents	●	●			●
15 Carry plate		●	●		●
16 Pour kettle	●	●	●		●
17 Carry milk bottle	●	●			●
18 Carry mug		●	●		●
19 Wipe surfaces		●			●
20 Squeeze cloth		●	●		●
Other tasks not included:					
1 Close box				●	●
2 Turn knob on	●				●
3 Close drawer			●	●	●
4 Stir pan contents			●		●
5 Washing up pan		●	●		●

Key: ● Principle applied in "correct" method
 (●) Principle applied in "borderline" method

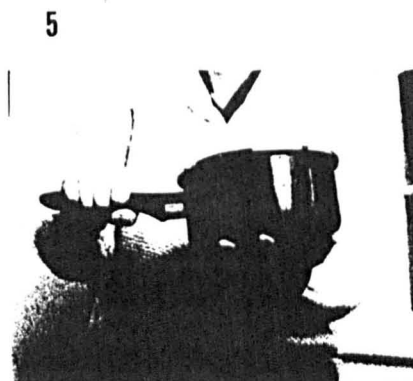
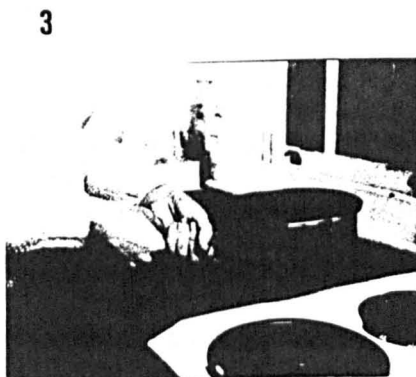
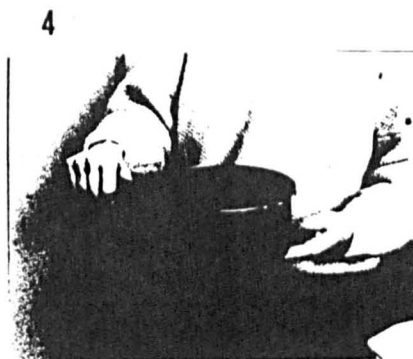
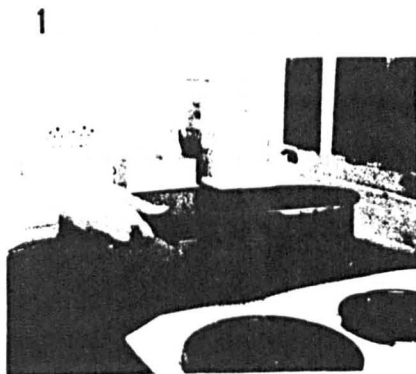
APPENDIX 6 - SAMPLE PAGE. JPBA CONTENT VALIDITY STUDY - TASK
DEFINITIONS REVIEWED BY EXPERTS.

11) Carry pan to cooker.

(Pan weighs 850g or 1lb. 10oz.)

- 1) Using one hand - wrist extended or flexed. 1_
- 2) Carrying part-way one-handed and completing two-handed. 2_
- 3) Using 2 hands on handle. 3_
- 4) Using two-hands - one however obviously not taking weight but only guiding (eg. fingertips of one hand in contact only with handle or at side of pan). 4_
- 5) Using one hand on handle, other supporting base with palm of hand. 5_
- 6) Carrying half-way two-handed but completing task one-handed. 6_

eg.



APPENDIX 7 - CONTENT VALIDITY JPBA EXPERTS.

1. Marian Ferguson, DipCOT.

Senior 1 Rheumatology OT,

St. Albans City Hospital, Herts.

Experience: 10 years rheumatology OT practice. Runs weekly out-patient metrology clinic. Special interests; development and running early intervention programme for inflammatory joint disease patients. Regularly lectures on patient education and OT in rheumatology. Assisting in multi-centre research project on early RA. Currently Chair of OT Special Interest Rheumatology Group.

2. Valerie Kulkarni, DipCOT.

Senior 1 Rheumatology OT,

Leeds General Infirmary.

Experience: 8 years rheumatology OT practice. Special interests; development and running of patient education programmes, pre-operative hand assessments, splinting. Regularly lectures on OT and joint protection.

3. Paula Jefferson, DipCOT.

Senior 1 Rheumatology OT,

Robert Jones and Agnes Hunt Orthopaedic Hospital,

Oswestry, Shropshire.

Experience: 2 years Rheumatology OT practice. Special interests: development and running of arthritis education in-patient group, hand assessments, splinting, joint protection.

4. Anne McGee, DipCOT.

Senior 1 Rheumatology OT,

Derbyshire Royal Infirmary, Derby.

Experience: 2 years Rheumatology OT practice. Special interests; development and running arthritis education out-patient group; splinting; footwear and foot orthoses. Co-author advice booklet for

RA patients (Smith, McGee and Whitworth, 1990).

5. Jane Purser, DipCOT.

Head 3 OT,

West Suffolk Hospital, Bury St.Edmunds, Suffolk.

Experience: 6 years Rheumatology OT practice. Special interests; arthritis education groups, currently researching into knowledge increase following education.

6. Heather Unsworth, DipCOT., FETC.

Senior 1 Research OT,

Odstock Hospital, Salisbury, Wilts.

Experience: 18 years Rheumatology OT practice and research. Special Interests; development, running and evaluation of an arthritis education programme (the SPIRE programme); development of hand assessments; pre-operative hand assessment and post-operative hand programmes; splinting. Regularly lectures on OT and joint protection. Author "Coping with Rheumatoid Arthritis" (1986).

APPENDIX 8 - JOINT PROTECTION KNOWLEDGE ASSESSMENT.

Name.....

Date.....

The following questions are about what you think are good and not so good ways of using your hands in a variety of everyday tasks.

Each question has 3 possible ways of doing the task.

Please:

[] TICK the answer you think is the best method, ie. puts less strain on hand joints

It can be hard to think about how to do everyday tasks in words. When answering, try to imagine the actions described or even try out the different methods at home.

PLEASE COMPLETE ALL THE QUESTIONS AND MARK [] AGAINST THE BEST METHOD.

Here is an example:

Q: Getting up from an armchair, should you:

- a. grip the front edge of the chair with palms of hands to help get up []
- b. push up with your knuckles to help get up []
- c. use your leg muscles to do the work and don't use hands []

Please turn over.....

1. Taking a hot dish out of the oven (using oven gloves) and across to the dining table should you:

- a. firmly grip the sides of the dish between fingers and thumbs, lift out and carry to the table [0]
- b. slide dish out between palms of hands, lift out to top of cooker and serve there [2]
- c. firmly grip sides between fingers and thumbs, lift out and put on top of cooker and serve up there [1]

2. When cleaning the inside of windows, should you:

- a. grip the handle of a squeegee/ or grip a sponge [1]
- b. use a cloth in the flat of the hand with circular movements [2]
- c. grip a cloth in fingers and thumb [0]

3. Carrying a basket of washing to hang out, should you:

- a. wrap arms round sides of the basket and hold it close to the chest [2]
- b. grip edges firmly with both hands [1]
- c. hold on your hip, using your arm and palm of hand to steady it on top [0]

4. Writing a long letter should you:

- a. hold the pen normally and stop occasionally to stretch out your hand and fingers straight [1]
- b. hold the pen normally and write the letter without stopping [0]
- c. wrap some foam round an ordinary pen and stretch your fingers occasionally [2]

5. When hoovering downstairs should you:

- a. push the hoover with one hand and clean all the rooms in the same day [0]
- b. grip with two hands and clean all the rooms in the same day [1]
- c. hoover one room a day, pushing with two hands [2]

6. When ironing the laundry, should you:

- a. lift iron across from the iron rest to board and grip handle as lifting [0]
- b. slide iron across from rest to board and push iron keeping fingers straight [2]
- c. lift iron across but push it keeping fingers straight [1]

7. When organising doing the household chores, should you:

- a. swap between doing heavier and lighter tasks [1]
- b. get as many done at once as possible [0]
- c. make sure to give your hands a few minutes rest every 10 to 15 minutes [2]

8. When getting the weekly shopping home or to and from the car, should you:

- a. use a trolley [1]
- b. get it delivered or ask a friend or the family to take it out of the car [2]
- c. carry bags one at a time yourself [0]

9. When preparing potatoes for several people should you:

- a. use an ordinary peeler [0]
- b. use a wide grip peeler [1]
- c. buy ready washed potatoes, cook them in their skins (and remove peel after if wish) [2]

10. When turning off a tap should you:

- a. use a tap turner [2]
- b. press down on top of the tap and turn, using the palm of hand [1]
- c. grip tap firmly with fingers and tighten [0]

11. When serving up stew from a pan should you:
- a. hold pan in one hand, whilst spooning out the contents with the other [0]
 - b. leave the pan on top of the cooker and spoon out from there [2]
 - c. grip the handle with both hands and allow the contents to pour out slowly [1]
12. When closing a drawer should you:
- a. push it closed with your palm [1]
 - b. push it closed with your fingers [0]
 - c. push it closed with your hip or thigh [2]
13. When bringing a carrier bag of groceries home, should you:
- a. hold it using both arms and hands, holding it close to your body [2]
 - b. carry it with the handle over your forearm [1]
 - c. take hold with a firm grip in one hand [0]
14. When carrying a tray should you:
- a. take a firm grip on the edges of the tray with both hands [0]
 - b. grip the tray edge with one hand to steady and support the weight on your forearm beneath [1]
 - c. slide the tray onto your palms and forearms to carry it [2]
15. When undoing a new jar should you:
- a. use the palm of the hand pressing down on the lid to turn, rather than the fingers [1]
 - b. use a jar opener [2]
 - c. firmly grip the lid with the fingers and twist off [0]
16. When moving a full pan across to the cooker should you:
- a. slide the pan as much as possible [2]
 - b. lift across by the handle using one hand [0]
 - c. use two hands, one on the handle and one supporting underneath [1]

17. When reading a book should you:

- a. hold it with the weight resting on your palms [1]
- b. rest the book on a cushion on your lap [2]
- c. hold the edges of the book [0]

18. If your household jobs are often causing aching or painful hands should you:

- a. stop, look at how you do tasks and alter the activities that cause pain [2]
- b. carry on as usual and work through the pain [0]
- c. stop, wait until it eases off and then carry on [1]

19. When inviting family or friends round for a meal, should you:

- a. plan in advance and do some preparation the day before [2]
- b. plan in advance and prepare the same day [1]
- c. plan and prepare on the same day as the meal [0]

20. When you feel your arthritis is worse should you:

- a. go to bed and get up at your normal time [0]
- b. go to bed for longer and take an extra rest during the day [2]
- c. go to bed for longer (resting for 8-9 hours) [1]

THANKYOU VERY MUCH FOR YOUR HELP BY COMPLETING THIS FORM.

Footnote:

Numbers in brackets denote the score assigned to each option and do not appear on the questionnaire.

Appendix 9A:
Face Validity of JPKA

JP PRINCIPLE:	JPKA QUESTION NOs.																			
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
1 Respect pain																		●		
2 Balance rest and work				●	●		●												●	●
3 Use of energy conservation			●		●			●	●			●	●					●	●	
4 Avoid activities cant stop					(●)			(●)											(●)	
5 Avoid holding one position				●			●										(●)			
6 Reduce effort a) using aids										●						●				
b) Avoid lifting/carrying	(●)					●		●			●					●	●			
7 Distribute load	●	●	●		●	●				●		●	●	●	●					
8 Stable positions		(●)								(●)					(●)					
9 Strongest joint/s			●									●	●							
10 Avoid positions deformity	●	●	●	●		●			●	●				●	●		●			

Appendix 9B:
JPKA Content Validity Study

		JPKA QUESTION NOS.																			
JP PRINCIPLE:		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
1 Respect pain					1			1									1		5		3
2 Balance rest and work					7	7		15	2	1									3	8	11
3 Use of energy conservation				4	1	5	1	2	7	6		1	4	4			1		6	11	
4 Avoid activities cant stop																					
5 Avoid holding one position					6			2		1											
6 Reduce effort a) using aids										1	10					9					
b) Avoid lifting/carrying	1						5		5			13				3	5	4			
7 Distribute load	10	8	17	1	9	5		3	1	6	1	7	11	12	7	4	2			2	
8 Stable positions	1	1				1				1			2		1		1				
9 Strongest joint/s			5		1					3		14	2		2		1				
10 Avoid positions deformity	6	7	3	7		5		1	4	10	2	1	2	3	3	2	2				

n = 18

SESSION 1.

A. Introduction - General description of the disease and how it affects joints (Rheumatology nurse).

The main objective of this programme is to teach people with Rheumatoid Arthritis how to live with their disease, understand what is happening in their joints, and how to cope with it. In doing this we will introduce you to the patients to the theories and ideas of Joint Protection, exercise, resting and working positions, energy conservation, relaxation, pain management and any other topic you as a member of the group would like us to include in an open session at the end of the course.

All of the members of the Rheumatology team work together for the good of you the patient. Should you want to discuss anything at any time, do not hesitate to ask.

The team consists of:

Consultant

Nursing Staff, Physiotherapists, Occupational Therapists

(Dietician, Pharmacy, Radiography, Pathology/Lab staff)

YOU

In order to understand how to help arthritis, it is important to know a little about it.

There are in fact over 180 varieties of arthritis.

Everyone has heard of rheumatoid and osteoarthritis. Quite often people get confused by using the term "arthritis" which can mean any problem with a joint.

Basically osteoarthritis is the wear and tear or degenerative arthritis, where the cartilage inside the joint gradually deteriorates over a period of time, the bones around it thicken and grow stiff.

In rheumatoid arthritis, inflammatory polyarthritis or erosive arthritis, the joints (usually the smaller joints eg the hands and feet initially) become inflamed. No one knows the cause of rheumatoid arthritis, although some trends have been shown:

There is a familial tendency, it can be passed on through families. It can in some cases be brought on following physical or mental stress eg bereavement.

It may well be started by an infection or virus.

It affects mainly women between 20-50. (70% of patients affected are female).

People with psoriasis can develop joint problems.

Let us look at a normal joint, then you will be able to understand more about what is happening in a joint with rheumatoid arthritis.

DIAGRAM OF NORMAL JOINT ON POSTER/ OHP.

Joints in the body are there to allow us to move. A joint is formed where 2 bones meet, eg the knee joint is where the thigh bone (femur) meets the shin bone (tibia). The ends of the bone are covered with cartilage: this slippery resilient substance reduces friction and is a shock absorber. To hold the joint together there is a strong fibrous capsule. This is firmly attached at both ends and strengthened by ligaments; which make the joint stable. Motion of the joint is brought about by muscle activity. Muscles are very important as they support and protect the joint and help prevent damage.

Inside the joint and surrounding it is a layer of tissue called the synovial membrane (joint lining); this secretes a thick fluid called the synovial fluid that lubricates and nourishes the cartilage which makes movement easy. In a normal joint there is only a small amount of this fluid.

DIAGRAM OF AN INFLAMED JOINT.

As mentioned before, RA does vary between people. Not all RA sufferers have the same problems or the same joints involved, but there are general features that are seen to some extent in all patients with RA.

INFLAMMATION

Inflammation is nature's response to tissue irritation or infection. With inflammation there is heat, redness, swelling and pain. This is due to the opening of small blood vessels and the movement of cells and fluid from the vessels into the tissue space. The joint lining becomes inflamed, it gets thicker and swells, there is more blood flow and it gets warmer. As the lining swells it pushes out against the tight capsule and ligaments, stretching them: this causes pain and stiffness. The thickened lining produces too much fluid and this stretches the capsule and ligaments even more. The fluid can attack the cartilage, which can become thin and worn away, eventually it invades the bone to produce erosions.

Often after the inflammation and swelling has subsided the capsule and ligaments holding the joint together are overstretched and remain slack. This means the joint is not as stable as before and could slip out of alignment. The joint can sometimes feel as if it is giving way. With pain and stiffness in the joints, movement is impaired; this means the muscles surrounding the affected joints are not used normally. This leads to weakness and wasting. As the muscles become weaker they ache and provide less protection for the joint. This can lead to damage and deformity.

In a few people other parts of the body also become inflamed. Nodular swellings under the skin can develop, especially over the elbows and other pressure areas. These are known as rheumatoid nodules.

HOW YOU MIGHT FEEL.

As we have already said, the exact cause of the disease is not yet known. It has been shown that the immune system plays a part in the disease.

The onset is usually gradual. The first symptoms often occur in the wrist, fingers or balls of the feet. The joints become uncomfortable; they may swell and are particularly stiff in the morning. Occasionally it starts suddenly in several joints at the same time. With RA you can feel irritable and depressed. The inflammation can make you feel generally unwell; it can cause anaemia and loss of

weight - if there is only minimal joint involvement and the inflammation not too active you may feel quite well. Widespread or active disease can make you feel rotten, tired, no energy. The inflammation, like the disease, does vary from person to person in severity. People with RA also suffer from "flare-ups" in which the inflammation becomes more intense for a few days or weeks before subsiding again. Various complications can arise at any stage of the disease, these are usually mild. Constant inflammation of the wrist and hand can cause pressure on the nerves resulting in tingling or numbness of the fingers. Sometimes the tendons may be trapped in swollen tissue causing sticking or "trigger" finger. The pads under the balls of the feet may be displaced so that it feels like you are walking on pebbles. The tear secretion in the eyes is sometimes affected, making them sore and gritty. there may also be a decreased production of saliva, causing excess dryness of the mouth. All these conditions can be treated by your consultant.

B. Management and drug therapy (Rheumatologist).

Explanation of various treatments possible. The aims of drug therapy. First, second and third line drugs and the action of common drugs prescribed. Importance of using anti-inflammatories as well as painkillers. Common side-effects of drugs, ways to reduce these. Problems in prescribing drugs.

SESSION 2.

A. THE USE OF ALTERNATIVE REMEDIES AND THERAPIES (Rheumatology nurse).

Introduction.

Why a discussion about the use of alternative remedies and therapies?

Well, there is increasing evidence that more and more people are turning towards them for the relief of chronic conditions such as Rheumatoid Arthritis.

A recent survey by Arthritis Care carried out in 1989 may offer explanations for this. Their results suggested that a significant proportion of respondents complained of pain being present most of the time, despite taking medication prescribed by their GP/specialist. It is not surprising therefore that a fair number will look for relief elsewhere. Another factor of course, could be the increased publicity by companies selling such products as Cod Liver Oil, Evening Primrose Oil and Seatone (Green lipped mussel extract) and heightened public awareness generally.

There hasn't been a lot of research carried out into the effectiveness of various remedies and therapies, and what has been done seems to be divided equally into "fors" and "againsts." We therefore rely heavily on anecdotal evidence, which is not terribly reliable, as effects can vary from person to person.

There is research however, that supports Cod Liver Oil as having anti-inflammatory properties, which is obviously going to benefit people with inflammatory conditions such as arthritis, with little evidence of side effects. The active ingredient in Cod Liver Oil is EPO which is also present in Evening Primrose Oil - hence its popularity. There is a theoretical risk however, that the effective

ingredient in Evening Primrose Oil is counteracted by another ingredient. Still, it seems to work for some people, but not everybody.

If you are considering trying an alternative remedy/ therapy, then the following advice might be helpful:-

- a) Try and gather as much information on the remedy as possible.
- b) If you are considering consulting a therapist such as a homeopath/ acupuncturist ensure they are properly qualified
- c) Always discuss the remedy/ therapy with your GP/ specialist, as they will need to know whether you benefit or experience side effects, particularly in relation to your prescribed drugs.
- d) NEVER stop taking your prescribed medication without first consulting your GP/ specialist, as this could do you more harm than good.

DISCUSSION POINTS

1. Has anybody in the group tried alternative remedies/ therapies, if so what?
2. What benefits/ side effects were experienced?
3. Are users GPs/ specialists aware?
- 4 How did users obtain information?

B. Advice on diet (Rheumatology nurse).

Importance of a balanced diet in combatting ill-health and maintaining health. Constituents of common foods. A balanced diet. Taking mineral and vitamin supplements - is it necessary?

C. Rest and relaxation (OT).

Rest and relaxation can be seen as further tools to independence allowing the body to recuperate after stress to joints.

The joints that are most used are often the most inflamed.

Rest can be from reducing an activity which overuses a joint to complete bedrest, or a change to lighter work or spending 1-2 hours resting on a bed each day.

It may be difficult to lay aside specific times for resting but it can often be incorporated into other general activities, eg relaxing in the bath, or whilst watching television.

Your body may need more rest when you have a flare-up.

Rest for individual joints is helpful and may be achieved through the use of light splints.

Relaxation:

Total relaxation takes practice and requires that both the mind and

the body are totally relaxed. If, for example, the body is relaxed and the mind is not and vice versa, then total relaxation cannot be achieved.

This may be difficult to achieve due to pain in the joints but there is evidence that relaxation can be an active way of reducing pain. Tension makes it easier for the brain to receive pain stimuli. therefore if the mind and body are relaxed it is mor difficult for the pain stimulus to be received.

If you have difficulty relaxing there are many commercial relaxation packages available.

Two relaxation sessions will take place in sessions 2 and 3.

POSTERS -

1. Benefits

- relieves pain and lowers anxiety level
- relieves pain of joints and muscles
- relieves insomnia
- relieves stress that leads to high blood pressure and heart attack and stroke

2. Preparation

- a quiet environment
- a positive attitude
- a comfortable position
- an object or thought to dwell upon

3. When

- before exercise or after
- 20 minutes morning and evening
- anytime you feel stressed
- importance of deep breathing

4. Techniques

- importance of choosing technique that works for you
- Jacobsens Progressive Relaxation
- Benson's
- Guided Imagery

PRACTICAL : JACOBSENS PROGRESSIVE RELAXATION.

HOMEWORK TASK:

Practice relaxation method at home 3x/ in week.

SESSION 3

Initial Discussion

Group's progress in practising relaxation methods at home, and how found this. Suggestions to overcoming barriers to relaxing.

A. Exercise and Pain Control (PT)

Exercise.

What is exercise? - not aerobics or weight training. Its main benefit is that it can help to support the joint structure, but there are also other benefits.

- usually enjoyment, a chance to see friends
- a good muscle work-out and improves breathing and heart action

So the benefits are:

flexibility
stronger muscles, ligaments and bones
increase d function in everyday jobs
balance and co-ordination
joint nutrition
increased stamina and energy
social interaction
sense of well-being
increased quality of sleep
helps prevent constipation
(each point discussed).

Principles of Exercise:

to achieve these benefits need to:

1. When -

- do DAILY except HOT joints
- specific time and place, so many other things in life, best to think of a routine
- when least pain, stiffness and fatigue, there may be sometime in the day when you feel at your best, some like later in the day, others earlier.
- when medication is at its maximum effectiveness.
- if joints are HOT, do NOT push them through a painful experience.

2. Preparation

- heat, use caution. It may help to receive pain, eg a hot water bottle, or heat lamp. Occasionally people can find heat aggravates a joint and then may be better using Cold. Heat is often helpful on muscular areas, around the neck or thighs. A hot bath can help, if not too much of a struggle to get in.
- Cold, a coldpack of peas on swollen joints (10 mins max per joint only) can also give pain relief.

- ALWAYS WARM-UP, always limber up before start, ease yourself up all round.

- Massage, a good rub can help
- relaxation, either before or after

- Proper use of medication, take it before exercising

3. HOW

- be consistent, build up slowly, ensure there is time to limber up and don't overdo it, at eg a keep-fit class.
- minimise joint stress, relates to which joints bothering you most, eg if the knee is particularly painful, then support the knee as you do the exercises, use a gravity assisted position like lying down gives better shoulder movement.
- use a smooth, steady rhythm
- relax in between, don't do "pumping actions" but stretch and relax, as it gives time for muscles to recover, or otherwise muscles can fatigue.
- co-ordinate your breathing, never hold your breath as this increases tiredness.

What exercise or sports do you do?

- discussion of how find the activity, problems encountered and possible solutions.
- exercise bikes, can be good, if doing without too much resistance and recommended to do for short periods.

4. TIMING

- 2/3x per day for 10-15 minutes each is best, although this depends on your day's structure.

CAUTIONS.

- AVOID:
- high tension or stressful exercises, take care in game situations where may have to push too far. If a joint is hot or painful you may be doing too much. Don't push the joint if it is painful.
- vigorous exercise of "hot" joints
- extra medication to mask the pain, it may be masking a problem and making things worse
- high number of repetitions

WHEN HAVE I DONE TOO MUCH?

- listen to your body
- 2 hour rule, if you still have pain after 2 hours, you have done too much (stiff, achy muscles are OK).

SETBACKS

- expect some, don't give up, try again more gently.
- SET REALISTIC GOALS, plan your programme with you in mind
- EXERCISE SHOULD BE FUN!

Exercise is not necessarily what the Physiotherapist has instructed you to do. It can be other things, but it shouldn't cause you pain. The advantage of exercising is to keep more mobile in future so that you can use your arms and hands better and can do more. You may need to use more protective techniques in everyday life, but the exercises should be able to keep up your joint Range of Movement and strength of muscles.

The basic aim is to avoid strain on joints and strengthen the ligaments. But with the best will in the world, you may get stiff joints that are less mobile.

There are 3 types of exercise:

Stretching - to increase range of movement

- Strengthening - to build up muscles
- Repetition - to build up stamina

HANDOUT - Exercise sheet for whole body (see below)

If you have a particularly problem joint, then work on that one more and try to do the whole programme several times a week. Doing your daily activities may not always fully stretch your joints, so doing an exercise programme that goes through full range of movement for all joints can help.

If a joint is hot or swollen, move it as far as you can. When it improves try and move it further. If a joint is painful, then only exercise it 2 or 3 times. If stiff, do it 6 times and try and do it a bit further each time/ each day.

Work through the whole programme, and concentrate most on your problem joints. If a position is uncomfortable to exercise in then try another.

EXERCISE PRACTICE

Questions:

Shouldn't you push yourself?

It is important not to push too much, you must build up gradually and not overstrain muscles, which does them no good. Pain, increased inflammation can result and increased tiredness and stiffness the next day.

What if you creak?

if there is no pain this is OK. But if there is pain then stop at point pain starts. Creaking can occur in people without arthritis, necks particularly creak. Try doing the exercise a few times slowly.

Exercise Programme

Sitting

1. Head and neck movements

- look up to ceiling
- look down to chest
- look to right/left
- take left ear to left shoulder
- take right ear to right shoulder

2. Shoulder girdle movements

- shrug shoulders up to ears
- let shoulders relax
- take shoulders back and relax

3. Shoulder movements

- lift arms above head as far as possible
- take arms out to side, then clap above head
- put both hands behind neck without bending head forward
- put both hands behind back reaching up the back as far as possible

4. Elbow movements

- stretch arms out to front, then bend elbows and try to touch

shoulders

- put hands on knees, palms down, turn hands over, palms facing up

5. Wrist movements

- put hands together and lift elbows out to side, keeping palms firmly together
- reach arms over a table, letting hands hang down over far side. Bend hands down as much as possible, then lift hands up, moving only at wrist and keeping arms on table.

6. Hands and fingers

- touch pad of thumb and pad of each finger in turn
- try and make a fist with each hand in turn, getting fingers right down into palm.

Lying on back.

1. Lift arms above head, stretching them as far as possible back.
2. Put arms out in front and try to sit up, aiming to touch knee with hands
3. Bend left hip and knee as far as possible and then repeat with right leg
4. Tighten thigh muscles as much as possible. (By pushing knee back to the bed and pulling foot towards head.) There should be no gap between back of knee and floor. relax. (Each leg in turn).
5. Tighten thigh muscles and brace knees, then lift leg in air, keeping it straight. (Only one leg at a time).
6. Legs straight, push both feet down, then pull both feet up towards head, only moving at ankle joint.
7. Turn feet inwards, soles facing each other
turn feet outwards
8. Bend both knees, feet on bed. Keeping knees together, let them drop down to the right, then over to the left.
9. Knees still bent up - lift bottom off bed as far as possible - can use arms to help by pushing down on the bed with them.

Lying on side - left then right.

Lie on side so body is straight. Lift top leg up in air, keeping it straight - so don't let the leg move forward in front of the other one.

Lying on front.

1. Lift leg a few inches off the bed - hold, then relax. repeat with right
2. Hands behind back, lift head and shoulders off the bed - hold then relax.

Instructions

Repeat exercises morning and evening and preferably during the day as well.

Perform 5 repeats of each exercise - 10 if you find them easy

If any of the exercises cause a lot of pain, miss that exercise. You can always try again later.

Not all the exercises have to be performed each session.

An EXERCISE DIARY HANDOUT PROVIDED.

Pain Control (PT).

Rest - is important, and again a matter of sorting out your day and routine. If you don't take a rest, joints are strained all the time. so rest and relaxation are important to allow them to recuperate. You may find it best to rest before or after exercise.

Hot and Cold can help as can Massage, particularly if your partner learns, eg shoulder massage. If you have a stiff painful neck it can relieve tight shoulder muscles.

Listen to your body's signals - be aware when you should rest and when you need to sit or lie down, even for 5 minutes can help

Joint Protection - if you think before the action, eg lifting a pan with 2 hands is better than not feeling pain.

B. INTRODUCTION TO JOINT PROTECTION (OT).

1. What is Joint Protection?

- i) discussion of group's ideas of meaning
- ii) definition of term - recognising the warning signs of stress on joints and using alternative techniques to perform tasks to avoid this.
- iii) emphasis that not "protecting joints" does not necessarily mean that deformities will occur. Even if some deformity should occur, although unsightly a person can still function with these.
- iv) importance of not comparing self with others who have arthritis - who may have a different type of arthritis/ had disease for longer/ lack of treatment etc.
- v) aim of protection is not "cossetting self in cottonwool" and not doing everyday tasks, but doing these differently, and knowing when sensible to seek help or leave things until tomorrow.

2. Explanation of mechanisms of deformities arising (illustrated)

- i) simple anatomy of a normal joint
- functions of capsule, ligaments, tendons.
- ii) effect of RA on joint structures - swelling stretching these and possibly causing joint instability.
- iii) putting certain additional pressures on joints can lead to damage. Brief explanation of mechanisms of common hand deformities, of wrists, MCP's and finger joints.

3. Examples of stressful activities (illustrated)

- i) tight grips on small objects, eg pinching a teacup or mug handle causes x3 pressure exerted on MCP joints lifting small objects than larger. Using a large handle / using 2 hands reduces joint stress.
- ii) pushing up from chairs with knuckles encourages position of ulnar deviation deformity.
- iii) holding a book - better to rest on palms
- iv) opening jars and bottles, pushes knuckles to side
- open so turning towards thumb, swap hands, use palm to turn or use a jar opener.

Joints initially cope with these stresses but if continued over a

longer period of time, particularly when joints are inflamed, deformities can occur.

4. Importance of good posture to avoid stress on joints - discussion of members' sitting positions.

5. Apply 4 Principles when doing tasks:

- i) Pain - can it be avoided by altering task.
- ii) Planning - of day/ of task / seek appropriate help before start / break down into manageable stages. Consider self as having an energy reservoir to be wisely spent.
- iii) Pacing - do a little at a time, stop if pain occurs.
- iv) Protection - eg. by distributing load over joints.

6. Pain control increased by -

- i) planning - never start any tasks that cannot stop readily.
- ii) energy saving
- iii) alternate methods of working, eg using a labour-saving device, alter technique, get someone else to do it. Emphasis that this is not "giving in" but outwitting the arthritis or else in long run "it may win." Need to swallow pride a little and be sensible.
- iv) wearing splints (reassurance that not a sign of severe arthritis or a stigma)
- v) using aids/ gadgets
- vi) use of diaries for short periods to track flare-ups and pain episodes to seek triggering factors, eg. noting what ate and drank, what exercises or heavy/ continual tasks done during day, so that can systematically eliminate what think may be a problem.
- vii) get to know body signals
- viii) try regular rest periods and monitor effects to see if beneficial.

Do's and Dont's (poster and discussed).

DO think carefully each time you use your joints
DON'T think that you must do a job because it is good for you to push yourself. You cannot work off pain and inflammation.
DO start a job understanding you can stop for a rest, stop altogether or at least get help.
DON'T get involved in lengthy jobs that tax beyond endurance and leave you exhausted.
DO take adequate rest. Balance work and rest periods sensibly to suit your needs not everyone else's.

The hand joints are particularly at risk

- wrists
- knuckles
- small joints of fingers and thumbs

as use hands for so much, important to use hands in a different way to reduce strain.

GUIDELINES TO FOLLOW (poster and discussed):

1. Small joints cannot take great pressure
2. Avoid prolonged or continued grip
3. Avoid strain on individual joints
4. Avoid pressure on the knuckle joints (eg standing up from a chair)
5. Avoid handling heavy things

6. Use each joint in its most stable position
7. Aim to achieve a balance between
 - a) activity and rest
 - b) physically demanding and physically easy jobs.

HANDOUT:

THE PURPOSE OF JOINT PROTECTION IS TO:

- A. reduce stress and pain in the affected joint
- B. reduce inflammation
- C. Help preserve the correct structures of the joints.

THE FOLLOWING ARE THE KEY PRINCIPLES OF JOINT PROTECTION.

1. USE EACH JOINT IN ITS MOST STABLE POSITION- as explained by the therapist.
2. AVOID STAYING IN ONE POSITION FOR TOO LONG - as this can cause pressure, damaging joint surfaces.
3. AVOID UNNECESSARY STRESS ON JOINTS by:-
 - USE LABOUR SAVING EQUIPMENT
 - REORGANISING WORK AREAS
 - AVOIDING BEGINNING JOBS WHICH DO NOT LEND THEMSELVES TO PERIODS OF REST, SUCH AS CARRYING HEAVY ITEMS UPSTAIRS OR HANGING CURTAINS
 - SITTING RATHER THAN STANDING WHEN POSSIBLE
 - NOT OVEREXERCISING R OVERUSING SWOLLEN PAINFUL JOINTS
4. AIM TO ACHIEVE A BALANCE BETWEEN:
 - activity and rest
 - physically demanding and physically easy jobs
5. DISTRIBUTE WEIGHT OR STRESS OVER AS MANY JOINTS AS POSSIBLE eg.. using 2 hands instead of one.

Homework Task:

- review joint protection principles on handout. Choose 2 or 3 practical problems encountered daily and try to work out a solution using these. be ready to discuss ideas next week for group to contribute ideas also.

Emphasis that aim of group is to "encourage members to be partners in own health care."

C. RELAXATION PRACTICE (OT)

Guided imagery.

D. HOMEWORK TASKS.

1. Try guided imagery relaxation 2x/week for 5 minutes.
2. Think of 2-3 activities that are problematic and use JP principles to find solutions.
3. Try exercises 2- 3 times.
4. Next week is last session, bring along any questions want to ask team members.

SESSION 4.

A. ENERGY CONSERVATION/ WORK SIMPLIFICATION (OT).

There may be easier ways to do things, simplify them and use less effort.

1. Planning - is most important.

Most of us start doing things without planning, but can question:

- is there enough time
- is it necessary? can it be left until another day or is it necessary at all?

It could be a big or a little change, eg after washing up dishes can be left to drain or getting someone else to do decorating.

- if you can't do it, get someone else to.

It can be difficult to ask others as you feel you are letting yourself down, but it may be better to, to avoid the pain.

If you decide you are doing the job:

- plan out the sequence of the job
- are all the items together at the start?
- collect all the items to avoid several trips
- decide on the sequence of events
- where and how are you working? standing for a long time? can you avoid this by sitting, eg to iron or fold clothes.
- what is the best time of day? - if you know it will take a while do it at the time of day you know you have most energy
- look at how you could do everyday jobs more efficiently
- rearrange things if necessary, eg store things downstairs that use most there, keep things to hand, put frequently used items on work surface or a cupboard to hand to avoid bending and stretching frequently.

Save energy by using body differently:

- use leg muscles to lift rather than stooping using back, bend knees, keep an upright posture and hold object close to body.
- move things by leaning with your body rather than pushing with hands
- keep to one surface level, rather than moving to different heights

B. JOINT PROTECTION.

a) Problem-solving (Poster and discussion)

How can you simplify things?

1. Identify the problem
2. List ideas to solve the problem
3. Try these out and evaluate:
 - is it less tiring, do you ache less at the end of the day?
4. If no good solution:
 - can it be avoided?
 - can someone else do it?
 - can it be altered at all?

b) Discussion of homework tasks:

examples of activities discussed:

- using a screwdriver
- drying dishes
- cutting cheese
- holding a jug kettle

c) Detailed explanation of mechanism of ulnar drift deformity. Examples of tasks encouraging this, eg unscrewing jar lids, wringing cloths.

d) How to prevent / counteract deformities:

- i) exercise the small muscles of the hands, eg grip a piece of cloth between fingers and try to pull away, "walking" the fingers towards the thumb on a flat surface
- ii) protect joints

e) Principles of Joint Protection (POSTER and discussion - see handout)

f) Application of principles to everyday tasks -

making a hot drink. Demonstration of normal methods and explanation of stresses occurring during these. Demonstration of alternative "correct" methods. Group members try methods.

Practical tasks:

- filling and carrying a kettle
- turning on and off taps
- putting in and pulling out plugs
- opening and closing jars
- opening and closing drawers
- pouring from a kettle
- holding a mug
- carrying a tray
- opening and closing jars and bottles

Display of aids to try eg electric knife, Stirex knife, easy peeler

Practical problem-solving hints:

- adopt new methods ALL the time, not some of the time
- note when an activity causes pain and aim to change it
- in your spare time, sit and practically problem-solve
- work on changing things all the time
- find what suits you best.

Patients provided with: "RA - Helping Yourself" - a booklet produced by Doncaster OT department provided to all members, containing diagrams of many of these alternative methods and other ideas; "Your Home and Your Rheumatism" (ARC booklet).

APPENDIX 11 - TRADITIONAL JP EDUCATION, SELF-REPORTED AND OBSERVED JP BEHAVIOUR.

Subjects generally experienced difficulty stating methods they had changed. Methods cited are shown below and whether these were observed in the JPBA recorded at time of interview (4 weeks pre- and 12 post-education).

Key: X = not observed / = observed (C = correct, B = borderline, I = incorrect methods).

Subject	Self-reported JP methods		Observed on:	
	Pre-	Post-ed.	JPBA1	JPBA4
3	Adapted plug		X	X
	Jar aid		X	X
		Tap turner	X	X
4	Lifting with arms		/(B)	X
	Carry bag over arm		X	/
	El. can opener	El. can opener	/	X
	Pad handles, eg. kettle, pan.	Pad handles	X	X
		Hold with 2 hands	/	/
6	Kettle tipper	Kettle tipper	/	/
	Jar aid	Jar aid	/	X
	Wrap cloth to wring		/(B)	X
		Carry tray on arms	X	/(B)
7		Jar aid	X	X
		Adapted plug	X	/
8		Jar aid	X	X
9	Wipe with flat hand		X	X
	El. can opener		/	/
	Tap turner	Adapted tap	X	/
		Carry tray	/	/(B)
11	Carry bag over arm	Carry bag over arm	/	/
	Jar aid	Jar aid	X	X
	Carry with 2 hands		/(B,C)	/(I)
12		Jar aid	X	X
		Tap turner	X	X
13		Jar aid	X	X
		Use 2 hands to lift kettle	X	/(I)

14	Carry bag on arms		X	X
		El. can opener	X	/
		Jar aid	X	/
		Use 2 hands	/(B,C)	/(I)
		Tip not lift	X	X
15	El. can opener Adapted plug	El. can opener	/	/
			X	X
		Jar aid	X	X
16	El. can opener Jar aid Adapted tap		/	/
			X	X
			/	/
		Hold mug 2 hands	X	X
17	Jar aid		X	X
		Lift pan 2 hands	X	X
		Lift kettle "	X	/
		Hold mug 2 hands	X	X
		Carry plate on palm	/	X
18	Jug to fill kettle Carry plate on palm Jar aid		/	/
			/	/
			X	X
		El. can opener	/	/
		Adapted plug	X	X
		Kettle tipper	X	/
		Hold mug 2 hands	X	X
		Lift kettle 2 hands	X	n/s
		Carry tray on arms	/	/(B)
21	Carry plate on palm Jug to fill kettle Jar aid		/	/
		Jug to fill kettle	/	/
		Jar aid	X	X
		Use 2 hands	X	X

MANAGING YOUR ARTHRITIS

**a cognitive -
behavioural Joint
Protection education
programme.**

Instructor's manual.

©A Hammond, 1992.

"MANAGING YOUR ARTHRITIS" - A COGNITIVE-BEHAVIOURAL JOINT PROTECTION
EDUCATION PROGRAMME.

Programme objectives:

1. Understand effects of RA on joints.
2. Increase knowledge about disease: cause, outcomes, treatment.
2. Know basic joint protection principles.
3. Know a range of hand joint protection methods.
4. Know the process of problem-solving and goal-setting.
5. Increase problem-solving abilities for practical tasks.
6. Increase use of hand JP methods during everyday activities.
7. Know local resources and other information sources to obtain further advice from.
8. Increase belief in ability to perform daily tasks using JP methods.
9. Increase belief in ability to control pain using JP methods.
10. Improve belief in control of other arthritis symptoms.
10. Increase satisfaction with ability to do everyday tasks.
11. Increase range of behavioural coping strategies.
12. Gain a sense of support from meeting others with arthritis.

Materials needed:

For a group of six patients (relatives/friends may also attend, max. group size nine).

1. Suitable room with 6-9 comfortable height chairs, table.
2. Flipchart and stand.
3. Direction notices
4. Upper limb skeleton (optional)
5. Ready access to kitchen facilities:
 - two work areas allowing patients to work in twos/threes comfortably, ie. gas and electric cooker areas (with eye-level / waist-height grills), with worktops, sinks, cupboards and drawers.
 - Gas and electric kettles (jug, traditional and travel styles x 2),
 - six pans (minimum 850g. each),
 - six shopping bags
 - screw-top jars x 6, containing coffee, tea and sugar x 2. (Ensure jar lids tightened before patient use).
 - trays (no handle) x 2
 - plates (heavy pottery) x 6
 - mugs (heavy pottery) x 6
 - soup bowls (heavy pottery) x 6
 - cutlery
 - wooden spoons and selection of ladles (round and flat bottom)
 - selection of can openers (wing/ stab-style/ wall-mounted/ electric hand-held/ electric table top models)
 - selection of vegetable peelers (lancashire/ easy grip)
 - selection of sharp knives (ordinary/ padded handle/ Stirex)
 - kettle tippers (for jug and traditional style)
 - tapturners (selection of styles x2)
 - plastic measuring jugs (x 2)
 - vegetable strainers (x 2)

- vegetable masher (x 2)/ moulinex.
- spikeboards (x 2)
- selection of wash-up materials (sponges/ cloths (foam and cloth)/ wash-up brushes and mops)
- kitchen scales
- empty tins (for practising using can openers).
- Selection of other aids:

Foodstuffs:

Session 1: coffee, tea, sugar, milk, biscuits.

Session 2: coffee, tea, sugar, milk, biscuits. Potatoes/ carrots.

Session 3: coffee, tea, sugar, milk, biscuits. Cans of soup (x 6).

Bread (unsliced x 2). Cheese (2 x 1/2 lb. blocks, ie. shape easy to slice, hard from fridge). Margarine.

Session 4: coffee, tea, sugar, milk, biscuits. Ingredients for home-made soup/ spaghetti neapolitan/ stew: tins of tomatoes (x 6), carrots, onions, mushrooms (selection of vegetables), potatoes/ spaghetti.

Useful resources for display:

Sourcebook for the Disabled

Equipment for Arthritis reference books

Equipment for the Disabled series

Aids to Daily Living manufacturers catalogues

Information sheets/ booklets on local Resource Centre for the Disabled, Arthritis Care, Arthritis News (back copies), ARC booklets and ARC magazines (back copies).

General comments:

Ensure between activities allow pause for questions, discussion and patients to move about if want to.

The text used during this programme is reproduced in full to demonstrate use of recall and adherence enhancement principles.

Session 1.

Activity 1 - Introduction and aims.

a. Introductions - self (experience) and members (eg. how long had arthritis, where live). Distribute name badges. Funded by ARC.

(Flipchart)

b. Aims of group are:

- practical, to investigate different ways of managing everyday activities, to help stay independent and active,
- to investigate how you can reduce pain and strain on joints during daily tasks and prevent or slow down joint damage and deformity occurring,
- to practice different methods to make these changes here in the group and to continue practising these during the week, putting these ideas into reality at home in daily life.

The content of the group will include short talks, videos, discussions and trying out ideas and methods. To include:

(Flipchart)

- what arthritis is,
- how it affects joints,
- and therefore what you can do to limit joint damage:
- particularly Joint Protection methods,
- increasing your Problem-solving skills, to help find practical answers to practical problems more quickly,
- how to make any necessary changes to put these new skills into practice,
- what barriers, practical and psychological there can be to making these changes and how you could get round these,
- and how you can try to reduce tiredness at the end of the day by using energy conservation methods (Planning and Pacing).

The group also aims to be a forum for you to swap practical ideas as

you will have lots of tips and solutions that you have come across yourself already that can be a help to others. So the course aims to provide ideas and skills to help with managing your arthritis. Each week I'll be suggesting things you can practice at home, a home programme, which is designed to help you make these changes more quickly and is in a workbook that comes as part of the programme (show).

So the course is about self-help, practical management of your arthritis, or Joint Protection, which we can summarise as the 4 P's:
(Flipchart)

Pain - how to reduce or avoid it.

Planning - how advance planning can reduce some problems.

Pacing - how pacing your day can help reduce tiredness and principally:

Protecting - from risk of deformities by using your joints in different ways and using gadgets if need be or changing ways of doing jobs to make them easier.

Today, we'll be discussing what rheumatoid arthritis is, how it affects joints and the principles of protecting joints and how to start putting this into practice. This session will be mainly talk with some demonstration and practical work, but over the next three sessions we'll be mainly practising different ways of reducing strain on your joints. During any of the sessions, please feel free to chip in with ideas, your experiences, any questions or points you want to raise. The meetings don't intend to be formal, you'll get more out of it if you ask as much as you like and swap experiences. If you want me to go over something again, I'll be more than happy to - and probably everyone else will be thinking "I'm glad she asked." Studies from education show university students only remember about 25% of a lecture, so I don't expect you to remember everything and some of the

information, about the disease, isn't essential to know, but I hope you'll find it an interesting background. I've tried to build in repeating some information, having the main points down in the workbook (show) each week so you can read it up again afterwards and allowing time for questions and discussion. But it isn't a test of how much you remember, as long as you get a general understanding and mainly get something out of the practical sessions, that is what matters.

Distribute information packs - tell what in it. Any queries.

Activity 2 - Understanding arthritis.

In order to understand how to help reduce the difficulties arthritis may cause, it can be useful to know something about it. The booklet I sent you earlier had some information, so this is an opportunity to discuss this further and to answer any queries you may have and your understanding of what arthritis is.

Arthritis is not one disease, but a collection of over a hundred separate diseases - rheumatoid arthritis being one of these. However, it can occur in different forms and to differing degrees of severity. For some people it starts slowly and only affects the hands and feet, or may come to affect more joints. In others it may start suddenly and severely, but can go again. For some others it seems to start quickly and goes on to steadily affect more joints.

- Discussion of onset and pattern of RA.

For this reason, it is a good idea never to compare yourself with another person with RA, and think because they have severe problems so will I. They may have a different form.

(Flipchart)

Long term studies of people with RA show out of every 20 people:

6 will have no further trouble (after a short episode of a few

years)

- 4 will have a few problems after a short episode
- 6 will have active disease and some deformities, particularly in the hand joints
- 2 will have active disease and will have more deformities, but will continue to manage most daily activities with maybe some help or modifications
- 2 will eventually need a wheelchair.

- Discussion of group's ideas of outcome.

So few people will end up with severe disease and even so this does not mean the end of everything.

Much of how you manage or cope with arthritis is not just the practical changes you may make, or have already made, which we will be aiming to achieve in this programme. It's also about how you feel about having arthritis - and again this is something we can discuss throughout the sessions.

However, these figures do show to us that half of people with RA will get some form of deformity, and everyone will have some degree of pain, aching and stiffness and weakness. So everyone can benefit from taking active steps to avoid or reduce these.

We'll start first by finding out more about what the disease is and how it affects joints. I'll aim to give a straightforward explanation and please do ask when there are things you want to know more about or if I have not explained something well.

A lot of the information booklets start by explaining what a normal joint looks like and how it is changed by RA. Most people I meet with RA say it's interesting but they tend to forget about it! or don't understand! I will repeat some of this information next week, as the more often you hear it the more it makes sense, but it doesn't matter if you don't know the detail, it just helps to get some insight into

why I will be suggesting you make changes to how you do everyday jobs, to reduce strain on your joints, over the next few weeks.

What I'll discuss is:

- What a normal joint looks like,
- having some understanding of this helps to
- understand how RA then affects joints,
- how deformities occur, which I'll describe.
- This helps understand why it is useful to apply the Joint Protection methods we'll be practising.

(Flipchart - diagram of a joint)

What does a normal joint look like inside? This is a rough sketch, perhaps of what a finger or a knee joint looks like.

Discussion: Have you seen a diagram like this before? Have you heard of any of these words? (cartilage, capsule, ligaments, synovial membrane or lining of joint, synovial fluid). What do you understand these are from what you've heard or read before?

Explain during:

a. cartilage, end of each bone is covered in cartilage, a tough material which cushions and protects the end of bones and helps us have smooth movement. To get some idea of what it is like you can feel the middle of your nose or your ears, these are also made of cartilage. When get bones from butcher's may also have seen a grey shiny substance on ends of bones, that's cartilage.

b. capsule - an elastic like sheath that connects the two bone ends together. It allows the joint and bones to move easily, but not to slip apart from each other (demonstrate at knee). Some parts of this are specially stronger, the ligaments, that footballers are always damaging. These help to make a joint stable and not to slip or slide apart when moving. So at the knee you can move forward and back, but not side to side, because of these ligaments. (Move knees and feel as

do so).

c. Synovial membrane or synovium, or lining of joint. It protects the joint as it produces fluid, synovial fluid. Normally this is a very thin layer.

d. Synovial fluid - the small spaces inside a joint are filled with fluid that helps to oil or lubricate the joint. It helps with smooth movement.

e. Muscles are elastic tissues that move joints and you. They work through tendons (or sinews) - you can see these on the back of your hand - (demonstrate) as the muscle in your forearm works, so the tendons pull up your fingers.

- Discuss any questions arising.

So what is rheumatoid arthritis and what does it do to joints?

- Discussion: what do group think it is? - from reading, programmes, own ideas. What does it feel like to you?

- Provide following information and tie in points made with explanation.

The latest theory is that it is triggered off by some kind of bacterial infection. Perhaps this is quite common, but it's only those people with a particular genetic make-up, that means a particular cell-make-up, that find they can't fight this off as well as others, so they go on to develop RA.

(Flipchart)

The bacteria particularly attacks the synovial membrane or lining of the joint. You may have heard before, that in any infection, the body's defence system - the immune system, comes into action and produces special cells to fight the germs, these are antibodies.

For people who have this particular genetic make-up, something goes wrong with these antibodies and the synovium and other parts of the body, become a battleground of antibodies fighting each other and

attacking the body's own tissues or cells. This carries on long after the initial infection may have gone. You may have heard about RA being an auto-immune disease? Auto- means self, and refers to these antibodies attacking the body. It is this process that many of the drugs used are aiming to control.

The disease has two main effects:

i) it uses up a lot of energy, lots of calories. So a very common problem is tiredness and fatigue. The disease, when active, literally does drain you of energy, and many people describe it like a flu-like tiredness, much worse than just being tired at the end of the day from working. (Discuss group's fatigue symptoms and that caused by disease).

ii) the synovium or joint lining is changed firstly by the infection attack and then, even though that has long gone, the antibodies continue to attack it. The immune system doesn't seem to switch off. Whatever the cause, the effect is that this lining swells and thickens, perhaps becoming 10 or 20 times thicker than normal. All this extra lining in the joint also means there is much more fluid produced than normal, because there is so much more lining than normal. So this extra lining and extra fluid make the joint swollen. (Discussion, group's ideas of RA, eg. that not a lack of fluid, that joints feel spongy).

Short periods of swelling are very painful. But in itself this does not necessarily cause long-term problems. It is really when the swelling lasts for longer and when it occurs frequently that problems are caused. Then it can start to damage the joints and cause long-term problems and even deformities. The major problem is that it starts to stretch and weaken the capsule and ligaments supporting the joint. If these are over-stretched for long periods or repeatedly because of swelling, these start to go slack and the bones can start

to slip apart and change position in relation to one another - that is the start of deformities. People can still use the joints and do ordinary everyday jobs, but these start to become more difficult, because joints "feel" more unstable or wobbly. Your muscles have to work harder to try and control these movements, because they are trying to compensate or make up for the job that the capsule can no longer do so well, (ie the support). Because your muscles work harder, they get tired more easily and people find they can't do things for so long, they say their grip feels weaker.

Because the muscles have to work harder and tire more easily, people find they ache more generally. Overworking muscles can mean they work less well in the long run. The joints as well are painful from the swelling and from the strain being put on the already weakened structures supporting the joint (the capsule and ligaments).

So pain, aching, weaker muscles and grip and feeling tired all happen because the arthritis is gradually, slowly weakening these support structures round the joints which have arthritis, and the bones gradually start to move into the wrong position (ie. deformities).

Later on in the disease, the arthritis can start to eat away at cartilage and bone, so that these start to collapse gradually. This makes the deformities worse and can cause further pain.

(Any questions so far. Tie in information with comments made by group members. Emphasises importance of taking drug therapy to control inflammation, the underlying cause of joint damage. That JP and drugs are complementary).

Activity 3 - Identifying Deformities

So what are these deformities and how do they happen?

Certain common patterns occur in people with RA - it can be useful to know what these are, because then you can be more aware of avoiding

these or preventing them getting worse. Not all can be preventable, but the joint protection methods, using your hands in different ways to reduce strain that we'll be practising in the programme, do certainly help reduce pain, aching and tiredness on a daily basis. They can also prevent or at least slow down any deformity, so that in the long-run, when your arthritis goes away, as it will, any deformities you may have are less severe. You will have less long-term problems in your joints, so you will remain active and getting on with everyday life.

As the hand joints are the most commonly affected in everyone with RA, we'll be concentrating most in the programme on what to do to prevent deformities, pain, aching in your hands. But the information applies equally to any other joint you have a problem with.

(Flipchart & upper limb skeleton).

In the wrist, as the wrist's capsule or supports, starts to weaken, so the wrist starts to slip (or sublux) so that the hand drops down in relation to the forearm bones. The bone at the wrist seems to stick up more and the tendons or guiders on the back of the hand seem to stand out more, as the bones in the hand are slipping downwards. Why is it important to try and stop or slow this? It becomes harder to try and lift the wrist up and to grip firmly (demonstrate lifting eg. kettle with flexed/ neutral/ extended wrist, ask a group member to try and say what difference feels like).

Lifting heavy weights, strong gripping actions, pushing or pulling heavy objects particularly strain the wrist, they can make the capsule and ligaments, those support structures, more stretched and weakened, so as time goes on, even things that you would not normally think of as heavy jobs, like carrying a bag of shopping, lifting a pan of vegetables to strain it, pushing and pulling a Hoover, using the garden shears, lifting boxes and files at work - all these become

slowly more difficult and can cause strain. So progressively, over time, normally quite easy tasks become heavier and gradually damage to the wrist occurs and the bones start to slip down.

Wrists: demonstrate full normal RoM, ask patients to RoM wrists. Point out to each where are losing RoM and if/ how much wrist deformity. Ensure others can see. Emphasise need to be aware of and use joint protection methods will practice to stop it getting worse.

In the knuckle joints, again this downward slipping can occur. The everyday movements that slowly make it worse are:

- gripping things tightly for long periods, like a pen, knitting, steering wheel, tools (demonstrate),

and the fingers also start to slip sideways towards the little finger and everyday movements making that worse are:

- twisting actions, like screwing jars (demonstrate), wringing out, screwdriving,

- lifting heavy objects with the weight of it pushing the fingers to the side. A heavy object might be a full kettle (demonstrate) or even a mug (demonstrate), as lifting this with just a few fingers can put a lot of strain on these small joints.

This wandering to the side is known as ulnar drift or deviation, ever heard of that?

MCPs: demonstrate full RoM. Ask patients to all RoM MCPs. Point out where losing RoM and if/ how much deformity. Ensure others can see. Emphasise importance of using JP.

In the fingers, three deformities commonly occur: swan-neck, buttonhole and mallet fingers.

Again tight grips or gripping things for a long time and pushing/ pulling or pressing with the finger ends or thumb ends, can make the fingers and thumb joints buckle up.

Fingers: demonstrate full RoM. Ask all patients to RoM

fingers/thumbs. Point out where losing RoM and if/ how much deformity. Ensure others can see and importance of JP to prevent. Similar types of deformity can also occur in the feet and toes. If you have those problems, there is a chapter in the book in your information pack (Unsworth, 1986, show) that you might like to read for more advice.

Whilst these deformities can look unsightly, they don't have to mean you give things up. Joints can be replaced as a last resort. But if you can avoid them or slow them down and limit how bad they get by using preventative methods, ie. Joint Protection in the first place, this will be much better in the long-run.

Activity 4. - Attitudes to change.

(Flipchart)

So a key to helping manage your arthritis is to apply the self-help principle of the 4 P's - or Joint Protection to reduce strain on joints and not contribute to weakening joints and their supports (the capsules and ligaments) by over-using and over-working joints.

This does NOT have to mean giving things up, or worrying you could become an invalid asking others for help all the time. What it means is looking to find a DIFFERENT way of doing a job and then actually making the change.

I never believe in people with arthritis giving up. The people I have met with arthritis who manage best and just get on with life and are enjoying themselves are those that say "I won't let it beat me, I'll just do it a different way." But I think they have all said, it was not as straightforward as that. The attitude of accepting making changes in your life was something that took months or even years to achieve - they didn't like always to see their standards for doing a job, housework, cooking, the garden, at work or whatever alter. And

it was difficult to change the habits and routines of a lifetime. Different ways of working and moving had to be thought out and adopted and they sometimes begrudged the changes they had to make, the time it took to do things an easier way and more slowly, not being able just to whip round doing things like they used to, and how frustrating this was.

That's where the idea of this group came from - providing practical ideas, looking at ways of making those changes and meeting others who are also in the same situation. That rather than taking a number of years to work out and make these changes yourself, that this course could help to speed those natural changes up, to make more of them and more quickly, so that rather than having years of strain and frustration, saying "why didn't I do this before?" you can take the short cut and learn from other people's experiences.

(Discussion: prompt if have felt frustrated? Organise video once group discussing amongst selves).

I have a video produced by the Arthritis and Rheumatism Council, who are funding this programme, which is called "Help is at Hand - getting the better of your arthritis." It has a lot of practical tips for doing everyday jobs more easily and will give you more of a flavour of what we'll be up to. But what I think is also helpful is that it interviews people with RA who talk about how they've made changes and how they feel about it. At the end, it lasts just under 20 minutes, we'll take a break and have a drink and if you feel there are any points you'd like to talk through, or questions so far we can talk about that. Then for the last half hour or so, we'll look practically at Joint protection methods.

VIDEO: Help is at Hand. (20 Minutes)

BREAK & Discussion - stretch (20 minutes).

Activity 5. - Joint Protection

(Flipchart)

Earlier I mentioned that we'd be discussing the self-help principle of the 4 P's which aim:

- to reduce pain/ aching, inflammation and tiredness,
- prevent or limit weakening of structures supporting joints
- and avoid or limit the amount of deformity, so that when your RA goes, you are left with as few problems as possible.

So we'll discuss a little more about the four approaches and why they are worthwhile adopting.

1. Respecting Pain - if an activity causes:

- pain or aching in a joint that doesn't ease off quickly with rest,
- if you find you are in pain/ aching at night, because of overwork during the day,
- when your hands ache and your grip feels weak,

then you need to pay attention to the signals your body is giving you. Aches and pains are a warning sign. If you struggle on as usual, hoping to work through the pain, you will only damage your joints.

(Discussion: what do people usually do? If work through pain, emphasise using joint diagrams on flipchart, how are straining joint supports. Often feel more in control now by doing this but may be at a cost long-term which need to consider).

Listen to your body and use the following principles to make changes:

2. Protect your joints.

- If you are lifting, pushing, twisting, these can all contribute to straining joints. Look at how you use your joints. become more aware of how you use your body,
- think about how you could move your joints differently to cause less strain,
- what labour-saving gadgets could you use,

- how could you change the task to make it less effort.

3. Planning

- could a task be organised more efficiently, could you organise storage areas to make things easier to get hold of, could you save some energy by planning some things ahead a little more?

4. Pacing

- taking short few minute breaks and stretching your joints whilst you are doing jobs at home or work, swapping round tasks more regularly from light to heavy to light jobs, means you move your joints and body in different ways. This can help from feeling cramped and strained and saves energy.

What I've found interesting when talking to people with arthritis is that most people start to make these changes themselves to some degree because of the pain and weakness they experience. So in this group the aim is to help you:

- be more aware of how you do everyday activities,
- what changes you have already made to make jobs at home and work easier,
- how you went about making those changes,
- what changes you can further make to reduce strain on joints and keep them as fit and mobile as possible,
- and the quickest way to actually make those changes everyday.

Knowing how to do things differently is usually the easy part. Doing them is what's difficult, as you are changing the habits and routines of a lifetime. Some movements you do in everyday life, like turning a tap or lifting something, housework, a task at work, are a strain all the time. Others may be a strain some days and not others. But it can be better to change how you do things all the time and just develop a new set of habits and routines, rather than trying to remember to do it some days and not others. If you do this, when your

arthritis is causing you more problems at times, you've already automatically changed doing things to make them easier to put less strain on joints, so it's one less thing to worry about.

Activity 6 - Practical task.

Let's start looking at how to make these changes. We're going to first look at different movements we make when doing kitchen jobs, and how they could be easier. Then make a cup of tea or coffee and try and feel and watch how you are using your hands whilst you do so. I want you to work in pairs (or threes) and watch each other in turn. Try doing actions normally and then try some of the ideas you saw on the video or that you suggest to each other to make things easier. So during this session, and at home over the next week, what I'd like you to do is:

1. Start to become more aware of how you actually use your joints. What actions do you do that could put a strain or pull on them? What actions or movements put your hands in those positions of deformity we discussed earlier? - dragging down the wrist, twisting the fingers, pushing them sideways or down at the knuckles, pressing or pulling on the fingers (demonstrate as talk).
2. Demonstrate: lifting full kettle, turning (tight) tap, open (tight) jar, carry full mug, hold full milk bottle - highlight hand position. Ask group members each to try and feel weight on joints and see position.
3. Have a go at a common thing we all day every day - making a drink. I've put kettles and jars and mugs around the room and I'd like you, in pairs, make a cup of coffee or tea, taking it in turn. Watch how you are using your hands and watch each others movements. Could anything be putting unnecessary pull or weight on your wrists, be pushing your fingers sideways, using a tight grip? Try doing it just

as you would normally and think about how you are doing it and then see if you have any new ideas about how to make it easier. Were there any in the video? Or from each other. Try those afterwards and feel the difference.

NB. Go round two groups as working, focus on: feeling the difference, positions, any alternate ideas coming up from group, spread ideas coming up between groups, eg "Anne had a good idea to make this easier, why not try that."

Take tea back to table.

Activity 7 - Home programme.

(Flipchart and workbook).

I said earlier in the programme, that the group would have a home programme to help you put the ideas into practice. In the workbook that goes with the programme, if you could turn to page 7, I've written down some suggestions for what you could do this week to start putting things into practice.

1. Spend some time during the week in generally just becoming more aware of how you are moving your hands and arms particularly, and any other troublesome joints, whilst you are doing everyday tasks. If you are very busy during the week, set aside some time specially to do this. Write down when you are going to and tick each time you do it - to remind yourself to do so. Watch how you make a hot drink and then try and watch a friend or relative doing the same. Do you do it any differently?

2. Make a list of anything that you notice can cause you pain or aching in your hands and arms particularly and in any other joints. Be specific in this. Rather than housework, say pushing Hoover, wiping high windows, lifting, ironing, so you become aware which particular movements are a problem.

3. There is a series of pages with common everyday tasks which can pull on the hand joints. The photos show easier ways of doing these that people with arthritis have come up with. Look at the different methods shown for these and have a go at each. Feel how they are to you and decide which one is best for you.

Decide on 4 of tasks that you are going to practice. Aim to practice these a certain number of times each day if possible and tick the box for every time you remember doing it at the end of the day. The idea is that the more you practice something, the more it will become a habit.

4. If there are already any of these tasks you think you are doing differently, mark these and check during the week whether you are REALLY doing it, that way it will help you do it more of the time.

5. If you have time, try and read chapter 1 and chapter 6 in the book "Coping with RA" as a reminder of the information we've covered today. You may find it helpful to let your husband/ wife/ family read this as well to help them see what you are up to!

That's the end of today's session. I hope it has been interesting. Next week, we'll be looking at how to make more changes and practising these and how to consciously change habits and routines to help you make these changes more quickly. Look forward to seeing you again. Please do remember to bring the information pack and workbook next week.

Session 2.

Activity 1 - Introduction. Review of Home programme.

- a. Distribute name tags again, check everyone knows names.
- b. Outline of today's session:
 - we'll be going through how you got on with the home programme, the main points from last week and any questions you have come up with during the week,
 - looking at Joint Protection in more detail, how the principles are applied in practice,
 - we'll be doing a practical task applying these
 - and discussing the process of changing old habits and learning new,
 - drawing the session together with next week's home programme at the end.
- c. Home programme review.
 1. Did you all manage to set aside some time during the week to look more closely at how you used and moved your joints - to become more aware of stresses and strains on them? What did you think of doing this? What did you notice if you could compare yourself to someone else? Was there anything you are doing differently?
 2. What sort of activities or movements did you find caused you any pain or aching in the hands or other joints (list on flipchart). How many found these problems? (discuss). In the last session we will be doing a session on problem solving and how to think of new ways to do problem activities, so we can come back to this list and have a go at finding solutions to these.
 3. How about choosing the tasks from the workbook to practice - like opening taps, jars and so on.
 - Ask each person which tasks tried, which methods preferred, how often practised (give verbal reinforcement).
 4. Any questions from last week?

Activity 2 - Joint Protection.

Last week I talked about the idea of the 4 P's of Joint Protection. So this week we'll be looking at this in more detail. What activities do help push your hands particularly into deformities and cause aches and pains.? What can you do to stop this happening or limit it? What is Joint Protection and what principles can we apply to lots of movements to make everyday jobs easier?

The four ideas or 4 P's I discussed last week are ways to look after your joints, to try and reduce pain/ aches, to reduce strain and try to prevent or slow deformities.

Pain - the need to listen to your body, and if you have pain or aching to take a rest and look at how you can do things differently to reduce aching by changing the way you do things rather than working through the aches and pains which only causes more damage.

Protecting joints - changing movements, changing tasks, or using gadgets to make them less effort,

Planning - to help increase your efficiency and organisation, a time and motion approach, to save energy,

Pacing - swapping activities more often to prevent keeping cramped positions and taking regular short rests.

For instance, an office worker who gets cramp and hand pain writing and signing letters. Could protect - by using a dictaphone rather than giving written copies to be typed, delegate the signing to someone else. Pace - by changing office jobs regularly, writing for a short while, making a phone call etc. (Or give example relevant to one or two group members occupations if possible).

Lets look at joint protection in more detail.

(Flipchart)

Last week, we looked at how the structure of a joint can be gradually altered by RA. That the disease causes inflammation or swelling of

the synovium or joint lining and that too much fluid is produced. Both these effects gradually weaken or slacken the structures supporting the joint (the capsule and ligaments). As these supports weaken, stresses and strains from everyday activities can cause further stretching and weakening, so that the bones start to gradually drift into positions of deformity.

(Flipchart)

Some common problems are of the wrist drifting downwards, the fingers drifting sideways and the fingers buckling out of shape.

Quite ordinary everyday activities performed many times a day, day in day out, can all help slowly to contribute to this process.

((Have kitchen scales to hand to demonstrate weight of objects)).

For instance:

a) in the wrist: (demonstrate by i) lifting heavy bag of shopping, ii) full kettle, show weight of objects on scales and iii) closing drawer. Point out wrist movements). Lifting, carrying, pushing heavier objects causes strain.

As arthritis gets worse, lighter tasks can prove a strain and heavier tasks are done less often.

b) in the knuckles: everyday activities that can push the fingers sideways include opening and closing jars, lifting heavy jugs or pans and twisting cloths (demonstrate)

c) in the fingers: buttonhole and swan-neck deformities can be encouraged through holding things tightly in the fingers or for long periods without changing position, like holding a knife handle to peel vegetables, gripping the edges of plates and trays, and lifting things with the finger ends (demonstrate).

Of itself, any one of these activities done once won't cause any damage. It is the cumulative effect, doing all these little things, lots of times, many times a day and a week, that cause the damage. So

there is a need to change many little things all the time, rather than just a few things all the time, or more things just some of the time. What is best is to develop a different way of habitually doing things.

It's important to use joints to stop them stiffening up and to use muscles to stop them weakening. So Joint Protection isn't about giving things up, but about doing them differently. It's also important to realise that it's not just when pain is present that it's important to use your joints differently. Even though the swelling has gone, the support structures (capsules and ligaments) remain weaker and more prone to stress, as they don't just suddenly go back to normal. So even if your joints don't hurt it is important to change how you use them.

(Flipchart)

Some basic principles or guidelines of Joint Protection have been developed that you could use to think up different ways of doing everyday jobs to make them less strain:

1. Distribute the weight over a number of joints.
2. Use larger, stronger joints.
3. Reduce the effort to do a job:
 - use a gadget or different equipment design,
 - use a lever,
 - slide, don't lift or avoid lifting,
 - reduce the weight of what you lift.
4. Avoid positions of deformity,
 - avoid doing things with your wrist bent down,
 - avoid pushing your fingers sideways,
 - avoid pressing on or lifting with the fingers only,
 - avoid tight grips.

Activity 3 - Practical

Let's look at some examples of how you can put these into action. We'll try a few actions for each of these guidelines to help you get the idea of what these mean in practice. Again, I hope you'll find a number of these ideas you are already doing, so this may help confirm to yourself why it's a good idea to keep on doing so and you may also come up with some more ideas. (Demonstrate all tasks as discuss).

1. Distribute weight of objects over several joints.

Many things you need to lift and move around could save strain on especially the finger joints, if you use the whole of your hand or two hands to lift them.

Normally when carrying a plate (demonstrate), people use just their fingertips with one hand or their fingers and thumb. (Try) - it puts a strain on the finger joints. Instead if you use the whole hand or both hands this is better, especially if you have several plates you are putting away or a tray of dishes you are carrying through (try). You can do the same thing if you are carrying dishes from the oven. (Ask: anything else could use this method with?).

When lifting a full mug, usually people lift with 2 or 3 fingers through the handle, which strains the knuckles (try). Make sure instead you have a good grip and put your palm under to take the weight. (Ask: other similar activities?)

What you need to make sure when you use 2 hands is that you get the weight on the flat of your hand as much as possible. With a mug, don't use just the fingertips to support the weight underneath. Or lifting a grill, don't just guide with the fingertips of the second hand, get the palm fully under. If it's hot use a cloth.

2. Use a stronger, larger joint:

If you can shift the effort from your smaller hand joints to stronger, larger joints, this saves strain as larger joints are more

able to take a given amount of pressure.

For instance, carrying shopping (try) is less strain if you put the handle over your forearm, as the elbow is larger than your wrist or finger joints. If this isn't the best method for you, there may well be another way, for instance, lift it close to your body with your arms wrapped round, like americans do with their shopping. (Ask: similar activities?)

In the garden, if you are weeding, using a trug or a bucket for the weeds, put the handle over your forearm rather than gripping with fingers.

When closing a drawer, if its stiff, rather than pushing with your fingers or hands, use your hip. (Ask: any similar activities?)

3. Reducing effort-

a) Using gadgets can help. Try comparing the effort of using a wing can opener with an electric or a wall-mounted one. There are two styles of electric can opener - ones you need to hold as you open and ones that sit on the table top. Although both are less strain on the fingers, the hand-held one can still be rather heavy, so the table one is better as you don't have to take any weight on your hands at all, apart from holding the can in place under the blade (try).

Or peeling vegetables - an ordinary peeler can pull on the knuckles and needs a tight grip, whereas the easy peeler model needs a looser grip and a very light stroking action, so it's less effort.

b) Avoiding lifting or holding.

When carrying a kettle to the sink or moving pans around, rather than lifting a pound or so of kettle and a few pounds of water, you may find (it depends on your kitchen layout) that you could slide it all or part of the way. Rather than holding the kettle under the tap as it fills, slowly pulling your wrist down with the weight of water, rest it on the bottom of the sink edge or better still, if the sink

is clear, put it on the bottom while it fills.

c) or better still, reduce the weight you are lifting by using a plastic jug to fill it, so you don't have to lift the weight of the kettle, just the water (try).

When you need to empty out and change the water, again slide the kettle or use 2 hands to lift, but don't let them drop down at the wrists. Keep your wrists straight (try).

4. Avoid positions of deformity.

a) avoid working with the wrists bent down. The last thing we tried, lifting the kettle, was a good example of keeping your joints in a stable position. Don't work with them in a position they can tend to deform into.

Watch for this as well when you lift other things, like pans or moving gardening equipment, moving laundry baskets - keep your wrists steady and again use 2 hands.

b) avoid twisting joints. Particularly again the fingers and wrists. With taps and jars, struggling to turn a tight tap or a stiff jar lid pushes the fingers into the position of ulnar drift. Using the palms or the sides of the hands avoids this position (demonstrate) and again do the same to tighten.

Wringing a cloth again twists the wrist and pushes the fingers sideways, its better to press out the cloth using the flat of your hand or use a sponge which presses out and dries easier for mopping up spills.

A screwdriver or a whisk twists the wrist, but models with pump handles, use the wrist and fingers in a straight position. So its worth looking at the design of the equipment you use.

c) and avoiding tight grips and pressing on fingertips.

For instance when cutting with an ordinary knife, a tight grip is needed putting pressure on the fingertips. Padding a handle makes

cutting easier or using a knife with a different type of handle means the pressure is distributed (try).

Very often we press on our fingertips without realising it, pushing in a plug people often do with their finger tips and thumb causing strain. Better again to use the palm of your hand or the side of your fist, but not the front of your fist, as it pushes the knuckles downwards.

Activity 4 - demonstration of making hot drink.

Break down into steps. Use JP methods shown. Talk through each step.

Activity 5 - Practical, making hot drink.

Nearly time for a break, so lets put some of those ideas into practice. You can make your own drink this week!. Remember the different methods I've just demonstrated and you've tried earlier and over the last week. I'd like you to work in pairs (threes) again like last week and to take it in turns to make the drink from beginning to end. Watch each other as you do so, and try and give each other reminders if you forget an idea. Try and watch to keep your fingers and wrists straighter. As the point is to practice the methods, and we have plenty of time, try and each do all the steps or movements, rather than doing something for someone else to save time. You'll get more out of the practice that way.

(Give verbal feedback on movements, manual feedback to correct and repeat demonstrations as necessary to individuals. Talk re- ideas coming up from group. Discuss how feels to use these new methods. Ask any relatives to participate if room. Ask them to try individual movements and JP methods - encourage discussion between if insufficient rom to participate).

BREAK - discussion.

Activity 6 - Developing new habits to reduce strain.

So far we've looked at how ordinary everyday tasks can cumulatively, during the day, contribute and add up to more and more pain, aching, strain and deformity. And we've looked at general principles to protect joints and practised examples of those different ways of working. Some ways may already be familiar to you because you have started to do them naturally already, but others may be new ideas.

So how do you go about changing the way you've done things all your life, old habits to make new habits? That's what we'll look at next. How do people learn new skills and develop new habits? How do you learn to do a new tasks, like learning to drive or a new job at work? I thought it would be useful to spend 5 minutes thinking about how people do learn new skills and movements, how they go on to perfect them and then how they come to do them automatically. When we learn a new job, to drive, a new hobby, when athletes train and learn a new sport movement and perfect their batting or kicking skills, the same process occurs.

(Flipchart)

There are 3 main stages:

1. Learning

2. Fixing

3. Automatic stage.

1. In the learning stage - you get an "overall" picture of the skill. You learn what is going to be achieved by the skill, what it's purpose is, how the different movements all fit together in a sequence and how long it should take. You learn these things from demonstrations, from watching others do it, from instructions, pictures and videos, from being physically guided. So in this course, I'm using all these methods to help you learn the movements and how it feels to get them right.

People also use "mental practice" - they imagine doing the task in their mind, to "rehearse" the sequence of movements to be clearer how they all fit together. This mental practice helps to reinforce this overall picture in your mind of what to do, so when you go to do it, it's clearer. So when learning these joint protection methods it helps to imagine doing these new movements, to check back with the pictures in the workbook that you've got the positions right. Sports psychologists use this approach to help athletes improve their skills. We often use this for complicated tasks, like learning to drive, where co-ordination is important. Let's have a go at doing that just for a few minutes. We'll try imagining what it's like to make a cup of tea using these methods you've just tried.

Think in your mind now of making a cup of tea. If it makes it easier close your eyes or stare at the ceiling and visualise doing it. I'll have to pick examples of how to do it, which may not all be the methods which work best for you personally, so try and imagine the movements you find best: You're sliding the kettle across the worktop, putting it down in the bottom of the sink, turning the tap on by pressing down with the palm of your hand, let go as you watch the kettle fill. Press down with your palm and turn again as it's full. Hold the handle firmly, keep your wrist straight as you lift, put your other palm flat and square underneath to take the weight. Lift it to the side and slide it back.....(continue).

Try doing that at home when you are watching a dull programme on TV but feel too tired to actually go out to the kitchen and practice. Or try it for other jobs which you can think how to use joint protection movements for. The more you practice in your mind, as well as in reality, the quicker the movements will be learnt.

2. The fixation stage:

this is the stage when this new skill starts to fix into a new habit

pattern. This stage needs:

a) Practice - the more often you can practice and the shorter the period of time between practices, so the more regular the practice is, the quicker will this overall picture in your mind be reinforced and the quicker will your body, the muscles, become familiar with the movements you need to use, and the less thought will be needed to get the movements right and co-ordinated.

b) Feedback - you also need to know that you're getting the skill or the movement right. If you practice something wrongly, you'll accidentally learn the wrong habit, which will then only need unlearning. You get feedback in several ways:

i) you provide your own - you feel yourself whether you had your joints in the right position, whether your muscles worked the right amount, if there was less or no strain and you "talk to yourself" in your mind, eg. "I need to move my hand a bit more to the left, I'll try that next time." Again sports psychologists encourage athletes to do this.

ii) you get feedback from other people - as to whether you got it right or wrong. The more detailed the feedback on what part was wrong and how to improve it - the quicker the movement becomes fixed. So it's especially helpful if you can get someone at home to help with this (encourage relatives to be involved if present), by asking them to read the information and give you feedback.

So in the group, we're trying to include as much practice in the sessions as possible, with the opportunity for feedback from me and from each other to help fix these new habits. The home programme suggests you practice as often as possible at home, to help to fix these movements, as once a week here will not be enough. Try to remember consciously to think about how you do the movements as you practice at home, how are you doing it? Is it right? Tell yourself in

your mind whether you are doing it right or wrong as you go along. If wrong, then tell yourself how you can improve it next time, so you're giving self-feedback. Once you've got it right - you still need more practice for it to become a habit.

The third stage is:

3. Automatic - ie a habit, when you can do the movement subconsciously, without thinking. You can hold a conversation, listen to the radio or TV, scream at the kids and still get the movement right. So even more practice is needed to achieve this - just like learning to drive. You practice a lot with the instructor, you learn how to "operate" the car, you practice at home with friends, you even pass the test - but if you stopped driving at that point you would get rusty. You have to keep on driving and maybe after a few months you feel you're driving on "automatic pilot."

So PRACTICE really is the key to learning new movements and skills until they are a habit. It can be easy to think that you have learnt a new way, or even that you are doing it some of the time, when you consciously remember to or the pain makes you stop and say "that hurt, I should do it that other way." But you need to check that you really ARE doing it all the time and not to stop practising too soon.

Summary: (Flipchart)

So in the course, we're using as many different methods as possible to help you get these "pictures in your mind" of the movements you are aiming to do.

It helps to consciously imagine or mentally rehearse in your mind what they are.

That's the learning stage. This is reasonably easy.

The real effort comes when you're aiming to fix these many movements -so as much practice as possible here and at home helps. I'll aim to give as much feedback as I can. You need to compare what you are

actually doing with your "mind picture" and give yourself feedback - and to give each other feedback during the sessions - tell each other how you're doing, if the wrists were bent and need to be straighter. It isn't criticising one another, it's going to help you learn quicker. If you can get your family or friends involved, get them to read the information so they know why you are doing this, get them to come for a session if they can, and get them to give you feedback too.

Then to make it automatic, so you still do it right even when distracted, you need lots more practice.

Knowing what to do is the easy part. Doing it all the time is what takes the hard work! I think people can often expect that courses like this will be more talks and learning facts. But people only learn new skills that way, not how to do them all the time. So that's why as the course progresses there's more practical content. Don't worry if you don't get it right first time or forget something, this isn't as easy as it seems!

Activity 7: Practical - hot drink.

So we'll try again making a hot drink one more time today to help you feel that you're getting the movements right before you go off and practice them all week at home. Try and concentrate on your own movements, work in pairs again and give feedback, check the other person's movements against your own "mental picture." If it's right, say it's right. If it's wrong, say it's wrong. It's important to give feedback to help each other learn. Say why you think it's wrong, how to get it right and then have a go again doing that bit right before you carry on.

PRACTICE CUP OF TEA/COFFEE.

Activity 8. Home programme.

In page 15 of the workbook:

1. Aim to practice using the methods when making a hot drink as often as you can this week. Decide on how often you think you could do this, during the next week, 5 times? 7 times 10 times? Write it down and tick each time during the week when you practice. If you do more, give yourself extra ticks.

2. Again review the pictures in the workbook. Carry on practising the 4 tasks you chose last week - probably part of making a hot drink anyway - choose another 4 this week, try the methods shown, decide which is best for you and again tick each time you practice, if you can.

3. Those you thought last week you are doing anyway - try to be more aware again this week, are they automatic yet? Would it still help to practice some more?

Try and make a specific time for practice sessions if you can, rather than feeling that you always have to be watching yourself, which can get irritating and there are lots of other things that you have to get on with during the day.

If you can make a specific time, say during preparing lunch or a time when you are not so rushed, to watch yourself and practice regularly, then over the week's it will become more of a habit to do it all the time. If you ask a relative or friend at home to help with giving feedback, arrange specific times when they do this or you may begin to feel they are b nagging you. (Encourage relatives/ friends to help by giving feedback).

4. Spend some time mentally rehearsing or picturing the movements in your mind, like making a cup of tea. It all helps. Try if you can to do this for 5 minutes on five days one after the other.

5. Spend a little time watching how you use your hands in one of

those everyday activities you listed last week in your workbook that was a problem. Bear the JP principles in mind that we discussed today, of using stronger joints, reducing the effort, distributing load, and avoiding positions of deformity. Think about how you could use these to make a job easier.

Ending:

In the course so far, I've concentrated on general principles of Joint Protection (flipchart) and practical methods applying these. They've mainly been for the hands, as these are the commonest joints you've all got affected. We've used kitchen tasks - because these are the commonest problems people tend to notice first. We'll still be focusing on these areas over the next two weeks, but we'll be broadening out more - in general applying the principles yourself into practice and also how to conserve energy, your energy!

Please do remember to bring the information pack and workbook again next week. Look forward to seeing you again.

(Time for individual questions).

Session 3.

Activity 1 - review of home programme.

a. welcome, check if everyone remembers names by now.

1. How did you get on practising a hot drink? - ask each member how many times did it. Did everyone meet their goal of doing it however many times?

2. Did you practice any other tasks/ the original 4 or new 4 - how got on?

3. Those things that you thought you were doing automatically anyway, are you really doing so or did you decide you need more practice?

4. How did you get on with mentally rehearsing?

Activity 2 - Review of JP.

So far we've looked at how everyday stresses and strains on joints can contribute to pain, aching and even joint deformities (flipchart diag). We've looked at some broad principles or guidelines of Joint Protection (flipchart):

1. Distributing weight over joints.

2. Using stronger, larger joints.

3. Reducing effort to do a task,

- using gadgets, levers, sliding not lifting, and reducing the weight of what is lifted.

4. Avoiding positions of deformity in the hands particularly,

- avoiding doing things with the wrists bent down, pushing the fingers sideways, pressing on or lifting with the finger ends and avoiding tight grips.

We've looked at how everyday tasks can be done differently to reduce strain and practised some common everyday kitchen jobs.

Last week, I also talked about how people go about learning new movements and skills:

(Flipchart)

The process of Learning, Fixing and Automatic stages.

1. Learning - is getting the idea or "overall picture" - the many joint protection ideas there are that you can get from books, from each other, from this session and how you can help the idea "stick" of how to do it by mentally rehearsing or imagining it, watching demonstrations, looking at the photos.

2. Fixing - is the stage of practice, as regularly and frequently as possible and with feedback, from yourself by looking if you're doing it right, and from others.

3. Thirdly, when the new movement or skill has replaced the old one, to become a new habit. Having got it right, you've practised it right so often, that you can do it subconsciously even when you're doing something else.

So the home programme, I hope, is helping you to reinforce becoming more aware of how you use your joints. I hope you're getting more ideas yourself of how you can do things differently and see how important it is to practice, look at your own progress and feedback to yourself to help you actually put this ideas into practice daily.

As I said last week, I don't think that learning the new methods is difficult. Once you've got the ideas, it's actually putting them into practice enough that can be difficult. So far we've tended to look at the process of putting things into practice, particularly for the hand joints, what we'll be doing this session is practising more tasks and getting you to give feedback and swap your ideas, look at how to make goals each week to help you get on and practice and then try some more new ideas out.

Activity 3 - practice hot drink.

Feedback, manual guidance, reinforcement as necessary.

Activity 4. Practice making a snack meal.

Next we're going to try some more ideas out. This is not a cookery lesson as you are all probably better cooks than I am, but again we'll look at how you use your hands when making a meal, and how we can apply joint protection principles. You're going to work in pairs and take it in turn to each make a snack, watch yourself and each other and give feedback. I've had to pick something simple so it doesn't take us all afternoon, but making cheese on toast and heating up some tinned soup gives us the chance to try a lot of different movements and some new gadgets. First of all, I'll start by breaking down what we're going to do, demonstrating each part using a joint protection method and you can tell me why it's a good idea and what principle it uses. Then you can work away at doing it in pairs.

To help look at how to change activities, it can be helpful to break them down into the different stages involved - Task Analysis. If a job causes aching or pain, this can be a good way of trying to work out what part or parts of it might be causing the strain, and so then when you know what it is you can change it.

(NB. Need 6 shopping bags containing pan, bread, tin of soup, and other groceries to make bag heavier). Talk through and demonstrate each step as do so. Ask group to give reasons why need to change and how).

Task Analysis (flipchart):

1. Carry shopping bag across room - pushes fingers to side. Put over forearm.
2. Lift out items - lifting with finger ends or one hand. Use whole hand or 2 hands if possible.
3. Open tin - wing can opener pushes fingers to side. Try using wall and electric can openers (preferably table top model).
4. Pan to cooker - Weight? show on kitchen scales. Lift with one hand

strain on wrist/ fingers. Slide or use 2 hands, one underneath whilst cold.

5. Stirring - fingers bent, not much strain when just a liquid, but if a thick stew or mixing a cake, use a fist grip.

6. Lift grill into place - one hand strain on wrist. Use 2 hands, one with palm flat underneath or 2 hands on handle.

7. Cut cheese - pressure on fingers sideways. Use Stirex knife, padded handled knife or cheese slicer.

8. Taking out plate/ bowl from cupboard - holding edges presses on fingers sideways. Both hands under to spread load when taken out.

9. Pour out soup - pouring/ lifting pulls on wrist and fingers pushed sideways. Rest on surface and use ladle to save holding weight, tip last part (try using flat bottomed ladle). Or have good grip with 2 hands, avoid wrists bending.

10. Carry bowl and plate - fingers pushed sideways. Carry on palms use a cloth if hot or use a tray, with 2 forearms under. Use trolley if room in house.

11. Turn on/ off tap - fingers pressed sideways. Use aid/ flat of hand, side of hand.

12. Lift out heavy wash up bottle - fingers pressed sideways. Use 2 hands. Use liquid dispenser bottle pressing with flat of hand.

13. Wash up - tight grip with fingers. Use brush in a fist grip.

14. Wipe surfaces - tight grip. Use flat of hand.

15. Squeeze cloth/ sponge - twisting wrists and fingers. Press out or wrap round tap.

All try whole activity in turn. Feedback, guidance, repeat demonstration as necessary.

Make hot drink again after in turn.

BREAK. - discussion.

Activity 5 - Setting goals

I said earlier that another thing we'd do today is look at how you get ideas into practice. I've said over the last few weeks that what is important is PRACTISING as much as possible. That actually changing how you do everyday jobs to reduce strain and protect joints is the difficult part. People can learn and know better methods and can work out ideas for themselves and with others - it's getting on and breaking the old habits and making the new ones that's hard.

It's all very well to say PRACTICE is the key, but there are lots of things that make it difficult to get on and do enough practice. So next we'll look at what might be barriers to making changes, how we can set goals to make these and what goals are, and what we can do to help ourselves stick to these goals.

So what can be the barriers? - did you find it easy or difficult to find time to practice in the last 2 weeks.? What got in the way of practising as much as you thought you would? - discuss.

(Flipchart)

1. getting motivated!
2. amount of change, seem to be too many things at once,
3. too busy,
4. too many demands from others.

These are all very real problems. We're going to spend the last part of today's sessions looking at SETTING GOALS - which can help with the motivation and the amount of change, and we can discuss amongst the group what you are finding are the best ways to help you overcome "too busy" and "demands from others."

One of the big problems in using Joint Protection methods is over-riding your habitual movements and using the new. At first, your practice seems clumsy or awkward and it takes effort to remember to do it, especially if there isn't the extra motivation of pain or

weakness to help - it seems easier just to do it the old way. But think of the long-term benefits - the pains, aches and deformity you could save over the coming weeks, months and years.

One of the best ways to help you keep up with your practice is to set goals. In the next few minutes I'll outline some of the general guidelines of goal-setting and then we'll use these for setting the home programme for this week.

There are 2 types of goals - long-term and short-term. A long-term goal is something more general: such as reducing the amount of pain and aching I have when doing housework or my job, feeling less tired at the end of the day, stopping my fingers from drifting to the side. These are important because they put in mind why you really want to make all these little changes which add up to one big change, they help to motivate you because you think of the benefits at the end. Do I want to do all these things? They are like new year's resolutions. But on the way, you have to set short-term goals. The small steps, the things you are going to do today, this week to help you on your way to these long-term goals. Perhaps that's why new year resolutions, so often aren't kept. We make these plans but never think through how to realistically achieve them.

So for instance, a short-term goal is "today I'll turn tap using an aid (or palm of hand) every time I turn on and off a tap, at home, at work, when I'm out." So the short-term goal relates to the long-term goal by reducing pain, but you do something specific now. You need to make promises to yourself that you will do, whatever, as often as you can, if you really do want to make such changes.

(Flipchart)

So to be specific your goals need to have:

1. An ACTION, eg practising a specific task like turning taps, lifting a kettle. Making a drink using JP methods, Listing solutions

to a particular problem.

2. HOW OFTEN, eg. every time do a task today. Twice a day. 4 times this week. Once this week.

Goals need to be REALISTIC though. You need to make sure that you know it is possible, but still a bit of a challenge. If you say you'll practice a method 20 times a day, you may do 5 or 10 but then get fed up, get too busy or forget. Then you feel annoyed with yourself that you didn't reach your goal. But if you said you'd do it twice - you may have done that by 10 am. and then feel, "too easy." Usually the problem is people making goals too difficult. We all tend to expect too much of ourselves and if you try to do too much, too soon, you feel bad about yourself, feel you can't do it, and increase your likelihood of giving up.

So to be successful:

1. Start where you are and start slowly. Start to change gradually - aim to change a few things at a time.
2. Give yourself time off. Allow days when you don't have to think about it and practice, then it won't seem a chore. For instance, practice 4 or 5 times a week rather than everyday. That way if you miss a day, you've still got the chance to meet your goal.

So to summarise:

1. Be specific about what your goal(s) are (the ACTION).
2. Say how many times you'll practice it.
3. Start with something reasonable and build up slowly the number of times you practice and the number of new goals.
4. Give yourself a reward for meeting goals.

Tell yourself that you have done a good job - give yourself a slap on the back. Try and get family or friends involved in your goal setting and practising, so they'll be encouraging you to keep it up.

Give yourself a treat! - maybe a break and a cup of tea and a

chocolate, or something else, for the times you've met your goal. If you meet all the goals you set for a week, give yourself something extra, a new plant for the garden, watch an old movie on TV, buy some smellies, a little present to yourself. Make it something to look forward to. Plan your treat ahead "if I meet all my goals this week I can..." and that's extra motivation.

Activity 6 - Home programme.

Page 24:

1. Again there are some pictures of tasks we've been practising and I'd like you to select those you'll particularly practice again. Go back over the photos from the last two weeks to make sure you feel you are practising these.

2. Try mentally rehearsing making a cup of tea and making a meal, using the methods we tried today. Try and do this once on at least 5 days if you can.

So we'll look at setting goals for your home programme.

3. Try and write in some short-term goals for the week, you can always add these at home this evening as well if you like.

How about practising making a hot drink 5 times this week? Practising making a meal 3 times this week? Keep up practice for the specific tasks you've chosen. How many times a day? (Make sure pens handy).

4. At home, make a list of what would be good rewards for you, to help you keep yourself motivated and use these.

Next week is the last session, and we'll be looking at some ideas for saving your energy to save getting so tired, and your problem-solving ideas for how to make jobs easier. We'll be practising some more tasks again and looking at what resources are available locally to get extra ideas, help and support from. Don't forget your pack and workbook again next week and look forward to seeing you.

SESSION 4.

Activity 1 - Review home programme.

a) Welcome to everyone by name.

1. How have you been getting on practising these joint protection methods shown in the pictures over the weeks? Have you each managed to identify a method which works best for you for each job?

2. Did you mentally rehearse making a hot drink? How often? Does it help?

3. How about doing the real practice - did you manage to keep to your goals?

4. How did you get on making goals?

5. Were there any problems managing to practice? Any ideas for how to get over these? (Group discussion: how to manage if family demanding etc.).

Activity 2 - Review of sessions.

(Flipchart)

Over the course so far we've looked at:

- why we need to protect joints, to reduce pain, aching, swelling, to reduce strain on the supports round the joints (the capsules and ligaments) to prevent or limit deformity occurring. So I've stressed the importance of avoiding lifting heavy items with the wrists bent down, pushing the knuckles sideways into ulnar drift or making tight grips and pressing or lifting with the fingers, which can encourage the swan-neck and buttonhole deformities to occur.

What can you remember about Joint Protection guidelines you can apply when doing everyday tasks?

1. Ask for each principle and ask for an example of.

2. Show flipchart after and repeat.

(Flipchart)

We've looked at how people learn, by getting a clear picture of the movement in their mind, seeing the correct movement, trying it and feeling it, mental rehearsal helps with this as does repeated practice and clear feedback, from yourself - by talking to yourself- and from others. This means the physical movement no longer seems so awkward and clumsy and it gradually develops into a new habit, if you practice regularly and often enough.

Discussion:

- do you feel that you give yourself feedback when practising? "I did that right or I needed to do it like that" etc. Keep it up.
- How about involvement of family or friends - were they able to give you feedback?
- If they have not been able to come to the group, has anyone at home been able to read the information and discuss it with you and get involved?

(Flipchart)

-Last week, we looked at setting goals and that these should be:

1. specific,
2. state how many times will be done each week,
3. build up slowly,
4. take time off,
5. and give yourself rewards.

How many times did you aim to practice a hot drink? Did you meet your goal? (Encourage to increase number of times this week). What rewards worked for you? Did they help? Swap ideas (list on flipchart, encourage to use).

Activity 3 - Practice snack, hot drink and clearing up.

Make home made soup/ spaghetti neapolitan/ stew and potatoes.

(Do task, demonstrate correct methods talking through, ask why each correct, eg. Carry bag, lift pan, carry tray, lift grill pan, open tin, cut bread, peel vegetables, chop, lift full pan, stir, strain, open/ close jar, turn tap on/ off, lift kettle, fill kettle, lift plate/ bowl, empty pan, etc.).

Make hot drink and meal at same time. Work in pairs and observe each other. Give feedback, repeat demonstrations, manual feedback etc. as necessary. Stress importance of giving feedback to each other).

BREAK. Discussion.

Activity 4 - Problem-solving process.

In week 1, you looked at what kind of tasks you found were a problem for you because of pain, aching or tiredness. First of all, we'll look at a way of solving problems, and then we'll tackle some of these using this method and see what we come up with.

You may well think as I go through this "ah, right, that is the kind of thinking that goes through my mind when I'm trying to find the answer to a problem." Lots of people also say they often come up with new ideas through trial and error when they make natural changes. It seems that those people who use this structured thinking process more, that I'm going to talk through now, that is the people who sit down and take the time to try and think through solutions to problems, rather than just using trial and error, are those that seem to make changes more often and more frequently. So to help you think through problems in a structured way, I'll go through some points on the flipchart (and this is in your workbook) of the problem-solving process.

1. Identify a specific problem - tackle one thing at a time.
2. Analyze the task - what are the different stages? The different

movements used?

3. Is there a particular part or parts that seems to need changing most. Identify the parts that need changing.

4. Review the Joint Protection principles and apply these to each part in turn.

5. List the possible ideas to solve the problem or part of problem.

6. Select one method and try it.

7. Did it work?

Yes: Check it is the best method (the least strain) for you.

No: Try another method from your list until you get it right.

8. Practice!

9. If no solution worked, can you: ask someone else to do it? Do it less often? Give it up? Carry on but try and make as many parts of the job as easy/ least strain as possible.

Let's talk through an example to give you the idea. One common problem you mentioned in the first week was Ironing. This will take us longer to talk through and problem-solve than you might find it in practice.

1. Problem: is ironing.

2. What does ironing involve? 3. Which part is a problem. 4. Review JP principles:

LIST FIRST

ASK FOR IDEAS AFTER

Lots of clothes to be ironed - cut down amount

buy easy care clothes over time

get everyone to do their own

only do small amount at one go

save for a tumble drier

Putting up the board

- metallised cloth on work surface

look for an easier design of board

to put up

- leave up if space
 - ask someone else to
- Get out iron
 - is it in easy reach? store better
 - make sure can pick up with two hands
- Plug in iron
 - push in with palm
 - use adapted plug
- Move iron round/ lifting
 - can you slide it from rest?
 - use a flex tidy to stop flex
 - snagging
 - save for a lighter model
 - don't upend it (unless need to), do
 - steam things last, only steam what
 - need to
 - position of board to avoid aching,
 - can you sit?
 - don't grip the iron handle tight,
 - push it with the flat of the hand
 - as much as possible

You may like to do this sort of thing when you are actually doing the task, as it can help with thinking things through, and keep a piece of paper handy to jot down ideas. Get your family involved, but remember what sometimes seems a good idea to someone without arthritis, isn't always for someone with, who is the only one who can tell if it will really work.

If an idea does not seem workable - think again, why not?

Is it really not workable, or is it that you are thinking it's too much effort to do it! For instance, changing where you store the iron might mean having to re-arrange cupboards and that seems to be more effort than you are saving. But maybe a lot of your cupboards could do with re-arranging to save effort long-term? Remember the lady in

the video in session 1? She had stored her plates upright on a plate rack to make them easy to lift out, had put small jars and spice jars on a spinning rack to hand on the worktop. You can get mini- stepped shelves to put inside cupboards to make things easier to reach and carousels to store pans on, rather than having to reach inside for ones stacked on top of each other, saucepan racks etc (ask for ideas).

Perhaps it is worth re-arranging things, and the iron is just part of it.

Or maybe the problem is finding and getting a gadget?

Would someone in the family be prepared to go and look for one? Look in catalogues for ideas.

Can you change some parts of the task, even if not all? Think positive, you can't change everything. Change those parts of a job which will reduce most strain, so even if it still causes aching, its a lot less.

Once you've decided, try it out and if it works, keep practising. If it was re-organising a job or using a gadget or a different model of equipment, these are good because once you've made the change you always do it right, every time you use it.

There are also some more ideas in the workbook on planning and energy conservation to make everyday jobs easier that you can read through whilst using this process.

Activity 6. Problem-solving other tasks.

Use ideas from group. Put on flipchart. What are best solutions for different members. Use ideas from housework, job, gardening.

So what works for one person, doesn't always for another. So it's helpful to know how to think through finding solutions for yourself, as well as getting ideas from others, books, the group, because then

you can be more flexible in finding answers to your own problems.

Activity 7 - Further Information

Leaflets from ARC. Introduction to Arthritis Care. Other books. Sources group members know about.

Activity 8 - Home programme.

1. As this is the last session, really you need once again to set your own goals. But not only to do this for this week, but to set yourself a goal to review your programme each week, and re-set goals. I suggest you try to do this for at least another 4 weeks. You should find that as the weeks go on, you need to do this less and less as things have become more and more of a habit. You need to set a goal to review the whole programme again in a month's time and see if there is anything else new that you can apply. I suggest you particularly try going back over your list of problems from week one, using the problem solving process we discussed today, and trying to find solutions to these, setting goals to practice them.

2. So decide on your own goals to practice for the next week and write these down - making a hot drink, meal ... how many times a week.

Activity 9 - Home Visits

Arrange home visits if required.

Activity 10 - Closing

Thank everyone for coming, look forward to seeing them on home visit. Encourage to consider joining local arthritis groups. Facilitate members making links with each other if not already done so. Encourage to keep using workbooks and re-read information. Wish all the best.

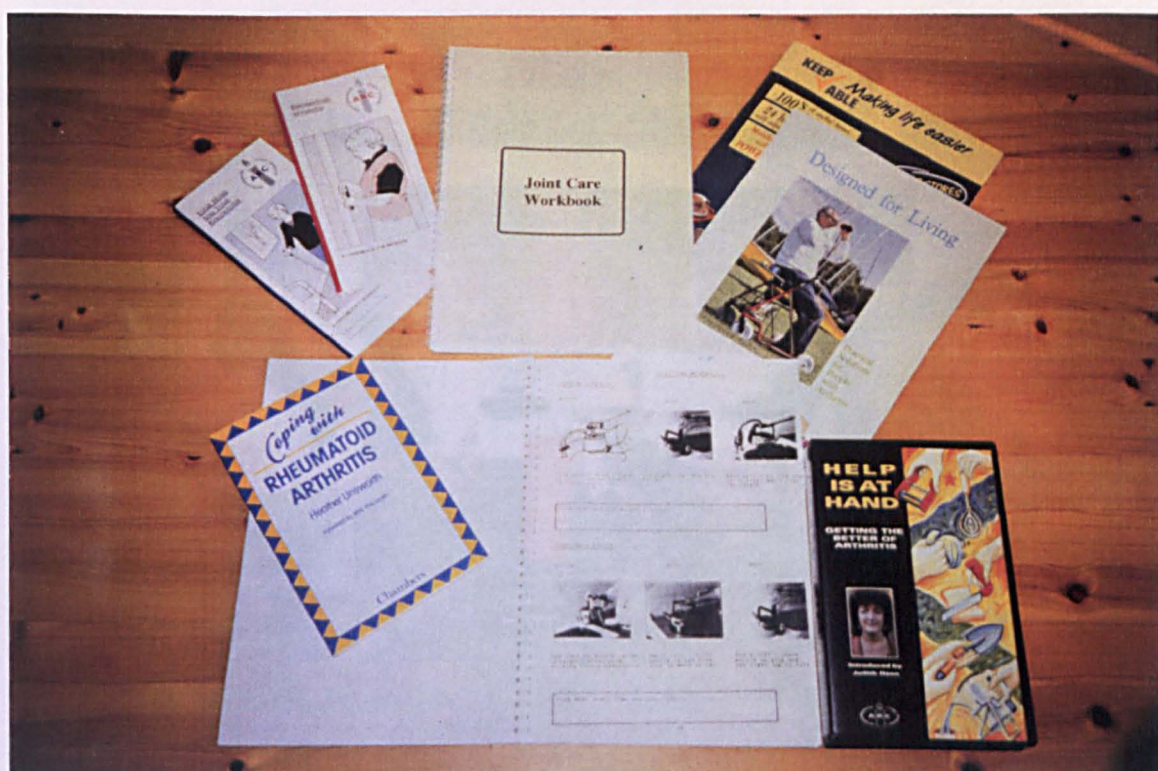


Figure 6.1: Information pack and videotape used in cognitive-behavioural JP programme.

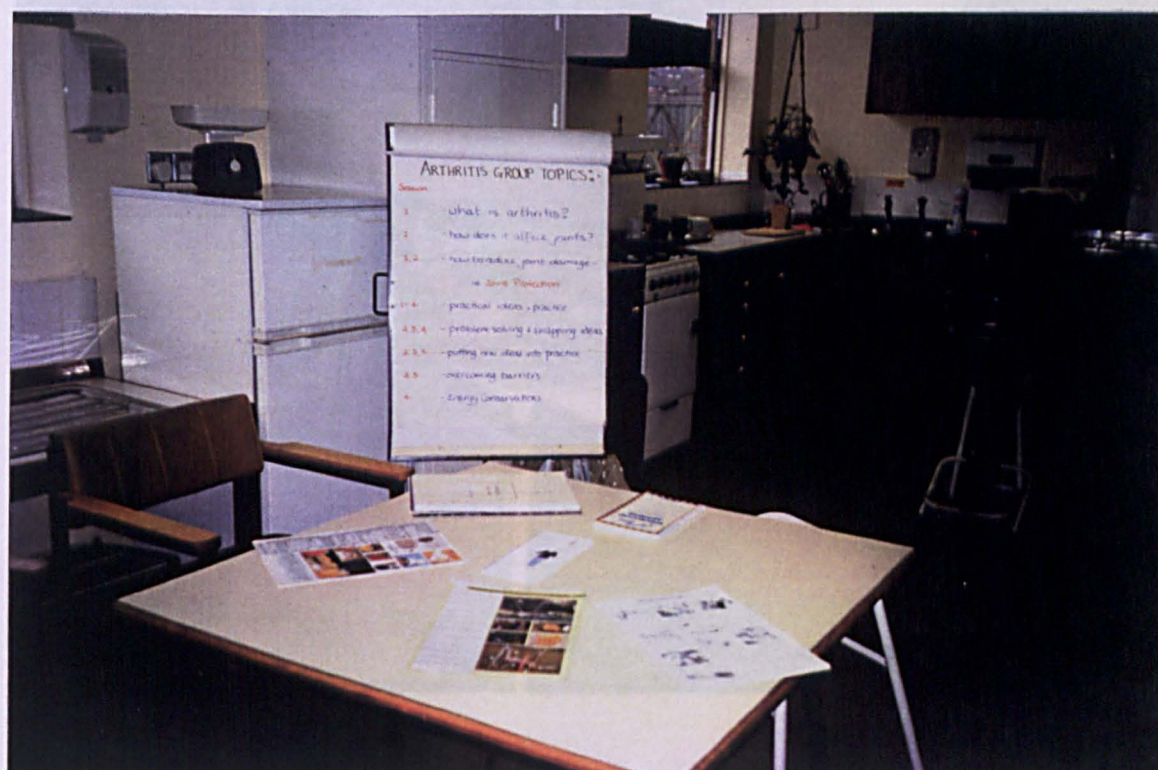


Figure 6.2: Cognitive-behavioural JP group venue.



Joint Care



Figure 6.3 a and b: Cognitive-behavioural JP programme - group in progress.

Joint Care Workbook

WELCOME.

This programme has been designed for people with rheumatoid arthritis who wish learn more about their disease, the principles and methods of joint protection, planning and pacing and how to apply these in their own daily lives to take a more active role in their own healthcare. Applying these methods of reducing strain on joints during everyday activities will help reduce pain, swelling and the likelihood of deformities developing (or progressing if you already have some).

The programme runs for 4 x 2 hour group sessions, which are a combination of short talks, practical tasks and discussions. These are followed up by an individual visit to your own home by the group leader. This is to give you or your relatives/friends the opportunity to ask any further questions, for individual advice on problems in the home and for further practice and individual training.

This workbook should be used each week with the course book "Coping with Rheumatoid Arthritis" and the Arthritis and Rheumatism Council booklets provided.

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This programme is funded by the Arthritis and Rheumatism Council.

PURPOSE OF THIS WORKBOOK.

The workbook and accompanying course materials should be read in the days following each session to reinforce the information given and the new methods learnt. The home programmes each week are designed to help you put the information you learn into practice. Experience has shown that the more time you can put into completing this "homework," the quicker results will be achieved.

Following the course and completion of the workbook you should;

- have a clear understanding of your disease and its possible effects
- be aware of your own everyday activities and movements related to joint protection, planning and pacing principles
- be able to analyse activities and movements and find solutions to practical problems appropriate for you
- gradually change activities and movements to reduce strain on joints, reduce pain and the likelihood of deformities developing

The course and workbook are designed to allow gradual skill development and learning of new behaviours over 5-6 weeks.

However, you will find it helpful if you keep this information and work through it again following the course, using the principles covered to develop new ideas of your own and make further changes.

DAILY HABITS AND ROUTINES ARE DEVELOPED SLOWLY AND THEREFORE NEED TO BE CHANGED SLOWLY.

SESSION 1.

Rheumatoid Arthritis is a disease which can cause joint damage because repeated periods of swelling cause the structures supporting joints (the capsules and ligaments) to weaken and go slack. Once this occurs, joints are much more prone to aches and pains, damage and strain from the movements involved in everyday activities, like cooking, housework, gardening, work.

This can lead on to the development of deformities in joints.

Re-read the booklet "Rheumatoid Arthritis" - pages 2 - 12.

This goes over how joints are affected by RA.

Pages 6 and 7 show that two-thirds of people with rheumatoid arthritis have continuing joint pain, swelling and flare-ups and are therefore at risk of deformities developing. The commonest joints affected are the hands and feet, so this programme particularly concentrates on hand problems, but you can apply the principles learnt to any difficulties experienced in other joints.

To introduce you to ways of reducing pain, swelling and limiting deformity, this programme uses the self-help principle called the "4 P's."

PAIN PLANNING PACING PROTECTION

PAIN.....If your everyday activity causes;

- pain or aching that doesn't ease off quickly with rest,

- pain/aching at night

you MUST see these as warning signs and change your way of doing everyday tasks. Working through the pain only damages joints further.

PROTECTION...Lifting, pushing, twisting movements all

contribute to joint strain. Look at how you use affected joints.....

- How could you move them differently to cause less strain?

- What labour-saving gadgets or aids would help?

PLANNING....Could you organise a task more efficiently?

Could storage areas be more organised?

Can you eliminate certain jobs, do less often, get someone else to do them?

Even out heavier and lighter jobs through the day and week

PACING.....Regular short few minute breaks, stretching,

swapping round between tasks to change position,

- all help save energy and avoid strain.

Being more aware how you use your joints in everyday activities will help you identify what movements can particularly contribute to deformity and so how you need to change them.

Read Chapter 6 in "Coping with Rheumatoid Arthritis"
--

This goes over why and how deformities, particularly in the hands, can develop. And what type of movements you should try to avoid where possible.

Knowing how to do things differently is often the easy part. Doing them differently is the difficulty, as you are trying to change the habits and routines of a lifetime and there are many other demands on your time from home, family and work. This programme aims to give you as many ideas as possible, and we hope that you will contribute the solutions you have already found yourself.

But it is making the change, putting the ideas into practice, that will be the main aim of these sessions. The home programme is designed to help you make these changes. But it is up to you to carry out the advice given or the programme can only be of limited benefit.

HOME PROGRAMME - SESSION 1.

1. Take some time during the week to start to become more aware of how you use your hands and arms in everyday activities.

For instance, ON AT LEAST ONE DAY WATCH YOUR HANDS AS YOU ARE MAKING A HOT DRINK. Are there any actions which push your hand and wrist joints sideways or downwards and could be straining joints? (jot down ideas below...)

2. Watch how a relative or friend makes a hot drink. Are there any actions you think you are already doing differently to them? Jot down these below;

3. Are there any everyday activities you noticed which caused pain/aching? Jot some of these down below and use them as reference for session 4 on problem solving. Try to be specific as possible. Don't put for instance "general housework" but "ironing," "hoovering," etc.

4. Look through the next 3 pages showing 6 everyday tasks. The pictures show better, strain reducing ways of doing these. Have a go at each task, trying the different ways shown. Decide which method for each YOU FEEL IS BEST FOR YOU and mark this with a tick.

5. Choose 4 of these everyday tasks. Practice the method you chose for each AS OFTEN AS POSSIBLE during the week. If you think you are already doing some or all of these, you may find you are only doing so part of the time, when your joints ache. Make a conscious effort to do it ALL THE TIME.

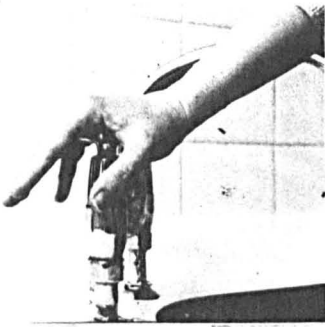
6. Read Chapter 1 and 6 in the book "Coping with Rheumatoid Arthritis" which cover many of the points discussed during the first session. You may find it helpful to ask a relative or friend to read these too, to help them understand why you are making these changes, and to help you with making them.

Spread the home programme out during the week and try to do as much of it as you can.

JOINT CARE METHODS 1.

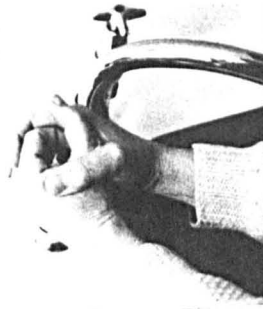
TURNING TAPS

BETTER



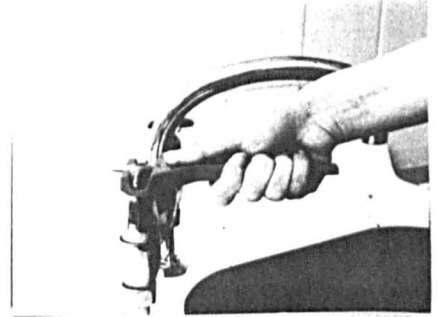
Use palm/heel of hand not fingers

BEST



Use 2 hands gripping between palms

BEST

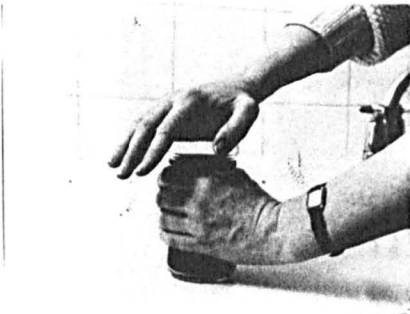


Use an aid-try different types.

TICK HERE every time you practice;

OPENING AND CLOSING A JAR

BETTER



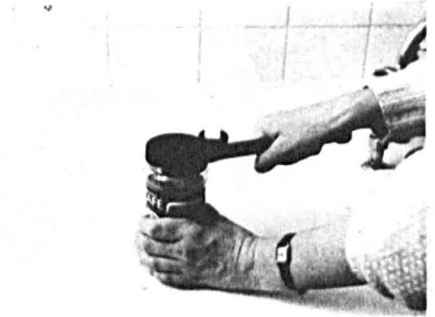
Use palm/heel of hands, not fingers.

BETTER



Grip side of lid with thumb, palm and fingers. (DO NOT loosen or tighten with fingers only)

BEST



Use a jar aid try different types.

TICK HERE every time you practice;

CARRYING A PLATE

BEST



Two hands squarely supporting plate/s on palms.

TICK HERE every time you practice;

CARRYING A MUG

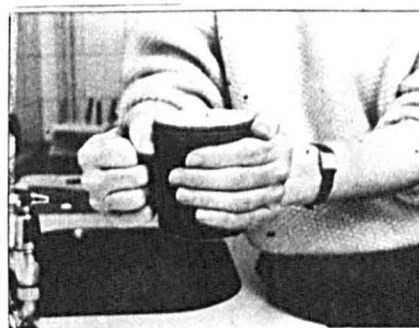
BEST



One hand holding handle, other palm squarely beneath.

TICK HERE every time you practice;

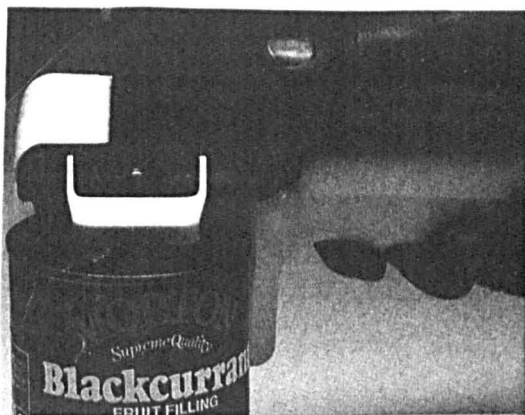
BEST



One hand holding handle, other hand wrapped firmly round.

OPENING TINS

BETTER



Hand held electric opener

BETTER



Wall mounted opener

BEST



Table top electric opener.

TICK HERE every time you practice;

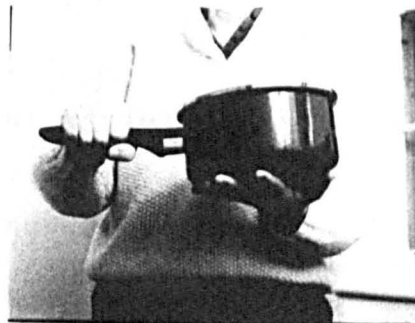
CARRYING A PAN

BETTER



Use 2 hands firmly gripping handle

BEST



One hand firmly gripping handle, other palm or forearm squarely underneath (use cloth if hot).

TICK HERE every time you practice:

SESSION 2.

Last week and this we have been looking at how particular movements in everyday tasks (like pushing the fingers sideways as you turn a tap, lift a pan, open a jar) can contribute to straining joints and deformities developing.

In themselves, one movement done once in the usual way will not cause damage. It is the effect of doing these movements many times, over a period of time that causes damage. Joints are at risk of damage:

- when they are swollen
- and even after the swelling has gone down, if you have had several periods of joint swelling, as these can have weakened the capsule and ligaments supporting the joint.

So there is a need to change many movements all the time to gain maximum benefit from Joint Protection. Not just some movements, some of the time.

But Joint Protection is not about giving up doing activities (unless there is no alternative). It is important to use joints or they will stiffen up and muscles weaken. Instead you need to

DO THINGS DIFFERENTLY.

Here are some GENERAL GUIDELINES FOR JOINT PROTECTION;

1. Distribute the weight of what you lift over several joints.
2. Use a stronger, larger joint to do the movement.
3. Reduce the effort to do a task;
 - use a labour saving gadget or aid, or different design of equipment
 - avoid lifting or slide instead
 - reduce the weight of what you lift
4. Avoid positions of deformity when using joints
 - keep wrists straight (don't bend downwards)
 - don't let fingers be pushed sideways
 - don't press on fingerends or lift with fingers only
 - avoid gripping tightly

See Chapter 7 and the booklet; Your Home and Your Rheumatism
--

These have many practical ideas which use these basic principles.

So how do you go about changing the normal way you have been doing an everyday activity for the last 10, 20 years to a new way?..... It is not as easy as it sounds to change the habits of a lifetime, when we do these movements normally without thinking.

There are 3 main stages to LEARNING NEW HABITS;

1. Learning - this is getting an "overall picture" in your mind of how to do the movement.

We learn in various ways; watching demonstrations, hearing and reading instructions, seeing pictures, watching others, being physically guided doing the movements. And we learn by "mental rehearsal" - by imagining in our minds how to do the action, to make this "overall picture" clearer.

2. Fixing - helping our body move to match this "picture" until it feels comfortable, and no longer odd or clumsy. This stage needs;

PRACTICE - regular and as often as possible

FEEDBACK - to know if you are getting it right;

- 1) from yourself - watch what you do and tell yourself in your mind if you are doing it right or wrong and how you need to improve.

- 2) from others - the more specific this feedback the quicker you can correct yourself and can do the movement properly.

3. Automatic - being able to do the movement automatically, without thinking, even whilst you are doing or thinking something else or being distracted. This takes MORE PRACTICE. Even when you think you do it, it may still only be for some of the time, SO KEEP ON PRACTISING.

HOME PROGRAMME - SESSION 2.

1. Practice making a hot drink using the joint protection methods you learnt in session 2 AS OFTEN AS POSSIBLE during the week.

Decide how often you think you could do this during the next week - 3, 5, 7, 10 times? Write down your decision below.

I AIM TO PRACTICE TIMES DURING THIS WEEK.

Tick here everytime you practice;

--	--	--	--	--	--	--	--	--	--	--	--

2. Review the photographs of joint protection methods shown from last week and this. Carry on practising the 4 methods you chose last week and add a further 3. Tick the box below the photos for every time you have remembered to practice, if you can, for all 7 tasks.

Are last week's methods 'automatic' yet? Keep on practicing!

3. Spend time "mentally rehearsing" or picturing the movements in your own mind that you are learning, for instance, all the movements involved in making a cup of tea - this all helps!

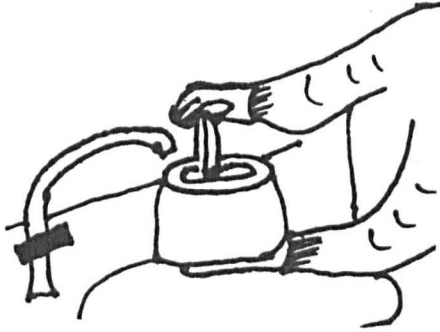
4. Continue to spend some time during the week "watching" how you use your hands during everyday activities, for instance choose a job that you do when at work, doing the gardening or housework.

Think about the joint protection principles we have discussed this week (listed on the next page), how could you change any parts of that job to reduce strain?

5. Read Chapter 7 on Guidelines to Joint Care in the book.

FILLING A KETTLE

BETTER



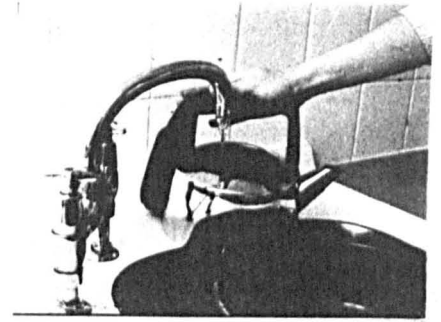
Hold kettle with 2 hands as fill, one on handle, one underneath

BEST



Use light jug, mug etc. to fill

BEST



Rest kettle on sink edge or in sink, don't take the weight.

TICK HERE every time you practice;

CARRYING A KETTLE

BETTER



One hand on handle (wrist straight) other palm holding kettle underneath

BEST



Don't lift - slide kettle to and from sink as much as can.

BEST

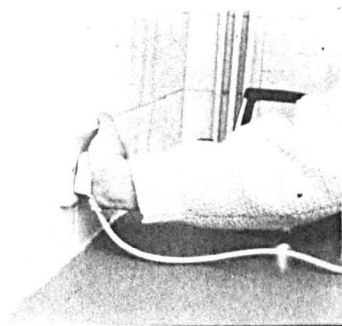


Don't lift - leave kettle by plug and use light jug to fill

TICK HERE every time you practice;

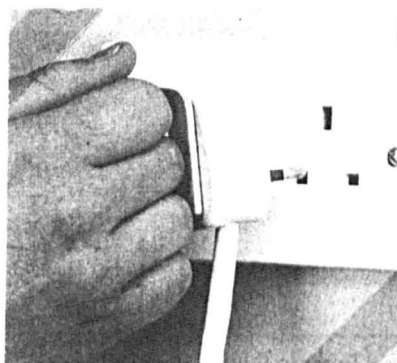
PUSHING IN A PLUG

BETTER



Use the palm of your hand
- or the side of your fist
or forearm.

BEST

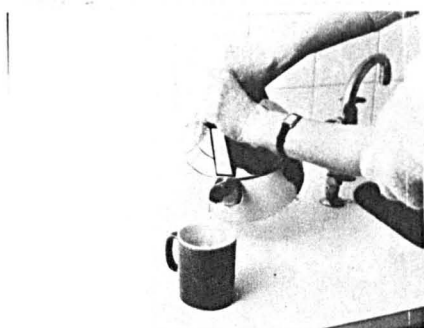


Use an adapted plug with
a loop.

TICK HERE every time you practice;

POURING A KETTLE

BETTER



Firmly grip with two
hands - keep wrists
held up or straight.

BEST



Use two hands, one on
handle, other with
palm taking weight
beneath.

BEST



Use a kettle tipper or
put kettle on a block
and rock or tip rather
than lift.

TICK HERE every time you practice;

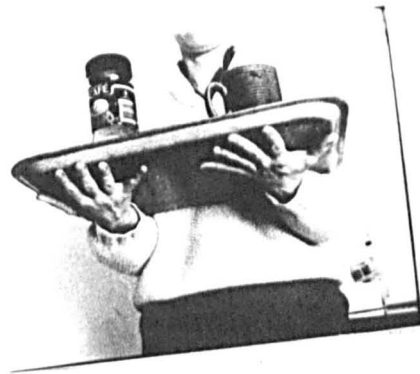
CARRYING A TRAY

BETTER



One hand grips tray edge, other palm and forearm take weight beneath.

BEST



Slide tray onto both palms and forearms.

TICK HERE every time you practice;

CARRYING A SHOPPING BAG

BETTER



Carry in your arms, close to body.

BETTER



Put handle over forearm.

TICK HERE every time you practice;

HOLDING A BOTTLE

BEST



Use two hands wrapped firmly
round bottle.

TICK HERE every time you practice;

SESSION 3.

Last week, we discussed how changing to new habits is not just a matter of learning what to do. Once you have got the ideas, you need to actually put them into practice in your everyday life. This needs regular, frequent practice for the movements to begin to feel natural and automatic to you.

However, it can be all very well to say "do it regularly at home" but this is not always easy. There are many barriers;

- eg.
- too busy, too much to do
 - too many demands from others at work and home
 - getting bored or forgetting
 - feeling there are too many things to change and it's impossible.

These are all very real problems. One way of trying to motivate yourself or overcome these barriers is to make an agreement with yourself to do certain things at certain times,

ie. SETTING GOALS.

There are 2 types of goals - longterm and short-term.

1. A long term goal is general eg.

"I want to reduce the amount of pain or aching I have when working (at home/work) and feel less tired at the end of the day."

If this is important to you, then you need to look at the steps to help you achieve this goal, ie. -

2. The short-term goals. The small steps, the things you will do today and this week to help you on your way.

Short term goals need to be SPECIFIC, stating;

ACTION - what you will do, eg. practice turning tap with palm, practice making a hot drink using joint protection methods.

HOW OFTEN - you will practice, eg. twice a day, 4 times this week.

But remember to make them REALISTIC. Something you know that you could do, but is still a bit of a challenge (Remember how many New Year Resolutions you have broken in the past, because you bit off more than you could chew).

So to be successful in changing behaviour, you need to set yourself realistic goals;

1. be specific about what the goal/s (the ACTIONS) are
2. say to yourself how many times you'll practice it each week.
3. start with something reasonable and build up slowly. Aim to change a few things at a time
4. give yourself time off. Allow days when you don't feel you have to think about practicing, then it won't seem a chore.
5. give yourself a reward for achieving goals!

It may be, for instance, a rest, a cup of tea and a chocolate bar when you've completed one goal. Or if you do all the goals you'd set for the week - get yourself something extra or do something you find a treat.

Plan your reward ahead, so you've got something to look forward to.

The home programmes you have done so far have been goals already set for you. This week you should start to set your own goals. When the sessions finish you will need to keep on doing this yourself, to continue the changes begun here, until new habits have developed.

HOME PROGRAMME - SESSION 3.

1. On the next few pages, there are more photos of strain reducing ways of doing everyday tasks that we have practised during the session. Try each method and decide which is best for you and mark with a tick.

2. Look through all the photos of Joint Care Methods from sessions 1-3 to get a clear picture in your mind of these strain reducing ways.

3. "Mentally rehearse," or practice in your mind, making a hot drink and making a meal using these movements.

State here how many times you will do this in the next week.....

Tick below every time you have done this;

Making a hot drink	
Making a meal	

4. Decide on your own goals for practice in the week -
(eg. - making a drink using joint protection methods 5 times
this week.
- making a meal using joint protection methods 3 times
this week
- practice 4 new tasks (state which ones) at least
once a day each this week etc.

5. Write your goals down on the Home Programme sheet on the
next page and record how often you did each.

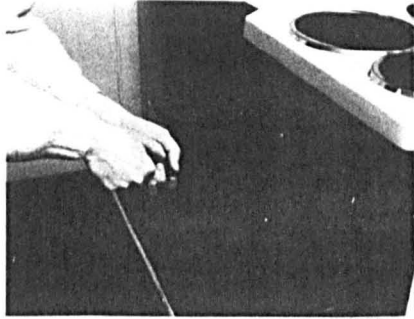
HOME PROGRAMME - WEEKLY GOALS

eg. turn tap with palm 3x/day for 1 week.	Mon: ✓✓✓ Tues: ✓✓✓

JOINT CARE METHODS 3.

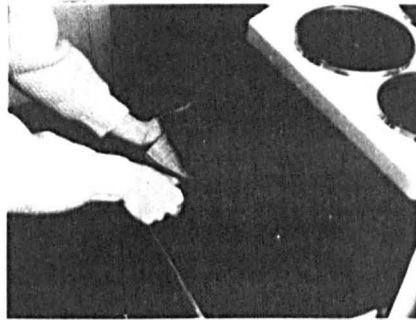
LIFTING A GRILL PAN

BETTER



Use 2 hands on the handle

BEST

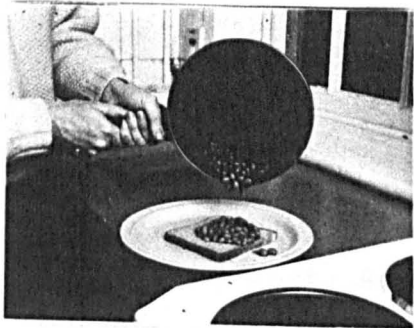


Use 2 hands - one on handle, other with weight on palm, not finger ends.

TICK HERE every time you practice;

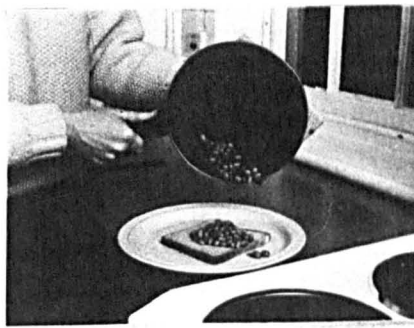
EMPTYING A PAN

BETTER



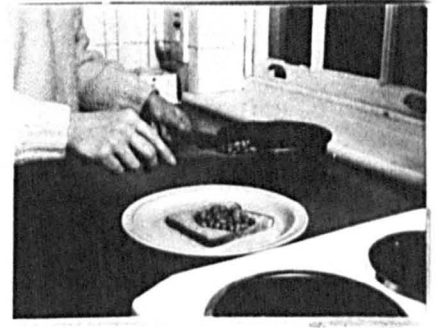
Use 2 hands on handle, as pour out.

BEST



2 hands, on on handle, other palm supporting base, as pour out.

BEST

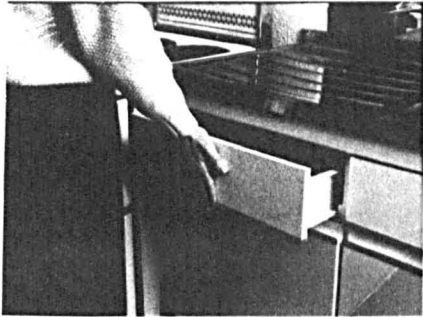


Leave resting/tipped on surface as spoon out

TICK here every time you practice;

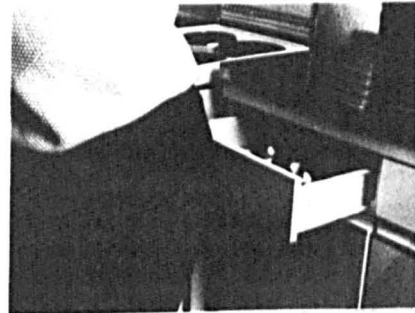
CLOSING DRAWERS

BETTER



Use palm, keep wrist straight as possible.

BEST

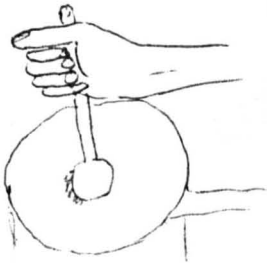


Use hip

TICK HERE every time you practice;

WASHING UP

BETTER

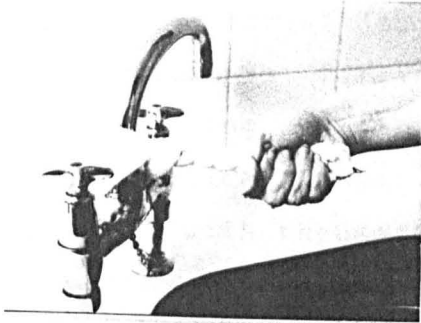


Use a brush held in fist.

TICK HERE every time you practice;

SQUEEZING CLOTHS

BETTER



Wrap cloth ends round tap and twist

BEST



Press out cloth/sponge with palm.

TICK HERE every time you practice;

WIPE SURFACES

BEST



Wipe with cloth/sponge using palm of hand (not fingers).

TICK HERE every time you practice;

SESSION 4

In the home programme in session 1, you identified a number of everyday activities that can cause you pain, aching and/or tiredness. So far in the course we have looked at principles for reducing strain on joints (Joint Protection principles) and practiced these particularly in kitchen tasks. For many people with rheumatoid arthritis, these are your commonest problems, because the hands are usually affected early on. However we use our hands in almost every other activity we do and you may find that other joints are also affected. So you may need to apply these principles of protection, planning and pacing to other everyday tasks.

Often people with arthritis say that, on the whole, they have found solutions to everyday problems through "trial and error" - when a problem comes up, they try a different way and if that does not work, then next time, try something else.

Whilst this can be a very practical and effective approach, it can often take time to make changes. Experience shows that it is those people who use a more planned approach, that change more quickly and effectively.

This process is termed:

PROBLEM SOLVING

PROBLEM SOLVING PROCESS

1. Identify a specific problem - tackle one thing at a time
2. Analyse the task:
 - what are the different stages and different movements involved in the task?
3. Are there particular stage/s that seem to need changing most?
4. Use the ideas in the Joint Protection, Planning and Pacing principles shown overleaf to help you plan solutions for each stage.
5. List the possible solutions (on paper can be helpful) to solve the problem.
6. Select 1 method and try it.
7. Did it work?

YES

check it is the best (ie. least strain) for you.



8. PRACTICE

NO

try another method from the list.



NO

can you ask someone else?
can you do it less or give it up?



In the last resort, there isn't always a solution to everything. But if you try to reduce strain in as many things as possible, then you will be gaining enormous benefits.

PLANNING PRINCIPLES

1. How many trips were made between two points?
2. Could the number of trips be reduced?
3. Could the order of performing different parts of the jobs be more efficient?
4. Are the materials and equipment needed in easy reach?
5. Do storage areas contain only the needed materials, easy to hand or are they cluttered with seldom used things?
6. Can any part of the job be left out and still get the results?
7. Are good body mechanics used when standing, sitting, lifting? How can they be improved?
8. Are two hands used to the best advantage?
9. Would the use of wheels be helpful?
10. Are seats/stools comfortable and the right height?
11. Are the materials easy to hand or assembled ready to use first?
12. Is the rate of work too fast?
13. Should someone else do part of the task?

JOINT PROTECTION PRINCIPLES

1. Distribute weight over several joints.
2. Use a stronger or larger joint.
3. Reduce effort - use a gadget, don't lift
4. Avoid positions of deformity (pushing joints downwards or sideways).

If you have problems with tiredness at the end of the day then the following may also help;

PACING PRINCIPLES

1. Plan a daily rest period - rest for an hour if possible during day
2. Balance rest and activity - take a 5 minute break every half hour.
3. Plan the rest breaks before you start jobs
4. If you find resting difficult - plan to do something restful during the break, eg read a book, watch TV etc.

Remember; when muscles that help protect and move damaged joints are tired, more stress is put on the joint itself, possibly causing increased pain and potential damage to the joint.

CONCLUSION

This is the last group session. On the next page is the last home programme. The group leader will be visiting you in the next few weeks - this is to help you in adapting the ideas further to use in your own home and to suit your individual needs. If you have any questions related to managing your arthritis not answered in the course, please use this opportunity to ask them.

HOME PROGRAMME - SESSION 4.

1. Review again all the photos of strain reducing methods of doing everyday tasks. Have you decided which is the best method for you for each of the 19 tasks illustrated? If not, do so and mark the best method with a tick.

2. Continue to practice "mentally rehearsing" making a hot drink and a meal, until you feel sure you are clear in your mind the best way to do the tasks.

3. Look through the list of everyday problems you made in the home programme for session 1. Go through this;

- have you found a solution to each of these during the course?
 - If yes, are you doing this now?
 - if yes, cross it off your list.
-

4. For those problems left, set yourself the goal of trying to "problem solve" and find a solution to a specific problem each week and setting a second goal of putting your solution into practice. Write these goals into the "Home Programme - Weekly Goals" sheets included over the page, week by week.

5. Decide on your own goals for practice in the week -
(eg. - to again practice making a hot drink, making a meal
using joint protection methods ... times a week,
- to use joint protection methods during a specific
housework, work or gardening task
-

6. Write these goals down on the home programme sheets
provided and record how often you did each.
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7. Aim to continue to make weekly goals and put these into
practice for at least a further 3 or 4 weeks after the end
of the programme. You should find that as time goes on, and
joint protection methods become more of a habit, you
have less need to do this.
-

Finally, you may find it helpful to go through this workbook
again in a month's time. Go through all the tasks we have
practised. Have some become automatic yet and are you doing
some, say, half of the time? Try consciously to practice
regularly again and you will find these too become a habit.

Remember;

DAILY HABITS AND ROUTINES ARE DEVELOPED SLOWLY AND THEREFORE
NEED TO BE CHANGED SLOWLY.

HOME PROGRAMME - WEEKLY GOALS

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THE SPIRE PROGRAMME BOOKLIST

<u>Title</u>	<u>Details</u>	<u>Where obtainable & Cost</u>
ARTHRITIS - YOU AND YOUR MEDICINE	Small pamphlet	Arthritis Care - Free
THE ARTHRITIS HELP BOOK	What you can do for your arthritis by Kate Lorig and James F Fries (U.S.A.) Hardback edition.	Souvenir Press, 43 Great Russel Street, London WC1B 3PA or through bookshops. £8.95 (published in 1983).
CONTROLLING CHRONIC PAIN	by Connie Peck. A self-help guide. Paperback edition.	Published by Fontana at £2.95 (1985)
COPING WITH RHEUMATOID ARTHRITIS	by Heather Unsworth, Paperback edition	W & R Chambers, Edinburgh. Available through bookshops £3.95 (published in 1986, reprinted in 1990)
DRUG FREE PAIN RELIEF	by George Lewith M.D. & Sandra Horn. A self-help guide Paperback edition	Published by Thorsons (1986)
LIVING WITH YOUR PAIN	by Annabel Broome & Helen Jellicoe. A self-help guide to managing pain. Paperback edition.	Published by the British Psychological Society in association with Methuen & Co Ltd (1987) cost £3.95
MARRIAGE, SEX AND ARTHRITIS	by Dr. Wendy Greengross in conjunction with ARC pamphlet (28 pages)	Arthritis & Rheumatism Council (ARC). Free if a member of ARC.
OVERCOMING ARTHRITIS	by Dr. Frank Dudley Hart. A positive health guide. Paperback edition	Martin Dunitz Limited. 154 Camden High Street, London NW1. £3.10 inc p&p (published in 1981).
RELAXATION - modern techniques for stress management	by Sandra Horn. A guide to the prevention and control of stress related illness, with the emphasis on self-help. Paperback edition.	Thorsons publishing group £4.99 (published in 1986) Available through bookshops.
RHEUMATISM & ARTHRITIS	by Malcolm Jayson and Allan St. J. Dixon. A Pan Paperback	Pan Paperbacks. Available through bookshops (published in 1974). Inexpensive.
RHEUMATOID ARTHRITIS - Helping Yourself	A booklet produced by the Occupational Therapy and Department of Health Education, Doncaster. (30 pages).	Available from the Department of Health Education, Doncaster Health Authority, Doncaster, Yorks.
UNDERSTANDING RHEUMATISM	by Dr. Frank Dudley Hart. A family Doctor booklet. (32 pages).	Published by the British Medical Association, BMA House, Tavistock Square, London, WC1H 9JR. Also available from Arthritis Care.

EXERCISE AND ARTHRITIS

Should you do more exercise than normal or less? It is a dilemma people with arthritis and rheumatism face. Some discover that exercise makes the pain in their joints worse and so they avoid it. Others think, wrongly, that exercise might damage their joints because they have heard that arthritis is caused by joint 'wear and tear'.

There are benefits and risks in both exercise and rest for anyone suffering from arthritis. So it is important to weigh up the pros and cons in order to find a way of life that fits best with your circumstances and condition.

These are the main factors to consider:

REST

BENEFITS - helps decrease inflammation during acute attacks.

RISKS - causes stiffness and loss of muscle power.

EXERCISE

BENEFITS - produces increased movement, more strength, improved function and better all-round physical and psychological well-being.

RISKS - can increase pain if you exercise too much.

CONCLUSION

Resting is helpful if your joints are particularly inflamed and swollen.

Exercise prevents joints becoming unnecessarily stiff and painful and keeps your muscles strong. If you allow your muscles to grow weak then it will become harder to move around; you are also more likely to trip or fall and so cause even more injury.

REMEMBER, EXERCISE CANNOT WEAR OUT YOUR JOINTS

WHAT KIND OF EXERCISE?

There are three main types to consider:

- * Exercises to help keep your joints moving.
- * Exercises to maintain and improve the strength of your muscles.
- * Exercises to keep up the level of your general fitness and health.

No one exercise can do all three jobs so, depending on what each individual needs, groups of exercises need to be performed separately.

JOINT MOVEMENT EXERCISES

These involve repeatedly bending and straightening the joint. You need to move the joint as far as it will go without causing increased pain. You can exercise your arms and shoulders simply by gently swinging the joint through the maximum range available. Many people with arthritis of the back, hips, knees and feet find it easy to exercise when sitting or lying because in these positions, the joints do not need to support the weight of your body.

Gentle exercises like pedalling (on a normal bicycle, exercise bike or set of pedals) are good because they move many of the joints in the leg. Exercising in a swimming pool or hydrotherapy pool can be particularly helpful as many people find they can move more freely in water (because it supports their body weight instead of putting pressure on the joints). Warmth helps loosen up joints and muscles before exercise and also aids relaxation afterwards. In either case a warm bath, for instance is to be recommended.

MUSCLE STRENGTHENING EXERCISES

The idea here is to make your muscles work as hard as they can without causing extra pain. This is usually achieved by lifting weights (of differing amounts according to the requirements of the individual or of particular muscles). There are two different approaches using exercises like these. One is to make the muscles move the joint (and weight) through the maximum range available. Another is to use the weight to tense the muscles without actually moving the joint at all. Wherever possible, it is better to use the joint-moving exercise as this will help mobility as well as strength. But muscle strength is important too as strong muscles protect the joints from abnormal pressure which might cause further joint damage.

There are two exercises of particular value in maintaining function and avoiding deformity:

- * Tightening the muscles on the front of the thigh (quadriceps) helps prevent 'flexion contracture' of the knee joint, a common cause of disability in arthritis.
- * Extension exercises of the wrist joint help to maintain the hand in a good functional position.

GENERAL HEALTH AND FITNESS EXERCISES

These are to be done for a few minutes at a time and should leave your muscles feeling slightly tired and you feeling a little breathless. It is best to use as much of the body as possible - swimming, walking and cycling are ideal. Swimming has an additional advantage in that the joints do not have to support the weight of the body. General health and fitness exercises are often the most difficult of the three but they are very well worth the effort if you can find a way of doing them comfortably. They will also help you relax, sleep and feel generally better.

You should be able to get more information about exercise and, if need be, a specific programme of exercises from a doctor or, in particular, a physiotherapist.

The latter are specialists in this field, trained to develop exercise programmes for people's individual problems, as well as give general advice about exercise.

IMPORTANT GUIDELINES FOR ALL EXERCISE

- * Always start off very gently so you can find out how much you are able to do without making the pain worse.
- * 'Little and often' is better than the occasional exercise binge!
- * Gradually make very small but regular increases in the amount of exercise you take. If you take it too easy it will not do you much good.
- * Do not worry that you might be making your arthritis worse. As long as you start off gently, you will not.
- * Be adventurous; find a form of exercise which is fun. But be sensible; hand-gliding is probably not a good idea!

JANUARY 1992

INFORMATION SHEET

DRUGS AND ARTHRITIS

You would think with so many hundreds of drugs available today that a few of them at least would be able to get rid of arthritis. Unfortunately drugs that can do this are the exception rather than the rule. Antibiotics can be used, for instance, in the successful treatment of a single, infected joint. In the main the drugs we have available are able to control the joint disease but not get rid of it.

There are of course many different types of arthritis and some of these are more easily controlled than others. Gout, for example, is one of the easier forms of joint disease to treat with drugs. This arthritic disease is caused by the presence of sodium urate crystals in the joints. Sodium urate is the end product of a complicated process which takes place when your body breaks down different types of protein. A drug called "allopurinol" has been developed which stops the final part of the process from happening, which in turn stops sodium urate from being formed and therefore prevents many attacks of gout. In most other forms of arthritis, drugs either reduce the symptoms or damp down the disease process, without producing a cure.

SOME BASIC ADVICE

(A) Tablets are usually best taken with or after a meal. That way they are less likely to upset your stomach. Do read the instructions, though, as occasionally a drug needs to be taken on an empty stomach (D-Penicillamine, for example).

(B) Drugs should obviously be kept out of the reach of children, preferably, in a locked cupboard. Some tablets are supplied in containers with child-proof lids. Unfortunately, people with arthritis in the hands often find these difficult to open. With this problem in mind, some companies are manufacturing tablets in strip packs where only light pressure is required to push the pills from the foil strip.

(C) Your ability to drive a car should not normally be affected by drugs you are prescribed for arthritis (toxic effects can, rarely, make a difference). Sedative and anti-depressant drugs may slow your reactions down and be dangerous, but these are only prescribed to people suffering from anxiety, depressions or pain (which normal painkillers cannot cope with), not for the rheumatic disease itself.

(D) You may need to avoid alcohol if you are taking drugs which affect the immune system (these are known as "immunosuppressives"). This also applies to some painkillers. If you're in any doubt at all, ask your doctor or pharmacist.

(E) Doctors try to avoid prescribing several different drugs to one person because of possible drug interactions. However, it sometimes has to be done - especially with elderly patients who are suffering from several problems - but doctors are usually well aware of the risk of such interactions.

(F) If you have any drugs left over at the end of a course of treatment, please return them to the pharmacy you bought them from or throw them away.

(G) Literally dozens of drugs are used to help treat the various forms of arthritis. But in order to understand how they are used we can group them in a number of ways. They fall into these categories either because they are broadly similar in make-up or because they are used at similar stages of disease. These groups are listed in the table attached under appropriate headings together with warnings about possible side-effects.

(H) Always follow the instructions carefully: stick to the dosage and the method of taking the medicine recommended by your doctor and/or pharmacist.

IMPORTANT POINTS ABOUT DRUGS AND THEIR EFFECTS

- * If you do not respond to one drug in a group, that does not mean another drug in the same group cannot help.
- * If side-effects are experienced from one drug in a group that does not mean all the drugs in that group will produce the same reaction.
- * Sometimes combinations of drugs are useful. In fact many people suffering from rheumatoid arthritis may require two or three different types.
- * As long as your rheumatologist or GP monitors any of the more powerful drugs you might be taking, side-effects can be recognised early and stopped by lowering the dose or changing the drug.
- * There can be problems in buying drugs "over the counter". Most preparations used by arthritis sufferers contain combinations of aspirin, paracetamol and/or codeine. One non-steroidal, anti-inflammatory drug (Nurofen) can also be bought without prescription.

These drugs can be troublesome if you have had an ulcer. So check with the pharmacist on duty or your doctor before using these sorts of preparation on a regular basis. This is particularly important if you are already being prescribed other drugs by your doctor.

- * If you are on a number of different drugs it is a good idea to carry a list of them on you, giving details of the names of the drugs and how many tablets of each you take every day.
- * It is **NOT** a good idea to swop drugs with other people!

DRUG GROUPS

The drugs in groups one and two are often used in the treatment of osteoarthritis, rheumatoid arthritis, ankylosing spondylitis, arthritis associated with psoriasis and in "soft-tissue" rheumatic problems like bursitis and tendonitis. The drugs in group three and four are most frequently prescribed for more severe forms of rheumatoid arthritis (especially group three), systemic lupus erythematosus (excluding gold and D-penicillamine), and other less common, but very serious forms of arthritis.

TYPES OF DRUGS

1. Pain-relieving drugs

MAIN EFFECTS

This group-including paracetamol, codeine, temgesic and various proprietary combinations -simply helps to reduce pain. These drugs are often used in treatment of osteoarthritis, rheumatoid arthritis, the arthritis associated with psoriasis and in "soft-tissue" rheumatic problems like bursitis and tendonitis.

SIDE-EFFECTS

Rare, occasional headaches; codeine causes constipation.

2. Non-steroidal, anti-inflammatory drugs

Including aspirin there are still over 20 of these available (eg. naprosyn, ibuprofen etc). They can reduce inflammation,

Drugs - rashes, irritation of the lining of the stomach or duodenum, occasionally may lead to ulceration.

TYPES OF DRUGS

MAIN EFFECTS

SIDE-EFFECTS

	but do not prevent the underlying cause of the inflammation. They often reduce joint swelling and pain. They are used for the same sort of problems as the pain-relieving drugs and also in ankylosing spondylitis.	
3. More powerful non-steroidal drugs	Used in rheumatoid arthritis and also known by some as "disease modifying" or "second line" drugs include gold D-penicillamine, the anti-malarials (also used in systemic lupus erythematosus) and salazopyrine. They also have anti-inflammatory actions but may have some effect on the underlying disease mechanism.	Rashes. Occasional effects, on the bone marrow which produces cells for the blood. This is why blood tests for those on D-penicillamine and gold are particularly important. Sometimes there may be temporary, effects on the kidney.
4. Corticosteroids, and other immuno-suppressive drugs	Prednisolone (a steroid) and other drugs such as azathioprine, cyclophosphamide and methotrexate have powerful effects on the immune system and may be very helpful in some cases of rheumatoid arthritis, systemic lupus erythematosus and other conditions. Given by injection, steroids can be used effectively in a wide range of rheumatological disease.	Can affect bone marrow (fairly uncommon), but regular blood tests are required. Skin rashes may occur. Steroids taken in large doses for long periods can cause high blood pressure, diabetes, facial swelling and obesity. The other drugs may have different side-effects which your doctor will discuss with you before starting on them.

January 1992

WELCOME TO THE MANAGING YOUR ARTHRITIS GROUP.

This is to let you know that the course you wished to attend to help you manage your arthritis will be starting on:

By concentrating on your difficulties, you will be shown how you can control your symptoms and manage problems with everyday tasks as quickly and effectively as possible.

You will be offered advice and instruction about your symptoms and problems and will plan and carry out a home programme week by week. It will be up to you to follow these if you wish to reduce strain and fatigue quickly.

Experience has shown that the more effort you can put into your home programme, the more quickly results will be achieved. The therapists are there to help you to resolve your problems.

You may find it helpful to enlist friends and relatives to help you follow the home programme. A relative or friend is very welcome to attend the group with you. Enclosed is an information booklet about Rheumatoid Arthritis, which we would like you to read before the first session. Please ask your family, and particularly anyone coming to the group with you, to read this also.

May we wish you speedy progress with managing your arthritis.