Hammond A, Adams J, Prior Y (2020). **Chapter 26: Occupational Therapy: in Oxford Textbook of Rheumatoid Arthritis. Eds:** DL Scott**,** J Galloway**,** A Cope**,** A Pratt**,** and V Strand. Oxford University Press: Oxford. ISBN: 9780198831433

Estimated publication date: 17/09/2020

Contributors: Alison Hammond [1]; Joanne Adams [2]; Yeliz Prior [1].

1. Centre for Health Sciences Research, University of Salford
2. School of Health Professions, University of Southampton

Abstract:

People with rheumatoid arthritis can find it painful, tiring and frustrating to perform their daily activities, work, family and social responsibilities, and leisure. Whilst drug therapy has improved outcomes, many still experience limitations in their daily lives. Occupational therapy aims to:

- improve clients' abilities to perform their activities and participate in their social roles;
- reduce pain and fatigue;
- improve or maintain physical function;
- improve or maintain psychological status;
- help people self-manage their condition successfully and adapt to changes in their lifestyle;
- and achieve a healthy work and personal life balance.

People with participation restrictions have poorer psychological and physical outcomes. Helping people participate in their roles, as and when they wish to, is an important part of rehabilitation to maximise clients' quality of life. Occupational therapists use a wide range of educational, physical, social, psychological and work-related interventions to help people live their lives as successfully as possible.

Key words:

Occupational therapy; assessment; self-management; hand therapy; orthoses; joint protection; daily activities; work rehabilitation; psychological therapies; leisure rehabilitation.

Introduction

Rheumatology occupational therapy in the UK has been a specialist area of practice for nearly 40 years. Therapists most often work in secondary care as part of Rheumatology teams. The NICE Guidelines for management and treatment of adults with RA emphasises the importance of access to specialist occupational therapists [1]. A recent survey identified 75% of rheumatology teams have access to occupational therapy, although funded staffing levels varied considerably across the UK, impacting on the range of services offered [2].

Contents List

Impact of rheumatoid arthritis on lifestyle and how occupational therapy helps

Occupational therapy integrates the provision of self-management, physical, psychological and social interventions to enable people to maximize their occupational performance, that is to perform their activities and participate in the social roles that are necessary and meaningful to them. Rheumatoid arthritis impacts on lifestyle from an early stage of the disease. Some 60% of people with rheumatoid arthritis have hand and activities of daily living (ADL) problems, 60% with household, leisure and social activities, 28 to 40% stop work within five years of diagnosis and 50% by 10 years [1, 3]. Once unemployed, people are unlikely to return to work, with potentially serious personal and financial consequences [4]. Accordingly, these figures suggest some two-thirds of people with rheumatoid arthritis could benefit from occupational therapy to help with hand and ADL problems, leisure and social activities and at least a half with work problems. Adjusting to and living with a progressive and variable chronic disease can lead to a range of emotional reactions, which vary over time (e.g. stress, depression, anxiety, anger) impacting on family, social and work relationships, activity ability and participation. Loss of valued activities is associated with poorer psychological status, functional and disease outcomes [5]. Occupational therapists have training in both physical and psychological therapies and are well-placed to support people through such transitions.

Occupational therapists use a wide range of interventions: improving upper limb function through hand exercise, ergonomics, assistive devices, and orthoses; fatigue management; pain and mood management (e.g. stress management, relaxation training, mindfulness); activity and environmental modifications; ADL training; transport and mobility advice; benefits and community resources advice. Avocational counselling (i.e. advice and practical assistance

with leisure, voluntary work and adult education opportunities) is highly valued by people with rheumatoid arthritis, as they regularly comment “there is more to life than just looking after yourself, the family, the house and working.” As work problems occur early, timely identification of work problems is essential so that therapists can provide stay at work (job retention) work rehabilitation and advice to reduce negative long-term personal, health, social and financial consequences of unemployment or early retirement [1]. A major focus is self-management education to help people manage pain, fatigue, frustration and difficulties performing daily roles. Occupational therapists provide interventions to enable people to make changes so they can maintain or adapt their valued activities and roles. Consequently, occupational therapists commonly use motivational interviewing, counselling, and cognitive-behavioural approaches to facilitate people making cognitive and health behavioural changes.

Two case studies help to illustrate the impact of rheumatoid arthritis on people’s lifestyles and on what an occupational therapist can offer. The examples are for: early (see Box 1) and established (see Box 2) rheumatoid arthritis.

Impact of rheumatoid arthritis on hand function

Good hand function is essential for daily, work, leisure and social activities and thus a focus of occupational therapy programmes. Frustration performing activities because of limited grip and hand pain is common amongst people with rheumatoid arthritis. In spite of recent advances in biological treatment for rheumatoid arthritis, persistent active disease remains common and hand impairment and dysfunction continue to be prevalent and progressive for many [6]. Hand impairment and hand function thus remain an important consideration for all

the rheumatology team. Hand function can progressively worsen over time [7]. Recent evidence indicates that for some patients, hand function can improve within three months of starting medical treatment, although such improvements plateau over three years to leave ongoing hand function limitations [8]. Women report more hand pain than men and hand pain and dysfunction are more closely related to disease activity than articular wrist and hand joint damage, with localised synovitis contributing substantially to hand dysfunction [9,10]. Hand deformities, if present, are an indicator of disease severity. The impact of rheumatoid arthritis on hand function remains significant.

Muscle cachexia, lower bone density and weakening of ligaments and capsular soft tissue associated with rheumatoid inflammatory processes contribute to loss of hand functional ability [11]. These pathological processes contribute to muscle imbalance between the extrinsic and intrinsic hand muscle groups so that the hand is unable to work smoothly and efficiently. Such muscle imbalances in turn contributes to progressive changes in biomechanical forces when the wrist and hand are used functionally. This chain of events can contribute to further muscle imbalance, reduced range of wrist and hand joint motion, grip strength and functional ability [12]. The hand unit can become less flexible and the hand arches less able to adapt and accommodate the different grips necessary for daily hand use. Associated rheumatoid hand deformities can include z type collapse of the thumb alongside swan-neck and boutonnière finger deformities and distal radio ulnar joint instability [13]. Such changes cause further reductions in hand function, strength and dexterity for people ageing with rheumatoid arthritis.

Whilst general activity limitations are multifactorial for people with rheumatoid arthritis, greater hand pain, reduced grip strength and hand range of motion are most associated with self-reported disability [12]. Thus, hand function contributes substantially to an individual's ability to carry out daily activities and work. Although rheumatoid disease processes are now more effectively controlled than in previous years, hand impairment and dysfunction remain significant issues for people living with rheumatoid arthritis. As such, reducing hand pain and improving grip and hand function remain important targets for sustained interdisciplinary team attention [9].

Assessment

Assessment is the foundation for identifying the impact of rheumatoid arthritis on the client's lifestyle, physical and psychological abilities and hand and upper limb function. During any assessment, the reason for problems will be explored: is it pain, fatigue, stiffness, physical limitations, environmental factors, psychological factors, lack of confidence (self-efficacy) or lack of information? Following assessment, the therapist and client collaboratively identify treatment priorities and goals and will then re-assess therapy outcomes following treatment.

Assessing activities and participation

Assessments are designed to evaluate occupations. Occupation, in this sense, can be any activity deemed important and meaningful to an individual, ranging from daily personal activities, such as eating, dressing, mobility, engagement in sexual activities, and domestic activities, such as housework, gardening, shopping and caring, through to task specific

activities, such as driving and communication. It also includes other key aspects of people's lives such as work, leisure, social activities, education, rest, civic life and spiritual activities.

Assessments include:

The Canadian Occupational Performance Measure (COPM) identifies occupational performance issues and measures individuals' perception of change in occupational performance and satisfaction. It has good clinical utility, is easy to access with a manual and training resources available online [14]. A semi-structured interview, taking about 40 minutes, is used to aid the client identify daily occupations of importance that they want, need or are expected to do but have difficulty with. Once all relevant issues are identified, the client rates the personal importance of these activities on a 10-point scale (1 poor to 10 good/high), they select five key problems, and these form the basis of treatment goals. The client then rates performance and satisfaction with performance on a 10-point scale. Following treatment, the client re-rates performance and satisfaction. The COPM has good validity, reliability and responsiveness to change, with a two-point change in performance/ satisfaction being clinically significant.

The Evaluation of Daily Activity Questionnaire (EDAQ) is a patient reported outcome measure (PROM). It includes 138 activities commonly identified as problematic by people with rheumatoid arthritis and musculoskeletal conditions. Activities are grouped into 14 sub-scales, each of which is reliable and valid, and can be scored and used separately or combined into two components of self-care and mobility [15]. The EDAQ is currently available in English, German and Dutch. Clients can be given or mailed the EDAQ prior to a therapy

appointment and complete it at home in their own time, allowing reflection on abilities and solutions already in use. During the appointment, the therapist can quickly focus on those personal, household, caring, mobility, communication, leisure and social activities the client reports difficulty with. This speeds up assessment allowing more time to focus on identifying and trying solutions. The EDAQ and manual are freely available on line [16].

The Work Experience Survey Work - Rheumatic Conditions was developed in the USA and is modified for the UK [17,18]. This semi-structured interview identifies information about work and medical history and includes 8 sub-scales identifying work barriers: getting ready for/travel to work; workplace access; completing job activities: physical demands; mental demands; time, energy, emotional demands; relationships with people at work; environmental factors; and company policies; job satisfaction and life-work balance. Together the client and therapist identify the three main areas to focus on and jointly agree a work rehabilitation plan.

The Work Activities Limitations Scale is a 12-item PROM, which is reliable, valid and responsive to change. This can be quickly completed to identify key difficulties. It is as a quick method of evaluating outcomes of work interventions [19].

Activity diaries are also valuable in identifying how a client spends a typical week and weekend day. Each day in the diary is divided into half-hour slots. This helps identify the balance of activities and rest within a person's day and night, and aids the client reflecting on activity difficulties, pain and fatigue experienced through the day, as well as their work-leisure-personal life balance. Several diary designs are available.

Assessing hand function

Assessment of hand impairment and function starts with clinical hand examination following the three principles of observation, feel, move [20,21]. Therapists may use the Jamar dynamometer to evaluate grip strength, although the GRIPPIT dynamometer is more sensitive for those with weaker grip and measures both peak and sustained grip strength. PROMS are an excellent way to assess the personal impact of hand impairment. General functional outcomes, such as the Arthritis Impact Measurement Scale II, include some hand specific components. However, regional questionnaires, such as the Michigan Hand Outcomes Questionnaire [22] will give more detailed results and are also useful for audit and research. The Disability Arm Shoulder and Hand questionnaire (DASH) [23] is useful in clinical practice, freely available and easy to administer. Both have sound psychometric properties in rheumatoid arthritis populations.

Assessing educational needs and psychological status

Self-management education needs can be assessed using the Educational Needs Assessment Tool, including 39 items, many of which are relevant to occupational therapy. This can be used to develop educational priorities and inform goal setting and shared decision-making [24]. Psychological assessments are less commonly used in practice as therapists tend to rely on observation and interview and using their psychological and counselling skills to appraise status. However, useful measures are the Hospital Anxiety and Depression Scale, which has been shown to have high clinical utility and is free of physical symptoms, such as insomnia and weight loss, as well as distinguishing well between anxious and depressive states and

examining the impact of cognition on depression or anxiety [25]. Self-efficacy for using self-management methods can also be assessed using the Rheumatoid Arthritis Self-Efficacy Scale [26]. This identifies confidence to use health behaviours and as a relevant outcome measure for self-management interventions.

Interventions

Interventions selected are based on the occupational performance limitations identified through assessment, consideration of the client's adjustment to living with their condition, their psychological status and self-management education needs. Occupational performance can be affected by limited:

- knowledge of rheumatoid arthritis, its management and progress
- knowledge and skills to adopt ergonomic approaches to reduce pain, fatigue and joint strain
- energy to manage a full day of activity and ability to balance rest and activity
- range of movement, muscle strength and endurance
- self-efficacy to use self-management approaches and redesign lifestyle.

Comprehensive occupational therapy programmes maintain activity ability, participation and increase self-management in rheumatoid arthritis [27,28,29,30]. A recent systematic review identified there was strong evidence supporting the use of: self-management and patient education provided by occupational therapists using cognitive-behavioural approaches; and ergonomics/ joint protection. Comprehensive occupational therapy, including self-management education and work rehabilitation, has been shown to improve self-reported coping, function, pain and work productivity [28,29].

Ergonomics

Ergonomic approaches aim to reduce pain and fatigue during daily activities, work and leisure These include:

- Altered movement patterns and use of proper joint and body mechanics
- Restructuring activities, work simplification and altering the environment
- Using ergonomic equipment and assistive technology.
- Activity pacing, planning, prioritising and problem-solving to modify activities and routines.

Ergonomic approaches are also termed joint protection and energy conservation techniques. Many people find their own ways through trial and error of reducing pain, fatigue, and consequently frustration, to make activities easier but this often takes time. Ergonomics education applies a systematic approach to enabling people to change habits, find new solutions and speed up change. Education should be provided when clients are experiencing pain, particularly in the hands, and fatigue, which is not being controlled by medication. If they have little or no pain and fatigue, with few or no activity limitations, they are unlikely to perceive the need to change and education may be of little value. Effective teaching techniques must be used to enable people to make sufficient ergonomic changes to gain benefits. Several randomised controlled trials of group ergonomics education (joint protection) demonstrate using cognitive-behavioural and self-efficacy enhancing approaches are significantly more effective than traditional teaching teachniques in improving use of ergonomics, activity ability and reducing hand pain, general pain and early morning stiffness [31]. Benefits continued for four years and the behavioural group had fewer hand deformities

[32]. However, education must be timed appropriately and provided applicable to clients' needs, as those with less than 6 months disease duration, minimal hand pain or activity problems did not benefit [33]. An individual programme, based on similar approaches, also demonstrated significant improvements in use of ergonomics, grip strength and self-efficacy [34].

Hand ergonomics includes changing movement patterns to limit: using strong, sustained grips, and twisting movements; lifting heavy objects; and tight, prolonged key, tripod and pinch grips. These help reduce forces on metacarpophalangeal, wrist and thumb joints and thus reduce hand pain and muscle fatigue. The rapid decline in hand function early in rheumatoid arthritis suggests effective ergonomic education should be provided when increased pain and reduced grip strength are impacting hand function.

Changes recommended include:

- altering movement patterns and use of proper joint and body mechanics. Examples include: using two hands to lift items; holding objects closer to the body when lifting; changing positions regularly; avoiding prolonged sitting and standing; ensuring work surfaces are within the reach envelope; maintaining efficient working postures when working; sitting correctly using ergonomic chairs. Poor posture and positioning have greater energy demands which increases muscle fatigue and pain.
- Restructuring activities, work simplification and altering the environment. Examples include: filling a kettle with a lightweight jug; shopping via the Internet; reordering sequences of activities to increase efficiency; eliminating unnecessary tasks; keeping frequently used equipment within the reach envelope; decluttering and using efficient storage methods.

- Using ergonomic equipment and assistive technology. Examples include: reducing effort required by using ergonomically designed equipment with universal design features, such as non-slip larger handles and lighter weight; avoiding lifting by using wheels.
- Activity pacing, planning and prioritizing. Pacing examples include: taking microbreaks for 30 seconds every 10 minutes whilst stretching and bending joints being used in sustained positions; periodic rest breaks or "moving round" 5 minutes every hour to allow muscle recovery time. Sleep hygiene principles include: using supportive pillows and mattresses; having a regular bedtime and relaxing evening routine; and avoiding stimulants. Planning examples include: balancing activities to alternate between light, medium and heavy tasks during the day and week; avoiding a "boom and bust" cycle of doing too much on good days, with consequences of resultant crashes. Fatigue activity diaries can be particularly helpful in enabling people to perceive such patterns.
- Active problem-solving. Teaching people a structured approach to analyzing activities, breaking these down into separate tasks and evaluating the movements, psychological demands and equipment used, enable people to apply ergonomic techniques themselves to identify better solutions to making activities easier.

A multi-modal group programme delivered by a psychologist and occupational therapist, including cognitive-behavioural approaches to enable improved activity pacing and alter cognitions about fatigue and improve mood, has been shown to be effective in reducing fatigue in those with moderate to severe fatigue [35].

Hand exercises and orthoses

Hand exercises should be taught alongside ergonomics education. Reducing hand pain and muscle fatigue through ergonomics mean clients are better able to increase and maintain hand exercise frequency and improve grip strength. The provision of effective hand exercise programmes, and wrist and hand orthotics, are supportive and practical ways to reinforce individuals' abilities to contribute to their self- management of any hand pain or dysfunction experienced.

There is strong evidence hand exercise programmes of high intensity (i.e. daily with 30 repetitions of medium resistance exercises for 10-20 minutes, cumulatively) lead to significantly better outcomes in function, pain and grip strength than low-intensity (i.e. range of movement or low resistance exercises at lower frequency) [36]. Supervised hand exercise training (1 x/ week for 4 to 6 weeks) using cognitive-behavioural approaches, is essential to enable people to perform high intensity medium resistance exercises, as many have concerns about whether this is safe initially [36]. This is a cost-effective approach to helping people to manage their hand dysfunction [36]. The SARAH trial is one such high intensity, individually tailored, programme delivered using a health psychology approach with 1 x/ week sessions over 6 weeks, plus a home programme continued during and after, leading to significant and clinically effective results after 12 months and is strongly recommended for clinical practice [37]. It is essential to regularly prompt people to continue hand exercises. Effectiveness decreases over time if exercise is not maintained [38].

Wrist and hand orthoses remain a popular conservative approach. A review of the effectiveness of hand and wrist orthoses identified just two types had sufficiently robust

research evidence to support their effectiveness in reducing pain and increasing hand function. A functional elastic wrist orthosis to provide support to the wrist and hand during daily tasks can provide pain relief and improve function. Swan neck deformity splints also have strong evidence that they improve hand dexterity [39].

Recently it has been identified that long term adherence to self-management strategies, such as ergonomics, hand exercise programmes and orthotic wear, can be improved by carefully considering the social context within which people live [40]. Occupational therapists are ideally placed to maximise upon this considered approach in their daily collaborative practice with patients.

Activities of daily living

Joint pain impacts on independence, self-esteem, has considerable effects on personal relationships and reduces quality of life. Therapists' skills in ergonomics and theoretical understanding of the impact of the environment and personal factors on individual's performance enable detailed analysis of activity limitations. Occupational therapists work collaboratively with clients to identify solutions, the need for assistive technology and environmental adaptations to prevent or reduce future dependency and maintain independence. ADL training is provided through tailored interventions for individuals as well as via self-management education programmes, such as the Lifestyle Management for Arthritis Programme employed UK wide [41]. Assistive technology (e.g. electric tin openers, bottle openers, adapted knives) helps reduce pain and fatigue and minimises biomechanical stress and forces placed on joints during activity, as well as minimising risks associated with undertaking the task.

Sexual activities are a central aspect of being human. Rheumatoid arthritis affects the sexual lives of individuals. Many are afraid that they will be in pain, or will cause their partner pain, and sore joints limit initiating sexual relations. Occupational therapists can help by offering a safe environment to discuss such issues, and provide psychological support, reassurance and practical advice to address sexual issues, within the therapist's boundaries of expertise. For those not wanting to discuss sexual matters, it is helpful to offer written information and the option to seek help in the future.

Whilst there have been considerable improvements in the treatment of inflammatory arthritis using biologic agents and most clients report much improvement, individuals can still have difficulties in performing ADL through previous biomechanical damage causing joint pain, stiffness, fatigue, as well as experiencing anxiety and depression [42]. Additionally, socio-economic and environmental factors, such as access to help and support, education and health and social care, can determine health-related quality of life outcomes. Whilst independence in ADL may be the central aim, interdependence may be the best choice for some. Person-centred occupational therapy is used to initiate therapy goals to ensure the individual reaches their optimum function. Occupational therapists can also provide advice on social security and other financial benefits, third sector support, housing adaptations and refer on to social services, as applicable.

Work and leisure rehabilitation

Many factors influence work instability and disability including: greater pain, hand pain and fatigue; unadapted work environments and equipment; physically demanding jobs; poor work

self-efficacy; increasing stress or low mood related to work difficulties; lack of support, autonomy and participation in decision-making in the workplace; and limited use of self-management strategies [43]. Fatigue can have an additional impact on cognitive ability. Job retention work rehabilitation has the potential to prevent or postpone work disability through modifying such factors. For example, those with workplace ergonomic modifications are 2.5 times less likely to stop work. Work rehabilitation should be provided early, when work instability develops. However, many with arthritis lack access to work rehabilitation and may not even be aware of work information booklets available.

Two trials in the USA demonstrated reduced job loss following work rehabilitation in people with a variety of rheumatic conditions [44,45]. The intervention has been adapted for the UK and tested in a feasibility study with people with rheumatoid arthritis or early inflammatory arthritis. The intervention was delivered by occupational therapists, who received 3 days training in work rehabilitation and a work solutions manual. The trial included people on biologics who, though reporting they "felt the best they had ever been," still experienced work difficulties due to joint pain, fatigue and lack of confidence. Work rehabilitation included: assessment using the WES-RC; the participant and therapist mutually agreeing priority work problems; and action planning. A tailored, individualized programme was then provided including, as appropriate: applying ergonomic, fatigue and stress management approaches to the workplace; recommendations for assistive technology/equipment adaptation, workplace/work station modification, transport advice; practical advice and support enabling participants to disclose their condition and negotiate job modifications with employers; explaining rights under the Equality Act 2010 and what are "reasonable adjustments"; psychological support, through listening to and discussing work problems, encouraging ability and confidence in solving work problems, managing arthritis when

working and continuing working in future; advice on other ADL and hand function difficulties affecting work ability; provision of relevant work and self-management advice booklets and other information as appropriate; and referral to relevant rehabilitation and employment services. Participants were offered a work site visit, if needed. The intervention was provided for on average four hours in four monthly meetings, including a telephone review about two months after the final treatment session, to discuss progress making changes. Although a feasibility study, the results at nine-month follow-up demonstrated a larger effect size in reducing work instability, work limitations, physical ability, pain and perceived health compared to those receiving work information booklets only [43]. This now is being tested in a randomized controlled trial.

As the disease progresses, people steadily give up leisure and social activities and reduce household activities in order to retain the energy to work. People give up between a third to two-thirds of their leisure and non-work activities meaning life becomes increasingly unbalanced [46]. Being prescribed biologics means many are enabled to remain in or return to work and increase or resume participation in leisure and social activities they previously abandoned or were unable to take up. Increasing participation enables people to redefine their sense of self, increase self-confidence and many perceive themselves as becoming a healthier person. This improvement leads to testing new boundaries, but many find they still cannot do all they want to and continue to have an imbalance between work and other activities: “I push myself a bit more [42]. Occupational therapists enable people to effectively develop or take on new activities and social roles. Leisure and social activities are of central importance in people’s lives, providing meaning and enjoyment. Limiting these can lead to low mood and increased distress. Therapists therefore identify problems and recommend solutions and

strategies to increase participation in non-vocational activities to facilitate occupational balance.

Psychological interventions

> *"When we are no longer able to change a situation, we are challenged to change ourselves."* Viktor Frankl 1905-1997.

Occupational therapists are well placed to facilitate a holistic approach addressing the rehabilitation needs of individuals with rheumatoid arthritis, due to their dual training in physical and psychological therapies. The underpinning philosophy of occupational therapy is that therapists must be mindful of individuals' psychosocial needs and the impact of these needs on their health behaviours. Occupational therapists apply psychological theories of learning, motivation, personality and emotion to understand and facilitate health behaviour change, which underpins rehabilitation interventions for rheumatoid arthritis.

Occupational therapists often come into contact with people with rheumatoid arthritis who are trying to make sense of what is happening to them and coming to terms with the prospect of living with a chronic condition. At this stage, many are dealing with uncertainties around their differential diagnosis, treatment regimen and impact of these on their family and work commitments, as they try to process information acquired from a variety of sources (e.g. consultations with their GP, rheumatologist, health professionals, and from information leaflets, internet based-sources and friends) as to how they should manage their condition. This transitional process, more often than not, is accompanied with severe joint pain and

fatigue and associated symptoms of sleeplessness, stress, anxiety and depression. Hence individuals often present to occupational therapy with complex psychological needs, regardless of the nature of the referral.

Rheumatology occupational therapists employ advanced communication skills and therapeutic use of self, which are integral to the outcome of the occupational therapy process. These help maximise the development of a collaborative relationship that underpins engagement of individuals in an effective therapeutic alliance to maintain participation, motivation, involvement and autonomy. The therapist's warmth and genuineness, listening skills, reading non-verbal cues and ability to express and manage emotions within interactions are linked to the perceived efficacy of the relationship and to individual satisfaction. People with rheumatic conditions may have limited motivation to make necessary health behaviour changes to improve their health outcomes, due to their symptoms of pain and fatigue. Many are also ambivalent about change and implementing strategies to make the required changes happen. Rheumatology occupational therapists may employ motivational interviewing techniques to help resolve an individual's ambivalence to change and aid goal setting. Occupational therapists play a key role in facilitating behaviour change, through the use of enabling strategies and being mindful of the individual's roles, values, meanings, attitudes, beliefs and social context. Psychological interventions used by occupational therapists to support people with rheumatic conditions may include:

- self-esteem and self-efficacy building (e.g. problem solving, empowerment, assertiveness, self-monitoring and management, shared decision-making),
- developing coping skills and techniques (e.g. relaxation and stress management skills, mood management, pain and fatigue management, mindfulness).

Self-management education

Psychological interventions are integrated into self-management education. Occupational therapists often co-ordinate and lead arthritis self-management programmes, along with the multi-disciplinary team. Key features of effective self-management programmes delivered either in groups, mailed or via the Internet are: duration of at least six weeks to enable participants to develop skills, with sufficient practice, and instigate changes with support; explicit use of social cognitive theory and cognitive-behavioural approaches; individualized weekly action plans with weekly progress review; a leader manual protocolizing delivery with participant handbooks; and led by the same trained leaders. Exercise and graded home aerobic exercise (eg walking, Tai Chi) are key features alongside exercise action-planning with clear details about exercise performance [48].

Programmes provided by occupational therapists in the UK include the Looking After Your Joints Programme [31,32] and the modular Lifestyle Management for Arthritis Programme (LMAP), developed from this [41]. The LMAP starts with education about rheumatoid arthritis and it's management, enables participants to evaluate the impact of their condition on their valued activities and daily lives, in order to help them reflect on importance, confidence and readiness for making changes. Programme content includes: ergonomics, hand exercises, fatigue, pain and mood management and exercise (stretch, strength, a walking programme and an introduction to the Tai Chi for Arthritis Programme). The programme uses individual action planning and weekly reviews of progress, practice and feedback and home programmes to facilitate change. The LMAP results in significant improvements in pain, fatigue, functional ability, self-efficacy and use of health behaviours [41].

Future developments in Occupational Therapy

Rheumatology occupational therapy services have gone through a considerable change in the last decade. Health and social care initiatives for care in the community and self-management, advancements in early recognition of rheumatoid arthritis in primary care and increased use of biologic agents are helping reduce functional limitations and future disability. Although most rheumatology occupational therapy services in the UK are still based in outpatient departments in secondary care, there is increasing pressure to relocate to primary care musculoskeletal services. Rheumatology occupational therapists working in primary care can support the management of rheumatoid arthritis in the community and early recognition and referral of people with inflammatory arthritis to secondary care rheumatology teams to ensure optimal treatment outcomes. With better symptom control, more people with rheumatoid arthritis are able to continue working and thus occupational therapists can increasingly focus on provision of work rehabilitation to enable people to remain working and financially independent. Greater recognition of the psychological impact of rheumatoid arthritis will also mean therapists will increasingly use their extensive psychological skills in providing psychological support, psychological therapies and enabling occupational balance to improve mood.

Likewise, health and social care is moving towards digital/ mobile health technologies (mHealth). In 2017, the Office of National Statistics, identified 90% of households in the UK have Internet access, an increase from 57% in 2006. Emerging social media and digital technologies have shifted individuals' roles from consumers of health information to both consumers and co-producers by commenting and sharing health experiences and offering solutions to problems [58]. Such platforms enable people with health conditions to engage

with one another, providing information on experiences, treatment and symptoms that satisfy other peoples' information needs, thus increasing self-efficacy and self-worth. Given limited access to specialist occupational therapists, on-line platforms have the potential to enable therapists to: help people access PROMS online to facilitate personal problem identification and problem-solving; and design and provide online self-management education and rehabilitation interventions to extend access to practical solutions. The use of online platforms and apps, e.g. the MSKHUB (a self-management platform at the University of Salford [49]) and the future SARAH trial on-line hand exercise programme (Oxford University) can help people with rheumatoid arthritis self-manage and be actively involved in their care.

Conclusion

People highly value being independent in performing their daily activities, work, social and leisure occupations, maintaining a normal life and having a balance between different occupations and rest. They perceive these as central to good health. Occupational therapy promotes health by enabling clients to maintain independence and live a balanced lifestyle pursuing the activities and participating in the social roles meaningful to them.

Box 1. Early rheumatoid arthritis Case Study [Eliza Huey]

Eliza is a 41-year-old woman, recently diagnosed with rheumatoid arthritis. She reports pain, swelling and stiffness in her hands, wrists and hips, as well fatigue. She has been on disease modifying anti-rheumatic drug (DMARD) combination therapy (methotrexate and sulfasalazine) for five weeks and experienced multiple side effects, such as nausea, headaches and dizziness.

The occupational therapist assessed Eliza: she works full time as a marketing manager in a small firm and is a single mother of two school-age children. She has been on sick leave from work since being diagnosed, as she was unable to cope with the demands of her full time job. A work assessment identified her main problems in getting back to work were: getting up and ready in the morning; negotiating rush hour traffic doing the school run; and then commuting to work. Eliza found early mornings particularly difficult due to morning stiffness, having had no refreshing sleep in weeks and fatigue on wakening.

During goal setting, a return to work programme was negotiated with Eliza. Occupational therapy involved: liaising with the rheumatologist for a steroid injection to relieve symptoms whilst waiting for DMARDs to take effect; supporting Eliza in negotiating a graded return to work with her employer, i.e. working flexible hours to avoid the morning rush hour and working from home one-day-a-week; fatigue management training, particularly on sleep hygiene and activity pacing; and training in ergonomics (joint protection) at work and home to help reduce pain and fatigue and make activities easier. She was also offered the opportunity to attend the department's self-management education programme in future.

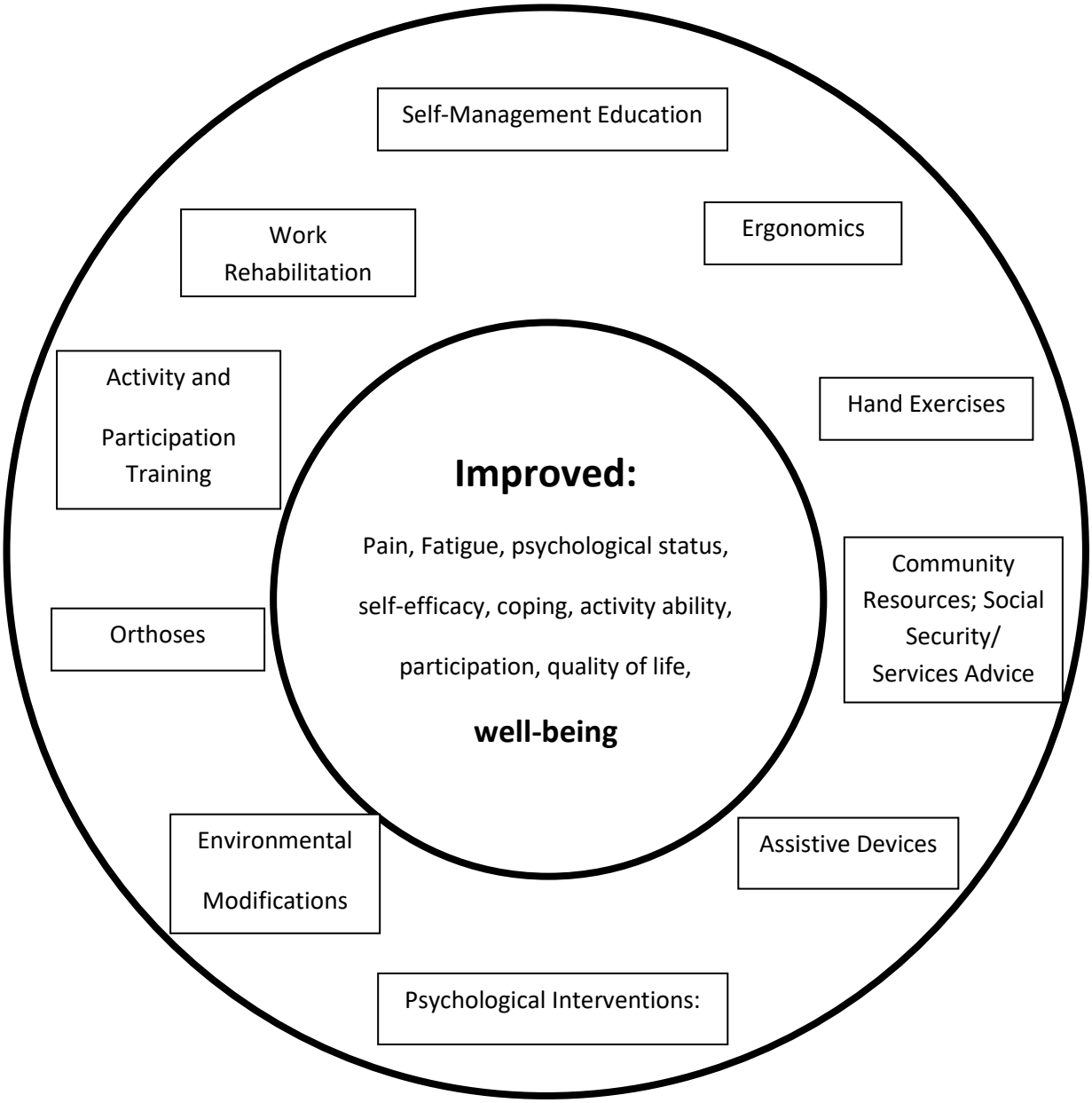
Box 2. Established rheumatoid arthritis Case Study [Alex Nielson]

Alex is a 61-year-old man with rheumatoid arthritis, which was successfully managed with DMARDs [i.e. methotrexate] until recently. Due to problems with kidney function he had to come off his DMARD. This resulted in a flare, which left him with hand, knee and foot pain and fatigue.

The occupational therapist assessed Alex: he previously led an active life style; enjoyed cycling, dog walking and playing an instrument. He took early retirement recently, with a view to spending more time with his partner, having outdoor holidays and playing the French horn in a local brass band. Since the flare he has been unable to walk his dog, as he cannot hold the lead because of pain and swelling in his hand joints. Hand and knee pain also mean he cannot ride his bike or play his French horn. He is depressed, due to loss of his life roles as an engineer, an active partner, dog walker, musician and cyclist, all of which had provided him with a sense of belonging and self-worth.

Occupational therapy involved: using mindfulness training and motivational interviewing to help Alex identify and modify negative thought patterns and develop problem-solving skills to overcome barriers to participation in his valued life activities; and fatigue management training. A graded approach to physical exercise (through graded walking and cycling programmes; and hand exercises) enabled Alex to start riding his bike and play his horn again. Recommending a waist-band dog lead with Halti collar helped him to walk his dog again.

Figure 1: Impact of Comprehensive Occupational Therapy in Arthritis



Chapter 28 References:

1. National Collaborating Centre for Chronic Conditions. *Rheumatoid arthritis: national clinical guideline for management and treatment in adults*. London: Royal College of Physicians; 2009.
2. Ndosi M, Ferguson R, Backhouse M et al. National variation in the composition of rheumatology multidisciplinary teams: a cross sectional study. *Rheumatol Int* 2017;37 (9): 1453–1459
3. National Rheumatoid Arthritis Society. *The Economic Burden of Rheumatoid Arthritis*. Maidenhead: NRAS; 2010.
4. Verstappen SMM, Boonen A, Bijlsma JWJ et al. Working status among Dutch patients with rheumatoid arthritis: work disability and working conditions. *Rheumatology* 2004; 44:202–206.
5. Katz PP, Yelin EH. The development of depressive symptoms among women with rheumatoid arthritis. *Arthr Rheum* 1995;38:49–56
6. Horsten, NCA, Ursum J, Roorda LD et al. Prevalence of hand symptoms, impairments and activity limitations in rheumatoid arthritis in relation to disease duration. *J Rehab Med* 2010;42: 10; 916-921
7. Kapetanovic MC, Lindqvist E, Nilsson JÅ et al. Development of Functional Impairment and Disability in Rheumatoid Arthritis Patients Followed for 20 Years: Relation to Disease Activity, Joint Damage, and Comorbidity. *Arthritis Care Res* 2015; 67(3):340-8
8. Björk M[1], Thyberg I, Haglund L et al. Hand function in women and men with early rheumatoid arthritis. A prospective study over three years (the Swedish TIRA project). *Scand J Rheumatol* 2006;35:15-9.
9. Thyberg I, Dahlström Ö, Björk M et al. Hand pains in women and men in early

rheumatoid arthritis, a one-year follow-up after diagnosis. The Swedish TIRA project. *Disabil Rehabil* 2016; 39:(3):291-300

10. Erol AM, Ceceli E, Uysal Ramadan S et al. Effect of rheumatoid arthritis on strength, dexterity, coordination and functional status of the hand: the relationship with magnetic resonance imaging findings. *Acta Reumatol Por*t 2016;41(4):328-337.
11. Glinatsi, D, Baker,JF, Hetland,ML et al. Wrist inflammation as assessed by magnetic resonance imaging is associated with patient-reported physical impairment, global disease activity and pain in early rheumatoid arthritis: long-term results from two randomized controlled trials *Ann Rheum Dis.* 2017;76:1707-1715.
12. Andrade, JA, Brandão, MB, Raquel C et al. Factors Associated with Activity Limitations in People With Rheumatoid Arthritis. *Am J Occup Ther*, 2016;70:1-7
13. Adams BD. Management of the Distal Radioulnar Joint in Rheumatoid Arthritis. In: Chung K. eds. *Clinical Management of the Rheumatoid Hand, Wrist, and Elbow*. Springer, Cham. 2016.
14. The Canadian Occupational Performance Measure. http://www.thecopm.ca. Accessed 1st September 2017.
15. Hammond A, Tennant A, Tyson S et al. The Reliability and Validity of the English version of the Evaluation of Daily Activity Questionnaire in people with rheumatoid arthritis. *Rheumatology* 2015; 54(9):1605-1615
16. Hammond A, Tennant A, Tyson S. *The Evaluation of Daily Activity Questionnaire: User Manual v3.* Salford: University of Salford, 2018. http://usir.salford.ac.uk/30752/.
17. Allaire S, Keysor J. Development of a structured interview tool to help patients identify and solve rheumatic condition related work barriers. *Arthritis Care Res* 2009; 61:988-995

18. Hammond A, Woodbridge S, O'Brien R et al. *The UK Work Experience Survey for persons with Rheumatic Conditions (UK WES-RC) Manual version 3.1*. Salford:University of Salford; 2018. http://http://usir.salford.ac.uk/29320.
19. Beaton D, Tang K, Gignac MAM, Lacaille D, Badley EM, Anis AH, Bombardier C. Reliability, validity and responsiveness of five at-work productivity measures in patients with rheumatoid arthritis or osteoarthritis. *Arthr Care Res* 2010:62;28-37
20. Versus Arthritis. Examination of the hand and wrist video. https://www.versusarthritis.org/about-arthritis/healthcare-professionals/useful-resources/regional-examination-of-the-musculoskeletal-system/examination-of-the-hand-and-wrist-video/ Accessed: 7th January 2020
21. Whalley K, Bradley S, Adams J. Ch. 37: Hand Therapy in: Curtin M, Egan M, Adams J eds. *Occupational Therapy for People Experiencing Illness, Injury or Impairment Promoting occupation and participation*. 7th Edition. New York, Elsevier. 2017. (pages 523-540).
22. Chung KC, Pillsbury MS, Walters MR et al. Reliability and validity testing of the Michigan Hand Outcomes Questionnaire. *J Hand Surg Am* 1998;23:575-87
23. Hudak P, Amadio PC, Bombardier C et al. Development of an Upper Extremity Outcome Measure: The DASH (Disabilities of the Arm, Shoulder, and Hand). *Am J Ind Med* 1996; 29:602-608
24. Ndosi M, Tennant A, Bergsten U et al. Cross-cultural validation of the Educational Needs Assessment Tool in RA in 7 European countries. *BMC Musculoskelet Disord* 2011;12: 110.
25. Smarr K, Keefer A. Measures of depression and depressive symptoms: Beck Depression Inventory-II (BDI-II), Center for Epidemiologic Studies Depression Scale (CES-D), Geriatric Depression Scale (GDS), Hospital Anxiety and Depression Scale

(HADS), and Patient Health Questionnaire-9 (PHQ-9). *Arth Care Res* 2011;63 S11:S454-S466.

26. Hewlett S, Cockshott Z, Kirwan J et al. Development and validation of a self-efficacy scale for use in British patients with rheumatoid arthritis (RASE). *Rheumatology* 2001;40: 1221–1230.
27. Hammond A**,** Young A, & Kidao R**.** A randomised controlled trial of occupational therapy for people with early rheumatoid arthritis**.** Ann Rheum Dis 2004; 63: 23-30.
28. Siegel P, Tencza M, Apodaca B et al. Effectiveness of occupational therapy interventions with adults with rheumatoid arthritis: a systematic review. *Am J Occup Ther* 2016;71: 7101180050. https://doi.org/10.5014/ajot.2017.023176
29. Macedo A, Oakley SP, Panayi GS et al Functional and work outcomes improve in patients with rheumatoid arthritis who receive targeted, comprehensive occupational therapy. *Arthr Care Res* 2009;61: 1522-1530.
30. Mathieux R, Marotte H, Battistini L et al. Early occupational therapy programme increases hand grip strength at 3 months: results from a randomized, blind, controlled study in early rheumatoid arthritis. *Ann Rheum Dis* 2009; 68:400–403.
31. Hammond A, Freeman K. One year outcomes of a randomised controlled trial of an educational-behavioural joint protection programme for people with rheumatoid arthritis. *Rheumatology* 2001;40:1044-1051.
32. Hammond A, Freeman K. The long-term outcomes of a randomised controlled trial of an educational-behavioural joint protection programme for people with rheumatoid arthritis. *Clin Rehabil* 2004;18:520-528
33. Freeman K, Hammond A, Lincoln NB. Use of cognitive behavioural arthritis education programmes in newly diagnosed rheumatoid arthritis. *Clin Rehabil* 2002;16; 828-836

34. Niedermann K, Buchi S, Ciurea A et al. Six and 12 months' effects of individual joint protection education in people with rheumatoid arthritis: a randomized controlled trial. *Scand J Occup Ther* 2012; 19:360-9, 2012 Jul.

35. Hewlett S, Ambler N, Almeida C et al. Self-management of fatigue in Rheumatoid Arthritis: a randomised controlled trial of group cognitive-behavioural therapy. *Ann Rheum Dis* 2011;70:1060-1067 J.

36. Hammond A, Prior Y. The effectiveness of home hand exercise programmes in rheumatoid arthritis: a systematic review. *Br Med Bull* 2016; 119 (1): 49-62

37. Lamb S, Williamson E, Heine P et al. Exercises to improve function of the rheumatoid hand (SARAH): a randomized controlled trial. *Lancet* 2015; 385: 9966:421-429

38. Williamson E, McConkey C, Heine P et al.. Hand exercises for patients with rheumatoid arthritis: an extended follow-up of the SARAH randomized controlled trial *BMJ Open* 2017;7:e013121. doi: 10.1136/bmjopen-2016-013121

39. Royal College of Occupational Therapists. *Hand and wrist orthoses for rheumatological conditions in adults.* London: Royal College of Occupational Therapists; 2015.

40. Ong BN, Rogers A, Kennedy A et al. Behaviour change and social blinkers? The role of sociology in trials of self-management behaviour in chronic conditions. *Sociol Health Illn* 2014;36: 226–238.

41. Hammond A, Bryan J, Hardy A. Effects of a modular behavioural arthritis education programme: a pragmatic parallel group randomized controlled trial. *Rheumatology* 2008;47:1712-1718

42. McArthur MA, Goodacre L. “Better not best”: a qualitative exploration of the experiences of occupational gain for people with inflammatory arthritis receiving anti-TNFα treatment. *Disabil Rehabil* 2015;37:854-863

43. Hammond A, O’Brien R, Woodbridge S et al. Job retention vocational rehabilitation for employed people with inflammatory arthritis (WORK-IA): a feasibility randomized controlled trial. *BMC Musculoskelet Dis* 2017; 18:315

44. Allaire SH, Li W, La Valley MP. Reduction of job loss in persons with rheumatic diseases receiving vocational rehabilitation: a randomized controlled trial. *Arthritis Rheum* 2003;48:3212–8.

45. Keysor JJ, LaValley MP, Brown C et al. Efficacy of a Work Disability Prevention Program for People with Rheumatic and Musculoskeletal Conditions: The Work It Study Trial. *Arthritis Care Res*. 2018;*70*(7):1022– 9.

46. Prior Y, Amanna AE, Bodell SJ et al. A qualitative evaluation of occupational therapy-led work rehabilitation for people with inflammatory arthritis: Participants’ views. *Br J Occup Ther* 2017;80:39-48

47. Reinseth L, Espnes GA. Women with rheumatoid arthritis: non-vocational activities and quality of life. *Scand J Occ Ther* 2007;14:108-115

48. Iversen M, Hammond A, Betteridge N. Self-management of rheumatic diseases: state of the art and future directions. *Ann Rheum Dis* 2010;**69:**955-963

49. Adams SA. Sourcing the crowd for health services improvement: The reflexive patient and "share-your-experience" websites. *Social Sci Med* 2011; 72:1069-1076

50. The Musculoskeletal Hub: online health assessment, community and self-management website https://mskhub.com. Salford: University of Salford. 2017.