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**The Elizabeth Casson Memorial Lecture 2014: Changing ways; changing times.**

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**Key words:** Behaviour change, self-management, implementation, arthritis, occupational therapy.

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The Elizabeth Casson Memorial Lecture 2014, given on 4th June at the 38<sup>th</sup> Annual Conference and Exhibition of the College of Occupational Therapists, held at the Brighton Centre, Brighton.

### **Introduction**

It is an honour and privilege to be invited to present the Elizabeth Casson Memorial Lecture.

A remit for the Elizabeth Casson This lecture reflects on:

- how Rheumatology occupational therapy practice and research has developed in the last 30 years;
- self-management in Rheumatology (a person's ability to manage the symptoms, treatment, physical, and psychosocial consequences and lifestyle changes inherent in living with a chronic condition (Barlow et al 2002) and why or clients may or may not adopt health behaviours
- And how therapists might need to change to implement evidence-based practice.

### **Changing times: the 1980s**

In the 1980's clients most often had rheumatoid arthritis (RA) and were referred to Rheumatology only when symptoms became severe. Commonly, people saw rheumatology occupational therapists for the first time if they were admitted because of a severe disease flare-up. Accordingly, most clients were in-patients, with multiple joint problems, who had often had to give up work, and were struggling to cope at home.

Melvin's (1982) *Rheumatic disease: occupational therapy and rehabilitation* described practice as incorporating:

- assessments of both hand and activities of daily living (ADL)
- ADL training, providing assistive devices, home visits, community equipment, and adaptation
- The provision of splinting, joint protection, energy conservation and positioning education, assistive devices, and upper limb and hand exercises
- The use of functional activities (such as therapeutic crafts, games, and leisure) in the light and heavy workshop, to improve strength

The prevailing approach in this text (and reflecting practice) was biomedical and biomechanical; a short chapter addressed 'Psychological considerations in patient education and treatment.' As well as ADL assessment and training, much time was spent on custom-made splints, since many people already had hand deformities (Beanlands 2001). By the mid-1980s, methotrexate was proven effective in slowing disease progression, was being prescribed sooner to patients, leading to more outpatient referrals to occupational therapy, as problems were identified earlier.

### Joint protection

Rheumatology referrals often requested joint protection. This is based on biomechanical analyses and observations (Cordery and Rocchi 1998) and is the application of ergonomic principles to everyday activities, work, and leisure, and is an active coping strategy (Hammond 2010). Joint protection education should encourage wide-ranging changes if it is to be effective, focusing on affected joints, and enable the person to:

- change patterns of movement, to reduce internal and external stresses on joints
- modify tasks and the environment
- balance rest and activity
- perform regular strength exercises to maintain muscle function
- use assistive equipment only if necessary
- use fatigue management, such as work simplification and energy conservation.

Throughout the 1980s, articles and texts were published about joint protection's potential benefits and applications (for example, Brattstrom 1987, Chamberlain et al 1984, Unsworth 1986). However, there was no evidence supporting its use. Do people use joint protection as we recommend? Do they only do it when their hands are really painful? Or do they simply forget? Are there better ways we could help people to change? Does joint protection really make a difference? Such clinical questions triggered my rheumatology research career.

### **Changing times: the 1990s**

By the early 1990s, in-patient rheumatology occupational therapy was shrinking as rheumatology hospitals and wards closed. Services were mainly outpatient based..

Rheumatology occupational therapy research increased, including development of standardized assessments and the first good quality randomized controlled trials (RCTs).

### Joint protection

Joint protection education took up on average 25% of occupational therapists' time, but over half (55%) of clients received less than an hour, typically about how arthritis affects joints, joint protection principles, examples of how to change activities, and written information. Two-thirds of therapists gave short demonstrations of some methods (such as opening a jar and pouring a kettle); but only half asked people to try these methods and gave feedback; only 12% practised methods in a sequence of activities, such as making a hot drink (Hammond 1997): the main reason for this was limited time. Many rheumatology occupational therapists still describe their practice similarly today.

The first studies evaluating joint protection were published during this period. Nordenskiöld (1994) demonstrated that people with RA had less pain performing activities using assistive devices. Barry et al (1994) demonstrated how one hour of joint protection education increased people's knowledge. A small clinical trial demonstrated that people with established RA, attending 2.5 hours of joint protection education over two sessions, increased their knowledge, but not their use, of joint protection (Hammond and Lincoln 1999). The education provided was similar to conventional practice, although longer, including a problem-solving homework task, group discussions, demonstrations, and practice. On interview, most participants thought that reducing strain on joints was 'very important' and they were so pleased that they had received the information, as it was so helpful for them. However, only a quarter thought they used joint protection regularly; almost a quarter thought they used it inconsistently: and over half stated with honesty that they were not doing it. Interviews highlighted that barriers to changing behaviour included one or more of the following:

- Believing change was inapplicable: ('my hands aren't that bad yet') — education raised understanding but not the perceived benefits of joint protection; some people had not accepted the need for change
- Difficulty recalling and understanding methods
- Difficulty getting used to the different movements (insufficient motor skill development)

- Difficulty ‘changing the habits and routines of a lifetime’: some had insufficient self-efficacy for using joint protection, or had not sufficiently made plans to or practice using it

Joint protection, or applying ergonomics, requires changing automatic behaviours performed during ingrained habitual routines at work and home. People must de-automatize habitual behaviours and re-automatize new ones, and this is difficult. To address these barriers, an educational–behavioural joint protection programme was developed. Theories selected included:

- The Health Belief Model, which emphasizes the importance of raising perceived severity, weighing up the pros and cons of behaviour change to help raise perceived benefits
- Educational strategies, to enhance recall and understanding
- Motor learning theory, to enhance skill development
- Self-efficacy theory, to enhance confidence in performing joint protection
- Self-management cognitive-behavioural approach (a self-regulatory theory) to facilitate change and
- Group processes

This programme significantly improved use of joint protection (Hammond et al 1999). This, and a trial in the Netherlands (Brus et al 1998), demonstrated that using cognitive–behavioural and self-efficacy approaches to enable change is more effective than conventional practice, based on what therapists think will work. However, whether joint protection is effective had still not been addressed.

### **Changing times: the 2000s to now**

In 2003, the College of Occupational Therapists Specialist Section — Rheumatology published clinical guidelines evaluating evidence for Rheumatology occupational therapy (Clinical Guidelines Working Party of National Association of Rheumatology Occupational Therapists [NAROT] 2003). These emphasized the importance of using cognitive–behavioural approaches to support change. In 2004, reviews of rheumatology occupational therapy concluded there was evidence for effectiveness of comprehensive occupational

therapy, joint protection, and wrist working splints, but insufficient good quality trials evaluating hand exercises, and only surveys and observational studies indicating the benefits of assistive devices, ADL training, psychological interventions, work rehabilitation, and leisure rehabilitation. Most research still focused on RA, and more research into other conditions was called for (Hammond 2004, Steultjens et al 2008).

### Comprehensive occupational therapy

In 2004 a comprehensive 4-hour individualized occupational therapy programme, plus a 2-hour group education programme for people with early RA, was shown to significantly increase use of self-management compared to usual care (Hammond et al 2004). This programme was developed by Marion Ferguson and colleagues at St Albans City Hospital, within the Early Arthritis service led by Professor Adam Young. A qualitative study alongside this, identified two key themes concerning clients' beliefs about how occupational therapy helped:

- Process: clients reported that therapists instilled confidence, understood the condition and its impact, were accessible, gave individualized treatment, were good communicators, and provided the opportunity to discuss issues of importance to the client.
- Outcomes: clients considered they had gained understanding of their condition and its management; and insight into their own capabilities. They felt they had changed attitudes, developing acceptance, and it was their responsibility to self-manage and gain control of the disease; that it was acceptable to pace; that joint protection and exercise would prevent deterioration; they were better prepared for what lay ahead; and had increased skills, such as regulating activity, decision-making, problem-solving, pacing, and joint protection (Kidao, 2001).

### Joint protection and self-management in the 2000s and onwards

An RCT in early RA, demonstrated that the educational-behavioural joint protection programme significantly reduces pain, stiffness, number of flare-ups, and improves activity ability (Hammond and Freeman, 2001). At 4-year follow-up, participants continued to have better daily activity ability and fewer hand deformities than the control group receiving conventional joint protection (Hammond and Freeman, 2004). However, those attending only one or two sessions did not change, emphasizing the importance of sufficient input. The same

programme was shown to be ineffective in very early RA (less than 6 months), indicating joint protection can be provided too early, when people are not yet psychologically ready to change (Freeman et al 2002).

The programme was extended to form the *Looking after your joints programme (LAJP)*, including joint protection, hand exercises, fatigue management and splinting advice. A second module was added, including exercise, physical activity, foot care, pain, and stress management, to form the *Lifestyle management for arthritis programme (LMAP)*. Modules were restructured to apply the Transtheoretical Model (a key construct of which are Stages of Change), to increase motivational components and facilitate clients identifying personal reasons and goals for change (Hammond 2010, Hammond 2013). The LMAP was shown to be more effective than a conventional multi-disciplinary arthritis education programme in reducing participants' pain, fatigue, and maintaining activity ability. Participants also significantly improved: self-efficacy to self-manage arthritis; perceived control of arthritis; psychological status; and adherence with using joint protection, fatigue management and exercise (Hammond et al 2008). Rheumatology occupational therapists, having attended a two-day training programme for each module, can successfully deliver the *LAJP* and the *LMAP* in clinical practice, obtaining similar results to these RCTs (Hammond and Rayner 2013). The joint protection beliefs of people with RA are that this: improves physical wellbeing (specifically reducing pain and improving function); and improves psychological wellbeing, through giving an increased sense of personal control of arthritis, being less stressed because activities are much easier and making an active contribution to one's own health (Niedermann et al 2010). Niedermann et al (2011) subsequently developed an individual joint protection programme, using the same self-efficacy and self-management CBT approaches, and individualizing therapy by using the Pictorial Representation of Illness and Self Measure (PRISM). This is a brief, interactive hands-on tool that helps people visualise and discuss the impact of their condition and identify priorities for change. Participants attended 5 weekly sessions of 45 minutes each, of either behavioural-PRISM joint protection or conventional joint protection. At follow-up, significantly more in the behavioural-PRISM group were using joint protection and had higher self-efficacy for managing arthritis.

#### Evidence for Rheumatology occupational therapy interventions

Throughout the 2000s and since, more RCTs of occupational therapy, or involving occupational therapists in treatment delivery, have extended our profession's evidence base.



The LAJP has been adapted for people with hand osteoarthritis and shown to reduce pain, improve hand function and self-efficacy compared to receiving usual care and written joint protection advice only (Dziedzic et al 2013). Hewlett et al (2011) demonstrated a cognitive-behavioural fatigue management programme, delivered by an occupational therapist and a clinical psychologist, reduces fatigue and improves self-efficacy. Ronningen and Kjekken (2008) and Williams et al (2013) have evaluated hand exercises for established RA demonstrating the safety of intensive programmes of flexibility and strength exercises, the effectiveness of using cognitive-behavioural approaches to facilitate adherence and improving pain, hand function, and self-efficacy for managing pain. Ramsay et al (2014) in a systematic review of wrist splints, identified these improve pain, have a moderate effect on grip, but a negative effect on dexterity, and non-adherence ranges from 20 to 42%. But not all splinting may be effective. Adams et al (2008) evaluated resting splints identifying there was only moderate adherence with wearing this and no difference at 1 year between people with early RA in splinted and unsplinted groups, in terms of pain, function, grip, or dexterity. The unsplinted group had less stiffness, suggesting resting splints might be detrimental in early RA.

Increasingly, in the 2000s, people with moderate to severe RA became eligible for biologic drug therapy resulting in marked improvements in pain and activity ability for many. For some rheumatologists this posed the question: if biologic therapy leads to such large improvements, why bother with self-management, such as joint protection and fatigue management? An RCT demonstrated people on biologic therapy attending an 8-hour self-efficacy-enhancing, joint protection, fatigue and pain management, and exercise programme had significantly less pain and better activity ability than those receiving usual care only (Masiero et al 2007). McArthur et al (2012) highlighted biologic drugs provide new opportunities to extend occupational roles, particularly in work, but people with arthritis can lack confidence in resuming roles or struggle with these because of activity limitations and fatigue. Yet few with RA, and fewer still with ankylosing spondylitis, were referred to occupational therapy.

The National Institute for Health and Care Excellence guideline for the management of RA (NICE 2009) led to further changes in rheumatology. Providing DMARDs in very early arthritis, tight control of drug regimens, and switching people with RA more quickly to biologic drugs has led to better outcomes. The NICE guideline emphasized early team management, meaning patients are seen sooner in occupational therapy. Almost 30 occupational therapy interventions were listed in the guideline, emphasizing the wide range

of interventions available, and the importance of work rehabilitation, although evidence for the latter was still inadequate. Many with inflammatory arthritis are of working age and up to 40% are work disabled within 5 years of diagnosis (Verstappen et al 2004).

### Work rehabilitation

Work rehabilitation is increasing. Two recent UK rheumatology therapy textbooks include work rehabilitation as a core component (Goodacre and Harkess 2010, Reeve and Harkess 2013). Two recent surveys (Coole et al 2013, Prior et al 2014) identified that most rheumatology occupational therapists provide written information about work problems when they identify them, but rarely get referrals direct from clinic. Two-thirds provide some work rehabilitation, although only 10% use a work assessment. A wide variety of interventions are used, the commonest being splinting, work modifications, pacing, joint protection, positioning, task rotation, alternate equipment, workstation modification, and stress management. However, over half spent only 'a little of their time' on work rehabilitation. Prior to developing and evaluating a 3-day work rehabilitation training programme, a survey identified that participating therapists, prior to attending, provided on average 45 minutes of work rehabilitation per client to 5 employed people with RA in a month. Prior to training, the occupational therapists rated their knowledge, skills, and confidence about work rehabilitation as limited; after training, they rated it as good (O'Brien et al 2013).

Macedo et al (2009) published a small RCT comparing comprehensive occupational therapy and work rehabilitation for employed people with RA, versus usual care. Occupational therapy lasted 6 to 8 sessions. At 6 months, the occupational therapy group had significantly lower risk of work disability, better work satisfaction, less pain and helplessness than the usual care group. A recent feasibility trial compared a structured work rehabilitation programme, provided by occupational therapists completing the 3 day training programme (above), versus usual care and written information only. The intervention was based on a trial by Allaire et al (2003) in the USA. Therapists collaboratively identified work problems and solutions with clients using a structured work assessment, activity diary and action planning to facilitate change. On average, participants received 3 hours of work rehabilitation over 3 sessions, with therapists spending a further 2 hours on indirect provision, such as identifying solutions, employer liaison, and referral to other agencies. This led to moderate to large effect sizes for changes in work instability, work productivity, pain, and fatigue compared to the control group, at a cost of £123 per client (Hammond et al 2014).

## Behaviour change

The evidence is developing that how rheumatology occupational therapists provide therapy makes a difference to both short- and long-term outcomes. Giving advice, persuading, and spending limited time on joint protection, fatigue management, hand exercises, work changes, and other interventions, over one or two sessions only, or providing written information only, does not help enough people to change enough. Behaviour change approaches need to be integrated into clinical practice to support clients effectively. Behaviour change is key to improving healthcare and health outcomes (Cane et al 2012).

### **Why don't people change?**

Adherence with self-management strategies and interventions is highly variable. Adherence refers to the equitable role of the client in goal-setting and treatment, with shared responsibility for outcome (Price 2008). Self-management goes beyond adherence as it emphasizes the active, decision-making role of the client in ongoing management of their condition, adjusting use of their health behaviours with changing health status. Sixty percent of people with arthritis do not adhere to physical activity guidelines (Austin et al 2012); and 30-80% do not adhere to recommended medication regimens (van den Bemt et al 2012). Adherence on average is 50%. Valuable resources are wasted if we do not: anticipate non-adherence; identify and address why clients do not change; help motivate them to change; help them to do so, and to overcome barriers; that is, if the person does indeed want to change. In the end, this is the person's choice and responsibility. Our role as therapists is to use the most effective strategies to support them.

Common reasons clients give for not adhering to advice given are 'I forgot' or 'I was too busy'; whilst these can be valid reasons, do they avoid addressing the real reasons? The person may not want to say why they do not want to change; they do not want to be seen as wasting time and as a 'non-compliant patient'. Seventy percent of all non-adherence is intentional, mainly influenced by the person's beliefs concerning their perceptions of the behaviour:

- Is it necessary — is it important enough to do it?
- Is it effective — does it work?
- Self-efficacy — am I confident I can do it?
- General concerns — Will I need to make too many changes; will it cost me too much (in terms of money, time, forfeiting other valued activities, changed attitudes of

others)? Are there negative effects (for instance, a belief that exercise can increase pain and fatigue)? How will it make me feel about myself?

- Beliefs about the illness, particularly about timeline and consequences: if the illness will be short and have few consequences, why change (Gadkari and McHorney 2012, Pasma et al 2013)?

Of these, perceived need to perform the behaviour and self-efficacy, seem to be the strongest factors influencing whether people change. Helping people change such beliefs can influence their future health status. Cognitive factors play a large part, but other influences include: not having necessary skills; environmental constraints; social control; and habit control (Knittle et al 2012, Michie et al 2011a).

### **Moving through change**

A simple way to address the need for change would be to start by asking the following questions of clients we are helping to make behaviour changes:

- ‘Tell me about your illness’ — to find out beliefs about timeline and consequences
- ‘Is it important enough for you to use ... [the health behaviour/s]’
- ‘Are you confident enough to [do the health behaviours]’
- ‘Are you ready to change?’ (Mason and Butler 2012).

This helps us identify those likely to have difficulties changing and why. Interventions can then be tailored to suit the individual. Identifying which factors are most relevant helps both the therapist and the client in discussing issues that address their personal priorities. Motivational interviewing is a collaborative strategy between therapist and client which can be used to help people identify ambivalence about change, discuss the pros and cons, and mobilize their own resources for change (Miller and Rollnick 2012, Rollnick 201).

Anticipate non-adherence is likely, and plan to overcome it from the start. However, do we believe it takes too long to do this in our treatment, because we are ‘too busy’? Why is this? We need to ask the same questions of ourselves as we do of clients. Is this because we don’t believe in the benefits of our treatment enough to take the time to help clients change? Or is it not important enough for them to change? Or we lack confidence in helping people change? Or believe others control what we do, we cannot change the way we provide treatment, and it is not possible to spend time supporting clients through change?

The Transtheoretical Model describes behavioural change as a process of five phases (Prochaska and Velicer 1997). The first two form the motivational stage: pre-contemplation

(not thinking about doing it) and contemplation (weighing up the pros and cons). Discussing pros and cons and providing tailored information related to the persons' beliefs about importance, confidence, and readiness, helps move people through these stages. People must *want* to take action first. The next two phases form the action stage: including preparation (starting to make some plans) and action (doing it). People need guidance and support to participate in a behaviour-change process. The last stage is maintenance. People need support to prevent relapse and modify self-management as their condition changes (Knittle et al 2012). This Model emphasizes that therapy should be tailored to the stage the person is at. We presume, for example, that people attending self-management education groups will be motivated to change. However, Keefe et al (2000) identified, amongst volunteers agreeing to take part in arthritis self-management programmes: 55% were in pre-contemplation or contemplation; 22% in preparation; 6% in action; and 17% in maintenance. Over half of participants were not yet ready to change. Even willing clients need motivational interventions to help change.

### **Changing ways**

A review of arthritis self-management education trials identified effective programmes were those that:

- explicitly used social cognitive theory and/or cognitive behavioural approaches to facilitate change
- promoted participants developing weekly individualized action plans with progress review
- were protocolized with leader manuals, ensuring standardized delivery
- included participant workbooks to support practice between sessions (Iversen et al 2010).

The LAJP and LMAP both include these. Social cognitive theory states behaviour is determined by a combination of cognitive, behavioural, and environmental factors. People must believe the health behaviour will be effective and they can achieve doing it (Bandura 1986). Four key strategies to enhance self-efficacy are used in these programmes:

- Mastery: succeeding enhances future beliefs about success; regular practice and home programmes support this
- Modelling: watching someone else like oneself succeed; group programmes provide this opportunity

- Verbal persuasion: praising people's attempts and telling them you are confident they can do it
- Reinterpreting physiological symptoms: helping people understand that not all pain and fatigue (for example) are wholly due to their condition.

In clinical practice, time constraints mean it is difficult to provide individual patients with sufficient practice. Group programmes can help overcome the problem. Our surveys showed occupational therapists on average take 1.5 hours to provide joint protection and 15 minutes to provide hand exercises. If 6 people are taught these individually, it takes the therapist 10.5 hours, whereas a group of 6 people attending the group LAJP can be taught in 10 hours. Each client gets 10 hours input, allowing time to motivate, build self-efficacy, practice, learn from each other, and psychologically adapt.

Michie et al (2011b) developed a taxonomy of behaviour change techniques to help describe what happens in interventions. Applying this to the LAJP shows almost 20 techniques are being used. An important feature is ensuring people set action plans themselves that they believe are personally important and achievable and not push them to achieve too much too soon.

### **Change in practice**

The last 10 years has seen the rise of evidence-based practice and clinical guidelines. Behaviour change is key to improving healthcare and health outcomes (Cane et al 2012). Implementing research into practice means therapists need to change behaviour too. Translational research, or 'research into practice', takes on average 17 years (Morris et al 2011). Such lags in translation mean patients are not benefiting from effective interventions. In the same way that we need to identify why our clients may not change, we also need to examine why we may not change to implement evidence and guidelines.

Implementing evidence-based practice depends on behaviour change, which is fundamental to effective rehabilitation (Michie et al 2011a). The Theoretical Domains Framework was developed to simplify and integrate behaviour change theories in both implementation and behaviour change research (French et al 2012, Michie et al 2005). Within this, 14 domains including 84 constructs are identified as barriers (or enablers) to health professionals changing. Research into why health professionals do or do not change is not new, but the framework provides a common terminology for identifying barriers and enablers across studies, and a standardised structure from which to build and evaluate interventions.

The Framework has been used to identify key barriers as to why therapists do not implement guidelines, using focus group interviews and analysis (McCluskey et al 2013). Barriers were:

- Knowledge and skills: a lack of awareness of research, how to assess research, what protocols were available, how to obtain or use them, and lack of skills to teach patients effectively
- Motivation, intentions and goals: how much the therapist wants to implement evidence-based practice
- Beliefs about capabilities: including beliefs as to whether the therapist is capable of performing the required assessment or treatment, whether their profession should be doing so, and whether they were able to motivate patients
- Beliefs about the consequences of providing an intervention: whether it would make a difference and improve outcomes, or have adverse consequences
- Memory and attention: included simply forgetting, especially when busy — lack of prompts to act, competing tasks, priorities, and lack of time
- Resources: having the staff, materials, space, time and predictability of such resources

Barriers and enablers varied with different target behaviours, and with different professions and individuals. Whilst a long list, the researchers found the process led to health professionals identifying actions they could take themselves to overcome barriers and apply guidelines, such as identifying research articles related to target interventions, reading and reviewing these, identifying protocols, inviting local experts to provide training, group discussions to determine actions, standard setting, and local audits. The Framework can be used by therapy teams to identify specific changes related to providing specific evidence-based interventions.

### **Changing times: the future**

In the UK, we work in an increasingly target-driven and resource-constrained National Health Service. Non-adherence is a huge waste of our limited resource. Our challenges for the future include ensuring that:

- undergraduates, and therapists, are competent in searching and research critical appraisal skills as the foundation for evidence-based practice
- we each truly implement evidence-based practice, know what the most effective interventions are and how to deliver them most effectively

- act as advocates for our clients' need for evidence-based services

What next? Clinical research cannot progress if clinical therapists are unwilling to take part. Please get involved when the opportunity arises. You too can then discover, as Katrina Bannigan recently wrote, that 'research is fun' (Bannigan 2014).

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