Occupational therapy and people with dementia in the UK

There are approximately 33 000 occupational therapists in the United Kingdom (UK), working in a variety of health and social care services. They work in inpatient units in hospitals, community settings such as people's homes, day care facilities as well as residential and nursing homes. Occupational therapists work with people who have physical problems, mental health problems and learning disabilities across all age groups - and approximately 70 percent work in Government funded posts (1).

Av *Richard Ledgerd*

Richard Ledgerd er forsker ved National Health Service Foundation Trust i London. På «fritiden» er han blant annet generalsekretær i WFOT.

Det er ingen interessekonflikter knyttet til dette manuskriptet.

Occupational therapists are educated at Universities, and the minimum qualification for practice is a Bachelor of Science degree. There are more than 30 universities offering more than 60 education programmes throughout the UK. Students are expected to complete one thousand hours of fieldwork or clinical practice, and all the education programmes have been approved by the World Federation of Occupational Therapists (WFOT).

The UK has an ageing population, which means that there are more people living longer into old age in comparison to a smaller number in younger generations (2). Dementia is a condition that leads to a loss of cognitive ability. Consequently, during the initial stages of this condition, a person may experience difficulty remembering recent events and learning new information. As the condition progresses, new symptoms may appear, including language disturbances and difficulties completing complex activities of daily life, such as managing finances and transportation. Later, the person may lose the ability to manage basic daily skills such as feeding and toileting, in addition to experiencing behavioural problems including agitation, psychosis, wandering, aggression, depression, and anxiety.

Dementia is sometimes considered part of the ageing process, which is not correct. It can affect any age group, however it is more prevalent in older than in younger people; and so, as the population is ageing, the number of people with dementia is rising.

The most prevalent types of dementia in the UK are Alzheimer's disease, accounting for 62 percent of those diagnosed, followed by Vascular Dementia (17 percent) and Mixed Dementia (10 percent). The less common types of dementia include Lewy Body Dementia (4 percent) and front temporal dementia (2 percent) (3).

The number of people in the UK with dementia is approximately 820 000, which equates to 1,3 percent of the total population and is expected to grow, with estimates that the number will increase to 940 110 by 2021, and will further rise to 1 735 087 persons by 2051 (3).

More than 50 percent of older persons in the UK live alone and rely on family carers, friends, and relatives to provide informal support. This is often called unpaid care and is estimated to be in excess of 1,5 billion hours, equating to a cost of £ 12 billion a year (4).

Already, the costs of health and social care services spent on dementia overtake the amount spent on other diseases, and this is only expected to grow. To illustrate this, in 2008 the costs for supporting people with dementia were £ 10,3 billion, in comparison to £ 4,5 billion for cancer, £ 2,7 billion for stroke, and £ 2,3 billion for coronary heart disease (5).

It is estimated that a quarter of inpatient beds in acute physical/trauma hospitals are occupied by people with dementia (6). In many instances these hospital admissions could have been avoided, and people with dementia end up staying too long and ultimately dying there.

The UK Government have published a range of policy and strategy documents and quality standards aimed at addressing the future needs of the population living with dementia; including:

- National Dementia Strategy (Department of Health, 2009)
- Quality Standards in Dementia (National Institute for Clinical Excellence, 2010)
- Improving Dementia Services in England (National Audit Office, 2010)
- Dementia Commissioning Pack (Department of Health, 2011)
- The Prime Minister's challenge on dementia (Department of Health, 2012)

These examples are some of many policies and strategies aimed at developing the provision of quality care for people with dementia and their families. They include raising awareness of the disease, earlier diagnosis and support, and also strategies to ensure people are able to live well with dementia.

A primary focus has been on the delivery of services to people in their own homes and avoiding the need to use inpatient hospital services.

The use of medication to manage symptoms in dementia is no longer seen as the primary intervention to support people. The use of psycho-social interventions that promote wellbeing, independent living and quality of life and support are seen to have equal benefits. These, combined with the delivery of services in a person's home, have elevated the need and platform for occupational therapists to provide their specialist input.

The configuration of services for people with dementia has changed over the past few years, with greater focus on community based services, choice, and easier access. A description of these services, and examples of how occupational therapists provide their unique contribution, are provided below.

MEMORY CLINICS

A Memory Clinic is a community based health service aimed at providing assessment and diagnostic services for people with memory problems, including those who may have dementia. The Memory Clinic provides an easier way for health care providers (particularly General Practitioners) to refer patients that they suspect may be experiencing memory problems. Rather than asking doctors to complete lots of complex referral procedures or waiting until someone's cognitive impairment deteriorates, doctors are asked to refer anyone they suspect of having memory problems, as soon as possible.

Memory clinics are staffed by doctors, nurses, psychologists and occupational therapists and usually open from Monday to Friday from 9 am to 5 pm.

The role of the occupational therapist is to provide home based assessments and interventions to identify any problems the person with dementia may be experiencing, and provide solutions to enable independent living. An occupational therapy assessment involves observing a person's routine – which is a very important aspect of living with dementia, as many retained skills are based on routine and long term memory.

Examples of such routines are getting washed and dressed in the morning, preparing meals and using appliances, going out of the house, shopping and managing household chores. Sometimes a person's memory can affect these routines and increase the risk of inadvertent harm to him- or herself or others. They might for example forget to light a gas appliance, or leave food to burn and catch fire. Identifying and managing risk is of particular importance, and wherever possible the occupational therapist will look at strategies to help the person overcome these pro-

Occupational therapists focus, among other things, on minimising safety risks.

blems. This could include memory prompts, assistive technology – such as specialist sensors and detectors, reminders and working with care services to provide specialist support – such as prompting with meal preparation and compliance with medication. Not only do occupational therapists assess how a person's memory is affecting what they do, they also look to see if there are any physical challenges that are impeding their independence for example how people move around their home, get on and off their bed and chairs, and use the toilet and shower. They can provide equipment such as rails or other adaptations to provide a safer environment. People who are referred to the memory clinic are sometimes in the early stages of dementia and still have the capacity to learn and retain new information, skills and techniques in addition to accepting and accessing more long term support services. Occupational therapists also work with family carers to provide advice and support about how to manage potential situations and care for their own mental and physical well being.

The Royal College of Psychiatrists in the UK established a Memory Service National Accreditation Programme (MSNAP) (7) to publish a range of quality standards. Individual memory services apply for accreditation, demonstrating how they meet these standards. The standards include the provision of occupational therapy (MSNAP 2015). MSNAP accreditation assures staff, service users and carers, commissioners and regulators of the quality of the service being provided.

The reduction of hospital based services has also led to an increase and extension of other community based services. As mentioned, memory clinics provide an early intervention service; however there is still a need to provide more intensive home support services, particularly at a time of crisis.

COMMUNITY MENTAL HEALTH TEAMS

Community Mental Health Teams include occupational therapists, and support people with more complex or enduring mental health needs. This includes providing specific occupational therapy assessments as previously described, or more generic work, such as managing and coordinating a person's care and providing general mental health assessments.

CRISIS TEAMS

Crisis teams provide services seven days a week, offering extended hours, and are in some instances available 24 hours a day. They have additional resources that enable visits to be made several times a day for prolonged periods of time. The main aim of these teams is to avoid admission to hospital and serve almost as a «community based ward».

Occupational therapists work in these teams alongside other members of the multidisciplinary team. Their role is to provide support to people and identify short term solutions at periods of crisis or sudden onset of different behaviours and needs. For example, a person with dementia may develop an infection which can dramatically change their cognitive abilities and increase levels of confusion. During these periods, individuals may display challenging behaviour and agitation, or no longer be able to cook for themselves. The occupational therapist can work with people to assess their immediate level of functioning, which may be drastically different to how they were managing previously. For example, a person may become agitated and want to leave the house. The occupational therapist may consider ways of making the outdoor environment safer, advise family carers on how to manage behaviours, or engage people in activities that they enjoy, in order to decrease their impulse to leave the house. People may not be able to care for themselves, and may be leaving the gas cooker on, burning food. Occupational therapists will recommend assistive technology to reduce this risk, or fit a temporary cut-off switch to prevent the gas from being used. They will work with the person to make alternative types of meals, or suggest short term solutions of meals being provided. Much of the occupational therapist's work will focus on minimising major safety risks, but also preventive measures that can be beneficial when the crisis has passed. The ultimate goal is to ensure people can remain in their own home, and avoid hospital or care home admission.

DRIVING ASSESSMENT

In many community services, occupational therapists are also involved in assessing the cognitive skills and driving skills of people with dementia. There are a number of protocols that have been developed to look at how these skills can be managed safely and with consideration. These involve examining the skills that are required for safe driving, and highlight those functional deficits that are most likely to impair a driver's ability.

COMMUNITY GROUPS

Historically, Day Hospital services were provided for people living in the community to attend specialist day care facilities that provided assessments and interventions from members of the multidisciplinary team. In the UK many of these services have been disbanded and replaced by Memory Clinics who undertake assessments in peoples' own homes. These changes have also led to the emergence of community groups, in which occupational therapists have a key role. Community groups are located in cafés, community halls, and residential buildings. They provide a range of activity- and therapy-led groups such as hobby and leisure interest groups, meal preparation, personal care, cognitive stimulation therapy, and reminiscence. The funding for these groups can include health and social services, in addition to charities and the voluntary sector. An increasing number of community groups are available at weekends and evenings, not just during daytime hours.

INPATIENT UNITS

The number of available inpatient hospital beds has been dramatically reduced, and only those who have severe challenging behaviours with significant risk of harm to self and others are admitted to hospital. Occupational therapists play an important role in these units, providing individual and group work-based activities, activities of daily living assessments, and recommendations for future living arrangements and services.

RESIDENTIAL AND NURSING HOMES

Individuals are often admitted to residential care facilities because they are unable to manage independently at home. Occupational therapists provide services to these facilities in a number of ways. For example, they can develop routines based on individual preferences and levels of functioning, and provide equipment to assist with communication and activities of daily living. Occupational therapists can also advise home care staff on how to promote independence, use of space, seating, and how to prevent falls and manage risk, which in turn has an impact on the number of avoidable hospital admissions.

RESEARCH- AND EVIDENCE-BASED

Occupational therapists provide evidence-based interventions in the field of dementia that include maintenance and development of functional skills, improving quality of life, person-centred care, and cost effectiveness. They use a range of outcome measures to demonstrate that what they do is effective. Research findings are usually published in high quality academic journals and clinical

practice newsletters. National occupational therapy associations play an important part in developing practice initiatives, sharing best practice and publishing standards. In the UK there is a specialist association of occupational therapists that work in the field of older people and dementia.

Historically the funding for dementia research has been particularly poor in comparison to other diseases, however the government has recently committed significantly more spending - approximately £ 66 million - to develop dementia research. Already the results of many high profile occupational therapy studies are reaching the government and commissioners, demonstrating the efficacy of occupational therapy. For example, Dr Maud Graff in the Netherlands found that providing ten sessions of occupational therapy to those with mild to moderate dementia over five weeks, improves functioning and reduces burden on the care giver. The effects remained significant after three months.

The author is employed in the Dementia Research Centre that was established by, and is led by, Professor Martin Orrell, an eminent old age psychiatrist at the University College London (UCL), with a strong professional and research interest in the use of psycho-social interventions and people with dementia. Professor Orrell has successfully bid and received millions of pounds worth of funding to undertake large, national, randomised controlled trials aimed at demonstrating the efficacy of a variety of psycho-social intervention for people with dementia and their carers. Examples include:

Cognitive Stimulation Therapy, known as CST, involves 14 sessions of themed activity groups run twice or once a week. This large-scale randomised controlled trial showed the effects of CST to be of comparable size to those reported for the currently available anti-dementia drugs. It is a recommended intervention for people with dementia as cited by the National Institute for Health and Care Clinical Excellence (NICE). Occupational therapists routinely use CST in their practice, and their publications are available worldwide.

Maintenance Cognitive Stimulation Therapy – a randomised controlled trial looking at whether additional and continued sessions of group work CST have a more prolonged effect on cognition and quality of life.

Individual Cognitive Stimulation Therapy – a randomised controlled trial exploring whether training carers to deliver CST on a 1:1 basis in a person's home has effects on cognition and quality of life.

Reminiscence – exploring the impact of reminiscence therapy - as in remembering the past- on memory, cognition, and quality of life for the person with dementia and their family carer.

Home Treatment Programme – this research involved developing a practice framework that could be used by community mental health teams to assess and manage risk and consider particular evidence-based interventions to assist in managing particular causes of crisis.

Cognitive Behavioural Therapy for Anxiety in Dementia – a study that involves providing ten sessions of Cognitive Behavioural Therapy to people with dementia and their carers to help them manage their feelings of anxiety.

Another major study currently underway is *Valuing Active Life in Dementia* (VALID), this large-scale study is being led by Dr Jennifer Wenborn, a leading dementia specialist and occupational therapist in the UK. VALID aims to build on the study undertaken by Dr Maud Graff in the Netherlands. This national randomised controlled trial aims to see if ten sessions of community based occupational therapy has similar outcomes as that of the Dutch trial. This five year study involves translating and adapting the original intervention to make it relevant for the UK practice and service context. This has involved piloting the intervention and generating feedback from occupational therapists that used it to see how it needs to be adapted for a full-scale trial. The intervention is known as Community Occupational Therapy in Dementia – UK (COTID-UK), and the randomised controlled trial will start shortly. If the outcomes prove effective, this could have a significant impact on the practice of occupational therapy.

CONCLUSION

Occupational therapy in the UK is an established health and social care profession, and is recognised for its unique contribution in meeting the needs of people with dementia and their carers. The number of people with dementia is expected to rise considerably in coming years. The role of the occupational therapist in delivering evidence-based interventions to maintain and increase occupational performance and quality of life, and decrease carer burden, is paramount. Government strategy and policy documents in the UK have recognised the important contribution of occupational therapy, and have been embedded in best practice standards and guidelines. This achievement is based on a number of factors, including occupational therapists' being able to demonstrate their outcomes and effectiveness through the use of standardised assessments and evidence-based interventions. The role of the national occupational therapy association has been imperative in articulating these outcomes, with representation, lobbying and support offered at the highest levels. This report focuses on occupational therapy service provision from a UK perspective, and outlines some of the research that the author is involved in. The purpose of sharing this information is to offer insight into developments within occupational therapy and dementia services from another international perspective, which may in turn resonate with dementia education, practice, and research in Norway.

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