Health Wellbeing and Local Government Committee

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Inquiry: Stroke Services in Wales - Written evidence from the College of Occupational Therapists

Introduction

The College of Occupational Therapists (COT) is the professional body for occupational therapists and represents around 29,000 occupational therapists, support workers and students from across the United Kingdom and 1,500 in Wales. Occupational therapists work in the NHS, local authority social care services, housing, schools, prisons, voluntary and independent sectors, and vocational and employment rehabilitation services.

The College of Occupational Therapists Specialist Section in Neurological Practice aims to improve knowledge, assessment and treatment of neurological conditions by encouraging awareness of up-to-date approaches, exchange of ideas, CPD and research. It provides expert knowledge and advice in influencing policy development and patient care and the development of national guidelines.

Occupation is essential to human existence and good health and wellbeing. It includes all the things that people do or participate in, such as caring for themselves and others, working, learning, relaxing, playing and interacting with others. Being deprived of or having limited access to occupation can affect physical and psychological health.

Key messages from the College.

Investment is needed in all multi professional services for stroke across the whole pathway in Wales to ensure consistent and safe services which will reduce the incidence and effects of stroke.

Preventative, early supported discharge and community rehabilitation stroke teams must be developed to ensure people maximise their recovery from stroke.

Investment in specialist training and research is needed in Wales.

Strong leadership and the development of consultant occupational therapy posts are critical to drive up the quality of services across Wales.

We believe that only with a clear stroke strategy with measurable outcomes to which Local Health Boards are held to account will this be achieved.

Recognition is needed of the importance of occupational therapy along the whole pathway for stroke care. This includes the role in the hyper-acute units and the importance of occupational home assessments during the acute stage.

The role of the Stroke Specialist Occupational Therapist.

In terms of service provision for stroke, occupational therapy has an important role to play in the acute phase within the first 48 hours, through intensive rehabilitation including early supported discharge, to long term rehabilitation and social care (Logan 2007).

The stroke specialist occupational therapist offers a unique professional intervention which facilitates the individual to return to maximum activity and meaningful participation within the community. Therapy is based on an holistic assessment of the individual's physical, cognitive, perceptual, emotional, social, work and environmental situation and the specific knowledge of the impact of that individuals own stroke on their abilities and skills. Therapy intervention maximises the person's ability to undertake the whole range of activities that make life purposeful: personal independence, driving, vocational rehabilitation (return to work), leisure and family activities (for example parenting).

Availability of specialist stroke units in hospitals across Wales and geographical variation in these services;

The availability of stroke units across Wales is very variable. Some organisations have one acute stoke unit, others two, some have additional stroke rehabilitation units, others do not: Powys has no units for either acute stroke treatment or stroke rehabilitation. Some organisations have combined their acute and rehabilitation units, others still only have co-located beds, but no specialist unit. This variability does not allow for the development of best practice as evidenced by the Royal College of Physicians guidelines (3rd edition 2008).

Effective treatment requires access to skilled, specialist therapists at all stages of the pathway: from immediately post stroke to continuing support in the long term. Yet some services only offer acute post stroke therapy, while others provide longer term rehabilitation; a few are able to provide early supported discharge and some have specialist community rehabilitation teams.

There is no consistent access to specialist occupational therapy personnel. Some units have specialist, stroke expertise. Others are reliant

on generalist practitioners who treat people with stroke as part of a mixed caseload, possibly only seeing a few people with stroke a year.

The profession is not aware of any specialist occupational therapy primary preventative services, although many occupational therapists are aware of the risk factors and attempt to increase patient carer awareness of public health initiatives and local services to promote health and wellbeing incorporating prevention into their care programme. Occupational therapists also reinforce secondary prevention as it is so critical to a person's chances of avoiding a further stroke.

The resources devoted to stroke services in Wales;

The recent investment is welcome but inadequate. The profession agrees with the report of the stroke services expert panel (2008), that substantial additional investment will be required to secure the development of other components of the stroke pathway. Northern Ireland, with a population of 1.7 million, allocated £14 million pounds to stroke services (08/09- £3m, 09/10-£2m, 10/11- £9m). Wales, with a 2.9 million population, allocated 2.5 million.

While there is a need to improve acute care and interventions such as thrombolysis, this should not be at the expense of other parts of a comprehensive stroke service (Sudlow and Warlow 2009). It is vital that investment to develop early supported discharge, community rehabilitation and long-term support is established.

There is inadequate investment in occupational therapy services in both dedicated stroke units and in co-located beds and non specialist rehabilitation units. Despite this committed, expert staff work tirelessly to improve the quality of services in Wales and have developed an All Wales occupational therapy clinical network to support best practice in stroke services. They receive no investment or formal support but have achieved a significant amount over the last two years (see appendix). The network provides in-service training, shared learning and support for those who are not able to secure the time or funding to undertake the necessary specialist training. This has now reached the limits of what can be achieved and further investment must be made to maintain the quality and staff skills in Welsh services. Research and development are similarly hindered by a lack of posts and access to funding.

The effects of having a stroke are often on-going and therefore once patients are over the immediate rehabilitation phase of approximately six months, they start to look to resuming their lives as much as possible and making changes to accommodate their new limitations (Lincoln et al 1998). The National Clinical Stroke Guidelines (Intercollegiate Working Party for Stroke 2008) recommend that people with on-going limitations after the initial rehabilitation phase should be offered a six monthly review and be provided with further rehabilitation if clear goals are identified.

And a longer-term holistic approach to the rehabilitation of stroke patients that includes leisure activities is needed (Murray et al 2003). There is inconsistent funding of such services across Wales.

Availability of specialist staff in acute settings, recruitment and training;

Availability of staff

There is insufficient access to specialist occupational therapy for stroke patients. Access is limited to most, but not all specialist units. Those receiving their care away from specialist stroke units are normally seen by generalist occupational therapists who have a mixed caseload. Acute stroke patients are often less than 5% of the generalist OT's caseload and this makes it difficult for therapists to maintain their skills at an appropriate level.

A survey of 140 stroke units in England, conducted for the Health Workforce Bulletin (March 2009) has shown that:

Patients are receiving low levels of nursing and therapy time, with wide variation in provision.

75% of patients receive less than one hour of therapy per day and 25% receiving less than half an hour in every 24 hours.

The survey estimates that to provide an optimal service, 435 additional occupational therapists would be needed in England.

The profession specific audit for Wales has still not been published and thus there is currently no data for Wales.

The extra finance provided so far was solely to enhance services in areas admitting acute stroke patients, but enhancement from such a low base remains inadequate. Where it was made available, the finance provided to date has been for band 6 occupational therapists, a grade which would require clinical supervision from more experienced therapists. However, such supervision is currently only available in the large neurological units. A better range of skill mix is required to maximise the use of the workforce.

The lack of occupational therapy in acute stroke services can mean that more complex problems, such as cognitive deficits, may not be identified. Without robust assessment these "invisible" impairments are often undetected at ward level. If untreated, patients may not attain their optimal level of function, leading to increased dependence, increased length of stay and higher rate of placements in residential or nursing care. Alternatively they and their families have to cope with severe difficulties in their own homes where it is even more difficult to access rehabilitation or therapy.

People may not be seen by a specialist occupational therapist within the recommended timeframe. Because of a lack of availability of specialist therapy staff, medical consultants are asking for non-specialist occupational therapists to assess patients simply to meet the target of an assessment within the required timeframe. This is neither safe nor effective.

Recruitment

There are insufficient posts available in occupational therapy. There would appear to be little difficulty in appointing to those posts if they were advertised. Current funding is insufficient and often posts are not advertised at the correct grade. Lack of posts is the problem not lack of interest in jobs when they are advertised.

Training

Post graduate education and training is essential to develop the necessary skills to work in this area. As identified above funding and study leave are currently inadequate. There is almost no funding available for specialist higher education stroke courses, many therapists also find they are not even allowed study leave if they are willing to pay for courses themselves. This requires someone to be in a position to give up their annual leave allowance to undertake courses, but even this is not sufficient to undertake anything other than short courses.

Research

There are no research active occupational therapists in stroke in Wales. Clinicians have expressed willingness to participate in research projects such as multi centre trials, but have been unable to commit to undertaking a project due to the impact upon their clinical caseloads. There is simply not the capacity currently to participate. Research funding and posts in university research units is essential.

Availability of specialist equipment, such as scanners to determine type of stroke;

From a specifically occupational perspective:

There are shortages of specialist seating and wheelchairs which are essential especially for early stroke patients. There are also long waits for assessment and delivery of specialist wheelchairs.

Postural support devices, specialist tables, manual handling, splinting and rehabilitation equipment are essential for effective rehabilitation and are also only available in some specialist units, not on general wards.

Investment is needed for evidence based standardised assessment tools and in the accredited training to correctly administer and interpret those assessments in order to accurately prescribe treatment.

The development of new integrated community equipment services across Wales is welcomed. Issues about cross border provision for equipment to facilitate discharge and sustained life at home must be resolved. Variance in eligibility criteria, procedures and processes can hinder rehabilitation. The college has responded to several previous consultations in respect of community equipment and can provide further information if needed.

Adaptations and delays in provision of grants are also an issue. Clearly, this type of work is complex and cannot easily be provided rapidly. The balance of waiting to see how much recovery is gained versus the need to initiate complex work quickly is extremely difficult. Improved housing design is critical in the long term. In the short term better integration and interagency working is essential to facilitate best outcomes.

Availability of aftercare and rehabilitation services, including speech and language therapy, physiotherapy, occupational therapy and other community based services

New finance has been allocated for the acute sector but is insufficient for developing rehabilitation and community services. The Royal College of Physicians guidelines (2008) recommend at least 45 minutes per day of each therapy if the patient is able to tolerate this. The College and Specialist Section are not aware of any units in Wales able to offer this level of occupational therapy at present due to insufficient staffing levels. For information, minimum staffing levels per stroke patient are given in the 2007 document 'Occupational Therapy Following Stroke' (see below). The recommendations state, for example, that in the intensive rehabilitation phase of the pathway, at least one Band 7 occupational therapist is needed for every five patients (Logan 2007). Currently, members from COT's Stroke Forum are reporting that the staff patient ratio is 1:10 on some units.

The minimum standards for an occupational therapy stroke service

(wte = whole time equivalent)

1.5 wte stroke specialist occupational therapist per 10 beds for acute units

1 wte stroke specialist occupational therapist per 5 beds for rehabilitation units.

1 wte stroke specialist occupational therapist per 15 patients in community teams.

(This may need to increase for very rural areas).

Each unit/ team should have an occupational therapist at band 7 or above to lead/supervise.

(Logan 2007)

A good quality multi professional stroke service should have the following staff as a minimum: occupational therapy, physiotherapy, speech and language therapy, dietician, generic support workers, care workers and access to stroke specialist medical consultant.

Some patients might be able to go straight home without going to inpatient rehabilitation services if these services were established and staffed to offer the intensity of therapy recommended Arrangements for early supported discharge should be being made with appropriate clients and there is usually a high demand for occupational therapy home assessments at this stage. Home visits are essential for many clients with stroke, because the stroke usually represents a sudden and major decline in functioning. However, they take a significant amount of occupational therapy time and also mean that occupational therapists are not available on site to be working with other clients whilst carrying out those visits. These factors need to be taken into consideration when determining staffing levels, to ensure that there is adequate occupational therapy cover.

Some of the data gathered appears to indicate that even the minimum standard on stroke interventions is not being reached. For example the sentinel audit standard is that all stroke patients have an occupational therapy assessment within four days of their stroke. One hospital in South East Wales shows in the audit that 92% of its stroke patients are seen within 2 days. Yet that organisation submitted a bid to the expert panel in last year's stroke funding allocation for a specialist occupational therapist, because they have no current establishment for a specialist occupational therapist.

There are insufficient community services to achieve early supported discharge. There is clear evidence of the effectiveness of specialist stroke community service teams yet these are very rare in Wales. Because of this, patients are being referred to re-ablement or other general community rehabilitation teams where staff do not currently have the specialist skills to achieve maximum outcomes for people with stroke. This could be overcome by more integrated working. A potential model would be to use specialist staff as a resource for generalist/ re-ablement community team staff. If basic training and a model of remote communication/ supervision and mentoring were developed then it may be possible to use local, generalist staff to provide high quality care. This would fit with the vision of the Assembly Governments' rural and primary care strategies and would provide a possible solution for providing stroke services across rural areas. However, this will not be delivered without that infrastructure of access to specialist mentors.

Good practice in the treatment and management of stroke in Wales, the UK and other countries and ways in which such practice can be disseminated

A Cochrane review of randomised controlled trials provides evidence that occupational therapy treatment for stroke patients is effective particularly in improving independence in personal activities of daily living and concludes that it should be available to all stroke patients (Legg et al 2006). This needs to be implemented in Wales.

The Royal College of Physicians (RCP) guidelines recommend specialist stroke occupational therapy to effectively assess and treat occupational performance including cognition/perception, vision, mood, driving assessment/advice and vocational rehabilitation.

The Stroke Outreach Service was set-up in December 2003 at the Regional Stroke Unit (RSU) West Wing as a result of intermediate care developments. The success of the pilot project, combined with other factors enabled the service to gain permanent intermediate care funding for an Occupational Therapy and Physiotherapy post in the Stroke Outreach service. The service is beneficial as it assists in the smooth discharge of patients' from RSU, focuses on their individual aims and goals at home, provides patient's with ongoing intervention from a Stroke Specialist OT and PT who are also often involved in their treatment on RSU, supports relatives and carers and provides patients with input and support from the Stroke Association Family Support Organiser who also works as part of the Stroke Outreach Service.

Early supported discharge teams (stroke specialist) reduce the length of stay and improve quality of life for patients and carers. These must be specialist teams not generalist rehabilitation teams. If generalist teams are used they must have access to specialist staff for support and training and guidance. The teams must work with people as long as they need and should not discharge because a pre-set length of time has been reached.

There is a good OT network via the College's specialist section across Wales and the UK network. The all Wales occupational therapy clinical network has begun good work which needs further investment.

The Welsh Stroke Alliance education sub group is an excellent network to support stroke education. It has developed new links with NLIAH and OCN and is seeking accreditation for a national stroke competence training programme. The problem is a lack of funding to pay whoever delivers the training in each organisation and for backfill of staff time to ensure treatment continues.

The RCP guidelines identify that geographically located stroke units are effective in saving lives and have better patient outcomes. These must be accessible across Wales.

Programmes for the prevention of stroke and the promotion of lifestyles that minimise the risk of stroke

Most services were originally funded to provide acute rehabilitation and have expanded and developed to provide the essential long-term rehabilitation. Many have been victims of their own success and are running greatly expanded services with little or no increase in establishment or resource. This is one of the reasons why providing the requisite 45 minutes of therapy per day may not be achieved.

Occupational therapy enables people to change and control their own lifestyle and manage their activities to achieve wellbeing. However,

the specialist section is not aware of any specifically funded occupational therapy prevention services. In some instances previous funding has been removed. The majority of occupational therapy services provide the essential preventative services without funding.

The Open College Network accredited course "living with stroke" for patients and carers is excellent in supporting lifestyle change and increase preventative behaviour. However, it is up to the individual health and social care organisations to prioritise this and commit funding to identify suitable trainers and release them from existing clinical caseloads to deliver the programme: few are delivered in Wales.

It is not simply medical or physical health factors which impact on healthy lifestyles. Occupational therapists help stroke survivors and their carers develop strategies for coping with behavioural and cognitive difficulties. If a person has cognitive or psychological problems as a result of the stroke, particularly if these have not been identified or treated, carers and friends and neighbours find it especially hard and can withdraw their support. It then becomes extremely difficult for a person to engage in social, healthy lifestyle activities. For those who lose the ability to drive there is often loss of independence and access to community life, particularly in rural areas. This can prevent a return to independent life and occupational therapy is essential in supporting people to return to driving after stroke or finding alternatives.

The effectiveness of indicators and performance measures applied to stroke services

The stroke sentinel audit is an effective measure of the availability and quality of services.

Wales needs to measure patient outcomes not organisational outcomes. Good quality of life measures such as Goal Attainment Scale show the effectiveness of outcomes for people who have had stroke and outcome measurement and intelligent targets need to take these factors into account and ensure that outcomes not outputs are measured.

The Welsh Assembly Government developing 'Intelligent' targets' with outcomes such as length of stay, morbidity, functional outcomes, readmission within 30 days. These organisational outcomes are heavily influenced by the admitting criteria of the unit i.e. those who admit less severe stroke patients will have better outcomes. Those who transfer patients who are not responding to other wards can reduce the length of stay on the actual stroke unit. Indicators must be able to differentiate between these units and those who are supporting people not actively undertaking rehabilitation who may be unwell or awaiting placement if accurate data is to be gathered.

The impact of NHS restructuring on stroke services in Wales

There has been an adverse effect on the development of cohesive acute stroke services and a lack of drive and leadership to establish well resourced acute units. The £2.5 million funding allocated last year has been spread across all existing admitting sites (even where there were two or more in a single organization because of the merger of Trusts). As restructuring is completed a more consolidated approach must produce rationalised, sustainable well staffed stroke units. Equitable quality and access to all acute and rehabilitation services including preventative services, early supported discharge and specialist community rehabilitation teams are essential.

The focus on developing rural health services is welcomed and there will need to be innovative approaches to ensuring that people in rural areas who have a stroke are also able to access the best quality services. We recognise it is unlikely that sufficient investment will be made to provide specialist occupational therapists in all areas. However, the minimum we would expect to see would be:

Acute stroke units placed in a well planned location to maximise access to urgent treatment such as thrombolysis

Stroke rehabilitation units to allow substantial rehabilitation for all, in locations that allows family and carer support

Both types of unit must be adequately staffed with specialist occupational and other therapists to ensure that people are enabled to reach their maximum potential - and to sustain it.

Adequate finance of early supported discharge, long term specialist community rehabilitation for those who need it

Improved use of telecare and telehealth programmes to ensure that those located away from specialist centres have access to specialist staff to support their care where it is provided by generalist occupational therapists or support staff in the long term

There is a desperate need to develop leaders in occupational therapy. Stroke champions and leaders must be designated and empowered to make decisions,

Adequate staffing to allow services to be provided optimally (as defined in the RCP guidelines: OT within 4 days, but by a specialist occupational therapist not a generalist)

Investment in training and developing those specialist skills needed to maximize outcomes in specialist services.

Equality issues relating to the provision of stroke services, including those for BME groups."

There are gross inequalities across Wales with regards to provision of stroke units and stroke skilled staffing levels for a number of groups:

Younger People

A quarter of the 110,000 people who have a stroke in England are under 65 years of age (National Audit Office 2005). 10,000 people under the age of 55 suffer a stroke every year - 1,000 of these are under the age of 30. Yet there are hardly any services for younger stroke survivors. This group in particular need focused occupational therapy, vocational rehabilitation and community follow up to enable them to achieve life goals.

Younger stroke patients may have to make massive changes to their lives and this can take a long time to come to terms with. They are often in work when they have their stroke, they may have young children, they may be students, they have many years ahead of them and they want to live as independently as possible. They may need to accept changes to jobs, loss of a car, changes to hobbies, breakdowns in personal relationships, depression, and reduction in wealth as well as any physical changes.

English second language speakers

It is often extremely difficult to provide specialist therapy in anything other than English, particularly where there are low numbers of therapists. Attempts are always made to try to find another staff member with that language and work through them. However, there is rarely funding to pay for professional interpreters and sometimes it is necessary to rely on family members, which is not good practice.

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Appendix: All Wales Occupational therapy Clinical Network

- Most participants are members of the College of Occupational Therapists Specialist Section in Neurological Practice.

- Video conferencing is used to maximum effect to enable learning and sharing between therapists.

- A standardised transfer of care summary documentation has been developed. This improves communication and eases transfers of care across areas and units and agencies. It is about to be published on the Welsh stroke website.

- Currently piloting forms for recording treatment plans to improve consistency and communication

- 'SOS: starting out in stroke' is a programme to support any occupational therapist moving to work in stroke care. It is run by the COT

Specialist Section in Neurological Practice and has been developed to help improve the quality of care because there is no funding available for training or development of specialist skills to help new staff.

- The specialist section runs study days/conferences twice a year. Speakers give their time free to keep costs down.

- An electronic Welsh Neurological newsletter has been developed which is focused on stroke care.

- The specialist section have also contributed significantly to map of medicine and the stroke pathway has been amended significantly with their contributions