Community Rehabilitation Needs Of Stroke Survivors – short and long term

Prepared by Emmah Doig
& Delena Amsters

For the Community Rehabilitation Workforce Project – Queensland Health
September 2006

Context

This literature review and synthesis, has been undertaken as part of the Community Rehabilitation Workforce (CRW) project, funded through the Commonwealth Pathways Home Programme. The aim of the CRW project is to optimise the capability of the current and future workforce to develop, implement and evaluate community rehabilitation (CR) programmes to meet the current and emerging health needs of the Queensland community.

The purpose of this review is to inform community rehabilitation workforce and service development, to best meet the needs of stroke survivors. Whilst the needs identified may have relevance for service provision to all stroke survivors, the literature review was undertaken with particular emphasis upon the needs of stroke survivors over 65 years of age.

Community rehabilitation needs (short and long term) as described in the literature

Studies that have followed up people with stroke at varying times post stroke indicate that some people continue to make functional gains following interventions, months (Koch, Widen-Holmqvist, Kostulas, Almazan, & Pedro-Cuesta, 2000) and years (Fjaerstoft, Indredavik, Johnsen, & Lydersen, 2004; Hanger, Walker, Paterson, McBride, & Sainsbury, 1998; Koch, Pedro-Cuesta, Kostulas, Almazan, & Holmqvist, 2001; Tangeman, Banaitis, & Williams, 1990; Thorsen, Holmqvist, Pedro-Cuesta, & von Koch, 2005) post stroke, across a range of functional abilities. This suggests a need for extended and/or sporadic rehabilitation services at various time points post stroke. Where gains have been made as a result of rehabilitation interventions this may not always be sustained if the focus of the intervention has not been on achieving re-integration into society with failure to consider and intervene at an environmental level (Lincoln, Gladman, Berman, Noad, & Challen, 2000). This requires rehabilitation to take place outside hospital settings, in the community.

A UK study looking at the needs of a group of 93 people one month after stroke onset who had not been admitted to hospital indicated that they experienced significant deficits. These included problems with personal ADL, extended ADL including shopping, household and leisure activities, advanced mobility such as walking outdoors, car transfers and stairs, and with cognitive impairment common to most participants. High levels of strain were reported in 15% of carers and aphasia in 18% of participants. This indicated considerable community rehabilitation needs amongst the cross section of people who were not admitted to hospital (Lincoln, Gladman, Berman, Luther, & Challen, 1998).
A group of patients with moderate to severe stroke were followed up at 3 months, 6 months, 12 months and 5 years post stroke onset (Thorsen, Holmqvist, Pedro-Cuesta, & von Koch, 2005). All patients in the group received initial acute stroke unit management and further rehabilitation, with half receiving services conventionally available in Stockholm and half receiving an individualised home rehabilitation program from an outreach team. Both groups reported being most affected in the domains of ambulation, household management and recreation with approximately 60% of the patients followed up at 5 years having fallen in the past 6 months (Thorsen, Holmqvist, Pedro-Cuesta, & von Koch, 2005). The frequency of social activities according to the Frenchay Activities Index (FAI) decreased after stroke when assessed at 3, 6 and 12 months post stroke (Holmqvist et al., 1998; Koch, Pedro-Cuesta, Kostulas, Almazan, & Holmqvist, 2001).

An Australian study which conducted semi-structured interviews with 10 people with stroke at point of discharge from outpatient, day hospital rehabilitation and at six months post discharge from day hospital indicated that their reported needs included the opportunity to practice activities that would improve their physical capabilities as physical limitations affected their motivation, morale and sense of self (Henderson, Milburn, & Everingham, 1998). Furthermore, after discharge participants indicated the need to participate in enjoyable activities they pursued prior to their stroke or to discover new activities to overcome physical and social isolation, however at 6 months felt their needs were being met either by support from family, involvement from community agencies or a change in how they performed certain tasks (Henderson, Milburn, & Everingham, 1998).

At six months post discharge from hospital, in a Canadian study, it was shown that health related QOL of a group of patients with stroke was lower than the overall population, most markedly in the areas of physical functioning, vitality and social functioning. Between discharge from hospital to 6 months follow up, statistically significant declines in the domains of emotional roles, mental health, social functioning, pain and general health perceptions were identified, whereas the domains of physical roles improved from discharge (Bagg, 2002). Participants reported that they would like to have the option of participating in groups for exercise either at hospital, gyms or health clubs and they noted the importance of having realistic expectations and information on the potential for mood disorders and depression after stroke (Bagg, 2002). Caregivers indicated they needed more information at discharge, funding for special needs, additional therapy for their relative and the need to access qualified help including support groups and access to exercise and social options in the community (Bagg, 2002).

A study of rehabilitation needs in Sweden using semi-structured interviews and formal assessment of function of people two years post stroke indicated that the most common neurological symptoms remained sensory problems, visual problems, hemianopia, dysarthria or aphasia and facial palsy (Nilsson, A., & Grimby, 2000). Dependence with ADLs had increased at two year follow-up compared to discharge from hospital in dressing, bathing, grooming and greater degrees of dependence were seen in instrumental activities such as large scale shopping, cleaning, washing, public transport, cooking and social interaction compared to self care items (Nilsson, A., & Grimby, 2000). Similar declines were seen from hospital discharge to follow-up at 6
months in the areas of health related quality of life of a group of 85 patients with stroke in Ontario, Canada (Bagg, 2002). More than 50% of the group were dissatisfied with the life domains of self care, work, leisure time, economic situation and social relationships, with persons living alone being more dissatisfied and distressed (Nilsson, A., & Grimby, 2000). A study further reinforcing the need of community interventions to focus on social participation, looked at younger people with stroke (aged 65 or below) and found that those people with stroke who were unable to return to work reported more unmet needs than those who had returned to some form of work, further reinforcing the need to assist people with stroke to participate in community activities whether that be employment or other social activity (Kersten, Low, Ashburn, George, & McLellan, 2002). Neimi and colleagues followed up a group of people with stroke over a four year period and found leisure activities and family relationships to be severely affected (Niemi, Laaksonen, Kotila, & Waltimo, 1988).

A study following up a group of 106 patients in London who were four to five years post stroke found that 1/3 of the sample were functionally independent, 1/3 mildly disabled and 1/3 moderately-severely disabled according to the Barthel index (Wilkinson, Wolfe, Warburton, Howard, & Ross-Russell, 1997) with very few of those moderately-severely disabled participating in activities. Activities people needed help with most often were bathing, climbing stairs, dressing and feeding. The majority of people living in private accommodations, needing help, were receiving the help from an identified caregiver (Wilkinson, Wolfe, Warburton, Howard, & Ross-Russell, 1997). According to the Hospital Anxiety and Depression scale, 23% had scores indicating depression and 19% indicating anxiety (Wilkinson, Wolfe, Warburton, Howard, & Ross-Russell, 1997).

Jorgenson et al. (2005) found urinary incontinence to be present in 17% of their sample of 213 people with stroke and this was more prevalent compared to the overall population and was found to be associated with depression, impaired cognition and lower limb weakness. Urinary incontinence has been shown to have considerable impact on quality of life (Brittain, Perry, & Peet, 2000).

The presence of a range of functional difficulties and self reported dissatisfaction with QOL and participation indicates a need for systematic follow up of patients with stroke not only in the subacute phase but years after stroke. Talbot et al. (Talbot et al., 2004) in exploring needs of people with stroke and their carers in the community indicated that health care workers should be available by telephone to counsel caregivers with intermittent follow up of the patient and specifically the caregiver to assist them to support the relative in their rehabilitation.

**Key clinical messages**

- Stroke survivors may experience significant changes (both positive and negative) in function for an extended period after hospital discharge.
- Interventions made in hospital may not always translate to functional gains when clients return to the community.
- Ambulation, household management and recreation/social activities should be key areas of community rehabilitation intervention.
Falls are common post stroke and risk management strategies should be implemented.

Those clients who are not hospitalised for rehabilitation may have significant rehabilitation needs concerning community functioning.

Attention to QOL and management of mood disorders is vital.

Carers have support needs which should be addressed through community rehabilitation.

Opportunity for social participation is essential for stroke survivors and access to work particularly so for younger stroke survivors.

Management of urinary incontinence is needed by a significant proportion of stroke survivors.

Extended community follow-up for stroke survivors and there carers is recommended as well as clear avenues for them to seek information and support at times of need.

References


follow-up of patient outcome, resource use and cost. Cerebrovascular Diseases, 12(131-138).


