

Community-based or home-based stroke rehabilitation: confusion or common sense?

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ABSTRACT

With the recent emphasis on primary health care in New Zealand, it is conceivable that the rehabilitation of people with stroke will become progressively more community-based, with less time spent on in-patient rehabilitation. With this in mind, this paper reviews current literature on stroke rehabilitation in the community and debates the issue as to whether it is truly community-based or just merely an extension of institutionalised care.

Although there is evidence that stroke rehabilitation in the community significantly improves personal and extended activities of daily living, and does not result in functional deterioration, there is some indication that this model of service delivery may result in greater carer stress. Few studies detail the content of the actual interventions used in the rehabilitation programmes, a situation, not only unhelpful for therapists, but one which makes the designing of future trials difficult. Furthermore stroke rehabilitation in the community is frequently termed "home"- or "domiciliary"-based, and does not strictly represent community-based rehabilitation as defined by the World Health Organisation. It is suggested that community-based programmes may result in different outcomes to home-or domiciliary-based programmes. **Hale L (2004). Community-based or home-based stroke rehabilitation: confusion or common sense. New Zealand Journal of Physiotherapy 32(3) 131-139.**

INTRODUCTION

Stroke results in a substantial rehabilitation problem for New Zealand (NZ) (Weir, 1999), where approximately 7000 people have a stroke each year (Bonita et al, 1997; Tobias et al, 2002; Gommans et al, 2003). In 2001 an estimated 32,000 people survived a stroke in NZ, an incidence that is expected to increase (Tobias et al, 2002). The total costs of people hospitalised with stroke (n=6000) in NZ in 2002 was NZ\$138m (Bonita et al, 1993; Bonita et al 1997), while the average lifetime healthcare costs for each stroke is NZ\$100,000 (NZ Guidelines Group 2004). Local NZ studies indicate that at 6 months post-stroke, 80% of stroke survivors will be living at home, 83% of whom will have a less than optimal recovery, requiring further rehabilitation input (Bonita et al, 1993; Bonita et al, 1997; Weir 1999). Despite the obvious need for sufficient, co-ordinated and effective stroke rehabilitation services, papers recently published in the New Zealand Medical Journal suggest that present rehabilitation services are less than optimal (Baskett, 2003; Gommans et al, 2003; Wilkinson and Sainsbury 2003). In spite of the overwhelming positive evidence for the care of people with stroke in a stroke unit, where services are rendered in a co-ordinated, organised fashion (Stroke Unit Trialists' Collaboration 1997), there is only one such unit in NZ (Wilkinson and Sainsbury 2003).

Presently, although the exact system differs across each health board, people with stroke in New Zealand are primarily rehabilitated as in-patients (though not usually in a stroke unit), and are discharged home once it is felt that the person and their primary caregivers can cope with an appropriate care package of carers and equipment (Hale and Piggot, 2004). At this point, in many areas the community-based rehabilitation services become involved.

In 1999 a NZ Health Technology Assessment Report (Weir 1999) critically analysed literature investigating a system of stroke rehabilitation in which people with stroke are discharged home as soon as realistically possible and are then supported at home by an interdisciplinary team. This report recommended that there was insufficient evidence to change the current management practices of stroke in NZ, a system focussed on in-patient rehabilitation.

However, with the release of the NZ Health Strategy (2000), which targeted Primary Health Care in its list of key objectives, community-based initiatives are becoming increasingly important and it is suggested that stroke rehabilitation may progressively be shifted more, and at an earlier stage, into the community. This shift in service delivery to a community-based model may challenge physiotherapists, especially those new to the field, as literature on community-based stroke rehabilitation is confusing and interventions and services are not well described.

This paper reviews relevant literature on stroke rehabilitation in the community with the aim of summarising current practice and the evidence-base for this form of service delivery, and debates whether it falls within the framework of community-based rehabilitation as described by the World Health Organisation.

Community-Based Rehabilitation

It is pertinent at this point to explore what is meant by the terms primary health care (PHC) and community-based rehabilitation before applying these concepts to the care of people following stroke.

In 1978 an international conference held in Alma Ata, Russia, on PHC (sponsored by the World Health Organisation (WHO) and the United Nations Children Education Fund) defined PHC as being "essential health care made universally accessible to individuals and families in the community by means acceptable to them, through their full participation and at a cost that the community and the country can afford. It forms an integral part both of the country's health system of which it is the nucleus and of the overall social and economic development of the community" (WHO 1978). Taken simply PHC means first contact health care (Bowerbank 1994). The Alma Ata declaration however views PHC as a more embracing philosophy of care embedded in which are five governing principles: equity, community involvement, focus on prevention, use of appropriate technology and a multi-sectorial approach (WHO 1987). From the WHO's vision of "Health for all by 2000" there merged the rehabilitation counterpart to PHC, that of Community-Based Rehabilitation (CBR) (WHO 1976; WHO 1979; Mitchell 1999a).

For many people, taking the term literally, CBR probably means rehabilitation within the context of the community as opposed to an institutionalised clinical setting. The idiom however has a much wider connotation. In 1994 the WHO published a definition of CBR in a joint paper along with the International Labour Organisation (ILO) and the United Nations Educational, Scientific and Cultural Organisation (UNESCO) stating that "community-based rehabilitation is a strategy within community development for the rehabilitation, equalization of opportunities and social integration of all people with disabilities. CBR is implemented through the combined efforts of disabled people themselves, their families and communities, and the appropriate health, education, vocation and social services" (ILO, UNESCO and WHO 1994).

Key to the implementation of CBR, as envisaged by the WHO, are the concepts of empowerment and inclusion (Mitchell 1999b; Kendall et al, 2000), in which the locus of control is within the community, and the disabled person, their family and their community decide on what the

priorities of the service should be (Stubbs 2004). In many ways, this model of service delivery has taken rehabilitation care a full circle back to that of a traditional model (Stricklin 1997), a model of care based on the importance of the group or community, as opposed to that of the individual (Loveland 1999).

In the past decade a number of studies investigating CBR in the context of stroke rehabilitation have been published, and it is probably timely to reflect on whether the principles of CBR, as envisaged by the WHO, have been embraced into stroke rehabilitation, or whether the concept of CBR has been used, as in other areas of rehabilitation, as rhetoric resulting in a "masterpiece of disinformation" (Gregory 2001, p.25).

Stroke rehabilitation based in the community

For many years now, the consummate evidence for care for people following stroke has been the dedicated stroke unit (Stroke Unit Trialists' Collaboration 1997). The evidence for this, provided by randomised controlled trials, is substantiated by that acquired from qualitative research (Lewinter and Mikkelsen 1995; Pound et al, 1995). Patient perspectives of in-patient rehabilitation are positive; the expertise, support and reassurance provided in hospital are psychosocial aspects that patients value (Lewinter and Mikkelsen 1995; Pound et al, 1995). Cant (1997) recounted his personal experiences following stroke, and wrote positively on the subject of institutionalised rehabilitation, enjoying the safety and predictability of the clinical environment. There comes a point, however when: "*there is nowhere like your own home, with your family (and the family dog!), and despite everyone's best efforts at providing the care needed, you still feel like a 'commodity' to be handled*" (Cant 1997, p 299).

In the early 1990s stroke outcome studies identified the long-term nature of recovery from stroke and this resulted in a revival of interest in home-based stroke rehabilitation (Forster and Young 1990; Young 1994). The realistic advantage of home-based stroke rehabilitation is financial as a result of the decreased length of hospital stay for rehabilitation (Rodgers et al, 1997; Rudd et al, 1997; Enerby and Wade 2001). In addition, reducing hospital stay potentially prevents the secondary complications of prolonged institutionalisation, particularly that of dependency (Mayo et al, 2000). Proponents of home-based rehabilitation argue that this type of service delivery empowers the patient and the family to set the goals of rehabilitation within the context of their own home environment, that it is a more accessible service for patients, it results in the inclusion of carers and in the development of local links (Rodgers et al, 1997; Rudd et al, 1997; von Koch et al, 1998; Enerby and Wade

Table 1. Outcome measures used in studies investigating the effects of home-based stroke rehabilitation

| Construct | Outcome measures used |
|----------------------------------|---|
| Impairment due to stroke | Scandinavian stroke scale, Toronto stroke scale |
| Speech | Sheffield Screening test for Acquired Language Disorders, Reinvang Aphasia test, Frenchay aphasia screening test |
| Perception | Minimental State Examination, Rey figure copy and recall, Behavioural Inattention test, star cancellation subtest, Adult, Memory and Information Processing Battery, story recall and half hour delay |
| Functional ability | Motor club Assessment, Rivermead Motor Assessment, Lindmark Motor Capacity Assessment, Nine-Hole Peg test, 10-meter walk test, Timed Up and Go, number of falls |
| Activities of Daily Living (ADL) | Barthel Index, Extended ADL, Katz ADL Index, Extended Katz ADL Index, Nottingham Extended ADL Scale, Older Americans Resource Scale for Instrumental ADL, Rivermead ADL Scale, modified Rankin Scale, Adelaide Activities Profile |
| Participation | London Handicap Scale, Oxford Handicap Scale, Reintegration into Normal Living, frequency of lifestyle activities, Frenchay Activities Index |
| Depression | Hospital Anxiety and Depression Scale, SF-36 Mental Health component, Montgomery Aasberg Depression Rating Scale, Wakefield Depression inventory, Beck's Depression Inventory |
| Perceived Health | Nottingham health profile, Sickness Impact Profile, Dartmouth Coop Function Charts, Measuring Outcomes Study Short-Form-36, EuroquoI |
| Carer and Family | Patient and carer satisfaction, General Health Questionnaire, Carer Strain Index, McMaster Family assessment of recovery, Care subjective health status (GHQ 30) |
| General | Placement, length of stay, morbidity, readmission rates, mortality, financial |

(Young and Forster, 1992; Rodgers et al, 1997; Rudd et al, 1997; Indredavik et al, 2000; Lincoln et al, 2000; Mayo et al, 2000; von Koch, 2000; Bautz-Holter et al 2002; Cochrane Library, 2003a)

2001). Mayo et al, (2000) argue that if the ultimate goal of rehabilitation is reintegration back into the community, then the sooner a person is discharged home the more likely reintegration will be achieved (Mayo et al, 2000).

The disadvantages of home-based stroke rehabilitation include inadequate resources, professional isolation, the physical restrictions and distractions imposed on interventions by the home environment, a high therapist to patient ratio, expensive transportation costs (in terms of time and maintenance), and potential safety issues for the therapist (Forster and Young 1990; Hale and Wallner 1996; Seymour and Kerr 1996; Enerby and Wade 2001; McMillan and Ledder 2001).

Types of stroke rehabilitation services provided in the community

Geddes and Chamberlain (2001) categorised community-based stroke rehabilitation services in the United Kingdom as follows: (1) Early-discharge supported rehabilitation in which patients were discharged home early from hospital and received most of their rehabilitation at home; (2) Post-discharge rehabilitation, additional community-based rehabilitation following a period of in-patient rehabilitation; (3) Community-based rehabilitation provided when the patient is not admitted into hospital at all;

(4) Late community rehabilitation that is provided well after the stroke event.

Of the four types of community-based rehabilitation, early-discharge support rehabilitation has enjoyed the most scrutiny, but the evidence for it remains inconclusive (Cochrane Library 2003a). A review of all types of home-based stroke rehabilitation however, concluded that home-based stroke rehabilitation per se appears to improve independence in personal activities and extended daily living activities, and minimises the chances of deterioration or death. (Cochrane Library 2003b).

Early discharge supported stroke rehabilitation

A model of stroke rehabilitation in which patients are discharged from hospital to home soon after stroke and supported at home by an interdisciplinary team has been investigated by a number of studies (Cochrane Library 2003a). Early discharge supported stroke rehabilitation is an extension of the principles of the stroke unit, where organisation and co-ordination of stroke services have been shown to be effective (Rodgers et al, 1997; Rudd et al, 1997; Indredavik et al, 2000; Mayo et al, 2000; Bautz-Holter et al, 2002; Donnelly et al, 2004). Randomised controlled studies conclude that early supported discharge is a feasible option

which does not result in functional deterioration and furthermore appears to be a cheaper alternative to inpatient rehabilitation (Rodgers et al, 1997; Rudd et al, 1997; McNamee et al, 1998; Widén-Holmqvist et al, 1998; Anderson et al, 2000; Indredavik et al, 2000; Mayo et al, 2000; von Koch et al, 2000; Bautz-Holter et al, 2002; Donnelly et al, 2004). Outcomes from these studies have been reported at three months, six months and 12 months (Rodgers et al, 1997; Rudd et al, 1997; Widén Holmqvist et al, 1998; Anderson et al, 2000; Indredavik et al, 2000; Mayo et al, 2000; von Koch et al, 2000; Bautz-Holter et al, 2002; Donnelly et al, 2004; Fjaertoft et al, 2004). Despite these favourable results, the evidence for early supported discharge is not conclusive as most studies have had small sample sizes of 100 or less participants (Rodgers et al, 1997; Widén-Holmqvist et al, 1998; Anderson et al, 2000; Mayo et al, 2000; Bautz-Holter et al, 2002; Donnelly et al, 2004), with only two studies having sample sizes of over 300 participants (Rudd et al, 1997; Indredavik et al, 2000). Some authors have argued that for a randomised trial to truly provide substantial evidence for this form of service delivery, samples sizes of 260 – 550 participants are required (Rodgers et al, 1997; Wolfe et al, 1998).

A Cochrane systematic review of the early discharge support model concluded that although there is a reduction in length of hospital stay the relative risks and benefits of this type of services remain unclear (Cochrane Library 2003a). Outcomes on a number of ongoing studies are still awaited (Cochrane Library 2003a).

Home-based stroke rehabilitation versus day hospital rehabilitation

Two trials in the United Kingdom have compared home-based stroke rehabilitation to rehabilitation in a day hospital following discharge from hospital (Young and Forster 1992; Gladman et al, 1994). The combined results of these two trials indicated that home-based therapy resulted in a small but significant improvement in Barthel Index scores at six month post discharge ($p < 0.05$), and the authors suggested that a community-based therapy service should aim to deliver 15-20 visits per patient, because less than this had no supporting evidence (Gladman et al, 1995).

Community-based rehabilitation for people not admitted to hospital after stroke

Two small studies demonstrated the feasibility of providing a community-based rehabilitation service for people who are not admitted to hospital following stroke, but failed to demonstrate the efficacy of such a programme (Wade et al, 1985; Wolfe et al, 2000). One study however was a pilot programme with small numbers ($n=43$) (Wolfe

et al, 2000) and the other study's intervention and control groups were not randomised (Wade et al, 1985). Occupational therapy was found in a randomised controlled trial, to significantly reduce disability and enhance participation in people ($n=185$) not admitted to hospital following stroke (Walker et al, 1999).

Content of stroke rehabilitation services based in the community

Stroke rehabilitation, no matter the setting, is complex as a number of factors such as individual patient needs and goals, cultural aspects, the ethos of the service, constraints on therapists, and the interests and expertise of therapists often complicate issues (Ballinger et al, 1999). The complex nature of stroke rehabilitation is probably the reason why most studies investigating community-based stroke rehabilitation fail to detail the content, frequency or intensity of rehabilitation provided. At best, the service itself is described (Young and Forster 1992; Gladman et al, 1994; Rodgers et al, 1997; Rudd et al, 1997; Indredavik et al, 2000; Mayo et al, 2000; Bautz-Holter et al, 2002; Cochrane Library 2003b).

Rodgers et al, (1997) described a service in which the stroke discharge team established a relationship with the patients, carers and the inpatient rehabilitation staff prior to discharge. A member of the team, prior to the patient being discharged home, carried out home visits and discussions with families and carers. On the day of discharge a member of the team brought the patient home and provided support and advice. The team continued to be available for patients until the patients and their families felt that they could take over responsibility for their own rehabilitation (Bautz-Holter et al, 2002). A similar supportive process was described by Indredavik et al, (2000) in which the extended stroke unit service co-ordinated the transition of patients from the stroke unit into the home and continued the home support service for as long as necessary. Mayo et al, (2000) described a service that was patient dependent and services were provided on a "as required" basis.

Widén-Holmqvist et al, (1998) broadly described an early supported home rehabilitation programme for people moderately disabled by stroke as being management based on a task-orientated approach emphasising prevention of learnt-disuse, education and individual counselling. The patients performed guided, supervised self-directed activities in a functional and familiar context. Activities were based on the patients' interests and, where possible, spouses were involved. Individual counselling provided information and problem solving skills. Later von Koch et al, (2000) further described early supported home rehabilitation providing greater detail based on both qualitative and quantitative

data collected from 41 participants. The average duration of the programme was 14 weeks with a mean of 12 visits. The process by which practice decisions were made was described as a partnership, with the therapist carefully listening to the needs and desires expressed by the patient. The actual interventions themselves were not described in any detail.

Most studies investigating early discharge stroke rehabilitation describe an interdisciplinary or multidisciplinary approach where physiotherapists, occupational therapists and speech and language therapists usually provide rehabilitation. Medical input, social workers, nurses and dieticians have also been included. Gilbertson et al, (2000) reported that a six-week programme of domiciliary occupational therapy for people newly discharged from hospital following stroke resulted in significant short-term improvements. Again the content of the programme was not detailed, but it was developed in consultation, using focus groups, with patients, carers and occupational therapists.

Two studies have investigated specifically designed community-based stroke rehabilitation programmes. Duncan et al, (1998), in a randomised pilot study, detailed a home-based exercise programme designed for individuals with mild to moderate stroke. Patients were seen three-times-a-week for eight-weeks and received a physiotherapist-supervised programme aimed at maintaining or improving balance, strength, endurance, and encouraging use of the affected extremity. In another home-based practice model, designed to improve gait in people with chronic stroke, interventions were not explicitly described but it was stated that they were aimed at normalising passive range of motion, and improvement in standing balance and weight shift. Isolated muscle recruitment was encouraged, using surface electromyography and mirrors for feedback (Rodriguez et al, 1996). Although gait and fear of falling improved, the study was an uncontrolled case series and utilised a newly designed scale to measure gait function, the Wisconsin Gait Scale.

Measuring Outcome of stroke rehabilitation services based in the community

A number of outcome measures that cover the spectrum of the ICF (WHO, 2001) have been used to investigate the effect of home-based stroke rehabilitation, in particular that of the early supported discharge model as can be seen in Table 1. In spite of the range of outcome measures used, it is difficult to see how these standardised, "one-fit" designed measures could conceivably measure something as complex and individualistic as stroke rehabilitation within the community-based setting (Pound and Gompertz 1998; Stilwell et al, 1998; von Koch et al, 1998; Ballinger et al, 1999).

Stilwell et al, (1998) developed an outcome measure to evaluate community-based rehabilitation services for people with traumatic brain injury (the Community Outcome Scale) that potentially offers a more individualised approach to the assessment of mobility, occupational, social integration and engagement, and is still in the process of further validation. Similarly, Trigg and Wood (2000) have developed a short questionnaire, which demonstrated promising psychometric properties, to measure physical and social integration following stroke, which may be a suitable measure of community-based rehabilitation. Patient satisfaction is another construct people have measured to evaluate stroke rehabilitation services (Pound et al, 1999).

In a recent qualitative study, physiotherapists working in community-based stroke rehabilitation discussed how they measured the effectiveness of their work (Hale and Piggot 2004). Whilst they all reported using standardised outcome measures, participants spoke of the achievement of patient-centred goals being pivotal to the evaluation of successful rehabilitation. Individualised goals were carefully set with patients, but no systems of quantifying the achievement of goals were described. One method of potentially formalising patient-centred goals would be to use Goal Attainment Scale (GAS) theory (Kiresuk and Sherman 1968; Malec et al, 1991; Reid and Chesson 1998; Gordon et al, 1999). This method allows for both the individualisation of goals and the quantification of summary outcomes, and has been used successfully in traumatic brain injury (Malec et al, 1991), elderly care (Gordon et al, 1999) and inpatient stroke rehabilitation (Reid and Chesson 1998), and is presently being investigated by the author in the context of community-based stroke rehabilitation.

Two qualitative studies have identified the need for patient-centred goals to guide and measure rehabilitation within the home-based setting (Pound and Gompertz 1998; von Koch et al, 1998), a function that standardised outcome measures, by virtue of their collective nature, would not easily achieve. von Koch et al, (1998) observed stroke rehabilitation interventions with the same patient both in the home and in the inpatient setting. The patient, during home therapy sessions took greater initiative in verbalising his/her needs and requirements, and in guiding their own rehabilitation goals, than when they were in the inpatient setting. von Koch et al, (1998) concluded that the home environment enabled the patient to take more ownership of their rehabilitation goals.

Patients perspective of stroke rehabilitation based in the community

In a review of home-based rehabilitation and care Tamm (1999) debates the issue as to whether the home is the best place for rehabilitation. Although people frequently express the desire to be at home

rather than in institutionalised care, the home is a person's personal refuge, their private sanctuary, and to have it invaded by medical personal and equipment may convert the home into a sterile clinical setting.

In two undergraduate physiotherapy student qualitative projects located in two NZ cities, people with stroke were interviewed as to their preference of location for rehabilitation, the home or the outpatient setting. A strong theme emerged from these studies of the appreciation of the social contact and motivation that is derived from the interaction of people within the out-patient setting: "I like to get out of the house" ... "this is the only place I go". Participants spoke of the isolation and the feelings of being "house-bound" if they were only to receive rehabilitation within the home. One participant stated: "I enjoyed going to the hospital because of the facilities and I feel more focused because I am using the facilities. But at home I am not feeling as focused cos this is my home" (Yeoman et al, 2002; Hale et al, 2003).

Furthermore, patients have reported in a number of studies that the transition stage from hospital to home is difficult and to be a likely cause of increased patient depression. Poor streamlining of services from the in-patient to the home-based setting contributed to these difficulties. Patients appeared uncertain of what they could expect from rehabilitation (Forster and Young, 1990; Pound and Gompertz, 1998; Baskett et al, 1999; Sabari et al, 2000; Wiles et al, 2002; Hale et al, 2003).

Caregivers perspective of stroke rehabilitation based in the community

The potential strain of home-based rehabilitation on caregivers has been suggested by a few studies (Anderson et al, 2000; Widén-Holmqvist et al, 2000; Hale and Piggot 2004). In a randomised controlled trial of home versus hospital stroke rehabilitation, at six months post-randomisation caregivers of the home-based group had significantly lower ($p=0.01$) mental health scores as measured by the SF-36 than caregivers of the hospital-based group. There were, however no differences in Caregiver Strain Index scores between the two groups (Anderson et al, 2000). In contrast, a Swedish study found no significant differences in subjective health-related quality of life (as measured by the Sickness Impact Profile) between spouses of an early discharge group to that of a hospital rehabilitation group six months after randomisation into the study (Widén-Holmqvist et al, 2000).

In a qualitative study (Hale and Piggot 2004) in which physiotherapists working in home-based stroke rehabilitation were interviewed, participants cautioned against involving family members too much in the rehabilitation process: "It is very demanding on the husband or wife to turn them into a therapist, they are already caring, doing

usually a lot more for their partner, and so they are often under stress."

DISCUSSION

Considering published information, home-based stroke rehabilitation certainly sounds attractive. Enabling patients to cope with the restrictions imposed on them in the actual places where they live and play sounds like common sense prevailing. There even appears to be concrete evidence, albeit slight, that home-based stroke rehabilitation results in improved personal and extended activities of daily living and does not result in functional deterioration. In addition it is also reported to be less costly than inpatient rehabilitation. Further reflection of the literature, however brings to mind a number of questions:

1. Studies investigating home-based stroke rehabilitation seldom report on the exact community location of participants (whether urban or rural or both) or on other aspects of the cultural make-up of the sample population. Do these factors influence the delivery and outcome of home-based therapy?
2. Nor do these studies describe the actual interventions conducted by therapists, resulting in the inability to replicate studies or improve on interventions to attain more favourable outcomes. Were optimal rehabilitation interventions applied? What are optimal interventions within the home setting?
3. Whilst it is acknowledged that health care is expensive and steps should be taken to reduce costs, does a home-based model reduce the costs of rehabilitation for all involved or just for the health provider? It is conceivable that the costs are simply transferred from the provider to the patients and their families, including the potential loss of income for the family member primarily concerned with the patient's care.
4. Does the early discharge home model result in prolonged or transient increased stress for carers and families? Has anyone qualitatively investigated community-based rehabilitation from the caregivers'/families' perspective?
5. Which location for rehabilitation do people with stroke actually prefer? Has anyone asked them? Small qualitative studies indicate that people with stroke may prefer to attend an institutionalised rehabilitation setting, preferring the social and "rehabilitation" atmosphere, to social isolation and "home invasion" by the members of the interdisciplinary rehabilitation team.
6. Although numerous outcomes measures have been used to gauge the success of home-based stroke rehabilitation are these outcome measures valid in the home-based setting and do they reflect the individualistic, complex nature of home-based stroke rehabilitation?

And then the crucial question, does community-based rehabilitation, as it is presented in the

literature reviewed, fulfil the principles envisaged by the WHO? Here, things become interesting. Although Geddes and Chamberlain (2001) describe four types of co-ordinated “community-based rehabilitation” for people with stroke, the papers reporting on these service models refer to therapy as being “home”- or “domiciliary”-based. I propose that the different wordings are a subtle play on words, in that “home or domiciliary” are not equivalent to “community”. The words “community-based rehabilitation” conjures up the WHO definition and the principles of inclusion and empowerment, whereas “home-based” or “domiciliary-based” are purely what they mean: services delivered in the home environment. In the literature reviewed on studies investigating “home-based” rehabilitation it would appear that these rehabilitation services have been driven by the health providers with little consultation or inclusion of the community in decision-making regarding the preferred service and its implementation. The power remains within the health service provider, dictating what service will be implemented. True, many of the studies do say that interventions are decided upon in consultation with patients and caregivers as to their needs and requirements, but not for the actual type of service. In addition, the existing “evidence” or lack thereof, for home-based rehabilitation is embedded in the “randomised controlled trial” paradigm, a method of evaluation which may be considered paradoxical were it actually measuring the success of “community-based” stroke rehabilitation (Sharma 2004).

On closer examination of the literature there were no studies that truly investigated “community-based” stroke rehabilitation. One could argue that community-based rehabilitation was a strategy developed by the WHO to enable people with disabilities in developing countries (Leavitt 1999), and thus is not relevant to more developed countries such as NZ. However, the concepts of CBR are relevant to both developing and developed countries as it allows disabled people to participate in decision-making regarding their own rehabilitation and participation in society (Leavitt 1999; Mitchell 1999a).

I wonder whether true community-based stroke rehabilitation would have a greater impact on outcome than home-based stroke rehabilitation has. Active partnerships of people with stroke, their advocates and service providers may result in greater “buy-in” into a mutually agreeable appropriate service, with all stakeholders having a better understanding of the advantages and disadvantages of the service provided. Alternative methods to measure relevant outcome may then be developed in consultation with all stakeholders. As Chatterjee (2001,p31) points out, just because a service is community-based, it does not necessarily mean it is “community-driven”.

Key Points

- Stroke rehabilitation based in the community significantly improves personal and extended activities of daily living, but may result in increased caregiver stress.
- The contents of published home-based stroke rehabilitation programmes are not well described.
- Stroke rehabilitation in the community is frequently termed “home”- or “domiciliary”-based, and does not strictly represent community-based rehabilitation as defined by the World Health Organisation.
- Community-based rehabilitations programmes, developed in consultation with all stakeholders, may result in better outcomes than the home-based programmes described in the literature.

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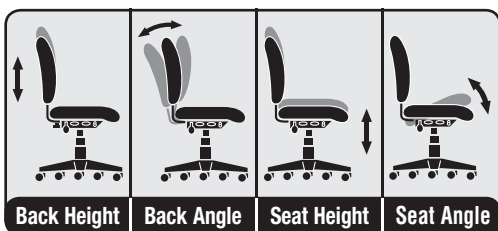
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