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Arm recovery: Time to empower people with stroke
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Arm recovery: Time to empower people with stroke

Paulette van Vliet, Valerie Pomeroy, Steve Wolf, Gert Kwakkel

Recently at a local hardware store an elderly employee responded to my request (first author) for help to retrieve something from a high shelf. He attempted the task with great enthusiasm, but with much difficulty. His stroke several years before had left him with a partially functioning arm. We talked. His saga was an all too common story of a stroke survivor with great potential which had not been achieved, through a lack of practice and guidance.

Approximately 60% of stroke survivors with severe impairment and 30% of those with mild to moderate impairment have one arm that remains non-functional 6 months after stroke.¹ Advances in neurorehabilitation and even greater intensity of current therapy promise further improvement in arm function but improvement is limited by the availability of therapy for people after stroke. This problem is global. For example, the UK Stroke Sentinel 2014 audit shows only 31% of persons with stroke receive the target of 45 minutes of physical therapy 5 days/week during their inpatient stay, and only 24 to 40% of people receive input from a community-based therapy team after discharge. In Australia, 78% people with stroke discharged to the home receive community rehabilitation.² There is little publicly available information on how many visits people receive from community teams or for how long. In the Netherlands, people receive an average of 9 treatment sessions of 20 to 30 minutes each in their own community and in the United States, outpatient therapy following stroke is guided by the reimbursement policies of the insurer and could range from no treatment to several months of treatment.

Stroke care is already expensive, so the provision of community rehabilitation is not likely to increase. Direct health care costs for stroke are an estimated 2.14 billion dollars annually in Australia,³ 2.8 billion pounds in the UK,⁴ 1.6 billion euro in the Netherlands⁵ and 28 billion dollars in The USA.⁶ The UK National Stroke Audit attributed the majority of these costs to rehabilitation and life after stroke.⁴ One way forward is to make more efficient use of existing resources. This could be accomplished in several ways. During inpatient care, therapist assistants and carers could be utilized to increase the amount of time available for supervised upper limb practice. In the community sector, people could be encouraged to make greater use of community exercise facilities, and exercise services provided by voluntary groups such as stroke support groups. However, health services will probably never have the capacity to ensure that maximum arm function is achieved for everyone with stroke. Consequently, many people will ultimately be responsible for their own arm recovery after stroke.

If stroke survivors are to be responsible for directing their own recovery, then it will be important to provide the training and support needed to empower people to take a more active role in the ongoing process of rehabilitation. To achieve this goal people need high

1 self-efficacy,⁷ which is defined as “people's beliefs about their capabilities to produce
2 designated levels of performance that exercise influence over events that affect their
3 lives”.⁸ Where possible, this behavior can be encouraged from the start of the person’s
4 recovery process. Means of encouraging self-efficacy include joint goal setting, using self-
5 managed workbooks and diaries to record goals and chosen exercises,⁷ allowing control
6 over the rehabilitation timetable, group training sessions⁹ and allowing extensive self-
7 administered practice in hospital, to prepare for independent practice later at home. To
8 practice safely, therapists can assist by ensuring people are aware of movements that may
9 be unsafe, and providing equipment or furniture for safe practice of exercises. For practice
10 to be effective, therapists can help people to acquire important knowledge about their
11 rehabilitation, such as the need for intensive repetitive practice to achieve neuroplasticity
12 for motor learning,¹⁰ what and how and they need to practice, compensatory movements to
13 avoid, and adverse effects of not exercising. Acquiring a good internal representation of
14 correct movement performance is necessary to learn a motor skill. Therapists can assist this
15 by clearly communicating the movement to be trained, but also allowing movement errors
16 and self-correction of these errors during training and teaching error-correction strategies.¹¹
17 In these ways, supported self-management is emphasised and people gradually move to the
18 point at which they have sufficient confidence for self-administered therapy. At least one
19 current clinical trial (FAST INDICATE) is using therapist-directed self-administered therapy to
20 deliver higher doses of rehabilitation than is possible in routine clinical practice for people in
21 the first three months after stroke.¹² The feasibility of therapist-directed self-administered
22 therapy will be uncertain until data from FAST INDICATE becomes available. Anecdotally,
23 however, reports of delivery of therapy for up to 1.5 hours a day, 5 days a week for up to 6
24 weeks are favorable.

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36 Empowering people with stroke to manage their own rehabilitation is only the first step.
37 Once the person feels empowered to practice on their own, how will they know what
38 exercises to practice? Right now, the ways that exist to assist people at home to continue
39 upper limb training independently include using the instructions last received from their
40 therapist to make an educated guess about new exercises to progress, exchanging ideas
41 between people at stroke support groups and using rehabilitation programmes available on
42 internet such as the GRASP programme.¹³ Assistive technologies may also be helping such as
43 dynamic orthoses for assistance with hand opening during practice¹⁴ and movement based
44 video game controllers.¹⁵ The uptake of these resources could be improved by giving people
45 more information on how best to use rehabilitation programs and assistive technologies as
46 well as information regarding which approaches may be most suitable based upon the
47 remaining impairment that needs to be addressed. It is advantageous for persons with
48 stroke to be informed about these available resources during the inpatient stay. After
49 discharge, information can be conveyed in a variety of ways including continued education
50 talks at community support groups, and organizing practical group courses that target
51 people with stroke. Social media could be better used to impart knowledge about how to
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achieve maximum function. For example, electronic information leaflets and books, written specifically to target the person with stroke, rather than at therapists, could be more widely available. Monitored internet chat rooms provide an avenue for persons with stroke to exchange information and get advice from experts, and professional organizations or support groups could accumulate information to be shared on designed websites. In fact, one might argue that each subsequent generation of stroke survivors will have acquired the skills for adept electronic communications and will expect the availability of such resources.

For those who enjoy group training, fitness centers can be utilized. However, better and more consistent guidance will be necessary to ensure the practice is safe and problems, such as painful shoulder, are avoided. This effort will require more organized communication between therapists and fitness centres, education of centre staff and provision of information to people with stroke about safe utilisation of fitness equipment.

Lastly, once people know what to practice, and have a means of doing so, how do they stay motivated? One possibility is implementing behavior modification strategies at home that will help sustain motivation and ensure adherence to planned programmes. Behavior modification programs have been effective in changing physical activity behaviors in other groups of persons with health conditions such as those with diabetes.¹⁶ These programmes may include strategies such as an initial visit from a coach to introduce the programme, with joint goal-setting, a booklet about recovery from stroke emphasising potential for 'rewiring' the brain through practice, upper limb training manual,¹⁷ using digital counters to record repetitions and exercise diary, membership of a group with group souvenirs (eg. Group T-shirt), social Media (Facebook/Twitter) to encourage social interaction in the group, weekly communication via phone call or email, and visual reminders in the home (e.g. posters).

At a system level, processes need to be improved within individual health settings for easy access to health services throughout the lifetime that would include periodic treatment/advice when the stroke survivor believes that these resources are warranted.

In conclusion, a paradigm shift is needed, so that training, knowledge and support is provided to empower people to engage in self-administered therapy after stroke. Optimally, this shift is initiated start during the person's hospital stay, and continues throughout the recovery process. Inevitably, the costs to sustain therapies following discharge from hospital may well become so overwhelming as to be compromised, thus creating the untenable possibility of diminished care. This possibility demands that early after stroke, we infuse in our stroke survivors a set of behaviors that instil a strong sense of self-efficacy while promoting continual activity. Such an approach to poststroke care will maximise upper limb recovery.

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