

## Recovery following stroke: The role of self-management education

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### Abstract

Current stroke rehabilitation tends to focus on the bio-medical course of disability, often responding to psychological and social issues only when they have been implicated in crises. Although this situation is costly, little evidence exists in relation to how psychological and social outcomes can be facilitated or how psychosocial decline can be prevented. In the area of adjustment following traumatic injury, there has been some suggestion that rehabilitation should focus on the expansion of resources, skills and self-efficacy as this will enable individuals to cope more effectively with their medical condition and circumstances. The current study was a longitudinal randomised controlled trial involving 100 people with stroke, 58 of whom were randomly allocated to an intervention based on the notion of psychosocial skill expansion. All were patients of a major hospital in Queensland, Australia. An existing self-management intervention (The Chronic Disease Self-Management Course, Lorig et al., 2001) was used to operationalise the concept of psychosocial skill expansion. The control group reported declines in functioning during the first year following stroke in the areas of family roles, activities of daily living, self-care and work productivity, that were not reported by the intervention group. Although the groups had reached similar levels by one year post-stroke, this intervention may have a protective function, presumably by improving capacity to manage the functional requirements of daily life. However, the intervention did not appear to have its impact through self-efficacy, as was expected, and failed to influence outcomes such as mood or social participation. Nevertheless, the intervention warrants further investigation, given that it appears to improve rehabilitation outcomes, at least in the short-term.

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### Introduction

Stroke is a major health problem in Australia, with high incidence rates of approximately 40,000

each year (Davis & Donnan, 1999). The annual cost of acute medical rehabilitation for people with stroke can reach \$40,000 per individual, representing an enormous investment in the recovery of this population (Kirsner, 1997). Despite this expense, dissatisfaction with rehabilitation is common following stroke, and psychosocial outcomes tend to remain problematic for many years (Thomas & Parry, 1996).

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Recovery from stroke is complex and multi-dimensional (Dowswell, Lawler, Dowswell, Young, & Hearn, 2000). Indeed, research in the area of chronic illness has confirmed that any recovery process can be viewed in terms of three complex and unique pathways (Robinson, 1990), namely bio-medical, social and psychological. The bio-medical pathway represents the physical course of an illness and focuses on medical diagnosis, prognosis and functional outcomes. The purpose of treatment within this bio-medical area is to restore an impaired individual to his or her former condition (Newsome & Kendall, 1996). In contrast, the psychological and social pathways represent the way in which individuals perceive their circumstances and how they are perceived by others.

Although the physical, psychological and social aspects of recovery are likely to be inter-linked, the relationship between these factors is poorly understood (Dowswell et al., 2000). In relation to stroke, the bio-medical pathway is likely to involve a sharp decline followed by a period of rapid improvement and stabilisation. In contrast, psychological and social pathways are more likely to follow one of two “regressive” patterns—either a continual and gradual decline over time or an extremely rapid and dramatic decline at a particular point. Although no common path of recovery has been found following stroke (Burton, 2000), some research has suggested that within the first few months, the extent and/or permanence of disability is likely to become apparent, leading to psychological turmoil (Kendall & Buys, 1998; Mackenzie & Chang, 2002). Individuals are likely to be initially overwhelmed by stroke and unable to comprehend their situation (Watson & Quinn, 1998). Similarly, the social interest of family members and friends is likely to be intense in the early stages of any injury or illness, artificially inflating the sense of being supported (Kendall & Terry, 1996). Within several months of returning home from hospital, however, social support networks tend to diminish, leaving individuals isolated at a time when support is most critical to stroke outcome (Robinson, Murata, & Shimoda, 1999). This sense of social isolation may compound the overwhelming nature of the condition, leading to psychological difficulties and potentially catastrophic outcomes (Godfrey, Partridge, Knight, & Bishara, 1993). Research has suggested that by 1 or 2 years post-stroke, psychological and social outcomes are likely to have stabilised (Hafsteinsdóttir & Grypdonck, 1997), although problems can still

remain evident for many years (Jones, Charlesworth, & Hendra, 2000).

It is important to note that the utility of such linear and time-dependent models of adjustment has been queried on the grounds that recovery processes are more likely to be cyclical and embedded in socially constructed contexts (Kendall & Buys, 1998). Nevertheless, knowledge about how bio-medical, psychological and social trajectories can differ from each other and interact is likely to be useful (Mackenzie & Chang, 2002). It is particularly important to acknowledge the fact that biologically-based rehabilitation will not necessarily influence the psychosocial well-being of individuals and, conversely, psychosocial difficulties may impede physical recovery. Indeed, Robinson (1990) argued that bio-medical recovery can be best facilitated if social and psychological needs are recognised and addressed appropriately, a claim that has received some support in the literature (Frank et al., 1998). Despite this recognition, some investigations continue to focus on only the physical course of disabilities and diseases. Current rehabilitation remains firmly based in the bio-medical trajectory, leaving gaps in the provision of psychological and social services and accelerating the decline into regressive psychological and social pathways (Catalano, Dickson, Kendall, Kuipers, & Posner, 2003).

Unfortunately, the rehabilitation system tends to respond to psychological and social issues in a post hoc and atheoretical manner, often as a result of crises or after a cycle of deterioration has become entrenched (Jochims, 1995). Consequently, it is pertinent to address psychosocial issues at an early point in the recovery process, thereby preventing decline and positioning individuals on a “progressive” pathway. Indeed, psychosocial rehabilitation has been characterised as a process of creating opportunities, facilitating positive perceptions of one’s future, re-establishing goals and valued social roles and enabling individuals to assert personal control over their bio-medical condition (Newsome & Kendall, 1996). Even though adjustment may decline initially in response to the trauma of a sudden-onset illness or disability, it is important that this pattern is redirected before it becomes entrenched (Robinson, 1990).

Although facilitating a progressive adjustment pattern would appear to be the ultimate goal of rehabilitation, the methods of facilitating such an outcome have not been well articulated. Given that stroke exposes individuals and families to a range of

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