

Returning to work after stroke: a review

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This review focuses on the experiences and rehabilitation needs of working age, higher functioning stroke survivors in relation to their 'return to work'. It grew out of the poststroke experience of one of the authors and her realization of the inadequacy of services to facilitate return to work and optimal recovery from stroke. The authors' aim is to present a practice-oriented review that can provide information for future practice and research. Returning to work and sustaining employment are considered key aspects of rehabilitation and recovery by younger stroke survivors. From a psychosocial perspective, successful return to work can enhance recovery and life satisfaction by consolidating self-esteem, confidence and social identity. However, even higher functioning stroke survivors with minimal or no obvious physical disability may experience workplace challenges relating to their neurological condition. Appropriate rehabilitation would include specific preparation for return to work, education within the workplace to facilitate return to work, participation by the stroke survivor in all aspects of the management of their return to work, and an ongoing role for a stroke educator/workplace advocate. In conclusion, further research is

Introduction

Stroke is a neurological condition recognized for frequently causing serious impairment in older people. It is rarely understood for the range of impairments experienced by younger stroke survivors, some of whom have only limited impairments after stroke and may be motivated to 'return to work' out of desire or necessity. Biomedical literature considers predictors (e.g. Saeki, 1993) and rehabilitative factors (e.g. Saeki, 2000) contributing towards a stroke survivor's return to work, and professionals' facilitation roles. However, research into the longer term experience of higher functioning stroke survivors after their return to work is less available, as noted by Alaszewski *et al.* (2007) and Medin *et al.* (2006).

The authors have drawn together available literature on return to work of higher functioning stroke survivors. This review incorporates the perspective of one of the authors who herself is a higher functioning stroke survivor. The authors' aim is to provide a practice-oriented review that can provide information for future practice and research.

For the purpose of this review, we adopt the definition of work in accordance with Vestling *et al.* (2003, p. 128), as being the 'continuing occupation in the production of supplies and services for payment', meaning formal

required in this area to support stroke survivors in returning to and maintaining employment to achieve their poststroke potential. Thirteen recommendations arising from the existing literature and the lived experience of one of the authors are presented at the end of the review. *International Journal of Rehabilitation Research* 32:93–97 © 2009 Wolters Kluwer Health | Lippincott Williams & Wilkins.

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paid work on a full-time or part-time basis. Returning to work for people experiencing neurological challenges may contribute significantly to their life satisfaction, wellbeing, self-worth and social identity, giving an opportunity to maintain independence as far as physically possible with the income generated through employment (Banks and Pearson, 2003; Vestling *et al.*, 2003; Stuart, 2004; Koch *et al.*, 2005; Medin *et al.*, 2006; Gilworth *et al.*, 2008).

Methods

For this review, 'higher functioning' refers to stroke survivors who not only manage personal self-care measures and related independence, but also have the ability to fulfill the diverse and often demanding requirements of paid merit-based employment or higher education. Our use of the term 'younger stroke survivors' refers to people generally considered to be of employment age, 18–65 years.

Search strategies for this review included keyword search in the Victoria University library catalogue, Google search for websites and database searches including *Academic Search Premier* (1975–2007), *CINAHL* (2000–2006), *Medline* and *PubMed* (2000–2008), *Sage Premier* (1999–2007), Science Direct *Freedom Collection* (1998–2007) and *Springerlink* (1997–2007). Search terms used were cerebrovascular disease, rehabilitation, young adults, return to

work, work, employment re-entry, employment (economic theory), discrimination, brain-wounds and injuries and qualitative.

In total, 71 studies were retrieved and 29 were included in the review. Studies were included if they incorporated some material on return to work of higher functioning stroke survivors. Studies were excluded if they focused on specific aspects of physical rehabilitation but did not address return to work; were about more severe stroke-related disabilities and did not indicate a higher functioning component; or were specifically about short-term medical management. Articles were initially read to determine whether they would be relevant to the focus of the study. If determined relevant, data were extracted by reading articles and summarizing or noting relevant key pieces of information from each chosen article. This material was then organized into the following categories and synthesized for the review:

- (1) Return to work following illness or injury;
- (2) Disability and workplace harassment;
- (3) Stroke recovery;
- (4) Stroke and return to work and harassment;
- (5) Recommendations for enhanced return to work for younger stroke survivors.

The types and study designs for the 29 articles selected for review include the following: 19 articles/reports reporting empirical research including review of records, one issue-focused article, two review articles, two case study reports and five information guides.

Stroke and recovery

The medical definition of stroke is 'a sudden interruption to the supply of blood to the brain, caused by haemorrhage, thrombosis or embolism' (Yallop *et al.*, 2005, p. 1397). This definition, however, barely touches on the lived definition as experienced by stroke survivors beyond the occurrence of the initial physical illness.

The physical impairments that are more obvious include walking difficulties, vision, speech/aphasia and use of one's dominant limb (Lock *et al.*, 2005). An anonymous respondent identified as David in a UK study of young stroke survivors stated, 'people should understand that stroke does not just leave physical disabilities – there's a whole psychological and cognitive dimension to it' (Work after stroke, 2007a, p. 11). This review focuses on younger people who have experienced stroke, and who are largely unimpeded by residual physical disability.

When one is not physically disabled after stroke, there may nevertheless be invisible cognitive limitations. Edwards *et al.* (2006) noted that neuroimaging detected lesions in supposedly fully recovered stroke survivors, 'raising the possibility that subtle but clinically significant

neurologic impairments may persist' (Edwards *et al.*, 2006, p. 152). These stroke survivors invariably encounter intolerance by some others, resulting in embarrassment and frustration by the stroke survivor (Reiter, 2003; Roding, 2003). Stroke survivors frequently experience a range of multiple impairments and added complications (Lock *et al.*, 2005), the most predominant and debilitating being fatigue (Banks and Pearson, 2003; Roding, 2003; Koch *et al.*, 2005; Work after stroke, 2007a, 2007b, 2007c). This is not necessarily experienced as general tiredness or even general exhaustion; it is often pervasive and long lasting across years and can be chronic. Alaszewski *et al.* (2007) determined that as many as 80% of stroke survivors experience fatigue. One of the authors personally understands that it is a huge obstacle to live with, successfully manage and eventually overcome, as it permeates all poststroke challenges.

Stroke survivors may face a combination of emotional challenges including emotional lability and mood disturbances (Edwards *et al.*, 2006). They can suddenly become teary and find this more difficult to control than before the stroke; they may also experience higher levels of anxiety, depression and frustration at their limitations and reduced tolerance levels poststroke (Banks and Pearson, 2003).

Stroke survivors often face subtle yet significant cognitive challenges including executive functioning, reduced attention and concentration (Edwards *et al.*, 2006), resulting in slower information processing, memory lapses or losses, literacy difficulties, loss of identity and a consequent need to rebuild their identity – something that continues across years with each new challenge they take on throughout recovery (Kersten *et al.*, 2002) – lower self-esteem or reduced social confidence sometimes resulting in isolation (Banks and Pearson, 2003; Reiter, 2003; Lock *et al.*, 2005). Baum *et al.* (2008), identified that '... higher order cognitive abilities underlie and support daily life performance; their impairment or loss compromises a person's ability to fully participate in society' (p. 446).

The stroke survivor may find themselves challenged developmentally and 'recycling through earlier career and life stages, ... some welcome the developmental changes ... triggered by stroke, others expressed dissatisfaction with the need to make these changes' (Koch *et al.*, 2005, p. 216).

The medical profession and the stroke survivor seem to hold a different perception of the meaning of recovery. The medical profession has traditionally focused on biomedical and frequently hospital-based rehabilitation with a focus on enabling 'functional independence' (Medin *et al.*, 2006, p. 1052). Those who experienced only mild stroke with minimal physical impairment have been expected to achieve full recovery with negligible

intervention. Edwards *et al.* (2006) found that 35% of mild stroke survivors 'were discharged to home with no postacute rehabilitation services' (p. 154), when in fact, 87% of the stroke survivors reported experiencing residual symptoms.

Medin *et al.* (2006) identified the frustration and perceived invisibility of younger stroke survivors 'which may be because of a lack of participative rehabilitation programmes that focus on individual needs beyond medical recovery' (p. 1052). The need for appropriate rehabilitation, even for mild stroke survivors, is highlighted by Baum *et al.* (2008). 'Daily life performance and the executive abilities that support it often require multitasking and the generation and implementation of adaptive strategies to accommodate to novel environments and perform tasks in the real world' (p. 446). Medin *et al.* (2006) found that factors leading to a successful return to work include the stroke survivor participating in decisions regarding the process of their own rehabilitation. Through such empowerment they devise workable solutions to their own problems (Medin *et al.*, 2006). We believe that greater understanding is required in the development of rehabilitation programmes for those who have experienced mild stroke, with a need to incorporate a focus on facilitating and sustaining successful return to work.

Most stroke survivors consider actual recovery from stroke to take much longer than just the rehabilitation period; recovery and growth in achieving life satisfaction can extend years beyond this (Kersten *et al.*, 2002; Lock *et al.*, 2005; Work after stroke, 2007b). Qualities required to achieve optimal recovery include huge determination (Raderstorf *et al.*, 1984), and also being patient, positive, proactive and persistent (Work after stroke, 2007a).

Stroke and return to work

Researchers have found that returning to work can have a positive impact on the psychological wellbeing of the stroke survivor, and fulfill many psychosocial needs (Koch *et al.*, 2005; Medin *et al.*, 2006). Nevertheless '... return to work is only a first step to re-employment. Job retention and performance on the job are also of major importance' (Possl *et al.*, 2001, p. 16).

Edwards *et al.* (2006) found that 62% of patients in their US study 'reported decreased ability in employment and volunteer activities after mild stroke' (p. 156). Despite having reached full independence physically, by 6 months poststroke results indicate that a significant number of those interviewed experienced a reduction in life satisfaction and some form of impairment (Edwards *et al.*, 2006).

According to a Canadian study, 3.7% of stroke victims are under the age of 45 years; and 3 months after discharge 6% of these stroke survivors were back in full-time

employment. Of stroke survivors who were employed full-time before their stroke, 9% had returned to full-time employment and 8% to part-time employment (Teassell *et al.*, 2000).

In a UK study conducted by Kersten *et al.* (2002) examining the unmet needs of young people who have experienced stroke, it was found that in projections for 2001, '21% of all new strokes occur in people under the age of 65 years' (p. 860). Furthermore, '65% of ... responders who were working before the stroke had to give up their job altogether, and a further 14% changed their hours or job as a result of [their stroke]' (Kersten *et al.*, 2002, pp. 861–862).

Return to work is seen as a significant indication of recovery by the stroke survivor (Medin *et al.*, 2006; Alaszewski *et al.*, 2007). Pressures such as financial hardship and lack of sick leave influence attempts to return to work (Banks and Pearson, 2003; Koch *et al.*, 2005; Lock *et al.*, 2005). A relatively rapid return to work may be viewed positively at the time, but in retrospect may have been too soon (Banks and Pearson, 2003).

Research in relation to traumatic brain injury (TBI) is relevant to this issue of return to work. Jacobs (1988) found that 13% of total people interviewed returned back to work after their brain injury but were unable to continue in employment. An Australian study found that 32% of TBI survivors who were working 2 years after their brain injury were no longer working at the 5-year mark (Olver *et al.*, 1996). As Possl *et al.* (2001) comment in relation to TBI survivors: '... particular attention should be paid to the long-term consequences of a reduced capacity for work, even if minor in degree. This is often neglected in the case of patients with good recovery who frequently wish to reach their premorbid level of employment. ... subjects who finally accomplish these [work] tasks run the risk of reaching performance limits and of decompensating, when critical changes regarding work environment place further demands on their abilities' (p. 26).

The workplace accommodations as suggested by the Canadian Human Rights Commission (A guide for managing return to work, 2007) may be complemented by a team approach involving rehabilitation and therapy professionals, the stroke survivor and a cooperative employer (Raderstorf *et al.*, 1984; Medin *et al.*, 2006). A safe, secure and stable work environment is vital (Medin *et al.*, 2006; Alaszewski *et al.*, 2007), and negotiating a gradual return to work according to the day-to-day needs of the stroke survivor is recommended (Banks and Pearson, 2003; Medin *et al.*, 2006; Work after stroke, 2007b). Consideration needs to be made for the stamina or endurance of the stroke survivor in returning to work. Allowance for the stroke survivor to manage their

workload and regulate their own hours during periods of stress or unpredictable fatigue is beneficial (Raderstorff *et al.*, 1984; Medin *et al.*, 2006). A quiet room where the stroke survivor can have complete breaks from work helps to manage fatigue (Work after stroke, 2007b). Of supreme importance, the employer/manager/supervisor needs to be open to listen to the stroke survivor's own assessment of what they can and cannot do on any one day, and to be guided by the stroke survivor themselves (Medin *et al.*, 2006; Work after stroke, 2007b).

Ignorance, embarrassment and minimal understanding on the part of management or colleagues can lead to the stroke survivor being alienated or ignored (Work after stroke, 2007a). This then further impacts on their vulnerable psychosocial position and may cause damage, resulting in leaving the workforce (Alaszewski *et al.*, 2007). Medical and occupational health advice needs to be taken seriously by the workplace, as the refusal to do so may be detrimental to the health of the stroke survivor (Work after stroke, 2007a).

Some stroke survivors are forced into retirement because of the perception of the employer or healthcare provider that the person is unable to do the job (Koch *et al.*, 2005; Alaszewski *et al.*, 2007), and yet if given flexibility and trust, the stroke survivor can generally address work issues adequately (Medin *et al.*, 2006; Work after stroke, 2007b). One stroke survivor reported being sent to the workplace doctor who gave an inconsistent diagnosis to that of their own doctor; consequently the stroke survivor was eventually made to retire (Koch *et al.*, 2005).

Negative attitudes of the employer or a workplace superior may adversely interact with the challenges faced by the stroke survivor (Lock *et al.*, 2005; Medin *et al.*, 2006; Alaszewski *et al.*, 2007), and result in harassment or discrimination as we do live in 'a disabling society with oppression of disabled people endemic in widely accepted institutional practices and expressed in some individuals' negative and patronizing words and actions' (Lock *et al.*, 2005, p. 44). 'The stress of unfairness in the workplace can lead to not only higher rates of illness but also longer and less successful recovery' (Shain, 2001, p. 365). Research into TBI has identified that early intervention (O'Brien, 2007) and reasonable accommodations need to be made to ensure a positive return to work (Opperman, 2004; O'Brien, 2007; Gilworth *et al.*, 2008), including the importance of natural supports within the workplace and employee mentoring (O'Brien, 2007). It has been acknowledged that the most significant barriers to employment arise from the environment, not the person (McMahon *et al.*, 2005).

The material in this review indicates that it is important for stroke survivors to be believed in and enabled rather than disabled in their endeavours, both within education

and within the workforce. They may also require advocacy to help to build understanding among peers and colleagues, and to optimize their contribution within the community.

Recommendations for the enhanced return to work by stroke survivors

These recommendations are drawn from both the literature review material and the personal lived experience of one of the authors.

- (1) Rehabilitation professionals have a role in socio-political change as well as in service provision (Kersten *et al.*, 2002). Change is required in perceptions of stroke survivors, and in resourcing of community education and support services for higher functioning stroke survivors.
- (2) Return to work should be seriously addressed within the rehabilitation phase (Koch *et al.*, 2005), with explicit consideration of the limiting impact of early discharge from hospital with no, or only minimal, follow-up rehabilitation.
- (3) All patients of working age admitted to stroke wards in hospitals need to be provided on discharge with support service contacts that they can refer to in the future if required, especially in relation to 'return to work' issues and employee rights.
- (4) Education is required within the community and the workplace with employers, professionals and community members to facilitate the participation and autonomy of younger stroke survivors (Kersten *et al.*, 2002).
- (5) Appropriately qualified stroke educators available through formal stroke services could carry out much of this education and advocacy in support of stroke survivors. A specific focus within the workplace, higher education, training programs or apprenticeships may be required in support of higher functioning stroke survivors who wish to reach their premorbid levels of functioning.
- (6) Rehabilitation in an appropriate form relating to the needs of the stroke survivor is required across the long-term recovery phase within the workplace (Kersten *et al.*, 2002), optimally 3–5 years post-stroke. For some, this may involve occupational therapy or rehabilitation, for others it may be a mentor or advocate who is able to advocate for the stroke survivor over time (Work after stroke, 2007a) as issues or needs arise at work.
- (7) Formal structured support is required to enable disclosure of stroke-related difficulties within a work team (Gates, 2000), with the intention of supporting the stroke survivor to remain a valued and functional member of the team.
- (8) The stroke survivor requires open support and a positive allowance to attend medical appointments

(Work after stroke, 2007b), and also flexibility to best manage their stroke challenges, including cognitive fatigue.

- (9) Some flexibility and creativity around sick leave entitlements may be considered, especially if sick leave is exhausted relatively quickly.
- (10) Workplaces should consider holding the job of the stroke survivor open as long as is possible especially within the first 6 months poststroke.
- (11) Employers/managers/supervisors should understand that returning to work can be very intimidating for stroke survivors (Reiter, 2003).
- (12) Workplaces should recognize that 'a stroke survivor may use different means [than expected] to achieve an equivalent result' (Work after stroke, 2007b, p. 5) at work. The stroke survivor need not be disabled, they may simply be differently abled.
- (13) The voice of the stroke survivor should be heard and given priority, and their needs accommodated as they arise to ensure optimal performance at work, optimal wellbeing and enhanced recovery.

Conclusion

Younger, higher functioning stroke survivors are likely to want to return to work. However, invisible, sometimes subtle impairments may, over time, compromise the success of return to work. In this review, we have drawn attention to the documented experiences of stroke survivors with return to work, and the implications for rehabilitation practice. We have presented recommendations for successful, appropriately supported return to work for this group whose vulnerability is not always recognized. We believe that further research is required in this area. Hopefully, further research will lead to a better understanding of the rehabilitative needs and the significance of natural supports and advocacy required by younger stroke survivors to enable a successful reintegration into the workforce and/or into higher education or apprenticeships.

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References

A guide for managing return to work (2007). Ontario: Canadian Human Rights Commission. http://www.chrc-ccdp.ca/pdf/GMRW_GGRT_en.pdf. [Accessed 16 May 2007]

- Alaszewski A, Alaszewski H, Potter J, Penhale B (2007). Working after stroke: survivors' experiences and perceptions of barriers to and facilitators of the return to paid employment. *Disabil Rehabil* **29**:1858–1869.
- Banks P, Pearson C (2003). Improving services for younger stroke survivors and their families. Edinburgh: Chest Heart & Stroke Scotland. http://www.chss.org.uk/pdf/research/Young_stroke_study_2003.pdf. [Accessed 30 March 2007]
- Baum C, Connor L, Morrison T, Hahn M, Dromerick A, Edwards D (2008). Reliability, validity, and clinical utility of the Executive Function Performance Test: a measure of executive function in a sample of people with stroke. *Am J Occup Ther* **62**:446–455.
- Edwards D, Hahn M, Baum C, Dromerick A (2006). The impact of mild stroke on meaningful activity and life satisfaction. *J Stroke Cerebrovasc Dis* **15**: 151–157.
- Gates L (2000). Workplace accommodation as a social process. *J Occup Rehabil* **10**:85–98. Retrieved from Springerlink database. [Accessed 18 April 2007]
- Gilworth G, Eyres S, Carey A, Tennant A (2008). Working with a brain injury: personal experiences of return to work following a mild or moderate brain injury. *J Rehabil Med* **40**:334–339.
- Jacobs H (1988). The Los Angeles head injury survey: procedures and initial findings. *Arch Phys Med Rehabil* **69**:425–431.
- Kersten P, Low J, Ashburn A, George S, McLellan D (2002). The unmet needs of young people who have had a stroke: results of a national UK survey. *Disabil Rehabil* **24**:860–866.
- Koch L, Egbert N, Coeling H, Ayers D (2005). Returning to work after the onset of illness: experiences of right hemisphere stroke survivors. *Rehabil Couns* **48**:209–218.
- Lock S, Jordan L, Bryan K, Maxim J (2005). Work after stroke: focusing on barriers and enablers. *Disabil Soc* **20**:3–47.
- McMahon B, West S, Shaw L, Waide-Ebbs K, Belongia L (2005). Workplace discrimination and traumatic brain injury: the national EEOC ADA research project. *Work J Prev Assoc Rehabil* **25**:67–75.
- Medin J, Barajas J, Ekberg K (2006). Stroke patients' experiences of return to work. *Disabil Rehabil* **28**:1051–1060.
- O'Brien L (2007). Achieving a successful and sustainable return to the workforce after ABI: a client-centred approach. *Brain Inj* **21**:465–478.
- Oliver J, Ponsford J, Curran C (1996). Outcome following traumatic brain injury: a comparison between 2 and 5 years after injury. *Brain Inj* **10**:841–848.
- Opperman J (2004). Interpreting the meaning that individuals ascribe to returning to work after traumatic brain injury: a qualitative approach. *Brain Inj* **18**:941–955.
- Possil J, Jurgensmeyer S, Karlbauer F, Wenz C, Goldenberg G (2001). Stability of employment after brain injury: a 7 year follow up study. *Brain Inj* **15**:5–27.
- Raderstorf M, Hein D, Jencsen C (1984). A young stroke patient with severe aphasia returns to work: A team approach. *J Rehabil* **50**:23–26.
- Reiter J (2003). Journey towards recovery: a brain injury guide for families. San Diego: San Diego Brain Injury Foundation. http://www.sdbif.org/Guide/SDBIF_Guide_Eng.pdf. [Accessed 2 May 2007]
- Roding J, Lindstrom B, Malm J, Ohman A (2003). Frustrated and invisible-younger stroke patients' experiences of the rehabilitation process. *Disabil Rehabil* **25**:867–874.
- Saeki S (2000). Disability management after stroke: its medical aspects for workplace accommodation. *Disabil Rehabil* **22**:578–582.
- Saeki S, Ogata H, Okubo T, Takahashi K, Hoshuyama T (1993). Factors influencing return to work after stroke in Japan. *Stroke* **24**:1182–1185.
- Shain M (2001). Returning to work after illness or injury: The role of fairness. *Bull Sci Technol Soc* **21**:361–368.
- Stuart H (2004). Stigma and work. *Healthcare Papers* **5**:100–111. <http://www.longwoods.com/product.php?printable=Y&productid=16&29&page=129>. [Accessed 18 April 2007]
- Teassell R, McRae M, Finestone H (2000). Social issues in the rehabilitation of younger stroke patients. *Arch Phys Med Rehabil* **81**:205–209.
- Vestling M, Tufvesson B, Iwarsson S (2003). Indicators for return to work after stroke and the importance of work for subjective well-being and life satisfaction. *J Rehabil Med* **35**:127–131.
- Work after stroke (2007a). Milton Keynes UK: Different Strokes. http://www.differentstrokes.co.uk/download/work_after_stroke/work_after_stroke.pdf. [Accessed 1 June 2007]
- Work after stroke: employer's guide (2007b). Milton Keynes UK: Different Strokes. http://www.differentstrokes.co.uk/download/WASEmployers_Guidefeb07.pdf. [Accessed 1 June 2007]
- Work after stroke: Information for family and friends (2007c). Milton Keynes UK: Different Strokes. <http://www.differentstrokes.co.uk/download/WASfamilyandfriendsleaflet-feb07.pdf>. [Accessed 1 June 2007]
- Yallop C, Bernard JRL, Blair D, Butler S, Delbridge A, Peters P, Wilton N, editors. (2005). Macquarie Dictionary. 4th ed. North Ryde, NSW: Macquarie Library.