

Return to Work after Stroke – Feasibility six year follow-up

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Background to the project

In the UK, in excess of 100,000 people have a stroke each year (Stroke Association, 2017). Approximately 25% of this population are under 65 years old, yet reported return to work (RTW) rates in systematic reviews vary between 7-81% (Wei et al., 2016). Low RTW rates result in costs for the stroke survivor and the economy. Lost productivity in the UK due to stroke is £1.6 billion per year (Patel et al., 2017). Additionally, the UK government acknowledges that 'good' work generally improves health and want to further develop the role that health professionals play in helping patients maintain employment (Department for Work & Pensions and Department of Health, 2017).

Vocational rehabilitation is defined as "*whatever helps someone with a health problem to stay at, return to and remain in work*" (Waddell et al., 2008). Although the National clinical guidelines for stroke (Royal College of Physicians, 2016) and the NICE stroke rehabilitation guidelines (NICE, 2013) recommend that the work needs of stroke survivors should be addressed, they also highlight the lack of evidence for the effectiveness of vocational rehabilitation (Royal College of Physicians, 2016). As few as 15% of the UK's post-acute services routinely support RTW after stroke (Royal College of Physicians, 2015).

A UK single centre feasibility randomized controlled trial (fRCT) recruited 48 participants in 2011/12 (Grant et al., 2014; Radford et al., 2013). Twenty five participants had access to an occupational therapist specializing in vocational rehabilitation (VR) in addition to their usual NHS rehabilitation (usual care) immediately post stroke and the others received usual care alone. The aim of the intervention was to help participants return to work where possible and support was provided up to one year post randomisation. At one year, 59.4% of the cohort had returned to work (19/32) with twice as many VR participants in work. However, the longer-term impact on participants' work status, mood and quality of life is not known. This study set out to determine whether it was possible to follow up participants in the fRCT to ascertain vocational status and explore the impact of the intervention on vocational status, mood and quality of life six years post stroke.

Aims

1. To ascertain the feasibility of prospective follow up of participants in a trial of vocational rehabilitation six-year after stroke onset.
2. To ascertain;
 - a. The proportion of people in work and the proportion living solely on welfare benefits.
 - b. Participants' levels of anxiety, depression and health related quality of life
 - c. Participants' use of health and social care resources
3. To identify and explore factors affecting long-term work outcomes from the perspective of stroke survivors who were working before stroke onset.

Methodology

In 2017, the Lead Stroke Clinician screened survivors admitted to a UK National Health Service (NHS) hospital between July 2010 and December 2011. Those that fitted the criteria for participation in the earlier feasibility trial of early stroke specific vocational rehabilitation (VR), i.e. aged 16 and over and in work at the time of admission, were identified. Work was defined as participating in competitive employment, supported work, vocational training, voluntary work or education for at least one hour per week. Having checked hospital records for known deaths, participants in the earlier trial were sent an information pack including an information sheet, a questionnaire and a consent form to complete if they wished to participate in a semi-structured

telephone interview. As participants in the earlier study were not asked to consent to follow up they could not be approached directly by the research team. Where envelopes were returned marked 'not known at this address' addresses were re-checked by the lead clinician and non-respondents resent the information pack after four weeks.

Questionnaires included demographic information, employment and benefit status (primary outcomes) and standardised measures of mood (Hospital Anxiety and Depression scale [HADS] (Zigmond and Snaith, 1983), health related quality of life [EQ5D-3L] (Dolan et al., 1995) and instrumental ADL ([the Nottingham Extended Activities of Daily Living Scale (NEADL)] (Nouri and Lincoln, 1987) – secondary outcomes. Retirement was classified as retired due to 'age', due to 'health' reasons or any 'other' reasons to give a clearer picture of the effect of stroke on work status.

Semi structured interviews were arranged at a time to suit participants to further explore participants experience of working or not working six years after stroke.

Quantitative data was recorded and analysed using Excel and SPSS 23. Interviews were analysed by two researchers (KM, JP) using thematic analysis (Braun and Clarke, 2006). Ethical approval was obtained from NHS Health Research Authority (REC 16/EM/0423), and R&D approval granted by Derby Research and Innovation department.

Key findings

Feasibility

Forty eight eligible participants were identified for follow up, all of whom were participants in the earlier trial. Of these, five (5/48 10.4%) had died, 19/48 (40%) questionnaires were returned, eight envelopes (8/48 16.6%) were returned 'not known at this address and 16/48 (33.3%) did not respond.

Excluding those who had died, the response rate was 19/43 (44.2%). As the numbers of participants in each group (VR= 7/19 [37%], Usual care =12/19 [63%]) was too few to draw meaningful between group comparison, only the overall results are reported. Most questionnaires were received after the first mail shot (n=16). Three participants lost to follow up at one year in the fRCT, responded to this follow up questionnaire at six years. Of the nine participants consenting to telephone interview, six interviews were completed (two declined when contacted and one number was unobtainable). Other participants agreed to contact by email (n=3) or letter (n=9) but did not want to be contacted by phone.

The response rate in this study is comparable to another UK postal survey five years post stroke, which received a 47% response (Westerlind et al., 2017). As respondents in this follow up study were mostly high functioning and more likely to be working, this is a possible biased response. Two similar studies have also recorded higher returns from usual care participants who have returned to work and conversely low responses from usual care participants who did not return to work (Grant, 2016; Phillips J, 2013). Ways of encouraging participants who did not receive intervention and do not return to work need to be found. Additionally, seeking consent to follow up participants in studies of early VR and/or having a population based stroke register may enable more complete follow up and may avoid bias (McKevitt et al., 2011; Westerlind et al., 2017).

Participants

The mean age of respondents was 62 years (range 24- 78 years) which is comparable to participants in the earlier trial (mean age 56 years). Respondents who had received VR (n=7) (mean age 67), were five years older than respondents who received usual care (n=12) (mean age 62). More men (14 [74%]) than women responded (5 [26%]), which is comparable to the fRCT (men 78%; women 22%). All respondents reported the same driving status at six years compared

to one year post stroke. Fourteen participants reported that they were still driving.

Work status

Of the nine fRCT participants who were in work at one year post stroke, seven (7/9, 77.8%) were in paid employment, full time education or voluntary work at six years post stroke, – see Table 1. Five were in paid employment (two in full time employment, one part time, two self-employed), one was in full time education and one in voluntary work. Two had retired and did not state any specific activity. Interestingly, two people in paid work were over the UK state pension age of 65.

Table 1: Participants in work at one year post stroke. Six year post stroke work status

Participants who were in work at one year post stroke. Six year post stroke work status									
Participant	Pre stroke work status				One year post stroke work status		Six year post stroke work status		
	Gender	Age at stroke onset	Work status pre-stroke ¹	Hours worked per week	1 year work status	Hours worked per week	6 year work status	Hours worked per week	
1 (VR) ²	m	58	Full time	35	Full time	missing	Retired - other	0	
2 (VR) ²	f	44	Full time	37.5	Full time	missing	Full time	38	
3	f	17	Full time education + Part time paid work		Full time	40	Full time education	Not stated	
4	m	50	Self-employed	49	Self-employed part time	24	Self-employed	25	
5 (VR) ²	m	59	Full time	36	Full time	37	Made redundant, then retired	0	
6 (VR) ²	f	66	Self-employed	Varied	Voluntary	missing	Self-employed	10	
7	m	66	Part time	30	Voluntary	n/a	Retired - age. Voluntary	12	
8	m	59	Self-employed	28.5	self-employed part time	6	Part time	6	
9	m	51	Full time		Full time	Missing	Full time	40	

¹ Paid work recorded as full time, part time or self-employed; voluntary work recorded as voluntary regardless of hours worked; full time education

² Received VR intervention in fRCT

Seven participants were not in work at one year post stroke – see Table 2. Of these, four (4/7, 57.1%) were in paid employment, full time education or voluntary work at six years post stroke–

see Table 2. One was in full time paid employment; one in part time work and two were undertaking voluntary work. Three had retired (two for health reasons and one due to age) and of these, two were undertaking voluntary work.

Three participants whose work status was unknown (lost to follow up) at one year post stroke responded to six year follow up questionnaire– see Table 2. All three were in paid employment (two in full time employment and one in part time employment). One who had retired due to health was working 12 hours a week at six years post stroke.

Table 2: Participants not in work at one year post stroke. Six year post stroke work status

Participants not in work at one year post stroke. Six year post stroke work status								
Participant	Pre stroke work status				One year post stroke work status	Six year post stroke work status		
	Gender	Age at stroke onset	Work status pre-stroke ¹	Hours worked per week		6 year work status	Hours worked per week	
1 (VR) ²	m	71	Full time	40	Retired	Retired –health. Works on own small holding	0 ³	
2	m	66	Voluntary	16	Not returned to work yet	Retired – health Voluntary + education	3	
3	f	31	Part time	12.5	Not returned to work yet	Part-time paid	6.5	
4	m	53	Full time	50	Unable to return to work due to other health reasons	Full-time paid	56	
5	m	65	Full time	40	Unable to return to work (reason missing)	Retired - health. Voluntary	16	
6	m	58	Full time	38	Unable to return to work (reason missing)	Retired – health	0	
7 (VR) ²	m	61	Full time	35	Retired	Retired - age	0	
8 (VR) ²	f	51	Full time	46	Lost to follow up	Full time	38	
9	m	50	Full-time	37	Lost to follow up	Part paid	24	
10	m	44	Full time	37	Lost to follow up	Retired – health, works part time	12	

¹ Paid work recorded as full time, part time or self-employed; voluntary work recorded as voluntary regardless of hours worked; full time education.

² Received VR intervention in fRCT

³ Recorded as not working as no hours stated

In summary, of the 48 potential participants, five had died and 19 responded. All were in work at the time of stroke. The 12-month work status of 16 participants was known. It was 56% (9/16). At six years post stroke, the work status of 19 participants was known. It was 74% (14/19). Ten

participants were in paid employment (53%), one in full time education (5%) and three in voluntary work (16%) at six years post stroke. Five participants stated that they had retired for health reasons at 12-months post stroke but at six years, one was in paid work and two were doing voluntary work. At six years, five participants aged 65 years old or older were working (two were self-employed and three doing voluntary work). This suggests that some stroke survivors can sustain working six years post stroke, that some people do return to work even after a year post stroke and some stroke survivors are productive post 65 years old.

Only one person in paid employment said they were not working with the same employer as before the stroke. Everyone else had remained with the same employer or moved into full time education or retired. Additionally, most reported that they were doing the same job that they had been doing prior to their stroke. Only 3/13 (23.1%) reported that they had changed jobs, one of whom had moved to full time education. When asked whether any change in work status was due to the stroke, 11/17 (64.7%) said yes, and 6/17 (35.3%) said no. Reported reasons for changes in work status were: a need to work in a quieter environment, 'low energy' and 'reduced concentration'. One person said that the 'stress of having children' caused them to change jobs suggesting that younger stroke survivors have a range of factors to deal with in addition to the effects of their stroke

Income

Of those responding to questions about their income, approximately half (8/15, 53.3%) reported a decrease in income and half (7/15, 46.7%) reported that their income had remained the same. No-one's income had increased in the six years since stroke. The mean income from paid employment reported by 11 respondents was £15,797 (range £3,620 to £31,500). Of those stating the source of their income, 7/14 (50.0%) reported living off their wages with no other income, one (7.1%) relied on wages topped up by benefits, one (7.1%) reported wages topped up with income protection insurance, 3/14 (21.4%) reported living on a pension and 5/19 (26.3%) did not respond. One person reported that he had reduced his working hours and that his wife had reduced her working hours to support him, resulting in a reduced household income.

Secondary outcomes

For all secondary outcome measures, participants with complete data at both 12 months and six years were compared. Self-reported NEADL scores (n=16) had increased slightly at six years (mean 59.4 SD 9, range 32-66) compared to 12 months (mean 56.6 SD 12, range 17-66).

Health related quality of life (HRQOL), measured using the visual analogue scale indicated that participants (n=15) rated their HRQOL lower at six years post stroke 70.7 (SD 14, range 30-90) than at one year post stroke 77.4 (SD 11, range 60-98).

Comparison of the HRQOL scores of participants who were in work to those who were not in work at one year showed those who were working at one year post stroke reported slightly better HRQOL at six years -see Table 3.

Table 3:- HRQOL scores between participants in work and not in work at one year post stroke

	HRQOL at one year post stroke	HRQOL at Six years post stroke
In work at one year (n=8)	77.0	72.5
Not in work at one year (n=5)	77.5	67.5

HADS scores of eight or above suggest that clinical depression or anxiety may be present (Stern, 2014). For respondents with scores available at both time points (n=16), the mean scores for both depression and anxiety at six years post stroke were below eight (which indicates clinical

depression or anxiety not indicated) despite scores for depression and anxiety worsening over time. The mean self-reported HADS depression score (n=16) at one year was 2.7 (SD 3, range 0-6) but at six years, it was 4.6 (SD 4, range 0-13). At one year, the mean HADS anxiety score was 3.3 (SD 2, range 0-8) and at six years, it was 5.3 (SD 4, range 0-17). As the scores for both depression and anxiety were under eight, that suggests that no clinical depression or anxiety was present. However, at six years, out of all the respondents (not just those who had scores at one and six years), 8/19 (42%) rated themselves as eight or over for either anxiety or depression or both. Specifically, one person rated themselves as moderately depressed and moderately anxious, two rated themselves as both mildly depressed and severely anxious, one was severely anxious and two more were mildly anxious and mildly depressed

Therefore despite having good functional ability, high levels of participation and mobility, some respondents reported a reduced quality of life and almost half reported levels of depression and anxiety that fell within the clinical range.

Health service resource use

Fewer than half of the respondents at six years (9/19, 47.4%) reported seeing a health professional in the last year. Five said they had seen their GP for a general review. Other reasons for visiting a health care professional were due to other comorbidities such as: Parkinson's disease and diabetes, fatigue management, anxiety, blood pressure and orthotics. Therefore it appears that these respondents had to deal with other co-morbidities as well as the residual effects of the stroke. No-one mentioned seeing a health professional for anxiety or depression.

Qualitative interviews

Six respondents were interviewed: - five men and one woman. Their overall mean age was 63 (range 51-73). Three had received VR in the fRCT and three had received usual care. Three were in work at one year post stroke. Of these, two were self-employed and one was retired at six years post stroke. One participant was not working at one year post stroke and at six years post stroke reported working full time. Another participant who was retired at one year remained retired at six years. The final interviewee was lost to follow up at one year post stroke and at six years had retired for health reasons but had returned to work part time. Five themes emerged as summarised in Table 4. They were: 'the importance of returning to work (RTW) after stroke', 'hidden disabilities', 'support after stroke', 'barriers and enablers' and 'life after stroke'.

Table 4: Interview themes

Themes	Description
Importance of RTW after stroke	A retrospective account of the role RTW plays in recovery after stroke
A retrospective account of the role RTW plays in recovery after stroke	The type of support received in the six-seven years post stroke, and where the gaps lie
Hidden disabilities	Types of residual hidden impairments six years post stroke and issues surrounding how the invisibility of these impairments impacts RTW
Barriers and enablers to RTW	The factors that helped or hindered RTW at the time of stroke and six years post stroke
Life after stroke	Changes to lifestyle following stroke and returning to normality versus a new normality

The importance of RTW after stroke

The over-riding consensus from interview participants was that they had made the right decision to return to work, all believed that work was beneficial to their recovery and “...with the benefit of hindsight, I wouldn't have done it any different” (pt 5). They saw it as a return to normality:-

“...made me feel as if I wasn't an invalid I was back to being the old the same person I was before even though deep down I knew I wasn't you know. It's difficult to put into words but yes I did need to go back to get life back to normal as much as possible (pt 2)

Even when the only option was to RTW, this was still seen as positive “it (work) helps your sanity. And we needed the money so it wasn't an option for me not to” (pt 6).

Support received after stroke

Support from occupational therapists initially after stroke was cited as being helpful. However, accessing help to cope with certain difficulties was not straight forward and not always seen as important by health care professionals, resulting in feelings of abandonment:-

“went to have a chat to him (GP) erm because I felt there were odd things that I should be able to do that I wasn't properly I can't even remember them now but and he looked at me and he said if you think you've got a problem I'll take you down to the nearest nursing home from here and you'll realise you haven't got any problems at all” (pt 2)

Hidden disabilities

Respondents reported hidden disabilities which included cognitive problems, language difficulties, psychological problems, visual deficits and epilepsy. All said these hidden disabilities were problematic and not obvious:

“I suppose if you've got err if you're paralysed down one side or (inaudible) then it's obvious somebody's got a physical disability. But err mentally there just not visible are they (pt 3)

Fatigue was a major problem for the interviewees and has been reported as affecting half of all stroke survivors (Stroke Association, 2017). One person was still trying to find answers six years post stroke:

“I've been in and out of my GP for the last 6 years, saying where has my energy gone and nothing's really sort of been found, I've had a referral to the err chronic fatigue clinic” (pt 2)

Another reported they were declined disability benefits “as I say it's really, really hard to prove a lack of energy” (pt 1)

The effect of these hidden impairments appeared to impact on quality of life with respondents reporting, loss of confidence, and mood swings. One reported taking anti-depressants

Barriers and Enablers

Barriers to employment included not driving, reduced cognitive abilities, fatigue and employers concerns about whether pressure of the job was too much for the employee:-

“After my stroke because of me, because of my peripheral vision but err that I got that you know I got cleared for that so well I’ve got my licence and then when I had my seizures I had to send in my licence again” (pt 4)

“I find it hard to pay attention, I find meetings and groups very confusing...” (pt 3)

“Yeah I should be careful if I’m driving back in the afternoon I have to have the radio on loud or the window open (inaudible) or make sure I stop (inaudible)” (pt 1)

Enablers supporting working included supportive employers, supportive work colleagues, supportive family, changes of work role, and support from occupational therapists to help the initial return to work, antidepressants and medical retirement. Adaptations included reduced hours, reduced roles and responsibilities:

“So I’m quite happy just to do the 12 hours a week” (pt 3)

“now they filter the calls and any they think I can do they send me an email detailing what the problem is and then ask me to have a look at it and get back to them if I can’t do it, if I can do it I go ahead” (pt 3)

“I used to I was a supervisor, a foreman but me err my employers asked me just to go back to being a plant operator again because they didn’t want to put any extra pressure on me” (pt 4)

“after the stroke I was able to goaccess to my works pension on ill health grounds..... without err any reduction for kind of early medical retirement so that took all the pressure off” (pt 3)

Life after stroke

Participants were still making changes and adapting to life after stroke both within and outside work. Examples mentioned included: feeling unable to dine out due to having to chew very slowly, needing to have an extra hour in bed in the morning to ‘*sort out in my mind what I have to do in the day*’ (pt 2) and making healthier lifestyle choices to help prevent further strokes:-

“Right well I’ve stopped smoking and I’ve stopped drinking, it may sound daft to you, but it’s the best I can come up with at the moment right?” (pt 5)

Returning to normality included having to deal with their own and other people’s experiences of stroke including a work colleague and a spouse having a stroke.

Although many of the participants were in work and/or high functioning, they were still experiencing and having to cope with and adjust to the effects of the stroke six years post stroke onset.

Strength and limitations

The strength of this study was prospective follow up of participants’ employment and benefit status and comparison of individuals work status at one and six years. A limitation was the inability to approach participants in the earlier ESSVR study directly and to prompt or support follow up. Additionally, response bias (most of the respondents were people who were still working) and the small sample may have influenced these findings. Participants in the earlier trial and this subsequent follow up study were people who were motivated to (return to) work. High self-reported instrumental activities of daily living (IADL) scores using NEADL and low self-reported health service resource use indicate that respondents were independent and high functioning. However, within this cohort, some individuals had hidden disabilities or psychological problems that were not detected using the standardised outcome measures or were obscured by group means.

Outputs to benefit service users

This study suggests that:-

- Returning to work (paid, voluntary or education) post stroke is possible and can be sustained for six years after stroke onset for some stroke survivors.
- Of those in work six years post stroke, most remained with a pre-stroke employer.
- For half of the respondents, income decreased between 12 months and six years post stroke. No one reported improved income at six years post stroke.
- Stroke survivors are left with residual problems such as anxiety, depression, fatigue, cognitive problems and language difficulties six years post stroke. In addition, they have to cope with new health problems and those of people around them as they age. Some reported an unmet need for help with these problems.

Outputs to benefit the profession

- It is feasible to follow up stroke survivors, employed at onset, six years post stroke.
- Work remains important to stroke survivors six years after stroke.
- Facilitating a return to a pre-stroke employer may have lasting benefits as the majority of respondents remained with their pre-stroke employer at six years post stroke.
- . Vocational rehabilitation should address the impact of hidden disabilities on stroke survivors' ability to work.

Recommendations

- Researchers should consider seeking consent to follow up in participants in studies of early VR, as follow up over time may lend a greater understanding of the effectiveness and impact of rehabilitation interventions in the longer term.
- Ways in which stroke survivors can access support, including specialist occupational therapy to help them manage hidden disabilities in the work place, should be explored.
- Future research should explore
 - how to record work and changes in work status over time when participants are approaching retirement age
 - The financial impact of stroke on work and the influence of RTW choices on long term health and financial wellbeing.

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