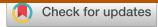
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ORIGINAL REPORT



DESCRIBING RETURN TO WORK AFTER STROKE: A FEASIBILITY TRIAL OF 12-MONTH OUTCOMES

Kathryn RADFORD, PhD, Mary I. GRANT, PhD, Emma J. SINCLAIR, DClinPsy, Jade KETTLEWELL, MSc and Connor WATKIN, MSc

From the School of Medicine, University of Nottingham, NG7 2UH, Nottingham, UK

Objective: Stroke is the greatest cause of disability in adults. A quarter of strokes in the UK affect people of working age, yet under half of them return to work after stroke. There has been little investigation into what constitutes "return to work" following stroke. The aim of this study is to describe the work metrics of stroke survivor participants in a feasibility randomized controlled trial of an early stroke-specific vocational rehabilitation intervention.

Methods: Retrospective analysis of trial data. Metrics on work status, working hours, workplace accommodations and costs were extracted from trial outcomes gathered by postal questionnaire at 3, 6, and 12 months' post-randomization for 46 stroke participants in a feasibility randomized controlled trial. Participants were randomized to receive vocational rehabilitation (intervention) or usual care (control). Results: Two-thirds (n = 29; 63%) of participants returned to work at some point in the 12 months following stroke. Participants took a mean of 90 days to return to work. Most returned to the same role with an existing employer. Only one-third of participants who were employed full-time at stroke onset were working full-time at 12 months post-stroke. Most participants experienced a reduction in pre-stroke earnings. Workplace accommodations were more common among intervention group participants. More intervention participants than control participants reported satisfaction with work at both 6 and 12 months post-randomization.

Conclusion: This study illustrates the heterogeneous nature of return to work and the dramatic impact of stroke on work status, working hours and income. Longitudinal research should explore the socioeconomic legacy of stroke and include clear definitions of work and accurate measures of working hours and income from all sources.

Key words: stroke; rehabilitation; work; brain injuries; vocational rehabilitation.

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Correspondence address: Kathryn Radford, The University of Nottingham, Queens Medical Centre, Nottingham, NG7 2UH, UK. E-mail: Kate. Radford@nottingham.ac.uk

Within the UK, 300,000 individuals in England alone live with moderate to severe disability resulting from a stroke (1). Every year 152,000 stro-

LAY ABSTRACT

Stroke is the single greatest cause of adult disability in the UK. A quarter of strokes affect people of working age; however, less than half of them return to work. This study described the nature of return to work and the help that people require to go back to work. A total of 46 participants were recruited from one English county. Participants were divided into 2 groups: a group receiving usual care and a group receiving extra rehabilitation. The study assessed their work status, the hours they worked, work accommodations, and what they earned at baseline, 3, 6 and 12 months after stroke. Most people returned to work after a mean of 90 days and stayed with the same employer. However, many people needed changes at work, worked fewer hours and earned less than they did before the stroke. Future research should investigate the implications of work adjustments for stroke survivors and whether the reported reductions in hours, status, roles and responsibilities are viewed as positive or negative.

kes occur in the whole of the UK (England, Scotland, Wales, and Northern Ireland) (2); a quarter in people of working age, many of whom have dependent families (3). Fewer than half of these people will return to work (3). The societal cost in terms of health and social care, informal care-giving, and loss of productivity is estimated at £9 billion (approximately 10.5 billion Euros or 11.8 billion US dollars) per year (4). A shift in stroke burden towards younger onset could exacerbate the indirect economic costs (5, 6).

Return to work (RTW) after stroke is a recovery indicator and rehabilitation goal (7). Employment may be critical to quality of life following stroke (8). People who do not RTW after stroke may be at increased risk of depression (9).

The health and economic consequences of worklessness (10, 11) highlight the need for vocational rehabilitation (VR), a process whereby those disadvantaged by illness or disability are enabled to access, maintain or return to employment or other useful occupation (12). Despite widespread research into VR in musculoskeletal or painrelated conditions (13), there has been little research into stroke-specific VR. Stroke-specific deficits can impede successful RTW; in particular hidden disabilities, such as fatigue, concentration, memory and attentional deficits, are rarely addressed in hospital (14), where the primary focus of rehabilitation is on functional recovery (5).

There is a need to support people who develop health conditions to return to and/or remain in work. This is a policy imperative (1, 15, 16) and is recognized as an important outcome of health interventions (17). The lack of evidence for the effectiveness and cost-effectiveness of stroke-specific VR and the paucity of work outcome measurement have hampered VR service development and commissioning (14). Moreover, lack of consensus about what is meant by RTW following stroke has resulted in disparate reporting, limiting comparisons between studies and resulting in wide variation in reported RTW success rates, which range from 7% to 81% (18).

Most studies investigating RTW after stroke have focussed on predictors of RTW (19, 20) or the lived experience of stroke survivors (21, 22). The only trials of RTW interventions post-stroke used a single question, "working yes/no" as the primary outcome (23, 24). Therefore, the nature of "work" and, indeed, what constitutes "success" in post-stroke employment, remain unclear. No studies have investigated what constitutes RTW after stroke. In designing research to measure the outcomes of stroke VR, it is important to understand the impact of stroke on the stroke survivor's work role, working hours and income and how this compares with pre-stroke role and earning; how long it takes to RTW after stroke, and whether this is to the same or a different employer. It would seem important to identify workplace accommodations that enable work participation, and to determine the impact of stroke on sickness absence, and workplace productivity (3, 25–28).

The aim of this study was to describe RTW after stroke, using the work metrics of stroke participants in a feasibility randomized controlled trial of an early stroke-specific VR intervention. Descriptions of the trial and content and dose of stroke-specific VR occupational therapy have been reported previously (29, 30).

Aims

- To describe work metrics of stroke participants in a feasibility trial of an early vocational rehabilitation intervention, i.e. work status, hours worked, time taken to RTW, financial impact, work satisfaction, role, workplace adjustments.
- To identify the impact of stroke on work status and income.

METHODS

Retrospective description of work outcomes and metrics of stroke participants in a feasibility RCT of an early stroke VR

intervention at 12 months post-stroke (trial reported elsewhere (29, 30)). The study received ethical clearance in April 2010 from the Leicestershire, Northamptonshire and Rutland Research Ethics Committee (ref. 10/H0406/21).

Sampling

Participants were 46 stroke survivors recruited to a single-centre feasibility RCT of an early VR intervention. Trial inclusion criteria were: aged over 16 years, in paid or voluntary work or education at the time of stroke and intending to RTW. Participants were randomized to receive either VR in addition to usual National Health Service (NHS) rehabilitation (intervention group) or usual care (control group). Work was defined as at least 1 h per week of paid work or unpaid (voluntary) work or full-time education. Voluntary work excluded family care-giving or housework.

Data collection and analysis

Data gathered from participants at 4 time-points were available for analysis: baseline (mean 21.4 days (standard deviation (SD) 17.2) post-stroke), 3, 6 and 12 months. At baseline, data were gathered face to face and at 3, 6 and 12 months by postal questionnaire. Questionnaires included standardized measures of work ability (Work Limitations Questionnaire (31)) and productivity (Work Productivity and Activity Impairment Instrument (32)) and bespoke questions on work, including work status, salary, workplace accommodations and costs. Data on work metrics were extracted using questions identified in Table I.

The treating therapist provided information on work status, time to RTW and workplace accommodations for 3 intervention group participants who did not return outcome measures.

Data frequencies were calculated using SPSS Version 16. Accuracy checks were performed independently on a randomly selected 10% of data.

RESULTS

Forty-six stroke survivors were recruited to the trial. Half were randomized to receive the intervention, which commenced a mean of 21.4 days (SD 17.2) post-stroke. Table II shows the demographic details. Data were available for 34 participants at 3 months (intervention group: n=16, control group: n=18), 36 participants at 6 months (intervention group: n=19, control group: n=17) and 32 participants at 12 months (intervention group: n=18), control group: n=14). Data were missing for 6 participants (13%) (intervention group, n=2; control group, n=4) at all time-points.

Vocational status

Two-thirds (n=31; 67.4%) of participants returned to work at some point following stroke; 9 (19.6%) did not RTW during the 12-month follow-up (intervention group: n=4; control group: n=5). Fig. 1 shows the number of participants in work at each time-point.

There were no differences between returners and non-returners in terms of stroke severity, age, disability, sex or marital status.

Table I. Metrics for return to work

Metric	Question used to elicit information	Response categories
Work status	Are you currently in work or education?	Yes/No
	Please tell us more about your current work situation	Qualitative data used to classify jobs using SOC codes and identify the self-employed
Time taken to return	What date did you return to work?	N/A
Working hours	How many hours do you work per week?	N/A
	Are you working full or part time?	Full-time employment, part-time employment
	Are you currently working the same hours as before your stroke?	Yes/No
	If no, do you work more or fewer hours compared with before your stroke?	More/Fewer
Job/employer change	s If you are now working or in education, please tick any of the following statements that apply:	I am with the same employer/university, doing the same job/course. Same employer/university, different job/course. Different employer/university, same job/course. Different employer/university, different job/course.
Workplace	Has your employer or tutor made any adjustments for you?	Yes/No
Accommodations	If yes, please complete the following:	Allowed you to take more breaks?
		Reduced the amount of work you have to do?
		Reduced your responsibilities?
		Provided more supervision or support?
		Allowed you to work at home?
		Used any outside help for you, e.g. governmental schemes?
Income	What is your annual income?	N/A
Job satisfaction	Are you happy with your work situation?	Yes, No

SOC: Standard Occupational Classification; N/A: not applicable.

Two people who were in full-time education at baseline returned to and remained in education at all 3 follow-up time-points. Seven participants reported volunteering at baseline, 3 at 3 months, and 4 at both 6 and 12 months post-stroke.

At baseline, 69.6% of intervention group participants (16/23) and 73.9% of control group participants (17/23) were working full-time, and 1 (1/23; 4.3%) and 3 (3/23; 13%), respectively, were working part-time.

Ten intervention group participants (21%) were selfemployed and working full-time at baseline, 6 (6/23; 26.1%) and 3 (3/23; 13%) control group participants

Table II. Demographic characteristics

Characteristics	Intervention group	Control group
Sex, n (%)		
Male	17 (73.9)	19 (82.6)
Female	6 (26.1)	4 (17.4)
Age, years, mean (SD) [Range]	58.3 (12.7) [24-78]	53.8 (12.6) [18-77]
NIHSS, n (%)		
Minor (score 1-4)	8 (34.8)	8 (34.8)
Moderate (score 5-15)	7 (30.4)	6 (26.1)
Moderate-severe (score 16-20)	2 (8.7)	2 (8.7)
Severe (score 21-24)	0 (0)	0 (0)
Missing	6 (26.1)	7 (30.4)
Length of stay, days, mean (SD)	19.6 (21.6)	27.1 (26.9)
SOC code, n (%)		
Non-professional	4 (17.4)	12 (52.1)
Professional and managerial	19 (82.6)	11 (47.8)
Work type, n (%)		
Employed full-time	16 (69.6)	17 (73.9)
Employed part-time	1 (4.3)	3 (1)
Student/casual worker	5 (21.7)	2 (8.7)
Volunteer	1 (4.3)	1 (4.3)

SD: standard deviation; SOC: Standard Occupational Classification; NIHSS: National Institute of Health Stroke Scale

were self-employed. Only one of the self-employed participants reported working part-time at baseline. Two of the self employed participants in the intervention group were not in work; one was made redundant and was working his notice at the time of stroke; another self-employed participant reported that he was working; however, it was later determined that he had not worked for some time prior to his stroke.

Only 2 people who were self-employed returned to full-time work and one of these retired and sold his business by 12 months. Several people who were self-employed were in higher paid consultancy roles, established later in working life. Of the self-employed people who did not RTW (n=2), both had physically demanding jobs (1 was a gardener, another a driver) and stroke severity affected their ability to return to work.

People employed in full- or part-time competitive employment returned to work and gradually increased

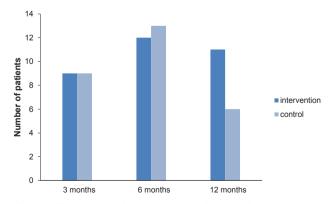


Fig. 1. Self-reported work status at 3, 6 and 12 months post-stroke.

their hours over the 12-month follow-up period, whereas the reverse a decrease of working hours was seen for those who were self-employed.

Fewer people reported full-time work at follow-up. Of those working full-time at baseline, 6/16 (37.5%) who received the intervention and 2/17 (11.8%) controls reported full-time working at 12 months. Nobody who worked part-time before their stroke resumed full-time work afterwards (Fig. 2).

Sustained work return

Only one-third (8/24) of participants who were employed full-time at stroke onset (52%) had resumed full-time work at 12 months post-stroke. Of those who returned to work, 12 (38.7%) did so by 3 months and sustained this until 12 months (intervention group: n=8, control group: n=4). Six (19.4%) participants returned to work by 6 months and remained in work at 12 months (intervention group: n=4; control group: n=2). Five people (16.1%) returned at 3 months, but were no longer working at 12 months (intervention group: n=2; control group: n=3). One intervention participant returned at 12 months. Sustained work return could not be determined for 7 participants.

Time to return

Participants took a mean of 90.2 days to RTW (SD 69.8), 94.9 days for intervention participants (range 7–227, SD 77.4 days) and 85.6 days for the control group (range 8–190, SD 62.1 days).

Working hours

At baseline, intervention participants worked a mean of 35.2 h per week (range 3–55, SD 15.8 h) and control participants a mean of 36 h (range 7.5–55, SD 13.2 h).

Most people who returned to work reported working fewer hours than before their stroke. This included 6 intervention participants at 3 months, 9 at 6 months, and 4 at 12 months. In the control group, 5 participants reported working fewer hours at 3 months, 7 at 6 months, and 3 at 12 months.

Only 3 intervention participants and 4 controls reported working their pre-stroke hours at both 3 and 6 months. At 12 months, 6 intervention participants and 2 controls reported working the same hours as before the stroke. Two participants, one in each group, reported working more hours at 12 months than before their stroke.

Changes in employer/job

Most participants returned to the same role with an existing (pre-stroke) employer. None reported working for a different employer doing a modified or different job. At 6 months, one intervention group participant reported change of employers but was doing the same job as before their stroke. The 2 students reported returning to and remaining on the same course at all 3 time-points (Fig. 3).

Workplace accommodations

At 3 months post-stroke, 10 participants reported workplace accommodations (21.7%); 16 (34.8%) reported these at 6 months, and 12 (26%) at 12 months. The types of accommodations in place are shown in Fig. 4. Outside help typically referred to the use of occupational health services.

At 3 months, 18 workplace accommodations were reported by intervention group participants; compared with 14 by controls. At 6 months 21 and 24 accommodations were reported, and at 12 months, 14 and 5 accommodations were reported, respectively.

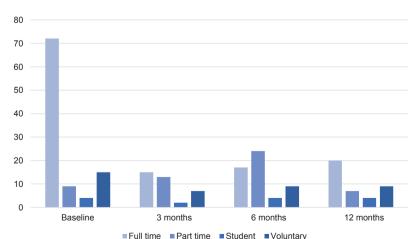


Fig. 2. Self-reported change in vocational status from baseline to follow-up at 3, 6 and 12 months post-stroke (%) for all participants by job status category.

Income

Most participants experienced a reduction in pre-stroke earnings. The mean, annual income was £17,069 for intervention group participants and £20,108 for controls. At 3 months, intervention participants earned a mean of £10,572 per annum and control participants £11,481, followed by £8,486 and £12,073 at 6 months, and £9,893 and £4,525 respectively at 12 months (Fig. 5).

Overall, 20 (43.5%) people reported claiming disability and unemployment benefits at some time during the study. More people were claiming

benefits at 12 months post-stroke than any other time-point (14; 30.4%) compared with 9 at 3 months (19.6%), and 10 at 6 months (21.7%).

Seven participants (3 intervention and 4 control group) were living solely on benefits at 12 months (i.e. Disability Living Allowance and Employment Support Allowance).

Work satisfaction

More intervention participants were satisfied with their work situation at both 6 and 12 months compared with the control group (Fig. 6).

DISCUSSION

The increasing incidence of stroke in younger people, economic implications, and clinical drivers highlight the need to support stroke survivors in RTW. However, what is meant by RTW after stroke remains unclear. This study describes the work outcomes of stroke survivors in a feasibility trial of an early VR intervention.

More than two-thirds of participants returned to work at some point in the year following stroke. This rate is higher than the pooled estimate of 56% reported in a systematic review by Duong et al. (33), but it is consistent with Hackett et al. (9), who found that 75% of stroke survivors were in full-time paid work at 12 months poststroke in an observational study of 271 Australian stroke participants, mean age 52 years, who were in paid work at stroke onset. Hackett's criterion for paid work was 1 h or more in the preceding month and included casual or temporary work.

Most of the participants in this study incurred mild or moderate strokes and a high proportion were in professional or managerial roles at stroke onset. Of those who returned to work within 3 months of stroke onset, most (13/18) were in higher socioeconomic groups. Less severe stroke, non-manual work, higher socioeconomic class and higher education levels are known determinants of RTW after stroke (9, 34, 35). It is likely that these people held positions with greater job security,

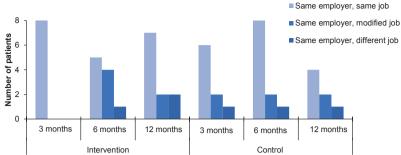


Fig. 3. Self-reported change in roles and responsibilities at 3, 6 and 12 months post-stroke.

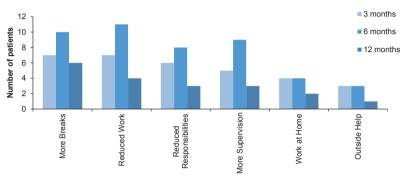


Fig. 4. Self-reported workplace accommodations.

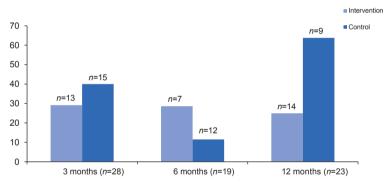


Fig. 5. Self-reported wage loss as a percentage of pre-stroke earnings at 3, 6 and 12 months post-stroke (% wage loss for complete data only).

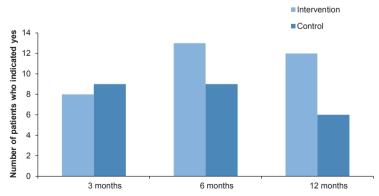


Fig. 6. Self-reported work satisfaction at 3, 6 and 12 months post-stroke.

better terms and conditions of employment, greater awareness of employment law and better policies and procedures in place to support people with disability in the workplace.

Most people reported a substantial reduction in working hours, which is reflected in reduced income. Similar evidence of vocational status change poststroke has been reported (3, 36, 37) and reflects the negative socioeconomic consequences of post-stroke employment (3, 25, 30, 36, 37). This has long-term implications for people with a mean age of 56 years at the time of stroke, particularly given that the state pension in the UK is currently not payable until 66 or 67 years of age. These people may potentially lose 10 years of their working life. In a 6-year follow-up study involving participants from this cohort, all reported that their income had either stayed the same or decreased (38).

However, what is unclear is whether reduced working hours are regarded negatively by all stroke survivors. This warrants further investigation. Reduced hours and changes in jobs, roles or employers may be construed as positive rehabilitation outcomes, particularly when this means the person can continue to work in some capacity, cope financially and achieve work-life balance. There was no upper age limit for inclusion in this study and some participants were at or near retirement age at the time of recruitment. This meant planned reductions in working hours and retirement were intended outcomes of the intervention. Planned changes in income from work to retirement pension or other forms of income, e.g. state benefits, suggest that measuring wage loss alone may be inadequate in studies that include stroke survivors at or near retirement age. Future research should consider measuring income from all sources, including benefit payments, and the impact of stroke on family carer(s)' working hours, productivity and household income.

Similar to Hackett et al. (9), most people returned to the same job with an existing employer. This is unsurprising, since the study focus was job retention. Stroke survivors who are unable to return to an existing job may find it difficult to RTW; previous evidence has highlighted the difficulty in finding new work or re-training post-stroke (39).

Participants took a mean of 90 days to RTW, which is consistent with previous reports (9, 40). However, time to RTW was complex and varied from person to person. Further research should investigate factors that influence stroke survivors' decision-making regarding the timing of RTW, as this may have implications for the timing and delivery of VR. Whilst early VR intervention is recommended (12, 41), the individual nature of stroke, readiness to RTW and the dangers of retur-

ning too early are acknowledged. In this study 5 people who returned to work within the first 3 months of stroke did not remain in work. The reasons for relinquishing work included, fatigue, physical demands of the job, unrelated health issues, and planned retirement. Stroke rehabilitation services should be organized to respond to these vocational needs by delivering "early", "late" and "responsive" interventions (14).

RTW alone has been criticized as an inadequate measure of success (42); the ability to sustain work is also important. Our findings suggest that, while most (18) of those who returned to work at some point following stroke remained in work at 12 months, poststroke fatigue, physical job demands, and co-morbidity may influence work outcomes. These factors should be captured in longitudinal research exploring the socioeconomic legacy and nature of work after stroke. Moreover, adopting consistent follow-up times would promote comparability of studies (33).

Study limitations

This was a small, single-centre study with follow-up limited to 12 months. Complexities regarding the timing of RTW and the fact that it is influenced by contextual factors (financial, stroke severity, disability-related, work environment, personal choice, family beliefs and attitudes) means some stroke survivors return to work after 12 months. This suggests the need for prospective long-term follow-up, e.g. 2–5 years, and exploration of contextual factors that influence work outcomes. However, in the sample studied, no outstanding participants in the intervention group planned to return beyond the 12-month follow-up.

The study relied on self-reported data regarding working hours, and included people in a variety of voluntary and flexible working roles that fluctuated dramatically with regards to hours worked per week. This made accurate measurement of working hours difficult, resulting in the use of best estimates. Requesting a "mean number of hours worked per week in the past month" may be a more reliable measure in future research.

This study omitted to measure the type and size of employer enterprise and other employer-related factors that are known determinants of RTW outcome success in other groups; for example, relationships with line managers (43–45). These should be included in future studies.

A final limitation of the current study was the inclusive definition of voluntary work. This could limit comparisons with other work-focussed studies, which define voluntary work more conservatively. However, some studies categorize voluntary work alongside

education and home-making, so comparison should still be possible (46).

Conclusion

Determining what constitutes RTW after stroke is an important step towards robust measurement of work outcomes, which are much needed in post-stroke VR, clinical practice, and research. Measuring vocational status after stroke is complex. Categorizing participants as employed or not fails to provide a comprehensive picture of the heterogeneity and individualized nature of RTW after stroke. Despite a high overall rate of return, the vocational status of participants changed dramatically. Few achieved their pre-stroke working hours. Some moved from paid to voluntary roles and others towards retirement. The inclusion criteria, which were informed by service users and providers, targeted all stroke survivors who were working at the time of stroke, including people who were self-employed, volunteers and those planning retirement. Given the limited health resources for supporting RTW after stroke, the question of whether resources should be deployed to those planning retirement is important. This study highlights some issues that would need to be addressed in a larger-scale investigation; notably, clearer definitions of work (including full- and parttime work), more accurate measures of working hours, and measurement of income from all sources.

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