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Research Article

Experiences of support to return to work after stroke: longitudinal case studies from RETAKE trial

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Abstract

Background: Returning to work after stroke has physical, psychological and financial benefits for stroke survivors. However, global evidence estimates return-to-work rates 1 year post stroke at < 50%. Although its importance is acknowledged by policy-makers and healthcare providers, vocational rehabilitation is not always part of National Health Service usual care post stroke. Currently, there is limited evidence of the effectiveness of return-to-work support interventions.

RETurn to work After stroKE was a multicentre individually randomised controlled pragmatic trial, with embedded process and health economic evaluations. RETurn to work After stroKE aimed to establish whether Early Stroke Specialist Vocational Rehabilitation plus usual care improves the likelihood of return to work at 12 months post stroke compared to usual care alone. As part of an embedded process evaluation, longitudinal case studies enabled exploration of participants' experiences of support to return to work in the trial.

Objectives: This article aims to understand participants' experiences of being supported to return to work and explores the social and structural factors which support, or act as barriers to, implementation of the Early Stroke Specialist Vocational Rehabilitation intervention.

Method: A longitudinal case-study approach was used to compare experiences of post-stroke return-to-work support received over 12 months by 15 participants who received the Early Stroke Specialist Vocational Rehabilitation intervention plus usual care, and 11 participants who received usual care only. Data were gathered at three time points using follow-up questionnaires, health records, intervention delivery records and semistructured interviews with participants and seven nominated informal carers. Interviews were also conducted with 1 employer and 11 occupational therapists delivering the intervention.

Setting: Sixteen National Health Service sites across England and Wales.

Findings: In the intervention arm, stroke survivors, carers and employers reported benefits from information and support from the treating occupational therapist to facilitate acceptance of, and adaptation to, post-stroke abilities. Participants also valued occupational therapists' provision of sustained and tailored vocational rehabilitation, co-ordinating their care and advocating for them in return-to-work discussions with their employers. Those unable to return to their previous employment were supported to consider alternative options.

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In contrast, participants who received usual care only reported feeling abandoned when community rehabilitation support ended, typically after 2–8 weeks. Usual care largely focused on restoring physical function, leaving these participants struggling to find return-to-work information, advice and support.
Longitudinal case studies enabled psychosocial and environmental factors impacting on participants' return-to-work experiences to be considered.
Limitations: Recruitment to the process evaluation was impacted by the COVID-19 pandemic. It proved difficult to recruit employers for interview, and fewer women participated in the case studies (21 men, 5 women). Direct observation of intervention delivery could not be carried out as planned due to pandemic restrictions on access to clinical areas.
Conclusions: These case studies highlighted self-reported differences between recipients of the Early Stroke Specialist Vocational Rehabilitation intervention plus usual care and participants allocated to usual care only. Aspects perceived as important in underpinning the differences in support included the length of Early Stroke Specialist Vocational Rehabilitation intervention, occupational therapist advocacy, employer liaison and ongoing workplace monitoring. Provision of these core components as part of post-stroke services may support and help to sustain return to work, with associated benefits for stroke survivors and wider society.
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Introduction/background

With increasing numbers of working-age people experiencing stroke, low return to work (RTW) rates post stroke are of concern worldwide.[1] In the USA, 38% of stroke survivors are of working age; in Australia, New Zealand and the UK, it is around 25%.[2–4] Although RTW is often a goal in rehabilitation,[5] < 50% of UK stroke survivors achieve this.[6] This directly impacts on the UK's economy, as stroke survivors are among the 2.5 million people currently economically inactive due to long-term conditions.[7] The COVID-19 pandemic also negatively impacted the labour market, with disabled people 1.5 times more likely to be unemployed than non-disabled people.[8]

Stroke survivors who cannot RTW are more likely to be reliant on welfare benefits, at risk of financial hardship, and more likely to need psychological interventions.[6,9] However, when supported to RTW or other meaningful activity, stroke survivors experience psychological, emotional and financial benefits.[9–12] These include benefits experienced individually (i.e. sense of purpose, financial security), as well societally, with less dependency on government support and increased contributions through tax and national insurance.[13–15] In addition, employers can avoid high costs involved in recruiting and retraining staff to replace employees who cannot RTW.[16]

National Health Service England recommends all stroke survivors are offered vocational rehabilitation support to return to pre-stroke employment or advice on alternatives, and a RTW plan to be implemented within 6 months of stroke.[17]

Although RTW post stroke is also an important issue internationally,[2,3,14,18] there is a lack of consensus around what vocational rehabilitation should consist of, how soon it should begin and how long it should continue. A longitudinal study of severely disabled stroke survivors from seven countries followed up at 6 and 12 months post-stroke reported access to rehabilitation services varied from 24% to 100%.[19] RTW rates are generally measured at 6 and/or 12 months post stroke, but people may take several years to RTW after stroke.[20,21] There is also variation in the support available to stroke survivors and employers; for example, in Sweden and Australia, employers can access government funds to facilitate workplace adjustments and provide wage subsidies,[9,22] as vocational rehabilitation is typically funded by insurance schemes or government initiatives.[18] In the UK, most stroke survivors are reliant on vocational rehabilitation provided by the NHS or through a third-sector organisation, and although government funds are available to facilitate workplace adjustments under the Access to Work scheme, wage subsidies are rare.

There is evidence that biopsychosocial factors affect the likelihood of RTW post stroke. These include stroke severity, gender, cognitive impairments,[9,23,24] motivation,[25–28] job type,[29] size of employing organisation[30] and educational level.[9,20] In addition, residual post-stroke impairments such as fatigue, anxiety and depression may affect both the prospect and sustainability of successful RTW.[18,21,31] The need for a biopsychosocial model of vocational rehabilitation has long been recognised.[32] However, current stroke provision tends to be based on a biomedical model, with little or no vocational rehabilitation provision.[33] Alaszewski and Wilkinson (2015) argue

that short-term rehabilitation, focusing on physiological recovery, is unsuitable for working-age stroke survivors because stroke is a debilitating *social process*, requiring long-term support.[34]

Although research demonstrates a clear need for vocational rehabilitation to enable stroke survivors to RTW, there are insufficient randomised controlled trials (RCTs) investigating its effectiveness.[27,35] To address this problem, RETurn to work After stroKE (RETAKE), a multicentre individually randomised controlled pragmatic trial, was developed, with embedded health economic and process evaluations. RETAKE compared Early Stroke Specialist Vocational Rehabilitation (ESSVR) plus usual care (UC), with UC alone in 16 NHS sites across England and Wales. Trial recruitment ceased in April 2022, with results expected late 2023. The process evaluation protocol was published previously,[13] as were full details of the ESSVR intervention.[36] Briefly, ESSVR seeks to provide a bridge between stroke services providing care and support, stroke survivors who want to RTW, and their employers. It builds on community stroke rehabilitation provision, adding ESSVR. The intervention logic model with core components of ESSVR is shown in *Figure 1.*

Most qualitative studies of RTW interventions have focused solely on the views of stroke or acquired brain injury survivors.[2,3,5,18,24] The RETAKE process evaluation, using a longitudinal case study approach, sought to include multiple perspectives from stroke survivors, nominated carers, occupational therapists (OTs) and employers. This paper reports findings from these longitudinal case studies. Overall findings from the process evaluation will be reported separately.

Aims and objectives

The aim of these longitudinal case studies was to understand participants' experiences of being supported to RTW. Also, to explore the social and structural factors which support or hinder implementation of the ESSVR intervention drawing on multiple perspectives from stroke survivors, carers, occupational therapists and employers.[13]

Methods

These are reported according to the Standards for Reporting Qualitative Research Guidelines (see *Report Supplementary Material 1*).

A longitudinal case-study approach was used to map post-stroke rehabilitation and RTW support received during the 12 months following participants' recruitment to the RETAKE trial. Adaptation to life after stroke is often a long-term process with individual variation evident. A longitudinal case-study approach allowed for exploration of individual experiences of adaptation to life after stroke at 3, 6 and 12 months post baseline. The approach seeks to incorporate the views of multiple stakeholders involved in RTW support. Social and structural factors influencing RTW can be explored individually and collectively. Within and cross-case comparisons contribute to identification of similarities and differences in participants' experiences of support to RTW.

Sampling case-study participants

Up to 5% of the RETAKE trial participants were randomly selected across both trial arms. Randomisation was carried out by the Clinical Trials Research Unit (CTRU) using a 24-hour computer-generated minimisation programme.[36] Potential case-study participants were sent an information sheet by post and then research assistants telephoned them after 7–10 days to confirm consent verbally. Signed consent forms were then returned to the CTRU. Consent was reconfirmed and recorded at each follow-up point.

Data collection

Three forms of data collection were planned. Semistructured interviews were conducted with stroke survivors at three time points [within 6 weeks of recruitment (T1), at 6 (T2) and 12 months (T3)]. Treating occupational therapists of ESSVR participants and nominated informal carers were interviewed at 12 months (T3). ESSVR participants' employers were interviewed where possible. Telephone interviews were conducted by research assistants with backgrounds in psychology and occupational therapy, who were experienced in conducting qualitative research. They had not met the participants previously. The topic guide was informed by Normalisation Process Theory.[37] (See *Report Supplementary Material 2* for the stroke survivor interview topic guide.) Stroke survivors were allowed to have carers/family with them during the interview to support them. They were given time to consider their answers, and questions were rephrased if needed during the interview. Stroke survivor participants were also given the option to do the interview at a time of day that suited them, and they could pause the interview at any time. Interviews were digitally recorded and transcribed professionally. In follow-up interviews, research assistants checked whether participants were still willing to be interviewed. Verbal consent was taken at the beginning of each interview; consequently, if a stroke survivor had a carer or family member with them, they were there for the consent form completion as well as the actual interview.

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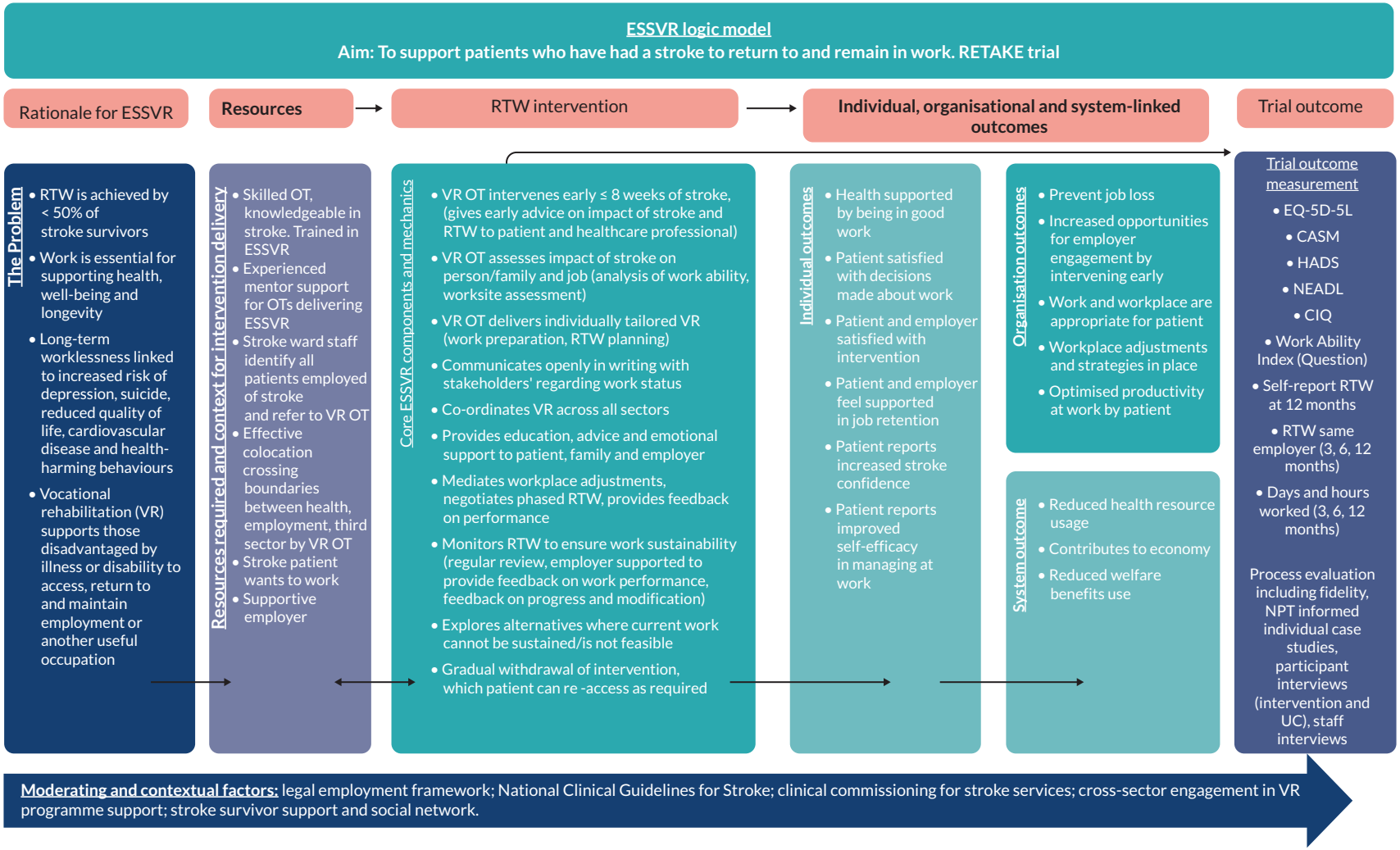

FIGURE 1 ESSVR logic model.[35] CASM, Confidence After Stroke Measure; CIQ, Community Integration Questionnaire; EQ-5D-5L, EuroQol-5 Dimensions, five-level version; HADS, Hospital Anxiety and Depression Scale; NEADL, Nottingham Extended Activities of Daily Living; NPT, Normalisation Process Theory.

The same topic guide was used in baseline and follow-up interviews but updated during the study to include pandemic-related questions. If it was not possible to complete an interview with a participant in the month before/after the interview due date, the participant was reapproached at the next interview time point.

Non-participant observations of intervention delivery and employer interactions with case-study participants were planned for each site.

Trial follow-up procedures[36] included questionnaires sent to participants at 3, 6 and 12 months post stroke. These included questions about participants' use of health and social care services over the previous time periods. These data, where provided, were used in these case studies to quantify and describe UC, which was defined as NHS rehabilitation provided by UC team; this may involve outpatient/community physio-, speech or occupational therapy, psychology, medical follow-up.[36] NHS therapy records for case-study participants were reviewed to identify which intervention and UC components were delivered and the duration of occupational therapist–participant contact. Data were stored electronically, organised per participant and by trial arm within a matrix to facilitate comparison. The published protocol provides a detailed description of these processes.[13]

Data analysis

Framework analysis was used with case-study data.[38] Interview data were coded in NVivo (version 12, QSR International, Warrington, UK) and then imported into a framework matrix for comparison of views within and across cases. The International Classification of Functioning, Disability and Health (ICF) and Normalisation Process Theory informed categories were used to create case study participant summaries.[39,40] The ICF is a framework for capturing contextual and environmental factors around functioning and disability at an individual and population level. Analysis proceeded iteratively with data collection until data saturation had been achieved. Researchers drew on the RETAKE logic model (see *Figure 1*), and Normalisation Process Theory was used as a sensitising framework, that is, as a lens through which to interpret the data.[38] Use of Normalisation Process Theory in the process evaluation as a whole will be reported separately.

Individual interview data and ICF profiles were summarised and then cross-referenced with the treating occupational therapist's therapy records. This facilitated within and cross-case analysis and understanding of the delivery and receipt of ESSVR and UC, the nature of employer engagement, and comparison with UC-only participants' experiences. To enhance reliability and encourage researcher reflexivity, each data set was independently coded by two or more research assistants who then met with the independent Process Evaluation lead (DJC) to discuss any discrepancies in themes derived from coding. Thematic summaries, cross-referenced to the study objectives, were developed and agreed and then shared in writing and through presentation with the wider RETAKE research team, patient and public involvement (PPI) group representatives, and the research active members of the Trial Management Group. These processes ensured that researchers' emerging findings and eventual conclusions were subject to robust questioning and the risk of bias in data analysis minimised.

Impact of the COVID-19 pandemic on sampling and data collection

The pandemic impacted on the longitudinal case-study element of the process evaluation as follows. Firstly, while we aimed to conduct at least one observation per participant, only five non-participant observation sessions had been completed (all with ESSVR participants) before researcher access to hospitals and occupational therapist–participant sessions were prohibited. The findings from the observational data are considered in a separate paper reporting on the overall process evaluation findings. Secondly, pre-pandemic (with ethical approval) research assistants could access participants' occupational therapy records to review ESSVR or UC provision. However, during and post pandemic, requests for these to be provided by secure file transfer were often unfulfilled. Thirdly, from March 2020 to early 2021, there was uncertainty regarding continuation of the trial; recruitment of participants to case studies was stopped when recruitment paused across all sites during the first UK lockdown. Lastly, during and post pandemic, it proved very difficult to recruit employers for interview. These impacts will be considered in the discussion section.

Patient and public involvement

A PPI group which consisted of four men and three women (six had experienced stroke; one had an acquired brain injury) were consulted in the RETAKE study.[36,41] The group met regularly and were involved at all stages, including developing the grant proposal and advising on participant recruitment, questionnaires and interview topic guides. They also contributed to data analysis and dissemination outputs.

Findings

There were 15 case-study participants in receipt of ESSVR plus UC (13 males, 2 females) and 11 participants receiving UC only (8 males, 3 females). In addition, 7 nominated carers and 11 treating occupational therapists were interviewed. For details of interviews conducted, see *Table 1*. Stroke survivor participants' characteristics are in *Table 2*.

Stroke severity in the RETAKE trial was measured using a combination of the Oxford Cognitive Screen tool and the EuroQol-5 Dimensions, five-level version (EQ-5D-5L) Mobility item score. Data for the case-study participants indicate that 19 participants had no impairments in mobility, communication or cognition, suggesting mild stroke; 6 (23.1%) participants had one impairment, suggesting mild-moderate stroke; and 1 person had 2 impairments, indicative of more severe stroke (see *Appendix 1*).

Of these, 19.2% (two ESSVR, three UC) were mobility impairments. Six participants (6.6%, five ESSVR, one UC) had cognitive impairment, and three participants (11.5%) had impairments in expressive language.

Except for cognitive impairment scores, the ESSVR and UC participants appeared similar in terms of stroke severity. The qualitative data reported below indicate that individual participants' lived experiences of their post-stroke impairments differed from the objective measures of stroke severity.

At 12 months post recruitment, 13/26 (50%) of the participants had RTW; 8/15 ESSVR and 5/11 UC-only participants. Common characteristics of those who had RTW included being male (11/13 of returners were men), having a supportive employer, no lasting physical impairments and being motivated to RTW. The presence of previously reported biopsychosocial facilitators or barriers to RTW[9,23,24] are identified in *Appendix 2*, along with details of UC received by each participant. Although we did not have complete data on the frequency and duration of individuals' UC provision (inconsistently reported), qualitative data indicated duration was typically between 2 and 8 weeks, with 2 weeks being more common. Factors affecting the likelihood of stroke survivors' RTW are discussed in the following sections.

The experiences of six exemplar cases are explored in more detail in *Appendix 3*. These case descriptions and commentaries further illustrate key factors impacting on RTW at individual and service provider levels and provide some insight into employer engagement with RTW support.

Factors affecting return to work at an individual level across both trial arms

At time 1 (~12 weeks post randomisation), impairments consistent with mild to moderate stroke were reported by > 50% of participants, including problems with walking and upper limb use. Fatigue was the most frequently reported problem (8/26 participants). Cognitive impairments such as short-term memory and concentration, along with aphasia, were commonly reported and appeared to be a potential barrier to RTW for 6/15 ESSVR participants and 3/11 UC participants. Visual impairments including hemianopia and unilateral spatial neglect were reported by 3/15 ESSVR and 2/11 UC participants, and for most of these participants, it was reportedly the primary reason preventing RTW. Other issues included communication difficulties, co-ordination and balance problems, hypersensitivity to noise, and dizziness.

These factors typically occurred in combination, impacting on participants' RTW plans and their perceptions of the likelihood of RTW. There were particular problems where work roles required high levels of concentration or involved activities requiring manual dexterity:

> *It's really difficult with the memory side of things … it doesn't sound like a major thing but for me personally in my work I would have to remember a lot of things.*
>
> *17VR Ken*

Participants working in manual roles were less likely to RTW compared to those in non-manual roles (5/13 who RTW were manual workers). This was influenced by the extent to which post-stroke impairments affected ability to perform required work activities. For example:

> *[Physios said] If you go back to work you will kill yourself, because it's such a heavy manual job.*
>
> *6UC Victor*

Participants in non-manual roles more commonly reported being able to adapt work roles as part of RTW activity, for example, undertaking different tasks and using strategies to reduce fatigue, improve concentration or vary routine tasks. Other non-manual workers described how RTW was facilitated by being able to work from home (particularly during the pandemic). Working from home helped participants manage fatigue and to overcome problems associated with reduced mobility, including being unable to drive or finding difficulty in using public transport. For example:

TABLE 1 Semistructured interviews with case-study participants

Interview timing:	ESSVR plus UC participants	UC-only participants	Interviews conducted between:	Time elapsed between recruitment and interview: average number of months (SD)
Time 1: within 12 weeks of randomisation	14	11	September 2018–June 2020	4 (2.3)
Time 2: at 6 months	9	6	May 2019–August 2020	8.2 (1.6)
Time 3: at 12 months	5	7	July 2019–January 2021	12.7 (1.2)
Total number of stroke survivor interviews	*n* = 28	*n* = 24		
Carer interviews (jointly with stroke survivor or alone with consent of stroke survivor)	5	2	March 2020–July 2020	
Treating occupational therapist interviews	11	0	March 2020–August 2020	N/A
Employer interviews	1	0	August 2020	

SD, standard deviation.

TABLE 2 Stroke survivor participant characteristics at recruitment and RTW status

Pseudonym	Intervention arm	Age group	Sex (M/F)	Employment role	12 months RTW status (Y or N)
Holly	ESSVR	< 55	F	Leisure and travel service professional	N
Roger	ESSVR	56–65	M	Metal machine setter	Y
Len	ESSVR	56–65	M	Skilled tradesman (music industry) (SE)	Y
Nora	ESSVR	56–65	F	Assembler and routine operator (senior manager)	N
Tom	ESSVR	< 55	M	Small business owner (SE)	Y
Sean	ESSVR	56–65	M	Welder	Y
Nathan	ESSVR	< 55	M	Cleaner	N
Patrick	ESSVR	56–65	M	Security guard	N
Bruce	ESSVR	56–65	M	Managing director (SE)	Y
Ken	ESSVR	< 55	M	Sales representative	N

continued

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TABLE 2 Stroke survivor participant characteristics at recruitment and RTW status (*continued*)

Pseudonym	Intervention arm	Age group	Sex (M/F)	Employment role	12 months RTW status (Y or N)
Dennis	ESSVR	56–65	M	Plasterer (SE)	N
Dave	ESSVR	< 55	M	Porter/handyman	N
Fred	ESSVR	56–65	M	HGV driver	Y
Gordon	ESSVR	56–65	M	Motor mechanic	Y
Tim	ESSVR	< 55	M	Specialist medical doctor	Y
Barry	UC	> 65	M	Chaplain	N
Phil	UC	56–65	M	Team leader	N
Victor	UC	56–65	M	Civil engineer (SE)	N
Harry	UC	56–65	M	Draughtsman (SE)	N
Nancy	UC	> 65	F	Sewing machinist	N
Malcolm	UC	56–65	M	Senior strategy performance officer	Y
Darren	UC	56–65	M	Project manager	N
Pete	UC	> 65	M	Builder (SE)	Y
Bridget	UC	56–65	F	Quality assurance and regulatory professional (2 roles)	Y
Adam	UC	< 55	M	Analyst	Y
Carol	UC	56–65	F	Receptionist	Y

HGV, heavy goods vehicle; SE, self-employed.

Note
Pseudonyms, age ranges and UK Standard Occupational Codes (rather than specific job titles) have been utilised to preserve anonymity.

> *I'm getting used to a new way of working. […] I don't drive nine miles to work, I walk downstairs now, the commute's a lot easier.*
>
> *13UC Malcolm*

> *I think it was to my benefit to be working from home […] removing the commute meant I had more energy for my day-to-day.*
>
> *24UC Adam*

Long waiting times for driving assessments, particularly during the pandemic, impacted potential for RTW for several participants who needed either to drive as part of their role or to get to their place of work.

> *I've requested sick notes because I couldn't drive and while I can't drive, I can't go to work because it's impossible to get there and back.*
>
> *1UC Barry*

This suggests that the participant was not referred to the UK Government's Access to Work scheme which may have mitigated this difficulty in RTW.

Participants across groups reported they experienced new, often stroke-associated health issues. These included reduced self-confidence, work- and health-related anxieties, social anxiety, low mood and depression. For several participants, these were disabling and impacted directly on RTW.

> *I've been really struggling with a lot of anxiety as well […] which I have never, ever in my life experienced before […] it's like I'm bereft of all the confidence that I've had previously in my work, it's a very odd sensation.*
>
> *17VR Ken*

Anxiety and/or depression were reported by 4/15 ESSVR and 5/11 UC participants, issues they indicated were often not addressed by health professionals. Participants also described the burden of stroke when they were already living with multiple health conditions; examples included pre-existing renal disease, sarcoidosis, Asperger syndrome, myasthenia gravis and diabetes mellitus.

An important factor impacting on participants' motivation to RTW was the significance and meaning of work. Financial concerns were often instrumental, particularly for some self-employed participants. They described the stress of needing to ensure that their business continued, as well as difficulties in obtaining alternative sources of financial support:

> *I knew I had to do some work because my money was running out and trying to go through universal credit and being messed about so much, I decided to not do it (secure benefit payments).*
>
> *5VR Len (self-employed)*

> *I just had to get on with it and get back to work, to earn money.*
>
> *15VR Bruce (self-employed)*

In addition to financial concerns, work was described as important for other reasons, including restoration of routine, and possessing a strong 'work ethic':

> *I'm a hard worker … that's the ethics that I have, and I love what I do … you don't want to be unable to do what you used to do.*
>
> *22UC Bridget*

> *'Sean' is a determined chap with a very strong work ethic who will get back to work no matter what.*
>
> *10VR Sean's occupational therapist*

Many participants described being motivated to RTW for social reasons, particularly after pandemic-related lockdowns had reduced social interaction. Others viewed returning to work as a significant step towards restoring some sense of normality to their lives following stroke.

Comparing participants' experiences of community stroke rehabilitation and vocational rehabilitation

As it was frequently not possible to distinguish between early supported discharge (ESD) and community rehabilitation provision, the term 'community stroke rehabilitation' is used in this article. Findings revealed major differences between participants, specifically in relation to the timing of the health professional intervention, receipt of vocational rehabilitation support, co-ordination of services and support in RTW discussions with employers.

Usual care

Community stroke rehabilitation was available to almost all UC participants and appears to have been of some value in helping begin the process of adapting to life after stroke. However, support for participants to prepare for, and to RTW as part of UC provisions, was often limited or absent. One UC participant described the support offered:

> *Someone from [a stroke specialist voluntary organisation] came here and gave me leaflets. It wasn't my cup of tea. It was tailored for older people. She said they do cooking and art classes.*
>
> *6UC Victor*

There were some examples of therapists providing support for UC participants to understand and address problems associated with cognition, memory, decision-making and visual impairment. Targeted speech and language therapy provision was also evident, although this was more commonly cited as an aspect of community stroke rehabilitation that was missing, delayed or infrequently provided. This participant reported delayed access to mental health services:

> *In hospital it was very, very good. Post-hospital, 2 weeks (community stroke rehabilitation) is not enough and what I am now tapping into with the neuropsychological support is very good, but I could have done with this 6 months ago.*
>
> *9UC Harry*

Generally, there was an absence of targeted and sustained support, making it difficult for some UC participants to begin the process of RTW.

> *My concern is I don't know if there's any activities I should be doing between now and returning to work.*
>
> *24UC Adam*

Usual care participants more commonly reported having little or no help to access support with contacting employers and exploring RTW opportunities. Several UC participants reported feeling abandoned once community stroke rehabilitation was withdrawn.

> *Moving onto the programme of returning to work, nothing has happened on that front; and I have really needed that because there are so many things that I need to be doing […] I have enormous difficulty in understanding any […] documentation.*
>
> *9UC Harry*

Two UC participants said that RTW was not mentioned at all during their community stroke rehabilitation. In two other cases, there was time-limited occupational therapist-led work preparation and exercises, signposting to local authority work support services and stroke specialist leaflets or advice. Most UC participants reported that although RTW was raised by community stroke rehabilitation team members, they received no RTW-related follow-up.

> *Interviewer: Did any of them [community stroke rehabilitation team] discuss returning to work with you? Participant: Yes, at the start, but as I only had them for about six weeks, it wasn't really something that – Because then it was just impossible.*
>
> *12UC Nancy*

Another UC participant reported a 6-month delay in receiving vocational rehabilitation.

> *That's been my only negative point […] That appointment was six months after my stroke […] my expectation of the appointment was to work out a return-to-work plan and I thought I'd be having this conversation a lot earlier, but I was already back to full time work when I met with them.*
>
> *24UC Adam*

Early Stroke Specialist Vocational Rehabilitation participants

In contrast to delays in or absence of RTW support experienced by UC participants, RTW discussions began early for ESSVR participants.

> *The RETAKE approach, getting them early … I think is extremely effective … In usual care they're sat on our waiting lists for many, many months.*
>
> *4VR Roger's occupational therapist*

> *It's providing information about stroke … about returning to work.*
>
> *14VR Patrick's occupational therapist*

Almost all ESSVR participants described the RETAKE occupational therapist's role in helping them understand the impact of stroke on their lives in general and specifically in relation to capability to RTW.

> *They helped me understand what's happened to me better. If I was left to my own devices, I would have gone mad, not the right frame of mind. They speak to you and normalise your feelings – it helped'. […] She's [occupational therapist] given us different ways to think about working. […] She helped my [business partner] who I work with, understand it differently.*
>
> *8VR Tom*

Occupational therapist support included understanding participants' emotional, as well as physical, adaptation to stroke. It involved signposting to other services, information provision and advice on activities related to confidence-building, accessing psychological support, and cognition-focused activities. One occupational therapist described her role:

> *I guess it works on two levels. One is about empowering your patient to understand their condition, how it's affecting them and (secondly) how that has implications and could impact on their workplace.*
>
> *4VR Roger's occupational therapist*

RETurn to work After stroKE occupational therapists also supported stroke survivors' families:

> *[Occupational therapist] let us know that we weren't alone … the emotional support was totally beneficial.*
>
> *20VR Dennis's carer*

> *It was a nice feeling for me to know that there are professionals who have 'Nora's interest at heart … I remember them saying, 'Here's my number. Give me a call at any time of the day or night'. That's a great boost for me personally, obviously, with my wife never having had a stroke before, just to have that security, I suppose, in the sense that I'm not alone.*
>
> *7VR Nora's carer*

Several participants described how occupational therapists instigated planning for RTW and provided individually tailored work hardening/work preparation tasks.

> *[Occupational therapist]'s giving me things to do at home, like hand grips and nuts and bolts.*
>
> *23VR Gordon*

> *[Occupational therapist] was aware of what he did for a living, and they tailored [exercises] to that.*
>
> *20VR Dennis's carer*

Co-ordination and advocacy across both trial arms

While some UC participants struggled with managing the various services involved in their care, ESSVR participants described the occupational therapist as the key health professional responsible for co-ordinating their post-stroke care.

> *I had a speech and language therapist and a psychologist and a physiotherapist as well. Between them, it's enormous, but brilliant. [RETAKE occupational therapist] has been like 'Polyfilla' [a commercially available plaster compound used for repairing gaps or cracks in plaster surfaces] between it all.*
>
> *25VR Tim*

Treating occupational therapists became the person who consistently responded to participants' questions about stroke as well as vocational rehabilitation and RTW issues and were available to discuss any concerns or problems. Occupational therapists were very aware of the importance of these elements of their work, as well as the need for (other) occupational therapists to be upskilled to provide this support.

> *A lot of my work has been around psychological anxiety management, building up confidence and self-esteem, those sorts of things, and I don't know whether every clinician would necessarily have those skills.*
>
> *4VR Roger's occupational therapist*

Early Stroke Specialist Vocational Rehabilitation participants and their carers valued having the RETAKE occupational therapist to advocate for them in RTW discussions with employers.

> *I had a long chat with [occupational therapist] about my concerns about going back to work because a year's quite a long time off […] she's explained that to my employer.*
>
> *20VR Dave*

> *His employer has been very good but if he were to have put pressure on him, he felt that [occupational therapist] would be able to say, 'No, hang on a minute. This is what he can do. This is what he can't do', where you can't always verbalise it yourself. He felt she was a good support there to assist him if he needed it for going back to work.*
>
> *21VR Fred's Carer*

The occupational therapist's role as advocate was particularly important where participants reported difficult relationships with their employers who were sometimes reluctant to discuss RTW.

> *[Occupational therapist's] gone to them and said, 'Come on, we need to get "Dave" back to work. He can work'. Because at first I thought […] they were trying to fob me off, to get rid of me. You know, thinking, he can't do the job anymore. And it turns out that that wasn't actually the case.*
>
> *20VR Dave*

RETurn to work After stroKE occupational therapists described the benefits of providing RTW support for up to 12 months, potentially increasing the feasibility of RTW.

> *People's needs don't stop at the end of Early Supported Discharge provision [...] Particularly the more complex ones, sometimes people are only just – it comes to […] six months to a year and that's when they're just kind of getting themselves in a place where they can think about work.*
>
> *17VR Ken's occupational therapist*

Return-to-work experiences: employer engagement

Key factors at the employer level included individual job demands and the ability and willingness of employers to accommodate adjustments to work environments or roles.

Although most UC cases indicated a lack of RTW support through community stroke rehabilitation and healthcare services, some UC participants described being supported to RTW by their employers. For example:

> *A phased return certainly was helpful … not having tight deadlines as well … and the flexibility to say if I want to work from home I could.*
>
> *24UC Adam*

Some large employers were able to suggest alternative roles, although these were not always appropriate.

In cases where employers lacked knowledge of supporting stroke survivors with specific impairments, they valued input from RETAKE occupational therapists.

> *The feedback I've got from employers is they've found it useful, especially the letters that we write as a summary of discussion points […] She said that she'd never experienced anyone who'd had a stroke before, so I did a lot of advice around, what a stroke was, how it might affect this chap, and what sorts of things he might need as a support.*
>
> *10VR Sean's treating occupational therapist*

Findings suggest that there were benefits for stroke survivors whose employers had occupational health provision and/or policies to facilitate RTW.

> *I work for local government […] so it was quite easy. There was a discussion with my line manager, he consulted with occupational health, and they said what I was proposing, which was a phased return over five weeks […] they said that's perfectly reasonable.*
>
> *13UC Malcolm*

Occupational health services generally worked co-operatively with RETAKE occupational therapists which ensured that approaches to RTW were tailored to ESSVR participants' individual requirements.

> *[Company name] pay for [team of occupational therapists] to do work reviews, but it's very much looking at the physical element of it all. So, I did work jointly with that team, and we did work visits together where I could discuss with them fatigue, cognition and the other aspects of his stroke that would have implications on his return to work.*
>
> *4VR (Roger)'s treating occupational therapist*

However, established occupational health services did not always work with RETAKE occupational therapists towards the shared goal of RTW.

> *The occupational therapist obviously can't work in isolation, you can make recommendations but, ultimately, it's up to work and HR. […] They use an external company, but they have their own procedures in place to look at return to work. So, he actually saw an occupational therapist who made their own recommendation, they prefer to use their own people, rather than me.*
>
> *15VR (Bruce)'s treating occupational therapist*

In one ESSVR case, there was a clash between the advice given by the employer's occupational health service that the stroke survivor should remain off work, and the RETAKE occupational therapist. The occupational health recommendation appeared to be based on a single telephone-based assessment.

> *They [occupational health] asked me about what had happened, [I] explained that my arm and leg were about eighty percent of original at the moment, it's getting better. And that was all really.*
>
> *23VR Gordon*

The treating occupational therapist, drawing on an established relationship with Gordon and knowledge of his post-stroke impairments, believed he could commence a phased RTW. Gordon agreed and trusted the occupational therapist's recommendations, apparently empowering him to challenge the occupational health decision. Without the support of the occupational therapist, it appears the occupational health assessment would have delayed or denied Gordon the opportunity to RTW at this company.

In ESSVR cases, occupational therapists described completing workplace visits (with and without participants) to undertake workplace and work role assessments. These visits underpinned occupational therapist's advice on workplace adaptations.

> *I met this chap in his working environment […] he [employer] did listen, and he made sure that he did have his chair and he was taking breaks and things.*
>
> *10VR (Sean)'s treating occupational therapist*

> *Participant: We met to do a worksite assessment and work were happy for me to carry on as long I didn't go back to nights.*
> *Interviewer: Was it helpful to have [occupational therapist] there for those meetings?*
>
> *Participant: Yes because [occupational therapist] helped them to know what I was doing/shouldn't be doing.*
>
> *4VR Roger*

It is possible that some of these employer responses could have occurred without occupational therapist involvement. However, findings revealed that most UC participants did not have sustained occupational therapist advice, advocacy and co-ordinated employer interaction. In contrast, ESSVR participants consistently reported that occupational therapists facilitated employer contact and involvement at an earlier stage in their post-stroke journey and in ways that several participants did not feel able to initiate themselves.

Self-employment and RTW (ESSVR)

There were different challenges for those who were self-employed or worked in small businesses. In some cases, participants returned to work very early (often due to financial pressures and/or to ensure continuation of their business), either prior to occupational therapist involvement or against occupational therapist advice. In other cases, self-employed participants appeared to receive little or no support to adjust to life after stroke and to review the impact of stroke on their continued self-employment. The cases of Tom and Harry (see *Appendix 3*) illustrate differing experiences of two self-employed participants.

The contrasting examples from case-study participants described above highlight the differences in the experiences of ESSVR plus UC or UC alone. We consider factors influencing these experiences and their consequences for vocational rehabilitation and RTW provision in the following discussion.

Discussion

This study used longitudinal case studies to compare experiences of 26 stroke survivors; 15 who received ESSVR plus UC, and 11 who received UC only. The study represents an important contribution to the literature with its exploration of vocational rehabilitation for stroke survivors and has several key strengths. Normalisation Process Theory was used to explore the experiences of intervention recipients who remain under-represented in many studies using this theory.[37] Longitudinal case studies allowed the psychosocial and environmental factors impacting on participants' RTW experiences to be explored; factors which are often missing from evaluations of RTW interventions.[25] Furthermore, the inclusion of data from multiple stakeholders enabled a fuller picture than previous studies focusing on stroke or acquired brain injury survivors' experiences alone.[2,3,5,18,24] The findings reveal the value of occupational therapy to individuals who have had a stroke and the wider employment environment. Specifically, the provision of long-term stroke specialist support by occupational therapists trained to provide RTW support, including employer and workplace liaison. Exploring the perceived value of these two key elements of the ESSVR intervention from the viewpoint of stroke survivors, carers and occupational therapists involved in the trial is a key contribution to the existing literature. Furthermore, the study supports the value to the society of people returning to work following stroke.

Gathering data at three time points over 12 months indicated most participants reported improvements over time, particularly in relation to physical impairments. However, post-stroke impairments and co- and multimorbidities required participants to learn to adapt to changed bodies, changed functional abilities, and often changed cognitive and communication abilities. Some also reported significant mental health problems with limited support to manage these. Comparing participants' experiences demonstrated that ESSVR facilitated acceptance of post-stroke impairments by providing stroke-specific information to participants, their families and employers. Few UC participants reported this kind of information provision. This lack of understanding and adaptation to post-stroke impairments sometimes led to stroke survivors refusing support or returning to work too soon, with negative consequences for job retention.[3,25,42] UC participants also possibly overestimated post-stroke impairments, resulting in a lack of confidence in their ability to RTW and deciding not to do so,[11] even when RTW may have been feasible and employers supportive.

Almost all ESSVR participants reported individualised, co-ordinated and sustained stroke-specific vocational rehabilitation and RTW support from RETAKE occupational therapists. This was consistent with the logic model's anticipated intervention outcomes (see *Figure 1*), facilitating collaborative planning and negotiation of RTW with participants and employers. There were multiple examples of individually tailored vocational rehabilitation in ESSVR participants' accounts, such as work-related exercises appropriate for their job role which facilitated

RTW.[3] This supports recommendations that age-appropriate information and vocational rehabilitation adapted to the needs of individual stroke survivors should be available for working-age stroke survivors.[3,5,17,18,26,43–45]

In contrast, post-stroke services received by UC participants were typically short in duration, fragmented and poorly co-ordinated. Support for UC participants focused on physical rehabilitation, despite the wide range of less visible impairments commonly reported by UC participants.[5,18,46] Another notable issue was that while RTW was quite regularly raised with UC participants by community stroke rehabilitation staff, it was rarely followed up with vocational rehabilitation advice or support, even though vocational rehabilitation is the main facilitator for RTW.[45] Overall, our findings confirmed previous research suggesting that in England and Wales, vocational rehabilitation provision in UC is either limited or non-existent, despite recent NHS recommendations for its provision.[17,43,47]

Although in many cases individual factors presented as barriers to RTW, this was often mitigated by participants' determination to RTW. In line with previous research, the significance of work and participants' motivations to RTW were revealed as important factors influencing RTW.[25,28] Financial need was one of the main motivators for RTW, including employed participants who often saw a reduction in their income when they only received statutory sick pay. However, this was particularly pertinent for self-employed participants who described the stresses involved in trying to maintain their business and/or find financial support. Their reported experiences indicate striking gaps in vocational rehabilitation provision and support for self-employed stroke survivors in both UC and, to a lesser extent, the ESSVR group. Other motivating factors included the social aspects of work and restoring a sense of structure to their days. As purposefulness, motivation and hope are known predictors in RTW,[28] our findings support suggestions that the meaning of work should be explored with stroke survivors during RTW discussions.[25]

Findings revealed the number of health professionals and complexity of interventions aimed at addressing the effects of stroke. Participants recognised the importance of this professional support which they frequently sought. But at the same time, it was clear that it could be overwhelming and difficult to co-ordinate healthcare and rehabilitation services without professional help.[3,43,48] In ESSVR cases, the occupational therapist was a single point of contact to lead, co-ordinate and manage the complex situation that is RTW after stroke for individuals, thereby removing that burden from stroke survivors. In contrast, UC cases revealed that RTW progression could be hampered due to uncoordinated support. Our findings therefore reinforce recommendations that stroke survivors should have a single contact person to provide information, answer questions and co-ordinate services.[3,5,10,18]

Previous research highlights the importance of communication and co-operativeness between all stakeholders for facilitating RTW discussions.[3,11,25] The case studies revealed that breakdowns in communications or relationships between stroke survivors, occupational therapists and employers were detrimental to RTW aims. In terms of employer engagement, findings revealed varying degrees of support. Only UC participants who worked for larger national or public sector employers were likely to have received advice or recommendations on RTW from occupational health services. Other UC participants had to negotiate with their employers without advice or support from professionals with vocational rehabilitation skills. This lack of specialist advice was also potentially problematic for employers who may have had no experience of stroke or its impact on individuals' ability to RTW. Again, the experiences of ESSVR case-study participants differed markedly, with clear evidence of RETAKE occupational therapists going into the workplace and adopting a co-ordination and advocacy role for stroke survivors and providing specialist vocational rehabilitation and RTW advice and support for nominated carers and employers.

Our findings echo previous research showing that employers appreciate being provided with information around stroke in general and, more specifically, how stroke might impact their employee's ability to perform their role.[42,49] Some ESSVR cases indicated that sharing information with employers facilitated acceptance of their employee's post-stroke abilities and enabled appropriate adaptation of the work environment. Effective communication with employers and their willingness to adapt to stroke survivors' abilities (where possible) have been identified as key mechanisms for facilitating RTW, along with healthcare providers and employers being adaptive, purposeful and co-operative with each other and stroke survivors.[11,25] This is borne out in our findings which suggest that employers preferred to discuss adaptations with a healthcare professional, rather than their employee who might be unaware of their limitations until they actually RTW.[42] Occupational therapists' provision of appropriate information often facilitated RTW under conditions befitting the stroke survivor's abilities, supporting recommendations that employer communication should be a standardised element of vocational rehabilitation.[18]

Findings point to further advantages of providing specialist advice to employers with little or no prior

experience of supporting someone to RTW post stroke. This acknowledges the differences between stroke and some other health conditions where RTW does not represent complete recovery but requires adaptations to consider less visible symptoms such as fatigue.[31] In this study, fatigue was the most frequently reported problem following stroke, supporting previous research which argues that post-stroke fatigue regularly impacts RTW.[21,50] There was also evidence that fatigue often became more apparent following participants' RTW,[21] with potential implications not only for the participant and the quality of their work but also the subsequent impact on their colleagues.[42] These findings may be generalisable to other conditions, and pertinent to emerging research such as the impact of long COVID on the workforce.

A particular environmental factor affecting RTW for our participants was the timing of the study which was ongoing during the COVID-19 pandemic. This created both barriers and facilitators for RTW. Barriers included delays or absence in receiving medical interventions and psychological support. Delays to, or lack of, psychological support for stroke survivors has previously been identified as a cause for concern in multiple studies,[5,42] and may have been exacerbated further during the pandemic. The prevalence of issues, including anxiety and depression in our sample, highlights the importance of improving mental health support for stroke survivors.[18] This might include alerting stroke survivors to the possibility that psychological issues may emerge,[48] and signposting them to appropriate sources of advice (an element of the ESSVR intervention).[13]

The possibility of experiencing post-stroke impairments which emerge over time such as fatigue, particularly following RTW,[21,31] underlines the importance of providing fatigue management techniques and continuing monitoring even after RTW has been achieved. The 12-month ESSVR intervention ensured that occupational therapists could continue to advise participants and employers about specific support needs such as reduced hours or regular breaks, thereby increasing the likelihood of job retention.[48] Current UC and vocational rehabilitation provision in the UK is not designed to provide long-term RTW monitoring or employer engagement.[17,47]

Limitations and future research

Conducting the study during the pandemic required adaptations to the sample size and some of the data collection methods planned.[13] It is possible that a larger sample of case-study participants would have indicated a wider range of experiences than we have reported. Similarly, additional opportunities to directly observe additional interactions between occupational therapists and participants would have enhanced understanding of the ways in which the ESSVR intervention was delivered and received.

This study is also limited in part by the gender imbalance of the overall sample as well as the case-study sample where only 5/26 participants were female. Future research should focus on female stroke survivors' RTW experiences which were under-represented in the current study. In addition, it would be useful to gather the perspectives of more carers to explore their support needs. Finally, the study was not able to recruit the planned number of employers; thus, the employer experience is reported through the experiences of participants and treating occupational therapists rather than first-hand. The challenges of recruiting employers to similar studies have been reported previously.[42,49,51] A further study is underway seeking to understand employers' perspectives of supporting a stroke survivor to RTW, particularly during the recent pandemic.

Another potential limitation in this type of research is possible researcher bias towards the intervention. We sought to minimise this risk by using a structured process of data analysis and interpretation. This included independent researcher and PPI group oversight and regular team review of emerging findings and their interpretation. Although this does not entirely eliminate the potential for bias, we have sought to make clear the rigour of the processes we used to demonstrate the trustworthiness of our findings.

Equality, diversity and inclusion

The case-study population included 21 males and 5 females stroke survivor participants; 80% (20) participants were white, with the remaining 20% of participants from black (1, 4%), Asian (2, 8%) and other ethnic groups (2, 8%), with missing data for one participant. The research team were racially homogeneous (white) and consisted of 15 women and 4 men. The PPI group included four men and three women, including one black female stroke survivor.

Conclusion

The case-study findings indicate that the ESSVR intervention, as delivered, was consistent with the components outlined in the logic model. Importantly, it was valued by participants who received it, their family carers, by employers and by the treating occupational therapists. By seeking to include all stakeholders in decisions and

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RTW plans with an occupational therapist as co-ordinator, stroke survivors were not passive recipients of care but active participants in the vocational rehabilitation and RTW process. ESSVR participants particularly valued the length of intervention, with occupational therapists providing advice and information for all stakeholders, advocacy, employer liaison and ongoing workplace monitoring for up to 12 months. Provision of these core components as part of post-stroke services may support and help to sustain RTW with the associated benefits for stroke survivors and wider society. Overall, the case studies provide evidence that ESSVR is perceived as more effective than UC alone in supporting RTW post stroke. If this finding is supported by the RCT analyses, these case-study data will help explain the underpinning therapeutic mechanisms.

Additional information

CRediT contribution statement

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Data-sharing statement

Data supporting this work are available on reasonable request. All requests will be reviewed by relevant stakeholders, based on the principles of a controlled access approach. Requests to access data should be made to CTRU-DataAccess@leeds.ac.uk in the first instance.

Ethics statement

Approval obtained through the East Midlands–Nottingham 2 Research Ethics Committee (Ref: 18/EM/0019) and the National Health Service Research Authority on 5 February 2018.

Information governance statement

The University of Nottingham and the University of Leeds are committed to handling all personal information in line with the UK Data Protection Act (2018) and the General Data Protection Regulation (EU GDPR) 2016/679. Under the Data Protection legislation, the University of Nottingham and the University of Leeds are joint Data Controllers, and you can find out more about how we handle personal data, including how to exercise your individual rights and the contact details

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Caroline Watkins: HTA Commissioning Committee September 2011–November 2015.

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List of abbreviations

CTRU	Clinical Trials Research Unit
ESD	Early Supported Discharge
ESSVR	Early Stroke Specialist Vocational Rehabilitation
GP	general practitioner
ICF	International Classification of Functioning, Disability and Health
NIHR	National Institute for Health and Care Research
OT	occupational therapist
PPI	patient and public involvement
RCT	randomised controlled trial
RETAKE	RETurn to work After stroKE
RTW	return to work
SALT	speech and language therapist
UC	usual care

List of supplementary material

Report Supplementary Material 1
Standards for reporting qualitative research guidelines

Report Supplementary Material 2
Interview topic guide

Supplementary material can be found on the NIHR Journals Library report page (https://doi.org/10.3310/WRKS9661).

Supplementary material has been provided by the authors to support the report and any files provided at submission will have been seen by peer reviewers, but not extensively reviewed. Any supplementary material provided at a later stage in the process may not have been peer reviewed.

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Appendix 1 Stroke severity in case-study population

	ESSVR intervention (plus UC) (*n* = 15)	UC only (*n* = 11)	Total (*n* = 26)
Number of impairments			
None	12 (80.0%)	7 (63.6%)	19 (73.1%)
At least one	3 (20.0%)	4 (36.4%)	7 (26.9%)
1	2 (13.3%)	4 (36.4%)	6 (23.1%)
2	1 (6.7%)	0 (0%)	1 (3.8%)
3	0 (0%)	0 (0%)	0 (0%)
Was there a mobility impairment (EQ-5D mobility score[a])?			
No impairment	13 (86.7%)	8 (72.7%)	21 (80.8%)
Impairment	2 (13.3%)	3 (27.3%)	5 (19.2%)
Was there an aphasia impairment (OCS picture naming score[b])?			
No impairment	13 (86.7%)	10 (90.9%)	23 (88.5%)
Impairment	2 (13.3%)	1 (9.1%)	3 (11.5%)
Was there a cognitive impairment (OCS mixed score[c])?			
No impairment	60 (92.3%)	25 (96.2%)	85 (93.4%)
Impairment	5 (7.7%)	1 (3.8%)	6 (6.6%)
Type of impairment (mutually exclusive)			
None	12 (80.0%)	7 (63.6%)	19 (73.1%)
Mobility	1 (6.7%)	3 (27.3%)	4 (15.4%)
Aphasia	1 (6.7%)	1 (9.1%)	2 (7.7%)
Cognition	0 (0%)	0 (0%)	0 (0%)
Mobility and aphasia	1 (6.7%)	0 (0%)	1 (3.8%)
Mobility and cognition	0 (0%)	0 (0%)	0 (0%)
Aphasia and cognition	0 (0%)	0 (0%)	0 (0%)
Mobility and aphasia and cognition	0 (0%)	0 (0%)	0 (0%)

a Mobility impairment defined as moderate or severe problems in walking about or unable to walk about on the EQ-5D-5L Mobility item.
b Aphasia impairment defined as a score of 3 out of 4 or less on the OCS picture naming task (based on the 5th centile of normative data in the OCS user manual indicating impairment on expressive language).
c Cognitive impairment defined as a score of 4 out of 13 or less on the OCS executive mixed task (based on the 5th centile of normative data in the OCS user manual indicating impairment on task switching/attention).

Appendix 2 Usual care received and presence of biopsychosocial facilitators or barriers to RTW

Pseudonym	UC received	Biopsychosocial facilitators to RTW	Biopsychosocial barriers to RTW
Holly	• PT (unrelated to stroke) • Contact with benefits advisor and Job Centre (at 12 months)	• Aged < 55 • Supportive employer • RTW support (ESSVR)	• Female • Physical function impairments • Fatigue • Anxiety • Single parent
Roger	• ESD (PT and OT) • Stroke education from consultant • Regular GP contact throughout 12 months	• Male • Supportive employer • No financial pressure to RTW • RTW support (ESSVR)	• Aged > 55 • Physical function impairments • Manual job role • Anxiety
Len	• ESD (OT) • Private therapy with osteopath (5 sessions) • Regular GP contact throughout 12 months	• Male • No lasting physical impairments • RTW support (ESSVR)	• Aged > 55 • Fatigue
Nora	• ESD (PT)	• Supportive family • No financial pressure to RTW • RTW support (ESSVR)	• Female • Aged > 55
Tom	• ESD (PT, OT and SALT) • Psychological support (from 6 months post stroke) • Regular GP contact throughout 12 months	• Male • Aged < 55 • RTW support (ESSVR)	• Manual job role • Memory and attention impairments • Comorbidities • Mood disturbances • Incompatible work environment • Financial pressure to RTW
Sean	• ESD (PT)	• Male • RTW support (ESSVR)	• Aged > 55 • Functional upper limb impairment • Fatigue
Nathan	• ESD (PT and OT) • Upper Limb Clinic	• Aged < 55 • No financial pressure to RTW • RTW support (ESSVR)	• Multimorbidity • Functional upper limb impairment • Manual job role • Unsupportive employer
Patrick	• ESD (PT) • Regular contact with neurologist 3 months post stroke	• Male • Supportive family • RTW support (ESSVR)	• Aged > 55 • Manual job role
Bruce	• Some early contact with GP and stroke consultant	• Male • No lasting physical impacts • RTW support (ESSVR)	• Aged > 55 • Fatigue • Financial pressure
Ken	• ESD (PT, OT and SALT) • Weekly exercise rehabilitation class • Psychological support (from 6 months post stroke) • Contact with Job Centre at 12 months post stroke	• Male • Aged < 55 • No residual physical impact • Supportive employer • RTW support (ESSVR)	• Short-term memory • Visual impairment • Loss of driving licence • Anxiety and depression • Multimorbidity
Dennis	• ESD (PT, OT and SALT) • GP (regularly from 3 months post stroke) • Benefits advisor (12 months post stroke)	• Male • Supportive family • RTW support (ESSVR)	• Aged > 55 • Functional upper limb impairment and dysphagia • Required knee surgery • Low mood

continued

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Pseudonym	UC received	Biopsychosocial facilitators to RTW	Biopsychosocial barriers to RTW
Dave	• ESD (OT and SALT) • Ophthalmologist (1 year post stroke)	• Male • Aged < 55 • Supportive employer • RTW support (ESSVR)	• Manual job role • Impaired vision and memory • Lack of supportive family • Loss of driving licence • Pandemic-related delays in care
Fred	• ESD support (not specified) • 6 × weekly exercise rehabilitation class • Support group	• Male • No physical impact • No comorbidities • RTW support (ESSVR)	• Aged > 55 • Visual impairment • Manual job role • Loss of driving licence
Gordon	• None reported.	• Male • Pandemic-related benefits (time to focus on rehabilitation) • RTW support (employer's OH and ESSVR)	• Aged > 55 • Functional upper limb impairment • Memory impairment • Fatigue • Manual job role
Tim	• ESD (PT, SALT, OT and psychologist)	• Male • Aged < 55 • Non-manual job role • Motivated to RTW • Supportive employer • RTW support (ESSVR) • Accessed profession-specific mentoring support	• Speech and swallowing impairment • Multimorbidity
Barry	• ESD (PT and OT) • Regular GP contact	• Male	• Aged > 55 • Physical, balance, visual impairments • Multimorbidity • Low mood • Loss of driving licence
Phil	• Regular GP contact	• Male • No residual physical impairments	• Aged > 55 • Some speech and language impairments • No RTW support
Victor	• ESD (PT and OT) • Stroke nurse (at 6 months)	• Male	• Aged > 55 • Manual job role • Multimorbidity • Financial pressure
Harry	• ESD (OT) • Neuropsychology service • Neuro-ophthalmology	• Male • Non-manual job	• Aged > 55 • Cognitive and visual impairment • Caring responsibilities • No RTW assistance • Financial pressure
Nancy	• ESD (PT and OT)		• Female • Aged > 55 • Functional impairments • Manual job role
Malcolm	• ESD (PT) • Regular GP contact	• Male • No residual physical or cognitive impairments • Supportive employer • Pandemic enabled working from home • RTW support (from employer's OH service)	• Aged > 55 • Depression and anxiety

Pseudonym	UC received	Biopsychosocial facilitators to RTW	Biopsychosocial barriers to RTW
Darren	• ESD (PT)	• Male • Aged < 55 • Supportive family	• Fatigue • Multimorbidity • Required surgery delayed by pandemic
Pete	• Regular GP contact • Vestibular rehabilitation service	• Male • No residual physical or cognitive impacts • RTW support (from employer's OH service)	• Aged > 55 • Initial physical impairments • Manual job role
Bridget	• Community rehabilitation service (upon discharge) • Rehabilitation exercise classes (run by rehabilitation charity) • Private PT	• No residual physical impairments • Pandemic enabled working from home • RTW support (from community stroke team)	• Female • Aged > 55 • Upper limb weakness • Loss of driving licence
Adam	• NHS vocational rehabilitation service (beginning 6 months post stroke) • Neuropsychological service (beginning 6 months post stroke)	• Male • Aged < 55 • Non-manual job role • No residual physical impairments • Supportive employer • Supportive family • No financial pressure to RTW • RTW support (from employer)	• Fatigue • Multimorbidity • Mood disturbances
Carol	• ESD (SALT and PT) • Private OT • Accessed GP for work 'fit note' (certificate of fitness to RTW)	• Supportive employer • Supportive family	• Female • Aged > 55 • Speech and language impairments • Family not supportive of RTW

ESD, Early Supported Discharge; ESSVR, Early Stroke Specialist Vocational Rehabilitation; GP, general practitioner; NHS, National Health Service; OH, occupational health; OT, occupational therapist; PT, physiotherapy; RTW, return to work; SALT, speech and language therapist.

Appendix 3 Exemplar case studies

Case 1 (UC only) Darren (56–65)

Pre stroke: Darren worked for a company supplying and installing medical equipment. His job involved driving long distances throughout the UK. Pre-existing comorbidities include an arthritis-like condition, asthma and hypertension.

Impact of stroke: Fatigue, low energy, dizziness, disorientation. Post-stroke diagnosis of heart problem.

Following stroke: At baseline, Darren described how he initially delayed seeking treatment for his stroke because he attributed it to a water infection associated with his pre-existing condition. He was shocked at having a stroke, as he had always been very active. Stroke had left him unable to pursue his hobbies of gardening and car renovation because he was unable to use tools. Being asked (in the interview) whether he had RTW gave Darren hope that it might be a possibility. He was getting full pay for 6 months. His only contact with his employer was texts and photos of medical certificates confirming his inability to RTW. Darren said RTW was not possible because he was unable to drive for the first month and then only for short distances; however, he wanted to RTW 'in the future'.

At follow-up 1 (4–5 months post stroke), RTW remained a goal, but he had lots of unanswered questions about his stroke. He described his employer as supportive, phoning regularly. There was no pressure from family to RTW, but he was aware that he would need money and was 'too proud' to claim benefits. Darren was waiting to see a cardiologist (related to his hypertension) and meanwhile felt 'stuck in limbo'.

Outcome: By 12 months, Darren had not RTW, although his job was still open. Darren's cardiology treatment had been cancelled due to the COVID-19 pandemic. He was still experiencing fatigue (comparing himself with a car without petrol), which he attributed to the cardiac problem. He was surprised to hear the phrase 'post-stroke fatigue' while at the vestibular clinic, which seemed to explain it. The first time he had seen an occupational therapist was 6 months after his stroke. Sick pay had ceased, and his wife pushed him to go to the Job Centre, which he found 'very belittling'. He was asked to look for work by the Job Centre staff and had to explain '3 times' that

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he already had a job but was 'incapable of doing it'. He felt that he had lost 3 months cardiology treatment due to the pandemic. At 6 months, Darren's employer had sent him for an independent assessment to see whether he was capable of RTW. This was not deemed possible, as he was still awaiting cardiac surgery. Darren's employer was very supportive, having some knowledge of stroke through experience of family members. He was willing to accommodate a phased return and change of role, but Darren said, 'Physically I know I'm not capable' and RTW 'doesn't cross my mind'. He described his employer as thoughtful for suggesting adjustments 'they don't want to lose my experience'. He had also been offered two other jobs while off sick. However, Darren wasn't even considering RTW until his cardiovascular problem was sorted out because he didn't want to set his 'mind on something that wasn't achievable … I know I can't do it'.

Comment: Darren's employers were apparently keen for him to RTW and willing to make adaptations (key facilitators for RTW). They appeared to value his expertise and experience, offering to help him to RTW in a reduced capacity. However, Darren reported he felt unable to try to RTW. His comment that he was incapable of working possibly indicates a lack of understanding of his post-stroke abilities, suggesting that the information he received during UC was insufficient to encourage him to pursue RTW discussions. In addition, Darren lacked strategies for managing fatigue. Although he reported seeing an occupational therapist at 6 months, there is no evidence that he received any information or support on how to RTW or manage his post-stroke problems, including his fatigue, as a result of this assessment. Neither was there support from a knowledgeable healthcare professional to provide advice to Darren and his employer during RTW discussions.

Case 2 (UC **only) Carol (56–65)**

Pre stroke: Receptionist. Role involved routinely communicating with members of the public by telephone and e-mail.

Impact of stroke: Expressive aphasia, finding it difficult to make the right sounds for words and numbers, impaired right upper limb grasp movement and grip strength.

Following stroke: At 4 months after experiencing stroke (our baseline interview), Carol had already RTW. The decision to RTW was prompted by financial concerns, as Carol only received statutory sick pay, as well her expressed need for social contact after the pandemic enforced lockdown. Carol had received 2 weeks of UC from a speech and language therapist (SALT) and an occupational therapist. She had two visits from a physiotherapist, who gave her grip-strengthening exercises. There is evidence of some vocational rehabilitation provision in Carol's UC. She was asked about her job, and vocational rehabilitation was tailored to practicing aspects of her role, including role-playing telephone conversations (with a SALT) and answering e-mails on an iPad (with an occupational therapist). Although Carol found these sessions useful, they were curtailed during the pandemic when face-to-face support was no longer possible as Carol was deemed clinically vulnerable.

Carol's son and daughter were included in discussions about RTW with her general practitioner (GP). Between them, they decided that a phased return with amended duties would be achievable, but the GP did not provide any referrals, information or co-ordination to support the process. Although Carol's employers initially agreed to reduced hours and duties which would not involve using the telephone, Carol was soon being asked to increase her duties to include face-to-face and telephone conversations. Carol's children were disappointed with the employer's actions and expressed concern that she was being expected to perform tasks which were incompatible with her post-stroke impairments. They were also anxious that they may have been instrumental in encouraging Carol to RTW before she was ready, because they lacked stroke-specific guidance. Carol had not had any medical assessments since leaving hospital because appointments with the stroke team had been cancelled due to the pandemic.

Outcome: Carol had RTW on reduced hours, which she was happy with and wanted it to be a permanent adjustment. Carol's children were concerned that she might be laid off at some point, as she was unable to perform her previous role fully. They were also suggesting she should retire, although that was not expressed by Carol herself.

Comment: Carol's case indicated that she received some time-limited but individualised vocational rehabilitation as part of UC. It highlights not only the importance of motivation for RTW but also the importance of continued support and monitoring once RTW has happened. Carol's GP had deemed her capable of RTW, but her ongoing difficulties with aphasia meant that she ought not to have been expected to deal with telephone calls and face-to-face enquiries. There is no evidence of any healthcare professional involvement to advocate for Carol in RTW discussions with her employer. Carol had expressed her wish to RTW for financial and psychosocial reasons, but with the employer apparently seeking to increase her workload contrary to the initial agreement on RTW arrangements, the likelihood of sustainability of her employment was uncertain.

Case study 3: (ESSVR) Nora (56–65)

Pre stroke: Nora was employed as a line manager, in charge of 40–50 staff. She worked long days and was on her feet most of the time. Nora described her employer as 'ruthless' with a history of threatening people with dismissal if they did not RTW even when unwell. Nora was very active despite some pre-existing health conditions, including a long-term condition that causes muscle weakness (this affected the participant's speech and swallowing, pre stroke, and continued to impact on her fatigue post stroke).

Impact of stroke: Initially, speech was very slurred, difficulty walking unaided and struggling with fatigue. Partner notes that participant's short-term memory is affected.

Following stroke: Nora suffered from fatigue; sometimes this was due to overexertion (e.g. she cleaned all her windows 3 days after hospital discharge), other times she slept all day. A physiotherapist attended for 2 weeks but discharged Nora when she was able to walk. The occupational therapist advised Nora to pace activities, to keep a sleep diary and to get dressed so that she was less likely to sleep during daytime. The occupational therapist gave Nora small tasks which Nora was more likely to do than if her husband had suggested them.

Nora and her husband valued having the occupational therapist as an advocate during RTW discussions. Nora (who described herself as 'shy') felt that without the occupational therapist's presence, she might have been pressurised to RTW too soon. The carer felt it was valuable to have someone 'neutral' to advise the employer, who admitted that they had no experience of supporting someone to RTW after stroke. Nora felt empowered to continue to discuss RTW with her employer when she felt ready.

Outcome: At 12 months, Nora's balance and walking had improved, but she had not RTW. However, that was due to non-stroke-related health issues, without which the occupational therapist was confident Nora would have started her phased return. Although there was no financial imperative to RTW, Nora was motivated to do so because she did not enjoy staying at home all day. Both Nora and her husband appreciated support from the occupational therapist, which gave them strategies to adapt to life post stroke. The occupational therapist helped them both feel less isolated and fully supported throughout the 12-month intervention.

Comment: The value of the ESSVR intervention in this case was that the occupational therapist advocated for Nora. This prevented Nora RTW too soon, which she suspected would be the case if she had to deal with her employer alone. Although there was no RTW at 12 months, the occupational therapist's continuing support and provision of strategies for managing fatigue fostered hope that it might be possible when other health issues were resolved.

Case 4 (ESSVR) Fred (56–65)

Pre stroke: Employed as a HGV driver for a large national employer.

Impact of stroke: Visual impairment. Minor cognitive issues (word-finding difficulties and slips of memory) and fatigue.

Following stroke: Along with minor cognitive issues and fatigue, the main impact of Fred's stroke was visual impairment. This directly affected Fred's ability to RTW because his driving license was revoked. Fred's employers were very supportive and offered to find him an alternative role in the company which would not entail driving. However, Fred was concerned about needing to take regular breaks due to fatigue and worried that his visual impairment might pose a safety risk. In addition, the remote location of the workplace and the times that he would need to be there to accommodate shift patterns meant that using public transport to reach work would not be feasible.

Outcome: In this case, the RETAKE occupational therapist provided psychological support and worked with Fred to explore alternative RTW options. These were informed by Fred's re-evaluation of his priorities following stroke. By the final interview, Fred had not ruled out returning to paid work, but there was no financial imperative to do so. Fred was enjoying a new voluntary role which enabled him to practise the strategies that the RETAKE occupational therapist had taught him for managing fatigue. After 20 + years with the same employer, Fred appreciated the lack of pressure in his voluntary role.

Comment: Fred's case illustrates the impact of visual impairments and post-stroke fatigue which prevented him from returning to his role as a driver and created anxieties that led him to decline his employer's offer of an alternative role. He also declined it for the more practical reason that his workplace was inaccessible by public transport. There is no evidence that Fred was made aware of possible support available through the Access to Work scheme, a government scheme aimed at helping disabled people to work. It shows that health professionals need specialist knowledge to fully support people to RTW.

Despite Fred's failure to RTW to his pre-stroke employment, the RETAKE occupational therapist enabled Fred to accept his post-stroke limitations and adapt his plans accordingly. The occupational therapist explored alternatives with him (a core element of ESSVR), and Fred was successfully supported back into meaningful work.

Case study 5: (ESSVR) Tom (< 55)

Pre stroke: Tom co-owned a business with a family member. The work involved dealing with customers in a noisy workplace. There were multiple comorbidities and a significant neurological medical history. Tom experienced a traumatic brain injury as a teenager, causing uncontrollable seizures until he was in his early 20s. He also experienced a road traffic accident shortly before the stroke.

Impact of stroke: Tom experienced multiple cognitive effects, including memory and attention issues, speech and communication difficulties and behavioural problems. Tom developed emotional, frustrated and sometimes aggressive moods, which negatively impacted his relationships with staff administering his care, and with family, friends and customers.

Following stroke: Early support included physiotherapy and assessments from occupational therapists and speech therapy. However, UC ceased, because Tom was not responding to, or engaging with, interventions. Tom

described feeling 'overwhelmed' by the amount of people seeing him immediately following stroke and admitted 'being horrible and falling out with some people'. A psychologist provided a neuropsychology assessment and strategies for managing emotions. At the baseline interview, Tom had already RTW due to financial pressures associated with being self-employed: '*everything we have is invested in this business. If I can't go back to work, we're going to lose it*'.

During his initial RTW, Tom was very short-tempered with staff and customers, which affected the business, as they could have potentially lost customers. The noisy environment affected Tom's fatigue and exacerbated his negative behaviour.

By follow-up 2, despite having RTW early, as Tom was an ESSVR participant, the occupational therapist continued to offer VR, which Tom claimed had '*stopped me from pushing myself too much*' and helped him RTW '*the right way*'. She initially advised Tom to work 4 hours per day (split between early morning and close of business), 4 days a week. Also, a third member of staff was hired.

In addition, Tom and his business partner worked successfully with the occupational therapist to adapt the workplace. For example, taking measures to lessen the noise and consequently Tom's stress levels. Tom was also given goals to work on his attention (e.g. by setting checklists).

Outcome: Tom praised the ESSVR intervention: '*everyone should have the help I've had … without it I would've been lost … just try to crack on like nothing's happened … that would've been the wrong thing*'. Although the adaptations suggested by the occupational therapist aided a successful RTW, Tom acknowledged the life-changing consequences of stroke, and that this environment was not manageable in the long term. Therefore, they were discussing potentially changing the nature of the business to allow Tom to continue working, but in a quieter environment.

Comment: Tom's case illustrates how ESSVR appears to be effective in helping to address some of the less visible effects of stroke, for example, hypersensitivity to noise and mood disturbances. Although physically able to RTW, Tom recognised that the workplace was detrimental to him personally due to the noise, but also potentially damaging to the business because of the way he was treating people. It demonstrates the value of occupational therapists continuing to monitor stroke survivors' progress even when they have RTW (generally the point at which they are discharged in UC). The occupational therapist developed a good relationship with Tom and his business partner, visiting Tom in the workplace and providing tailored vocational rehabilitation and suggesting adjustments to his working hours and work environment to make RTW more tolerable. In addition, exploring alternative futures for the business increased the likelihood of RTW being sustainable in the long term.

Case 6: (UC only) Harry 56–65

Pre stroke: Self-employed draughtsman, with his own business and several employees. He lives with, and cares for, an adult relative. In the 9 months leading up to stroke, Harry experienced a series of transient ischaemic attacks (TIAs) and hypertension. Cognition was severely impaired.

Impact of stroke: Visual and cognitive impairments. No longer able to draw; slower at reading, writing and using computer.

Following stroke: Harry described his rehabilitation from occupational therapists and SALTs while in hospital as 'excellent' but that when he was discharged '*things started to fall apart*'. Community occupational therapy stopped after 10 days, which Harry felt was insufficient because he still needed help with '*mental stuff*', reading and writing.

Visual, cognitive and communication impairments severely affected Harry's ability to perform his pre-stroke role because he was unable to draw and was having extreme difficulties in using technology. Specific examples included an inability to respond to e-mails or access his voicemail messages, which were vital aspects for running his business. At baseline (almost 12 months post stroke), Harry said there was 'no way' that he could RTW but hoped to do so eventually. Meanwhile, he was struggling to cope financially and had been unable to claim state benefits. Harry said that his application for Personal Independence Payments (a state benefit) had been refused because he could 'walk and talk', which they considered was 'good enough' but clearly was not sufficient for him to RTW. Harry was worried that the stress of potentially being evicted from his home might cause another stroke.

Harry had started to receive treatment from an ophthalmologist, neurologist, neuropsychologist and neuropsychiatrist at approximately 10 months post stroke, which he felt '*he could have done with 6 months ago*' but had been delayed due to the pandemic. Harry described how his mental energy was consumed by trying to understand '*who these people are*' and organising himself sufficiently to attend appointments. He had spoken to the neuropsychologist about RTW, but no plans or goals were set. The difficulty was that evaluation and rehabilitation were spread across different hospitals with apparently 'no communication or coordination' between them, which Harry found frustrating.

Outcome: By the final interview, Harry could not envisage RTW 'in the foreseeable future'. Although he was being assessed, he expressed a need for clear information about what his limitations would mean in a practical sense for his working life. He also wanted a rehabilitation path to help him to either relearn things or '*find alternative ways of doing stuff*'. Harry was aware that RTW might be possible with '*the right framework*'. However, being self-employed, he would need to create that framework himself, which he felt incapable of doing. Since his stroke, Harry had been

forced to let his employees go, so he had no help in the business. On top of caring for his adult relative, Harry felt responsible for his own rehabilitation and could not find anyone experienced in stroke to help him.

Comment: Harry's case indicates gaps in service provision for recipients of UC, particularly for the self-employed. There is no evidence that Harry received any advice or support to explore adapting his business or alternatives to returning to the same type of role. He was also unable to claim benefits, resulting in severe financial hardship and consequent stress.

During his interviews Harry clearly expressed a need for help to understand how his post-stroke impairments would affect his work life and how he might address them. Such support and information appear to be missing from Harry's UC provision.

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Trusson D, Powers K, Radford K, Bowen A, Craven K, Holmes J, *et al*. Experiences of support to return to work after stroke: longitudinal case studies from RETAKE trial [published online ahead of print March 26 2025]. *Health Technol Assess* 2025. https://doi.org/10.3310/WRKS9661