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# Sociodemographic differences in return to work after stroke: the South London Stroke Register (SLSR)

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## ABSTRACT

**Background:** Loss of employment contributes significantly to the burden of stroke on individuals and society. There is limited information on factors influencing return to work after stroke.

**Objectives:** To investigate the frequency and determinants of return to paid work after stroke in a multi-ethnic urban population.

**Methods:** Patterns of return to work were examined among people with first ever stroke registered in the population based South London Stroke Register.

Employment status and functional outcome (Barthel Index (BI), Frenchay Activity Index (FAI)) were assessed 1 year after stroke. Associations between baseline characteristics and return to paid work were analysed by multivariable logistic regression analysis.

**Results:** Among 2874 patients with first ever strokes in 1995–2004, 400 (15%) were working before the stroke. At 1 year, 94 (35%) of 266 survivors had returned to paid work. Black ethnicity (OR 0.41; 95% Cl 0.19 to 0.88), female sex (0.43; 0.21 to 0.91), older age (p<0.001), diabetes (0.25; 0.08 to 0.79) and dependence (BI  $\leq$  19) in the acute phase (0.24; 0.11 to 0.49) were independently associated with lower odds of return to work in multivariable analysis. Better functional outcome at 1 year was associated with return to paid work (p<0.001) but 53% of 161 independent (BI >19) and 39% of 96 very active (FAI >30/45) individuals had not resumed work.

**Conclusions:** There were important sociodemographic differences in return to work after stroke that were independent of clinical and service use variables included in the analysis. A large proportion of patients did not resume work despite excellent functional outcome.

Productivity losses contribute significantly to the socioeconomic burden of stroke and account for a high proportion of non-healthcare costs of stroke to society.<sup>1-3</sup> It has been estimated that over 9 million workdays are lost due to stroke morbidity in the UK each year<sup>2</sup> and that 26% of the total annual costs of stroke in England result from productivity losses.<sup>1</sup> In the USA, recent cost projections suggest that lost earnings will be the single largest cost contributor to the future economic burden of stroke from 2005 to 2050, constituting nearly one-third of the total projected costs.<sup>3</sup>

Loss of employment is also a significant issue for individuals with stroke, their families and carers.<sup>4</sup> Being able to return to work has been found to be highly important for younger individuals in terms of their own sense of recovery.<sup>5</sup> There is some evidence that working age people with stroke who are not able to return to work after stroke have greater levels of unmet needs  $^6$  and poorer psychosocial outcomes.  $^{5\ 7\ 8}$ 

In the UK, updated clinical guidelines9 and the recently published National Stroke Strategy<sup>10</sup> call for services that meet the specific needs of working age adults and include return to work as a quality indicator for raising the quality of stroke care. However, there is currently little information on the numbers of stroke patients working before stroke, on their chances of returning to paid employment and on factors influencing their vocational outcome. The interpretation of available data on return to work after stroke is difficult due to considerable methodological variation, particularly with regard to selection of study populations and definitions of work outcomes.4 11 Disability and sociodemographic factors such as older age, female sex and ethnic minority origin are all associated with employment disadvantage in the general population<sup>12</sup> but very little is known about interrelations between these factors with regard to vocational outcome after stroke.

We studied return to paid work among stroke survivors who were working before stroke and investigated the influence of sociodemographics, comorbidities, stroke severity and service use on vocational outcome after stroke in an urban, multiethnic population in South London, UK.

### **METHODS**

The South London Stroke Register (SLSR) is an ongoing, prospective, population based study of stroke incidence and outcome, which commenced in January 1995 and has been described in detail previously.<sup>13–15</sup> Briefly, the SLSR records all first ever strokes in people of all age groups within a defined area in South London, with follow-up interviews at 3 months, 1 year and then annually. At the UK Census 2001, the total population of the SLSR area was 271 817, with 63% white, 28% black and 9% other ethnic groups. Stroke is defined according to the WHO definition.<sup>16</sup> Standardised criteria are applied to maximise case ascertainment,<sup>17</sup><sup>18</sup> including multiple overlapping information sources in hospitals, primary care, community services and local health authorities. Completeness of case ascertainment has been estimated to range between 75% and 84%.15

### **Study subjects**

For the present study, all patients registered in the SLSR were included who had a first ever stroke between January 1995 and December 2004 and were working in paid employment immediately before stroke (including self-employed). Individuals doing unpaid charitable work or attending unpaid

	No (%)
Sociodemographics	
Age (years) (mean (SD))	53.8 (12.9)
Female sex	139 (35)
Ethnicity	
White	231 (59)
Black	128 (33)
Other	31 (8)
Occupational class	
Non-manual	162 (42)
Manual	225 (58)
Pre-stroke residence	
Private home alone	79 (20)
Private home with others	251 (63)
Sheltered home	1 (1)
Institutional care	2 (1)
Unknown	67 (17)
Comorbidities	
Pre-stroke disability (BI <15)	1 (1)
Hypertension	233 (62)
Diabetes	48 (13)
Atrial fibrillation	30 (8)
Coronary heart disease	41 (11)
Transient ischaemic attack	28 (8)
Current smoker	173 (45)
Stroke severity	
Dependence at 1 week (Bl ≤19)*	169 (55)
Coma (Glasgow Coma Scale <9)	57 (15)
Urinary incontinence	120 (33)
Dysphagia	114 (32)
Dysphasia	102 (28)
Motor deficit	281 (73)
Service provision	
Hospital admission	347 (87)
Length of stay (days) (median (IQR))†	16 (6-47)
Stroke unit treatment	147 (37)
Physio/occupational therapy within 3 months:	174 (73)
Stroke subtype	
Non-lacunar infarction	152 (38)
Lacunar infarction	93 (23)
PICH	78 (30)
SAH	64 (16)
Undetermined	13 (3)

\*Based on patients alive at 1 week.

+Based on admitted patients.

Based on patients alive at 3 months.

BI, Barthel Index; PICH, primary intracerebral haemorrhage; SAH, subarachnoid haemorrhage.

training programmes, and unemployed people were not included. As in other studies of return to paid work after stroke,<sup>19 20</sup> there was no upper age limit because continuing participation in paid work is of psychosocial and financial importance for many people above the official state pension age.<sup>21</sup> Moreover, employment rates among older people in the UK are steadily increasing and are higher than in the rest of Europe.<sup>22 23</sup>

### **Baseline assessment**

Self-reported employment status was classified into full time (>30 h per week) or part time ( $\leq$ 30 h per week), employed (including self-employed), unemployed and looking for work, carer for family or dependents, unable to work due to ill health, retired and unknown. Ethnicity was recorded from the patient's

own definition of ethnic origin using a UK Census question<sup>24</sup> and categorised as black, white, other or unknown. Socioeconomic status was recorded using the British Registrar General's occupational codes<sup>25 26</sup> and grouped into non-manual (I, II and III non-manual), manual (III manual, IV, V) and unknown.<sup>26</sup> Type of residence was categorised as private household alone or with others, sheltered housing, institutional care (residential home, nursing home, long term hospital) and unknown.

Classification of pathological stroke subtype (ischaemic stroke, primary intracerebral haemorrhage and subarachnoid haemorrhage) was based on results from brain imaging, cerebrospinal fluid analysis and/or postmortem examination. Ischaemic stroke was subclassified into lacunar infarction and non-lacunar infarction (including total and partial anterior and posterior circulation infarctions), according to the criteria of the Oxfordshire Community Stroke Project classification.<sup>27</sup>

Data collected on comorbidities included pre-stroke disability, as measured with the Barthel index (BI; categorised as 0–14, moderate/severe disability; 15–19, mild disability; or 20, independent),<sup>28 29</sup> vascular risk factors (hypertension (blood pressure >140/90 mm Hg), diabetes, atrial fibrillation, current smoking) and prior cardiovascular disease (transient ischaemic attack, coronary heart disease).

Stroke severity was measured using acute disability (BI  $\leq 19$  at 1 week) and acute impairments as proxies, including impaired consciousness (Glasgow Coma Scale<sup>30</sup> < 9/15), urinary incontinence, dysphagia (failed swallow test), dysphasia and motor deficit (categorised as no motor deficit, hemiparesis or hemiplegia).

Service use in the acute phase was measured as hospital admission, length of stay in hospital (days), stroke unit treatment and use of rehabilitation therapies (physiotherapy or occupational therapy) during the first 3 months.

## **Outcomes**

Primary outcome was return to paid work 1 year after stroke, as reported by the patients. Secondary outcomes were disability (measured with the BI) and social activity (measured using the Frenchay Activity Index (FAI)<sup>31</sup>) categorised as 0–15, inactive; 16–30, moderately active; or 31–45, very active) 1 year after stroke.

### **Statistical analysis**

Univariate associations between baseline characteristics and return to work at 1 year among survivors with complete followup were analysed using cross tabulations and the  $\chi^2$  test or Fisher's exact test for categorical, and the Mann–Whitney rank sum test for numerical variables. The relationship between return to work and functional outcome at 1 year was analysed by cross tabulations and likelihood ratio tests for trend across categories of BI and FAI scores.

Stepwise multivariable logistic regression analysis was used to model the influence of baseline characteristics on return to work adjusted for each other. A basic model included all sociodemographic variables as explanatory variables and return to work as the outcome variable. Other variables were added in blocks to subsequent models, with comorbidity variables being added first, then stroke severity variables and service use variables last. At each step, variables associated with return to work to the  $p \leq 0.1$  significance level were retained, while nonsignificant variables were eliminated before adding the next block of variables. For the final model, all variables excluded at

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	Working (n = 94) (No (%))	Not working (n = 172) (No (%))	p Value
	(110 (70))		p value
Sociodemographics			
Age (years) (mean (SD))	51.6 (13.3)	55.1 (11.7)	0.01
Female sex	33 (35)	70 (41)	0.37
Black ethnicity	27 (30)	67 (39)	0.13
Non-manual occupation	38 (41)	73 (43)	0.77
Living alone pre-stroke	17 (22)	27 (18)	0.57
Comorbidities			
Pre-stroke dependence (BI $\leq$ 19)	0 (0)	1 (1)	0.46
Hypertension	48 (53)	117 (69)	0.009
Diabetes	7 (8)	31 (19)	0.02
Atrial fibrillation	8 (9)	13 (8)	0.75
Coronary heart disease	9 (10)	17 (10)	0.98
Transient ischaemic attack	6 (7)	17 (10)	0.35
Current smoker	39 (42)	74 (44)	0.77
Stroke severity			
Dependence at 1 week (BI $\leq$ 19)	23 (29)	98 (66)	< 0.001
Coma (GCS $<$ 9)	1 (1)	18 (11)	0.004
Urinary incontinence	13 (15)	57 (35)	0.001
Dysphagia	17 (20)	53 (32)	0.04
Dysphasia	19 (20)	49 (29)	0.11
Hemiplegia	12 (13)	54 (32)	0.001
Service provision			
Hospital admission	77 (82)	156 (91)	0.04
Length of stay (days) (median (IQR))†	10 (4-24)	29 (8-72)	< 0.001
Stroke unit treatment	32 (34)	79 (46)	0.06
PT and/or OT within 3 months	50 (68)	112 (77)	0.15
Stroke subtype			
Non-lacunar infarction	29 (31)	78 (45)	0.04
Lacunar infarction	36 (38)	38 (22)	
PICH	16 (17)	28 (16)	
SAH	12 (13)	22 (13)	
Undetermined	1 (1)	6 (3)	

\*Cases with missing values for respective variables were excluded from analysis.

†Based on admitted patients.

BI, Barthel Index; GCS, Glasgow Coma Scale; OT, occupational therapy; PICH, primary intracerebral haemorrhage; PT,

physiotherapy; SAH, subarachnoid haemorrhage.

earlier model building stages were added again individually to assess whether they became significant ( $p \le 0.1$ ) in the presence of other variables or were relevant confounders (ie, their presence changed any of the effect estimates by 20% or more).<sup>32</sup> Significance of associations between explanatory variables and return to work was examined with the likelihood ratio test. Odds ratios (OR) and 95% confidence intervals (CI) were calculated to estimate the effect of explanatory variables on return to work. Interactions between age, sex, ethnicity and severity variables were examined by adding interaction terms to the final model.

In missing data analysis, three explanatory variables had more than 5% missing values (pre-stroke residence, 17%; BI at 1 week, 14%; rehabilitation therapy, 17%) because relevant questions were not included in questionnaires from 1999 to 2002. We assumed that data for these variables were "missing completely at random" according to Little and Rubin<sup>33</sup> because the probability of "missingness" was most likely not related to any other variable except time of stroke which was adjusted for in analysis. Separate analyses were made with and without an extra category for missing values for these variables. Other explanatory variables had less than 5% missing values and proportions of missing values are not specifically reported. With regard to missing outcome data, we analysed associations between baseline variables and the probability of data being missing.<sup>38</sup> The final model was fitted to complete case data (ie, restricted to cases without missing values) and adjusted for any baseline variables associated with "missingness" of outcome data.<sup>33</sup>

All statistical analyses were performed with Stata 9.2 (StataCorp, Texas, USA).

### Ethics

The SLSR and this study were approved by local research ethics committees and all participants or their proxies gave written informed consent.

# RESULTS

A total of 2874 individuals with first ever strokes in 1995–2004 were registered in the SLSR, and pre-stroke employment status

was known for 2702 (94.0%). Of these, 400 patients (15%) were working full time (85%) or part time (15%) in paid employment before the stroke. Their baseline characteristics are summarised in table 1. Of 2302 individuals not working before stroke, 2022 (87.8%) were retired, 134 (5.8%) were unable to work due to ill health or disability, 86 (3.7%) were unemployed and 60 (2.6%) were carers. Compared with those not working, people who were working prior to stroke were younger, more likely to be male and more often from black ethnic groups; they had lower prevalences of pre-stroke disability and all cardiovascular risk factors except smoking; they also had less severe strokes and shorter length of stay in hospital when admitted.

#### **Return to work**

A total of 337 patients (84%) who were working before the stroke were alive 1 year after the stroke. Information on employment status at follow-up was available for 266 survivors (79%). Of these, 94 (35%) had returned to paid work, with 61 working full time and 33 working part time. The prevalence of return to work was 37% among people who were working full time and 29% among those working part time before stroke (p = 0.32). Of 82 patients who were working full time before stroke and who had returned to work, 72% worked full time again at follow-up. Of those 172 patients who had not returned to paid work, 45% reported being unable to work due to ill health, 20% were retired, 3% were unemployed and looking for work, 1% were carers and 31% did not specify.

Comparison of individuals with and without outcome data indicated that individuals with missing outcome data were, on average, 3.8 years younger, more likely to live alone before stroke, less likely to have diabetes and less often comatose in the acute phase of stroke.

## Predictors of return to work

Characteristics of survivors with complete follow-up according to employment status at 1 year are given in table 2. Compared with individuals who had not returned to work at 1 year, those working at 1 year were, on average, 3.5 years younger, less likely to have hypertension or diabetes prior to stroke, less likely to be dependent at 1 week or have any other indicators of stroke severity except dysphasia at baseline, and less often admitted to hospital with shorter length of stay.

In the basic multivariable model, including all sociodemographic variables, increasing age (p<0.001 for trend across age groups), female sex (OR 0.45; 95% CI 0.23 to 0.9) and black

	OR† (95% CI)	p Value
Age (years)		
16–44	1.00	< 0.001
45–54	0.61 (0.22-1.64)	
55–64	0.14 (0.05-0.42)	
≥65	0.23 (0.07-0.76)	
Female sex	0.43 (0.21-0.91)	0.02
Black ethnicity	0.41 (0.19-0.88)	0.02
Diabetes mellitus	0.25 (0.08-0.79)	0.01
Dependence at 1 week (BI $\leq$ 19)	0.24 (0.11-0.49)	< 0.001
Coma (GCS <9)	0.12 (0.01-1.11)	0.06
Hospital admission	0.44 (0.17-1.18)	0.1

\*Based on complete case data.

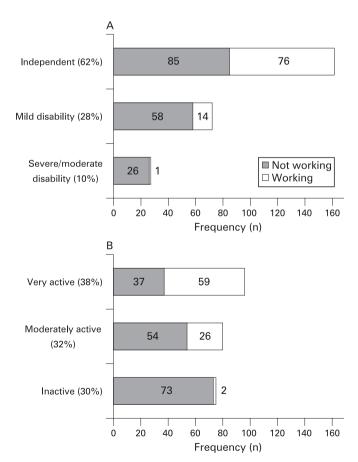
†Adjusted for all variables in the model and for stroke subtype.

BI, Barthel Index; GCS, Glasgow Coma Scale.

ethnicity (OR 0.47; 95% CI 0.24 to 0.93), but not socioeconomic status, were associated with lower odds of return to work. These associations did not change in subsequent models that additionally included comorbidities, stroke severity and service use variables. In the final model, older age, female sex, black ethnicity, diabetes and dependence at 1 week were independently associated with lower odds of return to work (table 3). Glasgow Coma Scale <9 and hospital admission were also retained in the final model because they were confounders of the effects of age, sex and ethnicity. Stroke subtype was associated with return to work in univariate analysis and a confounder of the effects of sociodemographic variables. Therefore, all models were also adjusted for stroke subtype. The effects of variables included in the final model did not vary by age, sex or ethnicity.

## Association between functional and vocational outcomes

Information on functional outcome at 1 year was available for 260 patients. Of these, 161 (62%) were independent in activities of daily living (BI >19) and 96 (38%) had a high level of social activity (FAI >30/45). In cross-sectional analysis of outcomes at 1 year, return to work was associated with higher BI and FAI score categories (likelihood ratio test for trend, p<0.001). Among survivors who had returned to work, 84% were independent and 68% had high social activity. Of 161 people who were independent at follow-up, 53% had not resumed work, and of 96 people with high levels of social activity, 39% had not resumed work (fig 1).



**Figure 1** Employment status at 1 year according to (A) disability level (Barthel index 20, independent; 15–19, mild; 10–14, moderate; 0–9, severe) (n = 260) and (B) social activity level (Frenchay Activity Index 31–45, very active; 16–30, moderately active; 0–15, inactive) (n = 251).

## DISCUSSION

In this longitudinal study from an urban, multi-ethnic, population based cohort of 2874 individuals with first ever strokes, 15% were working before stroke and the vast majority of them were still alive 1 year after the stroke. However, only a third of survivors had returned to paid work and there were substantial sociodemographic differences in return to work after stroke that could not be explained by the other case mix factors included in the analysis. Furthermore, a large proportion of survivors did not return to work despite excellent functional outcome.

The high proportion of strokes in people who were working in paid employment before stroke in our study provides indirect evidence for the important contribution of working age to the socioeconomic burden of stroke. Only one other population based study reported proportions of patients working before stroke. In the Auckland Regional Community Stroke (ARCOS) Study, 20% of 1423 patients with first ever stroke were in paid employment before stroke.<sup>19</sup> The slightly lower percentage of working patients in the SLSR may be explained by the characteristics of our source population, which has higher proportions of ethnic minority groups, higher levels of social inequalities and higher unemployment rates compared with the rest of the UK.<sup>34</sup>

Only about a third of people had returned to paid work 1 year after stroke in our study. In previous studies, post-stroke employment rates ranged from 0% to 100%.4 11 This wide variation can most likely be explained by considerable differences in study methodologies, namely selection of study participants, definitions of work at baseline and follow-up, length of follow-up periods and analytic strategies.4 11 For example, most previous studies included patients with transient ischaemic attack, unemployed people, homemakers or students; considered return to housework or university as work outcomes; and assessed rates of employment at variable follow-up times that sometimes varied between 2 months and 27 years.<sup>11 35</sup> Notably, most studies reported employment status as a proxy for recovery among hospital admitted patients and did not examine vocational outcome after stroke at the population level. Hence comparison of our results with other studies of return to work after stroke is difficult. Only three studies specifically examined return to paid work after stroke in samples of people working in paid employment before stroke and used uniform follow-up periods<sup>19 20</sup> or time to event analysis.<sup>36</sup> In two studies, approximately half of the patients had returned to work at 1 year.  $^{\scriptscriptstyle 20\ 36}$  In the population based ARCOS study, 53% of patients had returned to work at 6 months.<sup>19</sup> These findings are difficult to compare with our longer term results because some individuals who initially return to work after stroke may not sustain the pressure in the workplace in the long term.

A better understanding of factors influencing vocational outcome after stroke is essential for targeting return to work interventions. In our study, sociodemographic factors had a strong influence on return to work: women, black people and people older than 55 years were significantly less likely to return to work after a first stroke, after adjustment for differences in comorbidities, stroke severity and service use. It is unclear what caused these differences—whether people are unable to work due to biological factors; whether they genuinely prefer not to work; whether they have different pressures or barriers to return to work; or whether employers discriminate against them. Sociodemographic differences cannot simply be equated with discrimination although it is possibly a contributing factor.<sup>37</sup> There is evidence that return to work is influenced by individuals' perceived self-efficacy and external support from family, employers and state agencies.<sup>7 38</sup> The role of other factors such as cultural background, family structures, social networks or personal aspirations can only be speculated. Although further studies are needed to identify the reasons for the observed sociodemographic differences, they could already be considered in planning services to tackle inequalities in vocational outcomes after stroke.<sup>39</sup>

Stroke severity in the acute phase was an independent predictor of vocational outcome in our study and in other studies, which usually also found strong negative associations between acute disability or stroke severity and return to work.<sup>11</sup> Diabetes mellitus was also associated with reduced odds of return to work. Although the exact mechanism of an association between diabetes and outcome is unknown, some of the effect might be due to greater unmeasured comorbidities or to greater neuronal damage during the acute stage of stroke in diabetic patients.<sup>40</sup>

In cross-sectional analysis of return to work and functional outcome 1 year after stroke, people with good functional outcomes were generally more likely to have returned to work. However, even among people who had regained their functional independence in daily activities, only about half had returned to paid work. This disparity between functional and vocational outcome suggests that outcome after stroke is multidimensional and too complex to be measured by simple disability indices; it also implies that such instruments may have limited value for people at working age. Mild cognitive impairments, which would not necessarily lead to functional limitations, might have influenced vocational outcomes. Emotional consequences of stroke may also have influenced return to work behaviour. The ARCOS study from New Zealand found that people with psychiatric morbidity, as measured on the GHQ-28 at 1 month after stroke, were less likely to have returned to work at 6 months.<sup>19</sup> Other studies could not find an association between depression at the time of stroke and return to work at 1 year.<sup>20</sup> Data on cognitive and emotional consequences of stroke were not collected continuously in the SLSR and could therefore not be analysed in our study.

There may also be additional barriers to employment after stroke that are independent of apparent physical or cognitive impairment. These barriers may be located at the level of participation or in the environment, such as the workplace or the labour market.<sup>39</sup> Importantly, the economic context may have contributed to the low rate of return to work and the sociodemographic differences in our study. For example, the high level of social deprivation and a high unemployment rate in the study area are likely to aggravate any employment disadvantage associated with illness or impairment. The high proportion of people in manual occupations may also explain some of the observed differences, although we could not find an effect of occupational class on return to work in multivariable analysis.

The strengths of our study include the population based design with prospective case identification and standardised follow-up of all patients. An important limitation that needs to be considered is the fact that outcome data were missing for 21% of the study population. However, the follow-up rate of 79% is comparable with other follow-up studies with population based stroke registers<sup>19</sup> and generally acceptable considering that the study was conducted in an urban area with a socially diverse and mobile source population.<sup>15</sup> Individuals without follow-up were on average younger, healthier and had less

severe strokes. Thus it is possible that they had a higher prevalence of return to work than the individuals with followup. Another limitation is that the SLSR was not specifically designed to study return to work and no information was available on factors such as workplace modifications, time from stroke to work resumption or on specific demands of former and new occupation. Also, no information on psychosocial or material resources such as benefit payments was available.

In conclusion, return to work after stroke is a challenge that should be addressed in order to reduce the burden of stroke on individuals and society. Although the causal pathway from stroke to disability and vocational outcome is complex, this study points to important sociodemographic factors that influence return to work and could form targets for intervention. Further research needs to identify the reasons for the observed differences to inform development of stroke specific vocational rehabilitation programmes.

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