Returning to unpaid work after stroke: The Psychosocial Outcomes in Stroke (POISE) Cohort Study

Cheryl Carcel MD[1,2,3], Sara Farnbach PhD[1,2], Beverley M. Essue PhD [2] ,Qiang Li MBiostat[1], Nick Glozier MD PhD [2,3,4], Stephen Jan PhD[1,2], Richard Lindley MD[5], Maree L. Hackett PhD[1,2, 6]

[1]The George Institute for Global Health, University of New South Wales, Sydney, New South Wales, Australia

[2]The University of Sydney, Sydney School of Public Health, Sydney Medical School, New South Wales, Australia

[3]Royal Prince Alfred Hospital, Sydney, New South Wales, Australia

[4]Brain and Mind Centre, Sydney, New South Wales, Australia

[5] The George Institute for Global Health and Westmead Clinical School, University of Sydney

[6]Faculty of Health and Wellbeing, The University of Central Lancashire, Preston, United Kingdom

Author for correspondence:
Dr Cheryl Carcel
The George Institute for Global Health
PO Box M201, Missenden Road, NSW 2050, AUSTRALIA
T +61 2 8052 4508
Email: ccarcel@georgeinstitute.org.au

Cover title: Unpaid work after stroke

Key Words: stroke, unpaid work, gender, working age population

Word Count: 4344; abstract: 250

Tables: 3 **Figures: 2** **Supplemental Table: 2**

Abstract

Background: While returning to paid work is a crucial marker of stroke recovery, little is known about the differences in unpaid work by sex following stroke. We aimed to determine the sex differences in participation in unpaid work 12 months after stroke.

Methods: POISE (Psychosocial Outcomes In StrokE) was a prospective, multicentre observational study that recruited individuals, 18-64 years, within 28 days of stroke from New South Wales, Australia. Unpaid work was defined as ≥5 or more hours per week of one or more of: unpaid domestic work for the household; unpaid care of others; looking after own child(ren) without pay or looking after someone else's child(ren) without pay. Data were collected before stroke, 28 days (baseline), 6 and 12 month follow-up.

Results: Eighty percent of women and 52% of men engaged in ≥5 hours per week of unpaid work before stroke. At 12 months after, 69% of women and 53% of men completed ≥ 5 hours of unpaid work per week. For women, there was a significant association between participation in unpaid work at 12 months and having financially dependent children (OR, ~~3.54~~2.67; 95% CI, 1.~~2308-10.18~~6.59). ~~We found no significant associations for men.~~A return to unpaid work in men was associated with participation in unpaid work before stroke (OR, 3.74; 95% CI 2.14-6.53).

Conclusions: More women are engaged in unpaid work before and at 12 months post stroke, but there is a reduction in the proportion of women returning to unpaid work at 12 months not seen in men. Consideration may need to be given to the development of rehabilitation strategies targeted at the specific needs of ~~female~~ stroke survivors.

Introduction

Psychosocial outcomes such as depression, anxiety, employment and driving, are impaired after stroke contributing to post stroke disability.[1, 2] These outcomes are especially important to investigate in the working age group[3-6] where younger stroke survivors live longer than older stroke survivors.[7] Recent studies have shown that 55-75% of those in paid employment before stroke return to paid employment in the first year after stroke.[6, 8] Independence in activities of daily living, being male, younger, Caucasian, in full time employment before stroke, having less severe stroke, no psychiatric morbidity and having private health insurance after stroke are associated with a higher likelihood of returning to paid work.[6, 8]

Unpaid work (recognised globally as unpaid household work, childcare, volunteer or community work) [9, 10] is equally as important as paid work because it directly improves self-worth and the quality of people's lives by enabling engagement in productive activities and maintaining routines and habits.[11] In the working age population, unpaid work contributes almost half (48%) of Australia's Gross Domestic Product.[12] Internationally, The United Nations estimated that the value of unpaid work ranges from 5.7 to 72% of gross national product.[10] In 2006, the Australian Bureau of Statistics included questions on unpaid work in its census for the first time, recognising the contribution unpaid work makes to the economy and society. [12] In people with rheumatoid arthritis, participation in unpaid work is associated with having more formal education, children, and social support, increased physical exertion and psychosocial stress.[13] In major trauma, less permanent impairment and fewer co-morbidities are associated with unpaid work. [14]

Women of all ages have less favourable outcomes after stroke than men.[15, 16] There is increasing evidence that women are more likely to have depression,[17] mental impairment,[18] fatigue,[19] lower quality of life[20] and limitations in activities of daily living (ADL),[21, 22]

however there are no data whether participation in unpaid work after stroke varies between women and men. This study aimed to determine if there are differences in time spent in unpaid work before and at 12 months after stroke, by sex and to identify the determinants of participation in unpaid work at 12 months for women and men.

Materials and Methods

Study Design

The study methods have been published previously.[23] In brief, the Psychosocial Outcomes In StrokE (POISE) study was a 3-year prospective multicentre observational study that recruited participants from October 2008 to June 2010. English-speaking individuals, aged >17 and <65 years, or their proxy, were consecutively recruited to POISE within 28 days of stroke from 20 stroke units in the Stroke Services New South Wales network in Australia.[23] Participants with receptive aphasia, a severe language disorder, or cognitive impairment as determined by their clinician, were eligible to participate if their proxy consented and completed the assessments on their behalf.

Hospital-based staff collected demographic (name, date of birth, sex, contact information, cognitive competence, general practitioner) and ~~stroke~~ clinical (date, stroke subtype, Glasgow Coma Scale score, received recombinant tissue plasminogen activator, diagnosed or treated depression) information. All participants were interviewed over the telephone (or face-to-face when necessary) at baseline (28-days), 6 and 12 months after stroke by trained interviewers based at The George Institute for Global Health in Sydney. Data were also collected on whether participants had health insurance before their stroke, depression (Hospital and Anxiety Depression Scale depression subscale score ≥ 8, HADS-D),[24] anxiety (HADS anxiety subscale score ≥ 8, HADS-A),[24] and cognitive function (telephone interview for cognitive status,

TICSm). [25] and instrumental activities of daily living (ADL) (Frenchay activities index, FAI). [26]

Information on unpaid work before and after stroke was collected using modified versions of questions 34–51 of the Australian Bureau of Statistics 2006 Census.[12] Unpaid work was grouped as follows: unpaid domestic work for the household; unpaid care, help or assistance for a family member or others because of a disability or long term illness or problems due to ageing [hereafter referred to as unpaid care]; looking after own child(ren) without pay; looking after someone else's child(ren) without pay [hereafter referred to as unpaid child care]; and voluntary work through an organisation or group. Hours spent doing unpaid work were grouped as < 5, 5 to < 15; 15 to < 30 and ≥ 30 hours per week. Participants indicated their pre-stroke expected age of retirement, whether and in what capacity they had returned to paid and unpaid work following their stroke, and the date of return. Participation in unpaid domestic work, unpaid care or unpaid child care refers to work conducted ≥5 hours per week.

Ethical approval was received from the Human Research Ethics Committee of the Sydney South West Area Health Service in May 2008, protocol X08-0084, Australian New Zealand. Clinical trial registration: URL: http://www.clinicaltrials.gov. Unique identifier: 12608000459325. Requests for access to the de-identified data that underlie the study results should be made to datasharing@georgeinstitute.org. We will provide data to researchers with a methodologically sound proposal, and will work with interested parties to define and operationalise a data access agreement.

Study participants

Participants were included in these analyses if they performed any unpaid work before their stroke.

Statistical Analysis

Chi-square and McNemar's tests were used for comparison between women and men. Participant characteristics were summarised as mean ± standard deviation (SD) for continuous variables, and as number (%) for categorical variables, with comparisons made using t-test or chi-square tests. Correlation and first order interaction between variables was assessed. Self-reported time spent (average number of hours) per week, return to unpaid work at 12 months and factors associated with return to unpaid work were investigated by sex. For each sex, a multivariable logistic regression model was built using manual variable selection of all variables significant at p <0.30 during univariate analysis. The threshold of P<0.30 was chosen to avoid possible risk factors which would have been missed in the final model. In this study, we performed manual selection first and then a multivariable model with p <0.30 criteria to add possible risk factors in the final model without a large in ROC area under curve. Additional analyses included one multivariable logistic regression model built using baseline variables for which there is a priori evidence that they might predict participation in unpaid work after stroke, a second using backward elimination of all such variables. The variables for consideration in the additional models were age (18 to 35, 36 to 45, 46 to 55 and 56 to 65 years), education (with diploma/degree or without), marital status (married/de facto relationship/other or never married) , number of financially dependent children, living in a rural area, not living alone, absence of co-morbidities, independence in activities of daily living, intact cognition, not taking psychoactive medications, not depressed or anxious, in full-time paid work and without health insurance. Data were reported with odds ratios (ORs) and 95% confidence intervals (CIs). A *p* value <0.05 was regarded as indicative of statistical significance. All analyses were performed using SAS software (version 9.3; SAS Institute, Cary, NC).

Results

Of the 441 participants in the POISE study, 392 (88%, hereafter referred to as the study group) participated in ≥5 hours on average per week of unpaid domestic work, unpaid care and unpaid

child care before their stroke and were included in these analyses. One third (32%) of the study group were women.

Self-reported number of hours spent on unpaid work per week

Proportionally more women than men (80% vs 52%, p <0.01) performed unpaid domestic work per week before their stroke. At 12 months, there continued to be proportionally more women than men (69% vs 53%, p <0.01) participating in unpaid domestic work. Figure 1a subdivided unpaid domestic work into time spent per week by sex. Women worked more hours than men. Similar results were found for unpaid care (Figure 1b) and unpaid child care (Figure 1c).

Return to unpaid work at 12 months

Fewer women had returned to unpaid work (80% pre-stroke vs 69% 12 months, p = 0.03) than men (52% vs 53%, p = 0.68) where participation was relatively stable (Figure ~~2~~1d). There was no difference in the results for unpaid care and childcare between women and men (Figure 1d~~2~~). There were only 7 participants who performed volunteer work at 12 months; all were men.

Factors associated with return to unpaid work at 12 months

Compared to men participating in unpaid work at 12 months, women (Table 1) were younger, had no income protection, did not participate in paid work, had a history of depression and had more financially dependent children. However, there were no significant differences between the two groups in educational attainment, stroke subtype, anxiety, depression or accessing rehabilitation at 28 days.

For women, the only factor significantly associated with returning to unpaid work was having more financially dependent children (OR, 2. ~~9~~67; 95% CI 1.~~19~~08-~~7.33~~6.59)~~.~~ ~~There was a trend towards association with cognitive competence but this failed to reach significance~~ (Table 2).

~~There were no statistically significant factors associated with returning to unpaid work at 12 months for men after multivariate adjustment~~Men who participated in unpaid work before their stroke were more likely to return to unpaid work at 12 months (OR, 3.74; 95% CI 2.14-6.53) (Table 3). In additional analyses, returning to unpaid work at 12 months for women was significantly associated with having more financially dependent children (OR, 3.~~54~~46; 95% CI, 1.~~23~~42-~~10.18~~8.46), participating in unpaid work before stroke (OR, 11.06; 95% CI, 1.54-79.55) and the absence of depression at 28 days post stroke (OR, ~~13.82~~17.86; 95% CI, 1.~~01~~17-~~188.42~~272.18) Supplemental table 1). Having financially dependent children remained significant even after backwards selection (OR, 3.46; 95% CI, 1.42-8.46) (Supplemental table 1). Additional analyses in men showed significant association with not having ~~more financially dependent children~~private health insurance (OR, ~~1.4~~2.06; 95% CI, 1.0~~65~~-~~1.99~~4.03) and participating in unpaid work prior to stroke~~after backward selection only~~ (OR, 4.13; 95% CI, 2.30-7.40)(Supplemental table 2).

Discussion

In these pre-specified secondary analyses we found that women were more likely to be engaged in unpaid work before and at 12 months after stroke but there was a decline in the proportion of women who returned, which was not seen in men. Based on the analysis of factors associated with participation in unpaid work at 12-months after stroke, for every additional child a woman has, she is nearly 3 times more likely to perform five hours or more of unpaid work per week. On the other hand, men who participated in unpaid work before stroke were nearly 4 times more likely to return to unpaid work after stroke.

This is the first study to report data on unpaid work in a population of young stroke survivors. In the 2006 Australian Time Use Survey,[2~~67~~] Australian men performed fewer hours of unpaid domestic work per week than women (13.53 vs 26.50 hours) on average and women provided

more unpaid child care than men (6.53 hours per week vs 2.34). The sex distribution of unpaid domestic work corresponds to our findings before stroke, however at 12 months after stroke, the number of men participating in unpaid work remained unchanged (acknowledging that only up to 53% of men participated in unpaid work at both time points whereas 69% of women were participating in unpaid work at 12 months, down from 80% before stroke). This could not be explained by the 56% of women who preferentially returned to paid part or full-time work at 12 months.[6] There were fewer women in paid and unpaid work at 12 months in the POISE study. Further research into disability in the POISE cohort is needed.

In a study of people with rheumatoid arthritis,[13] the number of hours per week performing unpaid work was also associated with the number of children in the household/family. This likely confirms that having more children generates more unpaid work. None of the factors associated with unpaid work in POISE were modifiable, unlike factors associated with return to paid employment for young stroke survivors (independence in ADL at 28 days after stroke)[6] or people with rheumatoid arthritis and rectal cancer.[13, 2~~7~~~~8~~] As a marker of recovery, participation in unpaid work after stroke may be less influenced by socio-demographic and treatment-related factors because unpaid work is a necessity and can be taken up at the patient's own pace and time in keeping with their capabilities.[2~~7~~~~8~~]

The strengths of this study include the large sample size, including a broad range of people included from rural and metropolitan hospitals which enhances the generalizability of these results among working aged stroke survivors and the *a priori* plan for these analyses.[23] The limitations include selection bias where patients with aphasia and cognitive impairment whose proxies did not consent were excluded. Information on partner participation, post-stroke pain ~~or~~ hemiplegia, or stroke severity assessments were not collected in the study and we therefore could not evaluate whether these affected participation in unpaid work.

When assessing recovery of young stroke survivors, consideration should be given to whether people intend to return to unpaid work and the amount of unpaid work they will need to complete as the impact on them, the economy and society is substantial. Depending on circumstances, women and men may require additional support with rehabilitation and ~~supportive care~~ individualized care to address their concerns after stroke. Future research is needed to address the question whether ~~female~~sex-specific stroke rehabilitation strategies improve return to unpaid work.

Acknowledgements

The authors wish to thank the hospital research staff for their dedication and the POISE participants, their families and friends.

Disclosure statement

This study was funded by project grant APP 512429 from the National Health and Medical Research Council (NHMRC) of Australia. Cheryl Carcel is a recipient of a University of Sydney Postgraduate Award, Sara Farnbach The George Institute Postgraduate Scholarship. Beverley Essue is recipient of a NHMRC Sidney Sax Fellowship (1072148), Maree L. Hackett a National Heart Foundation Future Leader Fellowship #100034 and an NHMRC Career Development Fellowship Level 2 APP1141328, Stephen Jan an NHMRC Professorial Research Fellowship #1020403. No funding bodies had a role in the conduct or reporting of this study.

Figure Legends

Figure 1. The proportion of self-reported hours spent per week on unpaid work pre-stroke and at 12 months after stroke by sex categorised into (a) unpaid domestic work, (b) unpaid care and (c) unpaid child care. (d)

~~**Figure 2.**~~ **The proportion of women and men who return to unpaid work at 12 months categorised into unpaid domestic work, unpaid care and unpaid child care**

References

1. Mitchell AJ, Sheth B, Gill J, Yadegarfar M, Stubbs B, Yadegarfar M, et al. Prevalence and predictors of post-stroke mood disorders: A meta-analysis and meta-regression of depression, anxiety and adjustment disorder. *Gen Hosp Psychiatry*. 2017;47:48-60
2. van Mierlo ML, Schroder C, van Heugten CM, Post MW, de Kort PL, Visser-Meily JM. The influence of psychological factors on health-related quality of life after stroke: A systematic review. *International journal of stroke : official journal of the International Stroke Society*. 2014;9:341-348
3. Glozier N, Moullaali TJ, Sivertsen B, Kim D, Mead G, Jan S, et al. The course and impact of poststroke insomnia in stroke survivors aged 18 to 65 years: Results from the psychosocial outcomes in stroke (poise) study. *Cerebrovascular diseases extra*. 2017;7:9-20
4. Xu Y, Nguyen D, Mohamed A, Carcel C, Li Q, Kutlubaev MA, et al. Frequency of a false positive diagnosis of epilepsy: A systematic review of observational studies. *Seizure*. 2016;41:167-174
5. Essue BM, Hackett ML, Li Q, Glozier N, Lindley R, Jan S. How are household economic circumstances affected after a stroke? The psychosocial outcomes in stroke (poise) study. *Stroke; a journal of cerebral circulation*. 2012;43:3110-3113
6. Hackett ML, Glozier N, Jan S, Lindley R. Returning to paid employment after stroke: The psychosocial outcomes in stroke (poise) cohort study. *PloS one*. 2012;7:e41795
7. Carter KN, Anderson CS, Hackett ML, Barber PA, Bonita R. Improved survival after stroke: Is admission to hospital the major explanation? Trend analyses of the auckland regional community stroke studies. *Cerebrovascular diseases (Basel, Switzerland)*. 2007;23:162-168

8. Glozier N, Hackett ML, Parag V, Anderson CS. The influence of psychiatric morbidity on return to paid work after stroke in younger adults: The auckland regional community stroke (arcos) study, 2002 to 2003. *Stroke; a journal of cerebral circulation*. 2008;39:1526-1532

9. Australian Bureau of Statistics. Spotlight on the national accounts: Unpaid work and the australian economy. 2014;2015

10. Swiebel J. Unpaid work and policy-making towards a broader perspective of work and employment. *Discussion Paper of the United Nations Department of Economic and Social Affairs*. 1999

11. College of Occupational Therapists Specialists Section Neurological Practice. *Occupational therapy and stroke*. Blackwell Publishing Ltd; 2010.

12. Australian Bureau of Statistics. Measures of unpaid work. *2914.0 - 2006 Census of Population and Housing - Fact Sheets, 2006* 2007;2014

13. Backman CL, Kennedy SM, Chalmers A, Singer J. Participation in paid and unpaid work by adults with rheumatoid arthritis. *The Journal of rheumatology*. 2004;31:47-56

14. van Erp S, Holtslag HR, van Beeck EF. Determinants of limitations in unpaid work after major trauma: A prospective cohort study with 15 months follow-up. *Injury*. 2014;45:629-634

15. Phan HT, Blizzard CL, Reeves MJ, Thrift AG, Cadilhac D, Sturm J, et al. Sex differences in long-term mortality after stroke in the instruct (international stroke outcomes study): A meta-analysis of individual participant data. *Circulation. Cardiovascular quality and outcomes*. 2017;10

16. Martinez-Sanchez P, Fuentes B, Fernandez-Dominguez J, Ortega-Casarrubios Mde L, Aguilar-Amar MJ, Abenza-Abildua MJ, et al. Young women have poorer outcomes

than men after stroke. *Cerebrovascular diseases (Basel, Switzerland)*. 2011;31:455-463

17. Eriksson M, Asplund K, Glader EL, Norrving B, Stegmayr B, Terent A, et al. Self-reported depression and use of antidepressants after stroke: A national survey. *Stroke; a journal of cerebral circulation*. 2004;35:936-941
18. Glader EL, Stegmayr B, Norrving B, Terent A, Hulter-Asberg K, Wester PO, et al. Sex differences in management and outcome after stroke: A swedish national perspective. *Stroke; a journal of cerebral circulation*. 2003;34:1970-1975
19. Glader EL, Stegmayr B, Asplund K. Poststroke fatigue: A 2-year follow-up study of stroke patients in sweden. *Stroke; a journal of cerebral circulation*. 2002;33:1327-1333
20. Sturm JW, Donnan GA, Dewey HM, Macdonell RA, Gilligan AK, Srikanth V, et al. Quality of life after stroke: The north east melbourne stroke incidence study (nemesis). *Stroke; a journal of cerebral circulation*. 2004;35:2340-2345
21. Lai SM, Duncan PW, Dew P, Keighley J. Sex differences in stroke recovery. *Preventing chronic disease*. 2005;2:A13
22. Di Carlo A, Lamassa M, Baldereschi M, Pracucci G, Basile AM, Wolfe CD, et al. Sex differences in the clinical presentation, resource use, and 3-month outcome of acute stroke in europe: Data from a multicenter multinational hospital-based registry. *Stroke; a journal of cerebral circulation*. 2003;34:1114-1119
23. Hackett ML, Glozier N, Jan S, Lindley R. Psychosocial outcomes in stroke: The poise observational stroke study protocol. *BMC neurology*. 2009;9:24
24. Zigmond AS, Snaith RP. The hospital anxiety and depression scale. *Acta psychiatrica Scandinavica*. 1983;67:361-370

25. de Jager CA, Budge MM, Clarke R. Utility of tics-m for the assessment of cognitive function in older adults. *International journal of geriatric psychiatry*. 2003;18:318-324

~~26. Wade DT, Legh-Smith J, Langton Hewer R. Social activities after stroke: Measurement and natural history using the frenchay activities index. *International rehabilitation medicine*. 1985;7:176-181~~

267. Australian Bureau of Statistics. Trends in houshold work. 2009;2016

278. van den Brink M, van den Hout WB, Kievit J, Marijnen CA, Putter H, van de Velde CJ, et al. The impact of diagnosis and treatment of rectal cancer on paid and unpaid labor. *Diseases of the colon and rectum*. 2005;48:1875-1882