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The impact of stroke on spousal and family income: a difference-in-difference study from Swedish national registries

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ABSTRACT

Aim: To investigate the financial consequences in the overall population spouses of persons with stroke in Sweden as well as for subgroups based on spouses age, sex and modified Rankin Scale (mRS) of the person with stroke.

Methods: The study population consists of spouses aged ≤ 60 during the year of their partner's stroke event. Each spouse was matched to four reference individuals. This longitudinal registry data covers spouses and a reference population between 2005 and 2016. We use difference-in-differences to estimate the impact on individual income from paid work, disposable individual income, and disposable family income.

Results: The primary analysis shows a small and statistically insignificant decrease on spouses' individual income from paid work and disposable individual income. In the subgroup analysis based on mRS, the largest effect is seen in mRS 4–5, where spouses' individual income from paid work and disposable individual income increases after their partner's stroke. Further, younger female spouses' individual income from paid work decreases by 1 614 EUR ($p = 0.008$) on average.

Conclusion: The financial consequences are small in the overall population of spouses. However, for some subgroups, younger women, and spouses of persons with stroke and mRS 4–5, the financial consequences are more prominent.

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KEYWORDS

Spouse; informal care; caregiver; income; disposable income; stroke; modified Rankin Scale



Introduction


Stroke is a disease with an acute onset and one of the leading causes of disability and death globally. According to the Global Burden of Disease Study,¹ the overall age-standardized stroke incidence decreased between 1990 and 2019, while the stroke incidence for individuals below 70 increased during the same period. Simultaneously, the number of age-standardized deaths due to stroke has decreased.¹

Health shocks, i.e. an acute deterioration of health, may influence the quality of life for the affected individual and their family. While being an informal caregiver (e.g. spouse or relative) can be a positive experience,² it can also adversely affect informal caregivers' daily lives. It has previously been reported³ that younger informal caregivers and informal caregivers that cared for a spouse were considerably limited in daily life (such as in

employment and social activities). Further, spouses of persons with stroke have lower life satisfaction⁴ and health-related quality of life⁵ than unaffected matched control spouses (matching was based on age, sex and geographical area of residence).

Being an informal caregiver can also impact the income and employment status of the spouse. In a Canadian study investigating earnings among spouses of persons with cancer, individual earnings decreased after a partner was diagnosed with cancer.⁶ Further, earnings decreased to a larger extent if the spouse was a woman.⁶ Jeon and Pohl⁶ report that this decrease in earnings could be attributed to the “caregiver effect”, i.e. that informal caregivers reduce their employment to support their ill partner.⁷ The largest effect on the combined family earnings was seen if the person diagnosed with cancer was a man. García-Gómez et al.,⁸ who studied the effect of employment and

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disposable income (e.g. gross wages, profit, wealth earnings and transfers) among spouses of persons with acute hospitalization in the Netherlands, instead report the biggest decrease in employment and income among male spouses.

We have previously reported that spouses of persons with stroke were less likely to be employed after the stroke event. Specifically, younger spouses were more likely to stop working.⁹ Persson et al.¹⁰ have also found that spouses of persons with stroke who were dependent in daily activities carried out considerably more informal care than spouses of independent persons with stroke, potentially affecting spouses' ability to work. Another study by Jeon et al.¹¹ investigated the spouses of persons with stroke and did not identify any change in spouses' employment or earnings. However, when analyzing the effect on employment based on age, younger spouses (age 35–44) were more likely to stop working than the matched control spouses. Further, spouses of persons with severe stroke had a higher probability of quitting their employment and earning less than before.¹¹

While previous research suggests that spouses of persons with stroke are less likely to be employed^{9,11} and more likely to show reductions in income¹¹ after their partner's stroke event, previous studies have not quantified the extent to which earnings and disposable incomes are affected (the study that comes closest is Jeon et al.,¹¹ who study the *probability*, not the magnitude, of an earnings loss). This paper addresses this gap from a Swedish context. In Sweden, the healthcare system is publicly financed via taxes, and the Swedish population has access to formal healthcare such as hospital care, primary care, and municipality care (special housing and home care). In addition, Sweden has several social insurances that aim to support persons in various situations financially.¹² Furthermore, during the initial 14 days of sick leave, individuals receive sick pay from their employer, after which the Swedish Social Insurance Agency provides sickness benefits, covering approximately 80% of the individual's lost income.¹² Additionally, there is a provision for assistance compensation for those taking time off to care for a close relative.¹² Together with strong job security provisions, these measures ensure continuity of income even during health crises. These

social insurances may alleviate effects on earnings from paid work. To assess the impact on the spouses and family's overall financial situation, we investigate income from wages and disposable individual and family incomes. Our specific aims are to investigate the long-term financial consequences (both income from wages and disposable income) for spouses of persons with stroke on average and in the subgroups age, sex as well as the dependency in daily activities of the person with stroke.

Materials and methods

Study population and data material

This is a longitudinal study based on Swedish registries between 2005 and 2016. The study population consists of spouses who were a maximum of 60 years old when their partner (person with stroke) got their first-ever stroke in 2010 or 2011, i.e. still working age during the entire five-year follow-up period. This age criteria were chosen since the retirement age in Sweden is 65 years, which could affect the spouse's income. The person with stroke was identified through the Swedish stroke registry. The Swedish stroke registry is a national quality register, covering 88% in 2010¹³ and 90.5% in 2011¹⁴ of all strokes in Sweden. The spouses of persons with stroke are identified through Statistics Sweden's Register of the Total Population (RTB).¹⁵ When identifying spouses, Statistics Sweden applied their definition of a family, i.e. married couples, registered partners, cohabitant partners with joint biological children, or partners registered at the same address (house); however, cohabitant partners living in an apartment building without joint custody children could not be identified.¹⁶ In addition, spouses of the person with stroke were matched with four individuals from the general population based on age, sex, and the municipality of residence, which constitute the reference population. For both the spouses and the reference population, we have access to registry data five years before and after the stroke event. From RTB, we have access to demographic information such as age, sex, civil status and residence area. Further, we have extracted information regarding education, income

and social insurance from the Longitudinal Integrated Database for Health Insurance and Labour Market Studies (LISA) database.¹⁶ Statistics Sweden handled all linkage between the registries, and data were handed to the researchers de-identified. The study was approved by the Regional Ethics committee in Gothenburg, Sweden (# 813–17). The study is aligned with the Strengthening The Reporting of Observational Studies in Epidemiology (STROBE) guidelines.

Variables

In our primary analysis, we use three variables to estimate the effect on income: *individual income from paid work*, *disposable individual income* and *disposable family income*. The variable *individual income from paid work* presents the gross salary from work and estimates the change in income from paid work (cannot have negative values). We use *disposable individual income* to estimate the change in income after potential benefits and less of taxes. The *disposable individual income* summarizes gross salary together with payments from sources such as capital income, sickness benefits, benefits for the care of closely related persons, child allowance, pregnancy benefits, pension, and less of taxes and repayment of government student loans. Finally, *disposable family income* summarizes the *disposable individual incomes* in the family (according to Statistics Sweden's definition of family).¹⁶ Both disposable individual and family income can have negative values. We converted the income variables used in the analysis to the Swedish price level in August 2022,¹⁷ followed by translating them into Euro (EUR) using the exchange rate of 10.611 Swedish kronor = 1 EUR.¹⁸

For spouses and the reference population, we use age as a continuous variable, while sex is categorized into men and women. The spouse's disposable income is presented as an average of the disposable income during the year of the stroke event. We report educational level and country of birth as a categorical variable, where educational level is divided into three groups: *less than high school* (*less than 9 years of school*), *high school* (*between 9 and 12 years of school*), and *more than high school* (*more than 12 years of school*). Marital status is

categorized as *Married or registered partner*, *divorced*, *widow* and *unmarried*. The country of birth was divided into three groups: *Sweden*, *Europe* and *outside Europe*. We also report the number of persons who died each year.

The characteristics of the stroke of the person with stroke were categorized as *haemorrhagic stroke* (International Classification of Diseases 10th version (ICD-10): I60, I61 or I62), *ischemic stroke* (ICD-10: I63) and *other* (ICD-10: I64, I65 or I67). We also report if the person with stroke was alive at three months post-stroke and is reported as either *alive at three months* or *dead at three months* (persons with stroke who died during the index hospitalization are not included in the data material). No additional data on the mortality of the person with stroke was available in the original data material from the Swedish stroke registry. Therefore, reporting on the mortality of the person with stroke 5 years after the stroke (post-period) was impossible.

Analysis

We present continuous variables as means with standard deviation (SD), while we report categorical variables as frequencies with associated percentages (%). In our analysis, we apply a difference-in-differences approach to estimate the average effects on spouses of persons with stroke income and family income after their partner's stroke event.¹⁹ Difference-in-differences is a quasi-experimental method that estimates the average difference between the pre-and post-period in each group, followed by estimating the difference between groups.¹⁹ In our primary analysis, the pre-period consists of the year of the stroke event (t) and the five years before the stroke event ($t-5$). While the post-period includes the five years after the stroke event ($t+5$). The main assumption of difference-in-differences is that in the absence of a specific event (i.e. the stroke), both groups would have followed the same trend in the outcome. This is referred to as the parallel trend assumption. We assess the parallel trends in the pre-period by inspecting the plotted results. Further, we also tested the pre-trends by conducting an event study.^{20,21}

We present the average effect with a 95% confidence interval (CI) and standard errors adjusted for individual-level clustering. Further, to account

for multiple testing across four outcome variables and several demographic subgroups, we apply the Benjamini-Hochberg procedure²² and present adjusted p-values.

We performed the analyses in Stata (version 17.0, Stata, College Station TX, USA), using the command *xtddidregress* for difference-in-differences estimation and *xtevent* for pre-trend testing. For adjusting p-values according to Benjamini-Hochberg procedure, we used the *p.adjust* command in R (version 3.6.3).

Subgroup analysis

To estimate spouses' financial consequences based on the dependency in daily activities of the person with stroke, we carried out subgroup analyses according to the person with stroke's modified Rankin Scale (mRS). mRS is a tool to assess dependency in daily activities, ranging from 0–6. Persons with mRS 0–2 are considered independent in daily activities, persons with mRS 3–5 dependent in daily activities and persons with mRS 6 are dead.²³ We calculated the mRS of the person with stroke using the algorithm for mapping the variables in the Swedish stroke registry into mRS. Further, we divided mRS into three groups mRS 0–2 (independent), mRS 3 (dependent in some daily activities) and mRS 4–5 (dependent in daily activities). This categorization is because spouses of persons with stroke and dependency in daily activities (mRS 3–5) report the highest number of hours spent on informal caregiving.¹⁰ We hypothesized that spouses of persons with stroke and mRS 3 are particularly vulnerable, as they still live in private housing, while persons with stroke and mRS 4–5 often live in special housing.

We also conducted subgroup analyses based on age and sex. First, we analyzed men and women separately to detect possible differences in the effect on income depending on whether the spouse is a man or woman. Second, we separated the men and women into two groups based on age: *50 years old and below* and *older than 50 years*. To ensure that the younger age group was not too small, we chose the cutoff of 50 years.

Sensitivity analysis

The primary analysis includes the stroke year in the pre-period ($t = 0$). We assume this to be the most conservative approach as we do not consider the exact date of the stroke event. However, in the sensitivity analysis, we instead set the year of the stroke event equal to 0.5 as an alternative assumption about the timing of the stroke event. To test the robustness of the subgroup analysis based on age, we changed the cutoff value from 50 to 48 and 52 years old.

Results

Descriptive statistics

The original dataset of spouses to persons with first-ever stroke and reference individuals consisted of 64 734 persons (13 049 spouses and 51 685 references). 11 737 persons (2 248 spouses and 9 389 reference individuals) were excluded due to age > 60. The final study population consists of 2 348 spouses and 9 389 reference individuals, where 75% are women. The average age among spouses and the reference population is 52 years in the year of the stroke event. Spouses of persons with stroke are, to a larger extent, born outside of Sweden, and a larger share has less than a high school education (Table 1.).

Primary results

Our primary analysis showed no statistically significant changes in either of the spouse's individual income variables (Table 2; Figure 1). However, we found a significant reduction in disposable family income, which as an annual average was 3 995 EUR lower over the five years of follow-up compared to the reference population.

Subgroups

In the mRS 0–2 and three groups, we detected a statistically significant decrease in disposable family income by 3 485 EUR and 8 642 EUR per year, respectively (Table 2). Further, we identified a significant increase in individual income from paid work (2 868 EUR) and disposable

Table 1. Descriptive statistics of spouses of persons with first-ever stroke in 2010 or 2011 in Sweden and the reference population.

Variable	Spouse	Reference
Number	2 348	9 389
Women (%)	1 768 (75)	7 068 (75)
Age at the year of the stroke event (SD)	52 (7)	52 (7)
Marital status		
Married or registered partner	2 348 (100)	9 387 (99.98)
Divorced	0	2 (0.02)
Widow	0	0
Unmarried	0	0
Country of birth		
Sweden (%)	1 768 (75)	7 565 (81)
Europe (%)	309 (13)	1 013 (11)
Outside Europe (%)	271 (12)	811 (9)
Educational level (%)		
Less than high school	457 (19)	1 403 (15)
High school	1 110 (47)	4 336 (46)
More than high school	781 (33)	3 650 (39)
Mean individual income from paid work year of the stroke event (SD)	250 246 (219 421)	273 373 (206 117)
Mean disposable individual income year of the stroke event (SD)	233 123 SEK (181 403)	249 842 SEK (199 139)
Mean disposable family income year of the stroke event (SD)	523 278 SEK (436 534)	577 751 SEK (466 404)
Deceased		
2012	13 (.55%)	22 (0.23%)
2013	7 (.30%)	20 (0.21%)
2014	8 (.34%)	16 (0.17%)
2015	7 (.30%)	30 (0.32%)
2016	13 (.56%)	22 (0.24%)
Stroke type ^a of the person with stroke		
Hemorrhagic stroke ^b (%)	310 (13%)	NA
Ischemic stroke ^c (%)	2 000 (86%)	NA
Other ^d (%)	26 (1%)	NA
Person with stroke (%)		
Alive at 3 months	2 342 (99.7)	NA
Dead at 3 months	6 (.3)	NA

^aStroke type is missing for 12 observations.

^bHaemorrhagic stroke includes ICD-10: I60 Nontraumatic subarachnoid hemorrhage, I61 Nontraumatic intracerebral hemorrhage or I62 Other and unspecified nontraumatic intracranial hemorrhage ^cIschemic stroke includes ICD-10: I63 Cerebral infarction ^dOther includes ICD-10: I64, I65 Occlusion and stenosis of precerebral arteries, not resulting in cerebral infarction or I67 Other cerebrovascular diseases.

Table 2. Results from the primary and subgroup difference-in-differences analysis estimating the average impact of stroke on spouses' individual and family income in the five years following the stroke event.

	N persons	Individual income from paid work		Disposable individual income		Disposable family income	
		Coefficient (95% CI)	Adjusted p-value ^a	Coefficient (95% CI)	Adjusted p-value ^a	Coefficient (95% CI)	Adjusted p-value ^a
Primary analysis	11 737	−209 (−778; 360)	0.590	−108 (−676; 460)	0.937	−3 995 (−5 327; −2 664)	<0.001
Subgroup analysis							
mRS 0–2	8 290	−211 (−843; 420)	0.591	−335 (−1 061; 390)	0.521	−3 485 (−4 897; −2 073)	<0.001
mRS 3	723	726 (−1 249; 2 701)	0.590	−120 (−1 824; 1 585)	0.937	−8 642 (−14 033; −3 252)	0.008
mRS 4–5	710	2 868 (685; 5 051)	0.033	4 409 (958; 7 860)	0.036	−3 014 (−8 093; 2 064)	0.432
Women (all ages)	8 836	−297 (−877; 282)	0.497	280 (−425; 984)	0.590	−4 031 (−5 629; −2 432)	<0.001
Women ≤50	3 025	−1 614 (−2 622; −605)	0.008	−599 (−1 611; 413)	0.432	−6 877 ^b (−9 305; −4 449)	<0.001
Women >50	5 811	390 (−287; 1 068)	0.432	736 (−191; 1 663)	0.277	−2 544 (−4 601; −486)	0.041
Men (all ages)	2 901	−65 ^b (−1 410; 1 540)	0.937	−1 053 (−2 813; 706)	0.432	−3 899 (−6 196; −1 602)	0.005
Men ≤50	1 011	1 194 (−1 217; 3 605)	0.497	148 (−3 524; 3 821)	0.937	−2 681 (−7 181; 1 818)	0.432
Men >50	1 890	−600 (−2 359; 1 159)	0.591	−1 730 (−3 561; 101)	0.160	−4 621 (−7 107; −2 135)	0.002

^aP-values adjusted according to the Benjamini-Hochberg procedure due to multiple testing. Therefore, the interpretation of statistical significance can differ between the 95% confidence interval and the adjusted p-value.

^bp-value from pre-trend testing < 0.05, from the event-study.

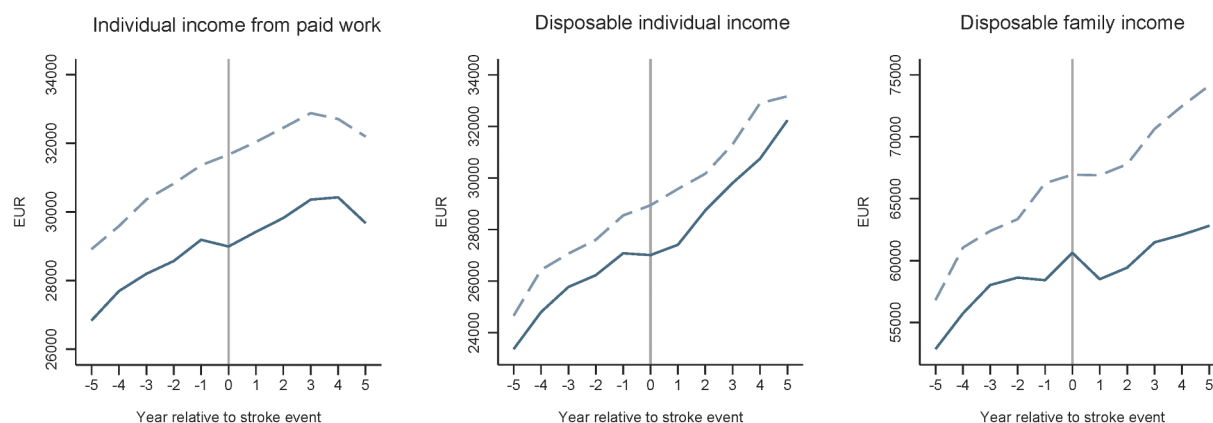


Figure 1. Individual income from paid work, disposable individual income and disposable family income among spouses of persons with stroke and a reference population from five years before to five years after the stroke (year = 0). The solid line represents spouses, and the dashed line represents the reference population

individual income (4 409 EUR) among spouses of persons with mRS 4–5 (Table 2).

When analyzing spouses' financial consequences after the stroke event based on sex and age, the most notable change is seen among young women. Among spouses who are young women (50 years or below), we found a statistically significant decrease in the income variables, individual income from paid work (–1 614 EUR), and disposable family income (–6 877 EUR) (Table 2; Figure 2). However, the decrease in the disposable family income among younger women should be interpreted cautiously, as the event study analysis shows signs of non-parallel trends in the pre-period ($p = <0.001$ for differential pre-trends; see also Figure 2). Significant decreases in disposable family income were identified among women (all ages) and women above 50 years, and we also found significant decreases in disposable family income among men (all ages) and men older than 50 years (Table 2; Supplementary material Figure S1).

Sensitivity analysis

The results did not considerably deviate from the primary analysis results when we coded the event dummy as 0.5 in the year of the stroke (Supplementary material Table S1). Among women, the results are robust to changes in the cutoff value (Supplementary material Table S1). When changing the cutoff value to 52 years or below among men, we identified a significant decrease in disposable family

income (Supplementary material Table S1), while when the cutoff value was 50 years or below, no significant decrease was identified.

Discussion

In this longitudinal study estimating the financial consequences among spouses of persons with stroke, we found that the disposable family income decreased (3 995 EUR per year) in the five years after the stroke event. Our findings suggest that the income of women spouses under the age of 50 decreases more significantly after their partner's stroke event than it does for other demographic groups. This effect seems somewhat alleviated regarding disposable income, suggesting that individual income from paid work decreases but may be partially recovered by other means (e.g. social insurance).

In terms of the financial situation for the entire family, we identified a decreased disposable family income in the primary analysis and several subgroups (Table 2). As expected, these impacts were larger than those on spouses' individual income, most likely due to including the person with stroke in the disposable family income. This somewhat corresponds to the results of Jeon and Paul,⁶ who studied income among spouses of persons with cancer in Canada and found that family income was affected to a larger extent if the spouse was a woman. Further, the same authors found that female spouses' income decreased to a larger extent after their husbands were diagnosed with cancer,

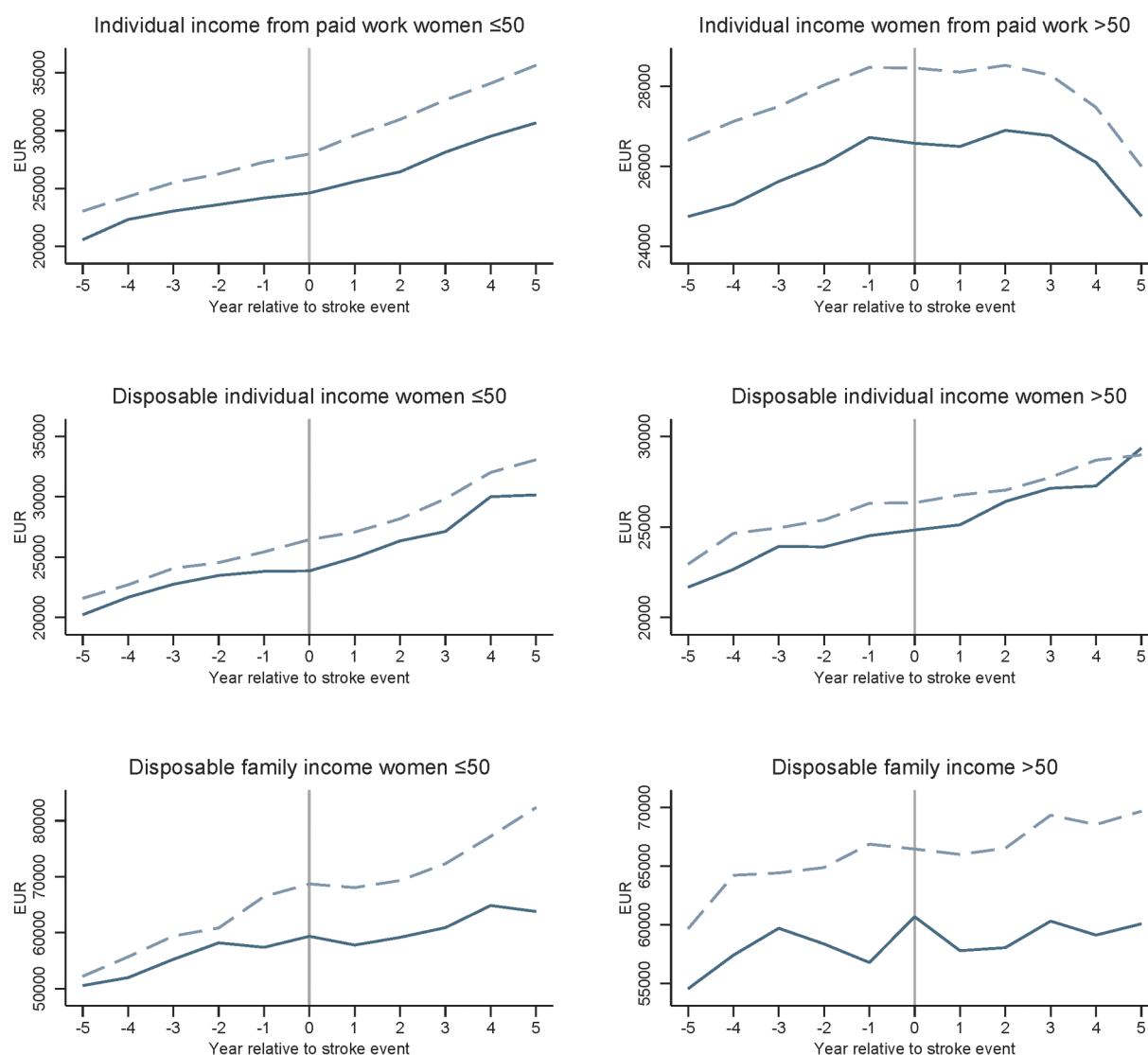


Figure 2. Subgroup analysis showing individual income from paid work, disposable individual income and disposable family income among younger (age ≤ 50) and older women (>50) spouses of persons with stroke and a reference population from five years before to five years after the stroke (year = 0). The solid line represents spouses, and the dashed line represents the reference population

which corresponds to our results. We also found that the average individual income from paid work among younger female spouses decreased. On the other hand, our result deviates from the findings by García-Gómez et al.,⁸ who reported the biggest decrease in income among male spouses, arguing that this may be due to a reduction in paid work to increase their contribution to household duties.

As mentioned, we identify a decrease in disposable family income in the primary analysis as well as in several of the subgroups. The disposable family income is the sum of the disposable individual income in the family (according to SCBs definition). Therefore, disposable family income could

be influenced by the number of divorces or deaths. When estimating the frequency of spouses and references who remain married in the post-period, spouses are less likely to remain married (Supplementary material Table S2), which might influence the decrease in disposable family income identified in our study.

We have previously reported that spouses of persons with stroke were more likely to stop working after their partner's stroke event.⁹ One might assume that this would lead to financial consequences for the spouse. We identified a decrease in individual income from paid work among younger women, but no (significant) changes in

disposable individual income in the same group. Additional research is required to fully explain the discrepancy between disposable income and income from paid work. However, one explanation could be that disposable income includes social insurance (e.g. sick pay) in Sweden, which may alleviate some of the loss of income from paid work.

To our knowledge, this is the first study to estimate the long-term effect of spouses of persons with stroke depending on the mRS category. According to our results, the individual financial consequences of the spouse are most pronounced in spouses of persons with stroke and mRS 4–5, who showed increases in income and disposable individual income in the five years after their partner's stroke onset. Persons with stroke and mRS 4–5 are dependent in daily activities and most often live in special housing. This could “allow” the spouse to increase the number of work hours and, indirectly, their income to cover up for the financial loss of the person with stroke.

Limitations

Due to limitations in the possibility to identify spouses in Swedish registers, we could not identify cohabitant spouses without joint children living in apartment buildings. Thus, our study sample may not be representative of all spouses of persons with stroke during the study period.

Our study is based on Swedish data, and our results may not be broadly generalizable to all other contexts. The disposable individual and family income are related to the social insurance included in the Swedish welfare system, which might affect the generalizability of these outcomes. However, our data could be generalizable to other countries with similar welfare systems. Further, we present the individual income from paid work as a separate outcome, which is less country-specific than disposable individual and family incomes.

The parallel trend assumption is crucial for the validity of our difference-in-difference estimates. When testing for pre-trends, we identified potential

violations in only two (out of 30) estimates in different subgroups, which we believe does not influence the interpretations of our primary findings.

In our sample, spouses of persons with stroke had lower educational level and were more often born outside of Sweden than the reference population. While the difference-in-differences methodology accounts for all time-invariant confounding due to such differences, we cannot rule out the possibility of non-parallel trend bias due to concurrent events or different income trajectories between groups.

Conclusion

Overall, the impact of stroke on spouses' individual incomes up to five years after the stroke event seems to be small in a Swedish context, and the impacts on the family's financial situation appear to primarily be driven by the person affected by the stroke. However, the individual financial consequences may be more severe in certain subgroups (e.g. younger women), highlighting important heterogeneity that needs further consideration in future research.

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Data availability statement

The data that support the findings of this study are available from the corresponding author, upon reasonable request.

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