**Educational attainment of children born to mothers with multiple sclerosis**

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**Abstract**

**Objective**

Multiple sclerosis (MS) causes long-term disability with broad socioeconomic consequences. This may influence educational attainment in children of affected individuals. We investigated whether having a mother with MS affects performance in Welsh national attainment tests.

**Methods**

We linked anonymised lists of 1584 women with MS diagnosed in two neuroscience centres (Cardiff, Swansea) to population level routinely-collected health and education data in the Secure Anonymised Information Linkage (SAIL) Databank. We identified children born to mothers with MS and compared performance in Key Stage (KS) 2–4 tests, taken at ages 11, 14 and 16, to a control group (matched for deprivation score, maternal age, year of birth, gestational age and birth weight). We measured core subject indicator (CSI) as an outcome measure (proportion achieving minimum standard in core subjects).

**Results**

525 children from mothers with MS had test results available from 2003–2016; there were 2217 matched controls. There was no significant difference in overall CSI achievement between cases and controls: KS2(85.3%v84.3%); KS3(75%v71.5%); KS4(52.1%v50.5%). Greater Expanded Disability Score Status did not significantly worsen performance but longer time since diagnosis improved performance in KS3 and KS4.

**Conclusions**

Having a mother with MS did not significantly worsen performance in national attainment tests and was associated with improved performance in some subgroups.

**Key words:** Multiple sclerosis, Educational attainment,

**Introduction**

Multiple sclerosis (MS) is a common chronic neurological disease where affected individuals can experience progressive disability and cognitive changes. The onset of symptoms in MS typically corresponds to an age when individuals are likely to have children. It is likely that children whose parents have MS experience several issues associated with chronic disease including adapting to and living with disability; coping with employment changes and restrictions; hospital visits and medication side effects.

Negative influences of having a parent with a chronic disease, or illness, include children having to undertake domestic caring responsibilities, parents being unable to help with physical or mental activities, having reduced household income due to employment changes or not being able to leave the family home. Positive influences include having more contact time with the parent, being more motivated to succeed educationally and being emotionally more mature.

These above factors might have both positive and negative influences on the educational attainment on a child with a parent with MS. Previous studies have shown that young carers can have reduced education attainment [ALDR08]. There are wide reaching implications of educational attainment and it is important to identifying any factors associated with poorer educational attainment that might be ameliorable. In this study we aimed to compare children born to mothers with MS to those born to mothers without MS in terms of attainment in national standardised educational attainment tests.

Other studies. Hypothesis that having Hughes N, Locock L, Ziebland S (2013) Personal identity and the

role of ‘carer’ among relatives and friends of people with multiple

sclerosis. Soc Sci Med 96:78–85.

Possible negative and positive effects of MS on children. – see references in Danish paper

Implications for other chronic diseases.

Maybe put opportunity to use DCells data set

**Methods**

We used the Secure Anonymous Information Linkage databank (SAIL)at Swansea University for this study. [FORD09,LYONS09,SAILwebsite] SAIL allows approved researchers to access and analyse a large number of linked, anonymised datasets (e.g. primary care records, hospital admissions records and demographic data). SAIL currently provides access to primary care records for around 2.4 million people (78% of the Welsh population) and many other linked datasets including the Department for Children, Education, Lifelong Learning and Skills (DCELLS) dataset of educational results for all Welsh children between X and X.

***Cohort Selection***

We uploaded and anonymously linked lists of women with confirmed diagnoses of MS to other routinely-collected datasets in the SAIL databank using an established split-file approach. [FORD09] The lists of women were obtained from MS registries at two regional neuroscience centres, Swansea and Cardiff. All diagnoses in the registries have been confirmed by consultant neurologists with a specialist interest in MS. The Cardiff MS registry … [reference]. The Swansea MS registry, contains all patients diagnosed with MS receiving disease modifying medication since X …

We used the using the National Community Child Health Database and thus identified children born to mothers with MS If mothers had more than one child then we randomly selected one child only to avoid clustering effects.

***Control selection***

Using X datasets, for each case, we randomly selected 3 women without MS who had given birth within the same time period as the case. We matched the control cohort on maternal age, deprivation (Welsh Index of Multiple Deprivation [WIMD] quintile), gestational age and year of study. Sentence and reference WIMD here.

***Outcome measures***

The main outcome measures were key stage results and the CSI.

***Statistical Analyses***

We used R version 3.2.0 to conduct the statistical analyses.

***Information governance and ethical approval***

This study obtained SAIL Information Governance Review Panel (IGRP) approval ref 0642.

The IGRP consists of members of professional and regulatory bodies, as well as lay members that provide feedback and approve study proposals to the SAIL Databank. All studies making use of the SAIL databank are subject to IGRP review and approved studies are therefore deemed to be in the national interest and are conducted in a way to minimize the risk of misuse and identification of patient data. The Research Ethics Service has previously confirmed that SAIL projects using anonymised routinely collected data do not need require specific NHS research ethics committee approval.

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***Figure 1 –*** *Cohort selection flowchart*

**Results**

Of the 1584 women with confirmed diagnoses of MS from registries, we could link X with SAIL data. Of note X% of these women with MS had diagnosis codes of MS in the primary care records.

|  |  |  |
| --- | --- | --- |
|  | *MS children cohort* | *Control cohort* |
| *Number* |  |  |
| *Proportion male* |  |  |
| *Proportion of mothers with RRMS at time of birth* |  | *0* |
| *WIMD* |  |  |
| *Quintile 1 (Most/least deprived)* |  |  |
| *Quintile 2* |  |  |
| *Quintile 3* |  |  |
| *Quintile 4* |  |  |
| *Quintile 5* |  |  |
| *Maternal age (mean, sd)* |  |  |
| *Gestational age* |  |  |
| *Gestational weight* |  |  |

*Table 1: Characteristics of the MS mothers, MS children (children born to mothers with MS) and control (children born to mothers without MS) cohorts. The control cohort was matched to maternal age, gestational age, birth weight and deprivation. MS (Multiple Sclerosis); RRMS (Relapsing remitting MS); WIMD (Welsh Index of Multiple Deprivation)*

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | *MS children cohort* | | *Control cohort* | | *Whole Wales* | |
|  | *n* | *%CSI (95%CI)* | *n* | *%CSI* | *n* | *%CSI* |
| *Key Stage 2* | *238* | *85* | *707* | *84* |  |  |
| *Key Stage 3* | *256* | *75* | *745* | *71* |  |  |
| *Key Stage 4* | *261* | *52* | *765* | *50* |  |  |

*Table 2 – Test results*

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**Discussion**

Main results.

Possible explanation of results.   
Motivated to do well at school given caring responsibilities at home.  
Increased time at home of parent

Strengths.   
Well definied cohorts of MS patients diagnosed by MS specialists  
Use of real life exam results and objective results not self reporting.

Limitations.   
Don’t have maternal educational attainment.   
Cant link fathers with children at present in SAIL (although smaller number of men with MS). Interesting though Danish study found no difference after adjusting for which parent had MS or parental educational attainment  
Don’t know if parents were single or not. It may be that children with single parents with MS are required to undertake disproportionately more caring responsibilities.

Comparison with other studies. A recent Danish study [MOBE16] studied the exam results of 4177 children born to a parent with MS (62% mothers) comparing with 33416 controls. This study also found that the MS cohort performed significantly better in the final exam at basic school (aged 15) but there was no significant difference in the highest level of educational attainment. The Danish education system is broadly similar to

Conclusions and implications

Reassuring for mothers with MS.

**Acknowledgments:**

This study makes use of anonymised data held in the Secure Anonymised Information Linkage (SAIL) databank. We would like to acknowledge all the data providers who make anonymised data available for research.

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**Disclosures**

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**Ethical Publication Statement:** We confirm that we have read the Journal’s position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

**References**

[ALDR08] Aldridge, J. (2008) All Work and No Play? Understanding the Needs of Children with Caring Responsibilities. Children and Society, Vol 22, Issue 4, pp 253-264.

[FORD09] Ford DV, Jones KH, Verplancke JP et al. The SAIL Databank: building a national architecture for e-health research and evaluation. *BMC Health Serv Res* 2009;**9**:157. [DOI: 10.1186/1472-6963-9-157](file:///C:\Users\arron\Downloads\eduaction%20paper%201\JNNP\Education_JNNP_submission.docx)

[LYONS09] Lyons RA, Jones KH, John G et al. The SAIL databank: linking multiple health and social care datasets. *BMC Med Inform Decis Mak* 2009;**9**:3. [DOI: 10.1186/1472-6947-9-3](file:///C:\Users\arron\Downloads\eduaction%20paper%201\JNNP\Education_JNNP_submission.docx)

[MOBE16] Moberg JY, Magyari M, Koch-Henriksen N, et al. Educational achievements of children of parents with multiple sclerosis: A nationwide register-based cohort study. J Neurol. 2016;263:2229-2237

**Footnotes**

**Contributors** Conceived and designed the study: AL, WOP, NR.   
Collected, formatted and Performed the study: AL. Performed statistical analysis: AL. Drafted the manuscript: AL, WOP. Critical revision of the manuscript: all authors.

**Competing interests** None declared.

**Patient consent** Not needed due to only using anonymised routinely collected patient data.

**Ethics approval** This study was approved by SAIL’s independent Information Governance Review Panel (project X). The National Research Ethics Service has confirmed that SAIL projects using anonymised data do not require specific NHS research ethics committee approval.