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Maternal substance misuse-related foetal anomalies: A data linkage study in Wales

Data Report

Authors

Ian Farr[1], Hywel T Evans[1], Columbus Ohaeri[2], Ryan Phillips[2], Josh Dixon[3], Josie Smith[2]

Affiliations

1. Population Data Science, Swansea University School of Medicine, Swansea
2. Public Health Wales, No 2 Capital Quarter, Cardiff, United Kingdom
3. Welsh Government, Cathays Park, Cardiff

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Background

An increased understanding of maternal health during pregnancy has shed light on the severe impact that substance misuse can have on foetal development. Foetal Alcohol Spectrum Disorder (FASD), and substance misuse-related foetal anomalies (SMFA), are among the most important consequences of substance misuse during pregnancy, with potential life-long physical, cognitive, and behavioural impairments for the affected children[1]. Substance misuse is defined here as 'recurrent use that is causing actual harms (negative consequences) to the person (including dependence, but also other health, psychological or social problems), or is placing the person at a high probability/risk of suffering such harms' [2]. Alcohol and drug misuse can affect foetal development by invoking placenta defects, respiratory issues, cardiovascular defects, low birth weight (through restricted nourishment caused by drugs and alcohol) and is also linked to sudden infant death syndrome (SIDS)[3]. These effects have downstream social and individual consequences throughout the life course.

This Data Insight presents the findings of a study conducted as part of the BOLD Substance Misuse Demonstrator Pilot (Phase 1) in Wales, which focuses on intergenerational substance misuse. Further information on the BOLD programme can be found here: Better Outcomes Through Linked Data (BOLD)

This research, focussing on foetal anomalies, forms part of a larger study examining the intergenerational impact of substance misuse on health, social care, education, and criminal justice in order to identify missed opportunities for prevention and promote earlier engagement to reduce substance misuse and related harms.

What we did

Using routinely collected administrative health data from the Secure Anonymised Information Linkage (SAIL) Databank for the study, we identified all babies born to mothers aged 15-44 in Wales between 2010 and 2019. This data was combined with primary and secondary healthcare records to identify those babies diagnosed with substance misuse foetal anomaly (SMFA). The study then compared mothers referred for SM treatment before or during pregnancy using the Welsh National Database for Substance Misuse (WNDSM). The frequency and type of maternal substance misuse-related healthcare interactions (primary, emergency, and secondary healthcare) before birth were examined.

The objectives of this study were to:

- Report the incidence of recorded substance misuse-related foetal anomalies in

Wales
- Identify substance misuse-related foetal anomalies in routine administrative data
- Investigate alternate data sources which can be used to estimate the number of undiagnosed substance misuse-related foetal anomaly cases
- Define and provide code lists to identify substance misuse-related foetal anomalies and FASD for the benefit of future research
- Provide guidance when researching substance misuse-related foetal anomalies using administrative data

As misdiagnosis and under-diagnosis of substance misuse-related foetal anomaly (SMFA) is common[4], three methods were used and compared in order to identify cases of SMFA:

- GP recorded SMFA – where a clinical record of SMFA was present within primary care identified on the Welsh Longitudinal GP dataset (WLGP)
- Hospital-recorded SMFA – where hospital admissions data were used to identify SMFA in neonates using specific ICD-10 codes
- Maternal substance use treatment at the time of birth – where the mother had an active substance misuse record (between referral and end of contact date) on WNDSM between the time of live birth (as recorded on the births register) and/or at some point in the preceding 9 months. Substance type was recorded at the point of referral to WNDSM. This was the least stringent method of defining foetal anomalies as no clinical assessment and diagnosis is made of the child, and inference is drawn based on self-report and/or clinical assessment of maternal substance use only.

To estimate the incidence of SMFA in Wales, the cohort data was pooled. The number of foetal anomalies and substance type (alcohol, opioids, stimulants and other drugs) were counted in terms of both births and mothers, as some mothers had multiple births within the period.

To investigate maternal substance misuse history before giving birth, the pooled cohort birth records were linked across datasets (primary care, hospital admissions, WNDSM). Maternal substance misuse health contacts in each dataset were identified within three different time windows preceding birth: 9 months, 36 months, and all available data. The number of events were stratified by the type of substance.

What we found

Cases of substance misuse-related foetal anomalies in Wales, derived from primary and secondary care diagnoses, are likely under-reported.

There were 993 mothers with 1,068 births where the mother was receiving substance misuse treatment as recorded on WNDSM between the child's birth and the 9 months prior to birth or where SMFA was clinically diagnosed (0.5% of all births, equivalent to 1 in every 200).

Of these, only 489 births to 374 mothers were identified in the primary or secondary care record as a newborn or foetus affected by maternal substance use (0.2% of all births, 1 in every 500).

A foetal alcohol syndrome diagnosis was identified for 42 babies (Primary care = 18, Secondary care/Hospital admission data = 33) representing 0.02% of all births (1 in every 5400).

Of the 358 births identified in secondary care with SMFA, 314 (87.7%) did not have a GP record relating to SMFA. This is important due to a potential shortfall in primary care provision for these cases.

Evidence of unmet need

Mothers, whose baby had clinical record of foetal anomaly, but who were not engaged with substance misuse treatment, or referred to specialist treatment by health care services prior to birth:

- 166 mothers (16.7%; births: n = 174, 16.2%) with no record on WNDSM during pregnancy and with no record of a substance-misuse related health event at any time before birth i.e. healthcare was potentially unaware of the mother's substance use.
- 18 mothers (1.8%; births: n = 18, 1.7%) with no record on WNDSM during pregnancy but who had a substance misuse-related health service contact within 9 months prior to birth. These births represent potential missed opportunity for intervention; the mothers presented to health services but were not referred for, or did not accept the offer of, substance misuse support or treatment.
- 53 mothers (5.3%; births: n = 53, 5.0%) with no record on during pregnancy, but had a substance misuse related health service contact in the 36 months prior to birth.

These births represent a potential lost opportunity to engage with women with substance misuse issues before childbirth. These engagements could be through early or continued engagement and discussion on the risks of pregnancy and substance use, alongside opportunities for rapid referral to low threshold or treatment services as appropriate.

Inequalities in substance misuse-related foetal anomalies in Wales

Overall, use of drugs, high deprivation as measured by Welsh Index of Multiple Deprivation (WIMD), and younger age (15-19 years) were associated with the highest number of substance misuse-related foetal anomaly births (see Appendix A).

Why it matters

Substance misuse-related foetal anomalies, including Foetal Alcohol Spectrum Disorder (FASD) are preventable lifelong disorders. Infant growth, behaviour and cognition are affected by maternal substance misuse in pregnancy[5].

Timely detection can lead to better healthcare management, early intervention, and improved long-term outcomes for the children and families facing these challenges. Despite the well-known risks of prenatal alcohol exposure, approximately 40% of mothers in the UK have consumed alcohol whilst pregnant (Popova, 2016), and around 1.5% (1 in 67) of women who consume alcohol during pregnancy deliver a child with FASD[6].

The multidimensional consequences of FASD and SMFA extend beyond the individual level. A 2015 inquiry estimated that FASD costs the UK £2 billion per annum[7]. Social and economic burdens weigh heavily on communities, including justice and healthcare systems, making it imperative to identify strategies to address prevention, treatment, and support.

The relative stability of foetal anomalies reported via coding in general practice and secondary care is in line with existing literature. This reflects poor diagnosis rates as well as emphasising the need for targeted interventions and screening for pregnant women referred to- or engaged with -specialist substance misuse treatment (WNDSM), as well as those who may become pregnant in the future.

Comparing this stability with the higher and increasing numbers of mothers receiving treatment for substance misuse (WNDSM) suggests either that foetal anomalies are being prevented or that there are potential gaps in foetal anomaly diagnoses. Our results provide an indication of service need that would aid planning and provisioning of services to better engage with those at risk of, or newly pregnant, and using drugs and/or alcohol.

What next?

Expansion of linked data

In future, it should be possible to link this, or more contemporary cohorts with the Ministry of Justice data, to investigate those who have been in contact with the criminal justice system as initial contact for identification and recording of substance misuse, alongside the health service data utilised in this study. This is likely to expand the maternal cohort, with wider implications in relation to early engagement and referral to specialist support from a range of low-threshold health and criminal justice settings.

Prevention

Prevention through engagement with specialist midwifery and antenatal care services, primary, secondary care and social services alongside women at risk or who have experience of foetal anomalies related to substance misuse

In order to better understand the range of services, resourcing and capacity currently in place aimed to prevent foetal anomalies related to substance misuse, engagement, collaboration with and evaluation of these services and providers is essential. These include specialist midwifery and wider antenatal screening and care services, primary and secondary care and social services. Alongside this, and in order to evidence the barriers to access or uptake of specialist support for women at risk, further research is recommended utilising mixed method approaches.

Investigation of existing under-reporting of substance misuse related foetal anomalies in Wales

Further research is also required to address the current under-reporting and consequential underestimation of substance misuse-related foetal anomalies.

Address potential bias

Challenges faced in investigating potential substance misuse-related foetal anomaly births are demonstrated here, including reliance on available clinical coding introducing potential biases and inaccuracies, underscoring the complex challenges of accurately capturing SMFA data within existing healthcare data systems.

Whilst this study emphasised specificity in clinical diagnoses, a wider range of less-specific codes might have yielded higher prevalence values[8].

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Appendices

Appendix A

Descriptive statistics of demographic information of the births cohort, stratified by method; GP record of foetal anomaly, secondary care ICD-10 record of foetal anomaly; or maternal record of specialist substance misuse treatment (WNDSM) prior to birth.

Characteristics	Foetal anomaly recorded in primary care; N = 80	Foetal anomaly recorded in secondary care; N = 358	Foetal anomaly with maternal substance misuse record N= 1068
Birth weight	2.9 (2.35, 3.27) †	2.86 (2.35, 3.27) †	3.08 (2.71, 3.44) †
Birth weight group			
Normal birthweight	50 (63%) *	237 (67%)	843 (79%)
Low birthweight	30 (38%) *	109 (31%)	166 (16%)
High birthweight	5 (6%) *	8 (2.3%)	57 (5.4%)
Unknown	1	4	3
Apgar score^	18 (17, 19)	19 (17, 19)	19 (18, 19)
Unknown	1	36	74
Sex			
Female	38 (48%)	173 (48%)	542 (51%)
Male	42 (52%)	185 (52%)	526 (49%)
Total birth number			
1	80 (100%)	350 (98%)	1,044 (98%)
2	0 (0%)	8 (2.2%)	24 (2.2%)
Maternal age	30 (25, 33)	29 (25, 33)	28 (23, 32)
Maternal age group			
15-19	<6	15 (4%)	112 (10%)
20-24	14 (18%)	64 (18%)	219 (21%)
25-29	20 (25%)	110 (31%)	289 (27%)
30-34	24 (30%)	114 (32%)	282 (26%)
35-39	16 (20%)	50 (14%)	134 (13%)
40-44	<6	5 (1%)	32 (3.0%)
Previous live births			
0	31 (42%)	127 (39%)	402 (43%)
1	11 (15%)	74 (23%)	220 (23%)
2	17 (23%)	56 (17%)	151 (16%)
3	6 (8.2%)	41 (13%)	103 (11%)
4+	8 (11%)	25 (9%)	65 (7%)
Unknown	7	35	127
WIMD Quintile			
5. Least deprived	7 (9%)	22 (6.1%)	84 (7.9%)
4	10 (12%)	26 (7.3%)	120 (11%)
3	18 (22%)	72 (20%)	180 (17%)
2	21 (26%)	83 (23%)	261 (24%)
1. Most deprived	24 (30%)	155 (43%)	423 (40%)

Categorical variables: n (%); continuous variables: median (IQR)
** Categories rounded up to mask low number in High BW; percentages will not add to 100% due to rounding.*
^ Apgar average test score.

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