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The Health Of Mothers Of Children With A Life-limiting Condition; A Comparative Cohort Study

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Director of the Martin House Research Centre

This Study

Workstream 1: Secondary data analyses- CPRD comparative cohort study. Incidence of common mental and physical health conditions higher in mothers of children with a life-limiting condition than in mothers of children with no long-term condition.

Workstream 2: Qualitative study: mothers' accounts of their own health, impact of conditions identified in WS1 and identify which services they think should support them.


Workstream 3: Stakeholder workshop

Workstream 4: Intervention development





Health of mothers of children with a life-limiting condition: a comparative cohort study

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► Additional material is published online only. To view, please visit the journal online (<http://dx.doi.org/10.1136/archdischild-2020-320655>).

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ABSTRACT

Objective This study aimed to quantify the incidence rates of common mental and physical health conditions in mothers of children with a life-limiting condition.

Methods Comparative national longitudinal cohort study using linked primary and secondary care data from the Clinical Practice Research Datalink in England. Maternal-child dyads were identified in these data.

Maternal physical and mental health outcomes were identified in the primary and secondary care datasets using previously developed diagnostic coding frameworks. Incidence rates of the outcomes were modelled using Poisson regression, adjusting for deprivation, ethnicity and age and accounting for time at risk.

Results A total of 35 683 mothers; 8950 had a child with a life-limiting condition, 8868 had a child with a chronic condition and 17 865 had a child with no long-term condition.

The adjusted incidence rates of all of the physical and mental health conditions were significantly higher in the mothers of children with a life-limiting condition when compared with those mothers with a child with no long-term condition (eg, depression: incidence rate ratio (IRR) 1.21, 95% CI 1.13 to 1.30; cardiovascular disease: IRR 1.73, 95% CI 1.27 to 2.36; death in mothers: IRR 1.59, 95% CI 1.16 to 2.18).

Conclusion This study clearly demonstrates the higher incidence rates of common and serious physical and mental health problems and death in mothers of children with a life-limiting condition. Further research is required to understand how best to support these mothers, but healthcare providers should consider how they can target this population to provide preventative and treatment services.

What is already known on this topic?

- There are growing numbers of children with life-limiting conditions in which the mothers provide healthcare 24 hours, 7 days a week.
- There is evidence of an increased risk of mortality among mothers whose infant has died or has a significant congenital anomaly.
- Most healthcare services focus on individual patients and not the whole family, thus ignoring the needs of parents.

What this study adds?

- Mothers of children with a life-limiting condition have significantly higher incidence of depression, anxiety and serious mental illness than other mothers.
- They also have significantly higher incidence of cardiovascular disease, hypertension and mortality.
- Much of this morbidity may be preventable.

both in terms of caring for their child but also in their own right to health and well-being. Most healthcare services focus on individual patients and not the whole family, therefore ignoring the needs of parents.

The lack of studies quantifying the mental health of mothers of children with a life-limiting condition has been highlighted by the National Institute for Health and Care Excellence.⁶ Although studies show that mothers of children with special needs⁷

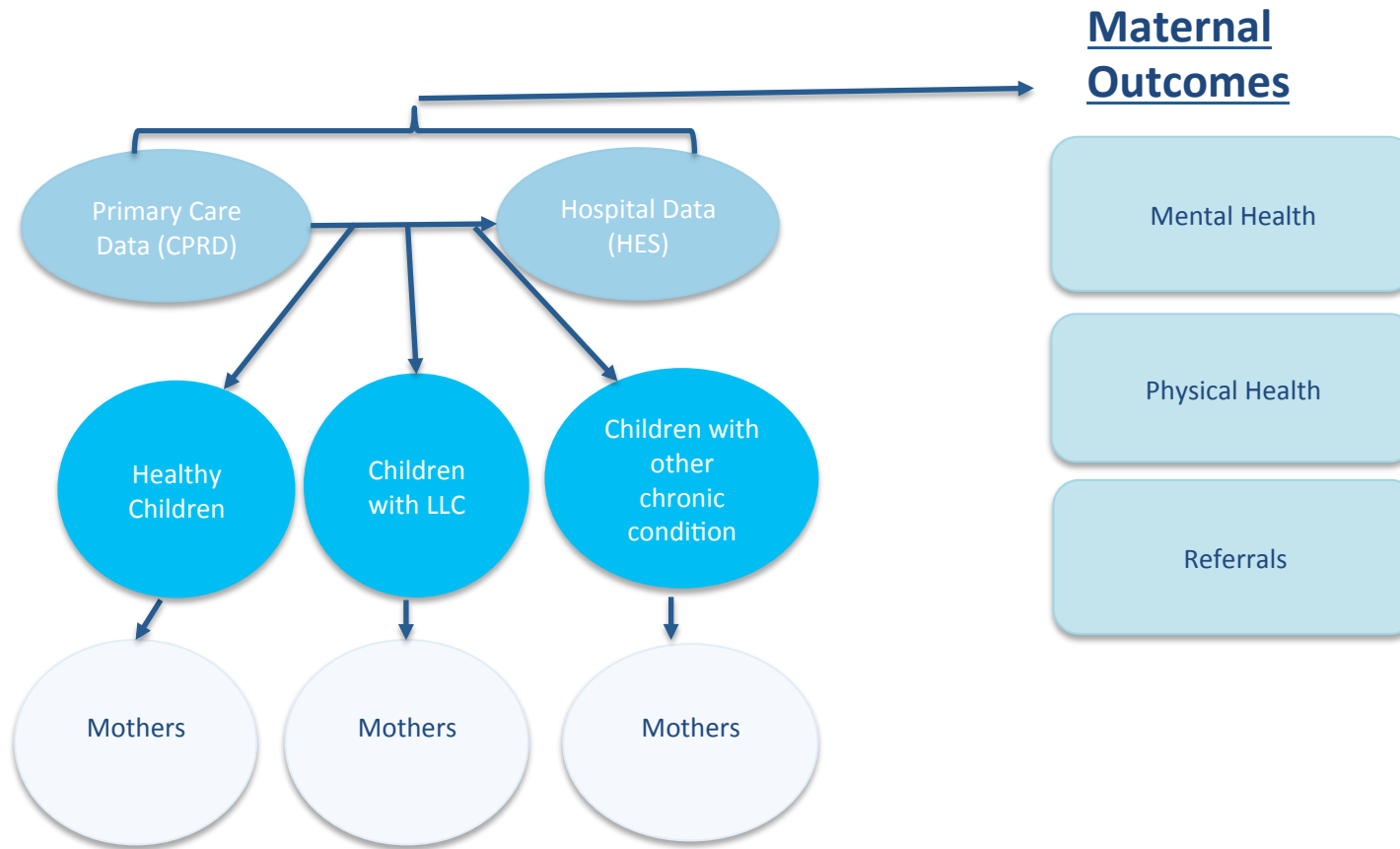


BACKGROUND

- 86,000 children and young people living with a life-limiting or life-threatening conditions in England.
- It is often expected that parents of these children, predominately the mother, become health care providers for these children as well as being their parents. This can involve being a co-ordinator and provider of healthcare 24 hours a day 7 days a week.
- Evidence about the mental or physical health of mothers of children with life-limiting conditions is limited; small cross-sectional studies of mothers of children with disabilities or surveys

AIM - to quantify the incidence of commonly occurring health conditions in mothers of children with a life-limiting condition using a nationally representative longitudinal healthcare dataset.

DATASETS



METHODS 1

- **Anonymised Extract** anonymised extract of data from the Clinical Practice Research Datalink (CPRD). 2007-2018
- **Comparative Cohort design:** matched on year of birth, sex and geographical region
 - Children with a life-limiting condition
 - Children with a chronic condition
 - Children with no long-term conditions
- **All primary and secondary healthcare data for mother and child were included**

METHODS 2

Physical Health Outcomes

- Back Pain
- Obesity
- Hypertension
- Cardiovascular Disease
- Type 2 Diabetes
- Death

Mental Health Outcomes

- Anxiety
- Depression
- Serious Mental Illness
- Referral to secondary mental health services

Primary Care data using READ codes (symptoms, diagnoses , prescriptions and referrals)

Secondary Care data using ICD 10 codes (diagnoses)

Crude Incidence Rates and adjusted incidence rate ratios using multivariable Poisson models

Time at risk was calculated from the point of child's diagnosis to the recording of the outcome of interest or end date of the mother.

Mothers who had a diagnosis of an outcome of interest prior to the record of diagnoses in their child were excluded from the analyses for that outcome



35,683 mothers:

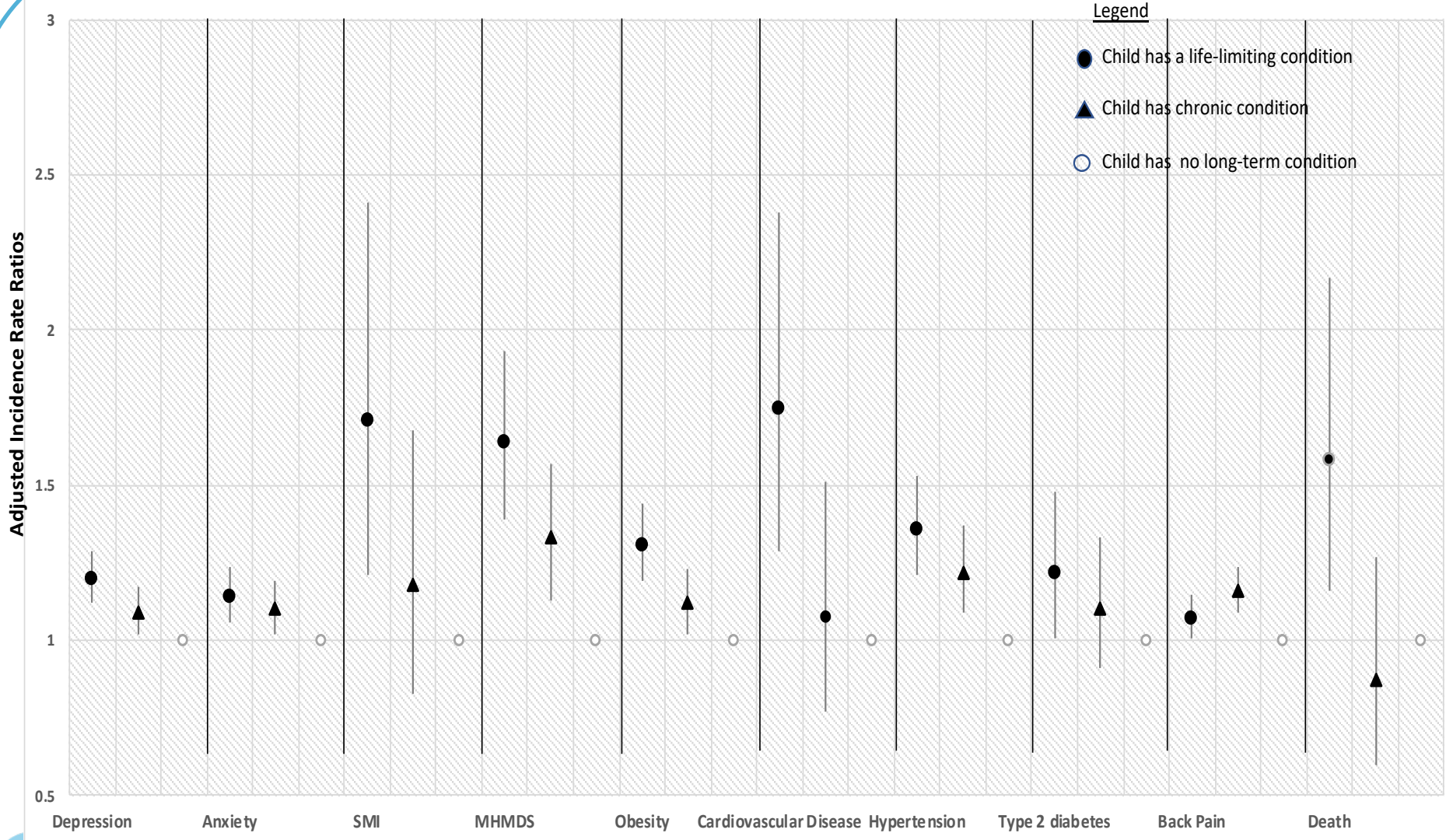
RESULTS 1

	Child has a life-limiting condition		Child has a chronic condition		Child has no long-term condition		Total	
	n	%		%		%		%
Total Mothers	8950		8868		17865		35683	
Mothers Age	34.0 (7.7)		33.8 (7.3)		34.1 (7.2)		34.0 (7.4)	
Deprivation category								
1 (least deprived)	1853	20.7	2037	23.0	4596	25.7	8486	23.8
2	1826	20.4	1749	19.7	3597	20.1	7172	20.1
3	1732	19.4	1685	19.0	3365	18.8	6782	19.0
4	1827	20.4	1753	19.8	3319	18.6	6899	19.3
5 (most deprived)	1706	19.1	1642	18.5	2979	16.7	6327	17.7
missing	6	0.1	2	0.0	9	0.1	17	0.0
Ethnic Group								
White	7272	81.3	7341	82.8	14578	81.6	29191	81.8
South Asian	584	6.5	520	5.9	940	5.3	2044	5.7
Black	323	3.6	310	3.5	524	2.9	1157	3.2
Chinese	42	0.5	29	0.3	94	0.5	165	0.5
Mixed	90	1.0	80	0.9	165	0.9	335	0.9
Other	156	1.7	133	1.5	310	1.7	599	1.7
Unknown	483	5.4	455	5.1	1254	7.0	2192	6.1

RESULTS 2 – CRUDE INCIDENCE RATES

	Child has a life-limiting condition			Child has a chronic condition			Child has no long-term condition		
	Incidence per 10000 person years	95% Confidence Intervals		Incidence per 10000 person years	95% Confidence Intervals		Incidence per 10000 person years	95% Confidence Intervals	
Obesity	128	119	138	115	107	124	91.1	85.9	96.6
Cardiovascular Disease	13.4	10.8	16.7	8.6	6.7	11.1	6.4	5.2	7.9
Hypertension	84.3	77	92.2	79.3	72.8	86.6	57.1	53.1	61.4
Type 2 diabetes	28.7	24.7	33.4	26.6	23	30.7	20.3	18.1	22.1
Back Pain	402	381	424	471	449	495	364	351	377
Death	11.4	9.0	14.4	6.0	4.4	8.1	6.8	5.5	8.3
Depression	341	322	361	340	322	359	268	257	279
Anxiety	201	188	214	212	200	225	168	160	176
Serious Mental Illness	10.1	7.8	13	8	6.2	10.4	5.5	4.3	6.8
Secondary Mental Health Service Use	46.2	40.7	52.3	37.5	33	42.6	26.8	24.1	29.8

Physical and Mental Health Conditions in Mothers



STRENGTHS AND LIMITATIONS

- *Longitudinal study* which utilised a nationally representative sample of primary healthcare data linked to secondary healthcare data.
- Causality cannot be fully established using an observational study design but we have demonstrated the *temporality* of the relationship between exposure and outcome and a *dose response relationship* with key health outcomes
- *Quality of diagnostic coding* within the datasets.
- *Missing information* including family history of CVD, nutrition and alcohol intake.
- It is also not currently possible to reliably identify *father-child dyads*

CONCLUSIONS

- This study clearly demonstrates the higher incidence rates of common physical and mental health condition in mothers of children with a life-limiting condition.
- Further research is required to understand how best to support these mothers, but healthcare providers should consider how they can provide preventative and treatment services for this population.

ACKNOWLEDGEMENTS

Parent Advisory Panel

Co-Investigators

Professor Fliss Murtagh

Dr Jan Aldridge

Professor Trevor Sheldon

Professor Simon Gilbody

Professor Catherine Hewitt

Funder



Questions



The screenshot shows the University of York website. At the top, there is a search bar and a navigation menu with 'Health Sciences' selected. The main content area features a navigation sidebar on the left, a central image of a family, and a 'Latest tweet' section on the right. The central text reads: 'Martin House Research Centre' followed by a paragraph: 'The Martin House Research Centre is a partnership between Martin House Children's Hospice, the University of York (Department of Health Sciences and the Social Policy Research Unit) and the University of Leeds Academic Unit of Palliative Care. It is a multi-disciplinary centre for research on the care and support of children and young people with life limiting conditions or medical complexity, their families and the workforce that care for them. The Centre is holistic in its scope, recognising that the care and support needs of children and families span clinical/medical, social, psychological, parenting/caring, spiritual, financial and practical domains.'

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www.york.ac.uk/mhrc

<https://www.york.ac.uk/research/themes/health-and-wellbeing/childrens-palliative-care/>



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