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Impact of sociodemographic and clinical factors on offer and parental consent to postmortem following stillbirth or neonatal death: a UK population-based cohort study

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ABSTRACT

Objective To identify factors associated with the offer of and consent to perinatal post-mortem.

Design National population-based cohort study

Setting The UK.

Population 26 578 perinatal deaths born between 1 January 2013 and 31 December 2017.

Main outcome measures Postmortem offer by clinical staff; parental consent to post-mortem.

Results Postmortem offer rates were high but varied significantly with time of death from 97.8% for antepartum deaths to 88.4% for neonatal deaths following neonatal admission. Offer rates did not significantly vary by gestation, year of birth, mother's socioeconomic deprivation, ethnicity or age. Only 44.5% of parents consented to a postmortem. Mothers from the most deprived areas were less likely to consent than those from the least deprived areas (relative risk (RR)=0.76, 95% CI 0.71 to 0.80). Consent rates were similar for mothers of white, mixed, Asian Indian, black Caribbean and black African ethnicity (43%–47%), but significantly lower for mothers of Asian Pakistani (20%) and Asian Bangladeshi (18%) ethnicity. Consent increased with increasing gestation (p<0.001) and was lower for deaths following neonatal unit admission than for antepartum death (RR 0.71, 95% CI 0.67 to 0.75).

Conclusions The current profile of cause of perinatal deaths in the UK is likely to be biased with less postmortem information available for babies dying in the neonatal period and those born to mothers from deprived areas and of Asian Pakistani or Asian Bangladeshi ethnicity. Such bias severely limits the design of effective strategies for reducing mortality in these high-risk groups. These findings have implications for high-income countries seeking to explore and improve the understanding of perinatal deaths.

What is already known on this topic?

- Reduction of inequalities in perinatal mortality within high-income countries requires interventions based on causative factors.
- Over the past 20 years, falling rates of postmortem have been observed across high-income countries which limits the understanding of cause of perinatal death.
- A knowledge base of the underlying cause of death for all births is necessary to facilitate the design of effective interventions.

What this study adds?

- Current consent rates for postmortem examination are low, particularly among mothers from deprived areas and mothers of Asian Pakistani and Asian Bangladeshi ethnicity.
- Understanding of the cause of death in the UK is likely to be biased towards causes affecting babies born to less deprived white mothers.
- Bias in the offer and consent for postmortem may severely limit the information required to reduce perinatal mortality among high-risk groups.

INTRODUCTION

While perinatal mortality has reduced across high-income countries over the past decades, wide variation in mortality exists between countries[1 2] and within high-income countries[3] with significantly increased mortality rates for disadvantaged groups. These inequalities seem to be sustained or widening despite overall reductions in mortality.[4–6] In order to reduce mortality while ensuring the equity gap narrows, focused intervention strategies are needed based on an understanding of the cause of death which impact on avoidable perinatal deaths among high-risk groups.[7–9]

The development of such strategies is limited by the poor understanding of underlying causes of death. Currently, a high proportion of perinatal deaths are reported as being of unknown or non-specific cause. Information from detailed post-mortem has been shown to change the reported clinical cause of death and reduce the proportion of deaths reported as unexplained by a fifth. This proportion falls further when including detailed placental pathology.[10–12] Postmortem information also helps parents planning a subsequent pregnancy and informs management of future pregnancies. Even when no 'cause of death' is identified, detailed postmortem examination may exclude other potential causes and inform ongoing research regarding population risk factors and effective care programmes.[13]

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Little is known about the scale of inequalities in postmortem offer and consent nationally. Here, we explore factors associated with variation in clinicians' offer of a postmortem and parental consent to postmortem in the UK to assess bias in knowledge of cause of death among high-risk groups and the potential impact on the effectiveness of interventions to reduce inequalities in mortality.

METHODS

Data were obtained from Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries throughout the UK (MBRRACE-UK)[4] on all stillbirths (here defined as births showing no signs of life $\geq 22^{+0}$ weeks gestational age) and neonatal deaths (live births $\geq 22^{+0}$ weeks gestational age dying before 28 completed days) born between 1 January 2013 and 31 December 2017 in the UK excluding terminations of pregnancy. We did not directly include Patient and Public Involvement in this study, but the data collected by MBRRACE-UK used in the study was developed with patient and public involvement and is updated by a committee that includes patient representatives.

Information was obtained on offer of a postmortem by health professionals and subsequent parental consent as reported in the mother's or baby's medical records. Deaths were categorised by timing of death: antepartum stillbirth (before onset of labour); intrapartum stillbirth (after onset of labour); neonatal death on the labour ward; neonatal death following admission to a neonatal unit (NNU). The baby's gestational age in weeks at the time of birth was categorised as 22^{+0}–23^{+6}; 24^{+0}–28^{+6}; 29^{+0}–31^{+6}; 32^{+0}–36^{+6}; 37^{+0} and over.

Maternal sociodemographic information included mother's ethnicity (categorised as: white British; white other; mixed; Asian (Indian); Asian (Pakistani); Asian (Bangladeshi); Asian other; black Caribbean, black African; black other; Chinese or other; unknown or refused), mother's age at birth (<20; 20–24; 25–29; 30–34; 35–39; 40+ years) and socioeconomic deprivation of residence. Socioeconomic deprivation was measured by the Children in Low-Income Families Local Measure based on the super output area where the mother lived (around 1500 residents). Deciles of child poverty were created with approximately equal numbers of total births in each decile.

Poisson regression analyses were used to explore variation in 1) offer of postmortem by a clinician and 2) subsequent consent to postmortem by the baby's parents; by timing of death, year of birth, gestation at birth and mother's sociodemographic factors. We calculated relative risks (RR) with 95% CIs to evaluate associations between offer of postmortem and consent to postmortem with the dependent variables using univariable and multivariable models. We used multivariable logistic regression to calculate adjusted RR, CIs and P values for associations between offer of postmortem and consent for postmortem, including variables in the multivariable models shown to be associated at the univariable level. Statistical analyses were performed using STATA/IC 15.0.

RESULTS

Offer of post-mortem

Data were available on 26 578 perinatal deaths of babies born between 1 January 2013 and 31 December 2017. Analyses were carried out on 25 316 (95%) of the cohort excluding those with missing information on offer of post-mortem (n=1091) and deprivation decile (n=172).

Postmortem examination was offered in 24 129 out of 25 316 deaths (95%). Univariable analyses showed no significant difference in the percentage of deaths where postmortem was offered by gestational age, year of birth, mother's deprivation, ethnicity or age (table 1). There was a significant difference in offer of postmortem by time of death (p<0.0001), with the highest rates following stillbirth (overall: 97.7%; antepartum: 97.8%; intrapartum: 96.6%) compared with neonatal death (overall 90.1%; death on labour ward: 93.5%; death postadmission to a neonatal unit: 88.4%). As only one variable was significant at the univariable level, no multivariable analysis was undertaken.

Consent for postmortem

Analyses were undertaken on 23 581 cases remaining where offer of a postmortem was made, excluding 548 deaths with missing parental consent information (2.3%). Consent to postmortem by parents was 44.5% (3.8% limited postmortem; 40.7% full postmortem). Here, we discuss the findings of the multivariable regression as there was only a small attenuation of effect for each variable but no qualitative change in conclusions (table 2).

Mother's socioeconomic deprivation was strongly linked to postmortem consent (p<0.001), with rates of 39% for parents from the most deprived areas compared with 54% from the least deprived areas. After accounting for other risk factors, this showed parents from more deprived areas were 24% less likely to consent to a postmortem than those in the least deprived areas (RR=0.76, 95% CI 0.71 to 0.80)).

Rates of consent were fairly similar at around one in two for mothers of white British (47%), mixed (43%), Asian Indian (45%), black Caribbean (44%) and black African (45%), but were significantly lower at around one in five for mothers of Asian Pakistani (20%) and Asian Bangladeshi (18%) ethnicity. Asian Pakistani and Asian Bangladeshi mothers were 56%–61% less likely to consent to postmortem than mothers of white British ethnicity after adjusting for other risk factors (RR 0.44, 95% CI 0.39 to 0.49 and RR 0.39, 95% CI 0.32 to 0.48, respectively).

Parental consent increased with increasing gestation from 35% at 22^{+0} to 23^{+6} weeks gestation to 52% for term babies (p<0.001). Timing of death was also associated with rate of consent. Antepartum stillbirths had the highest rate of consent for postmortem (49%) compared with intrapartum stillbirths (38%), and neonatal deaths on labour ward (37%) and following admission to a neonatal unit (35%) (p<0.001). Parents of a baby dying on the neonatal unit were 29% less likely to consent to a postmortem than parents whose baby died in the antepartum period (RR 0.71, 95% CI 0.67 to 0.75). Consent for postmortem did not appear to change over time (p=0.800) or with mother's age at the time of birth (p=0.215).

Impact of postmortem on reported cause of death

For births in 2016 and 2017, data were available on whether the reported cause of death to MBRRACE-UK was the final agreed cause of death following postmortem results. We compared the percentage of stillbirths reported as unexplained or unknown for those with a final agreed cause of death where there had been a postmortem and for those where there was no postmortem. Of the 2547 stillbirths with consent for a postmortem and a final agreed cause of death, 29.5% were allocated a final cause of death of unexplained or unknown. In contrast, of the 2822 stillbirths where there was no consent to a postmortem 38.4% were classified as unknown or unexplained, a third higher.

Table 1 Percentage of offer of and consent to postmortem by year of birth, gestational age, timing of death and mother's sociodemographic factors and P value from univariate logistic regression analysis

	Offer of postmortem			Consent to postmortem		
	N	%	P value	N	%	P value
Year of birth						
2013	5110	94.8	0.701	4704	43.9	0.800
2014	5167	95.6		4784	44.8	
2015	5053	95.0		4688	44.5	
2016	5122	95.6		4817	45.0	
2017	4864	95.6		4588	44.2	
Gestational age at birth						
22^{+0}–23^{+6}	4150	95.4	0.985	3889	34.8	<0.001
24^{+0}–28^{+6}	6405	94.9		5968	41.1	
29^{+0}–31^{+6}	3148	96.1		2959	45.4	
32^{+0}–36^{+6}	4163	95.5		3858	45.5	
37^{+0}+	7450	95.2		6907	51.9	
Timing of death						
Antepartum death	15 350	97.8	<0.001	14 725	49.4	<0.001
Intrapartum death	2112	96.6		2001	38.4	
Neonatal death on labour ward	2694	93.5		2443	37.4	
Neonatal death following admission	5160	88.4		4412	34.8	
Child poverty index						
1 (least deprived)	1855	95.8	0.447	1750	53.6	<0.001
2	1980	95.1		1842	51.8	
3	2068	96.3		1949	51.1	
4	2347	95.9		2205	46.9	
5	2394	95.8		2239	45.3	
6	2494	96.1		2347	45.0	
7	2825	95.2		2633	42.3	
8	2957	94.4		2695	39.3	
9	3106	94.8		2870	39.3	
10 (most deprived)	3290	94.5		3051	39.2	
Mother's ethnicity						
White British	15 182	95.5	0.906	14 202	46.7	<0.001
White other	2531	96.2		2375	54.9	
Mixed	469	95.3		433	42.7	
Asian Indian	958	95.1		894	44.6	
Asian Pakistani	1753	93.7		1620	19.9	
Asian Bangladeshi	524	95.6		490	17.6	
Asian Other	549	94.0		499	40.9	
Black Caribbean	467	97.6		445	43.6	
Black African	1721	95.9		1594	44.7	
Black other	134	94.8		124	38.7	
Other	627	95.7		585	42.1	
Unknown	401	86.0		320	39.7	
Mother's age (years)						
<20	1241	95.2	0.976	1145	44.6	0.215
20–24	4304	95.0		4008	44.4	
25–29	6532	95.7		6127	43.8	
30–34	7130	95.4		6639	45.6	
35–39	4588	95.6		4275	44.9	
40+	1511	93.8		1380	40.8	
Unknown	10	70.0		0		

DISCUSSION

This is the first national UK population-based study to look at factors affecting offer of postmortem and parental consent. Based on over 25 000 deaths over a 5-year period, we found offer of postmortem to parents following perinatal death was uniformly high in the UK at over 95%. However, parental consent rates were low at less than half. Consent was significantly lower among mothers from deprived areas compared with those from deprived areas and mothers of Asian Pakistani and Asian Bangladeshi ethnicity. This impacted on the proportion of deaths which

Table 2 Relative risk (RR) of parents' consent for postmortem from logistic regression univariate and multivariate models

	Univariate analysis			Multivariate analysis		
	RR	95% CI	P value	RR	95% CI	P value
Year of birth						
2013	1		0.929			
2014	1.02	0.96 to 1.08				
2015	1.01	0.95 to 1.08				
2016	1.03	0.97 to 1.09				
2017	1.01	0.95 to 1.07				
Gestational age at birth						
22^{+0}–23^{+6}	0.67	0.63 to 0.71	<0.001	0.70	0.65 to 0.74	<0.001
24^{+0}–28^{+6}	0.79	0.75 to 0.83		0.81	0.77 to 0.85	
29^{+0}–31^{+6}	0.87	0.82 to 0.93		0.87	0.81 to 0.92	
32^{+0}–36^{+6}	0.88	0.83 to 0.93		0.87	0.82 to 0.92	
37^{+0}+	1			1		
Timing of death						
Antepartum death	1		<0.001	1		<0.001
Intrapartum death	0.78	0.72 to 0.84		0.83	0.77 to 0.90	
Neonatal death on labour ward	0.76	0.71 to 0.81		0.82	0.77 to 0.88	
Neonatal death following admission	0.70	0.67 to 0.74		0.71	0.67 to 0.75	
Child poverty index						
1 (least deprived)	1		<0.001	1		<0.001
2	0.96	0.96 to 0.97		0.97	0.96 to 0.98	
3	0.93	0.91 to 0.94		0.94	0.93 to 0.95	
4	0.89	0.87 to 0.91		0.91	0.89 to 0.93	
5	0.86	0.83 to 0.88		0.88	0.86 to 0.91	
6	0.82	0.80 to 0.85		0.86	0.83 to 0.89	
7	0.79	0.76 to 0.83		0.83	0.80 to 0.86	
8	0.76	0.73 to 0.80		0.80	0.77 to 0.84	
9	0.74	0.70 to 0.78		0.78	0.74 to 0.82	
10 (most deprived)	0.71	0.67 to 0.75		0.76	0.71 to 0.80	
Mother's ethnicity						
White British	1		<0.001	1		<0.001
White other	1.17	1.10 to 1.24		1.18	1.11 to 1.25	
Mixed	0.91	0.79 to 1.05		0.94	0.81 to 1.08	
Asian Indian	0.95	0.86 to 1.05		0.94	0.85 to 1.04	
Asian Pakistani	0.43	0.38 to 0.48		0.44	0.39 to 0.49	
Asian Bangladeshi	0.37	0.30 to 0.46		0.39	0.32 to 0.48	
Asian other	0.87	0.76 to 1.00		0.87	0.76 to 1.00	
Black Caribbean	0.93	0.81 to 1.07		1.00	0.86 to 1.15	
Black African	0.95	0.88 to 1.03		1.01	0.94 to 1.10	
Black other	0.83	0.62 to 1.10		0.89	0.67 to 1.18	
Other	0.90	0.79 to 1.02		0.90	0.80 to 1.03	
Unknown	0.85	0.71 to 1.01		0.93	0.78 to 1.11	
Mother's age (years)						
<20	1.02	0.93 to 1.12	0.215			
20–24	1.02	0.96 to 1.08				
25–29	1					
30–34	1.04	0.99 to 1.10				
35–39	1.03	0.97 to 1.09				
40+	0.93	0.85 to 1.02				
Unknown	–	–				

were reported as unexplained with a third higher rate of unexplained death where there was no postmortem compared with when post-mortem information was available.

Following the well-publicised organ retention scandals at Alder Hey and Bristol in 1998, UK postmortem consent rates for stillbirths fell from 67% in 2000 to 49% in 2009[14] and remain at 48% based on this study. For neonatal deaths, the decline is more marked falling from 59% in 2000 to 48% in 2009[14] and 36% here. Fewer parents were offered a postmortem following neonatal death than following stillbirth confirming previous findings[14] and suggests that health professionals may be more likely to regard the cause of death of a baby following

provision of neonatal care as 'known' with postmortem seen as providing limited added value. Similarly, consent was lower for postmortem at earlier gestations where death may be regarded by professionals and parents as inevitable. A study of long stay intensive care patients showed that postmortem examination revealed major unexpected findings in around 20% of cases,[15] highlighting that the offer of postmortem should be universal even if there is an assumption that the cause is known as the presence of other significant underlying contributing factors to premature labour or findings such as an unsuspected anomaly (which is important for counselling parents about risk in subsequent pregnancies) may remain undiagnosed. Variation in consent with timing of death supports research suggesting that parents are more likely to engage with the postmortem process when they have time to reflect and consider their loss.[7 16] Parents may have already processed their loss following an antepartum stillbirth allowing them to engage with the clinicians as to how post-mortem may help future pregnancies.[16]

While our findings show limited support of the perception that clinicians may be reluctant to offer postmortem to certain groups of parents[17] or that black women were less likely to report being offered a postmortem than white women,[18] our study showed significantly lower rates for mothers of Asian Pakistani and Asian Bangladeshi ethnicity and women living in deprived areas. While religious diversity exists within ethnicity classifications used here, these findings may reflect conflict of the timing of postmortems with religious or cultural practises[19] as Muslim parents may be more likely to require burial within 12 hours[20] and more likely to accept their loss as the 'will of God'.[20 21] It is vital that where possible decisions are not influenced by delays due to transfer of the body to a specialist centre and that decisions are based on the provision of unbiased information leading to informed parental choice. The manner in which health professionals interact with parents and present the importance of the autopsy process may strongly influence parents' decisions around postmortem.[17 18 22] This may be due to the fact that information being provided is inaccessible for some groups of parents, assumptions that the cause of death is 'known' or that the consent process is too arduous and distressing. The perception of the process may be improved where staff interact unambiguously and professionally, imparting information surrounding autopsy in an unbiased fashion, allowing time for the family to reflect on the death and begin the grieving process.[23]

Research evidence has highlighted that a shortage of perinatal pathologists[24] and associated lengthy time wait for results[17] leads to a reluctance on the part of staff to offer postmortem. Here, this does not appear to have impacted on postmortem offer rates, but may have impacted on consent rates if parents are made aware of potential time delays in receiving results. Recent research suggests that good local access to pathologists leads to an increase in uptake[9] and there is the potential for less invasive postmortem such as using MRI scans to also increase consent rates[25] in addition to the importance of reassurances for parents that their baby's body will be treated with respect.[19] However, empirical evidence of the impact of this is still needed.

With regard to the coronial perspective in England, it is worth noting that the then Secretary of State for Health, Jeremy Hunt, called for coroners to be granted special permission to investigate stillbirths (https://www.gov.uk/government/news/new-maternity-strategy-to-reduce-the-number-of-stillbirths/ accessed 18 December 2019) in 2017, although this is yet to be decided. However, there have been landmark decisions by the Court of Appeal in 2013 that coroners do have the jurisdiction to carry out an inquest on a child that had been capable of being born alive.[26] This obviates the necessity of staff to request postmortem but may add to family distress.

Strengths and limitations

This study is based on an extremely large UK cohort data of over 25 000 stillbirths and neonatal deaths over a 5-year period. However, only limited information was available with no data on the role of the professional seeking consent nor reasons why parents consented or did not consent to postmortem. Furthermore, we had no detailed information on any prior discussions regarding the likely cause of death. The number of deaths reported as unexplained in the postmortem group may be overestimated as the final cause of death following postmortem was not consistently updated in our data set at the time of analysis which could suggest an even wider differential between the proportion of deaths reported as unexplained between deaths undergoing post-mortem and those not.

Implications for clinicians and policy makers

The lessons from this study have implications for the UK and other high-income countries seeking to explore and improve the understanding of stillbirth and neonatal death. The current profile of cause of death for stillbirth and neonatal death may be biassed as there are an increased number of unexplained deaths and consequently far less information about cause among babies born to mothers from deprived areas or of Asian ethnicity. This is of key importance to policy makers because babies born to mothers in these groups are at increased risk of stillbirth and neonatal death and a lack of information severely limits opportunities to design appropriate strategies for reducing mortality. If the profile of cause of death differs between these groups, then this biassed knowledge base may lead to the implementation of interventions to reduce perinatal death that subsequently and inadvertently exacerbate inequalities in mortality rates.

Moving forward, it is vital that all parents are offered a postmortem to provide the opportunity to understand the reason for their loss potentially reducing the burden of guilt when cause of death is defined[7 23] and allow for targeted care packages in subsequent pregnancies.[3] It is vital we offer more options to obtain information on cause of death in a timely manner and address concerns from those groups who in the past have had lower uptake of postmortem. Since several studies have suggested that decisions are heavily influenced by the manner and timings of discussion,[8] there is a real need to review how and when consent is sought with an unambiguous patient-centred approach allowing for differences between diverse groups of parents.

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