Learning from maternal Sudden Unexplained Death in Epilepsy (SUDEP): Thematic analysis of safety investigations in England

MNSI
Maternity & Newborn Safety Investigations

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BACKGROUND

The 2020 MBRRACE-UK Report identified an increase in Sudden Unexpected Death in Epilepsy (SUDEP). In the UK and Ireland in 2016-2018, 22 women died during or up to a year after the end of pregnancy from causes related to epilepsy, with 18 dying from SUDEP, a more than doubling of the rate compared to 2013-2015.

Issues were found in their care relating to:

- Prescription of or choice of anti-epileptic drugs (AEDs)
- Poor pre-pregnancy control
- Limited pre-pregnancy and/or antenatal specialist review
- Limited SUDEP risk assessment and education

MBRRACE made recommendations aimed at improving the care of women with epilepsy, including to develop:

- Guidance for SUDEP awareness and risk assessment
- Clear standards of care for joint maternity and neurology services to allow early referral, optimisation of AEDs, review of worsening symptoms, and prompt postnatal review.

The Maternity and Newborn Safety Investigations (MNSI) programme is part of a national strategy to improve maternity safety across the NHS in England. MNSI has completed over 3500 independent safety investigations, using a standardised, systems-focused methodology, into maternity events, including 237 maternal deaths. MNSI makes recommendations to improve services at local level and across the whole maternity system.

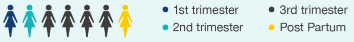
We reviewed MNSI-investigated maternal deaths from SUDEP using a systems-focus, with the aim to add to existing recommendations from MBRRACE-UK.

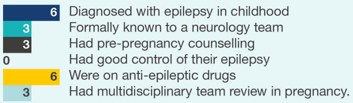
METHOD

We identified 8 investigations into maternal deaths from SUDEP between 2020 and 2023; 1 was excluded as the cause of death was unascertained. We undertook a deductive, systems-focused, thematic analysis of 7 MNSI reports. The Systems Engineering for Patient Safety (SEIPS) model was used as a framework for initial coding.

RESULTS

The 7 women who died were between 20 and 36 years old:





Three key themes were identified:

① Delivery of individualised specialist multidisciplinary care
② Communication across multiple providers
③ Communication with healthcare professionals

THEME 1: DELIVERY OF INDIVIDUALISED SPECIALIST MULTIDISCIPLINARY CARE

'There was no multi-disciplinary shared mental model, and the pathway did not provide opportunities for care decisions to be reached in a collaborative way, drawing on different spheres of expertise.'

- There are clear schedules for maternity care in the NHS. These pathways are not always suitable for women with additional medical and/or social complexities.
- The women who died had multiple risk factors, which would have increased the complexity of their pregnancy care and their risk of SUDEP. Providers did not identify their significance, leading to no referral for or delay in review.
- There were multiple opportunities for prompt optimisation of epilepsy management that were not taken. Seizure frequency was normalised; women not taking medication were considered to be at low or no risk.

  "She shared that she had experienced a seizure in the week. A plan was made for an appointment in one weeks' time."

  "…her recent seizure was more related to her housing needs and an inability to get a continued supply of medication."

MEDICAL RISK FACTORS:
- Obesity
- Mental health diagnoses
- Smoking
- Substance misuse
- Previous preterm birth

EPILEPSY-RELATED RISK FACTORS:
- Not on anti-epileptic drugs
- Decision to stop medication by woman
- Frequent seizures
- Nocturnal seizures

SAFEGUARDING PERINATAL MENTAL HEALTH

SOCIAL RISK FACTORS:
- Homelessness
- Known to social services
- Multiple moves – of home, primary care provider and maternity care provider
- Care between NHS trusts
- Living alone / limited social support
- Relationship difficulties

- The complexity of the women meant that they required input from multiple teams and different providers.

  "It was unusual for a mother to be seen in different obstetric clinics… staff considered the four clinics the Mother was expected to attend was excessive… [this] contributed to her non-attendance and resulted in the Mother's antenatal care missing key elements."
- Providers attempted to care for complex women within linear care pathways, with no recognition of their cumulative risk factors for SUDEP. This meant care may have been suboptimal or missed entirely.
- The women's multiple risk factors required care to be delivered in an individualised way, with holistic oversight. Women with complex pregnancies require antenatal care co-ordinated by a named clinician specialising in their specific condition, with the care wrapping around the mother.

THEME 2: COMMUNICATION ACROSS MULTIPLE PROVIDERS

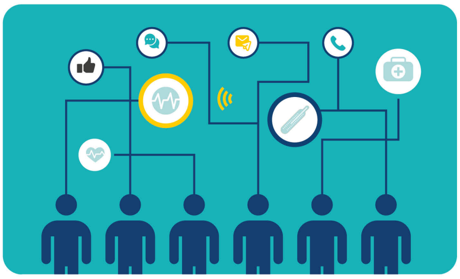
'There was no obstetric or neurological oversight of the Mother in the last few weeks of her life… Other members of the team were aware of the Mother's seizures…there is no evidence that this information was shared'

- Women often had multiple different care providers within both primary and secondary care; these may also have been geographically separate. It was often not clear who was leading on the care of a woman:

  "The investigation learnt that Trust A considered that they had oversight of the Mother's pregnancy and that Trust B would manage the Mother's epilepsy."

  "Some staff had assumed that the Mother's GP was managing her epilepsy care."
- When information needed to be shared, there were not pathways for effective communication, or ineffective, unreliable tools such as letters were used. This led to reliance upon the woman to be the pathway of communication between providers.

  "The investigation learnt that there was no pathway or expectation for the obstetric and midwifery team at Trust A to share the Mother's worsening seizure activity with the epilepsy team at Trust B and that there was a reliance on the Mother to communicate this information to the epilepsy team."



- Multiple different paper and electronic systems were used for documentation and communication, both within and between care providers. Often these were not visible to all and the systems did not communicate with each other, meaning there was limited information sharing.

  "The neurology and obstetric teams did not have access to the Mother's notes from when she was under the care of a different hospital and it was documented that 'without old notes, very difficult for me to manage in epilepsy antenatal clinic'."

  "The maternity computer systems and neurology computer systems "do not speak to each other""
- This led to omissions, including assessment of symptoms, medication compliance and neurology review.
- Collaborative working and communication between providers could be enhanced by having shared access to information through shared IT systems and shared care toolkits.

THEME 3: COMMUNICATION WITH HEALTHCARE PROFESSIONALS

'The Mother found it difficult to navigate the healthcare system when she had seizures during the pregnancy'

- It was not easy for women to engage with care due to the logistical challenges posed by the system. This included at care transitions (paediatric to adult services, or from primary to secondary care) and due to discharge polices. This was often compounded by social vulnerability.

  "In the three years leading up to her death, the Mother had changes in her home circumstances which led to her changing address several times. During this time, the Mother accessed care through three different GP surgeries, with different doctors for most appointments…Throughout these interactions her epilepsy remained uncontrolled."
- Care was difficult to navigate, especially when it did not fit the linear maternity care pathways:

  "The Mother experienced nausea and vomiting…The organisational pathways in operation for mothers with epilepsy do not support timely and early access to additional information and monitoring of their epilepsy."
- Significant responsibility was placed upon the woman to coordinate her own care or be the main pathway for communication between different care providers.

  "She shared that she was having increased seizures. The Mother was advised to inform the epilepsy team."

- Even once engaged with care, there was evidence of limited education to the woman about SUDEP. This was partly due to limited knowledge and recognition of risk factors by care providers, which led to opportunities to enhance safety not being taken.

  "The level of knowledge of the recognition and management of epilepsy varied depending on experience. This led to there being a reduced understanding of the risks presented by epilepsy."
- There was also reluctance to discuss SUDEP clearly.

  "SUDEP is not routinely mentioned to mothers and there was a perception this may be frightening for them to hear as "there's lots of anxiety anyway around pregnancy"."
- Care pathways need to be flexible, to allow women to easily access care in early pregnancy and when they need help. Women need to be partners in their care and be educated about their condition and its risks. This requires collaboration between women and care providers. Shared care toolkits could empower women in this way.

To find out more about MNSI and our investigations or to attend a webinar discussing this topic further please scan the QR code.

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CONCLUSION

The systems-focused approach to both MNSI investigations and this review can support the development of recommendations for improving the safety of care for women with epilepsy throughout the NHS. Whilst there is evidence of progress in epilepsy care since the MBRRACE-UK 2020 report, our thematic review of deaths from SUDEP echoes their findings.

Beyond MBRRACE-UK's call for SUDEP guidance and clear standards of care for joint maternity-epilepsy services, we emphasise that epilepsy care in pregnancy is complex and is optimised when delivered in a bespoke, flexible way informed by individual risk factors. Essential to this is collaborative working, between care providers and with women; this requires shared access to information, as well the allocation of a lead professional with holistic oversight. Care pathways would benefit from being supported by IT systems and a shared care toolkit to promote collaboration and to empower women with epilepsy as partners in their care.