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Background and introduction

Pregnancy is a high-risk period for women with epilepsy, associated with adverse outcomes, including sudden unexpected death in epilepsy (SUDEP).¹ The national maternity surveillance programme, Saving Lives, Improving Mothers’ Care (MBRRACE-UK), identifies epilepsy as a leading cause of maternal death, with 14 maternal deaths being attributed to SUDEP between 2019 and 2021 (0.63 per 100,000 maternities).^{1,2} Case series on SUDEP in pregnancy are limited. A nationwide Japanese study reported a lower SUDEP-related maternal mortality rate of 0.066 per 100,000 pregnancies and a need for further research on whether pregnancy poses as a risk factor in SUDEP.³ National guidelines emphasise specialist-led care, optimisation of anti-seizure medication (ASM), and effective risk communication, yet real-world adherence to these standards remains unclear.^{2,4,5} This study aims to address this gap by identifying recurring themes in pregnancy-related SUDEP and assessing adherence to guideline-recommended care.

Method

Retrospective analysis of pregnancy-related SUDEP cases from the SUDEP Action Epilepsy Deaths Register (2013–2025).⁶ Data derived from third-party reports provided by bereaved contacts. Quantitative analysis assessed adherence to guideline-recommended care domains and qualitative analysis was performed to identify recurring themes in clinical care and communication.

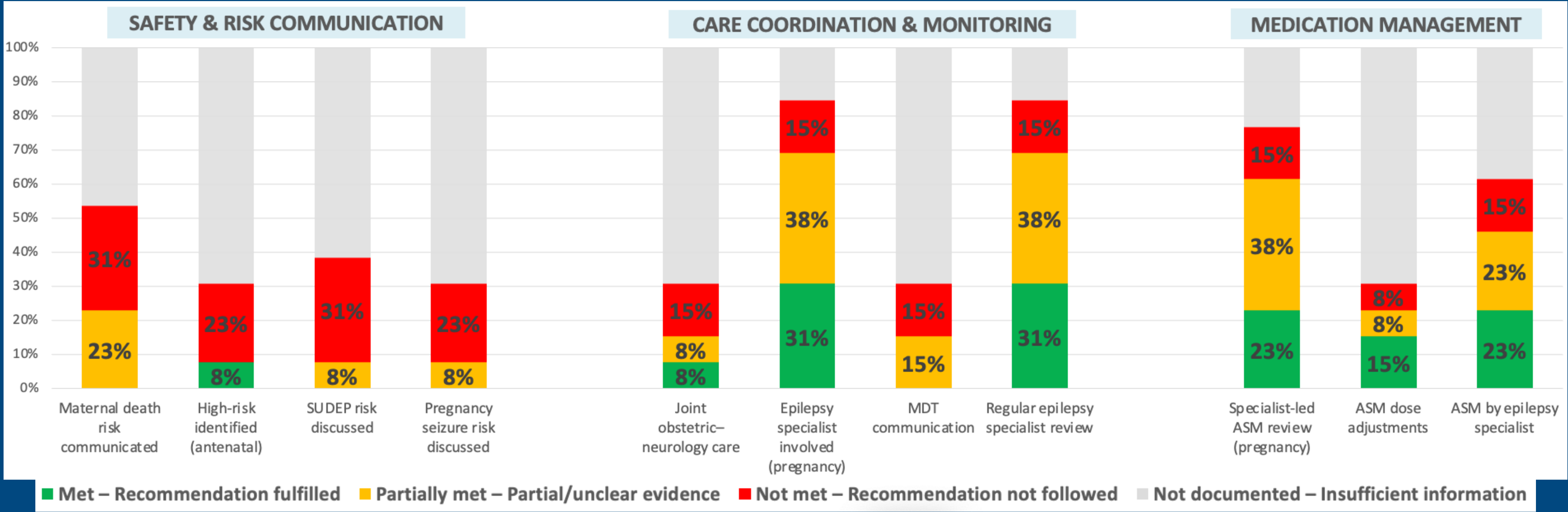
Results

“The two departments did not
liaise together”

“We were never told of SUDEP”

“She refused to take it as she said
that the side effects were horrendous”
(anti-seizure medication)

Adherence to Epilepsy Pregnancy Care Standards in SUDEP Cases (Care gaps are most evident in risk communication domains)



Demographics (n = 13)	
Age	Median 25 (range 17–37)
Pregnancy/post-partum	85% antenatal; 15% postpartum
Location of death	92% home; 8% hospital
Position found	54% prone; 31% other; 15% unknown
Living situation	85% cohabiting; 15% living alone
Last specialist contact (n=11)	82% less than 12 months ago; 18% more than 12 months ago
Prescribed ASM (n=11)	82% prescribed; 18% not prescribed

Limitations

The sample size was limited (n = 13), which may reduce generalisability, although this represents one of the larger reported cohorts of pregnancy-related SUDEP. Data relied on third-party reports, introducing potential recall and reporting bias, and it is difficult to ascertain whether these accounts accurately reflect patient–healthcare interactions. Clinical records were not available for verification. Additionally, “not documented” findings reflect uncertainty in reported care rather than confirmed absence of care.

References

- MBRRACE-UK. Saving Lives, Improving Mothers’ Care: State of the Nation Report 2019–21. Oxford: NPEU; 2023.
- MBRRACE-UK. Saving Lives, Improving Mothers’ Care: Lessons learned... 2021–23. Oxford: NPEU; 2025.
- Tanaka H, et al. Maternal death related to sudden unexpected death in epilepsy: a nationwide survey in Japan. Brain Sci. 2021;11:995.
- Royal College of Obstetricians and Gynaecologists. Epilepsy in pregnancy. London: RCOG; 2016.
- National Institute for Health and Care Excellence. Epilepsies in children, young people and adults (NG217). London: NICE; 2022.
- SUDEP Action. Epilepsy Deaths Register (EDR) [dataset]. Wantage (UK): SUDEP Action; 2013–2025.
- Tan M, et al. Adherence patterns in antiseizure medications influencing risk of sudden unexplained death in epilepsy. Epilepsia. 2023;64:641–653.
- van der Lende M, et al. Nocturnal supervision and SUDEP risk at different epilepsy care settings. Neurology. 2018;91:e1508–e1518.

Key findings from narrative analysis

- Limited awareness and communication of epilepsy mortality and SUDEP risk in pregnancy (9/13 cases)**
 - With 4 cases explicitly describing inadequate risk communication from healthcare professionals.
- Challenges in balancing medication management and seizure control during pregnancy**
 - With 4 cases expressing concerns about ASM side effects and 5 cases describing increasing seizure frequency during pregnancy or after ASM changes.
- Specialist care reported in 11/13 cases. However, nature of epilepsy-specific specialist involvement was frequently unclear.**
- 2 cases described gaps in care coordination** between services (e.g. epilepsy specialist, maternity services and GP)

Conclusion

Adherence to pregnancy-specific epilepsy care standards was variable. Risk communication was frequently not documented or not met, with limited awareness among relatives despite most individuals cohabiting. As behavioural factors (e.g. medication adherence, nocturnal supervision) may modify SUDEP risk, effective clinical communication is important.^{7,8} In majority of the cases, individuals were under specialist care, prescribed ASM, and reviewed by a specialist within the previous 12 months, suggesting risk is not confined to traditionally high-risk groups. Specialist involvement and care coordination were often unclear, and medication management varied. Overall, risk communication may be inadequate or not effectively shared, and pregnancy may alter established risk patterns. In line with MBRRACE-UK findings, clinicians may benefit from greater support to engage in clear, repeated conversations around risk, medication safety, and adherence. Improved communication, medication management and coordination may improve SUDEP risk management in pregnancy.