

Improving Perinatal Palliative Care: Impact of a Perinatal Service on Referrals and Symptom Management

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Background

In the context of uncertain prognoses, parallel planning for the perinatal population allows active treatment and palliative care simultaneously.[1] Specialist palliative care services play a critical role in complex symptom management, advance care planning and end-of-life care. [2,3] Despite growing recognition for specialist palliative care to be provided for the perinatal population, consistent practices and improved knowledge sharing remain needed. [4] Data on referrals, symptom experiences and management are not commonly reported. In 2022, a hospice-based specialist paediatric palliative care team strengthened links with perinatal services through attendance at fetal medicine meetings and neonatal ward rounds in acute hospitals. The team expanded to include a dedicated perinatal clinical nurse specialist and a consultant with an interest in the speciality.

Aim

To measure the impact, referral patterns, presence of symptom management plans and use of symptom medicines within a specialist perinatal palliative care service.

Methodology

- A retrospective review of referrals in utero and up to 28 days after birth to a specialist perinatal palliative care service.
- Perinatal referrals from 2020 - 2025.

Results

Perinatal service

Table 1. Medication use

Medication	Given and documented
Morphine Breathlessness Pain	12 (17.4%) 0
Midazolam Seizures Agitation	2 (2.9%) 12 (17.4%)
Glycopyrronium	2 (2.9%)



Figure 1. Key components of perinatal service

Table 2. Demographics

Babies referred to service (n = 69)	
Gestational age at referral (weeks):	
Before birth	Mean: 28.2 Range: 14 – 38
After birth	Mean: 35.2 Range: 23 – 42
Gender	32 Female 37 Male
Perinatal referral criteria:	
Neurological / neuromuscular	n = 20
Genetic / chromosomal / syndromic	n = 17
Structural / organ-specific	n = 15
Prematurity and pregnancy-related	n = 11
Infection-related	n = 3
Complex / multi-system / other	n = 3

Key findings

- The number of referrals and Symptom Management Plans increased from 2020 to 2025 by 188% and 113%, respectively.
- Average gestational age at antenatal referrals decreased from 29 weeks in 2020 to 27 weeks in 2024.
- Overall, this indicates improved partnership and integration leading to referrals at the point of diagnosis, not only at end of life.

Impact of the service

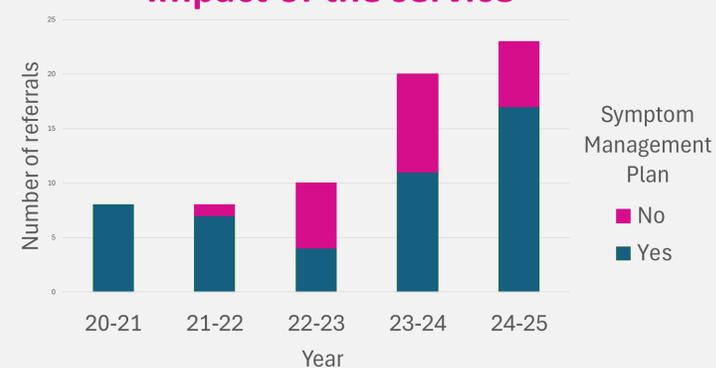


Figure 2. The bar chart demonstrates a gradual increase in referrals and use of symptom management plans over the last five years.

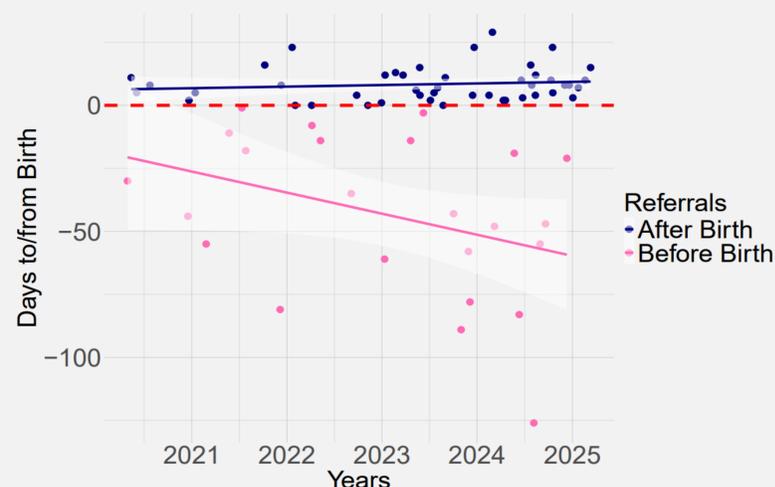


Figure 3. The pink regression line shows a significant increase in referrals earlier in pregnancy over the last five years ($R^2=0.67$, $F(3,65)=43.83$, $p<0.001$).

Feedback from healthcare professionals

“Your presence on the unit brings so much for the babies and their families and so much for the healthcare team.”
(NICU Consultant)

“This case...is a good example of multidisciplinary team planning.”
(Fetal Medicine Consultant)

Your expertise and guidance were invaluable ... thank you once again for your exceptional care and support.”
(NICU Matron)

Conclusion

- The introduction of a specialist service had a positive impact on perinatal palliative care delivery.
- Increased number of referrals and babies with symptom management suggest improved identification, earlier engagement and better coordination of care for families facing life-limiting fetal and neonatal diagnoses.
- Medication use was not consistently reported and is highlighted as an area for improving data quality and clinical documentation.
- Findings indicate that perinatal services strengthen care through structured planning and enhanced support for clinicians and families.
- Feedback reflected positively on the service, emphasising the quality and significance of the perinatal care offered.

References

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