

Layers of Care: Thematic Insights of Complexity in Specialist Paediatric Palliative Care Practice from Regional Multidisciplinary Caseload Meetings



Introduction: Multidisciplinary team (MDT) meetings are a cornerstone of safe and effective clinical decision-making in Specialist Children's Palliative Care, particularly for babies, children, and young people (BCYP) with deteriorating or end-of-life care needs (NICE, 2016, NHSE 2023).

Objective: This study aimed to explore complexity in paediatric palliative care and consider how this might inform future models of care delivery, team communication, and workforce learning and development needs.

Method: Thematic analysis of documentation, anonymised by Managed Clinical Network Coordinator (MCN), of complex cases at weekly regional MDT meetings between 1/4/24 and 31/3/25. Case classification by lead professional: **Red:** Deteriorating / Dying; **Amber:** Unstable; **Yellow:** Stable.

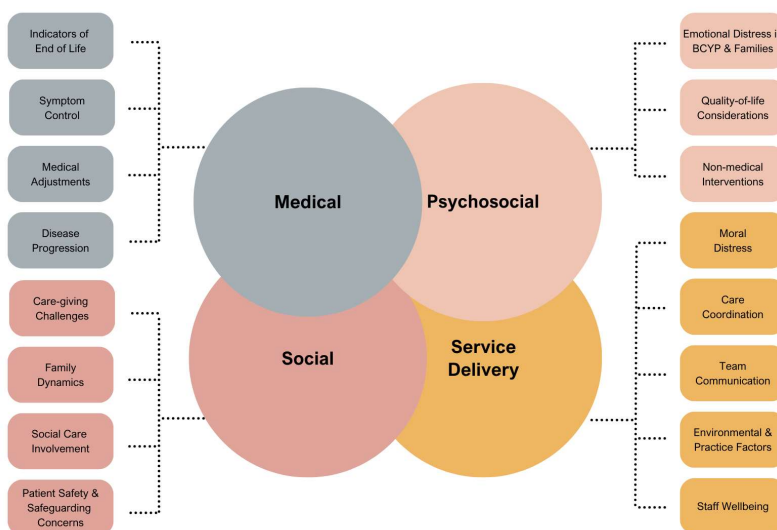
Demographics of MDTs during study period:

- MCN Network Coordination
- Lead Nurse Chairperson
- Meetings n=51
- Duration 60 minutes
- Consultant present 44/51
- Contemporaneous record
- Organisation participation n=15 (hospice, hospital, community, tertiary)
- Average professional attendance n=15 (range 13 to 28)
- BCYP discussed n=108
- BCYP who died n=53.



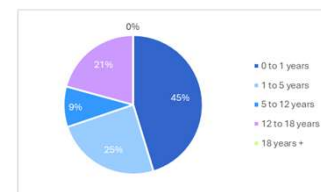
"...when a family and the team can work in collaboration, we can overcome complex side effects of a primary diagnosis"
Lilian's mum

Domains of Complexity



"...sometimes the situations are very complex, it may be helpful to prioritise [discussion about] the most complex or sickest [cases]"
Survey Respondent

Age category of children who died during reporting year:



Diagnostic Category	Total No. Patients	No. Patients Died	Days on Caseload within reporting year			Days Categorized 'Red' within reporting year		
			Mean	Min	Max	Mean	Min	Max
Circulatory	10	6	29	1	143	9	1	28
Congenital	17	12	34	1	108	8	1	18
Gastrointestinal	4	3	83	8	147	30	8	68
Metabolic	1	1	1	1	1	N/A	N/A	N/A
Neurology	41	14	56	1	287	17	1	105
Oncology	27	13	86	2	360	32	5	91
Perinatal	2	1	24	21	26	5	5	5
Respiratory	4	2	21	1	64	N/A	N/A	N/A
Other	2	1	47	10	84	10	10	10
TOTAL	108	53						

Guide to Paediatric Palliative Care in the East of England



Conclusion

- Structured MDT case discussion for children with life threatening or life limiting conditions who are unstable, deteriorating or dying helps care planning, service development and identify learning needs of professional teams
- Analysis of contemporaneous notes from these MDT meetings identified several constructs of complexity: individual medical / clinical needs, social and psychological issues and service delivery consideration
- Observing these constructs through an holistic family system lens promotes high quality individualised patient care, recognises the importance of developing family resilience and supports local neighbourhoods health care teams deliver collaborative care
- Further research is needed to develop an objective measure of complexity and outcome of care for this group.

References

Maynard et al (2024) How do regional multidisciplinary children's palliative care meetings support system development? Global Gathering Conference, Rome. The Specialist Palliative and End of Life Care Services: Children and Young People Service Specification (NHSE, 2023). NICE Guidelines NG61 (2016) End of Life Care for Infants, Children and Young People with Life-Limiting Conditions: Planning and Management. RCN (2025) Caring for Infants, Babies, Children and Young People Requiring Palliative Care: A career and education framework.

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