

Topic Expert Group: Medical care and clinical practice

Diagnosis and management of necrotising enterocolitis (NEC)

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Target group

Infants at risk of or being treated for necrotising enterocolitis (NEC) and parents

User group

Healthcare professionals, neonatal units, hospitals, health services

Statement of standard

Neonatal services provide a high standard of care in terms of diagnosis and treatment of necrotising enterocolitis (NEC) and infant/family experience and strive to continuously improve care and outcomes for NEC.

Rationale

Necrotising enterocolitis (NEC) is a leading cause of mortality and morbidity in preterm infants. About 40-50% of preterm infants who require surgery for NEC do not survive. Our improved understanding of the causation of NEC has not yet translated into improved outcomes, especially for surgical NEC. (1)

Outcomes for newborns at risk of NEC are best improved by preventing NEC. In those in whom NEC occurs, a much earlier diagnosis and intervention can improve outcomes. Unfortunately, we do not at present have reliable biomarkers to predict or detect NEC early or delineate it from various confounders. (2,3)

It is estimated that 1 per 1.000 live-born infants develop NEC and among these about 25% progress to surgical NEC. Apart from mortality, NEC can have life-long severe impact on infants and families and a significant socio-economic burden on society. (3,4) Among survivors of NEC, the average length of hospital stay increases by approximately 3 weeks for medical NEC and about 2 months for surgical NEC. (5) NEC can account for nearly 20% of the annual neonatal unit expenditure and a potential cost-saving of \$200,000 per patient could be achieved if progression to surgery is prevented. (2,3,6–10)

Optimising long-term neurodevelopment is critical and we need to shift the focus from survival alone to minimising impairment as the primary goal. (3) There is evidence that the overall mortality rate and rate of neurodevelopmental impairments (NDI) is very high for infants with surgical NEC. Surgical NEC significantly increases the odds ratio of cerebral palsy (mean=1.55), visual impairment (mean=2.31), cognitive impairment (mean=1.44) and psychomotor impairment (mean=1.72). (9,11–13) Hence, prevention should be the primary quality improvement goal but if NEC does develop, the early detection and attempt to prevent progression to surgical NEC is of paramount importance.

While the last 6 decades have seen a lot of research into the pathogenesis of NEC to try to generate a 'cure' (1,14), we have missed opportunities for quality improvement (QI) and standardisation. In parallel with efforts to improve our understanding of etiology of NEC, we need to focus on our standards of care with regard to diagnosis and treatment of NEC as well as family experience. We need to focus on improvements that units can make tomorrow, over the coming weeks and months.

Reports on variation in incidence and mortality (incidence between 2-7% overall – fourfold difference, between 5-22% in <1kg- almost fivefold difference) also suggest

that QI efforts to improve standards of care may help in decreasing unwanted variation and improve outcomes. (15)

Benefits

Short-term benefits

- Earlier identification of NEC (16–18)
- Reduced mortality and morbidity (19)
- Decreased need for surgery (20)
- Improved surgical outcomes (e.g. extent of resection required) (17,19,21)
- Reduced risk of complications of NEC (22)
- Decreased other neonatal morbidities which are worsened by NEC e.g. chronic lung disease (22)
- Reduced length of hospital stay (consensus)
- Improved growth and nutrition (23–25)
- Improved family experience (consensus)
- Timely access to appropriate surgical opinion (26)
- Timely access to appropriate pain relief/comfort care (27)

Long-term benefits

- Reduced mortality (28)
- Decreased need for repeated surgery (21,22)
- Improved surgical outcomes (22)
- Decrease in complications of NEC e.g. short gut syndrome, long-term parenteral nutrition, need for transplantation (17,22,29)
- Improved quality of life (30,31)
- Reduced rate of readmissions (consensus)
- Reduced healthcare costs (32)

Components of the standard

Component	Grading of evidence	Indicator of meeting the standard
For parents and family		
1. Parents are informed by healthcare professionals about risk factors and symptoms of NEC.	B (High quality)	Audit report, patient information sheet
2. Parents are informed about clinical course of illness, possible complications and treatment options.	B (High quality)	Audit report, patient information sheet
3. Parents are provided up-to-date information about outcomes of NEC.	B (High quality)	Parent feedback
4. Parents are offered support and counselling.	B (High quality)	Audit report, parent feedback
For healthcare professionals		
5. Up-to-date education and training on detection and management of NEC is attended by all responsible healthcare professionals.	B (High quality)	Training documentation

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| 6. A unit guideline on detection and management of NEC is adhered to by all healthcare professionals. | B (High quality) | Guideline |
| 7. Appropriate equipment for diagnosis and management of NEC is available for all healthcare professionals (as appropriate to role). | B (High quality)
C (High quality) | Audit report, healthcare professional feedback |
| 8. Surgical opinion regarding diagnosis and management of NEC is available for healthcare professionals 24/7. | B (High quality) | Audit report, healthcare professional feedback |

For neonatal unit

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| 9. A unit guideline on diagnosis and management of NEC is available and regularly updated. (1,33–35) | B (High quality) | Guideline |
| 10. Clear guidance is available to healthcare professionals regarding indications for surgical opinion and transfer of neonates with NEC to surgical centre (if appropriate). (36–41) | B (High quality) | Guideline |
| 11. Relevant equipment and products are available and appropriate guidance for use e.g. X-ray & US machines, central venous lines, peritoneal drain, parenteral nutrition. (36,37,39,40) | B (High quality) | Audit report, healthcare professional feedback |
| 12. All cases of NEC are discussed with the relevant surgical team in a proactive and timely manner. (36–41) | B (High quality)
C (High quality) | Minutes of debriefings |
| 13. Data regarding NEC outcomes is collected and reviewed on a regular basis including parental/family feedback. | B (High quality)
C (High quality) | Audit report, parent feedback |
| 14. A well-defined process for post discharge care and multi-disciplinary follow-up of infants treated for NEC is available and regularly updated. | B (High quality) | Guideline |
| 15. Quality indicators regarding NEC outcomes are contributed to regional and national databases (see standard Quality indicators). | B (Low quality) | Audit report |

For hospital

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| 16. Appropriate staffing, expertise and equipment required for optimal diagnosis and management of NEC is provided. (36,37,39,40,42) | B (High quality)
C (High quality) | Audit report, healthcare professional feedback |
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17. Appropriate locations for operating facilities for NEC are provided. (36,37,39,40,42)	B (High quality) C (High quality)	Guideline, healthcare professional feedback
18. Robust processes to ensure appropriate management of NEC and regular audit of all relevant outcomes are in place.	B (High quality)	Audit report guideline,
For health service		
19. A national guideline on management of NEC is available and regularly updated.	B (High quality)	Guideline
20. Services are configured in terms of location and access to medical and surgical NEC care such that equity and effectiveness of provision is optimised.	B (High quality)	Regional network agreements, guideline, parent feedback
21. Clear guidelines in terms of retrieval of neonates with NEC to surgical and higher acuity centres including timelines are available to transport services.	B (High quality)	Audit report, guideline

Where to go – further development of care

Further development	Grading of evidence
For parents and family	
<ul style="list-style-type: none"> Parents and family are provided options to feedback on the care provision and family experience and encouraged to offer suggestions for improvement. 	B (High quality)
<ul style="list-style-type: none"> Parents of infants diagnosed with NEC and adult survivors of NEC are engaged with, to develop priorities for research and quality improvement (QI) in various aspects of NEC. 	B (High quality)
<ul style="list-style-type: none"> Parents of infants diagnosed with NEC are encouraged and supported to be involved in research studies related to NEC. 	B (High quality)
For healthcare professionals	
<ul style="list-style-type: none"> Review practice and outcomes on a regular basis (at least annually) and share learning and latest advances. 	B (High quality) C (Moderate quality)
<ul style="list-style-type: none"> Engage in quality improvement work related to NEC and explore newer practices e.g. use of abdominal ultrasound in the diagnosis and monitoring of NEC. 	B (High quality)
For neonatal unit	
<ul style="list-style-type: none"> Encourage and support healthcare professionals to engage in quality improvement work related to NEC and explore newer practices in the diagnosis and monitoring of NEC. 	B (High quality) C (Moderate quality)
<ul style="list-style-type: none"> Review and act upon parental feedback and outcomes data of patients with NEC including family experience regularly (at least annually). (36,39,40) 	B (High quality)

For hospital

- Facilitate continuing professional development and training of staff and involvement with collaborative research and innovative and improvement practices in terms of NEC diagnosis and management. (36,39,40,43) B (High quality)
C (Moderate quality)

For health service

- Review outcomes of NEC regularly including family experience and ensure learning from variation, adverse incidents and feedback. B (High quality)
- Optimise provision of care for NEC in terms of its safety, timeliness, efficiency, effectiveness, equitability and family centredness. B (High quality)

Getting started

Initial steps

For parents and family

- Parents are verbally informed by healthcare professionals about a suspected or confirmed NEC diagnosis in a timely way by a senior member of the neonatal team and their questions are appropriately answered.
- Parents receive relevant information about NEC and advised on suitable websites or resources.
- Parents of infants diagnosed with NEC are offered support and counselling.

For healthcare professionals

- Attend training on management of NEC to receive relevant up-to-date information about NEC and advise on suitable websites and other resources for education and training.

For neonatal unit

- Develop and implement a comprehensive unit guideline for diagnosis and management of NEC and audit their practice at least annually.
- Develop information material on NEC for parents.

For hospital

- Benchmark NEC rates and outcomes against regional/national or other relevant comparators (e.g. eNewborn, VON data).
- Support healthcare professionals to participate in training on management of NEC.

For health service

- Benchmark NEC rates and outcomes of various providers of care against regional/national or other relevant comparators (e.g. eNewborn, VON data).

Description

This standard focusses on key general standards of care provision that can positively impact on infant and family outcomes. We have chosen not to include specific diagnostics or therapies that may have a role in diagnosis and management of NEC. Many of these have variable degrees of evidence supporting them and are dynamic and evolving.

The standard highlights areas with poor evidence as well as areas that have robust evidence but are not part of day to day practice in all neonatal units. We are elaborating the former as recommendations for research and the latter as key priorities for quality improvement.

Key priorities for research

While all of the listed standards would benefit from more robust evidence, the following areas are especially recommended as priorities for further research:

- Impact of standards on implementation of good practice and improving outcomes
- Impact of better communication and support for parents on parental experience and improving outcomes
- Impact of earlier diagnosis on NEC outcomes
- Newer diagnostic and treatment modalities for NEC
- Development of large datasets to test relevant hypothesis regarding diagnosis and management of NEC
- Development of machine learning and other forms of AI to improve outcomes of NEC
- Optimising post-discharge care and follow up of infants with NEC
- Long-term outcomes of NEC
- Optimising care for NEC survivors

Key priorities for quality improvement (QI)

- Review of standards, gap analysis and development of appropriate action plan and timelines
- Standardisation in various aspects of NEC diagnosis and treatment
- Every neonatal unit and relevant provider of services should review their NEC service provision and outcome data regularly (including parental and staff feedback), benchmark and develop a plan for improvement with appropriate timelines
- Every neonatal unit and relevant provider of services should develop key priorities for their service in terms of NEC e.g. early diagnosis, optimal communication and support for parents, implementation of 'better' modalities like ultrasound, appropriate multi-disciplinary follow-up and support for NEC survivors and their families, development of appropriate datasets and optimal use of data to understand risks as well as effectiveness of various interventions

Source

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