



Topic Expert Group: Ethical decision-making and palliative care

Communication in ethically complex decisions

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Target group

Infants, parents, and families

User group

Healthcare professionals, neonatal units, hospitals, and health services

Statement of standard

Parents and healthcare professionals share all relevant information such as the conditions, prognosis, and choices for care of the infant, as well as the social situation, values, and preferences of parents.

Rationale

The goal of this standard is to ensure that caregivers understand the conditions of the infant, values, and preferences of the parents and those parents understand the prognosis and choices for care for their infant and receive support in their role in decision-making.

Parents often report that they do not feel that they participate meaningfully in important decisions for their infant's care (1), especially when the clinical team has identified a life limiting condition or a high risk of survival with significant long-term disability (2), where communication is particularly challenging. Parents value shared decision-making (3) particularly where they are given choices for the direction of their infant's care. (4) In order to participate in the decisions they need a trustful relationship with emotionally supporting healthcare professionals. (5,6) Effective communication skills are needed regardless of language, educational, cultural or socio-economic barriers, and a suitable, unpressured environment.

Open and honest information sharing is an important priority for parents of ill infants. (7,8) Healthcare professionals must seek to understand the social situation of the parents, their family values, and personal preferences, and must be able to explain the situation in plain language and compassionate manner. They must make sure that parents understand the situation, and that arising questions are elicited. Transparency and continuity of communication with parents is vital (9) whilst acknowledging that spontaneous communication that responds to changing needs and priorities is also crucial. (10) Care should be taken to ensure consistency in communication when different healthcare professionals members are involved.

Benefits

- Increased trust of parents that decisions are individualised, based on clinical factors and respect for their family values (1,2,6,9)
- Improved understanding of healthcare planning in the short term, but also in the longer term when parents may reflect on the decisions that were made (2,3)



- Reassurance that the best decisions have been made by healthcare professionals in close dialogue with families (1,2,6,9,10)
- Improved ability to cope with stress that comes with caring for ill infants (2,3,9)

Components of the standard

Component	Grading of evidence	Indicator of meeting the standard
For parents and family		
1. Parents are informed by healthcare professionals how ethical decisions are made in the neonatal unit. (9,10)	A (Low quality) B (High quality)	Patient information sheet
2. Parents are informed about the clinical situation. (1,2,11,12)	A (Low quality) B (High quality) C (Moderate quality)	Clinical records, parent feedback
3. Conditions and preferences of the family are actively explored. (3–5)	A (Low quality) B (Moderate quality)	Clinical records, parent feedback
4. Parents are offered assistance from an interpreter if necessary. (7,10)	B (Low quality)	Clinical records
5. Parents are given the right to bring family support or a spiritual adviser to meetings. (9,10)	B (Low quality)	Clinical records
6. For important decisions sufficient time to allow for appropriate reflection is given; multiple encounters may be required. (2,10)	A (Low quality) B (Moderate quality)	Clinical records, parent feedback
For healthcare professionals		
7. Training on communication of complex clinical issues is attended by all responsible healthcare professionals.(10)	A (Low quality) B (High quality)	Training documentation
8. Sufficient time for meetings with parents is provided. (10)	A (Low quality) B (Moderate quality)	Clinical records, parent feedback
For neonatal unit		
9. A private area for meetings between healthcare professionals and family is provided. (see TEG NICU design)	B (Moderate quality)	Audit report



10. Regular case reviews and training that includes discussing challenges in communication is conducted.	A (Low quality) B (Low quality)	Training documentation
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For hospital

11. Training on communication of complex clinical issues is ensured.	B (High quality)	Training documentation
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12. When designing neonatal units private rooms for parent meetings are included. (see TEG NICU design)	B (Low quality)	Audit report
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13. Healthcare professionals are adequately supported and appropriate facilities are ensured. (see TEG Infant- and family-centred developmental care, TEG Patient safety & hygiene practice, TEG NICU design)	C (Moderate quality)	Audit report
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For health service

14. In national curricula for healthcare professionals communication of complex clinical issues is included. (see TEG Education & training)	B (Moderate quality)	Training documentation
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Where to go – further development of care

Further development	Grading of evidence
For parents and family	
<ul style="list-style-type: none"> Organise parent support groups. (10) 	A (Low quality) B (Moderate quality)
For healthcare professionals	
<ul style="list-style-type: none"> Organise annual communication training for healthcare professionals. (9,10) 	A (Low quality) B (Moderate quality)
For neonatal unit	
N/A	
For hospital	
N/A	
For health service	
<ul style="list-style-type: none"> Develop resources for interpreters to work face-to-face, via telephone or internet. (13,14) 	A (Low quality)



Getting started

Initial steps

For parents and family

- Awareness is increased among parents of their right to be fully informed and involved in discussion of the clinical course of their infant by healthcare professionals.

For healthcare professionals

- Attend training on communication of complex clinical issues.
- Include parents in the discussion of the clinical course and prognosis of their infant from admission to the neonatal unit.

For neonatal unit

- Develop information material on the process of ethical decision-making in the neonatal unit for parents.

For hospital

- Support healthcare professionals to participate in training on communication of complex clinical issues.

For health service

N/A

Source

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Lifecycle

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