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ORIGINAL ARTICLE

Development of a palliative approach in neonatology[☆]



Développer une démarche palliative en néonatalogie



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Summary

Context. — Neonatal end-of-life situations present numerous ethical dilemmas. End-of-life is part of palliative care.

Purpose. — To discuss the question of unreasonable, futile or inappropriate treatment and neonatal end-of-life in cases with multiple complications in which all possible medical treatment has been attempted but has failed to relieve symptoms that are considered to be intolerable. Questions on the meaning of care as well as ethical issues that arise in these situations are analyzed.

Discussion. — In these situations, it is necessary to define whether the goal of the clinical plan for treatment and care is to maintain life for the short, intermediate or long-term, or if this life can no longer exist because it is physiologically impossible and death will occur rapidly. If life is physiologically possible, we can speak of a life project and a plan for adapted care. In the latter case, speaking of a life project creates ambiguity and it is more appropriate to speak of an adapted care plan for the baby's comfort.

[☆] Some elements of this text were previously published as an article entitled "Démarche palliative au cœur des limites en néonatalogie et pédiatrie" (Viillard ML, Greco C, Dufayet L. *Ethica clinica* 2015;76:22–30). The text has been completely rewritten and now includes notions from new research from the palliative medicine research team at the Laboratory of medical and legal medicine of the University Paris Descartes–Sorbonne Paris Cité.

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MOTS CLÉS

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Conclusion. — It is important to go beyond moral principles and be pragmatic about what can be done socially and materially so that the time alive of this life is not to the detriment of other lives. The decisions should be made following one or several pluridisciplinary meetings. The reasons for this decision should be recorded in the newborn's file by the physician who is responsible for the case.

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Résumé

Contexte. — Les situations de fin de vie en néonatalogie posent de nombreux dilemmes éthiques. La fin de vie relève d'une démarche palliative.

Problématique. — Aborder la question des traitements déraisonnables, futiles ou non appropriés, celle de l'arrêt de vie dans le cadre de complications multiples pour lesquelles toutes les possibilités de la médecine ont été mobilisées sans obtenir un soulagement de symptômes ressentis comme intolérables. Les questions du sens du prendre soin comme celle des tensions éthiques émergeant de ces situations sont analysées.

Discussion. — Dans ces situations, il semble nécessaire de préciser si le plan de soins et traitement décliné en pratique clinique permettra de maintenir une vie à court, moyen ou long terme ou si cette vie ne peut s'exprimer plus longtemps par absence de possibilité physiologique avec une mort survenant rapidement. Si la vie est possible physiologiquement on peut parler d'un projet de vie et d'un plan adapté de soins. En cas contraire, parler d'un projet de vie est source d'ambiguïté.

Conclusion. — Il paraît nécessaire, au-delà des principes ou positions morales de penser pragmatiquement, ce qui est mis en place socialement et matériellement pour que cette vie ne puisse pas être seulement temps de vie potentiellement au détriment d'autres vies. Les décisions se doivent d'être prises après une ou plusieurs réunions de concertation pluriexpertises. Les arguments mobilisés lors de la prise de décision doivent être colligés dans le dossier du nouveau-né par le médecin qui la prend en responsabilité. La version française de cet article est disponible en ligne (voir annexe).

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Introduction

Neonatal end-of-life cases present numerous ethical dilemmas requiring healthcare professionals and parents to make (participate in, or give their opinion about) decisions on how to care for the neonate. These cases are influenced by the cultural and legal contexts of the society. In Western medicine, the end-of-life is part of palliative care and depending on the country may be managed by specialized teams, teams caring for the newborn or by a collaborative effort including both.

Palliative medicine and the ethical dilemmas at the beginning of life

Palliative care can play a role very early in a newborn's life because the better the neonates' discomfort can be controlled, the less the child will have to deal with symptoms that are difficult to control, and the better his/her quality of life will be throughout his/her life and in the last moments of life.

The problem of unreasonable, futile or inappropriate treatment is a major issue.

The problem of ending life occurs in very rare cases with multiple complications for which all possible medical treatment has been attempted but has failed to relieve symptoms that are considered to be intolerable by the parents and the healthcare personnel.

Unlike adults, adolescents or children who can express their feelings, the situations in this paper involve the newborn, a "child-subject" who cannot express him/herself. The opinions and the feelings of the parents are taken into account, but what they might consider intolerable, may not be for the child. Furthermore, although professionals try to be objective, they are aware that their subjectivity may affect their reasoning. Finally, an element of uncertainty adds to the complexity of any decision, whether the uncertainty concerns the diagnosis, the prognosis or the child's future if s/he survives. The notion of ending life, in this particular case, concerns stopping treatment that artificially maintains or prolongs a child's life. The idea is not to force a child to live something that his/her body makes it impossible to live (to avoid unreasonable obstinacy and prolonging a painful and torturous end-of-life). The idea is to let the child

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