The ‘ouR-HOPE’ approach for ethics and communication about neonatal neurological injury

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Predicting neurological outcomes of neonates with acute brain injury is an essential component of shared decision-making, in order to guide the development of treatment goals and appropriate care plans. It can aid parents in imagining the child’s future, and guide timely and ongoing treatment decisions, including shifting treatment goals and focusing on comfort care. However, numerous challenges have been reported with respect to evidence-based practices for prognostication such as biases about prognosis among clinicians. Additionally, the evaluation or appreciation of living with disability can differ, including the well-known disability paradox where patients self-report a good quality of life in spite of severe disability. Herein, we put forward a set of five practice principles captured in the “ouR-HOPE” approach (Reflection, Humility, Open-mindedness, Partnership, and Engagement) and related questions to encourage clinicians to self-assess their practice and engage with others in responding to these challenges. We hope that this proposal paves the way to greater discussion and attention to ethical aspects of communicating prognosis in the context of neonatal brain injury.
the outcomes and progress of the child and the well-being of the family unit.

Given the nature of neurological prognosis early in life, and the stakes raised by early decisions, a number of challenges can surface and, correspondingly, a number of practice points need to be reinforced during communication with families engaged in discussions about the care of their infants. For example, there are challenges to evidence-based practices for prognostication and there are biases about prognosis in the views of clinicians. Also, the evaluation or appreciation of living with disability can differ among clinicians and parents, including the well-known disability paradox where patients self-report a good quality of life in spite of severe disability.⁸ We propose an approach to foster practice self-assessment based on a series of practice principles (Reflection, Humility, Open-mindedness, Partnership, and Engagement) and related questions (Table I) to help clinicians reflect on their practice individually and as teams.

**METHOD**

A task force on ‘Ethics and communication of neurological prognosis’ was proposed by the first author and one of the co-authors (EB) to undertake reflection on the topic of communication and ethics in the context of severe neonatal brain injury, under the auspices of NeuroDevNet, a Canadian Network of Centres of Excellence. The task force followed a process inspired by the procedures for position paper development of the American Academy of Neurology and the Society for Adolescent Health and Medicine,⁹,¹⁰ although our aims were less formal. Co-authors were invited based on their interest and their willingness to participate in such a collaborative thinking and writing exercise. Physicians from different specialties (paediatric neurology, neonatology), parents of children who suffered brain injury, and bioethicists formed this task force. These members received a background presentation of the task force goal and process, a background literature review on this topic of communication, ethics, and prognosis prepared by a member of the advisory committee of the task force under the supervision of the first author,¹¹ and two highly relevant papers on the topic of communication of neurological prognosis.¹²,¹³ The task force operated on the basis of consensus for the inclusion and revision of content. An advisory committee was constituted to provide more external and diversified feedback on the work of the task force. This advisory committee included nine members who provided additional representation from parents, bioethics, and medicine, and additional perspectives from nursing, psychology, and rehabilitation sciences. The author group was engaged in teleconferences and email exchanges to produce different iterations of the outline and draft manuscript, while the advisory committee provided input at discrete moments (outline, draft manuscript, penultimate manuscript).

A first teleconference between the task-force members (the authors) took place to settle on the topic and the objectives, define the target audience for the paper, and discuss potential publishing venues. We agreed that our goal was not to produce a systematic review, but rather to engage in a collaborative effort to reflect on the literature and identify important practice points for clinicians. Subsequently, an outline was drafted by the first author and sent to the co-authors. This draft included the initial basic principles that were generated from the first teleconference discussions and initial directions to explain these points. A second teleconference between the co-authors took place to discuss this brief document, which contained the working title, the rationale for the paper, the goal of the paper, estimated completion date, and proposed methods. The basic principles defining the ‘ouR-HOPE’ approach were reviewed critically. After this, the paper outline was enriched and circulated to the advisory committee members. The feedback received from the advisory committee was compiled and the outline revised. The initial draft of the paper was then generated by the first author. Literature known to the authors was reviewed to substantiate the principles and then targeted searches were undertaken in PubMed to find additional literature of relevance. This task was undertaken by two research assistants working under the supervision of the first author. The literature was summarized and then condensed to define the principles and their relevance. An advanced draft paper was shared with the co-authors, who were invited to review it critically and make appropriate suggestions for content, literature, and the proposed questions to support reflection. This process occurred by e-mail and suggestions for changes were compiled and integrated by the first author. A revised draft paper was cleared by the authors and then sent out for review to the members of the advisory committee. Their feedback was received and integrated to produce a second draft by the first author. This second draft was then shared with co-authors and revised critically for content in a third teleconference. Subsequently, a revised third version was sent to the advisory committee for their acceptance and permission to be listed in the acknowledgements as members of the advisory committee and to capture any remaining smaller issues to resolve. These final changes were carried out by the first author and accepted by all co-authors.

The proposed approach is not intended to provide complete resolution of specific and explicit dilemmas, but rather offers a set of reflections and questions to foster self-assessment of clinical practice that capture a set of desirable attitudes and actionable behaviours for clinicians. Each principle or practice point is first described and then its relevance is established with respect to documented

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**What this paper adds**

- An interdisciplinary deliberative process offers relevant guidance for communication about neurological prognosis in the neonatal setting.
- Practice principles of the ‘ouR-HOPE’ approach for ethical communication include Reflection, Humility, Open-mindedness, Partnership, and Engagement.
- A practice self-assessment tool supports individual clinicians’ and teams’ ethical practices.
| General framework | Indicators of meaningful response<sup>b</sup> |
|-------------------|---------------------------------------------|
| Relevant questions: How am I ... | • I am knowledgeable of the background, general values, and beliefs of the parents |
| ... ensuring that the initial grounding for communication and discussion of prognosis is broad enough to make room for different narratives and backgrounds? | • My exchanges with the parents broach issues other than therapeutic success or failure |
| ... receptive to the unique circumstances surrounding the situation of this family? | • Parents feel understood and elaborate on their answers; they share their view on the nature of the situation (and are encouraged and supported to think about the meaning of the situation) |
| ... sensitive to the asymmetries at stake in the relationship with the parents? | • I know about the family’s history and I take it into account to tailor discussions about prognosis and outcomes |
| Reflection | • I have shared relevant information about the family’s situation with other clinicians |
| Relevant questions: How am I ... | • The parents rapidly become familiar to members of the clinical team |
| ... aware of my values and personal experience and how these inform my prognosis and discussion of outcomes? | • I adopt communication strategies (e.g. all sitting or all standing; eye-to-eye contact; allowing silences to help parents talk and communicate emotions) to make parents feel comfortable and welcomed. I call their child by his/her first name |
| ... showing openness to unexpected clinical outcomes or different values? | • If the parents seem uncomfortable to speak, I explore other strategies and recommend discussion with others in my team |
| ... recognizing the possibility of living well with disability? | Evidence of meaningful response |
| Humility | • I identify sources of fact and sources of value judgements in my prognosis and discussion of outcomes (to the extent that this is possible) to catch implicit biases or simply identify my own stance |
| Relevant questions: How am I ... | • I check that my recommendations in this case are consistent with those I have made in the past for similar cases and reflect on the reasons why they are not consistent if that is the case |
| ... adjusting my communication style to best serve the interests and adjust to the situation of the family? | • I consult academic literature on biases about prognosis and reflect upon the value of different types of outcomes (e.g. through discussion with colleagues) |
| ... appreciative of the prognostic uncertainty that exists based on the literature and my observations? | • My exchanges about prognosis and outcomes explicitly identify aspects which could change, or under the circumstances of which, the prognosis could change |
| ... being sensitive to the situation of the parents and its influence on my appreciation of the child’s potential outcomes? | • I am prepared and willing to discuss important changes to the case progression even if these could be stressful and hard to deal with for the parents or myself |
| ... being sensitive to the situation of the parents and its influence on my appreciation of the child’s potential outcomes? | • My discussion alludes to and describes the positive and negative experience of raising a child with disability |
| Evidence of meaningful response | • Examples of children and families who have had different experiences with disability are mentioned |

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<sup>a</sup>Table I: Practice self-examination tool supporting the ouR-HOPE approach for ethics and communication about neonatal neurological injury

<sup>b</sup>Evidence of meaningful response
practice pitfalls. Questions to support the self-assessment of clinical practices follow from each point captured in Table I, as well as indicators of a meaningful response.

**THE 'our-HOPE' APPROACH**

The general intention of our-HOPE is to engage clinicians in critical self-reflection about their clinical practices...
related to prognostication in the context of neonatal brain injury given significant challenges therein. Five key principles guide reflection on distinct areas of clinical practice. However, a number of general questions are provided to reflect the general spirit of the approach (first section of Table I) and encourage clinicians to adopt a broad paradigm for communication. For example, attention is brought to the family’s narrative, receptivity to the family’s experience is encouraged, and a ‘comfortable’ context of exchange is recommended. Although our primary goal was to support self-reflection or team discussions, it would be possible to engage others such as parents in this process using a modified version of Table I.

Reflection

Meaning

Reflection (or self-reflection) describes an ability to look critically at oneself, one’s attitudes, and behaviours, through self-examination and discussion with others. It can lead to greater self-awareness about one’s own deeply held values (what they are and the influences or biases therein) and about one’s own approach to clinical practice, including its strengths and limitations.

Relevance

Non-reflective engagement in neurological prognosis has clear pitfalls. There is a well-constituted literature that highlights the influence of message framing on the medical decision-making process, including on intents to resuscitate in the neonatal context (e.g. impact of framing options as survival with lack of disability rates vs framing as death and disability probabilities). Given these effects, clinicians may nudge and influence consciously or unconsciously the clinical decisions of parents.

Another important dimension of self-reflection concerns the awareness of one’s own values and opinions, and the possibilities of biases that might influence the decision-making process. Vignette studies have reported, for example, a puzzling effect of age on decisions to resuscitate (e.g. greater agreement to resuscitate older children than newborn children born at term and preterm), as well as a preference in medical students to resuscitate previously disabled children over previously healthy children. Research, based notably on surveys and standardized scales to measure attitudes toward disability, has shown the existence of biases against children with disability (e.g. cerebral palsy) in clinicians in training. Likewise, ‘lethal’ terminology (e.g. to describe conditions like trisomy 18 and 13) has sometimes been used to describe treatable conditions (e.g. cardiac malformations, gastrointestinal dysfunctions) to mask a judgement about the quality of life of children with profound disabilities, and to encourage particular decisions about treatment. Most of these effects do not necessarily occur through explicit thoughts or reasoning, and may be the result of more implicit processes (e.g. implicit attitudes). There are various ways for clinicians to become aware of and mitigate these biases in order to avoid their insidious influence on practice.

Included among these are a particular attention to one’s own reactions in discussions with patients, attention to others’ feedback, or even ‘tracking’ oneself with psychological tools such as the Harvard Implicit Association Test (e.g. the disabled/abled Implicit Association Test).

Prognosis could also be influenced by a clinician’s unacknowledged emotional reactions. For example, for clinicians, ‘guilt over the long-term implications for families when a neurologically devastated infant survives’ is a common source of distress in neonatal care as the child’s survival is partly a result of clinical actions and decisions taken. However, evidence that parents of children with disabilities regret their decisions is lacking and the presumption that they do might be based on clinicians’ own values. Therefore, the emotional engagement of physicians (e.g. guilt), if not recognized, might unduly influence decisions that will be taken. Emotional reactions are unavoidable, but they can influence the discussion with parents.

Finally, attitudes toward quality of life constitute an important value-laden, but very real, practical concern. Data suggest that expectations of quality of life from physicians are associated with their recommendation about life-sustaining intervention. Studies have shown that physicians underestimate the outcomes for neonates. Some have pointed out that ‘among physicians, even pediatricians expect less favorable outcomes for premature babies than published national rates of survival and freedom from handicap’. Such attitudes could negatively affect attitudes toward resource allocation for neonatal neurological care.

Application

Self-reflection can be supported by paying greater attention to one’s values and personal experiences, as well as considering critically one’s attitudes toward the initial prognosis or eventual disability (see Table I).

Humility

Meaning

Humility refers to a modest attitude with respect to the evaluation of the importance of oneself. Consistent behaviours are, for example, a non-judgemental attitude in service of the specific needs and abilities of each family, as well as a disposition to adjust one’s clinical style accordingly, to avoid any form of arrogance. A humble attitude is relevant to one’s wielding of scientific knowledge (e.g. step back and ask others for help when needed), as well as one’s positioning in the clinical situation (e.g. authority and power of the physician in the clinical situation; vantage point of the clinician who is able to take an objective distance while parents struggle to do so).

Relevance

The current state of knowledge about neurological prognosis, where much uncertainty exists, calls for a careful and humble attitude, given the existence of intrinsic and extrinsic factors affecting outcomes. These factors complicate a conversation about what exactly the disability
will be like, how severely it will affect individual capacities, the capacity of the family unit to adapt to the child’s disability, and what the child’s general quality of life will be, as well as that of the family. To reflect this decisional uncertainty some have proposed a distinction between a standard view (or zero-line view) where ‘treatment may be withdrawn only where an infant is predicted to have a life not worth living’, in contrast to a threshold view. The latter maintains that ‘it is not obligatory to continue life support for infants who will have very low levels of well-being’, although this in no way means treatment should be withdrawn in those cases. Rather, parents and clinicians can decide whether it is more ethical to withdraw care or to continue with life-sustaining interventions. Such decisions must be based on open-ended discussions that do not imply that severe disability should necessarily be the single factor to consider since, for example, functional outcomes and impairments may not be indicative of quality of life or family burden. Despite some enduring fundamental clinical and ethical uncertainties, strategies to increase confidence in prognosis include consulting a larger medical team and asking other professionals their opinions on the situation, or by allowing the necessary time to establish a clearer and more certain ultimate prognosis.

Nevertheless, some clinicians might be uncomfortable with acknowledging prognostic uncertainty because it could be seen as reflecting a professional or personal deficit. Humility could be one of the most contradictory attitudes that specialty physicians are asked to display in such situations, given the stereotypical image of the physician as an asserted and confident expert. Some clinicians may be tempted to protect families from uncertainty, in order to provide them with the best perspective possible on the situation, but this could actually conflict with the wishes of parents. A study of surrogate decision makers concluded that most patients want to talk about uncertainty and most of them believed that uncertainty ‘is an unavoidable reality of life-threatening illness’ and wanted ‘more information, including clear communication about uncertainty itself’. Rather than seeing the physician’s acknowledgement of uncertainty as a professional shortcoming, they saw it as a mark of trustworthiness. However, not all patients share this view, and clinicians should remain sensitive – without compromising their engagement to truth – to the actual receptivity of parents to uncertainty consistent with research showing variations in patient decision-making preferences.

Another important facet of humility concerns the clinician’s positioning within the situation. Disparities in health care related to SES are well known and their effects documented in the neonatal context (e.g. effects of race on infant mortality). It is also known that SES may influence the clinical consultation, and that clinicians may show a more paternalistic attitude toward patients who have lower health literacy. The influence of SES on communication and decision-making is less clear, although some recent cases have exposed the consequences of a lack of training about cultural and socioeconomic issues for neonatal intensive care unit (NICU) staff at all levels, and that educational programmes might be a way to address this problem.

**Application**

The unpretentious open attitude – featuring an honest self-disclosure of uncertainty, modulation of communication style, and the avoidance of arrogance – is consistent with the features of a patient-centred approach, and therefore parents will benefit from clinicians’ humility (see Table I).

### Open-mindedness

#### Meaning

Open-mindedness is a receptiveness to eventual medical outcomes which defy one’s prognosis, as well as a willingness to consider fairly evaluations of prognosis that differ from one’s own (e.g. values and beliefs of parents; value of having a child with disability) based on, for instance, different spiritual or ethno-cultural backgrounds.

#### Relevance

Being open to unexpected medical outcomes can be challenging given anchoring biases (e.g. being committed to one’s initial prognosis). The well-documented existence of self-fulfilling prophecies in the context of neuro-intensive care is of relevance here, as clinical nihilism in the early stages of clinical management of brain injury may negatively affect outcomes in self-fulfilling ways. Additionally, a host of factors has been shown to insidiously modulate prognosis and attitudes about life-sustaining therapy in ways that call for an open-minded approach to the discussion of prognosis, and recognition that these factors can have an influence. These factors include the geographical location of the clinical practice, as well as physician-dependent characteristics such as a physician’s age and experience, cultural and religious background, and specialty and subspecialty training. The influence of local clinical culture has been captured under the concept of an ‘ecology of knowledge’, and has been identified in the NICU setting. One study reported the effects of a NICU’s general policy toward resuscitation for neonates on the residents’ attitudes toward resuscitation. Other research has suggested that the neurological prognosis for neonates by physicians may be heavily influenced by biological markers without due consideration of interpersonal factors, especially in cases of mild-to-moderate injury, and less so in severe injury where the outcomes may be clearer.

Thus, in sum, several factors can influence a clinician’s prognosis and decision-making. Importantly, these factors and potential biases are not always acknowledged by clinicians themselves, despite the literature. When asked to rank factors that could influence prognosis and end-of-life decision-making, physicians have ranked patient characteristics and clinician’s personal experiences as highly influential, while work environment and personal background of the clinician were ranked low. The fact that the latter factors do indeed have some influence is not a problem in and of itself, but it does become one when a clinician
consistently ignores such factors. He or she may then be lured in an uncritical faith in his or her own objectivity. Importantly, the acknowledgement of the existence of regional variations in prognostic opinions found in vignette studies can support further reflection on the best practices to adopt and their justification.

**Application**

Open-mindedness is a desirable attitude for clinicians in service of families (see Table I). There are, of course, limits imposed to the open mind by known evidence about outcomes, as well as the nature of family preferences given a clinician’s deontological and legal obligations to protect the best interests of the child.

**Partnership**

**Meaning**

Partnership refers to an approach where there is a genuine collaborative discussion about the goals of care, and where such collaboration is reflected in the communication and the style of the clinician (e.g. shared decision-making). A partnered approach recognizes the valuable knowledge and experience brought by parents in discussions at the bedside. In other words, parents are intrinsic and important actors in the care team, and can be accommodated following a model of ‘shared expertise’ that allows them to make meaningful contributions.

**Relevance**

The call for partnered care and shared decision-making approaches was first heard more than three decades ago, and has become an integral aspect of family-centred care, patient–partner care, and ‘relationship-centred care’, where it holds a clear and unequivocal relevance to ethical practice. Yet general obstacles to such partnership also bring about the possibility of benefitting from the expertise of parents (a recommended practice of the American Academy of Pediatrics in 2012). It is possible that there are greater differentials in assessing subjective factors (e.g. emotions, pain, cognition) than visible or objective factors (e.g. vision, motor capacity) associated with quality of life.

Values and backgrounds of parents can vary tremendously and their perspective can change over time as a result of intrinsic resilience and coping mechanisms. Perspectives of children are also important to consider. For example, extremely low birthweight children had no differences with individuals of normal birthweight in their self-reported quality of life, based on a study that followed them for 16 years. A large study that surveyed parents, siblings, and individuals with Down syndrome reported that they are happy and have a positive influence on siblings and parents. Many may consider abilities such as walking, talking, and the potential to live independently to be integral to quality of life, yet this perspective is not universal. One study based on children with severe disability reported that almost all parents described their child as happy and an enriching influence on the family, although they admitted to significant challenges in caring for the child. Payot and Barrington report a parent saying, ‘The fact that the result is wonderful doesn’t mean that the road has not been painful’. These perspectives should be reflected in physicians’ engagement with prognosis and the prediction of outcomes. This acknowledges the subjective factors involved in assessing quality of life, and the necessity for clinicians to recognize the possibility of living well with a disability when discussing quality of life with parents.

A partnership approach should also be sensitive to strategies that help empower parents and make them feel more comfortable, including feeling that their values and beliefs are respected and built on to support their coping abilities. Clinicians can prepare for meetings with parents using some of the available resources to engage with parents in the neonatal context, or those suggested for engaging with surrogate decision makers. Ethics consultation could also be helpful. Communication strategies can be adopted to help toward such a partnership: sitting down is a practice supported by many authors. Informal communication (‘chatting’) can reflect a humane and appreciated form of exchange which sets a good climate for collaboration and partnering. Parent-friendly ways of providing information (e.g. use of plain language, presentation of statistical information using absolute risk [and not relative risk]) – and the use of pictographs to communicate risk and benefit information – can help, and written information is helpful to parents. Visual aids (e.g. risks about infants born preterm) and more technologically savvy avenues (e.g. computerized simple graphic representations of aggregated risk of mortality for parents) have been tried with some success.

Partnership also brings about the possibility of benefitting from the expertise of parents (a recommended practice of the American Academy of Pediatrics in 2012). Parent-to-parent mentoring and support can take many different forms, such as one-to-one partnering, parent support
groups, visiting parents, or veteran parents. Training programmes for parents have been put in place and the overall experience has been positive. Another strategy involves a part-time parent-to-parent manager (hired because of prior experience of having an infant in the NICU). This approach has been reported as useful to implement family-centred care and formalize a series of services for parents. One interesting and recent development is the Family Integrated Care model, which includes veteran parents in the design of the model of care and as a resource for parents in the NICU (peer-to-peer support). The veteran parents had a positive impact on comfort and hope gained from shared experiences; facilitation of bonding; and then provision of psychological support, yielding increased confidence in caring for their infant through parent-to-parent education. This approach can become a true bridge between the family culture and the clinical culture.

**Application**

Partnership is now a frequently used term capturing a set of good practices such as shared decision-making (see Table I). However, overstressing the shared aspect of a decision-making process can have the drawback of actually increasing stress in surrogate decision makers. Therefore, partnership should be envisioned as a personalized, relational model of care based on parental needs, and predicated on the clinician’s humility and open-mindedness. It can take the form of a continuum and adjusted to the evolving needs and preferences of families (and changes to them, if any) across time.

**Engagement**

**Meaning**

Engagement designates a commitment of the clinician to step outside of comfort zones in the pursuit of the well-being of patients and families (e.g. through the establishment of supportive environments such as having support systems for families and children; ongoing advocacy), as well as of best scientific practices for prognostication (e.g. evidence-based science and evidence-informed clinical ethics).

**Relevance**

In the acute care setting, an engaged physician is one that is concerned about how the parents are doing now and in the long run. For example, providing information and exercising good communication have been shown to alleviate the feeling of estrangement that can be felt by some parents in the NICU environment. Interestingly, a cross-cultural study of NICUs in France and the USA suggests that parents reportedly felt more appeased when the physicians took a more active role (in France) than when decisions where deferred to parents (in the USA). American parents reported that their physician, who assumed a more informative and expert role, appeared disengaged from the health outcomes of the infant. Research suggests that many parents benefit from memory-making efforts (e.g. holding the infant, taking pictures). However, the need for more follow-up and bereavement support is nonetheless a salient issue beyond acute care (e.g. parents feel alone once they get back home). In addition, the role of palliative care cannot be neglected to bring additional expertise to the parents, notably to support their decisions and provide greater continuity in care.

Engagement entails a broader view on neonatal outcomes and corresponding gestures on behalf of clinicians. In general, and despite the diverse international health-care practice settings and different roles of different clinicians involved, there should be a commitment from clinical teams to ensure that there will be a structured follow-up, appropriate for the condition of the child and his family. Parents should be reassured that clinical teams will not cease to take care of their child, regardless of their decision after discharge. In the longer run, and beyond the acute care setting, too often families, depending on where they live and the nature of the disability, face situations of poor or non-existent services that they might have expected post discharge. Hence, questions remain for families, such as ‘Can I bring up my child alone?’ and ‘What kind of help will I need and will that help be available (or not)?’ Clinical environments need to do better to know if, how, and when to advocate for home help that may or may not be medical in nature. Accordingly, clinicians should be knowledgeable of support offered by other clinicians and about resources outside the immediate clinical environment (e.g. community resources). This is especially important given the numerous transitions that these children may experience (e.g. from the NICU to general paediatrics, then to specialized paediatric services, and eventually to adult services). Clinicians should also be active in voicing the concerns of families and children, and help others engage in advocacy.

The engagement to evidence-based medicine and best practices in neonatal neurological prognostication remains an ongoing goal and, generally speaking, this holds true of other areas of medical practice where there could be an insufficient focus on outcomes and prognosis given the focus on diagnosis. Looking forward, more research efforts need to be mobilized to provide a stronger evidence base to prognosticraft practices and related interpretive, ethical, and communication issues.

**Application**

An engaged clinician is one who is committed to evidenced-based medicine and to the outcomes of his or her practice on the well-being of the child and of the parents within and beyond his or her immediate actions or clinical environment (see Table I). For the parents, this dedication may be felt as ‘kindness’ of the clinician; for the clinician, it is an extension of his or her professional commitments.

**CONCLUSION**

The ethical stakes of communication in acute neonatal neurological injury are high; the pitfalls of decisions based on neurological prognosis are many. It is not an exaggeration...
to state that parents are dealing with extremely stressful situations in which they are making important decisions that they will live with and reflect on for the rest of their lives. Our proposed approach presents desirable clinical practices for clinicians, which reflect attitudes and behaviours responsive to the nature of the clinical situations encountered to support ethical communication and decision-making. We acknowledge the limitations to the validity of the wisdom shared in this paper and hope that further discussion and research will support the integration of more adequate, evidence-informed, practices in the communication of neurological prognosis in the neonatal context. For example, the ‘ouR-HOPE’ approach could be further implemented in education (with role play and simulated or real patients) or in learning modules that evoke more concretely what is consistent with the approach and what is not.

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