



ELSEVIER

Available online at www.sciencedirect.com

Seminars in Perinatology

www.seminperinat.com

Palliative care approaches to neonates with chronic respiratory failure

Nicolas F.M. Porta, MD

Ann & Robert H. Lurie Children's Hospital of Chicago, Northwestern University Feinberg School of Medicine, 225 E. Chicago Ave, Box #45, Chicago, IL 60611

ARTICLE INFO

Keywords:

Bronchopulmonary dysplasia (BPD)
Pulmonary hypertension (PH)
Premature/prematurity newborn
tracheostomy uncertainty

ABSTRACT

Neonates with chronic respiratory failure have uncertain prognosis and can face significant treatment burden. As the trajectory of the illness becomes more concerning, consultation with a pediatric palliative service should be considered, especially as therapeutic options shift from standard to “innovative.” Benefits include as follows: supporting emotionally conflicted providers and parents, maintaining transparency in determination of goals, and balancing medical progress with each individual patient's and family's best interests.

© 2016 Elsevier Inc. All rights reserved.

Introduction

Respiratory distress is common in premature neonates and can also occur in neonates born with congenital abnormalities or whose lungs become injured after birth. In these cases, neonatologists commonly provide mechanical ventilation, usually with the understanding that the baby will only require such assistance for a relatively short time. However, sometimes these patients develop severe bronchopulmonary dysplasia (BPD) and chronic respiratory failure, and become dependent on mechanical ventilation indefinitely. Such patients may have significantly different medical paths, prognoses, and long-term consequences—becoming NICU outliers. With prolonged stays and uncertain outcomes, these patients and their families may benefit from incorporation of palliative approaches and services and are the focus of this discussion.

Scope

Many extremely premature babies will develop BPD¹⁻³ though only a fraction will have severe BPD, defined as requiring respiratory support with supplemental oxygen or positive pressure by the time they have reached 36 weeks of

post-menstrual age.⁴ Within this sub-group, a minority will go on to require ongoing respiratory support and develop associated comorbidities, such as pulmonary hypertension (PH), a finding that correlates with increased risk of death.⁵⁻⁸ Some of these infants have seemingly unrelated morbidities also associated with extreme prematurity (which may directly and independently affect morbidity and mortality), and sometimes the combination of conditions can compete therapeutically, such that treatment for one condition may worsen other conditions. This can further complicate care.

Premature babies with multiple comorbidities have longer hospital stays, higher costs of care, and a greater need for surgical procedures.⁹ These factors may have important negative effects on parents, siblings, other family members, or even on society at large, given the economic and emotional consequences for all parties. As a result, at times it becomes reasonable to consider forgoing further life-sustaining treatments. Thus, the introduction of palliative care services may make sense once “chronic respiratory failure” has been recognized, especially if PH is also present. Unfortunately, we have no widely accepted definition chronic respiratory failure, with clear thresholds and well-defined prognosis. The determination that a patient has become a NICU outlier usually occurs through subjective assessments by adequately experienced clinicians who have cared for similar patients.

E-mail address: n-porta@northwestern.edu

<http://dx.doi.org/10.1053/j.semperi.2016.11.009>

0146-0005/© 2016 Elsevier Inc. All rights reserved.

Uncertainty

The uncertainty surrounding the outcomes for these patients has multiple origins and raises numerous concerns. Uncertainty may develop even before delivery, with the threatened birth of an extremely preterm infant. In that situation, most parents will ask about the odds of survival and many will worry about morbidities among survivors. After birth it can remain difficult to predict which baby will thrive and avoid long-term respiratory (or other) problems and which will require prolonged support. Despite ongoing research, we have not developed readily identifiable early characteristics that predict later poor respiratory outcomes. Some prognostic markers include placental histology, need for mechanical ventilation beyond the first week, and early infection;^{10,11} however, those findings only predict development of BPD, not its severity. Most babies who develop BPD do not require long-term mechanical ventilation, adding a layer of further uncertainty in prognostication. Other factors contribute to uncertainty, such as waxing and waning clinical courses, with some patients having relatively unremarkable beginnings, giving families and clinicians hope for uncomplicated and relatively short NICU “careers,” while other patients have terribly difficult early days or weeks, such that continued survival instills a sense of investment that can drive parents and staff to continue escalating ever more aggressive treatments. This variability in the course can make it hard to appreciate an overall trajectory, as “good” days raise hopes, while “bad” days engender anxiety and discomfort that one faces a progressively poor prognosis. If better (and ultimately good) days cannot be anticipated, then continuing to pursue aggressive interventions may no longer be justified.

Pulmonary evaluation and management

Neonatology’s remarkable advances have allowed increasingly immature babies to survive, and more aggressive interventions have contributed to this success. Examples of evidence-based preventive and therapeutic strategies that have improved outcomes for premature infants include prenatal steroids, surfactant, development of sophisticated neonatal ventilators, and smaller and more specialized equipment. Other approaches, sometimes borrowed from other fields, have not had rigorous testing and their value remains unclear. Most of these interventions are designed to be temporary and clinicians and families may tolerate discomfort, inconvenience, and/or emotional stress associated with their use if adequately good outcomes result. However, use of unproven treatments can amount to virtual “experiments,” conducted without the benefits and safeguards of formal clinical research, raising ethical concerns about well-intentioned but inadequately tested innovations.

In neonates with respiratory failure, the principal therapeutic target is improving lung function. Many approaches have limited effect. Clinicians commonly use beta agonists (to improve airway resistance), diuretics, and corticosteroids, though these agents do not consistently improve long-term outcomes.¹² Early extubation to improve long-term

respiratory morbidities in preterm infants has not been shown to be consistently effective. Efforts to avoid mechanical ventilation may only succeed through prolonged exposure to corticosteroids, which can lead to adverse non-pulmonary effects, including neurocognitive impairment.

In severe cases, infants can become fully dependent on mechanical ventilation, or demonstrate poor growth and/or development without it. Without adequate respiratory support, these infants can suffer air hunger, dyspnea, and hypoxemia. They can develop episodes of acute respiratory deterioration, which may further compromise their survival as well as increase discomfort. Even with mechanical ventilation, as the babies mature and develop, orotracheal (or nasotracheal) intubation becomes less well tolerated, leading to use of increasing doses and classes of sedative medications. Thus, once clinicians determine the need for long-term mechanical ventilation (to reduce metabolic demands and overall caloric needs), a tracheostomy may facilitate comfort and allow more effective developmental and rehabilitation therapies. While staff and parents hope these patients can eventually become free from these invasive measures, attention must also focus on overall health and especially neurodevelopment.

Since the presence and severity of PH can predict death and neurodevelopmental impairment,¹³ evaluation for PH over time can help guide management. Echocardiography can suggest the existence of PH, and perhaps more importantly, can also demonstrate its effects on cardiac function. At times ultrasound findings may need to be confirmed by cardiac catheterization, a more invasive tool with relatively low but measurable risks to the patient, including the risk of death. In general, optimizing respiratory support deserves greater priority than treating PH, but in some cases actual or expected cardiac dysfunction from progressive and/or severe PH can lead to serious clinical deterioration and demand therapeutic intervention. The most appropriate treatment for BPD-associated PH in infants has not been established, but many practitioners use pulmonary vasodilators approved by the Food and Drug Administration (FDA) for other indications. While there is growing experience with this off-label use of medications, none has achieved status as “standard” treatment for BPD-associated PH. In addition, many of these drugs have important side effects that can interfere with overall improvement or well-being. Sildenafil has been used increasingly in infants with BPD-associated PH over the last decade, but may aggravate gastroesophageal reflux (GER), which itself can lead to worsening respiratory function. Prostacyclins are considered the “gold standard” for severe PH in adults, but can cause generalized discomfort and jaw pain when given systemically and, depending on their route of delivery, can also cause local infusion-site pain.

Associated medical symptoms

In addition to respiratory and circulatory symptoms, babies with chronic respiratory failure can also have secondary symptoms, such as agitation, discomfort and pain, neurologic irritability, withdrawal from analgesic and sedative medications, spasticity, GE reflux, dysphagia, and infections—all of

Download English Version:

<https://daneshyari.com/en/article/5684594>

Download Persian Version:

<https://daneshyari.com/article/5684594>

[Daneshyari.com](https://daneshyari.com)