The Infant Patient: Ensuring Appropriate Medical Care for Children Born Alive

Senator Graham: Question for the Record

For Dr. Robin Pierucci:

Dr. Pierucci, in your testimony, you stated that "all babies should be assessed and then receive the appropriate degree of intervention as outlined by the Neonatal Resuscitation Program."

1. Is this a one-size-fits-all approach that requires every infant to receive the same care? Or is the program intended to guide healthcare practitioners to customize care according to the specific medical requirements of the infant by first assessing the infant's condition and then targeting care to that diagnosis?

   With every medical interaction, there is always an inherent requirement to assess what is best to do for the particular patient in front of you and then tailor medical care accordingly. In emergency situations, the default goal is to stabilize the patient sufficiently to figure out what the appropriate next step is. NRP provides pathways to consistently evaluate newborns and customize treatment to as little or as much as is appropriate. Built into the assessment are decision trees: (1) what does a successful response to a given intervention look like, (2) what does *not* responding to treatment look like, and what do you do next—including when do we stop, and (3) when should aggressive resuscitation not be started and palliative care interventions be used. At any birth, there are a number of common problems that can be anticipated; however, precisely because this is a newly born person, there is always the potential for discovering unanticipated issues. The need to customize care for newborns and their families is the rule, not the exception.

2. Could both palliative care and more invasive interventions be options under the NRP? Please define palliative care. How is palliative care different from passive care or lack of care?

   Perinatal palliative care helps the baby and his or her family live better with what we do not have the medical acumen to heal. For little ones who are too premature, have absent or multi-organ failure, or other overwhelming inherent pathology, this means providing care that is "humane, compassionate and culturally sensitive" (Weimer 2016, pg 269).[1] Thus, palliative care is noteworthy for the medical interventions not started, limited, or stopped because the treatment's risk of doing harm is greater than providing a cure, or it may merely prolong suffering. Under palliative care, it is still reasonable to treat what is possible (such as providing antibiotics for an infection), as well as provide oxygen from a small nasal cannula, or play soothing music. Palliative care patients also usually have fewer lab draws, x-rays or other tests that neither change the outcome nor contribute to their level of comfort. There is no pathway in NRP or in my experience that calls for abandoning a living baby to an empty room, or table, or tossing pieces of him or her into a bucket. Instead, alarms and beeping machines are silenced and intentionally replaced by the quieter but no less profound care of being held by caring arms.

3. How does the after-birth assessment and customized care process help practitioners determine when invasive interventions are necessary and when palliative care should be pursued?

As imperfect as any medical assessment is, it's where we always start. Particular to newborn babies, after delivery, their breathing, heart rate, and circulation are immediately assessed, as well as color, muscle tone, and spontaneous movement. If the "ABC's" of airway, breathing, and circulation are problematic, basic interventions may be sufficient to help. If respiratory insufficiency or diminished heart rate persists, then either more advanced resuscitation is indicated or, given the lack of response to simple interventions plus additional findings on physical exam or from prenatal information, palliative care may be appropriate. It is also true that we often cannot immediately tell how well a baby will respond until we try, though it is simultaneously true that at the edge of viability, different healthcare providers differ on when exactly we should attempt to intervene. Thus, deciding when to change our goals from curative to palliative care is a customization that declares itself based on a combination of multiple factors including a baby's response to reasonable medical interventions, the family's values, and the expertise of the involved healthcare system. What is *not* a factor is how popular the baby is with people in the delivery room. No human being is ever worth-less. Medical treatment might be, but not a person.

4. Is the care requirement in the Born-Alive Abortion Survivors Protection Act a requirement of one-size-fits-all care or a requirement of individualized care following assessment?

The Born-Alive Protection Act was written because all liveborn babies do not currently receive the same medical standard of care, a standard which holds that the degree of medical intervention should be tailored to each individual. Because providing palliative care is one arm of this medical standard, our inability to cure a newborn never negates our obligation to care.

The uncomfortable problem is that there are newborns whose live births are the result of a mistake; these babies were born alive despite the intent of the medical provider. The Born Alive Protection Act neither resolves the ethical paradox created by its being legally permissible for an obstetrician to intentionally harm the same patient a neonatologist is medically responsible for, nor does this bill even remotely address the myriad genuine crises that bring either a single woman or a set of parents to intentionally find someone to end their unborn baby's life. The only issue this bill speaks to is what to do for a baby who is born alive, regardless of wantedness, prematurity, or malformation. The ethical and medical standard of care is to care for all liveborn babies. According to the NRP this means: (1) if viable, the baby should be resuscitated, (2) if viability is unclear, attempt to stabilize the baby while calling for help, and (3) if not viable or the baby does not respond to resuscitation, provide palliative care. Many hospitals and most outpatient clinics are not prepared for an emergency delivery, but all of them are supposed to be equipped to stabilize their patients until additional help arrives. This bill states that all babies should be treated the same, they should be assessed and then provided a medically tailored plan. Potential medical plans range from full resuscitation to keeping the baby as comfortable as possible for as long as we have the privilege of caring for him or her. The wide spectrum of medical care exists because the first non-negotiable and primary diagnosis is, it's a baby.

[1] Weiner, Gary M., Jeanette Zaichkin, and John Kattwinkel. *Textbook of Neonatal Resuscitation*. Elk Grove Village, IL: American Academy of Pediatrics, 2016.