Pomp and Circumstance:
Primary Care of the NICU and PICU graduates

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I did NOT do any fellowships in care of medically fragile children. Nor do I have any formal training other than experience.
Objectives

- Discuss the increasing primary care needs of medically fragile infants.
- Develop systematic approach to care for medically complex infants and toddlers.
- Increase level of comfort in caring for children with intimidating problem lists.
- BRIEFLY review some common medical issues in premies in the primary care setting.
Overview of the growing task at hand
Strategies to care for children with complex medical needs
Assessing development
Addressing feeding/growing
Discuss management of some common conditions in premature infants
Shorter discussion re: PICU graduates
Goal of pediatrics

- And raising children in general.
- Help every child reach their potential while experiencing life and all of its joys as fully as possible.
Our job has changed.

- We no longer have to work-up most infants with fever.
  - Our population of the “sickest” and most “at-risk” has shifted from all infants (in the pre-vaccination era) to a better defined group.
    - We less often have to find the needle in a haystack.
    - The needle is often sticking us in the arm when we look at our schedules.
  - We have a new population group with worse baseline health on whom we need to focus.
Medically Complex Care: The Newest Competency for Primary Care?

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Abstract
Nola is a complicated 22-month (19-mo corrected) former 34-week premature girl who presents to your practice in the company of her foster caretaker, a maternal aunt. The history you have comes mostly through the lens of her aunt’s recall of a variety of clinical encounters and emergency room visits that have taken place at 2 of the region’s tertiary care centers, including a prolonged recent hospitalization for failure to thrive. Regrettably, you have no discharge summary on hand from the outside institution. Fortunately, Nola’s aunt has come prepared. From her notes, you learn that Nola has a history of feeding difficulties and “global developmental delay.” The details of Nola’s prenatal and neonatal intensive care unit admission are scant. Nola has been described as having “unusual facial features, such as smallish eyes, low tone, some vision problems.” A physical examination demonstrates significant delays in all streams of development. Nola’s aunt recalls that she may need a gastrostomy tube pending her weight gain in the next few months. At present, Nola’s aunt/foster caretaker is caring for her at home and expresses her concern about 4 major areas: coordinating multiple appointments at various sites, keeping track of involved medical information, getting all of the “paperwork” done to get needed upgrades for a feeding chair, and buying expensive special formula with her own money. Nola’s aunt is intelligent and motivated, but she has limited help at home and is overwhelmed with all the aspects of the care. The aunt acknowledges the importance of multiple appointments—feeding support, developmental evaluations, vision, and neurologic assessments. When you inquire who Nola’s aunt identifies as her niece’s primary care provider, she reports that she has seen different doctors due to the vagaries of her schedule. You conclude that Nola’s situation is not likely to improve without a dramatic intervention. As you try to pull together a plan, you wonder what the most effective approach is for the busy clinician. Who should take the lead on a child’s care? Can a primary care pediatric clinician partner with other specialists and programs
Case

- 6 month-old term infant with history of laryngeal atresia, truncus arteriosus, absent cochlea, malrotation, and hydrocephalus coming out of the NICU. Family only speaks Spanish.
A few things to consider:

- Tracheostomy
- Ventilator
- G-tube
- Cardiac medications
- Labs
- Home health
- Parent education
- Developmental delays
- Communication
- Parental concerns about prognosis
Case

- I felt GREAT about taking this patient on in my first week out of residency.
- But I have learned a TON from this family.
- And even though he was “supposed to die” he’s now almost ten years–old and pretty happy.
- His last unscheduled admission was in August, 2010.
Why it matters

- On a systems level, these patients have high level of health care consumption.
  - 0.67% of children make up about one-third of child healthcare costs.
- On personal level, see previous slides.
Our goals as their pediatricians

- Keep alive
- Keep out of the hospital
- Grow and develop
- Happy, school, etc
But we don’t have time to do this!

- How are we supposed to tackle all of these things in short visits???
  - Staying organized
  - Frequent SCHEDULED follow-up
  - Prioritizing
  - Utilizing support teams
    - Many ICN’s have Special Infant Care Clinics aka high-risk follow-up clinic, etc.
    - Some, such as Duke, even have a “Transitions” program with an on-call pager.
How to Organize Your Visits?

- Develop YOUR own way.
- Utilize your EMR to help you, not inhibit you.
MY way to organize note/visit

- Summary of interval visits and plan from last visit with me
- New parental concerns
- Developmental progress
- Feeds
- Medications
- Supplies/home health
- Therapies
- Exam
- Assessment/plan
Developmental Progress

- Move from “Is your child doing xyz…” to “What can your child do now that they couldn’t do last time?”
  - Less choppy
  - Gets REAL information.
  - Allows you to “age-grade” & assess if bridging gap
  - Allows parents to brag about their kid!
    - All they ever hear is that their kid is behind…
Developmental Services

- Don’t hesitate to use your area’s Early Intervention programs
  - BabyNet in SC
  - Children’s Developmental Services Agency in NC
- Especially if more than one domain of delay
- Allows for coordination of services, including in–home
- At 3 y/o, transition to public school system/”preschool”
Feeds

- Okay, now the meat and potatoes.
  - Or transitional formulas. Whatever.
Case

- Overwhelmed mom (nurse) with 5 month-old ex-27 week female.
  - Reports consistent feeding history.
  - Initially was not mixing formula correctly.
  - On 26 kcal/oz Gentle-ease, omeprazole, but worsening reflux, runny/green stool over next month and NO wt gain
    - Mom had switched to Enfamil AR in interim without success.
  - Difficult finances.
    - Queried dilution, etc?
Home from NICU
Feeds—Brief Review of Formula

- Standard formula (like MBM) is 20 kcal/oz
- Transitional formulas are “defaulted” to 22 kcal/oz (Neosure, Enfacare)
  - Can be mixed to 24 kcal, 26/27 kcal/oz if needed
- Other specialized formulas are still only 20 kcal/oz (hydrolyzed formulas such as Nutramigen, Pregestamil and elemental formulas such as Neocate, Elecare).
Advancing Feeds

- Weight gain goal of 25–30g/day until infant at 50% for weight for adjusted age
- Decrease calories if weight gain >35g/day or weight-for-length rising!
- Adjust calories step-wise with frequent follow-up
- For catch up growth:
  - For infants with g-tube/NGT:
    - Increase bolus feeds by 5ml/per feed every Monday
  - Increase continuous feeds by 2ml/hr every Monday (alternate with bolus feeds if on both)

- Growth maintenance (when weight >25%)
  - Increase bolus feeds by 5ml/per feed every other Monday
  - Increase continuous feeds by 2ml/hr every other Monday (alternate with bolus feeds if on both)
G–tube or NG tube feeds

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Fortifying to higher caloric density

- Always look up specific mixing instructions—varies for each formula.
- Should always use the scoop that comes with the formula—different products have different sized scoops!
- While this can allow an infant to feed smaller volumes to get more calories, it does increase likelihood of reflux.
When feeders/growers don’t grow

- Start by understanding all that we’re asking these families to do.
  - 8+ feeds/day (in babies who are notoriously difficult to feed)
  - Manage fussy, developmentally atypical infants
  - Multiple medications
  - Diapers
  - Siblings
  - MANY appointments
Troubleshooting poor wt gain

- Missing feeds– The most common reason for insufficient wt gain
- With the previous slide in mind, (try to) keep judgment in check.
- Q3 Hours SHOULD mean from the start of one feed to start of the next.
- Use a feeding log!
  - Have them come back three days later to review!
Other causes of poor wt gain

- Reflux
- Formula intolerance (mucus in stool?)
- WE forgot to weight adjust their feeds!
- Increased energy expenditure (chronic lung disease, cardiac disease)
- Improper formula mixing
Misdiagnosed Poor Wt Gain

- User error– make sure that the scale is accurate (including if the weight gain seems TOO good)
- Make sure that weight recorded in grams
Other difficulties

- Not being able to purchase the formulas.
  - MANY patients eligible for WIC. Make sure they have WIC prescriptions!
- G–tube related issues
  - Pump not running
  - Leaks
  - Wrong tubing, connectors
- Other organic illnesses
  - Metabolic disorders
  - Infections
  - Hepatoblastoma (more common in ex–premies, TPN–related)
Back to our case

- Overwhelmed mom (nurse) with 5 month-old ex-27 week female not gaining weight.
  - reflux symptoms not responsive to typical management.
  - social/financial stressors.
  - abnormal stools
Home from NICU
Back to our case...

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Laboratory work-up unremarkable.

- Switched to Nutramigen 26 kcal/oz
Home from NICU

Nutramigen
Update

- Last seen by me in May, 2018 at 18 months-old.
- Meeting all 15–18 month milestones.
- Has healthy baby sister.
- Mom thriving, back at work part time.
Growth Chart: WHO
Weight-for-age Percentiles (Girls, birth to 2 years)
Most NICU grads have SOME
If untreated, can lead to poor weight gain, aversive feeding, irritability.
PPI, such as omeprazole (2 mg/kg/day) vs H2 blocker, such as ranitidine (8 mg/kg/day)
More complicated cases– reglan, but has irritability and dystonia as side effect.
WEIGHT ADJUST YOUR MEDS!!!
Reflux medication drawbacks?

- Some demonstration of increased risk of NEC, sepsis in neonates treated w/ PPI’s and ranitidine
  - However these are generally studies IN NICU.
  - Often confounders including gestational age.
- More clear is some risk in terms of gut microflora.
Those NICU discharge summaries can be intimidating:
- Was intubated, then on cpap, then on RA, then on HFNC, then intubated, then extubated, then intubated again, then on cpap.
Chronic Lung Disease

- Try making your reading be goal-directed!
  - At what age did they come off supplemental O2?
    - CLD/BPD means oxygen > 28 days or at 36 weeks corrected.
  - Did they come home on diuretics?
Pulmonary Hypertension

- The “new” NICU grad problem.
- Leads to increased anesthesia risk, morbidity + mortality with illnesses.
Which of the following would be diagnostic for pulmonary hypertension?

- 1) low oxygen saturations at 36 weeks corrected
- 2) recurrent pneumonia
- 3) wide pulse pressure
- 4) septal wall thickening on echo with RVH and tricuspid regurgitation
Which of the following would be diagnostic for pulmonary hypertension?

- 1) low oxygen saturations at 36 weeks corrected
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- 4) septal wall thickening on echo with RVH and tricuspid regurgitation
Read the section of the echo report that comments specifically on septal wall thickening/tricuspid regurgitation.

Often the interpretation summary won’t comment on this!

And it usually won’t say “pulmonary hypertension” ANYWHERE.
Diuretics

- Need to check BMP with ANY dose change or at least once/month
- Weight adjust diuretics
  - Typically when weight is up 10% from last change.
  - So it’s important to have a way to know when dose was last changed.
    - USE YOUR EMR SMARTLY!
Anemia of prematurity

Why?
- Diminished iron stores
- Iatrogenic
- Physiologic nadir
- Anemia of chronic illness
- Malnutrition
Anemia– what do you need to do?

- Look at last hematocrit.
- Check one month post-discharge if <30.
- If they’re not on iron at discharge, try to figure out why:
  - Not indicated/needed?
  - Recent transfusion?
- If the latter, then need to restart iron two weeks later (3–6 mg/kg/day elemental)
  - And probably check labs two weeks after that.
Osteopenia

- Check labs 1 month post-discharge
  - (just like anemia labs!)
  - If last alk phos > 400
- Check alk phosphatase, phosphorus, calcium
- If alk phos > 600, then start extra vit D (not just poly vi sol).
- Recheck a month later.
Guidelines frequently change.
Most recently, any infant younger than 29 weeks gestation qualifies
Also qualify if born before 32 weeks and needing supplemental O2 beyond 28 days.
Also qualify if hemodynamically significant heart disease or airway malformations
Once monthly, November thru March
Start applying in ~September.
These babies should get ALL age–appropriate vaccines.

Please note, if they were in ICN, they likely didn’t get rotavirus vaccine, so even if they got their 2 mo vaccines, they’ll still need Rota.

Flu vaccine at 6 months!!!
PICU Graduates

- Depending on their illness, can either have similar or different sets of challenges
  - And strengths!
Two broad categories from PICU

- Congenital severe illness such as cardiac disease
  - Increasingly cared for in specialized pediatric cardiac ICU vs NICU vs PICU
  - Often repeat admissions

- Previously always healthy, then medical or surgical severe illness.
  - Life-altering sequelae vs benign recovery
PICU graduates – congenital

- Carry a lot of the same things to think about as NICU graduates.
  - Diuretics for many
  - First time coming home
  - Young/fragile requiring many appointments and weight checks, med and feed adjustments
Getting into the nuances of the various congenital heart disease patients is WAY beyond the scope of this talk.
Key points

- Know their baseline and goal O2 sats
- Be wary of large amounts of weight gain
  - (edema vs caloric!)
- Develop clear understanding with cardiologist if goals are to weight adjust meds or outgrow doses
PICU Graduates– CHD

- Generally, these parents have had a long time to get used to the idea of a chronically ill infant.
Previously healthy PICU grad

- In contrast...
12 year-old boy—Summer 2014

- Biologic mother not in his life since infancy
- Father convicted of murder
- Went to lake to “blow off steam”
- Did not know how to swim
- Underwater for 15 minutes
- After 12 minutes CPR, 2 doses of Epi, regained pulses
Hospitalized for 2 months

- Tracheostomy, g-tube
- Home oxygen prn
- Med list:
  - Albuterol
  - Baclofen
  - Clobazam
  - Clonidine
  - Robinul
  - Keppra
  - Lorazepam
  - Phenobarbital
  - Glycopyrrolate
  - Chlorhexidine
  - Colace
All of the above care...

- Now to be done by his stepmom.
  - Has two of her own biologic children, preschool-aged
  - Without the help of her husband, who’s incarcerated
Ensuring that family understands the medication plan
Ensuring family understands trajectory
  ◦ Code status?
  ◦ Different than an ex-premie
Ensuring adequate home health support
  ◦ Include documentation in your notes of his care needs
Respite care
Ensuring financial resources—SSI, disability, guardianship
Course of our patient

- Remains neurologically quite limited
- Difficulty with appointments, logistically
  - Since not much to tweak, we try not to overdue
- Occasionally, but rarely, hospitalized
- Family considering long-term placement
Wow, a lot to think about!

- And do.
- So bring them back often so that fewer issues can pop up in between.
- And so that you can paid for the work you’re doing.
- And so that you can wt adjust meds, feeds.
Duke’s Transitions Program

- Program within SICC for highest risk infants:
  - Birth weight $< 1$kg
  - Gestational age $< 26$ wk
  - Discharged with technology
  - NAS on medications
  - Chronic condition on multiple medications
  - Partner with pediatrician to manage growth and development, minimize doctor and emergency room visits
Duke’s Transitions Program

- Patients and Pediatrician have pager access to SICC team 24/7
- Limit subspecialty follow-up appointments
- Consults on Transitions patients admitted in the hospital to help with discharge planning
- Pager Number: 919–970–8695
- Lynn Byrd, staff assistant– 919–681–3501
- Kim Lutz, nurse clinician– 919–681–6027
Take Home Points

- These babies need frequent general–peds type tweaks.
- Use your EMR to help you organize!
- Delegate when possible!
- Warn families that you’ll want to see them often!
- Don’t be afraid of these patients!
References

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