



# Infant Complex Care at Duke: Special Infant Care Program and Transitions Medical Home

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William Malcolm, MD

Neonatal-Perinatal Medicine

Department of Pediatrics



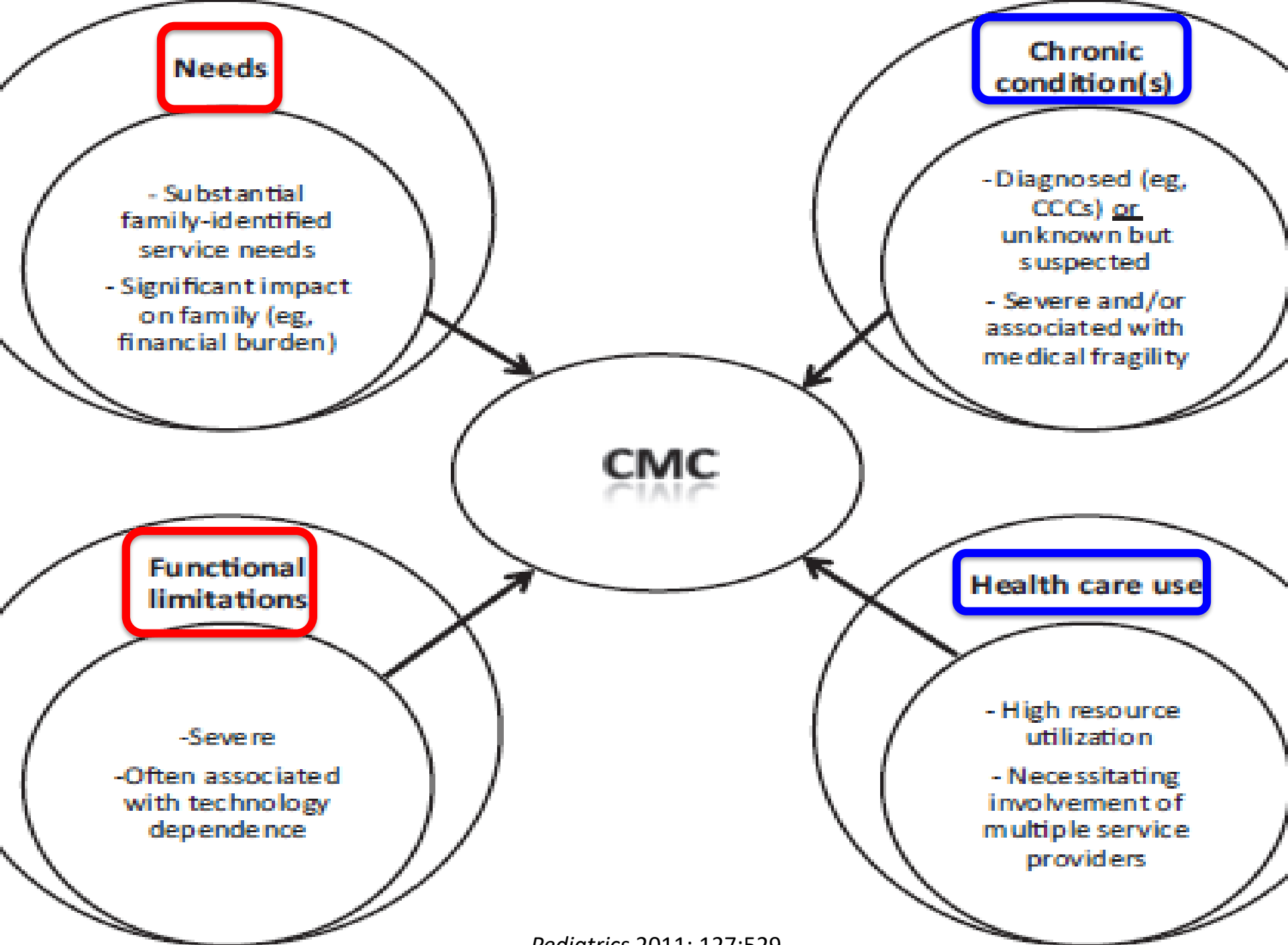


- Patient photos and quotes are presented with permission from parents



# Who is the medically complex infant?

- Subset of Children with Special Health Care Needs (CSHCN)  
“defined as children who have or at risk for a chronic physical, developmental, behavioral, or emotional condition and require health and related services of a type or an amount beyond that required by children generally”
- No specific operational definition
  - Multisystem involvement
  - Technology dependent
  - Frequent or prolonged admissions
  - Multiple medications/subspecialists



# The Medically Complex Infant

- Prolonged NICU hospitalization
- High risk for readmission and death in first year post discharge
- Uses disproportionate amount of healthcare dollars and community resources





# Duke's Special Infant Care Clinic (SICC)

## What is Special Infant Care Clinic?

When babies are born early or experience complications as a newborn, they are at increased risk for ongoing medical and developmental problems after discharge from the hospital. The Special Infant Care Clinic (SICC) is a developmental follow-up clinic that helps monitor high risk infants' medical condition(s), feeding, growth and development after they have gone home. SICC is available to assist your pediatrician in caring for your child during the first two years of life. We are committed to helping and supporting babies and their families so they reach the best outcome possible. The staff in SICC include pediatricians who specialize in caring for high risk infants, a nurse practitioner, nurse clinician, child psychologist, physical therapist, speech/language therapist, occupational therapist and social worker. You may recognize many staff in clinic who helped care for your baby in the Intensive Care Nursery.

## SICC team

William Malcolm, MD  
Patricia Ashley, MD, PhD  
Deesha Mago-Shah, MD  
Jen Peterson, MD  
Mollie Warren, MD  
Katie Gustafson, PhD  
Shelly Kutchma, PNP  
Kim Lutz, RN, BSN  
Erika Johnson, LCSW  
Lynn Byrd, Staff Assistant

## Contact Us:

Lynn Byrd (scheduling)  
Phone: 919-681-3501  
Email: [edith.byrd@duke.edu](mailto:edith.byrd@duke.edu)  
OR  
Kim Lutz, RN (patient needs)  
Phone: 919-681-6027  
Email: [kim.lutz@duke.edu](mailto:kim.lutz@duke.edu)

Duke Children's Health Center  
2301 Erwin Road  
Durham, NC 27710



Duke Children's  
Special Infant  
Care Clinic

*We care for you in and  
out of the hospital.*







# Who are we?

- General pediatricians who work in the NICU and follow-up clinic
- SICC/Neo Fellow
- Pediatric Psychologist
- Pediatric Nurse Practitioner
- Social Worker
- Nurse Clinician
- Staff Assistant
- Physical, occupational, and speech therapy
- Dietician





# SICC: Who do we follow?

- Premature infants <32 week and/or <1500 grams
- Respiratory failure (PPHN, CDH, s/p ECMO)
- HIE, neonatal seizures, ventriculomegaly
- Feeding difficulties (home GT/NG)
- Infants who required medications for NAS
- Various disorders- omphalocele/gastroschsis, chromosome abnormalities, malformations
- Infants with technology (oxygen, monitors, etc)
- Accept new referrals up to 1 year of life for infants with growth or developmental delay or moved to NC
- Follow patients until ~3 years of age





# What do we do?

- Manage growth- adjusting calories, volume of feeds, etc
- Management of morbidities-
  - CLD, GER, etc
- Developmental follow-up
  - PT,OT,ST evals
  - Developmental testing
- Manage technology
- Referrals and case coordination
- Community outreach/resources





# Transitions Medical Home



- Program within SICC for highest risk infants:
  - Birth weight < 1kg
  - Gestational age < 26 wk
  - Discharged with technology: GT/NGT, oxygen, trach, ventilator, glucometer, pulse ox/apnea monitor
  - Neonatal Abstinence Syndrome (NAS) on medications
  - Chronic condition on multiple medications
- Patients and pediatrician have pager access to SICC team 24/7



# Transitions Medical Home



- Follows these infants more frequently in SICC and partner with pediatrician/ER mds/consultants to reduce NICU LOS and minimize emergency room visits and readmissions
- Limit subspecialty follow-up appointments
- SICC also consults on TMH patients admitted in the hospital to help with discharge planning



# Why?

## American Academy of Pediatrics

- Recommends high-risk infant discharge be based on physiologic rather than weight parameters:
  - Medically stable and growing infant
  - Family completion and mastery of discharge education to care for infant at home
  - Close outpatient follow-up with experienced physicians and connection with community programs



# Why- Parents

Parents' perceptions at discharge:

- “anxiety-provoking”, “renewed crisis”
- “It’s that fear of I don’t have the monitor now for my babies, so I will be the monitor”
- “It’s so regimented here and monitored that you just don’t have those tools at home, so how was I going to recognize that she was full or that she was getting adequate nutrition?”



- Good overall care...
  - Access/availability
  - Know my child
    - Avoid “reinventing the wheel”
  - Outstanding communication and coordination





# Benefits to families

- Comprehensive, coordinated medical care
- 24/7 availability of provider familiar with child's medical history (TCN care team)
- Decrease unnecessary sub-specialty clinic or ER visits
  - Avoid duplication of care
  - Only SICCC/PCP visits first couple of months



# Why- Outpatient providers

- PCPs
- Community agencies (CC4C, CDSA, DME and home nursing, etc)
- Early interventionists (PT, OT, ST)
- Subspecialists



# Benefits to providers

- Coordination of care for complicated patients
- 24/7 availability of provider familiar with child's medical history
- Receive education about complex medical problems and treatments
- Continue to provide well-child care during infancy
  - Well child checks and immunizations
  - Acute visits
- Transition of care into general pediatric medical home when more medically stable



# Outcomes- NGT Statistics

- Enrolled in Transitional Medical Home Program from 2014 to 2018:
  - **68** babies discharged with NGTs
    - Excluding those who could obtain surgical g-tube at time of discharge
  - **11** infants required g-tube placement
    - On average at 3.5 months post discharge
  - Infants on average born at **31 weeks** with birth weight of **1930 g**
  - Discharged with NGT on average at adjusted age of **44w2d** and **DOL 88**



## NGT Statistics, cont.

- NGT needed on average for **19 days** post discharge
  - Excluding 4 infants who used NGT for > 3 months
  - More than half, 32 infants, fed some amount of breastmilk
  - 30 were female, and 30 were Caucasian
- Average oral intake of total daily volume feeds **58%**
  - 43% for those who obtained g-tube
- Both groups gained on average **22-23g/day** in first month post discharge



## Other outcomes...

- ED visits, re-hospitalizations, PICU admissions
- Pager usage
- Parental confidence and satisfaction





# Where do we go from here? Expanding the model of care...

## Your developmental team:

**Pediatrician:** specializes in caring for infants with feeding issues, poor growth, and developmental concerns.

**Nurse Clinician:** educates families about development and initiates early interventions.

**Neurologist:** specializes in caring for infants with neurological conditions.

**Occupational Therapist (OT):** works with babies and their families to promote feeding, motor, and sensory developmental skills.

**Physical Therapist (PT):** evaluates the infant's development and provides education to improve motor skills.

**Speech Therapist (ST):** evaluates feeding, swallowing, communication skills, and provides treatment to achieve safe feeding by mouth.

**Dietician:** will help to ensure optimal growth and nutrition of the infant.

**Child Neuropsychologist:** performs cognitive, neurodevelopmental, and social-emotional evaluations.

**Social Worker:** helps patients and families to identify emotional, social, and environmental strengths and problems related to their diagnosis and/or life situation.

## Contact Us:

Lynn Byrd (scheduling)  
Phone: 919-681-3501  
Email: [edith.byrd@duke.edu](mailto:edith.byrd@duke.edu)  
OR

Meghann McCoy, RN (patient needs)  
Email: [meghann.bryant@duke.edu](mailto:meghann.bryant@duke.edu)

Duke Children's Health Center  
2301 Erwin Road  
Durham, NC 27710



## Duke Children's Pediatric & Congenital Heart Center

*Pediatric Cardiac  
Neurodevelopmental Clinic (PCNC)*





# Where do we go from here? Partnerships with community...

- Prenatal clinics...
- Specialty programs...