Disclosures

- Work in this presentation was supported by HRSA Grant R40MC23626.
- I have no financial conflicts of interest to disclose.
- No commercial support was received.

Objectives

- Understand the epidemiology and health care use of preterm infants who are NICU graduates
- Analyze the real-world challenges for care beyond the NICU
- Identify opportunities to improve care for preterm infants who are NICU graduates
Subobjectives

- Understand what makes a system of care
- Learn needs of preterm infants after discharge from the NICU
- Learn about potential models of care
  - Care coordination
  - Comanagement
  - Roles of neonatal, primary care, and others
- Understand payment reform and the potential to support health system redesign

Case presentation

- 26 week gestation – discharged to home at 37 weeks post gestation
- 2400 grams, on 24 calorie Neosure
- Slow feeder, responds well to pacing
- Home oxygen
- Apnea monitor
- ROP
- ... what is this child/family at risk for and what can we try to mitigate through excellent care delivery?
- ... what role can you play in ensuring the child/family achieve the best outcomes?

What is a system of care?

- A range of services and supports
- Guided by a philosophy
- Supported by an infrastructure

Requirements

• Defined population
• Defined components
• Defined roles of components
• Values and principles

Changing health care systems

• Activities of change must be grounded in system of care values and principles
• Activities should address structure, processes, and relationships
• Coordinate changes across administrative and funding jurisdictions


Principles of the care system for children with special health care needs

• Responsive to family challenges, priorities, and strengths
• Developed in partnership with constituents
• Reflective and respectful of cultural norms and practices of families
• Accessible to everyone
• Affordable to those who need assistance
• Organized and coordinated through collaboration

Questions

• What are the values of a health care system for preterm infants after discharge from the NICU?
• What are the structure, processes and relationships of a system of care for preterm infants?

Epidemiology of prematurity

• Eight percent of births result in stay to NICU
  • 6% born under 28 weeks
  • Prematurity costs over $26 billion
• Medical risk continues after discharge
  • Chronic lung disease
  • ROP
  • Poor growth and feeding difficulties
  • Behavior and neurodevelopmental disabilities
  • Increasing # children discharged home with GT, trachs and other technologies

What happens after they leave the NICU?

• Frequent outpatient visits and prescription medication use
  • In first year ~20 outpatient visits/year
  • Excess hospitalization, particularly in the first two years after discharge
  • Readmission rates of 15-23% in first year of life
  • ELBW infants have readmission rates approaching 50%
  • Some infants >50%
• Readmission causes
  • Respiratory is primary cause
  • Other: infectious, growth/ nutrition
Post-NICU health care utilization per year during first three years of life.

<table>
<thead>
<tr>
<th>Year of Life</th>
<th>% Utilizers Median [IQR] Among Utilizers</th>
<th>% Utilizers Median [IQR] Among Utilizers</th>
<th>% Utilizers Median [IQR] Among Utilizers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inpatient Encounters</td>
<td>10.5 [1, 2]</td>
<td>7.8 [1, 2]</td>
<td>5.8 [1, 2]</td>
</tr>
<tr>
<td>ED Encounters</td>
<td>93.7 [2, 12]</td>
<td>87.0 [5, 9]</td>
<td>84.2 [3, 7]</td>
</tr>
<tr>
<td>Specialty Encounters</td>
<td>88.5 [7, 10]</td>
<td>62.0 [3, 10]</td>
<td>59.3 [4, 12]</td>
</tr>
<tr>
<td>Pharmacy Encounters</td>
<td>91.5 [10, 18]</td>
<td>86.0 [8, 14]</td>
<td>80.0 [6, 10]</td>
</tr>
<tr>
<td>Total Encounters</td>
<td>100.0 [1, 3]</td>
<td>99.0 [1, 3]</td>
<td>99.0 [1, 3]</td>
</tr>
</tbody>
</table>

Post-NICU discharge spending per year during the first three years of life.

<table>
<thead>
<tr>
<th>Year</th>
<th>Inpatient, post-NICU</th>
<th>Outpatient Specialty Care</th>
<th>Outpatient Primary Care</th>
<th>Outpatient Therapies</th>
<th>Outpatient Home Health</th>
<th>Outpatient Laboratory Testing</th>
<th>Outpatient Pharmacy</th>
<th>Outpatient Emergency Services</th>
<th>Outpatient Mental Health/Substance Abuse</th>
<th>Outpatient Durable Medical Equipment</th>
<th>Outpatient Dental</th>
<th>Total Spending</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>28,134</td>
<td>1,117</td>
<td>641</td>
<td>1,178</td>
<td>218</td>
<td>474</td>
<td>434</td>
<td>216</td>
<td>179</td>
<td>2</td>
<td>33,276</td>
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<tr>
<td>2</td>
<td>3,816</td>
<td>1,064</td>
<td>461</td>
<td>761</td>
<td>473</td>
<td>359</td>
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<td>473</td>
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<td>35</td>
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<td>2,351</td>
<td>1,165</td>
<td>354</td>
<td>604</td>
<td>659</td>
<td>275</td>
<td>309</td>
<td>659</td>
<td>93</td>
<td>112</td>
<td>6,512</td>
<td></td>
</tr>
</tbody>
</table>

Summary of findings

• Health care spending for infants discharge from NICU is substantial
  • Hospital care accounts for majority, particularly in the first year
  • Recurrent ED visits after NICU discharge are common
• Infants with medical technology have the highest risk of hospital and ED use
Additional risk factors

- ELBW infants, particularly with male gender, prolonged NICU stay for pulmonary reasons
- Late preterm infants (33-36 weeks) still hospitalized at a rate greater than that of term infants
- Other costs include EI, special education, lost employment

Long term issues

- Impaired neurodevelopmental outcomes: cognitive, motor deficits, CP, vision and hearing
- Higher likelihood of psychological and behavioral issues (ADHD, autism, difficulty in peer interactions)
- Adult outcomes
  - Increased rate of insulin resistance, hypertension
  - Overall lower rates of educational achievement, independence
  - Many adults do report similar quality of life to adults born at term

Questions

- What are modifiable factors that can improve care for children born preterm, particularly AFTER they leave the NICU?
- What health outcomes might be modifiable?
- What roles can we play in ensuring that ALL children who leave the NICU have access to such care?
The current system for NICU graduates

- (Almost) all children have primary care
- Somewhat population based
- Bright Futures guidelines for preventive care
- Largely tailored towards typically developing children
- Few guidelines for children who are born premature

- NICU followup clinics
  - Strong emphasis on developmental surveillance
  - Medical follow-up is variable
  - Not all children have access — not population based

- Education system — IDEA, Early Intervention
  - Population based
  - Developmental screening and natural environment therapies

Kuo DZ, Lyle RE, Casey PH, Stille CJ. Care System Redesign for Preterm Children After Discharge From the NICU. Pediatrics 2017 Mar 1. pii:e20162969.

Broad issues to address

- Medical issues
  - Neonatologist is often the medical authority
  - Few neonatologists provide continuous outpatient care
  - Many primary care physicians are not comfortable with the care of the child with medical complexity

- Care coordination
  - Addresses fragmented system of care
  - Sometimes multiple care coordinators can make things even more difficult

Medical care is a relatively small part of determining health
Care mapping
• 25 week gestation – discharged to home at 37 weeks post gestation
• 2400 grams, on 24 calorie Neosure
• Slow feeder, responds well to pacing
• Home oxygen
• Apnea monitor
• ROP
• Etc...........

Care map

Call to action
• System change is needed for preterm infants
• Consider principles of care, values, components, and the roles that the components play
Definitions of a few important terms

• Care coordination: team-based activity addressing “interrelated medical, social, developmental, behavioral, educational and financial needs to achieve optimal health and wellness outcomes”

• Co-management: “Effective division of responsibility among team members”

• Team-based care: families and providers work across multiple settings to “identify, coordinate, and address shared goals that meet the needs of the whole child”

System framework: Chronic Care Model

Components of effective care delivery for preterm infants in the primary care setting
What might this look like?

- Clinical care protocol. Care may be standardized among providers to take advantage of decision-making support. The protocol should be evidence- or guideline-based when available, with outcomes utilized for QI data purposes.
- Designated care team. Each preterm infant should have a designated physician who provides continuity of care, and a practice staff member such as a nurse who acts as a key contact and/or provides care coordination.
- Decision-making support. Each care team should have appropriate access to a consulting neonatologist and/or neonatology service such as a high-risk follow-up program who may provide expertise and guidance as needed, particularly for aspects of clinical management such as oxygen support, feeding management, and developmental surveillance.
- Family-centered care. Practitioners should be versed in the principles of partnership and the culture of family-centered care, including shared decision making, self-management, and utilizing families as partners in the QI team process.

Kuo DZ, Lyle RL, Garty M, Stille CJ. Care System Redesign for Preterm Children After Discharge From the NICU. Pediatrics 2017 Mar 1. pii:e20162969.

Neonatal graduate co-management

- Tertiary care service works with primary care practices to improve care for NICU graduates in the community
- Protocol of care for NICU graduates
- Protocol of co-management
  - Scheduled calls with family
  - Regular communication between staff
  - Telephone and email support from ACH

Four themes

- Improved health
- Improved practice delivery
- Overcoming distance
- Challenges with implementation
Improved health

- I think of the kids who have been identified thus far, they actually have care plans. I think parents are actually more aware what their diagnoses are. They know, I think, better about what kind of follow up the kids’ needs are and I think overall, I think our present generation right now is a little healthier. I think they are actually doing better because of that.
- We have that dysphagia section on our charts. It’s something you think about, but it seemed liked in the old days we had so many babies who had chronic needs – chronic wheezing, chronic feeding issues, chronic reflux and they all seemed to be tied together. Now that little questionnaire: how does your baby tolerate feedings, does he choke with feedings, does he cough. It’s amazing. I hate to say it, but I’m willing to bet you 75% to 80% of my ex-preemies have dysphagia and just by putting them on thickeners, I’m not having any problems with respiratory disease.

Improved practice delivery

- I think it’s made me more aware of who all is seeing each child and when they are coming in, just to make sure they are coming in for their visits.
- We had more past medical history within our EMR than we have ever had before for these babies…we have more discharge summaries than we ever had before…it’s better than it’s ever been before.
- I think it help at least in our practice, we make sure we were more standardized in our regards to the approach for the kids that we are seeing…I actually spent a little more time with parents hearing their perspective.
- I think this is a particular area where everyone has the opportunity to have protocols that will drives successes in practices. Those successes can hopefully be applied to some other diseases processes.

Overcoming distance

- It’s important for us to know what the kids look like well so we can identify when they are getting sick. “Why do I have to come in? I’m going down to Little Rock for everything.” Well, you know when he gets sick, Little Rock is 2 ½ hours away. What are you going to do?
- Allow the local guys some insight or have a discussion, have your discharge planners call and kind do a discussion about who does the best with what you need.
Challenges with implementation

- Anytime you have an EMR upgrade, there is, at least anticipate a three or 4-month window, just learning how to make it work before you can even start to do anything.
- We built a template that we could use for our preemies, but it covered every subject that we had talked about and it was very labor intensive since you ask all the questions each visit. Finally, I realized I could merge the template from the last visit over and then change anything relevant in terms of feeding volume, medication dosage, wheezing, on oxygen and new problems… It’s realizing the need to get more savvy with your computer system.
- When we talk about distance, it’s navigating the health system where you may have several providers. Having someone assist with that process is being helpful – that is probably the biggest challenge.

Results over six seasons

- Care plans rose from 38% to >95%
- Early intervention referrals rose from 36.4% to 91.7%
- NICU summary in chart rose from 60% to 75%
- Sick visits may have dropped? 5.2 to 4.6
- Hospitalizations unchanged (20-23%)

Collaborating with primary care

- Conclusions from comanagement study
  - Primary care physicians often do want the opportunity to personally provide improved care for NICU graduates
  - Time, expertise, payment, EHR are major challenges
- Engaging PCPs
  - Some practices are more likely/willing to collaborate
  - Ensure smooth transition (including neonatal abstinence, e.g.)
  - Clinical support: expertise, availability for consults
  - Co-manage and communicate
Alignment with health care reform

- Payment reforms, clinical practice guidelines, and outcomes research have the potential to transform the care of the preterm infant after NICU discharge.
- Defined population, clinical guidelines, potential for health care savings.

The future way of paying for health

- Four basic methods of payment:
  - Capitation – per person
  - Bundled payment – fixed amount for a given condition or event
  - Incentives – for quality
  - Shared savings – for costing less than predicted
- Note that these payments are not always tied to an encounter. This enables practices and hospital to be more flexible in how these dollars are used.

Example: how we currently pay for ADHD medical management

[Diagram showing primary care encounter, behavioral health encounter, and medication dispensed]
The evolving picture of the future

Future directions
- Population focus on preterm infants
- Opportunity with improvement – how low can hospitalization rate go? How can we improve developmental outcomes?
- Integrated care system
- Payment reform supporting change
- What primary care practices likely should do
  - Practice transformation
  - Care coordination
  - System reform
- How neonatology might consider collaborating
  - Determine and set care standards
  - Participate in co-management and collaboration
  - Support and maintain data registries
Takeaways

- Preterm children are a population focus of interest
  - High rates of hospitalization
  - High cost
- System reform is needed to transform care, including practice transformation, care coordination, comanagement
- Payment systems can support system change
- There is tremendous opportunity! We can make a difference!

References

- Kuo DZ, Lyle RE, Casey PH, Stille CJ. Care System Redesign for Preterm Children After Discharge From the NICU. *Pediatrics* 2017 Mar 1. pii:e20162969.