Sickle Cell Trait Notification: A Community Needs Assessment

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Acknowledgements:
Jessica Tarnowski, Nancy Silva,
Mom Tatahmentan, Nancy Vanderberg, Tony Steyermark, Patti Constant
Objectives

1) Obtain a basic understanding of newborn screening
2) Understand unique disparities present in the Sickle Cell Community
3) Understand a specific example of a community needs assessment
4) Understand the importance of asking questions
The Complete Newborn Screening Experience in Minnesota

Blood spot – more than 50 - metabolic, endocrine, blood, pulmonary/digestive, and immune disorders

Hearing – loss of hearing in the range where speech is heard

Pulse oximetry – critical congenital heart disease
A Changing Experience Over Time

1961: Dr. Guthrie develops the first screening test for PKU
   - Same method used today (filter paper)
1965: MN began newborn screening
2001: MN newborn screening panel doubles with addition of MS/MS testing
2007: MN adds hearing screening
2013: MN adds heart screening
2016/2017: MN adds lysosomal diseases
Newborn Screening’s Statewide Reach

• Infants screened: ~70,000/year
  – Heart screen – 125/year
  – Hearing screen – 250/year
  – Blood spot screen – 150/year

• A few examples:
  – Hemoglobinopathies (sickle cell disease) – 25-30/year
    » Sickle cell trait/hemoglobin trait - >1,000/year
  – Cystic Fibrosis – 35/year (270 positive screens)
Health Equity and Newborn Screening

Well, clearly, as this test is done on ALL babies this isn’t a problem for us....right???
What is sickle cell disease?

Affects shape of red blood cells

Clinical features:
- Anemia
- Dactylitis (swelling of hands and feet)
- Jaundice
- Acute Pain (vaso-occlusive) crisis
- Chronic Pain
- Splenic sequestration
- Infections
- Acute Chest Syndrome
- Strokes
Sickle Cell Disease (SCD)

MN began screening in 1988 for SCD

SCD affects nearly 1 in 500 African Americans

SCD affects the hemoglobin

SCD is recessive, both parents pass it

When you carry it, you have ‘trait’
  – 1 in 12 African Americans have trait
  – 1 in 10 West Africans have trait

Screening finds BOTH!
Sickle Cell Trait

- **AS**

Parents:
- **AS**
- **AS**

Children:
- **SS**: Sickle Cell Disease
- **AS**: Sickle Cell Trait
- **AS**: Sickle Cell Trait
- **AA**: No Trait or Disease
Health Inequities, Social Determinants, and Sickle Cell Disease

- **Health inequities** are the results of social, economic and environmental disadvantages, such as structural racism and a widespread lack of economic and educational opportunities.

- **Social Determinants of Health** are the conditions in which people are born, grow, live, work and age, including the health system (WHO)

- **Sickle cell disease**
  - primarily impacts folks of color,
  - is a complex chronic health disease which requires emergency care (opioids),
  - has a single treatment available,
  - has no adult providers in our state who want to see this population,
  - Lifespan continues to remain low, critical time between 16-24 years of age.
What’s your project?

• An idea, a thought, a plan...

Keep that in mind while we move through this...
This study shows that as many as 1.5% of babies born in the United States have SCT. Based on previous studies, there are no standardized methods or protocols for alerting families or healthcare providers to this information, educating them about the potential health outcomes that might be associated with the condition, or counseling them about the impact that this might have on the family's future reproductive choices. By including educational materials and providing genetic counseling at the same time that families are given positive SCT results, the occurrence and public health burden of SCD might be reduced.
Minnesota Trait Notification Process
1988-2015

- Passive process
  - Included on result document as though it’s ‘normal’
    - Lab mails it to hospital (always)
    - Hospital scans into EMR (should)
    - PCP gets report (hopefully)
    - PCP acts on it (possibly?)

*Requires a LOT of things to go right!
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<tr>
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<td>No (included on mailer)</td>
<td>Not directly</td>
<td>No</td>
<td>No</td>
<td>Yes (9 months)</td>
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<td>Ohio</td>
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<td>Yes</td>
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Why this Happened...

• Fear? Assumption?
  – What is our message? Don’t reproduce! Yikes!
  – Too close to the problem
  – It was how we always did it
  – Any option would be too much work
  – They (parents) don’t want to know anyway
  – Not my job? Provider responsibility?
Ok, Now What?

• What do we know?
  – We have information
  – Parent’s aren’t getting it

• What don’t we know?
  – What do parents think?
  – Do they even want this?
  – How do they want this?
  – Can deliver on their ask?
What Do We Need?

• Find the community
  – Community outreach to identify resources and contacts
• Ask the community
  – Training
• We need support
  – Hired student worker
  – Time to commit to this
  – Manager/supervisor support
Community Needs Assessments

What is my question?

Who are your Partners?

What assumptions do we have?

Who are your Stakeholders?

How do we proceed?
Community Needs Assessment

• Surveys
  – Lots of information
  – May be generalizable, may not be
  – Quantitative

• Focus Groups
  • Great for asking about perceptions, opinions, beliefs, and attitudes
  • Lots of work!
  • Not generalizable
  • Qualitative
Focus Groups

- Demographics
  - 5 focus groups total
  - 29 Participants
  - Ages 20-40
  - Self-identified as African American or West African
  - All parents
  - Locations for recruitment:
    - People Serving People (PSP)
    - North High
    - MAWA (MN African Women’s Assoc.)
    - PICA (Parents in Community Action)
    - River of Life Lutheran (church)
Goal

Identify an approach to trait notification that would be generally accepted by parents within communities with a high incidence of sickle cell trait (SCT)
## What Did We Ask?

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<th>Minutes</th>
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<td>1. Is it important for people to be contacted or made aware of this? Why?</td>
<td>5</td>
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| 2. For each notification method (letter, phone call, in-person visit, electronic method):  
  Who is providing you with this information?  
  What is being said?  
  Identify the barriers/weaknesses of this form of notification  
  Identify the successes of this form of notification | 10      |
| 3. Is there any other way you could find out about your newborn’s trait status that we haven’t discussed? | 5       |
| 4. Out of all the ways to find out that your newborn has sickle cell trait (letter, phone, in person) pick your top 2 for how you would want to find out. | 5       |
| 5. What is the most important thing we should consider when notifying parents? | 5       |
| 6. If your newborn was found to have trait, when would you want to find out?    | 5       |
| 7. Is there any reason you wouldn’t want to know your newborn’s trait status?  | 5       |
What We Got Back…

• Why they want to know
• What needs to be included in notification
  – Rather than how it is done.

* It was different information then we thought we would get – benefit of focus groups vs survey
Important Qualities of Notification

- Knowledge Base: 62%
- Provision of Support/Resources: 13%
- Personal Relationship: 19%
- Timeliness: 6%
Why Parents Want To Know

• Knowledge is Power
  – “I would want to know, it affects the child, and there are so many genetic traits that get passed on from one generation to another. You don’t have any control over it, but you can prevent [sickle cell disease] from happening by having the right information.”

• Reproductive Risk
  – “If they are aware, they can also plan. You can teach your children how to plan, and you can tell them ‘you aren’t sick but you are carrying something that could possibly make your child sick if your partner has it as well.’”
Why Cont.

• Health Burden of SCD
  – “Speaking from where I come from [in West Africa] it is serious because... the life expectancy of people that actually have the disease is very limited. Most of them die in their twenties... So people would go as far as actually getting tested to make sure you don’t have the trait before approving marriage. It is that high level of a priority. So definitely if a baby has trait, or if the parents don’t know they have it themselves they would want to know.”

• Prior Awareness
  – “It’s good for you to find out that information to educate yourself, and if you see others, you can also educate them, give them hope, not the false hope, but hope.”
Themes For Notification

• Knowledge base of person conducting the communication
  – “I need somebody that is definite on what they are talking about, I don’t need anybody that’s like “look let me go ask the doctor and then I can get back to you.”... because now I don’t feel confident talking to you.”

• Personal relationship with the person conducting the communication
  – “[it should be] somebody that I feel cares for my baby”
Themes Cont.

• Provision of support and resources
  – “Refer me to someplace where I can get my questions answered... So pointing out hey you can go to this website and read more about the disease and the potential impact it will have on your child if they have it because they aren’t going to sit with you and tell you everything on the spot. They are pointing you to where you can go to get more information if you want to know more.”

• Timelines
  – “I just want to know, that’s my top priority, just knowing does my child have it. Call me, come by, send me a letter just let me know.”
Recommendations

• Notifications for SCT should include the following as a minimum standard:
  – Multi-faceted
  – Timely
  – Facilitated by an individual with a working knowledge of hemoglobinopathies and counseling

• Sufficient resources and support groups that services parents are needed

• Continued efforts to increase general awareness in culturally and community appropriate ways for:
  – SCT
  – Newborn screening
MDH Process Change Implemented

• MDH Newborn Screening has developed a multi-faceted notification process
  – Letter/mailing directly to parents when SCT is identified
  – Phone number of SCT educator will be provided to answer additional questions
  – PCP (listed on NBS cards) will be contacted and directly sent results with resources
  – Began June 2015
  – Continue outreach to increase awareness of sickle cell trait and disease
# Implementation

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*NOTE: The symbols ①, ②, and ③ represent specific instructions or additional steps for each state.
Measureable outcomes....

• I hate them ;)
• They are important!

• What might yours be? And how do you get them?
A Complete SCT Notification

1. Report is received by clinic listed on the newborn screening specimen card
2. Infant is registered and seen at clinic
3. Provider discusses result with family
4. Provider confirms the result through hemoglobin electrophoresis
Analyzing the process prior to changes:

214
Returned checklists from providers: 144
Infants whose providers received newborn screen report: 81

38%
Infants that were confirmed patients in listed clinic:

32%

68
Infants whose results were reviewed with family:

56
Infants that had confirmatory testing:

48

22%
Infants that had all actions completed:

44

21%
Importance of Education
Impact of Community-Informed Process

1. Report is received by clinic listed on the newborn screen specimen card
2. Infant is registered and seen at clinic
3. Provider discusses result with family
4. Provider confirms the result through hemoglobin electrophoresis
AFTER – Infants whose results were reviewed with family

60%
Other Positive Impacts

- **Beyond the pilot**
  - We now notify on all traits, not just S trait
  - >1000 infants and their families per year

- **We now have important partners**
  - Sickle Cell Foundation of Minnesota (SCFMN)
  - Children’s Sickle Cell clinic
  - Region 4 Genetics Collaborative state partners
  - MDH internal partners
    - Children and Youth with Special Health Needs – Long Term Follow-up Unit
    - Deputy Commissioner, Paul Allwood
    - Center for Health Equity

- **We are increasing population level awareness of SCD**
  - Juneteenth
  - Shades of Beauty
  - State Fair
  - Sickle Cell Summit
Your project...

• What else could come from your engagement? Where else could this go? Who do you need to get there?
Why Did This Work?

- We asked what the community wanted
- Followed-up
- We made improvements
  - Minor messaging and material improvements
- Barriers didn’t stop us

The key to success??
The community INFORMED this process
Authentic Engagement Leads to Increased Partnerships

- Community/Gen population awareness and education
- Re-education of teens
- Parental testing for trait
- Challenges for this sickle cell community:
  - Advocacy is parent and volunteer driven
  - Emergency Department care
  - Transition to adult care
  - Reproductive risks for SCD patients

*We are not done yet, and we can’t do it alone!
How Do You Do This?

- Challenge your assumptions
- Learn from other states
- Involve the community in finding a solution
- Find MDH partners to help
- Find outside partners to help

*Be brave and take chances!
Questions?

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