

# Improving Outcomes in Sickle Cell Anemia: The Role of a Transition Program

**Mailman Center for Child Development**

May 27, 2016



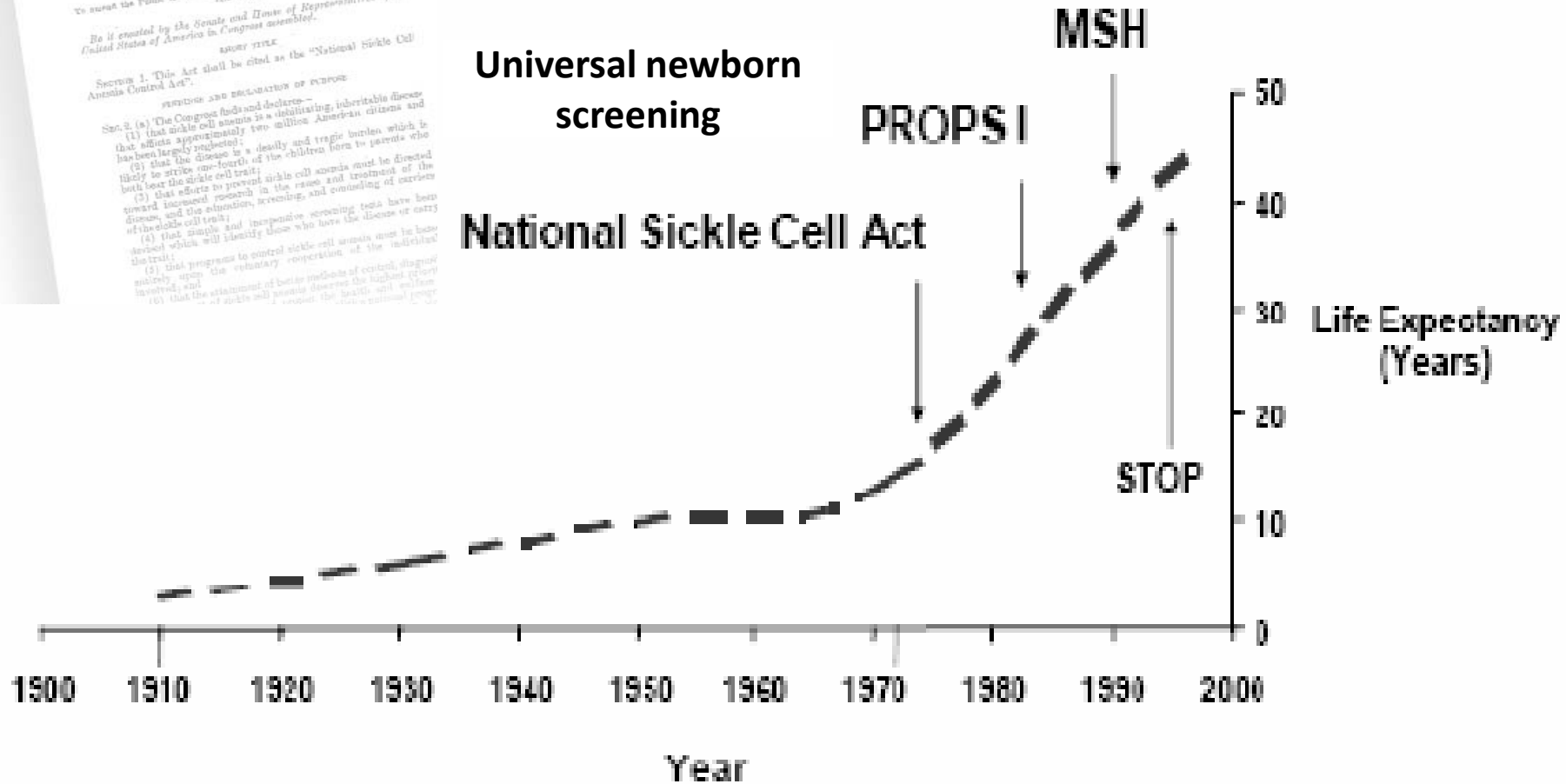
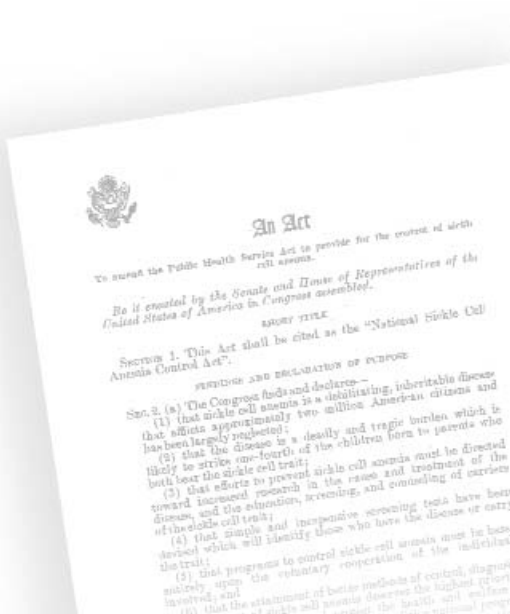
**Ofelia Alvarez, MD**

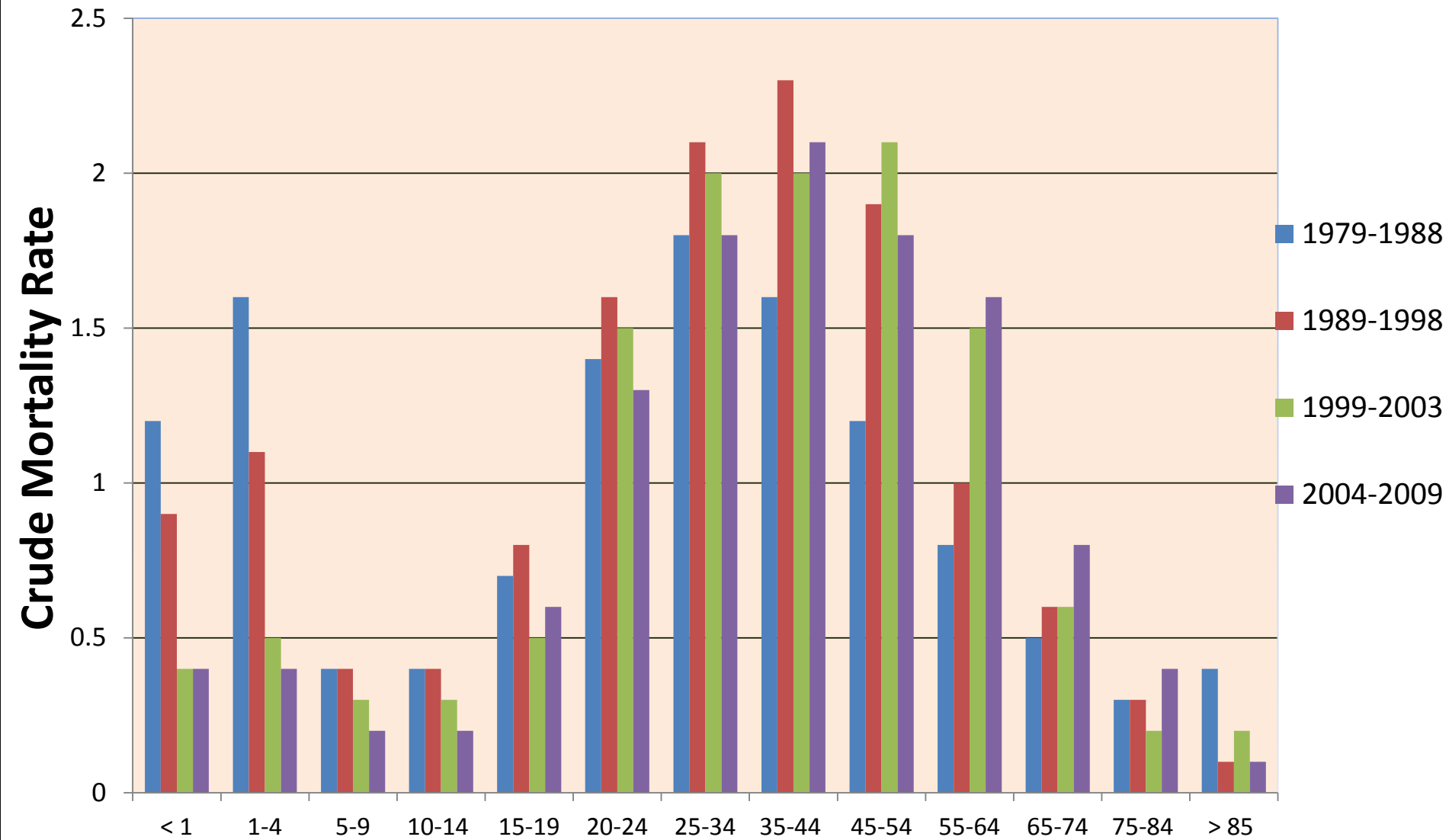
Director

University of Miami Sickle Cell Center

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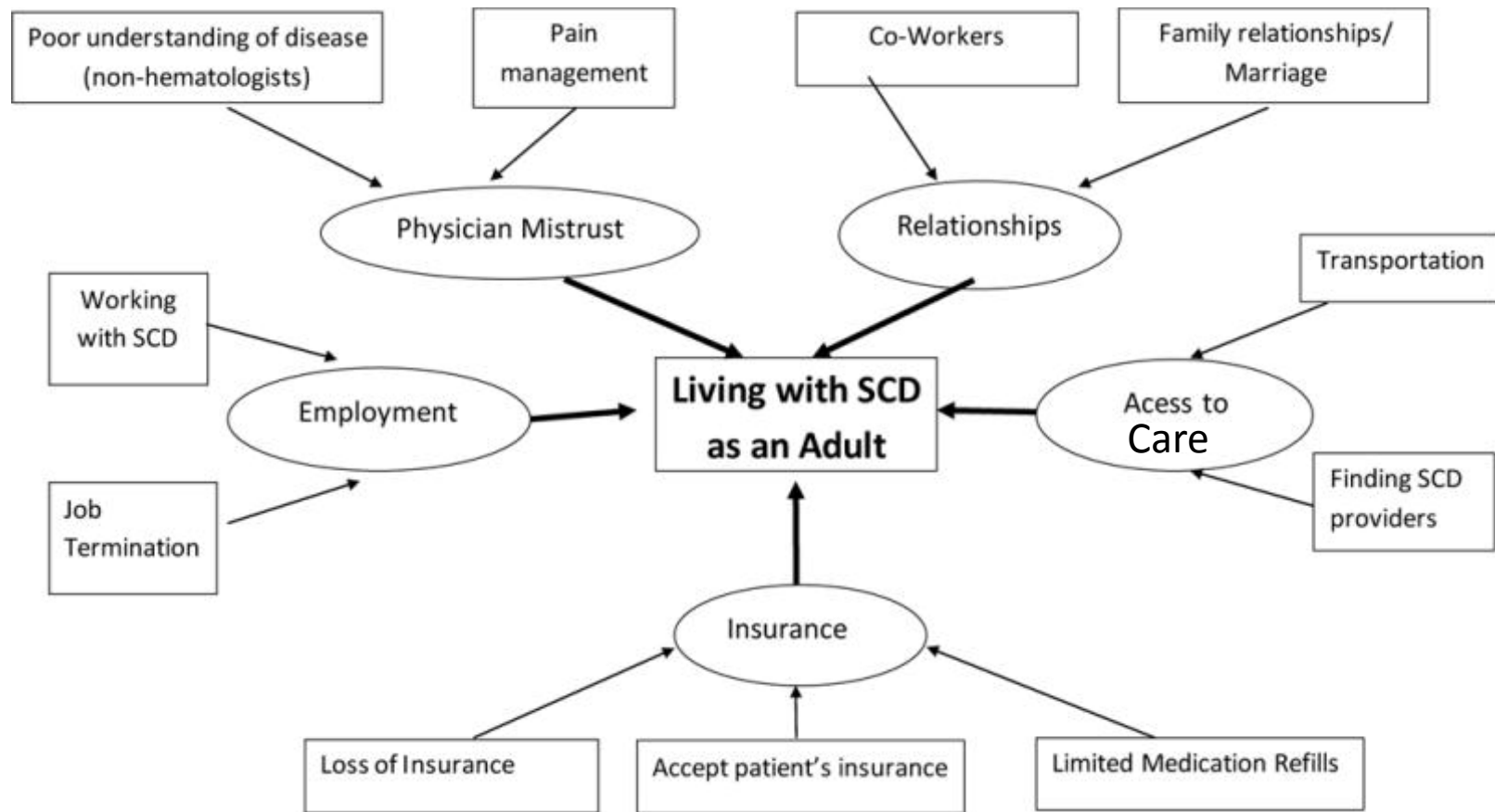
# SCD Survival Timeline in the US and Developed Countries





**SCD Mortality Per Age Group in the US according to Death Certificates  
National Center for Health Statistics, 1979-2009**

# Challenges an Adult with SCD Faces





# **TRANSITION FROM PEDIATRIC TO ADULT CARE**

# The Definition of Transition for Young People with Chronic Health Condition

- “**Purposeful, planned** and **timely transition** from child and family-centered pediatric health care to patient-centered adult-oriented health care,” with the goal “to **optimize health** and to **facilitate** each young person’s attaining his or her maximum potential.”

*Blum, et al., Position paper of the Society of Adolescent Medicine. J Adolesc Health, 1993*

*Rosen, et al. Society for Adolescent Medicine, J Adolesc Health, 2003*

- Transition is a **process** towards engagement in their **own medical care** as well as increasingly adopting “adult roles and functioning.”

A consensus statement on health care transitions for young adults with special health care needs. *American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians-American Society of Internal Medicine, Pediatrics. 2002*

# Factors Affecting the Transition of Young Adults with SCD

## Positive Influence

- Parental support
- Education
- Self-efficacy and maturity

## Negative Influence or Barriers

- Negative ED experience
- Cognitive deficits
- Not finding a doctor interested in caring for SCD patients
- Insurance changes

# Challenges to Provide Health Care to Young Adults with SCA 18-30 Years of Age

- **High medical utilization in ED and hospitalizations**

ED utilization > 2 x/year

Higher # admissions & reutilization of acute care services within 14 days of discharge compared to adolescents (10–17 years) and patients 31-45 years.

Lebensburger, *J Blood Med*, 2012

- **Period of increased mortality**

6 of 7 deaths occurred within 2 years after transitioning to the adult care provider (Dallas cohort).

Quinn, *Blood*, 2010



# Steps for a Successful Transition

## Transitions Clinical Report Authoring Group

- 1. Discuss office transition policy with youth and parents.**
  - Define responsibilities for the patient, physician, and caregiver.
- 2. Begin discussion of the transition plan.**
  - Utilize readiness tools to assess a patient's ability to participate in transition education.
  - Assessment should include education/vocation, independent living and self-advocacy, and patient awareness of medical needs and age-appropriate preventive care.
- 3. Practitioners should review the response to transition and assess readiness.**

Tailor the specific transition plan for that patient on individual needs.
- 4. Complete transition plan.**
  - Direct communication between pediatric and adult providers and development of a portable medical summary.

Supporting the health care transition from adolescence to adulthood in the medical home.

American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians  
Transitions Clinical Report Authoring Group, Cooley WC, et al. Pediatrics. 2011 Jul; 128(1):182-200.

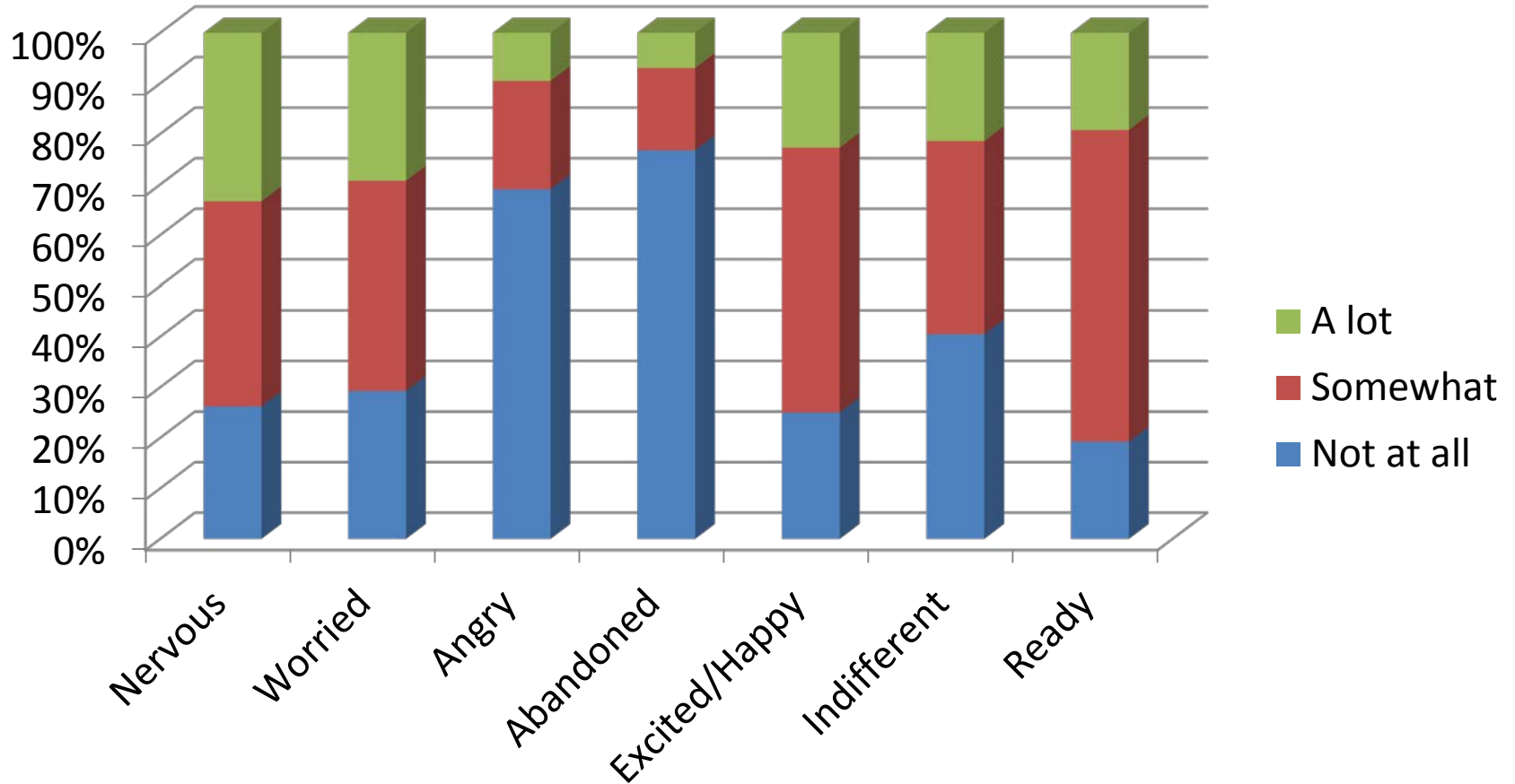
# Our Transition Program

Task	Visit Number
Independent parent and patient program introduction	1
Questionnaire about Transition expectations and maturity assessment: Transition Readiness Assessment	1
Health and SCD education	2, 3, 8
Vocation and college guidance	4
Genetic counseling	5
Social work needs and insurance assessment	6
Depression and Anxiety Screening	7
How to Navigate the Health System	9
Transition Readiness Assessment and Written Transition Plan Portable Medical Record	10
Meet the adult provider and his clinic	10
Short and long-term appointments with adult provider Impact on patient outcome	Post-transfer

# UM Transition Program

- Program started on October 2012
- 75 patients have been eligible (42 M, 33 F)
- We begin at age 16, but plan to start at 12
- 58 patients have started (77%)
- 24 completed Transition from Peds to Adult
- One of 24 programs nominated for Exemplary Care in Coordinated Services for Children with Heritable Disorders (2014)
- One of 2 for sickle cell disease

# Feelings Towards Transition from Pediatrics to Adult Care on Visit 1 (N=43)



- 30-40% are very nervous and worried and are not indifferent, but many are happy or somewhat happy and ready
  - 20% are not happy
- Majority are not angry and do not feel abandoned

Questionnaire from Joseph Telfair, DrPH, MSW, MPH  
Professor, University of N Carolina at Greensboro

# Transition Readiness Assessment Tool

I can explain my medical needs to others

I know my symptoms including ones that I quickly need to see a doctor for.

I know what to do in case I have a medical emergency.

I know my own medicines, what they are for, and when I need to take them.

I know my allergies to medicines and medicines I should not take.

I carry important health information with me every day. (e.g. insurance card, allergies, medications, emergency contact information, medical summary)

I understand how health care privacy changes at age 18 when legally an adult.

I can explain to others how my customs and beliefs affect my health care decisions and medical treatment.

Using Health Care I know or I can find my doctor's phone number.

I make my own doctor appointments.

Before a visit, I think about questions to ask.

I have a way to get to my doctor's office.

I know to show up 15 minutes before the visit to check in.

I know where to go to get medical care when the doctor's office is closed.

I have a file at home for my medical information.

I have a copy of my current plan of care.

I know how to fill out medical forms.

I know how to get referrals to other providers.

I know where my pharmacy is and how to refill my medicines.

I know where to get blood work or x-rays if my doctor orders them.

I have a plan so I can keep my health insurance after 18 or older.

My family and I have discussed my ability to make my own health care decisions at age 18.

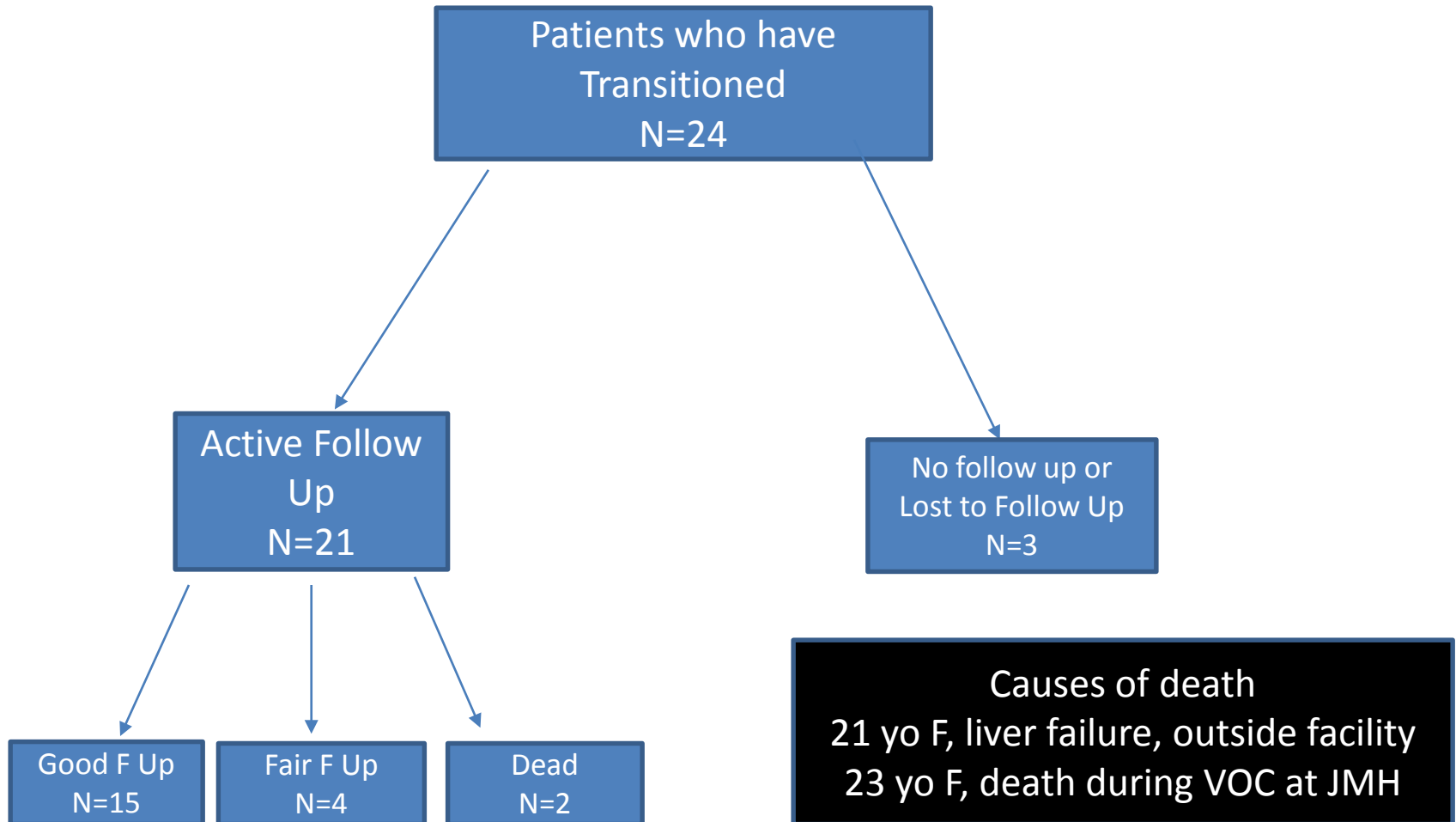
[gottransition.org](http://gottransition.org)

Things Patients Identified as Needing to Learn or to Have	N=25
Have copy of current plan of care	11
Know how to get referrals to other providers	9
Know what to say to the doctor	8
Plan to keep health insurance	7
Make own appointments	7
Discuss with family ability to make their own decisions	6
Understand how health privacy changes after age 18	6
Know doctor's phone number	6
Carry important health information	5
Know their allergies	4
Know their pharmacy	3
Know what symptoms require medical attention	1
Know their medicines	1
Nothing to learn	6

# Practice, Practice, Practice

- Patient should meet alone with the doctor
- Make his or her own appointments
- Know about health insurance and needed approvals for visits
- Know what is important for their health
- Know about the meds he or she is taking and follow instructions
- Speak or advocate for self in an efficient way

# Transition Outcomes





# System Quality Improvement

- Transition coordinator
- More insurance coordination/case management
- To have more shared clinical time between the pediatric and the adult provider
- Assess and provide education of medical team(ED, PCP, hospitalist, nurses)

# SAVE THE DATE

- 17th Annual Chronic Illness and Disability Conference:  
**Transition from Pediatric to Adult-based Care**  
Houston, TX October 27-28, 2016
- Southeast Regional Newborn Screening and Genetics Collaborative (SERC) & 34<sup>th</sup> Annual Meeting of the SE Regional Genetics Group (SERGG):  
**Transitioning and Medical Home Workgroup**  
Ponte Vedra Beach, FL July 14-16, 2016