

MDCH & SCDA-MI Presentation of Focus Group Data

October 13, 2014



Purpose

- The purpose of this study was to understand the views of populations affected by sickle cell disease (SCD).
 - Identify gaps in services or other needs specific to the SCD population in MI.
 - Identify strategies to improve SCD management across the lifespan.
 - Use qualitative data to inform the SCD strategic plan.
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Description of Participants

- Individuals ages 18+ diagnosed with SCD
 - Parents/family representatives of children diagnosed with SCD
 - Recruited by 5 SCDAAM-MI Patient Advocates via home visits, phone, office visits
 - Detroit
 - Saginaw
 - Lansing
 - Benton Harbor
 - Grand Rapids
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Participant Description

Meeting Locations & Dates	# of Adults living w/SCD	# of Parents of children w/SCD	# of Caregivers	Total
Detroit (9/10)	4	2	-	6
Saginaw (9/16)	6	8	1	15
Lansing (9/22)	3	6	1	10
Benton Harbor (9/23)	3	3	1	7
Grand Rapids (9/30)	2	3	-	6*

** One MDCH Nurse Practitioner participated in Grand Rapids focus group session*

- n = 40 {39 sickle cell disease diagnosis, 1 sickle beta thalassemia diagnosis}
 - 42 participants black; 2 white
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Participant Description*

AGES	PARENTS	ADULTS
0-5	2	-
6-10	5	-
11-18	9	-
19-30	-	8
31-50	-	4
51+	-	7

** Ages captured are based on written transcriptions during focus group meetings*

Focus Group Questions

1. What community resources have you found most helpful in managing your/your child's diagnosis of SCD?
 2. What gets in the way of you/your child being able to attend scheduled appointments for SCD care?
 3. Have you talked with anyone about using a medication called hydroxyurea as treatment for your/your child's SCD? Was it recommended that you/your child take hydroxyurea? What factors influenced your decision to take/not to take this medication?
 4. When you/your child need immediate care because of pain episodes due to SCD, where do you usually go for care?
 5. What has been done to prepare you/your child for transitioning from pediatric to adult care for SCD?
 6. Is there anything else you would like to tell us about SCD that we haven't discussed?
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Findings

Q1: What community resources have you found most helpful in managing your/your child's diagnosis of SCD?

- SCDA – MI (transportation, education, Project Enrich, assistance and education from Patient Advocates)
- Children's Special Health Care Services
- Hematologist and clinics
- Transportation Services (Spectran, DHS, Medicaid, Red Cross)

Additional needs:

- Psychosocial support
 - More attention and funding for SCD
 - CSHCS Coverage beyond 21 years of age
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Findings

Q2: What gets in the way of you being able to attend scheduled appointments for sickle cell care?

- Transportation (the weather, lack of transportation, cost)
 - Scheduling
 - School & Work
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Findings

Q3: Have you talked with anyone about using the medication called hydroxyurea as treatment for your sickle cell disease? Was it recommended that you/your child take hydroxyurea? What factors influenced your decision to take/not to take this medication?

- Majority of participants reported yes
- Reports of adverse side effects
- Unsure of varying dosages
- Some patients reported overwhelmingly good results when taking the drug

Additional needs:

- Education from clinicians
 - Insurance Coverage
 - Participants reported child protective services involvement
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Findings

Q4: When you need immediate care because of pain episodes due to sickle cell disease, where do you usually go for care?

- Emergency Department
- Manage pain at home
- Children's Hospital
- Saint Mary's Ambulatory (Short Stay)

Additional needs:

- Specific ED protocol for treating SCD patients
 - More doctors treating patients
 - Patient empathy
 - Day treatment or short stay clinics
 - Holistic approaches to treating pain
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Findings

Q5: What has been done to help you prepare for transitioning from pediatric to adult care for sickle cell disease?

- Discussions with SCDAAs Patient Advocates
- Discussions with pediatrician or hematologist
- Some participants with children younger than 18 were unsure what transition of care meant

Additional needs:

- Education from doctors and nurses
 - Education for parents to transition child
 - Navigate healthcare system with appropriate medical terminology and medications
 - Emotional support
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Findings

Q6: Is there anything else you would like to tell us about sickle cell disease that we haven't discussed?

- Lack of life insurance coverage
 - Medication authorization
 - Racial disparities compared to other blood disorders
 - New drugs on the market
 - MI lobbyist advocating for sickle cell disease
 - Additional apheresis centers in MI (full exchange)
 - Better care coordination and communication w/ SCDA-MI Patient Advocates and hematology clinics
 - Education and availability for bone marrow transplant
 - Physician/nurse training
 - Better utilization of social media
 - Employ hospital-based advocates
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Hemoglobinopathy Quality Improvement Committee

Strategic Thinking Responses

Q1: When you reflect on the burden of SCD, what are the 3 most important issues impacting populations affected by this disease?

- Pain/pain-related hospitalizations
- Transition/continuing care
- Lack of adult providers
- Early mortality
- Employment
- Myths
- Medication compliance

Q2: List 3 medical management resources within your agency that could help to address these issues.

- New transition clinics
 - NBS follow-up
 - SCDA-MI (education resources)
 - University of Michigan Gynecological Clinic
 - Red blood cell exchange
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Q3: What are 3 underutilized opportunities available for individuals living with sickle cell disease to improve their quality of life?

- Compliance adherence
- Mental health services
- Hydroxyurea
- Transportation
- Financial services for prioritization
- Cord blood collection
- IEP 504 Plans

Q4: List the 3 most important/critical issues that MDCH must focus on and accomplish in the next 3 years to address SCD across the life span, and why?

- CSHCS beyond age 21
 - IEP 504 plans
 - Health insurance quality and access
 - Employment
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Q5: What do you see as 3 major opportunities with health insurance to improve the quality and access to healthcare individuals with SCD?

- Awareness of services
- Preventative services

Q6: If money were no object, what are 3 new services/programs you would implement to address SCD?

- Increase social work services/resources
 - Comprehensive sickle cell clinic
 - Develop patient and physician incentive opportunities
 - Fellowship programs
 - Train physician assistants and nurse practitioners
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Health Status Assessments of Persons with SCD in MI 2013-2014

- Survey tool for assessing medical care, services, and needs (55 questions)
 - Self-report health information on health care utilization, disease history, and socio-demographic characteristics
 - Developed by MI Hemoglobinopathy Surveillance Quality Improvement Program (MiHSQIP)
 - Healthy People 2020 Objectives for Blood Safety Disorders & Blood Supply
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HSA Preliminary Findings

- 405 interviews; 95% African-Americans; 1.5% and 1% Arab/Chaldean ethnicity
 - 59% had SS; 29% SC disease; 5.7 Sickle beta thalassemia
 - 47% receive SSI
 - 73% enrolled in CSHCS
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Findings

Annual Household Income	N	%
<\$20,000	219	54.1
\$20,000 - <\$35,000	92	22.7
\$35,000+	54	13.3
Refused/Missing	40	9.9

Findings

Health Insurance	N	%
None	13	3.2
Public only	312	77.0
Private only	53	13.1
Public and Private	18	4.4
Other/Don't know/missing	9	2.2

HSA Next Steps

- SCDA-MI continue ongoing data collection
 - Further data analysis
 - *Healthy People 2010* Objectives
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Questions
