Recommended Curriculum for Transition from Pediatric to Adult Medical Care for Adolescents and Young Adults with Sickle Cell Disease: Suggested Topics, Methods, and Efficacy Measurements

WISCH Transition Affinity Group Members: Jane Hankins (chair), Sheila M Anderson, Michael Barnett, Fernando Barreda, Wondwessen Bekele, Suzanne Bell, Jeannie Byrd, Mary Campbell, Yvonne M Carroll, Maria Champigny, Miralda Charles, Alice Cohen, Audrey R Cole, Lori Crosby, Donna Dixon, Mark Goodwin, Oba Hollie, Ashley Houston, Alana Lopez, Kelley Mansker, Michael Matthews, Owita Mays, Brandi McClain, Amanda Norton, Wanda Payton, Jerlym Porter, Michael Regier, Sandra Sledge, Amy Sobota, Marcus Stevenson, Marsha Treadwell, Lauren Whiteman, Andrea Williams, Michelle Williams
The Transition Curriculum for adolescents with sickle cell disease was developed as a joint effort with funding from the Health Resources and Services Administration (HRSA); Sickle Cell Disease Treatment and Demonstration Program (TDP) grant. The grantees consist of a network of comprehensive sickle cell centers (pediatric and adult), sickle cell community organizations, and federally qualified healthcare centers. These organizations worked in a collaborative effort with the HRSA Sickle Cell Disease for Newborn Screening Program (NBS) grantees and the coordinating center for both programs, the National Initiative for Children’s Healthcare Quality (WISCH—Working to Improve Sickle Cell Healthcare) to develop this transition curriculum.

The curriculum was initiated as a result of numerous discussions among grantees concerning the dearth of guidelines available for practitioners, parents, and patients, for transition of adolescents with sickle cell disease (SCD) from pediatric to adult care. A transition affinity group was formed consisting of representatives from the TDP and NBS grantees, and WISCH representatives. The group held monthly conference calls and created a transition curriculum with input from all team members. The draft was disseminated to the TDP and NBS grantees for input, and once feedback was received, the curriculum was formatted and finalized.

The Sickle Cell Disease Transition Curriculum (SCDTC) is a reference for healthcare practitioners, patients, and parents to provide useful, practical, and meaningful guidelines to assist with the transition of adolescents with SCD from pediatric to adult medical care. It is divided into age groups; 12-14 year olds; 15-17 year olds; and 18-25 year olds. Each age group consists of three domains: Medical, Social, and Academic. Each domain includes guidelines for medical topics, methodology, and techniques to measure efficacy. The curriculum is meant as a guideline only and should be customized to each center and each individual patient.
## Medical Topics

- Introduction of transition policy
- Pain triggers/types
- Disease modifying treatment options
- Fever management
- Hydration
- Meaning of laboratory values
- Good nutrition habits
- Disease complications: priapism, gallstones, AVN, retinopathy cardiovascular, pulmonary, delayed puberty
- Medical visit process/How to schedule visit, where to go, etc.
- Risk of illicit drug, smoking and alcohol use
- Importance of physical activity
- Knowledge of own genotype and pattern of disease inheritance

## Methodology

- **Universal methods for all topics:** provide literature and discuss topics in clinic or at educational forums, on-line modules.
  (Additional methodologies per topic below)

- **Transition:** use positive language and different teaching methods (video, PowerPoint slides, role playing)

- **Pain:** develop individualized pain plan or diary and give copy to patient

- **Hydration:** provide water bottle

- **Labs:** provide copy of lab results with explanation; graph labs over multiple visits

- **Nutrition:** use growth chart; discuss *MyPlate*

- **Physical activity:** older patient shares experience; provide community resources, i.e., YMCA

## Measuring Efficacy

- **Pre/post tests:** for measurement of immediate- and long-term retention

- **Self assessment:** ask about knowledge in a particular area; keep ongoing graph of self-perception to see change

- **Project completion:** e.g., fill out pain dairies, pill box, demonstrate how to call for appointments

- **Surveys:** e.g., satisfaction and confidence with own self care

- **Role play:** simulate an event and have the patient participate, e.g., “You have chest pain. What would you do?”

*Universal assessment methods for all social topics*
## Social Domain 12–14 yrs

### Social Topics
- Sexuality and pregnancy
- Sharing diagnosis with friends
- Self-advocacy
- Peer influence

### Methodology
- **Universal methods for all topics**: suggestions for additional methodology in bold
- **Provide literature**
- **Discuss topics in clinic**
- **Peer support groups**
- **Use of technology**: video, Internet, self-tutorials
- **Refer to community based organizations**
- **Sexuality**: offer condoms and provide resources for more information

### Measuring Efficacy
- **Pre/post tests**: for measurement of immediate- and long-term retention
- **Return demonstration**: role play
- **Mock event**: simulation, e.g., simulate a situation in which the patient has to express the need to receive pain treatment
- **Project completion**: i.e., complete own health record, listing prior complications and medications in use

*Universal assessment methods for all social topics*
### Academic Domain 12-14 yrs

<table>
<thead>
<tr>
<th><strong>Academic</strong></th>
<th><strong>Methodology</strong></th>
<th><strong>Measuring Efficacy</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Short- and long-term</td>
<td><strong>Universal methods for all topics:</strong> provide literature/discuss topics in clinic/use of technology</td>
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</tr>
<tr>
<td>goals</td>
<td>(Additional methodologies per topic below)</td>
<td><strong>Project completion:</strong> e.g., complete mock resume</td>
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<tr>
<td></td>
<td><strong>Career interest:</strong> offer some form of interest inventory</td>
<td><strong>School attendance</strong></td>
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<tr>
<td>Assess job/career</td>
<td><strong>Jobs/vocational rehab:</strong> research available community resources, i.e., school counselor</td>
<td><strong>Enrollment in 504/Individualized Educational Plan (IEP)</strong></td>
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<tr>
<td>interest</td>
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<td><strong>Tracking of school performance</strong></td>
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<tr>
<td>Evaluate for possible</td>
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<tr>
<td>vocational careers</td>
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</tbody>
</table>
### Medical Topics

- Knowledge of own genotype and pattern of disease inheritance
- Current medications
- Disease complications; i.e., AVN, gallstones, priapism, retinopathy, stroke, nephropathy, delayed puberty, acute chest syndrome
- Knowledge about transfusion
- Pain triggers/treatment
- Fever management
- Nutrition and hydration
- Meaning of own laboratory values
- Importance of exercise/sports
- Immunizations: influenza, meningococcus, pneumococcus
- Risk of illicit drugs/alcohol/smoking
- Compliance strategies

### Methodology

- **Universal methods for all topics:** provide literature and discuss topics in clinic, on-line modules, educational forums
  
  (Additional methodologies per topic below)

- **Option:** offer private visits with parents out of the room

- **Pain:** develop individualized pain plan or diary

- **Hydration:** provide water bottle

- **Labs:** provide copy of lab results with explanation; graph labs over multiple visits/show slides

- **Nutrition:** growth chart; discuss *MyPlate*

- **Exercise:** have patient keep an exercise log

### Measuring Efficacy

- **Pre/post tests:** for measurement of immediate- and long-term retention

- **Return demonstration/teach back method**

- **Self assessment:** ask the consumer about knowledge in a particular area; keep ongoing graph of self-perception to see change; provide summary of results at graduation (for positive enforcement of progress)

- **Project completion:** i.e., completion of exercise log

- **Interactive results:** i.e., Punnet Square worksheet

*Universal assessment methods for all social topics*
### Social Topics

- **Advance directives/living wills/ durable power of attorney** (at 17 yrs)
- **Insurance coverage/social work appointment**
- **Available government benefits**
- **Sexuality/high risk pregnancy**
- **Options for adult care for care in community**
- **Medical system navigation**
- **Stress reduction/anxiety and depression symptoms and how to seek help**
- **Identification of support networks**

### Methodology

- **Universal methods for all topics; suggestions for additional methodology in bold**
- **Provide literature**
- **Discuss topics in clinic**
- **Peer support groups**
- **Conversations between younger and older consumers with sickle cell disease**
- **Education on differences between adult/pediatric offices**
- **Use of technology: video, Internet, self-tutorials**
- **Refer to local Sickle Cell Disease Foundation office and community-based organizations**

### Measuring Efficacy

- **Pre/post tests: for measurement of immediate- and long-term retention**
- **Return demonstration**
- **Mock event: simulation**
- **Project completion: i.e., complete health record**

*Universal assessment methods for all social topics*
<table>
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<th><strong>Academic</strong></th>
<th><strong>Methodology</strong></th>
<th><strong>Measuring Efficacy</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Short- and long-term goals</td>
<td><strong>Universal methods for all topics</strong>: provide literature/discuss topics in clinic/use of technology (Additional methodologies per topic below)</td>
<td><strong>Project completion</strong>: i.e., college application, preparation of resume</td>
</tr>
<tr>
<td>Job/career interest</td>
<td><strong>Planning</strong>: Review goals to ensure educational track matches goals</td>
<td><strong>Self-assessment</strong>: i.e., can verbalize requirements for educational/vocational track</td>
</tr>
<tr>
<td>Vocational careers</td>
<td><strong>Goals</strong>: career worksheet review</td>
<td>Takes SAT/ACT (college admissions test)</td>
</tr>
<tr>
<td>College admission/prep</td>
<td><strong>Jobs/vocational rehab</strong>: refer to outside resources; i.e., vocational counselor</td>
<td>Demonstrates knowledge of status of 504/IEP/obtains copy</td>
</tr>
<tr>
<td></td>
<td></td>
<td><em>Universal assessment methods for all social topics</em></td>
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</tbody>
</table>
## Medical Topics

<table>
<thead>
<tr>
<th>Topic</th>
<th>Methodology</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowledge of genotype; genetic counseling</td>
<td><strong>Universal methods for all topics:</strong> provide literature and discuss topics in clinic, on-line modules, educational forums (Additional methodologies per topic below)</td>
</tr>
<tr>
<td>List of medications</td>
<td><strong>Medications:</strong> discuss dose, name, purpose of current meds; explain hydroxyurea if not a current medication</td>
</tr>
<tr>
<td>Disease complications: Gallstones, leg ulcers, priapism, AVN, nephropathy, pulmonary and cardiovascular complication, pregnancy</td>
<td><strong>Pain:</strong> review pain triggers/stress management/relaxation techniques</td>
</tr>
<tr>
<td>Transfusion indication and risks</td>
<td><strong>Hydration/nutrition:</strong> demonstrate visually (with cups/water bottle) how much daily fluids are required</td>
</tr>
<tr>
<td>Pain triggers/treatment</td>
<td><strong>Labs:</strong> provide copy of lab results with explanation</td>
</tr>
<tr>
<td>Fever management</td>
<td><strong>Complications:</strong> Discuss major complication individualized for consumer history, refer as required for disease complications</td>
</tr>
<tr>
<td>Nutrition/hydration/exercise</td>
<td><strong>Genotype/pregnancy:</strong> Discuss SCD inheritance individualized to consumer and need for high risk OB-GYN for female patient</td>
</tr>
<tr>
<td>Meaning of own laboratory values</td>
<td><em>Universal assessment methods for all social topics</em></td>
</tr>
<tr>
<td>Immunizations: Influenza, meningococcus, pneumococcus</td>
<td><strong>Pre/post tests:</strong> for measurement of immediate- and long-term retention</td>
</tr>
<tr>
<td>Risk of illicit drugs/alcohol/smoking</td>
<td><strong>Self assessment:</strong> ask the consumer about knowledge in a particular area; i.e., average Hg level; major disease complications</td>
</tr>
<tr>
<td>Compliance strategies</td>
<td><strong>Demonstration/teach back</strong></td>
</tr>
<tr>
<td></td>
<td><strong>Project completion:</strong> i.e., completion of pain diary and coping mechanisms</td>
</tr>
<tr>
<td></td>
<td><strong>Interactive results:</strong> i.e., SCD inheritance risk worksheet</td>
</tr>
</tbody>
</table>
### Social Topics

- Advance directives/living wills/ durable power of attorney
- Insurance coverage
- Support networks/family counseling
- Government benefits/FMLA
- Sexuality/high risk pregnancy
- Options for adult care in the community
- Coping skills/conflict resolution
- Medical system navigation
- Stress reduction/anxiety depression

### Methodology

- **Universal methods for all topics;** suggestions for additional methodology in bold
  - Provide literature
  - Discuss topics in clinic
  - Community support groups
  - Patient navigators
  - Use of technology: video, Internet, self-tutorials
  - Refer to Sickle Cell Disease Foundation and community-based organizations
  - **Sexuality:** Offer condoms and provide resources for more information

### Measuring Efficacy

- **Pre/post tests:** for measurement of immediate- and long-term retention
  - **Role Play:** i.e., demonstrate how you would make an appointment with the adult provider
  - **Mock event:** simulation
  - **Project completion:** i.e., medication diary

*Universal assessment methods for all social topics*
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<td>Short- and long-term goals</td>
<td><strong>Universal methods for all topics</strong>: provide literature/discuss topics in clinic/use of technology (Additional methodologies per topic below)</td>
<td>Meets with a career counselor</td>
</tr>
<tr>
<td>Job/career interest</td>
<td><strong>Planning</strong>: review goals to ensure educational track matches goals</td>
<td><strong>Project completion</strong>: e.g., applies for college.</td>
</tr>
<tr>
<td>Vocational careers</td>
<td><strong>Goals</strong>: review career interests</td>
<td><strong>Self-assessment</strong>: i.e., can verbalize requirements for college/career track</td>
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<tr>
<td>College admission/prep</td>
<td><strong>Jobs/vocational rehab</strong>: refer to outside resources; i.e., vocational counselor</td>
<td><strong>Applying or in college/job</strong></td>
</tr>
<tr>
<td></td>
<td></td>
<td><strong>Know status of 504/IEP/obtains copy</strong></td>
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