

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

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Introduction

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.

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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?"

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

Conversations between younger and older consumers with sickle cell disease

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

Academic Domain 12-14 yrs

Academic

Short- and long-term goals

Assess job/career interest

Evaluate for possible vocational careers

Methodology

Universal methods for all

topics; provide literature/discuss topics in clinic/use of technology (Additional methodologies per topic below)

Career interest: offer some form of interest inventory

Jobs/vocational rehab:

research available community resources, i.e., school counselor

Measuring Efficacy

Project completion:

e.g., complete mock resume

School attendance

Enrollment in 504/Individualized Educational Plan (IEP)

Tracking of school performance

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

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

Sexuality: Offer condoms and provide resources for more information

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

Academic Domain 15-17 yrs

Academic

Short- and long-term goals

Job/career interest

Vocational careers

College admission/prep

Methodology

Universal methods for all

topics; provide literature/discuss topics in clinic/use of technology (Additional methodologies per topic below)

Planning: Review goals to ensure educational track matches goals

Goals: career worksheet review

Jobs/vocational rehab: refer to outside resources; i.e., vocational counselor

Meets with a vocational/ educational counselor

Measuring Efficacy

Project completion: i.e., college application, preparation of resume

Self-assessment: i.e., can verbalize requirements for educational/vocational track

Takes SAT/ACT (college admissions test)

Demonstrates knowledge of status of 504/IEP/obtains copy

Medical Topics

Knowledge of genotype; genetic counseling

List of medications

Disease complications:
Gallstones, leg ulcers, priapism,
AVN, nephropathy, pulmonary
and cardiovascular complication,
pregnancy

Transfusion indication and risks

Pain triggers/treatment

Fever management

Nutrition/hydration/exercise

Meaning of own laboratory values

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)

Medications: discuss dose, name, purpose of current meds; explain hydroxyurea if not a current medication

Pain: review pain triggers/ stress management/relaxation techniques

Hydration/nutrition:

demonstrate visually (with cups/ water bottle) how much daily fluids are required

Labs: provide copy of lab results with explanation

Complications: Discuss major complication individualized for consumer history, refer as required for disease complications

Genotype/pregnancy: Discuss SCD inheritance individualized to consumer and need for high risk OB-GYN for female patient

Measuring Efficacy

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

Self assessment: ask the consumer about knowledge in a particular area; i.e., average Hg level; major disease complications

Demonstration/teach back

Project completion: i.e., completion of pain diary and coping mechanisms

Interactive results: i.e., SCD inheritance risk worksheet

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 communitybased 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

Academic Domain 18-25 yrs

Academic

Short- and long-term goals

Job/career interest

Vocational careers

College admission/prep

Methodology

Universal methods for all

topics; provide literature/discuss topics in clinic/use of technology (Additional methodologies per topic below)

Planning: review goals to ensure educational track matches goals

Goals: review career interests

Jobs/vocational rehab: refer to outside resources; i.e., vocational counselor

Measuring Efficacy

Meets with a career counselor

Project completion: e.g., applies for college.

Self-assessment: i.e., can verbalize requirements for college/career track

Applying or in college/job

Know status of 504/IEP/ obtains copy

