Empoderamiento del paciente con Enfermedad de Células Falciformes

CON EL AVAL DE:

Sociedad Española de Hematología y Hemoterapia

SEHOP
SOCIEDAD ESPAÑOLA DE HEMATOLOGÍA Y ONCOLOGÍA PEDIÁTRICAS

Grupo Español de ERITROPATOLOGÍA

ASAFE

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Programa de formación acreditado

Empoderamiento del paciente con Enfermedad de Células Falciformes

MÓDULO 1

Viaje del paciente con ECF

TRANSICIÓN DE PACIENTES

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TRANSICIÓN DE PACIENTES

1. **Concepto y aspectos generales.**
2. **Transición en la ECF. Recomendaciones y guías.**
3. **Puntos clave en nuestro entorno.**

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Transición

Proceso determinado de transferencia planeada de adolescentes y adultos jóvenes desde un centro pediátrico a un sistema sanitario de adultos.

Idealmente: proceso estructurado y sistemático incluido en programas de transición.

Existe un aumento en la morbimortalidad en la etapa de los años de transición.

Una correcta transición se correlaciona con una mejor evolución de la ECF, menos días de hospitalización y menos costes sanitarios.

Transición

- **Capacitación** en habilidades: dirigida desde el Sistema de salud y continuada en la familia.
- Transferencia de conocimientos a través de la **promoción de la salud**.
- Adquisición de la **autoeficacia** de forma centrada en el paciente.
- **Coordinación** de la transición en los profesionales sanitarios.
- **Vinculación a los servicios de adultos.**
- **Evaluación de la preparación** para la transferencia de la atención.
  Evaluación del éxito de la transición.

Transición

- Edad: diferente en distintos países (12-18-21 años).
- Estructura de sistema sanitario.
- Financiación de sistemas sanitarios de adultos.
- Países de alta, media y baja capacidad económica.
- Programas estructurados/guías/recomendaciones.

Promoción de la salud en la adolescencia

Estándares globales y criterios de medida de los mismos:

- Educación en salud de los adolescentes.
- Soporte comunitario.
- Paquete de servicios adecuado.
- Competencias de los proveedores.
- Características de las instalaciones.
- Equidad y no discriminación.
- Mejora de calidad y análisis de datos.
- Participación de los adolescentes.

Nair M, Baltag V, Bose K, Boschi-Pinto C, Lambrechts T, Mathai M.J Improving the quality of health care services for adolescents globally: a standards-driven approach. Adolesc Health. 2015; 57(3): 288-98; Inusa BPD, Stewart CE, Mathurin-Charles S, Porter J, Hsu LL, Atoyebi W, De Montalembert M, Diaku-Akinwumi I, Akinola NO, Andemariam B, Abboud MR, Treadwell M. Paediatric to adult transition care for patients with sickle cell disease: a global perspective. Lancet Haematol. 2020; 7(4): e329-e341.

Global standards for quality health-care services for adolescents

Standard 1: Adolescents' health literacy
The health facility implements systems to ensure that adolescents are knowledgeable about their own health, and they know where and when to obtain health services.

Standard 2: Community support
The health facility implements systems to ensure that parents, guardians, and other community members and community organisations recognise the value of providing health-care services to adolescents, and support the provisions and use of services by adolescents.

Standard 3: Appropriate package of services
The health facility provides a package of information, counselling, diagnostic, treatment, and care services that fulfils the needs of all adolescents. Services are provided in the facility and through referral linkages and outreach.[1]

Standard 4: Providers' competencies
Health-care providers have the technical competence required to provide effective care services to adolescents. Both health-care providers and support staff respect, protect, and fulfil adolescents' rights to information, privacy, confidentiality, non-discrimination, non-judgemental attitude, and respect.

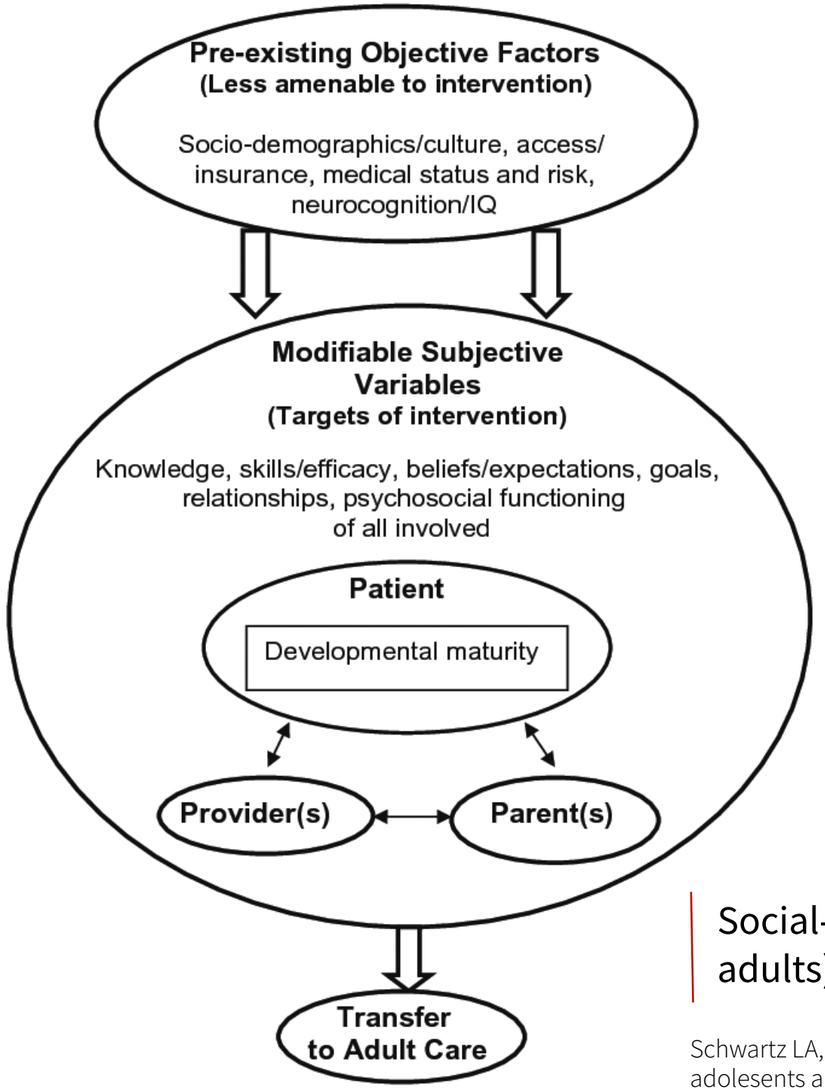
Standard 5: Facility characteristics
The health facility has convenient operating hours, a welcoming and clean environment, and maintains privacy and confidentiality. It has the equipment, medicines, supplies, and technology needed to ensure effective service provision to adolescents.

Standard 6: Equity and non-discrimination
The health-care facility provides quality services to all adolescents irrespective of their ability to pay, age, sex, marital status, education level, ethnic origin, sexual orientation, or other characteristics.

Standard 7: Data and quality improvement
The health facility collects, analyses and uses data on service use and quality of care, disaggregated by age and sex, to support quality improvement. Health facility staff are supported to participate in continuous quality improvement.

Standard 8: Adolescents' participation
Adolescents are involved in the planning, monitoring, and evaluation of health services and in decisions regarding their care and certain appropriate aspects of service provision.

Transición en trastornos crónicos



ESPECIAL ATENCIÓN EN ECF A:

- Manejo del dolor.
- Estigmatización.
- Raza.
- Madurez en el desarrollo.

Social-ecological model of AYA (adolescents and young adults) readiness for transition.

Schwartz LA, Tuchman LK, Hobbie WL, Ginsberg JP. A social-ecological molel of readnesss for transition to adult-oriented care for adolesents and Young adults with chronic health conditions. Child Care Health Dev. 2011; 37(6): 883-95.

TRANSICIÓN DE PACIENTES

1. Concepto y aspectos generales.
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Transferencia de habilidades. Aumento de autoeficiencia. Coordinación. Transferencia de conocimiento. Vinculación a los servicios de adultos. Evaluación de la preparación.

The SICKLE recommendations

Skills transfer

Patients should be empowered from an early age to manage their own condition by teaching them the necessary skills as soon as developmentally appropriate, including how to self-manage symptoms, such as pain; how to recognise when professional advice is required; and how to book their own health-care appointments.

Increasing self-efficacy

Every young person's voice should be at the centre of their health-care plan and their beliefs, goals and motivations should be discussed at each encounter to ensure they are active partners in managing their care. Parents and caregivers are important support systems for young people with sickle cell disease. Their knowledge and anxieties about the care transition process should be addressed so they can optimally support the young person's development of self-efficacy.

Coordination of transition

Every young person transitioning from paediatric to adult care should be supported by a named community health worker or nurse navigator who is appropriately trained in providing guidance on disease knowledge, self-management skills, medication adherence, and health-care system navigation. Paediatric and adult providers must maintain communication to ensure optimal transfer of care.

In low-income and middle-income countries, community health extension workers, clinical medical officers, and village council mobilisers should be trained and retrained specifically to implement and aid transition by offering continuous education, working with patients and their families to achieve self-efficacy and organise the various linkages to specialist care and transfer of sickle cell care to adult services. They already assist in education of patients living with other chronic diseases and are best suited to also reduce loss to follow up.

Knowledge transfer

All patients should have a good understanding of sickle cell disease, including its cause, signs and symptoms, potential complications, management, risks of non-adherence to medication (hydroxyurea and penicillin), and prognosis before transfer of care.
We recommend that multidisciplinary (including young people with sickle cell disease and their families) task forces develop a curriculum and handbook for the transition from paediatric to adult care.

Linking to adult services

All young people should know when their care will be transferred and who the adult provider is or could be, and they should ideally have either a joint first consultation or a period of overlap whereby their first consultation with their adult care provider occurs before their last paediatric appointment. They should also be introduced to other services that they would need to access in the course of their adult care.

We recommend a mapping of all facilities offering specialist sickle cell care in lower-middle income countries for easy referral and identification of the nearest adult centred service for patients in care at paediatrics only centres.

Joint paediatric and adult care clinics should be established where available resources permit. A minimum requirement is to offer such a clinic before care transfer, which might be as early as 12 years for adolescents who transfered at younger ages to adult oriented care, as done in the Middle East and countries in sub-Saharan Africa. Such an initiative is best driven by nurses and trained community health extension workers, engaging both paediatric and adult haematologists in multidisciplinary care.

Evaluating readiness

Before transfer of care, transition readiness should be assessed to ensure every young person is developmentally ready to assume complete responsibility for their healthcare and adequately prepared for doing so. Tracking the progress of the young adult for several years will enhance evaluation of the success of adolescent transition programme.

Inusa BPD, Stewart CE, Mathurin-Charles S, Porter J, Hsu LL, Atoyebi W, De Montalembert M, Diaku-Akinwumi I, Akinola NO, Andemariam B, Abboud MR, Treadwell M. Paediatric to adult transition care for patients with sickle cell disease: a global perespective. Lancet Haematol. 2020; 7(4): e329-e341.

Six Core Elements of Health Care Transition

- Política de transición.
- Seguimiento y monitorización de la transición.
- Evaluación de la preparación de la transición/autocuidado.
- Planificación de la transición.
- Transferencia de cuidados/visita inicial adultos.
- Conclusión de la transición y seguimiento de cuidados en centro de adultos.

American Academy of Pediatrics; American Academy of Family Physicians; American College of Physicians; Transitions Clinical Report Authoring Group; Cooley WC, Sagerman PJ. Supporting the health care transition from adolescence to adulthood in the medical home. Pediatrics. 2011; 128(1):182-200.

Programa de transición en la ECF

Health care transition interventions for SCD according to the Six Core Elements of Health Care Transition - Six Core Elements of Health Care Transition with intervention description

1. Transition policy (informs youth of timing and upcoming process for transition)

2. Tracking and monitoring transition progress

3. Transition readiness/self-care assessment

- Non–disease-specific instruments
  - Successful Transition to Adulthood with Therapeutics (STARx; parent and child forms)
  - Adolescent autonomy checklist
  - Newest vital sign37 (measures health literacy)
  - Transition Readiness Assessment Questionnaire (TRAQ)
- Disease-specific instruments
  - Disease knowledge and self-management (adapted to SCD from the National Hemophilia Foundation Transition guidelines)
  - Transition Intervention Program (TIP)–Readiness for Transition (TIP-RFT)
  - Self-administered Sickle Cell Transition Intervention Program skills checklists
  - American Society of Hematology (ASH) transition toolkit*

4. Transition planning (develop individualized transition plans, prepare individual, identify provider)

- Problem-solving education (cognitive-behavioral intervention that teaches problem-solving skills as a way to cope with life stressors): acceptability demonstrated through focus groups
- Skill-based educational handout (educational handouts provided in clinic and informed by items flagged in the readiness assessment as “needs practice”)
- Music therapy (music therapy–based intervention to increase disease knowledge, self-efficacy, clinic attendance, and reduce ED visits): disease knowledge improved, and patients reported satisfaction with intervention
- Education in clinic using hand-held device (general disease education, healthy living, general career and vocation guidance): found to improve disease knowledge
- SCD-Plane (individualized transition plan informed by neuropsychological testing): used to inform academic planning and local services
- SCD-specific web-based portal (designed to improve communication with providers, improve decision-making, facilitate access to laboratory results and scheduling): shown to be feasible, acceptable, and improve patient-provider communication, but not decision-making
- iManage, a prototype app designed to promote self-management skills: rated as feasible and beneficial by SCD users
- Chronic Disease Self-Management Program (a 6-week group-based intervention led by lay leaders with a chronic health condition): increased selfefficacy, but not disease-specific self-efficacy
- Education about sickle cell heredity (in-clinic sessions by a health educator): feasibility and increased knowledge demonstrated
- Personal health record education (tool used to increase knowledge of personal medical history given in clinic by social workers): shown to be feasible and able to identify areas of gap in medical history knowledge

5. Transfer of care/initial adult provider visit (schedule of first adult visit, transfer of medical records, care for patient until first adult visit completed, confirm adult visit completed)

- Visit of adult provider facilities prior to leaving pediatric care: shown to increase rate of fulfillment of first visit with adult provider
- Transition sickle cell clinic with early introduction to adult provider: lower levels of negative affect (fear and sadness) and higher levels of positive affect (serenity and joviality) among youth who participated in the transition clinic compared with adults who did not

6. Transition completion/ongoing care/consumer feedback

- Young adult perspectives of the most important topics to include in transition programming: help in selecting adult provider, seeking emergency care, medication knowledge and medication adherence support, disease education, and being aware of the impact of health behaviors on one’s health

*American Society of Hematology pediatric to adult hematologic care transition (https://www.hematology.org/clinicians/priorities/5573.aspx).

Saulsberry AC, Porter JS, Hankins JS. A program of transition to adult care for sickle cell disease. Hematology Am Soc Hematol Educ Program. 2019; (1): 496-504.

American Society of Hematology

Sickle Cell Disease Transition Readiness Assessment Template

Please fill out this form to help us see what you already know about your health and how to use health care and the areas that you want to learn more about. If you need help completing this form, please ask your parent/caregiver.

Date: Name: Date of Birth:

Transition and Self-Care Importance and Confidence *On a scale of 0 to 10, please circle the number that best describes how you feel now*

How important is it to you to manage your own health care?

0 (not)	1	2	3	4	5	6	7	8	9	10 (very)

How confident do you feel about your ability to manage your own health care?

0 (not)	1	2	3	4	5	6	7	8	9	10 (very)

How confident do you feel about preparing for/changing to an adult doctor before the age of 22? Not Applicable ☐

0 (not)	1	2	3	4	5	6	7	8	9	10 (very)

My Health *Please check the box that applies to you right now.*	No, I do not know	No, but I am learning to do this	Yes, I have started doing this	Yes, I always do this when I need to
Disease Knowledge				
I know what type of sickle cell disease I have.				
I know my medical needs and can explain them to someone.				
I know what a hematologist is and why I go to one.				
I know what to do in case of a medical emergency.				
I understand what causes a pain episode.				
I understand how drugs, alcohol and tobacco affect sickle cell disease.				
I have friends that I can talk to about sickle cell disease.				
I know about necessary screening exams (echo annually, kidney function annually, retinal exams, etc.).				
I know how to get blood work and x-rays.				
Medication Management				
I know what my medications are for.				
I know the names and doses of my medications.				
I remember to take my medications without my parent reminding me.				
I fill prescriptions before I run out of medications.				
I am aware of what hydroxyurea is and how it prevents sickling of my red blood cells.				
I know how to prevent a pain episode and what to do if I have pain.				
Appointments				
I make my own doctors' appointments.				
I know how to get medical care when the doctor's office is closed.				
I fill out my own medical history form				
I keep track of my own medical information.				
I keep track of my doctors' and other appointments.				
I make a list of questions before my visit with my doctors.				
I answer questions on my own during medical visits.				
I arrange my own transportation to medical appointments.				
Insurance				
I carry my own insurance card.				
I understand my insurance plan.				
Privacy Information				
I understand how health care privacy changes at age 18, when I am legally an adult.				

https://www.hematology.org/education/clinicians/clinical-priorities/pediatric-to-adult-care-transition

American Society of Hematology

Sickle Cell Disease Clinical Summary

Contact Information and Demographics	
Name:	**Nickname:**
DOB:	Preferred Language:
Address:	
Cell #: Home #:	Best Time to Reach:
E-Mail:	Best Way to Reach: ☐ Text ☐ Phone ☐ Email
Health Insurance/Plan:	Group and ID #:

Health Care Providers (clinical and emergency information)				
Specialty	Name	Clinic or Hospital	Phone # (daytime clinic # and after hours paging #)	Fax or E-mail Address
Hematologist				
Primary Care				
Name and number of Medical Records Department:				
Allergy Information:				

Educational and Employment Information		
Educational Status / Current Grade Level		
Name of School	Contact Person:	Phone:
Special Accommodations (i.e. Individualized Education Program)		
Employment Status	☐Employed ☐Not Employed	
Name of Employer	Contact Person:	Phone:
Special Accommodations:		

Sickle Cell History	
Diagnosis: SS / SC / SBeta0thal / SBeta+thal / other	Notes:
Has HLA Typing Been Performed? ☐ YES ☐ NO	If yes, please specify type.

Baseline Values					
Baseline Vital Signs:	Ht	Wt	RR	HR	BP
Hemoglobin	g/dL				
Reticulocyte Count	%				
White Blood Cell Count	10^3/mm3				
Total bilirubin	mg/dL				
Oxygen Saturation	%				
Myelosuppression					

Sickle Cell Complications	
ACS: ☐YES ☐NO	Stroke: ☐ YES ☐ NO
Aplastic Crisis: ☐ YES ☐ NO	Abnormal TCD: ☐ YES ☐ NO
Dactylitis: ☐ YES ☐ NO	ICU admissions: ☐ YES ☐ NO
Retinopathy: ☐ YES ☐ NO	Pulmonary hypertension: ☐ YES ☐ NO
Splenic sequestration: ☐ YES ☐ NO	Asthma: ☐ YES ☐ NO
Priapism: ☐ YES ☐ NO	Bacteremia: ☐ YES ☐ NO
AVN: ☐ YES ☐ NO	Nephropathy: ☐ YES ☐ NO

Emergency Care Plan		
Emergency Contact:	Relationship:	Phone:
Preferred Emergency Care Location:		
Please request individual care plan for patient, if available.		
SC Genotype		
# ED visit for pain in past year		
# hospitalizations for pain in past year		
Pain Plan (i.e. suggested test, treatment, preferred opioid dosing, number of pain episodes per year, other considerations).		
Home Pain Plan:		
ED/inpatient pain plan:		
Preferred opioid:		
Dosing:		
PCA: ☐ YES ☐ NO		
Notes:		

Common Emergent Presenting Problems	Suggested Tests	Treatment Considerations
Fever		

Medications	Dose	Frequency
Hydroxyurea ☐ YES ☐NO If no reason:		

Prior Surgeries, Procedures, and Most Recent Hospitalizations • *Please give dates of most recent admissions for pain*	
Splenectomy: ☐YES ☐ NO	Date
Cholecystectomy: ☐ YES ☐ NO	Date
Port: ☐ YES ☐ NO	Date
Most recent pain admission:	Date
Most recent admission for ACS:	Date

Transfusion History (*Please specify chronic transfusion or chronic exchange*)	(Please note, known Fyantibodies, reaction, and need for pre-medication)

Health Maintenance	Date	Notes
☐ Cardiology/Echo		
☐ Pulmonary visit		
☐ Dilated eye exam		
☐ UA/urine Microalbumin		

Immunization Summary	Date	Notes
Pneumovax #1:		
Pneumovax #2:		
Last meningococcal vaccine:		
Last influenza vaccine:		

Relationships
If patient is in a relationship, has she/he been counseled re: SCT testing for partner? ☐ YES ☐ NO
Is partner's SCT status known? ☐ YES ☐ NO
Have the following items been offered (hemoglobinopathy test, correct interpretation, referral to genetic counseling)? ☐ YES ☐ NO

FEMALE	
Menstrual History	
Menses: Onset (Date):	
Menstrual pattern (i.e. regular, irregular, absent):	
Menstrual complications ☐ cramps / non-sickle pain ☐ sickle cell pain	
Contraception	
Current hormonal contraception use and type:	
Previous hormonal contraception use and type:	
Contraception complications: ☐ VTE Thrombosis ☐ Pulmonary Embolism ☐ Other:	
Pregnancy	
Previous pregnancy (list all) ☐ yes ____(date preg #1). _____(date preg #2) _____(date preg #3)	
Pregnancy outcomes (list all) ☐ Live birth ☐ miscarriage ☐ termination	Treatments in pregnancy: ☐None ☐Crizanlizumab ☐Chronic transfusion ☐L-Glutamine ☐transfusion on demand ☐Anticoagulation ☐Hydroxyurea ☐Other: ☐Voxelotor
Mode of delivery ☐ c-section ☐ Vaginal Delivery (NSVD)	Fetal/infant complications: ☐ IUGR ☐Low birth weight ☐prematurity ☐other:
Pregnancy complications (maternal): ☐ Hypertension/ Pre-eclampsia / eclampsia ☐ still birth ☐ Preterm delivery ☐ pain crisis ☐ VTE/PE ☐ other:	

MALE	
Pregnancy	
History of getting someone pregnant? ☐ YES ☐ NO	
Pregnancy outcome:	

Additional information (i.e. psychosocial issues, family, social background, etc.)

Special information that the patient wants health care professionals to know

Patient/Guardian Signature Print Name Phone Number Date

Primary Care Provider Signature Print Name Phone Number Date

Care Coordinator Signature Print Name Phone Number Date

Please attach the immunization record to this form.

https://www.hematology.org/education/clinicians/clinical-priorities/pediatric-to-adult-care-transition

Recomendaciones para la transición

SICKLE CELL DISEASE IN CHILDHOOD: STANDARDS AND RECOMMENDATIONS FOR CLINICAL CARE

- Disponibilidad de una **política de transición** en el centro hospitalario, con un profesional de referencia, para iniciar la preparación y desarrollo del plan a edad temprana.
- **Revisión detallada del conocimiento** por parte del paciente de su enfermedad y su tratamiento, entendimiento del manejo de ECF, autosuficiencia, preparación general y emocional para la transferencia a adultos y preocupaciones con respecto a la misma.
- **Instalaciones** para la transición o población adolescente donde se realice el encuentro con el equipo de adultos y se lleve a cabo el paso a sistema sanitario de adultos.
- **Protocolos de manejo de complicaciones** pediátricos y de adultos, similares en lo posible especialmente en cuanto al manejo de episodios de dolor.

https://www.sicklecellsociety.org/wp-content/uploads/2019/11/SCD-in-Childhood_Final-version-1.pdf

Implantación de la transición a adultos

EVALUACIÓN DE LA SITUACIÓN:

- Existencia de un equipo multidisciplinar que incluya médicos de especialidades implicadas pediátricas y de adulto, enfermeras, trabajadores sociales y psicólogos.

PREPARACIÓN:

- Protocolo de transición.

TRANSFERENCIA:

- Presentación del hematólogo de adulto al paciente por parte del pediatra (deseable en las instalaciones de pediatría).
- Dar a conocer al paciente las instalaciones del centro de adultos.
- Supervisión de cumplimiento de las citas (del hematólogo de adulto y de los especialistas encargados de la prevención de las complicaciones de la ECF).

Sociedad española de hematología y oncología pediátricas (SEHOP) Enfermedad de células falciformes. Guía de práctica clínica SEHOP 2019. ISBN: 978-84-944935-5-3. Disponible en: http:// www.sehop.org/wpcontent/uploads/2019/03/Gu%C3%ADa-SEHOP-Falciforme-2019.pdf; Sociedad Española de Hematología y Hemoterapia. Grupo de Eritropatología. Guía de enfermedad de células falciformes. 2021 ISBN: 978-84-09-34321-8

Aspectos generales en el momento de la transición a adultos

- Se requiere un conocimiento adecuado del desarrollo del paciente, de las características de su enfermedad y la valoración de los recursos terapéuticos de que se dispone.
- Valorar problemas de **salud integral**: dificultades adaptativas, alteraciones en la salud mental, escolares, consumo de tóxicos, enfermedades de transmisión sexual…
- **Acceso a los servicios** de atención sanitaria, fragmentación de la atención en subespecialidades cuya coordinación debe realizar el hematólogo.
- **La edad** cronológica no debiera ser el criterio único. Valorar si existe, por ejemplo, desarrollo neurocognitivo o presencia de un episodio grave.
- **Respeto a la autonomía** del adolescente. Por encima de los 14 años: presunción inicial de su capacidad para decidir. Entre 12 y 14 años: valorar individualmente.
- Entrevista clínica primero en solitario y posteriormente con el conjunto familiar. Si existen conflictos por diferentes pareceres entre el adolescente y los padres, solicitar asesoramiento del comité de ética del centro.

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Dificultades en la transición del adolescente

- Negación de la enfermedad.
- Aislamiento social ocasionado por consultas recurrentes u hospitalizaciones, así como restricciones paternas.
- Voluntad de igualarse con sus coetáneos.
- Inicio de la actividad sexual antes de estar emocionalmente preparados.
- Alteraciones en la apariencia física (potenciales) por condicionantes de su enfermedad: posible retraso en la pubertad, ictericia, palidez, secuelas motoras, limitación en la actividad física, cicatrices posquirúrgicas o catéteres…
- Absentismo escolar o laboral, con la consecuente repercusión en el aprendizaje, actividad física o vocación futura.
- Dinámica de ambivalencias, entre la demanda de independencia y la incapacidad de responsabilizarse de las citas y la medicación.
- Retraso en el desarrollo neurocognitivo o episodio grave.

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Propuesta de cuidados

- Flexibilidad en la edad de la transferencia a las unidades de adultos adaptada a las características del paciente.
- Plantear la transición antes de la pubertad, con una fecha conocida con antelación por el adolescente.
- Anticipación en la información a los 12 años para su internalización. Plantear como un hecho positivo.
- Educación sanitaria para la prevención y el control de los síntomas de la enfermedad. Asegurar el entendimiento por parte del propio adolescente de las medidas de control del dolor, agudo o crónico. Información de episodios severos o potencialmente mortales si es apropiado.
- Informar sobre grupos, asociaciones, redes sociales y paginas web fiables.
- Fomentar la autoestima e independencia de forma realista con las limitaciones.

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Propuesta de cuidados

- Informar de un posible retraso en la pubertad, enfermedades de transmisión sexual, embarazo, fertilidad, consejo genético, contracepción.
- Participación en las decisiones de tratamiento.
- Pactar límites en actividades de riesgo.
- Relaciones sociales y amistades.
- Integración en el programa escolar.
- Evaluar por trabajadores sociales aspectos de capacitación profesional, entorno laboral, vivienda, vecindario y sostén económico.
- Incluir a los padres en programas de afrontamiento y separación de su hijo. Indicarles un adecuado balance entre supervisión y sobreprotección. Expectativas académicas realistas de sus hijos.

Sociedad española de hematología y oncología pediátricas (SEHOP) Enfermedad de células falciformes. Guía de práctica clínica SEHOP 2019. ISBN: 978-84-944935-5-3. Disponible en: http:// www.sehop.org/wpcontent/uploads/2019/03/Gu%C3%ADa-SEHOP-Falciforme-2019.pdf; Sociedad Española de Hematología y Hemoterapia. Grupo de Eritropatología. Guía de enfermedad de células falciformes. 2021 ISBN: 978-84-09-34321-8

TRANSICIÓN DE PACIENTES

1. Concepto y aspectos generales.
2. Transición en la ECF. Recomendaciones y guías.
3. **Puntos clave en nuestro entorno.**

- Equipo **multidisciplinar** en ECF, con especialistas de referencia.
- Aspectos a **incorporar** en la transición:
  - Conocimiento de la enfermedad.
  - Autogestión.
  - Comunicación con los profesionales.

  Conocimiento de la enfermedad, de sus cuidados, de su medicación y de los efectos de no tomarla. Capacidad para adherirse al tratamiento y cómo y cuándo conseguirlo. Capacidad de acceso a información sobre la enfermedad. Implicación en realizar las citaciones. Preocupaciones sobre el paso al sistema de adultos.
- **Documentación** de la etapa: edad de inicio, profesional o equipo de referencia para el paciente. Aspectos a desarrollar y evaluar.
  - Informe/resumen clínico del paciente.
- **Evaluación** de correcta preparación para la transferencia al sistema de adultos y realización de los pasos para la misma a nivel de instalaciones.
  - Seguimiento y comprobación de su éxito.

Elaboración de esquemas desarrollados en transición a nivel local en centros sanitarios/nacional en sociedades médicas, centros de referencia, sociedades de pacientes y grupos de trabajo.