

REHABILITACIÓN EN PERSONAS CON HEMOFILIA

XIII jornadas
farmacéuticas

SOBRE EL TRATAMIENTO
DE LAS COAGULOPATÍAS
CONGÉNITAS

MADRID
28, 29 y 30 DE NOVIEMBRE. 2018



H. de la Corte Rodríguez MD, PhD
S. Medicina Física y Rehabilitación



Hospital Universitario La Paz

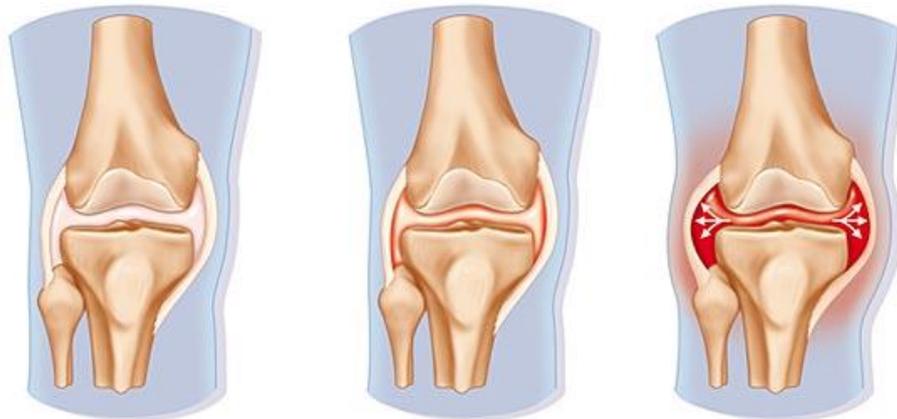
Hospital de Cantoblanco
Hospital Carlos III

 Comunidad de Madrid

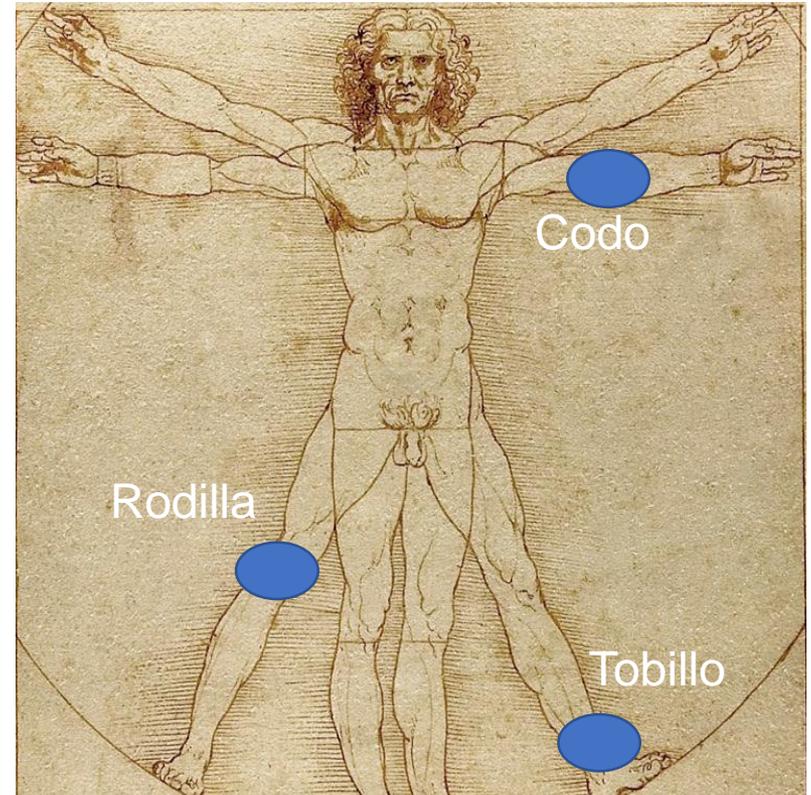
IdiPAZ
Instituto de Investigación
Hospital Universitario La Paz

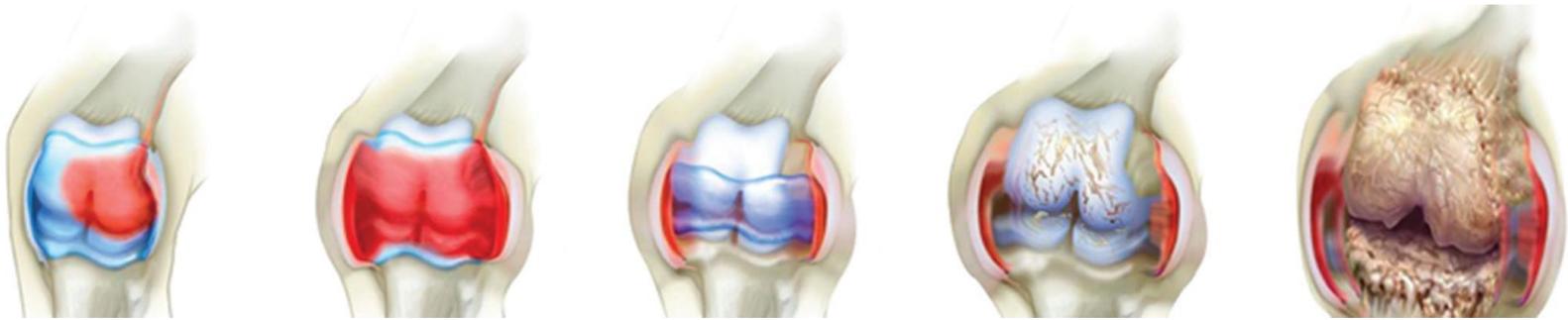
Hemartros

- El sangrado intra-articular procede de la membrana sinovial, originándose en el plexo subsinovial
- Suponen el 75-85% de todos los sangrados



- El 80% de los hemartros en pacientes con H grave ocurren en estas 3 articulaciones





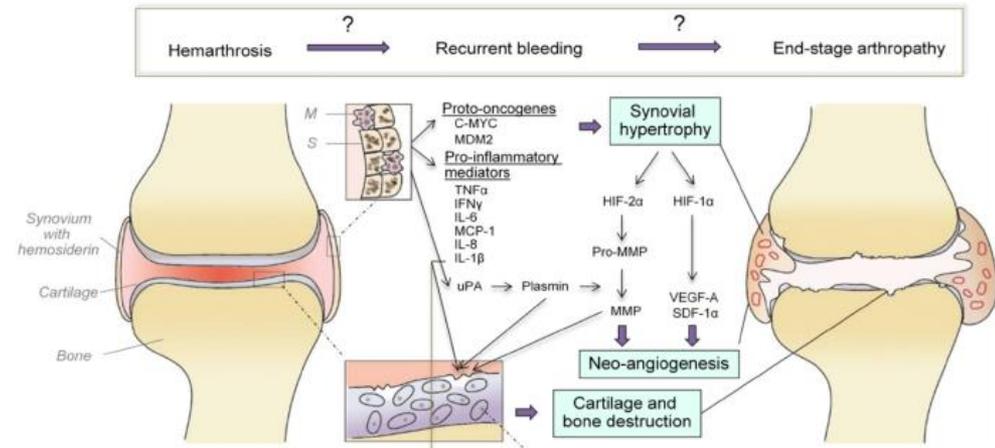
- La hemorragia recidivante sobre una misma articulación si no recibe el tratamiento adecuado hematológico y rehabilitador, dará lugar a la **artropatía hemofílica** y sus secuelas altamente invalidantes
- Principal causa de morbilidad y disminución de la **calidad de vida** de los pacientes con Hemofilia grave A o B

Artropatía hemofílica

- Es la consecuencia de la extravasación repetida de sangre en las cavidades articulares y se caracteriza por dos rasgos fundamentales:

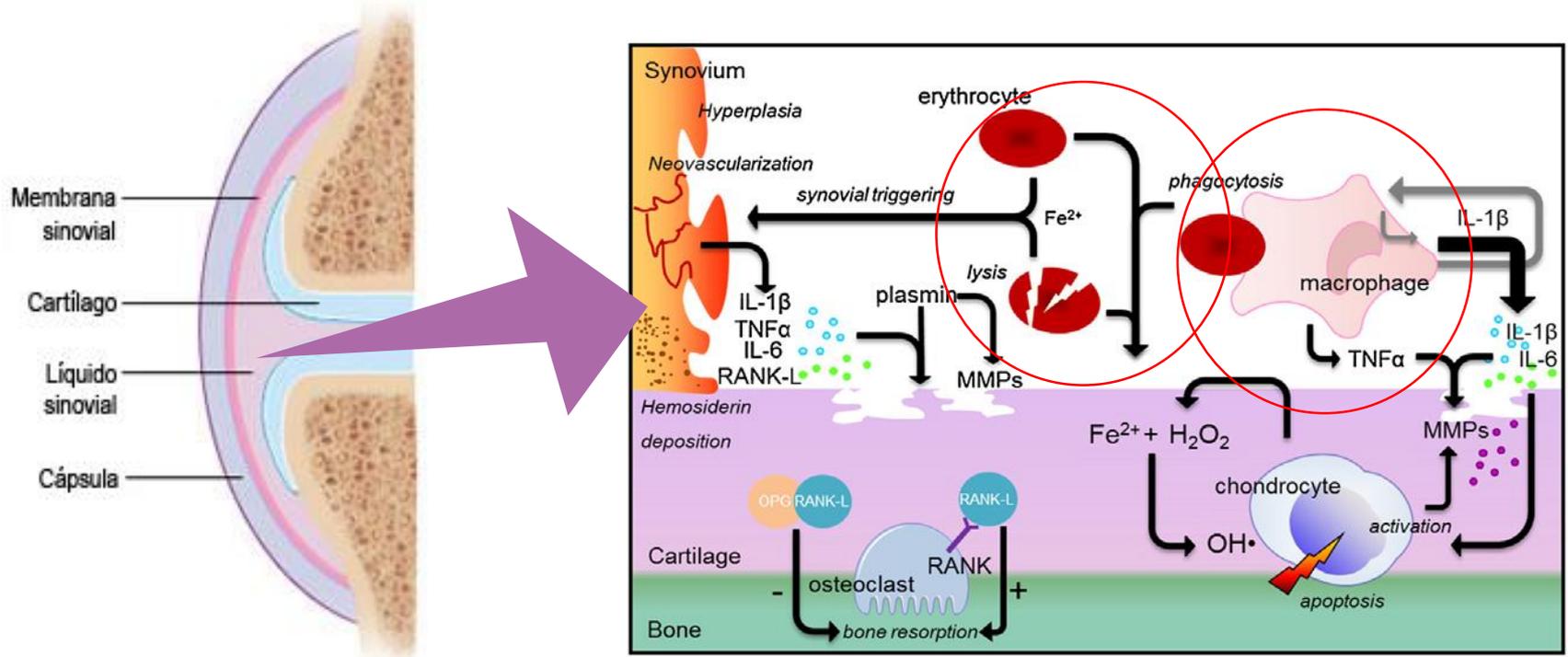
Sinovitis crónica (proliferativas)

Daño osteocondral (degenerativas)



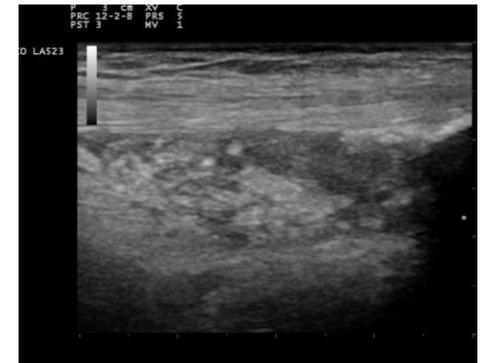
Procesos paralelos

Depósitos de hierro y proceso inflamatorio!!!



Manifestaciones músculo-esqueléticas

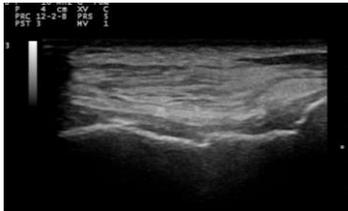
SINOVITIS



Roosendaal G. En: Rodríguez-Merchán EC, ed. Wiley-Blackwell, Oxford, 2003: 12-16.
Battistella LR. En: Sohail MT, Heijnen L, eds. Feroz Sons (PVT) Ltd, Lahore, 2001: 178-87.
Swanton MC. Lab Invest 1959; 8:1269-73.

Manifestaciones músculo-esqueléticas

ARTROPATÍA



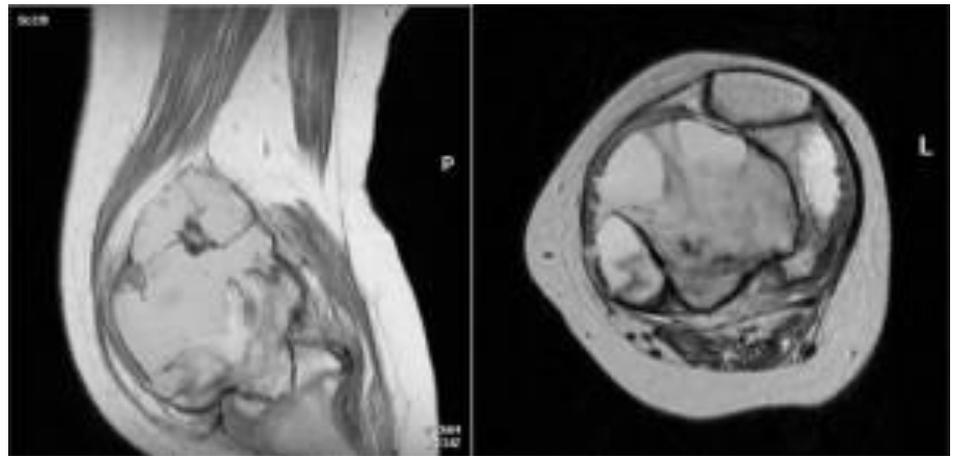
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Swanton MC. Lab Invest 1959; 8:1269-73.

Manifestaciones músculo-esqueléticas

QUISTES SUBCONDRALES

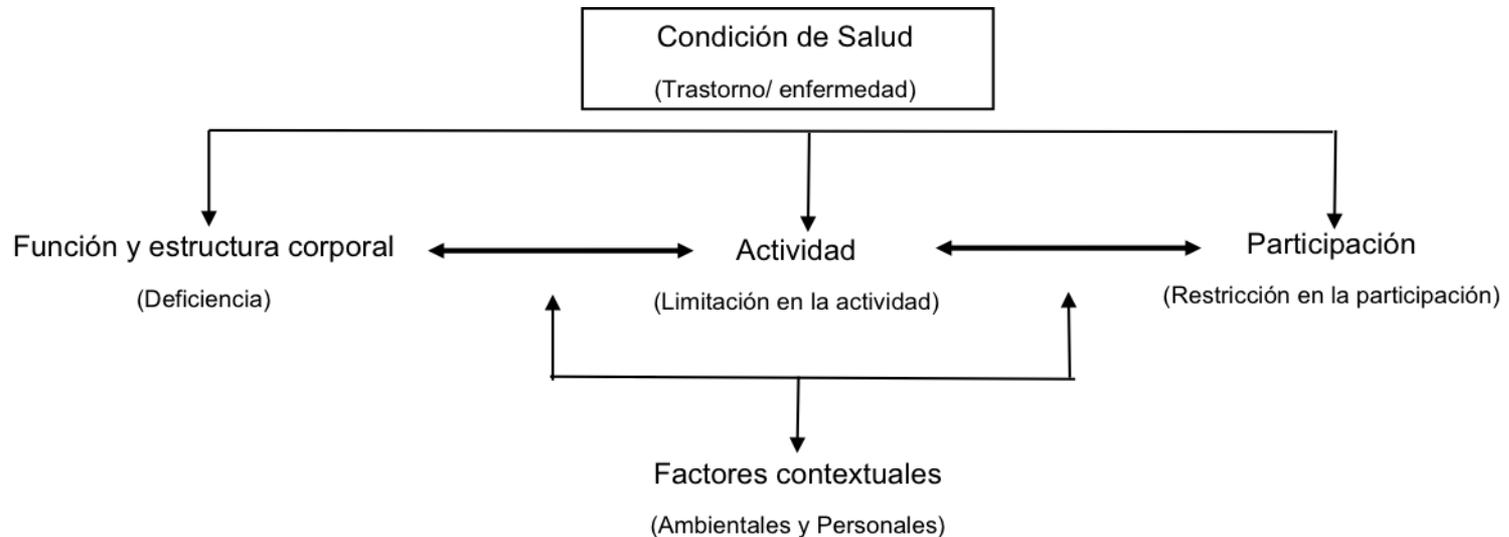


PSEUDOTUMORES
HEMOFÍLICOS



Modelo integral

- La introducción de la Clasificación Internacional del Funcionamiento (CIF) por la OMS (2001) ha permitido una mayor evaluación integral del estado de salud funcional. Este es el modelo actual para la descripción funcional el estado de salud de los pacientes.





REVIEW ARTICLE

Choosing outcome assessment tools in haemophilia care and research: a multidisciplinary perspective

K. FISCHER,* P. POONNOOSE,† A. L. DUNN,‡ P. BABYN,§ M. J. MANCO-JOHNSON,¶
J. A. DAVID,** J. VAN DER NET,†† B. FELDMAN,‡‡ K. BERGER,§§ M. CARCAO,¶¶
P. DE KLEIJN,*** M. SILVA,††† P. HILLIARD,‡‡‡ A. DORIA,§§§ A. SRIVASTAVA¶¶¶ and
V. BLANCHETTE¶¶ ON BEHALF OF THE PARTICIPANTS OF THE INTERNATIONAL
SYMPOSIUM ON OUTCOME MEASURES IN HEMOPHILIC ARTHROPATHY^a

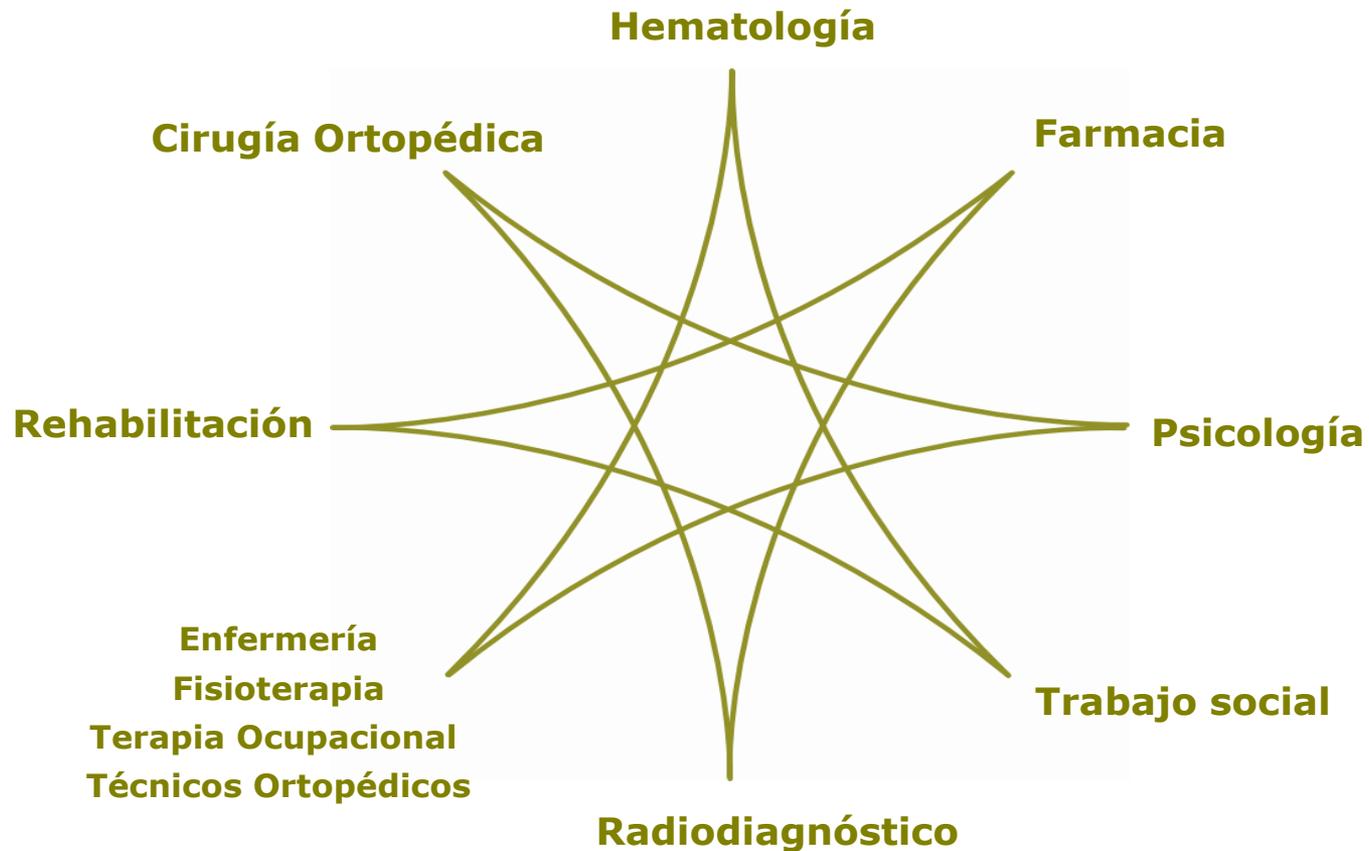
Table 5. Recommended and/or mandatory outcome parameters in haemophilia according to field of use and ICF domain.

ICF domain	Tool	Clinical	Research	Comments
Joint function and structure	Bleeding	M	M	– At least an annual review of bleeding – Reporting on periods of no less than 12 months – Use recommended definitions
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Activities	Observed activities	R	O/R	– FISH in populations with more advanced joint disease
	Self-reported activities	R	R (adults) R (children)	– HAL, from age 18 upwards – pedHAL, from age 4 onwards
Participation	Days lost from school/work	M	M	
Economic	Paid employment	M	M	Include information on full-time yes/no
	Clotting factor consumption	M	M	Combine with body weight and treatment regimen
	Haemophilia-related surgeries	M	L	Not for short term studies
	Hospital visits	M	O/R	
	Days in hospital.	M	O/R	
	Utility assessment	O	R/M	Not for short term studies Choice of tariff (calculation method) affects results

M, mandatory; O, optional; R, recommended; L, limited value; U, unknown; NR, not recommended.

Results and conclusion: Recommendations for choice of outcome tools were made according to the ICF domains, economic setting, and reason for use (clinical or research). The next step will be to identify a 'core' set of outcome measures for use in clinical care or studies evaluating treatment.

Equipo multidisciplinario



Medicina Física y Rehabilitación

Especialidad **MÉDICA** a la que concierne la **evaluación, prevención, diagnóstico y tratamiento de la discapacidad**, encaminados a mantener o devolver el mayor grado de capacidad funcional e independencia posible.

The role of the physiatrist in the haemophilia comprehensive care team in different parts of the world

L. HEIJNEN,*† G. DIRAT,‡ L. CHEN,§ A. B. M. TULAAR,*¶ L. MOYSISYAN,** N. M. M. NASSAR†† and L. R. BATISTELLA‡‡

*Van Creveldkliniek, University Medical Centre, Utrecht, The Netherlands; †Rehabilitation Centre De Trappenberg, Huizen, The Netherlands; ‡Department of Haemophilia Physical Therapy, La Perle Cerdane, Osséja, France; §Peking Union Medical College Hospital, Beijing, China; ¶Faculty of Medicine, University of Indonesia, Jakarta, Indonesia; **Republican Pediatric Rehabilitation Centre, Yerevan, Armenia; ††Department of Physical Medicine and Rheumatology Ain Shams University, Cairo, Egypt; and ‡‡School of Medicine, University of Sao Paulo, Sao Paulo, Brazil

The Utilization of Rehabilitation in Patients with Hemophilia A in Taiwan: A Nationwide Population-Based Study

Chien-Min Chen^{1,2,3}, Yao-Hsu Yang^{4,5,6,7}, Chia-Hao Chang⁸, Chih-Cheng Chen^{2,3,9,*}, Pau-Chung Chen^{5,10}

The role of physical medicine and rehabilitation in haemophiliac patients

Hortensia De la Corte-Rodriguez^a and E. Carlos Rodriguez-Merchan^b

Physical medicine and rehabilitation aim to evaluate, diagnose and treat disability in haemophiliac patients, while preventing injury or deterioration. They also aim to maintain the greatest degree of functional capacity and independence in patients with haemophilia, or to return them to that state. Rehabilitation, together with clotting factor replacement therapy, has revolutionized the management of these patients in developed countries and reduced their morbidity/mortality rates. A knowledge of the musculoskeletal signs and symptoms of haemophilia is essential for providing a treatment which is suitable and customized. Physical medicine and rehabilitation techniques, which are based on physical means, are intended to reduce the impact which these injuries and their consequences or sequelae can have on the quality of life of patients with haemophilia. Under ideal haemostatic control conditions (primary prophylaxis), people with haemophilia could achieve good physical condition which will allow them

to enjoy both physical activity and a daily life without limitations. Currently, children undergoing primary prophylaxis are quite close to this ideal situation. For these physical activities to be carried out, the safest possible situations must be sought. *Blood Coagul Fibrinolysis* 23:000–000 © 2012 Wolters Kluwer Health | Lippincott Williams & Wilkins.

Blood Coagulation and Fibrinolysis 2012, 23:000–000

Keywords: haemophilia, physical medicine, rehabilitation, treatment

^aDepartment of Physical Medicine and Rehabilitation and ^bDepartment of Orthopaedic Surgery, La Paz University Hospital, Madrid, Spain

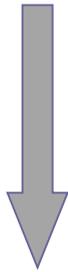
Correspondence to Professor E. Carlos Rodriguez-Merchan, Department of Orthopaedic Surgery, La Paz University Hospital, Paseo de la Castellana 261, 28046 Madrid, Spain.
E-mail: ecrmerchan@gmx.es

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Objetivos

Enfoque hematológico



Prevenir y tratar la hemorragia

Enfoque rehabilitador

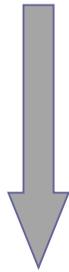


Prevenir y tratar las consecuencias MSK de los sangrados



Objetivos

Enfoque hematológico



Prevenir y tratar la hemorragia

Enfoque rehabilitador



Prevenir y tratar las consecuencias MSK de los sangrados

NO reversibilidad

Sangrado 0



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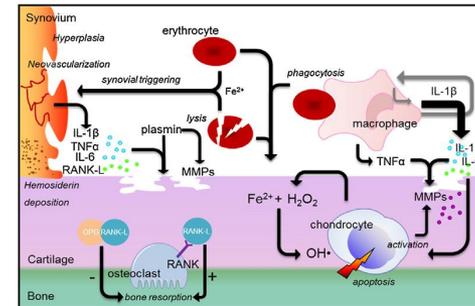
Review

Pathophysiology of hemophilic arthropathy and potential targets for therapy

Astrid E. Pulles^{a,b,*}, Simon C. Mastbergen^a, Roger E.G. Schutgens^b, Floris P.J.G. Lafeber^a, Lize F.D. van Vulpen^{a,b}

^a Department of Rheumatology & Clinical Immunology, University Medical Center Utrecht, Heidelberglaan 100, 3584 CX Utrecht, The Netherlands

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1. NO REVERSIBLES

Disease modifying treatment for HA to fill the gap between factor replacement therapy and orthopedic surgery is urgently warranted. Based on the pathophysiological processes discussed in this review iron chelating, anti-inflammatory therapy, anti-fibrinolytics and bone remodeling agents seem to be the most promising targets in this respect. However, we still have a long way to go for use in clinical practice, as most options are only tested in a preclinical setting.



REVIEW ARTICLE

The burden of bleeding in haemophilia: is one bleed too many?

A. GRINGERI,* B. EWENSTEIN† and A. REININGER*

*Baxter Innovations GmbH, Vienna, Austria; and †Baxter Healthcare Corporation, Westlake Village, CA, USA

Conclusion

The aspirational goal of zero bleeding episodes is conceivably attainable and undeniably critical to optimizing joint health and HRQoL in children and adults with haemophilia. Achieving this objective requires individualized, outcome-based, multidisciplinary care to maximize the effectiveness of the prophylactic regimen without increasing overall health care costs.

The massive proliferation of smaller blood vessels that occurs after an episode of joint bleeding may provide one explanation for subclinical bleeding. The walls of these new vessels are often defective, predisposing to the continual leakage of blood into the joint cavity [33]. Alternatively, intra-articular blood has been shown to adversely affect cartilage in the absence of inflammation [14] – in other words, without clinically evident pain and swelling.

2. DAÑO PRECOZ

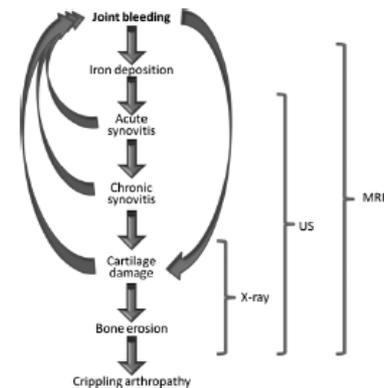


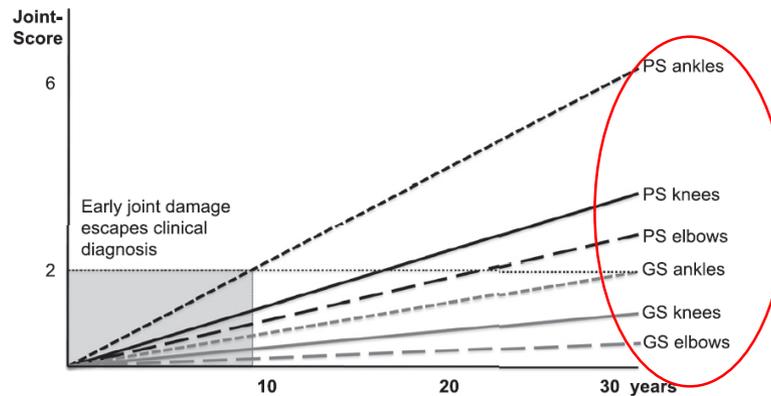
Fig. 1. Biological cascade of events triggered by joint bleeding.

INHERITED BLEEDING DISORDERS

Optimal treatment strategies for hemophilia: achievements and limitations of current prophylactic regimens

Johannes Oldenburg

Institute of Experimental Haematology and Transfusion Medicine, University Clinic Bonn, Bonn, Germany



3. SANGRADO 0 ?

prophylactic group. This study impressively demonstrated that prophylaxis is largely protective for joint disease over a 4-year period of observation. However, joint disease still occurred during this time in about 7% of the patients treated with an intensive prophylactic regimen (6000 IU/kg BW at the age of 6 years). Projected to a lifetime treatment, this means that at the age of 30 to 40 years, most hemophilia patients will suffer from some joint arthropathy.

- En la era moderna de la terapia profiláctica de reemplazo del factor de coagulación, la artropatía hemofílica no es totalmente prevenible (h objetivos y subclínicos)
- Para poder prevenir sus consecuencias es necesario un **diagnostico** precoz y certero

ORIGINAL ARTICLE *Musculoskeletal*Potential biomarkers of haemophilic arthropathy:
correlations with compatible additive magnetic resonance
imaging scoresJ. OLDENBURG,* R. ZIMMERMANN,† O. KATSAROU,‡ E. ZANON,§ E. KELLERMANN,¶
B. LUNDIN** and P. ELLINGHAUS††

Conclusions: Compatible additive MRI scores showed no clear correlations with any of the potential biomarkers for haemophilic arthropathy in the overall population. CS846 levels were significantly correlated with MRI scores in patients treated on demand.

Table 1. Biomarker levels* and correlation with compatible additive MRI score (per-protocol population).

Biomarker	Marker for	Normal range [†]	Biomarker levels (<i>n</i> = 117)		Correlation with MRI score [‡]
			Mean ± SD	Median (range)	
COMP, µg mL ⁻¹	Cartilage degradation	0.99–2.54	1.5 ± 0.3	1.6 (0.0–2.0)	0.100
CS846, ng mL ⁻¹	Cartilage formation	[§]	255.3 ± 213.9	200.3 (0.0–1722.2)	0.053
CTX-I, ng mL ⁻¹	Bone degradation	0.115–0.748	0.7 ± 0.6	0.6 (0.0–3.5)	–0.203
MMP3, ng mL ⁻¹	Joint cartilage destruction	2.1–64.0	17.4 ± 9.4	16.6 (0.0–74.4)	–0.121
MMP9, ng mL ⁻¹	Joint cartilage destruction	169–705	244.5 ± 161.8	219.1 (0.0–939.7)	0.156
TIMP-1, ng mL ⁻¹	Periarticular bone loss	87–524	121.3 ± 41.2	121.8 (0.0–242.9)	0.005
VEGF, pg mL ⁻¹	Inflammation and angiogenesis	62–707	226.4 ± 177.0	191.3 (0.0–845.5)	–0.084

COMP, cartilage oligomeric matrix protein; CS846, chondroitin-sulphate aggrecan turnover 846 epitope; CTX-I, C-terminal telopeptides of type I collagen; MMP, matrix metalloproteinase; MRI, magnetic resonance imaging; TIMP-1, tissue inhibitor of metalloproteinase 1; VEGF, vascular endothelial growth factor.

*Serum levels were measured for all the biomarkers except VEGF, MMP3, and MMP9, which were measured in platelet-poor plasma samples.

[†]Normal ranges for healthy patients as provided by supplier of test kits.

[‡]Spearman rank correlation coefficient for the correlation of biomarker and compatible additive MRI score.

[§]No normal range for healthy patients was provided by supplier of test kits. Serum CS846 levels in patients with haemophilic arthropathy who had not experienced any joint bleeds in the previous 3 months have been reported [5].



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Table 5. Recommended and/or mandatory outcome parameters in haemophilia according to field of use and ICF domain.

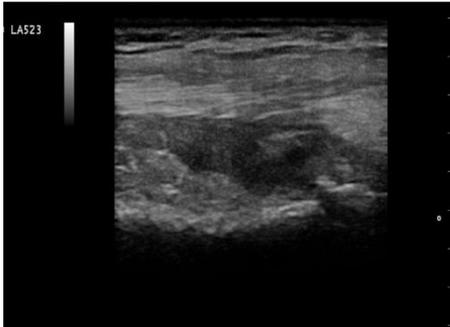
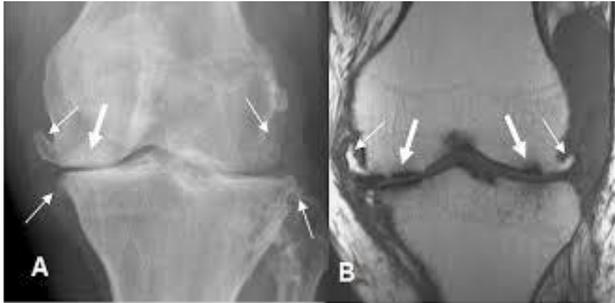
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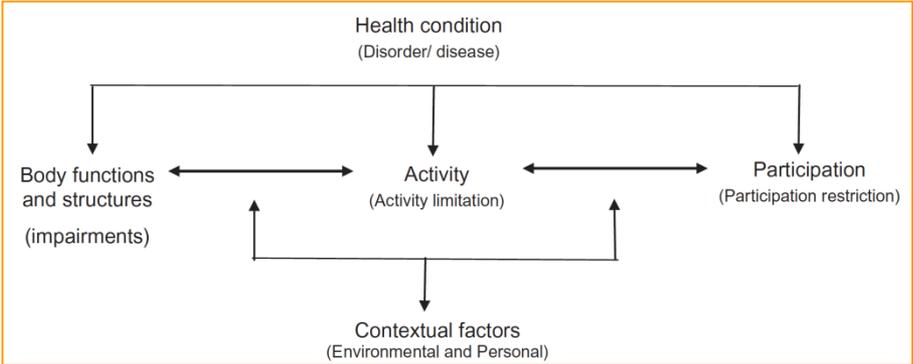
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EF

Imagen



Funcional



Exploración clínica

EXPLORACIÓN FÍSICA detallada a fin de conocer el estado basal y detectar posibles lesiones.

- **Análisis de 4EE :**

- Dolor
- Hinchazón
- Balance articular (BA)
- Trofismo muscular
- Balance muscular (BM)
- Estabilidad articular
- Alineación de ejes
- Propiocepción
- Pisada

- **Columna vertebral:**

- Estudio de las desviaciones axiales
- Valoración de discrepancia MMII

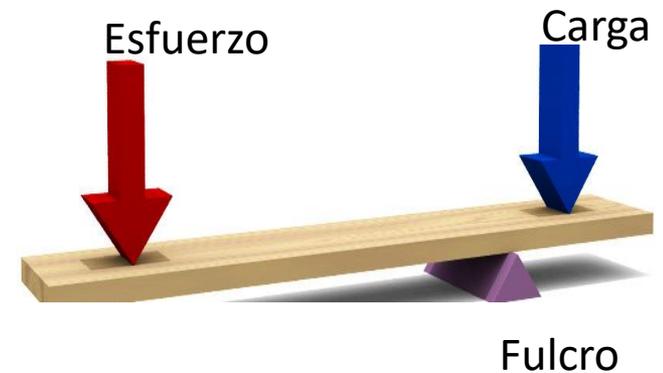
- **Análisis de la marcha**

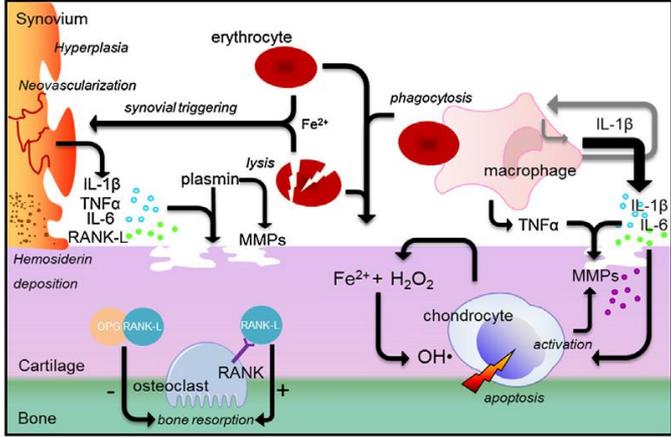
Valoración clínica del estado clínico

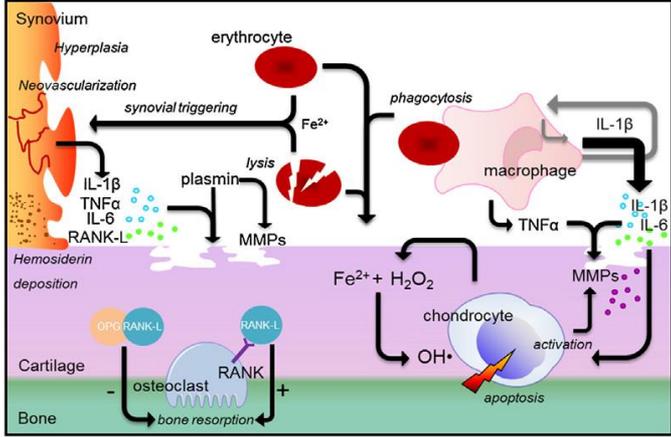


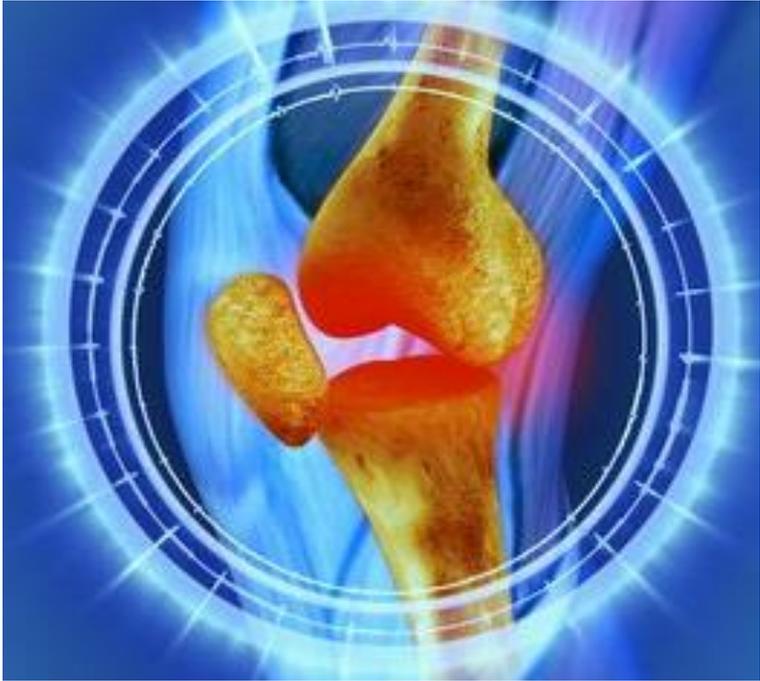
Articulación = fulcro

Sistema de palancas: permite amplificar la fuerza mecánica que se aplica a un objeto

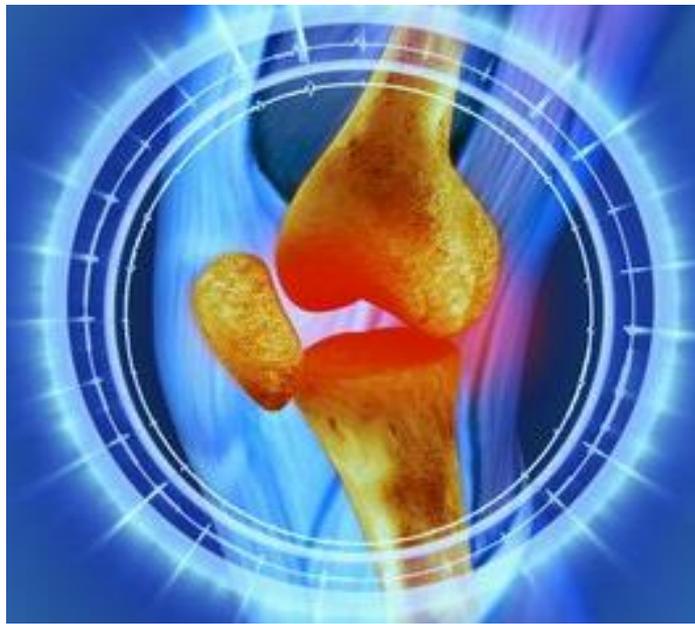




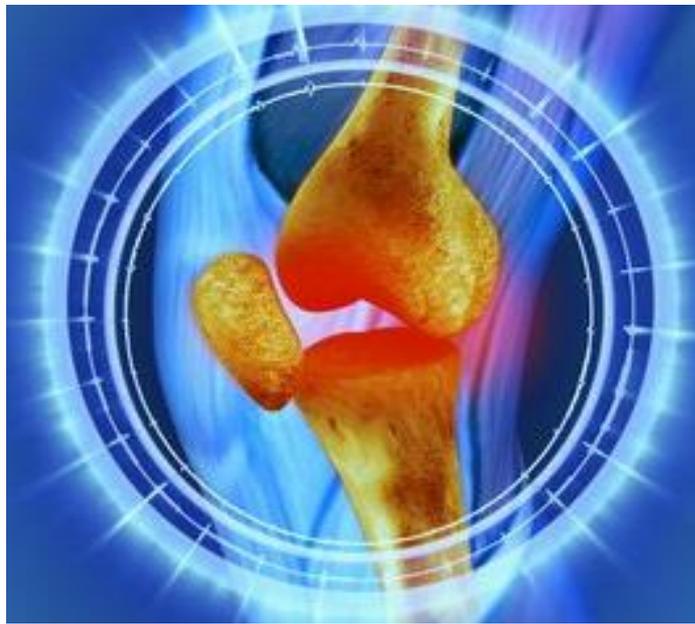




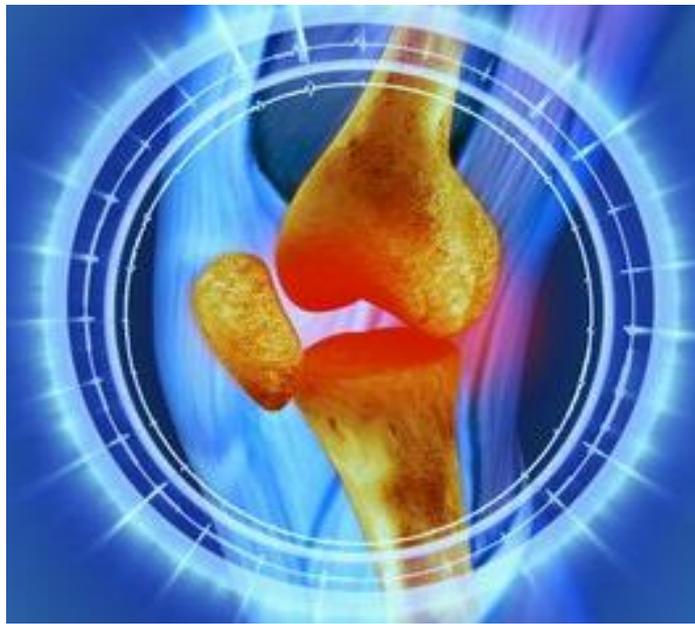
Dolor



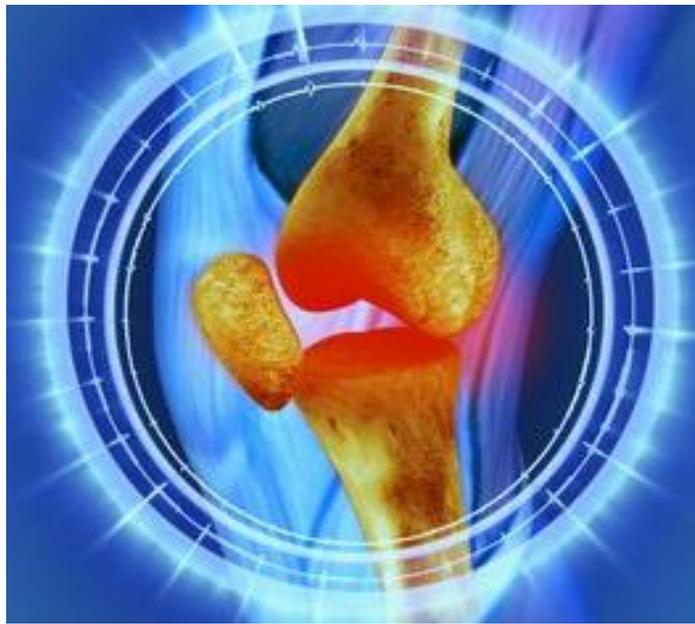
Balance articular



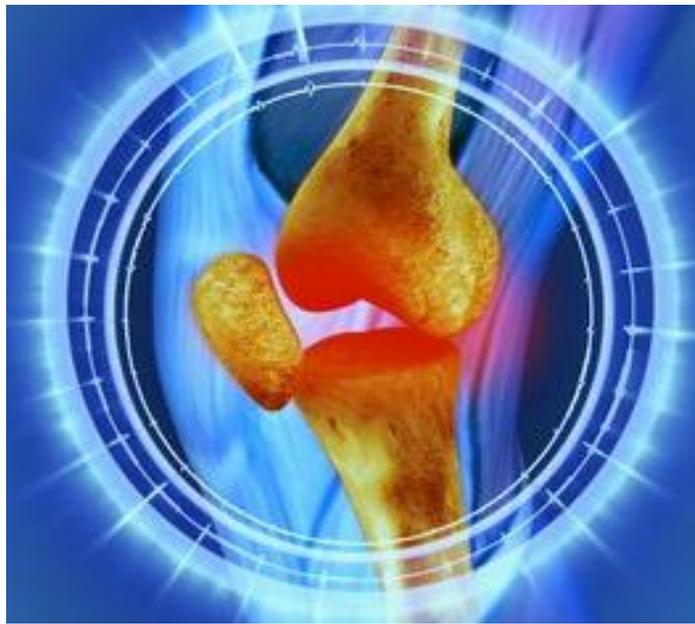
Propiocepción



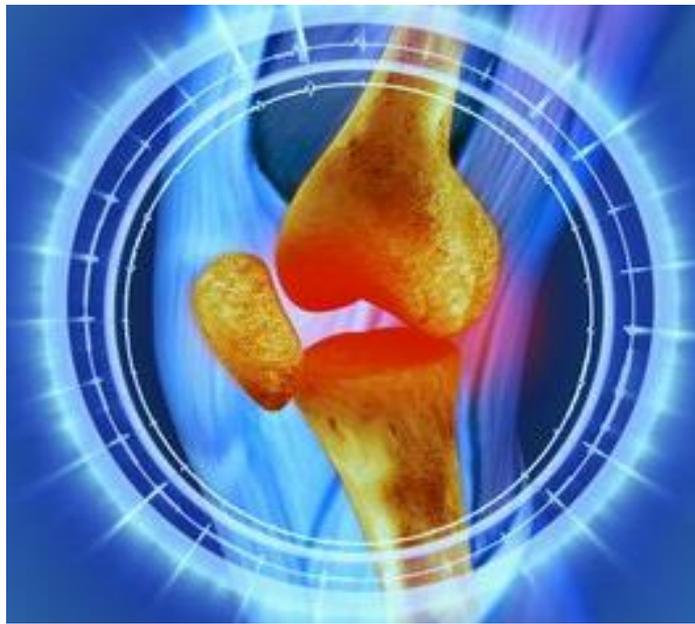
Balance muscular



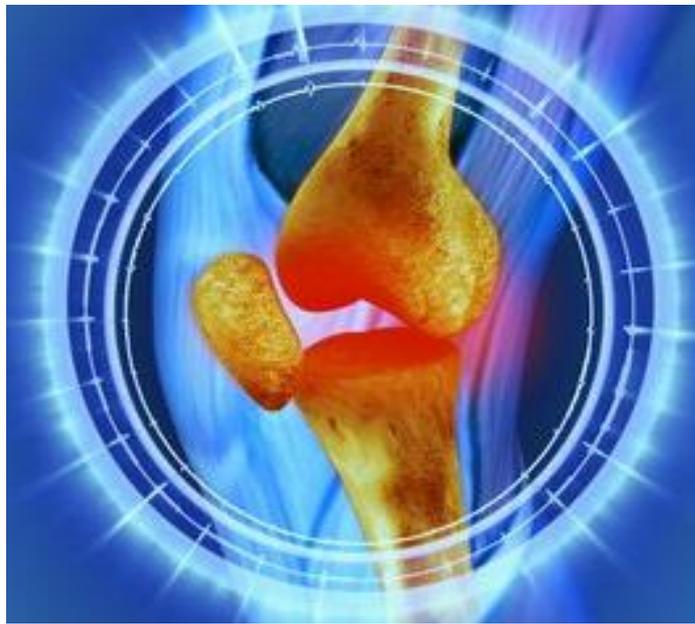
Estabilidad articular



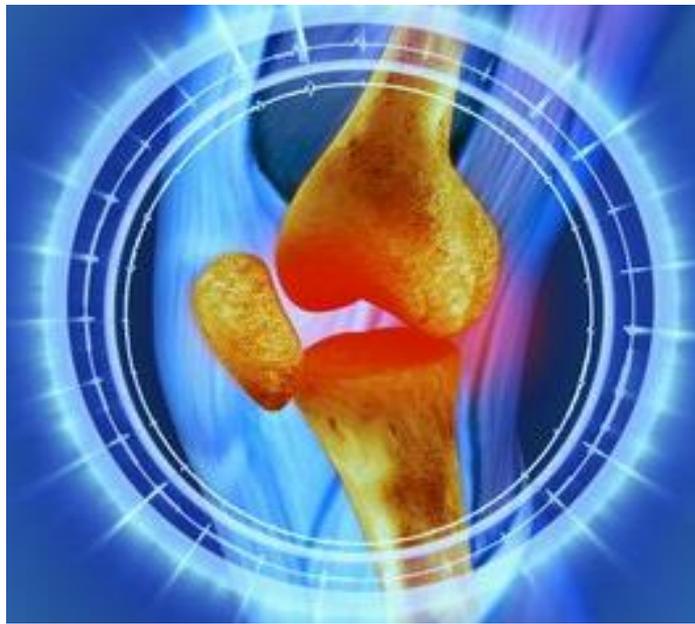
Crepitación



Pisada

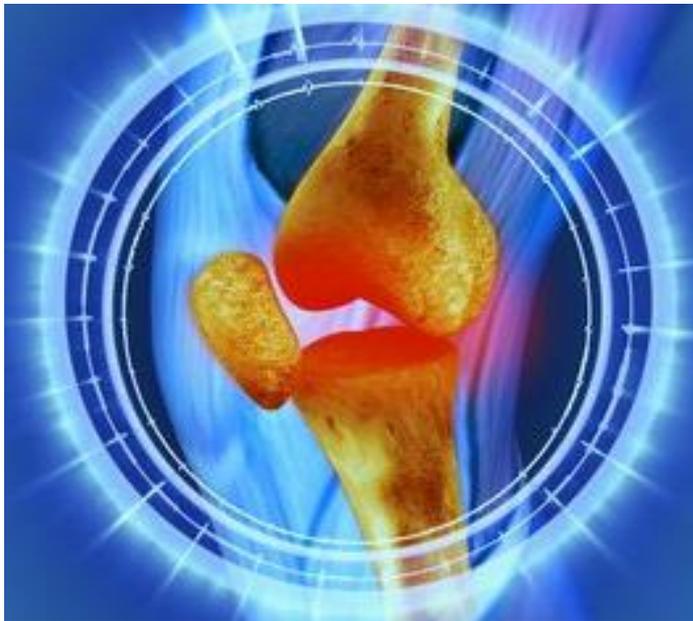


Alineación de ejes



Estática postural y marcha





LIMITACIÓN FUNCIONAL Y DE AVD



- En pacientes que comenzaron a utilizar la profilaxis, la incidencia es mucho menor
- En pacientes que usaron ttos a demanda o con inhibidor, la artropatía es mucho más frecuente

ESCALAS DE VALORACIÓN FÍSICA

- Las más utilizadas:
 - WORLD FEDERATION HEMOPHILIA O GILBERT (1980)
 - HEMOPHILIA JOINT HEALTH SCORE (2008)



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Activities	Observed activities	R	O/R	– FISH in populations with more advanced joint disease
	Self-reported activities	R	R (adults) R (children)	<ul style="list-style-type: none"> – HAL, from age 18 upwards – pedHAL, from age 4 onwards
Participation	Days lost from school/work	M	M	
Economic	Paid employment	M	M	Include information on full-time yes/no
	Clotting factor consumption	M	M	Combine with body weight and treatment regimen
	Haemophilia-related surgeries	M	L	Not for short term studies
	Hospital visits	M	O/R	
	Days in hospital.	M	O/R	
	Utility assessment	O	R/M	<ul style="list-style-type: none"> – Not for short term studies – Choice of tariff (calculation method) affects results

M, mandatory; O, optional; R, recommended; L, limited value; U, unknown; NR, not recommended.

Results and conclusion: Recommendations for choice of outcome tools were made according to the ICF domains, economic setting, and reason for use (clinical or research). The next step will be to identify a 'core' set of outcome measures for use in clinical care or studies evaluating treatment.

Escala de la WFH

Escala acumulativa

Desarrollada por Gilbert

Refleja mejor el estado articular en pacientes >20 a

Puntúa de 0-1 ó de 0-2 cada uno de los hallazgos

Puntuación máxima de 12 para el tobillo y la rodilla, y de 10 para el codo

Inflamación	0	No
	2	Presente (añadir S en caso de sinovitis)
Atrofia muscular	0	<1 cm
	1	Presente
Deformidad axial (rodilla y tobillo)	0	0 a 7° de valgo
	1	8 a 15° de valgo ó 0 a 5° de varo
	2	>15° de valgo o >5° de varo
Crepitación	0	No
	1	Presente
Movilidad articular	0	Pérdida <10% del total del recorrido
	1	Pérdida del 10-33% del recorrido
	2	Pérdida >33% del recorrido
Contractura en flexión (irreducible)	0	<15%
	1	>15%
Inestabilidad	0	No
	1	Presente. No interfiere con la función. No precisa férula
	2	Si interfiere con la función y/o precisa férula

Escala HJHS

Hemophilia Joint Health Score 2.1 - Summary Score Sheet

	Left Elbow		Right Elbow		Left Knee		Right Knee		Left Ankle		Right Ankle	
Swelling	<input type="checkbox"/>	NE										
Duration (swelling)	<input type="checkbox"/>	NE										
Muscle Atrophy	<input type="checkbox"/>	NE										
Crepitus on motion	<input type="checkbox"/>	NE										
Flexion Loss	<input type="checkbox"/>	NE										
Extension Loss	<input type="checkbox"/>	NE										
Joint Pain	<input type="checkbox"/>	NE										
Strength	<input type="checkbox"/>	NE										
Joint Total												

Sum of Joint Totals

+

NE = Non-Evaluable

Global Gait Score

+

(NE included in Gait items)

HJHS Total Score

=

Escala acumulativa

Desarrollada para niños 4-18 a

Puntuación de 0-1,2,3,4 hallazgos

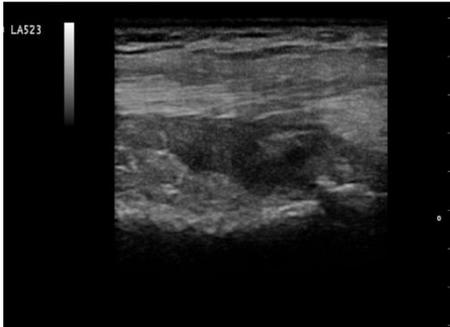
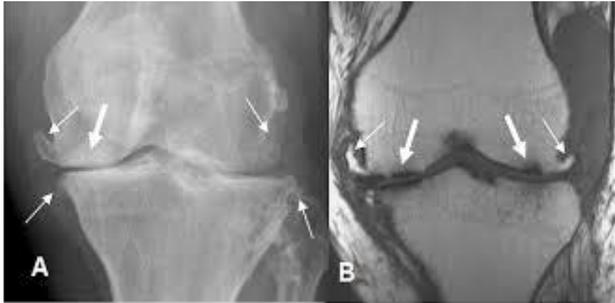
Puntuación máxima de 20 por

articulación y 4 para la marcha

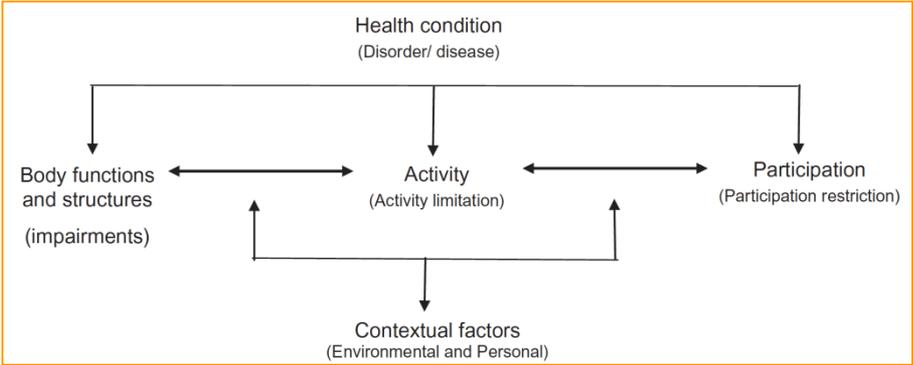
Parece haber una buena correlación entre ambas

EF

Imagen



Funcional



Pruebas de imagen

- Importantes para apoyar la sospecha clínica
- Objetivo
 - Alta sensibilidad para detectar lesiones
 - Técnica sencilla
 - Permita monitorizar cambios
 - Protocolo para construir escalas

- Las estrategias terapéuticas frecuentemente se dirigen al uso del factor
- Se ha demostrado que la valoración subjetiva de paciente y médico no son suficientes
- El diagnóstico por imagen permite hacer un uso racional de las terapias

- Las estrategias terapéuticas frecuentemente se dirigen al uso del factor
 - Se ha demostrado que la valoración subjetiva de paciente y médico no son suficientes
 - El diagnóstico por imagen permite hacer un uso racional de las terapias
-
- **Necesidad de complementar la valoración con pruebas de imagen !!!!**



REVIEW ARTICLE

Choosing outcome assessment tools in haemophilia care and research: a multidisciplinary perspective

K. FISCHER,* P. POONNOOSE,† A. L. DUNN,‡ P. BABYN,§ M. J. MANCO-JOHNSON,¶
J. A. DAVID,** J. VAN DER NET,†† B. FELDMAN,‡‡ K. BERGER,§§ M. CARCAO,¶¶
P. DE KLEIJN,*** M. SILVA,††† P. HILLIARD,‡‡‡ A. DORIA,§§§ A. SRIVASTAVA¶¶¶ and
V. BLANCHETTE¶¶¶ ON BEHALF OF THE PARTICIPANTS OF THE INTERNATIONAL
SYMPOSIUM ON OUTCOME MEASURES IN HEMOPHILIC ARTHROPATHY^a

Table 5. Recommended and/or mandatory outcome parameters in haemophilia according to field of use and ICF domain.

ICF domain	Tool	Clinical	Research	Comments
Joint function and structure	Bleeding	M	M	<ul style="list-style-type: none"> – At least an annual review of bleeding – Reporting on periods of no less than 12 months – Use recommended definitions
	Physical examination	M	M	<ul style="list-style-type: none"> – HJHS v2.1 when including patients with early joint changes (all paediatric studies) – If using HJHS is impossible, collect AROM
	Imaging	O	R	<ul style="list-style-type: none"> – US or MRI for evaluation of early changes – Pettersson score (X-ray) for advanced osteochondral changes (interval no shorter than 3 years)
Activities	Observed activities	R	O/R	– FISH in populations with more advanced joint disease
	Self-reported activities	R	R (adults) R (children)	<ul style="list-style-type: none"> – HAL, from age 18 upwards – pedHAL, from age 4 onwards
Participation	Days lost from school/work	M	M	
	Paid employment	M	M	Include information on full-time yes/no
Economic	Clotting factor consumption	M	M	Combine with body weight and treatment regimen
	Haemophilia-related surgeries	M	L	Not for short term studies
	Hospital visits	M	O/R	
	Days in hospital.	M	O/R	
	Utility assessment	O	R/M	<ul style="list-style-type: none"> – Not for short term studies – Choice of tariff (calculation method) affects results

M, mandatory; O, optional; R, recommended; L, limited value; U, unknown; NR, not recommended.

Results and conclusion: Recommendations for choice of outcome tools were made according to the ICF domains, economic setting, and reason for use (clinical or research). The next step will be to identify a 'core' set of outcome measures for use in clinical care or studies evaluating treatment.

Radiografía



Radiología simples

Ventajas:

- Fácilmente disponibles, proyecciones estándar y sus resultados son prácticamente instantáneos
- Radiografía digital es más sensible que la radiología convencional

Arnold WD, Hilgartner MW. J Bone Joint Surg Am 1977; 59:287-305.

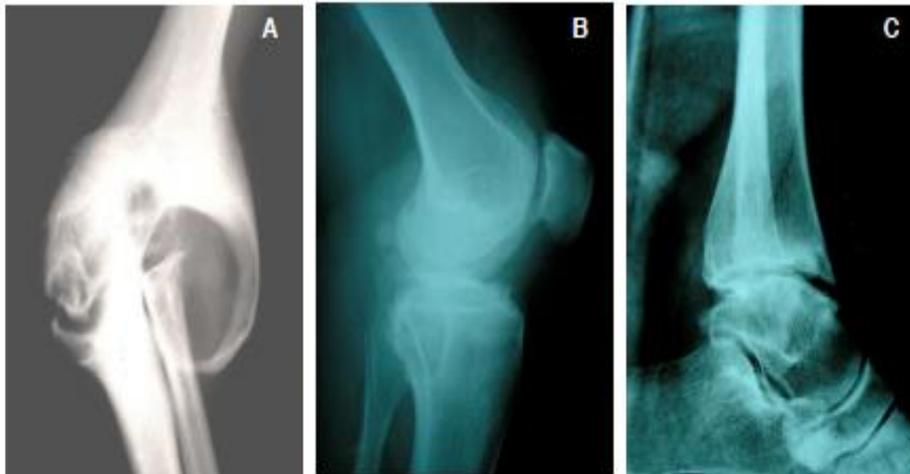
Pettersson H, Ahlberg A, Nilsson IM. Clin Orthop Relat Res 1980; 149:153-9.



Radiología simples

Limitaciones:

- Subestima el grado de patología articular real en fases iniciales y ppbb
- Su uso más apropiado es en pacientes adultos con enfermedad articular avanzada o sospecha de lesión ósea



Resonancia Magnética

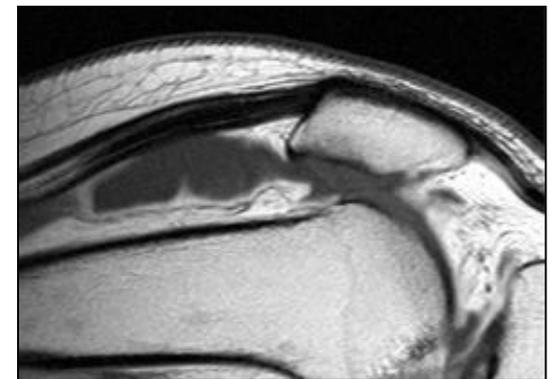


Resonancia Magnética

Ventajas:

- Tiene una alta resolución espacial y capacidad para distinguir los elementos intra y extraarticulares
- RM es útil para detectar microhemorragias
- Grandes avances por mejoras en antenas y secuencias, lo que permite una mayor resolución y un mejor contraste tisular

Nuss R et al. Haemophilia 2000; 6:162-9 (Denver)
Funk MB et al. Haemophilia 2002; 8:98-103
Soler R et al. Eur Radiol 2002; 12: 836-43
Dobón M et al. Haemophilia 2003; 9:76-85
Lundin B et al. Haemophilia 2004; 10:383-9 (Europea)
Lundin B et al. Haemophilia 2005; 11:109-15



Doria AS et al. Haemophilia 2010;16 (5):107-14
Pergantou H et al. Haemophilia 2006;12:241-7

Resonancia Magnética

Denver (10p)

Europea (20p)

Table 3. The compatible scales for progressive and additive MRI assessments.

(IPSG)	Progressive scale (P)	Additive scale (A)
<i>Effusion/haemarthrosis</i>		
Small	(1)___	
Moderate	(2)___	
Large	(3)___	
<i>Synovial Hypertrophy</i>		
Small	(4)___	(1)___
Moderate	(5)___	(2)___
Large	(6)___	(3)___
<i>Haemosiderin</i>		(1)___
Small	(4)___	
Moderate	(5)___	
Large	(6)___	
<i>Changes of subchondral bone or joint margins</i>		
Any surface erosion	(7)___	(1)___
Any surface erosion in at least two bones		(1)___
Half or more of the articular surface eroded in at least one bone	(8)___	(1)___
Half or more of the articular surface eroded in at least two bones		(1)___
At least one subchondral cyst	(7)___	(1)___
More than one subchondral cyst	(8)___	(1)___
Subchondral cysts in at least two bones		(1)___
Multiple subchondral cysts in each of at least two bones		(1)___
<i>Cartilage loss</i>		
Any loss of joint cartilage height	(9)___	(1)___
Any loss of joint cartilage height in at least two bones		(1)___
Any loss of joint cartilage height involving more than one third of the joint surface in at least one bone		(1)___
Any loss of joint cartilage height involving more than one third of the joint surface in at least two bones		(1)___
Full-thickness loss of joint cartilage in at least some area in at least one bone	(10)___	(1)___
Full-thickness loss of joint cartilage in at least some area in at least two bones		(1)___
Full-thickness loss of joint cartilage involves at least one third of the joint surface in at least one bone		(1)___
Full-thickness loss of joint cartilage involves at least one third of the joint surface in at least two bones		(1)___
	Highest number (max value = 10)	Add numbers (max value = 20)
Scores	(P)___	(A)___

Resonancia Magnética

Limitaciones:

- Sin embargo, la RM es más costosa, menos accesible y requiere más tpo
- En niños suele requerir sedación
- Aunque la objetividad es extraordinaria, resulta utópico poder realizar estudios seriados de RM, por el coste económico



Ecografía



Recuerdo histórico

En el año 1992, nuestra Unidad publica el primer estudio comparativo, concluyendo la utilidad del US en los tres aspectos

Table 1. References evidencing the use of ultrasonography for the diagnosis and/or treatment of musculo-skeletal lesions in haemophilia.

Year	Authors	Objective	USG								Therapy control	Remarks/conclusions
			Cases	Available, fast, effective, safe, cheap technique	Effusion	Synovial	Arthrosic disease	Haematoma	Pseudotumour	Identifies / points at value for:		
1992	Daly BD ¹⁷	Diagnosis of psoas haematoma	Yes	-	Yes	-	-	-	Yes	-	-	USG choice in children. CT and MRI complete the study.
1992	Hermann G	Describe techniques	Yes	Yes	-	-	-	-	Yes	Yes	-	USG method of choice, diagnosis and
1992	Merchan ECR <i>et al.</i> ¹⁹	Diagnosis of arthrosic disease	Yes	Yes	Yes	Yes	Yes	Yes	-	-	-	USG simple, effective technique diagnosis and/or control of effusion, synovitis and early stages of arthrosic disease.
1992	Merchan EC ²⁰	Description of pseudotumour	-	-	-	-	-	-	-	-	-	Proposes imaging techniques for diagnosis of pseudotumour.
2001	Klukowska A <i>et al.</i> ¹⁴	Protocol description	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	USG useful for effusion, synovial, and cartilage. Synovitis involves therapy with factor. MRI best technique, but not useful for routine. Good USG-MRI correlation.
2005	Balkan C <i>et al.</i> ²¹	Diagnosis of psoas haematoma	Yes	Yes	-	-	-	-	Yes	-	-	USG useful for psoas haematoma. CT and MRI best techniques, but practical disadvantages.
2007	Goddard NJ <i>et al.</i> ²²	Diagnosis of synovitis	-	Yes	Yes	Yes	Yes	-	-	-	-	USG particularly useful in effusion and synovitis. MRI best technique for diagnosis of arthrosic disease.
2007	Zukotynski K <i>et al.</i> ¹⁵	Protocol description	-	Yes	Yes	Yes	Yes	-	-	-	Yes	USG useful for diagnosis and assessment of therapeutic effects. Very complete protocol.
2008	Acharya SS <i>et al.</i> ²³	Comparative efficacy study of images	Yes	Yes	Yes	Yes	Yes	-	-	-	Yes	USG particularly important for diagnosis of synovitis.
2008	Acharya SS ⁷	Study of diagnostic approaches	-	Yes	-	Yes	Yes	-	-	-	Yes	USG useful in synovitis. MRI best technique, but practical disadvantages.
2008	Antunes SV <i>et al.</i> ²⁴	Evaluate USG for diagnosis of arthrosic disease	Yes	Yes	Yes	Yes	Yes	-	-	-	-	USG useful in diagnosis of arthrosic disease.
2008	Mausers-Bauschoten EP <i>et al.</i> ²⁵	Describe techniques	-	Yes	Yes	Yes	-	-	-	-	-	USG useful in synovitis. MRI best technique, but practical disadvantages.
2008	Querol F <i>et al.</i> ²⁶	Description of exploratory protocol	Yes	-	Yes	Yes	-	-	-	-	Yes	USG useful for diagnosis and control of haemarthrosis.
2009	Jelbert A <i>et al.</i> ⁸	Description of imaging techniques for arthrosic disease	-	Yes	Yes	Yes	Yes	-	-	-	Yes	USG useful in synovitis. Limitations for arthrosic disease. MRI best technique.
2009	Keshava S <i>et al.</i> ⁹	Protocol description	-	-	-	-	Yes	-	-	-	-	USG proposes protocol standardisation.
2009	Robertson JD ²⁷	Description of case report	Yes	Yes	Yes	-	Yes	-	-	-	Yes	USG useful for evaluating joint effusion and/or suction guide.

Literatura

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Results by year

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Desde entonces, y especialmente en los últimos años, se han multiplicado las publicaciones sobre el uso de la ecografía MSK en hemofilia

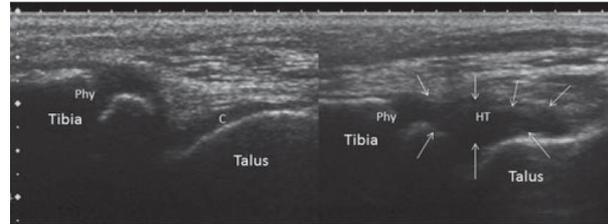
- Klukowska A et al. Haemophilia 2001; 7: 286-92,
- Doria AS et al. AJR Am J Roentgenol 2015; 204: W336-47.
- Martinoli C et al. Thromb Haemost 2013; 109: 1170-9.
- Melchiorre D et al. Haemophilia 2011; 17: 112-7.
- Muça-Perja M et al. Haemophilia 2012; 18: 364-8.
- Zukotynski K et al. Haemophilia 2007; 13: 293-304.
- Klukowska A et al. Haemophilia 2001; 7: 286-92.



REVIEW ARTICLE *Musculoskeletal*

The role of ultrasonography in the diagnosis of the musculo-skeletal problems of haemophilia

F. QUEROL* and E. C. RODRIGUEZ-MERCHAN†



Conclusions

Acute haemarthrosis is the condition with a diagnosis and control considered to be the target in prophylaxis of haemophilic arthropathy. The ultrasonographic image shows objective lesion characteristics (if compared with the healthy contralateral joint or if a study prior to the bleeding episode is available) which allow therapy to be adapted while there is evidence of abnormality. Ultrasonography is essential for the diagnosis and control of the evolution of synovitis. Magnetic resonance is still the most complete imaging technique, and the most sensitive for the diagnosis of musculo-skeletal lesions affecting haemophiliacs.

There is agreement on the benefits of ultrasonography in musculo-skeletal diseases: it is fast, effective, safe and readily available; it is a real-time, dynamic, comparative study that can confirm and/or clarify the clinical examination. It allows for evidencing the

presence of joint effusion, its extent and progression. It makes characterization of the clot easier; it diagnoses and differentiates synovitis, and allows it to be graded. It establishes an accurate diagnosis of haematoma, its location, depth and extent, and even evaluates its complication, such as encapsulation, neovascularization and calcification. Ultrasonography is also useful for optimizing drug therapy and orthopaedic-rehabilitation treatment for musculo-skeletal problems in haemophilia patients. It is interesting to note the importance of US in monitoring the treatment of the musculo-skeletal bleeding episodes in haemophilic patients.

Disclosures

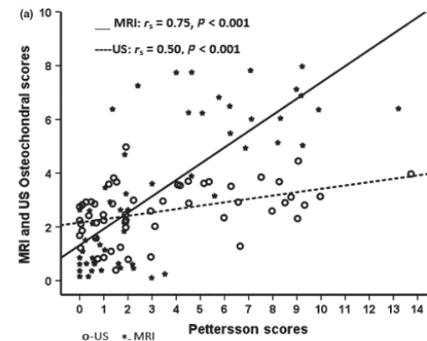
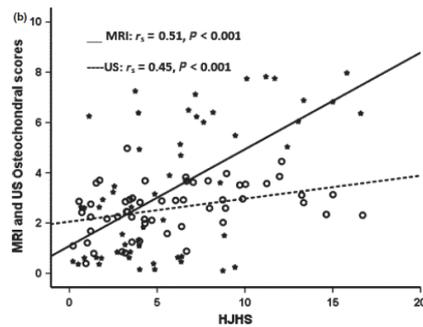
The authors stated that they had no interests which might be perceived as posing a conflict or bias.

ORIGINAL ARTICLE *Musculoskeletal*

Correlating clinical and radiological assessment of joints in haemophilia: results of a cross sectional study

P. M. POONNOOSE,* P. HILLIARD,† A. S. DORIA,‡ S. N. KESHAVA,§ S. GIBIKOTE,§
M. L. KAVITHA,¶ B. M. FELDMAN,* V. BLANCHETTE†† and A. SRIVASTAVA¶

Conclusion: US and MRI are able to identify pathological changes in joints with normal X-ray imaging and clinical examination. However, further studies are required to be able to differentiate early abnormalities from normal. Clinical (HJHS) and radiological assessment (US/MRI) provide complimentary information and should be considered conjointly in the assessment of early joint arthropathy.



Accepted: 30 April 2018

DOI: 10.1111/hae.13524

ORIGINAL ARTICLE

WILEY **Haemophilia** 

Diagnostic accuracy of point-of-care ultrasound for evaluation of early blood-induced joint changes: Comparison with MRI

W. Foppen¹  | I. C. van der Schaaf¹ | F. J. A. Beek¹ | W. P. T. M. Mali¹ | K. Fischer^{2,3} 

Point-of-care ultrasound according to the HEAD-US protocol can accurately assess the presence/absence of synovial hypertrophy in joints of haemophilia patients. The positive and negative predictive values of POC-US for synovial hypertrophy were high at 94% and 97% respectively. In addition, POC-US may also be used to provide a general indication of the cartilage and bone status. As synovial hypertrophy is associated with bleeding, POC-US performed by trained clinicians may play a role in tailoring haemophilia treatment in the future. Further studies are needed to establish the effects of POC-US guided treatment changes.

Haemophilia

The Official Journal of the World Federation of Hemophilia,
European Association for Haemophilia and Allied Disorders and
the Hemostasis & Thrombosis Research Society



Haemophilia (2014), 20, e51–e57

DOI: 10.1111/hae.1226

ORIGINAL ARTICLE *Musculoskeletal*

Comparison of ultrasound and magnetic resonance imaging for diagnosis and follow-up of joint lesions in patients with haemophilia

C. SIERRA AISA,* J. F. LUCÍA CUESTA,† A. RUBIO MARTÍNEZ,† N. FERNÁNDEZ MOSTEIRÍN,† A. IBORRA MUÑOZ,† M. ABÍO CALVETE,‡ M. GUILLÉN GÓMEZ,§ A. MORETÓ QUINTANA* and D. RUBIO FÉLIX†

Summary. Haematomas and recurrent haemarthroses are a common problem in haemophilia patients from early age. Early diagnosis is critical in preventing haemophilic arthritis, and recent years have seen excellent advances in musculoskeletal ultrasound as a diagnostic tool in soft tissue lesions. In this study, we compared the results of ultrasound imaging for the diagnosis of musculoskeletal injuries in haemophilia

ultrasound ($\kappa = 1.000$). By component of joint assessment, haemarthrosis was similarly diagnosed with both techniques in all joints ($\kappa = 1.000$). A good positive correlation was found between these techniques in detecting and locating synovial hyperplasia ($\kappa = 0.839$ – 1.000 , knees and ankles respectively), and erosion of margins ($\kappa = 0.850$ – 1.000). The presence of bone cysts or cartilage loss was



REVIEW ARTICLE *Musculoskeletal*

A systematic review of ultrasound imaging as a tool for evaluating haemophilic arthropathy in children and adults

C. C. LIGOCKI,^{†‡} A. ABADÉH,^{†‡} K. C. WANG,[†] T. ADAMS-WEBBER,[§] V. S. BLANCHETTE[¶] and A. S. DORIA^{*}

^{*}Conselho Nacional de Desenvolvimento Científico e Tecnológico – CNPq, Curitiba, Brazil; [†]Department of Diagnostic Imaging, The Hospital for Sick Children; [‡]Department of Medical Imaging, University of Toronto; [§]Hospital Library & Archive Services; and [¶]Department of Hematology & Oncology, The Hospital for Sick Children, Toronto, ON, Canada

methodological quality and 6/14 (43%) as having moderate quality. There is fair evidence (Grade B) to recommend US as an accurate technique for early diagnosis of HA, to demonstrate that US scores correlate with clinical/US constructs and to prove an association between US findings and functional status of the joint. However, there is insufficient evidence (Grade I) to conclude that US-detectable findings in HA are sensitive to changes in therapy.

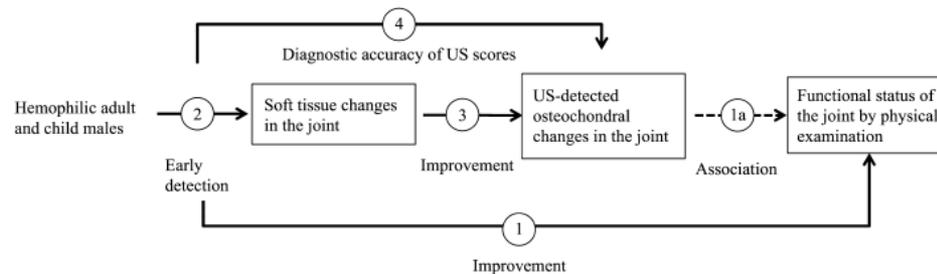
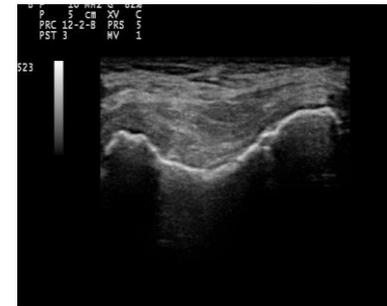
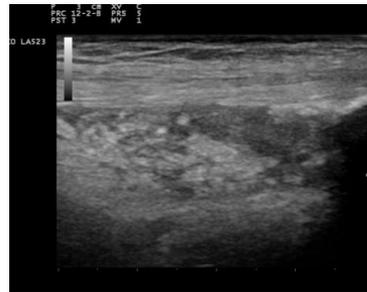


Fig. 1. Analytical framework for the use of ultrasound (US) as a screening and diagnostic tool for evaluating haemophilic arthropathy. Overarching questions of the study:

Ecografía

Ventajas:

- Fácilmente disponible, económica y no invasiva
- Pertinente en los estadios precoces de la enfermedad ya que puede detectar cambios incipientes
- Permite determinar la necesidad de otras pruebas de imagen.



Ecografía

Limitaciones:

- Imposibilidad de valorar simultáneamente el hueso
- Variabilidad interobservador
- Es necesaria una metodología bien establecida
- Precisa un evaluador experimentado



Diferentes protocolos

Se han publicado múltiples sistemas de puntuación estandarizados con el objetivo de estandarizar mediciones y minimizar en gran medida la dependencia del operador.

Klukowska et al. Haemophilia 2001;7:286-92
Zukotynski K et al Haemophilia 2007;13:293-304
Querol F et al. Haemophilia 2008; 14 (6):36-44
Keshava S et al. Haemophilia 2009;1: 1159-79
Melchiorre et al. Haemophilia 2011,17:112-7
Xavier F et al. Rheumatol Curr Res 2012, S2-S9
Martinoli C et al. Thromb Haemost 2013;109(6):1170-9
Doria As et al. AJR AM J Roentgenol 2015;204(3):W336-47.

Clasificados como :

1. Protocolos de US de art. periférica completa (**FPJ-US**), que son más exhaustivos y realizados por expertos en radiología.

No son comparables

2. Protocolos de US de punto de atención (**POC-US**), traída al paciente y realizada por el médico en tiempo real, para proporcionar una respuesta rápida en la práctica clínica y facilitar la toma de decisiones.

Development and definition of a simplified scanning procedure and scoring method for Haemophilia Early Arthropathy Detection with Ultrasound (HEAD-US)

Carlo Martinoli¹; Ornella Della Casa Alberighi³; Giovanni Di Minno⁵; Ermelinda Graziano⁶; Angelo Claudio Molinari⁴; Gianluigi Pasta⁷; Giuseppe Russo¹; Elena Santagostino⁸; Annarita Tagliaferri⁹; Alberto Tagliafico²; Massimo Morfini¹⁰

Thrombosis and Haemostasis 109.6/2013

Haemophilia

The Official Journal of the World Federation of Hemophilia, European Association for Haemophilia and Allied Disorders and the Hemostasis & Thrombosis Research Society

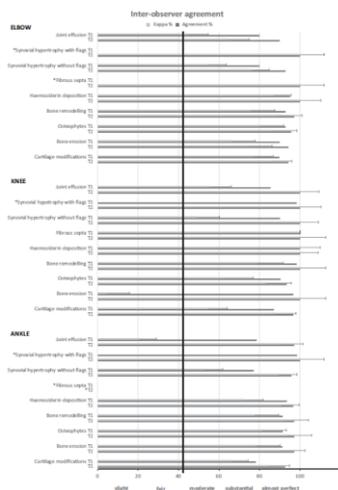


Interobserver reliability of ultrasound assessment of haemophilic arthropathy: radiologist vs. non-radiologist

C. LISI,* G. DI NATALI,* V. SALA,† C. TINELLI,‡ M. CANEPARI,§ G. GAMBA¶ and E. DALLA TOFFOLA*

*Physical Medicine and Rehabilitation Unit IRCCS Policlinico S. Matteo Foundation; †Physical Medicine and Rehabilitation Unit University of Pavia; ‡Clinical Epidemiology and Biometric Unit IRCCS Policlinico S. Matteo Foundation; §Institute of Radiology IRCCS Policlinico San Matteo Foundation; and ¶Centre for Haemophilia and Congenital Bleeding Disorders IRCCS Policlinico S. Matteo Foundation, Pavia, Italy

Haemophilia (2016), 22, e208–e244



In conclusion, it could be useful to perform US evaluation at every clinical assessment of haemophilic patients. Our data show that US evaluation can be performed by a trained non-radiologist when it is not possible to have a radiologist performs a specialistic evaluation.

US could be a valid and reliable tool for trained non-radiologists to evaluate and monitor HA over time.

Point-of-care Ultrasound (POC-US)

- Ayudar a promover una mejor evaluación de la artropatía en la atención rutinaria del paciente. Responde a preguntas clínicas concretas.
- Contribuye a un uso racional de los recursos médicos. Permite determinar la necesidad de otras pruebas de imagen.



Development and definition of a simplified scanning procedure and scoring method for Haemophilia Early Arthropathy Detection with Ultrasound (HEAD-US)

Carlo Martinoli¹; Ornella Della Casa Alberighi³; Giovanni Di Minno⁵; Ermelinda Graziano⁶; Angelo Claudio Molinari⁴; Gianluigi Pasta⁷; Giuseppe Russo¹; Elena Santagostino⁸; Annarita Tagliaferri⁹; Alberto Tagliafico²; Massimo Morfini¹⁰

Thrombosis and Haemostasis 109.6/2013

- Único desarrollado para POC-US
- Basado en un consenso de expertos multidisciplinar
- Describe la sistemática de exploración de codo, rodilla y tobillo

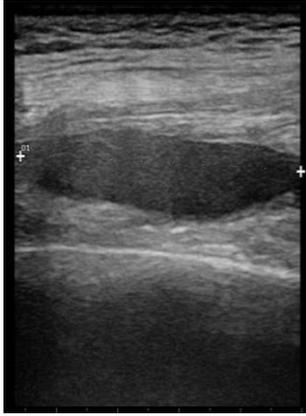
Recesos articulares

Superficie articular

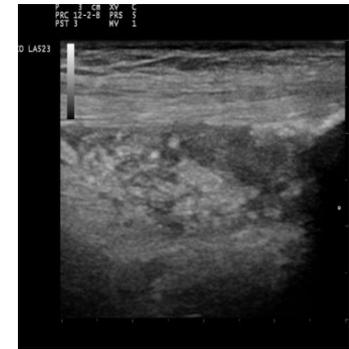


Hemartros, Sinovitis

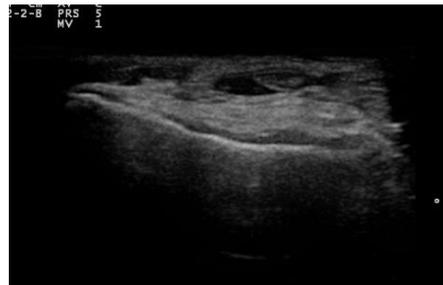
Daño condral y subcondral



1. hemartros



2. sinovitis



3. daño osteocondral

DISEASE ACTIVITY

SYNOVITIS

HYPERTROPHIC SYNOVIUM

0. Absent/Minimal	0
1. Mild/Moderate	1
2. Severe	2

DISEASE DAMAGE

ARTICULAR SURFACES

CARTILAGE

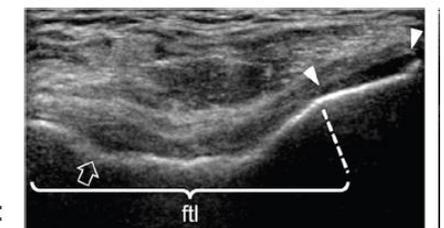
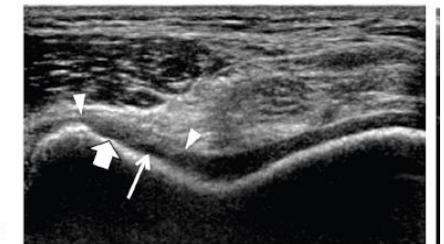
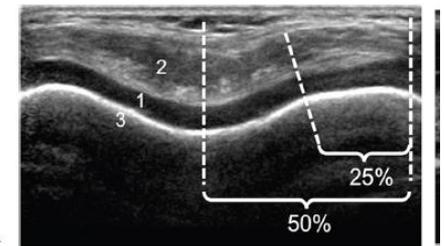
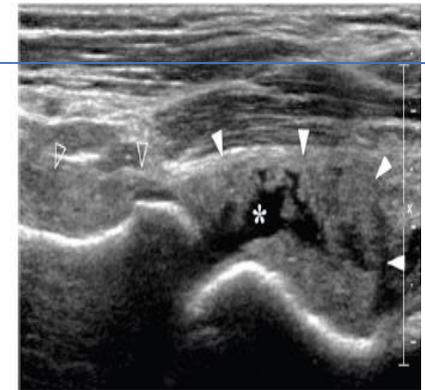
0. Normal	0
1. Echotexture abnormalities, Focal partial/full-thickness loss of the articular cartilage involving <25% of the target surfaces*	1
2. Partial/full-thickness loss of the articular cartilage involving at least ≤50% of the target surface*	2
3. Partial/full-thickness loss of the articular cartilage involving >50% of the target surface*	3
4. Complete cartilage destruction or absent visualization of the articular cartilage on the target bony surface*	4

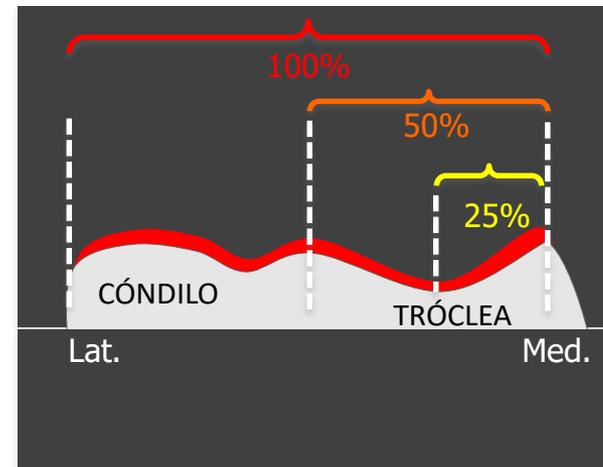
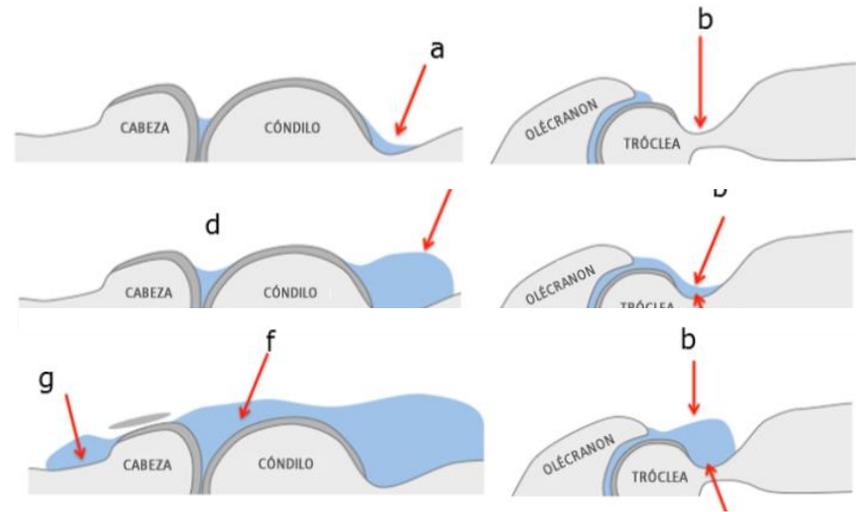
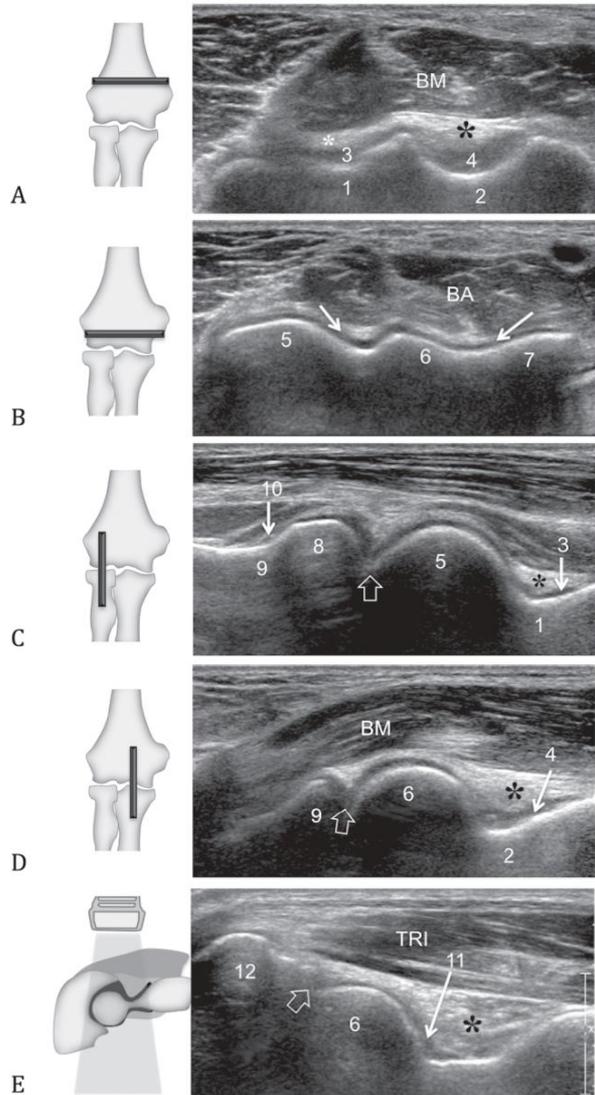
BONE

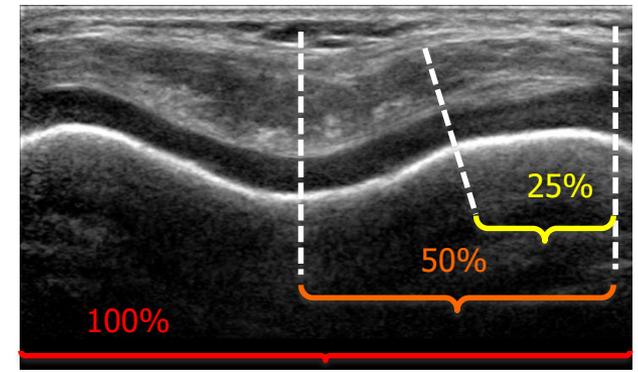
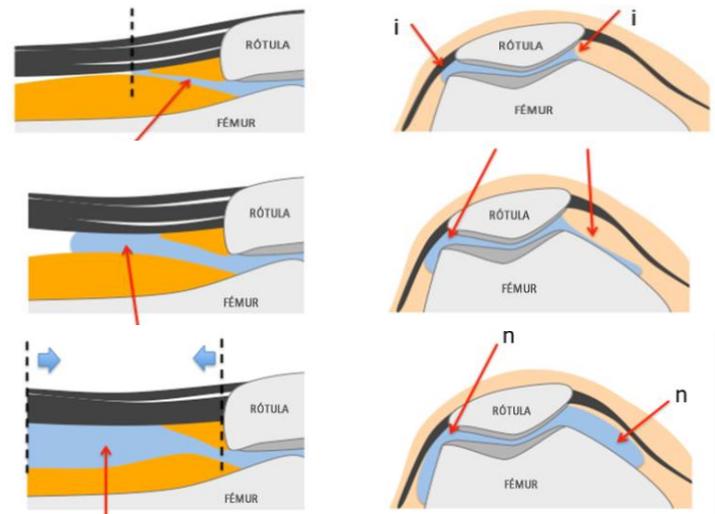
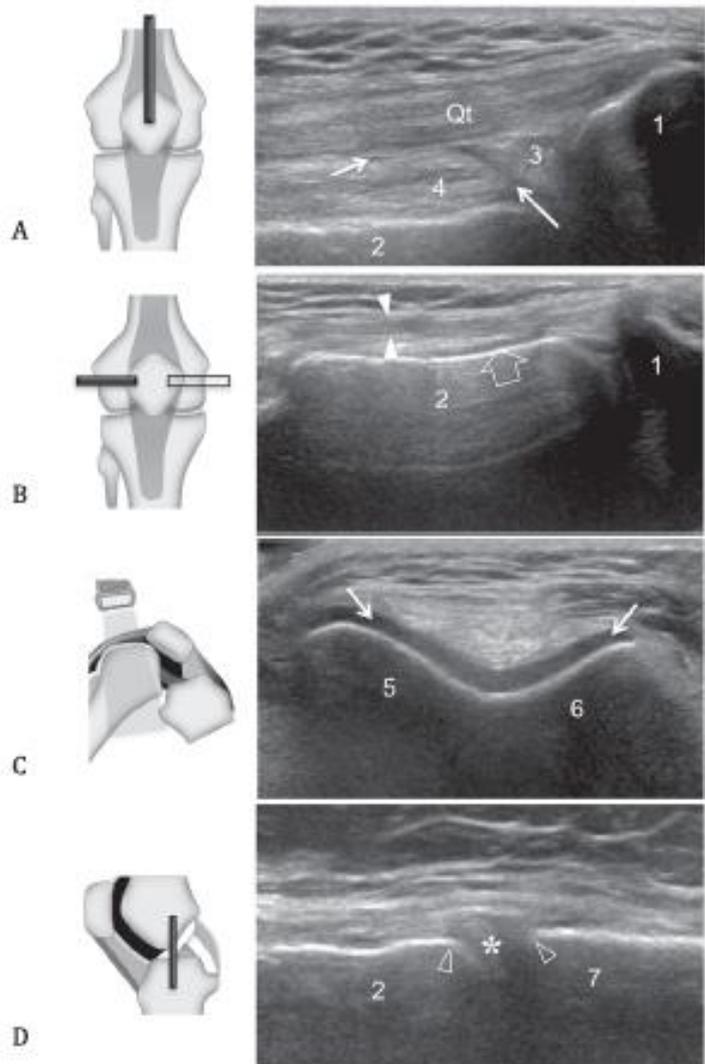
0. Normal	0
1. Mild irregularities of the subchondral bone with/without initial osteophytes around the joint	1
2. Deranged subchondral bone with/without erosions and presence of prominent osteophytes around the joint	2

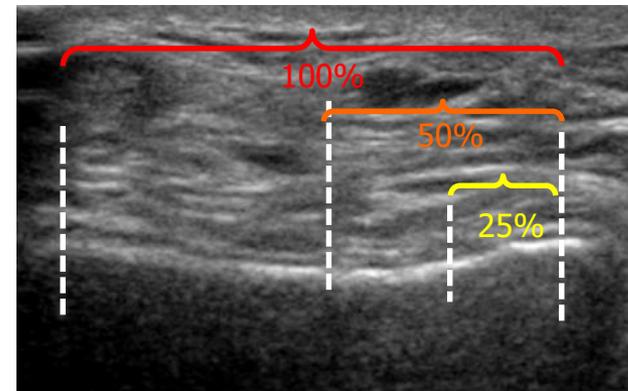
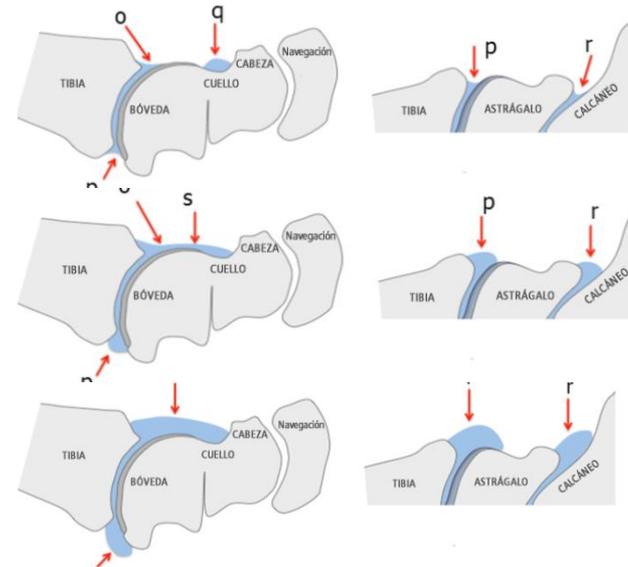
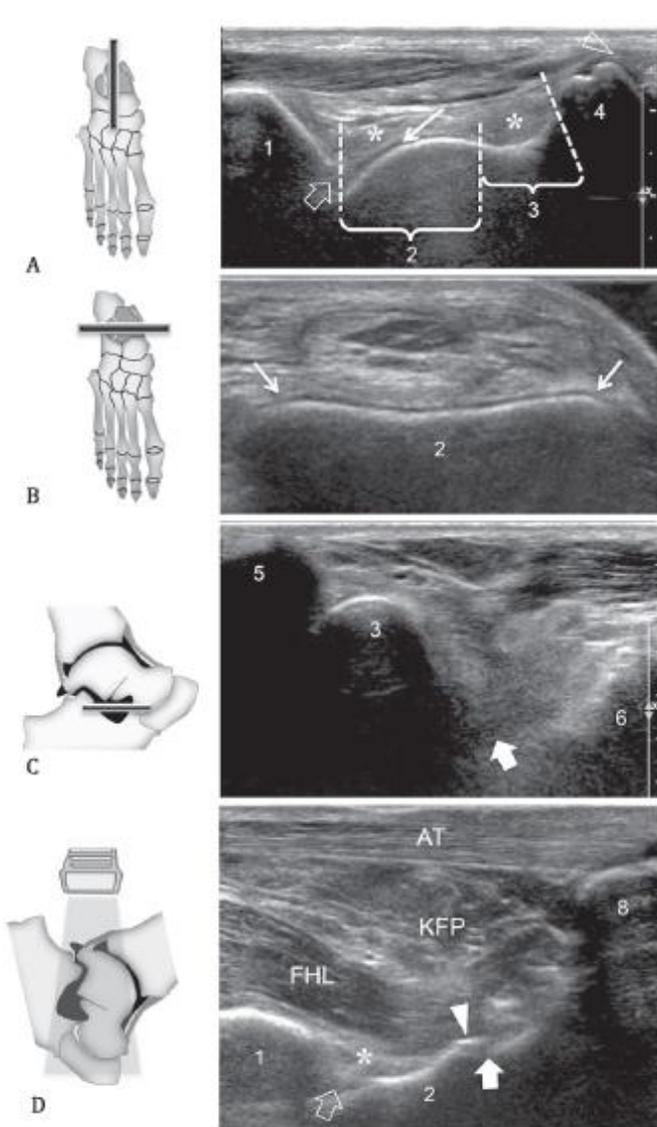
Notes:

- * ELBOW: anterior aspect of the distal humeral epiphysis
- * KNEE: femoral trochlea
- * ANKLE: anterior aspect of the talar dome











REVIEW ARTICLE

Choosing outcome assessment tools in haemophilia care and research: a multidisciplinary perspective

K. FISCHER,* P. POONNOOSE,† A. L. DUNN,‡ P. BABYN,§ M. J. MANCO-JOHNSON,¶
J. A. DAVID,** J. VAN DER NET,†† B. FELDMAN,‡‡ K. BERGER,§§ M. CARCAO,¶¶
P. DE KLEIJN,*** M. SILVA,††† P. HILLIARD,‡‡‡ A. DORIA,§§§ A. SRIVASTAVA¶¶¶ and
V. BLANCHETTE¶¶ ON BEHALF OF THE PARTICIPANTS OF THE INTERNATIONAL
SYMPOSIUM ON OUTCOME MEASURES IN HEMOPHILIC ARTHROPATHY^a

Table 2. Joint health assessment based on imaging.

Outcome tool	Disease-specific (SPEC) or generic (GEN)	Patient population (most suitable for)	Time	Setting (most useful in): Economically restricted/ unrestricted Clinic and/or research	Validated	Discrimination	Optimum interval	Additional research needed	Final recommendation	
									Clinic	Research
X-ray Petersson [22]	SPEC	Age > 6 Moderate-advanced joint changes	30 min/6 joints	Unrestricted More useful in Research than Clinic	Y	Y	3–5 years	Correlation with clinical function limited/unknown	O/R	R/M
X-ray Arnold Hilgartner [21]	SPEC	Age > 6 Moderate-advanced joint changes	30 min/6 joints	Unrestricted Research	N	Y	3–5 years		NR	NR
MRI IPSG scale [29]	SPEC	All ages Minimum-moderate joint changes -Sedation needed in young children	30 min/joint	Restricted -Specific clinical questions -Selected research	Y	Y	1–5 years	- Association of findings with clinical changes - Reversibility of changes - Assessment of	O (for specific information)	O/R
US radiologist operated [46–48]	SPEC	Age > 5–6 Minimum-moderate joint changes	20 min/joint	Unrestricted Clinic and Research	Y	Y	1–2 weeks (clinic) 1 year (research)	- Atlas of images - Assessment of haemosiderin, joint effusion, haemarthrosis - Correlation with clinical presentation	O/R	O
HEAD-US point of care [42,51]	SPEC	Age > 5–6 Minimum-moderate changes	3–5 min/joint	Unrestricted Clinic and Research	±Y	±Y	1–2 weeks (clinic) 1 year (research)	- Atlas of images - Performance in non-radiologists - Correlation with clinical presentation	O/R	O

Final recommendation: M, mandatory; O, optional; R, recommended; L, limited value; U, unknown; NR, not recommended.

Utilidades de POC-US

1. *Evaluación rutinaria articular*
2. *Diagnóstico diferencial del dolor articular*
3. *Seguimiento de lesiones*
4. *Procedimientos ecoguiados*



HSSJ
DOI 10.1007/s11420-018-9604-x

HSS Journal



REVIEW ARTICLE

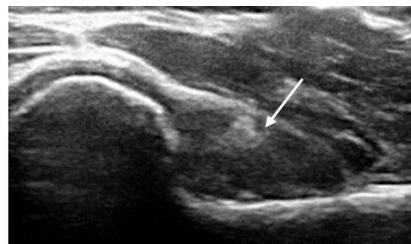
Point-of-care Ultrasonography in Orthopedic Management of Hemophilia: Multiple Uses of an Effective Tool

Hortensia De la Corte-Rodriguez, MD, PhD · E. Carlos Rodriguez-Merchan, MD, PhD ·
Victor Jimenez-Yuste, MD, PhD

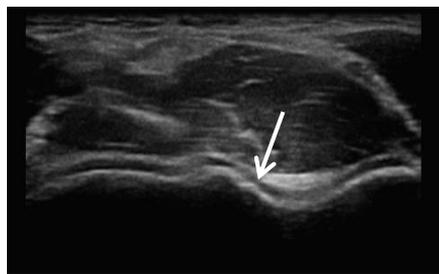
Received: 28 November 2017/Accepted: 25 January 2018
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Utilidades POC-US

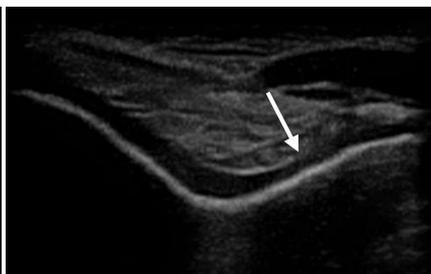
1. Evaluación rutinaria articular



Sinovitis en receso radial y olecraneano del codo



Codo



Rodilla



Tobillo

Daño osteocondral

ORIGINAL RESEARCH



The value of HEAD-US system in detecting subclinical abnormalities in joints of patients with hemophilia

Hortensia De la Corte-Rodriguez^a, E. Carlos Rodriguez-Merchan^b, M. Teresa Alvarez-Roman^c, Mónica Martin-Salca Carlo Martinoli^d and Víctor Jimenez-Yuste^c

Results: In our series, 14% of patients exhibited HEAD-US signs of incipient arthropathy in joints with no history of bleeding and with a HJHS 2.1 score of 0. The most severely involved joint was the right ankle. Synovitis, articular cartilage and subchondral bone damage scores in joints with subclinical findings were slower than in joints with previous hemarthroses or HJHS 2.1 > 1
Conclusions: Our study demonstrates that HEAD-US is better than hemarthrosis records and the HJHS 2.1 scale in detecting the early signs of joint damage in PWH.

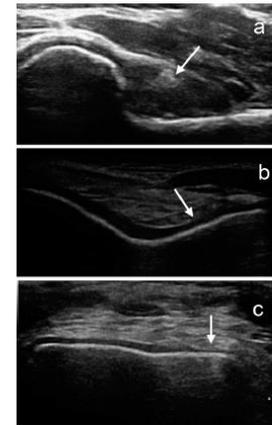


Figure 4. Examples of subclinical ultrasound findings. (a) Grade 1 synovitis in the radial recess of the elbow (arrow). (b) Grade 1 chondral damage in the femoral thurachlea of the knee (arrow). (c) Grade 1 chondral damage in the talar dome of the ankle (arrow).

Table 3. Previously reported studies on the role of US to know the articular status of hemophilia patients.

Authors [Reference]	Patients number	Age	Treatment regimen	Joints number	History of hemarthroses	Clinical signs	US protocol	Articular abnormalities in US	Articular abnormalities in US when no hemarthroses or clinical findings
Altisent et al. [37]	25	8.3 (median)	Prophylaxis	124	Annual rate 0.2 (median)	HJHS 1.8 (mean)	HEAD-US [22]	21%	19.6% when HJHS 2.1 = 0 (n = 107)
Foppen et al. [20]	32	11.5 (median)	Prophylaxis	64	Lifetime 3 (median)	HJHS 0 (median)	HEAD-US [22]	7.9%	0% when bleeding = 0, 1.8% when HJHS 2.1 = 0 (n = 56)
Timmer et al. [25]	15	53 (median)	Different regimens	76	-	HJHS 0 (median)	HEAD-US [22]	36%	2% when HJHS 2.1 = 0 (n = 46)
Di Minno et al. [38]	20	23.9 (mean)	Different regimens	40	Lifetime 0 (mean)	Asymptomatic joints	Zukotynski protocol [41]	55% synovitis, 80% chondral damage	55% synovitis, 80% chondral damage when no hemarthroses or clinical findings (n = 40)
Poonnoose et al. [16]	51	15 (median)	-	55	At least 1	HJHS 0-16 (range)	Doria protocol [33]	100%	100% synovitis and 75% osteochondral damage when HJHS 2.1 = 0 (n = 4)
Sierra-Aisa et al. [39]	30	4-82 (range)	Different regimens	120	-	Different signs in Gilbert score	Zukotynski protocol [41]	29% of the knees and 51% of the ankle	-
Kidder et al. [18]	34	39.3 (mean)	-	65	-	Acute or chronic articular pain	Full joint US assessment	Up to 76.5%	-

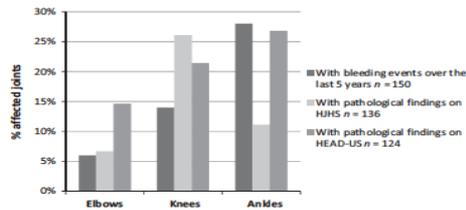
HJHS 2.1: Hemophilia Joint Health Score version 2.1; HEAD-US: Hemophilia Early Arthropathy Detection with Ultrasound; US: Ultrasound.



ORIGINAL ARTICLE *Clinical haemophilia*

Early prophylaxis in children with severe haemophilia: clinical and ultrasound imaging outcomes

C. ALTISENT,* M. MARTORELL,* A. CRESPO,† L. CASAS,‡ C. TORRES



In conclusion, we found a low joint bleeding rate and well-preserved joint status evaluated by clinical assessment in our cohort of children and adolescents with severe HA receiving FVIII prophylaxis at median doses of $65.4 \text{ IU kg}^{-1} \text{ week}^{-1}$. High-resolution ultrasound detected a higher percentage of abnormalities than the physical evaluation, but this procedure is still not validated and the significance of these findings is uncertain. Whether the ultrasound changes detected in this population correspond to haemophilia-related abnormalities, non-disease-specific changes or simply misinterpretations remain to be established. Future prospective evaluations of our cohort will further characterize their joint status and may help to validate the outcome measures used in young, severe HA patients on prophylaxis.



ORIGINAL ARTICLE *Musculoskeletal*

Value of routine ultrasound in detecting early joint changes in children with haemophilia using the ‘Haemophilia Early Arthropathy Detection with UltraSound’ protocol

W. FOPPEN,* I. C. VAN DER SCHAAF* and K. FISCHER†‡

Routine ultrasound assessment of joints in children with moderate or severe haemophilia on prophylaxis showed early joint abnormalities, mostly in joints with low HJHS scores. The ability of ultrasound to visualize anatomical joint abnormalities could be used for follow-up of abnormalities and to evaluate whether minimal losses of clinical function might be caused by anatomical changes.

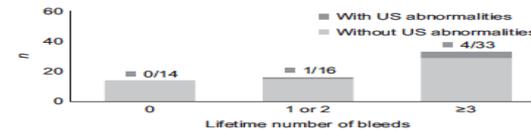


Fig. 1. Ultrasound abnormalities according to lifetime reported bleeding.

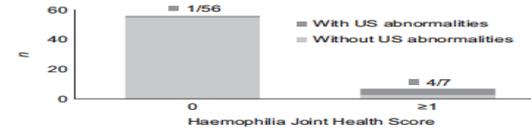
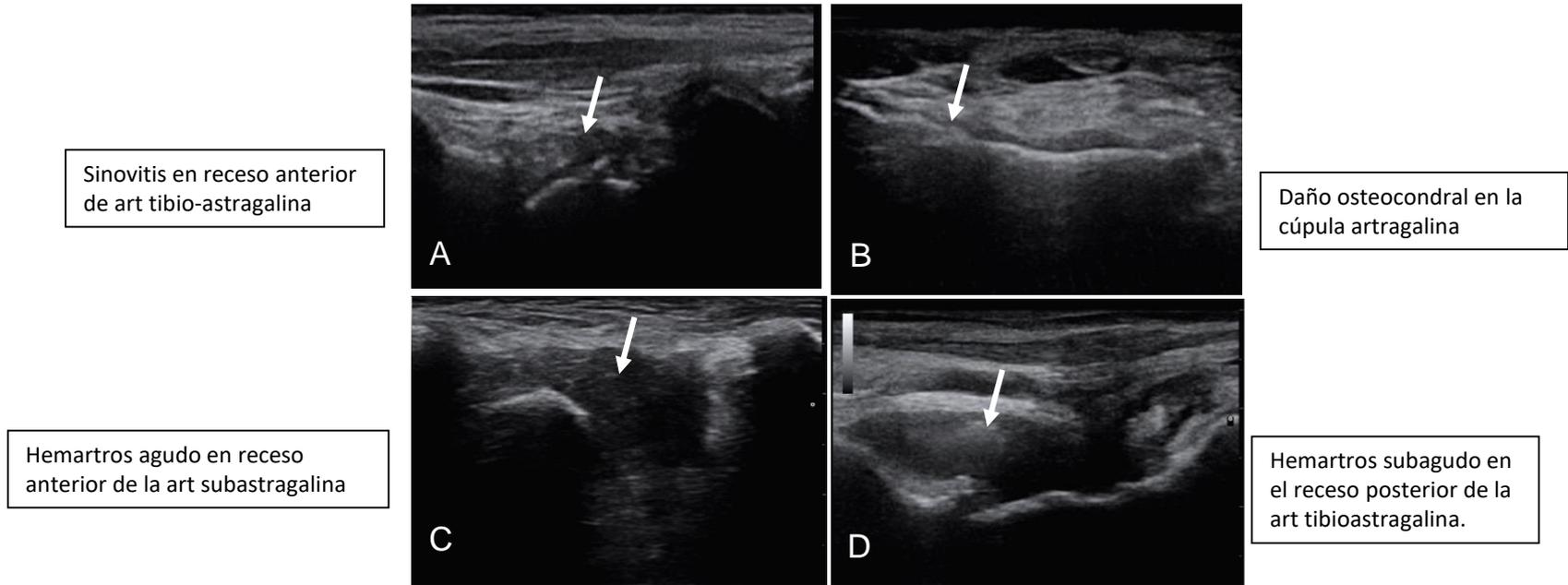


Fig. 2. Ultrasound abnormalities according to Haemophilia Joint Health Scores.

Utilidades POC-US

2. Diagnóstico diferencial del dolor articular





ORIGINAL ARTICLE *Musculoskeletal*

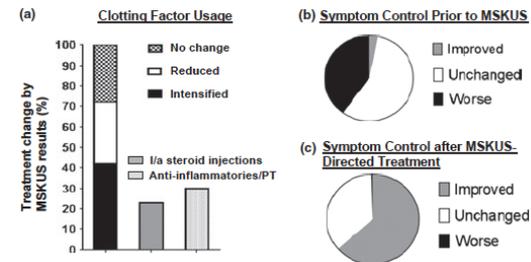
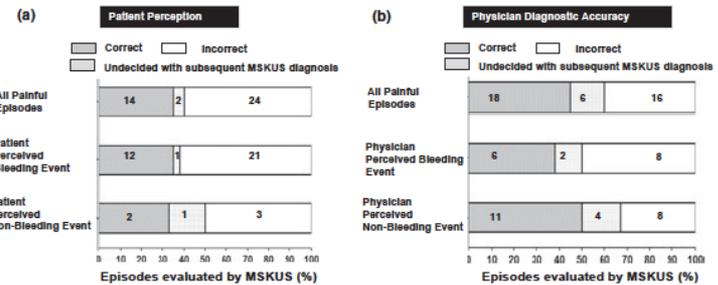
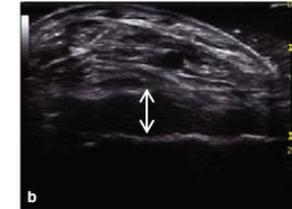
Rapid musculoskeletal ultrasound for painful episodes in adult haemophilia patients

A. CEPONIS,* I. WONG-SEFIDAN,† C. S. GLASS† and A. VON DRYGALSKI†‡

Summary. Little objective information exists about musculoskeletal bleeding patterns in haemophilic arthropathy. Bleeding is assumed to be the cause of painful joints or muscles. Clotting factor treatment is provided empirically, but often does not alleviate pain. We hypothesized that perception of pain aetiology is unreliable, and introduced point-of-care high-resolution musculoskeletal ultrasound (MSKUS) to differentiate intra-articular bleeds vs. joint inflammation, and intra-muscle bleeds vs. other regional pain syndromes. To assess painful musculoskeletal episodes in adult haemophiliacs, we used rapid MSKUS, employing grey scale and power Doppler examination. Forty episodes in 30 adult haemophiliacs were evaluated. Thirty three of the 40 episodes were patient-reported as 'bleeding', five as 'arthritis-type' pain and two as 'undecided'. Of the 33 bleeding reports, only 12 were confirmed by MSKUS; the other episodes revealed other pathology. In contrast, three of five perceived arthritis

flares were reclassified as bleeds. Similarly, p assessment was incorrect in 18 of 40 instances. and warmth were present in approximately confirmed bleeding and non-bleeding episodes, and therefore not useful clinically. Few of the painful episodes were symptom controlled at the time of MSKUS. Management changed based on objective imaging findings in >70% of episodes, which resulted in symptom improvement >60% of the time. Significant discrepancies exist between MSKUS findings and patient/physician-perceived pain classification as bleeding or other musculoskeletal symptoms. Current practice of prescribing clotting factor or conservative measures based on pain perception seems inadequate and suggests that point-of-care imaging should be included into modern haemophilia care.

Keywords: arthritis, haemophilia, hemarthrosis, pain, synovitis, ultrasound



- Se detectaron hemartros <1/2 de los episodios de dolor articular.



ORIGINAL ARTICLE *Musculoskeletal*

Point-of-care musculoskeletal ultrasound is critical for the diagnosis of hemarthroses, inflammation and soft tissue abnormalities in adult patients with painful haemophilic arthropathy

W. KIDDER,* S. NGUYEN,** J. LARIOS,† J. BERGSTROM,§ A. CEPONIS¶ and A. VON DRYGALSKI***

Summary. We previously demonstrated in adult patients with haemophilia (PWH) that hemarthrosis is present in only ~1/3rd of acutely painful joints by using point-of-care-musculoskeletal ultrasound (MSKUS). Therefore, other unrecognized tissue abnormalities must contribute to pain. Using high resolution MSKUS, employing grey scale and power Doppler, we sought to retrospectively (i) investigate soft tissue abnormalities in painful haemophilic joints and (ii) to determine to what extent MSKUS findings, functional or radiographic joint scores correlate with biomarkers of inflammation in PWH. Findings were correlated with Hemophilia Joint Health Scores (HJHS), Pettersson scores, high sensitivity C-reactive protein and von Willebrand factor activity and antigen levels. A total of 65 MSKUS examinations for acute and chronic joint pains were performed for 34 adult haemophilia patients, mostly for chronic joint pain (72.3%). The most prominent findings (66.5%)

pertained to inflammatory soft tissue changes including synovitis, tendinitis, enthesitis, bursitis and fat pad inflammation. Effusions were present in 55.5% and 46.8% of MSKUS performed for acute and chronic pain, respectively. Of those, 90.0% were bloody during acute and 47.6% during persistent pains. While inflammatory biomarkers correlated well with overall HJHS and total Pettersson scores ($P < 0.05$), they did not differ between those patients with synovitis and those without. MSKUS is emerging as an important modality to diagnose treatable musculoskeletal abnormalities contributing to pain in haemophilic arthropathy, and therefore seems critical for a personalized approach to haemophilia care. The role of biomarkers in this setting remains less clear and requires further investigation.

Keywords: arthropathy, bleeding, haemophilia, pain, synovitis, ultrasound

Edad media 39 años



Table 4. Ultrasound effusions.

	Acute pain visits (N = 18)	Persistent pain visits (N = 47)
Complex effusion (bloody)	9 (in 9 different joints)	10 (in 6 different joints)
Simple effusion (n on-bloody)	1 (in 1 joint)	11 (in 11 different joints)
Effusion absent	7 (in 7 different joints)	24 (in 20 different joints)
Indeterminate	1 (in 1 joint)	2 (in 1 joint)

Table 3. Inflammatory vs. chronic changes of joint damage seen on ultrasound.

	Acute inflammatory changes (N = 65)	Chronic degenerative changes (N = 51)*
Bone/cartilage		
Degenerative cartilage changes	na	39 (76.5%)
Osteophyte formation	na	32 (62.7%)
Synovium		
Synovitis and/or fat pad hyperemia	35 (53.8%)	na
Hypertrophy	na	34 (66.7%)
Tendon		
Tendinitis	6 (9.2%)	na
Tendinosis	na	5 (9.8%)
Ligament		
Enthesopathy	0	11 (21.6%)
Tear	2 (3.1%)	na
Sprain	6 (9.2%)	na
Bursa		
Bursitis	2 (3.1%)	na
Nerve		
Thickening/impingement	na	2 (3.9%)

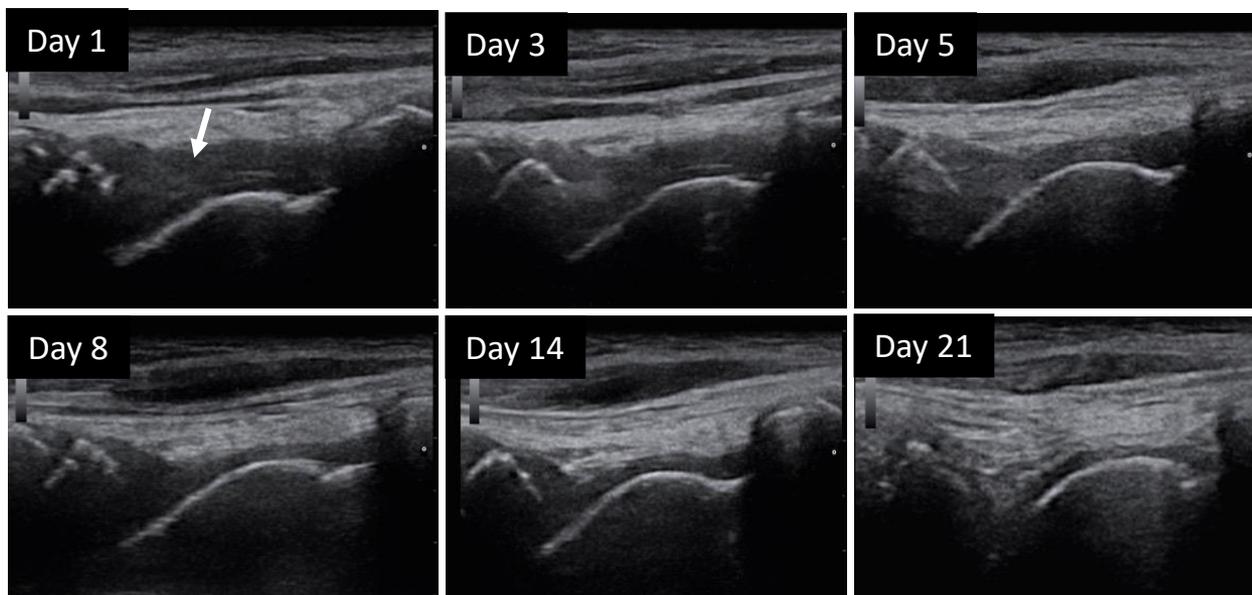
na, non-applicable.

*Excludes 14 ultrasounds performed for repeat patient visits for the same joint.

Con dolor agudo 2/3 presentaron sinovitis, tendinitis, esguinces, bursitis. Con dolor cronico 2/3 presentaban hipertrofia sinovial, daño condral y osteofitos

Utilidades POC-US

3. Seguimiento de lesiones



Hemartros en la tibiotalar de un niño de 9 años (flecha), el POC-US nos ayudó a hacer el diagnóstico y seguimiento



ORIGINAL ARTICLE *Musculoskeletal*

Ultrasonography of haemophilic arthropathy

M. MUÇA-PERJA, S. RIVA, B. GROCHOWSKA, L. MANGIAFICO, D. MAGO and A. GRINGERI

In conclusion, joint damage as assessed by ultrasonography is highly frequent particularly in ankles of adults treated on demand. Ultrasonography represents a valid and sensitive tool in the diagnosis and monitoring of joint status of patients with haemophilia.

Score	Knee	Ankles
Synovial hypertrophy	Absent Small (area <1 cm ²) Moderate (area 1–2 cm ²) Severe (area >2 cm ²)	Absent Small (area <0.5 cm ²) Moderate (area 0.5–1 cm ²) Severe (area >1 cm ²)
Synovial hyperaemia	Absence Minimal signal (1 spot) Moderate signal (2–3 spots) Maximal signal (>3 spots)	Absence Minimal signal (1 spot) Moderate signal (2–3 spots) Maximal signal (>3 spots)
Cartilage abnormalities	Normal Loss of anechogenicity and sharpness, thinning Cartilage loss <50% Cartilage loss ≥50%	Normal Loss of anechogenicity and sharpness, thinning Cartilage loss <50% Cartilage loss ≥50%
Bone erosion	Absence Presence	Absence Presence

Summary. Imaging is an essential tool for evaluation and monitoring of haemophilic arthropathy. Ultrasonography is increasingly used for joint assessment, due to its great sensitivity for soft tissue and relatively low cost. To assess the joint status and the role of ultrasonography in routine diagnosis and monitoring of joint disease in cohort haemophilic patients. Findings of patients with haemophilia, who routinely underwent ultrasonography were retrospectively evaluated to assess their joint status and the role of ultrasonography in routine diagnosis and monitoring of joint disease. Out of 325 joints examined (115 ankles, 210 knees), ultrasonography identified damages in 50% of ankles and 33% of knees in overall 111 patients, aged 7–80 years (median = 29 years). Synovial hypertrophy

and cartilage abnormalities were the most frequent observations (88% and 76% in affected knees, respectively). Pristine joints were more frequently found in patients on primary prophylaxis, young age or no bleeding in the year prior to examination. Furthermore, no concordance was found between presence of joint changes at ultrasonography, and clinical joint status. Ultrasonography was shown to be able to detect joint damage involving soft tissues and bone surface. Its use might allow frequent monitoring of patients with haemophilia and early detection of arthropathy. For these reasons it might represent a valid tool in the routine management of haemophilia.

Keywords: haemophilia, joint status, ultrasonography



Ultrasonography in the monitoring of management of haemarthrosis

J. A. AZNAR, L. ABAD-FRANCH, S. PEREZ-ALENDA, S. HAYA, A. R. CID and F. QUEROL
University Hospital La Fe, Thrombosis and Haemostasis Unit, Haematology Service, Valencia, Spain

Table 2. Ultrasound findings on day +7 in patients without previous chronic synovitis.

Patient	Joint	Day +3		Day +7			No. of days treatment
		Pain	Bleed	Pain	Bleed	Synovitis	
1	Right ankle	Yes	Yes	No	No	Yes	12
2	Right hip [†]	Yes	Yes	No	No	No	30
3	Right knee*	No	Yes	No	No	Yes	12
4	Left knee*	No	Yes	No	No	No	5
5	Left hip	Yes	Yes	No	Yes	Yes	13
6	Right ankle	Yes	Yes	No	Yes	Yes	12
7	Left hip	Yes	Yes	No	Yes	No	19
8	Left ankle	Yes	Yes	No	Yes	Yes	4
9	Left ankle	Yes	Yes	No	No	No	4
10	Left shoulder	No	Yes	No	No	No	7

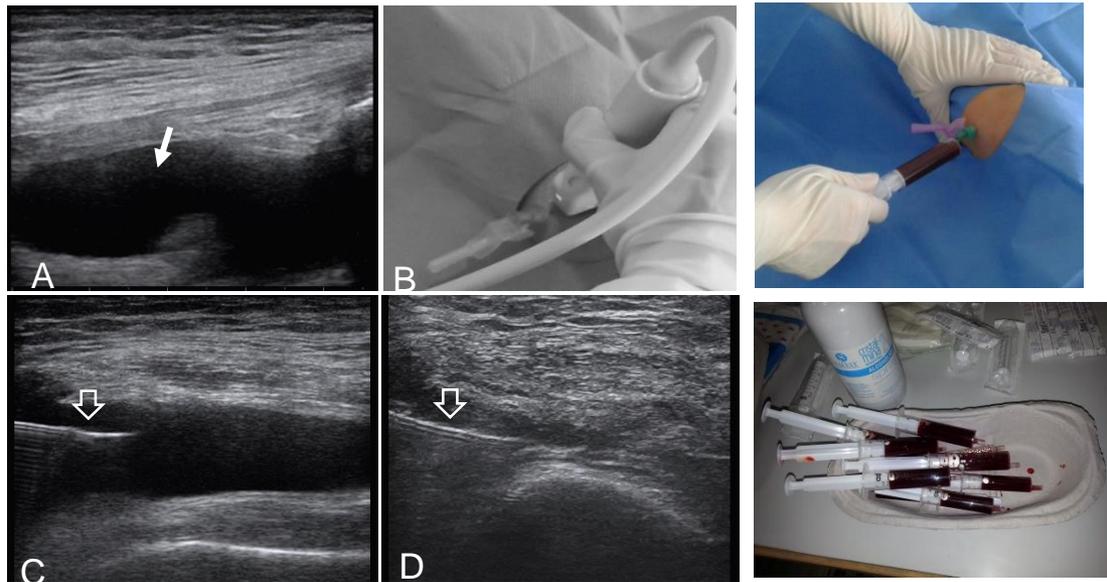
*A joint bleed evacuation was performed on day 0.

[†]As patient suffered from severe HA + inhibitors, treatment was followed over 1 week until complete motility was recovered despite the absence of ultrasound findings.

These ultrasound data demonstrate the persistence of joint alterations (in terms of joint effusion or synovial inflammation) while cessation of pain and clearly suggest that treating joint bleeding episodes during 1–3 days can often be insufficient for the complete healing of an acute haemarthrosis. Therefore, we strongly recommend that systematic ultrasound explorations are performed with own resources at the Haemophilia Treatment Centres in all muscle-skeletal haemorrhages to ensure that intensive replacement therapy is maintained while joint bleeding or acute synovitis persists, the patient symptoms notwithstanding.

Utilidades POC-US

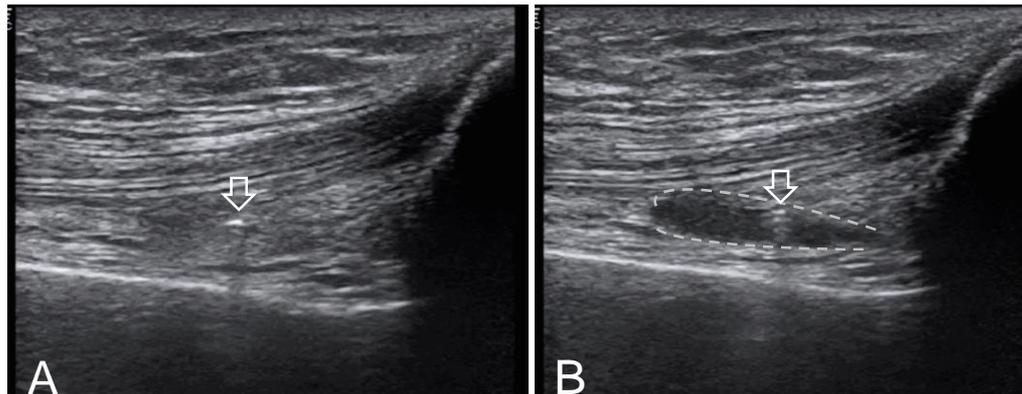
4. Procedimientos ecoguiados- ARTROCENTESIS



Hemartros agudo de rodilla en un paciente hemofílico. La ecografía nos ayudo ha hacer el drenaje ecoguiado.

Utilidades POC-US

4. Procedimientos ecoguiados- INFILTRACIONES MSK



Infiltración intra-articular de una rodilla en un paciente hemofílico, la guía ecográfica ayuda a la correcta posición de la aguja en el lugar deseado



Optimal Needle Placement for Ultrasound-Guided Knee Joint Injections or Aspirations

Boqing Chen¹, Lawrence P Lai^{2*}, Nitin Putcha², Todd P Stitik¹, Patrick M Foye¹ and Joel A DeLisa¹

¹New Jersey Medical School, Department of Physical Medicine and Rehabilitation, Newark, NJ, USA

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Abstract

Although the inferomedial and inferior midline approaches are commonly used for intra-articular injection or aspiration of the knee joint, they may not be ideal for optimal needle placement. With these approaches, the fat pad may be contacted, which may lead to the injection of medication in the incorrect region, cause severe pain during the injection procedure, or present a false sign of low yield of fluid aspiration. Therefore, the objective of this study was to compare various approaches for knee injection and aspiration to identify the optimal one for needle placement. In this retrospective study, the ultrasound images of bilateral knee joints in 33 consecutive patients with knee pain were studied. This patient population was divided into two groups: Group A with knee effusions (n=10) and Group B without knee effusions (n=23). The results showed that among 90% of patients in Group A and 100% of patients in Group B, the superolateral view allowed visualization of the greatest amount of intra-articular knee fluid and the least amount of fat pad. In conclusion, the ultrasound-guided superolateral approach appears to be an optimal approach for knee intra-articular injection or aspiration compared to the conventional inferomedial and inferior midline approaches.

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SPECIAL ARTICLE

Ultrasound in American Rheumatology Practice: Report of the American College of Rheumatology Musculoskeletal Ultrasound Task Force

AMERICAN COLLEGE OF RHEUMATOLOGY MUSCULOSKELETAL ULTRASOUND TASK FORCE

Efficacy and safety of point-of-care ultrasound-guided intra-articular corticosteroid joint injections in patients with haemophilic arthropathy

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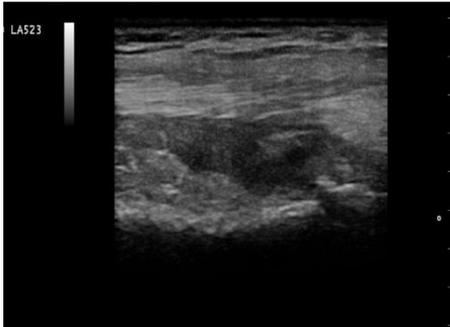
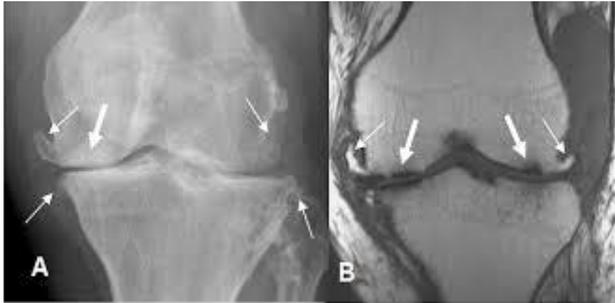
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Conclusion

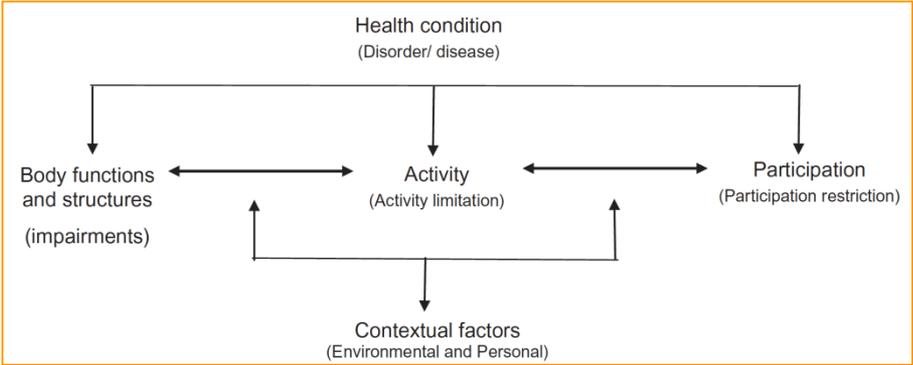
In summary, our results demonstrate that ultrasound-guided corticosteroid injections for painful haemophilic joints are safe and clinically efficacious, increasing the armamentarium of options for point-of-care pain management in clinic. Next steps would be to determine predictors of durable response, considering clinical and imaging findings that include vascularity changes in association with bleeding states. In the long term, however, new knowledge about the pathobiology of progressive haemophilic arthropathy is paramount to enable the discovery of novel molecular therapeutic targets to advance alternative and intra-articular treatment strategies for this disabling complication of haemophilia.

EF

Imagen



Funcional



Valoración funcional

FISH

Eating and grooming
Bathing
Dressing
Transfers-sitting
Transfers-squatting
Going up a step
Walking
Running

HAL

Lying/sitting/kneeling/standing
Functions of the legs
Functions of the arms
Use of transportation
Self-care
Household tasks
Leisure activities and sports

Se recomienda usar los dos instrumentos complementarios.
Medir diferentes dominios

Functional Independence Score in Hemophilia (FISH)

FUNCTIONAL INDEPENDENCE SCORE IN HEMOPHILIA (FISH)

Performance based instrument

Patient Name:	Patient Code:
	Today (dd/mm/yyyy): ___ / ___ / ___.
A. Self Care	
1. Eating and grooming	<input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4
2. Bathing	<input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4
3. Dressing	<input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4
B. Transfers	
4. Chair	<input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4
5. Squatting	<input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4
C. Locomotion	
6. Walking	<input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4
7. Stairs (12 - 14 steps)	<input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4
8. Running	<input type="radio"/> 1 <input type="radio"/> 2 <input type="radio"/> 3 <input type="radio"/> 4
Total Score	

No requiere validación transcultural porque no es autoadministrable.

Scores range from 1 - 4 depending on the degree of independence (see scoring key)

Comments:

4. The subject is able to perform the activity without any difficulty like other healthy peers.
3. The subject is able to perform the activity without aids or assistance, but with slight discomfort. He is unable to perform the activity like his healthy peers.
2. The subject needs partial assistance/ aids/ modified instruments/ modified environment to perform the activity.
1. The subject is unable to perform the activity, or needs complete assistance to perform the activity.

Haemophilia Activities List (HAL)

Requiere a validación transcultural

Lying down/ sitting / kneeling / standing

In the previous month, did you have any difficulty with:

- Sitting down (e.g. on a chair or couch)
- Rising from a chair with armrests
- Rising from a chair without armrests
- Kneeling / squatting
- Bending forward
- Kneeling for a longer period of time
- Squatting for a longer period of time
- Standing for a longer period of time

Functions of the arms

In the previous month, did you have any difficulty with:

- Lifting heavy objects
- Carrying heavy objects in the arms
- Fine hand movements (e.g. closing buttons)
- Reaching above your head (to pick something up from a high shelf)

Household tasks

In the previous month, did you have any difficulty, due to hemophilia, with:

- Going out shopping (for food, drink etc.)
- Washing the dishes, cleaning the sink
- Cleaning the house
- Other household tasks (ironing, making the beds)
- Doing odd jobs (both in and around the house)
- Gardening

	n/a	Impossible	Always	Mostly	Sometimes	Rarely	Never
Going out shopping (for food, drink etc.)	<input type="checkbox"/>						
Washing the dishes, cleaning the sink	<input type="checkbox"/>						
Cleaning the house	<input type="checkbox"/>						
Other household tasks (ironing, making the beds)	<input type="checkbox"/>						
Doing odd jobs (both in and around the house)	<input type="checkbox"/>						
Gardening	<input type="checkbox"/>						

Use of transportation

In the previous month, did you have any difficulty with:

- Riding a bicycle
- Getting in and out of a car
- Using public transportation (bus, train, subway)

Functions of the legs

In the previous month, did you have any difficulty with:

- Walking short distances (less than 1 kilometer / 15 minutes)
- Walking long distances (more than 1 kilometer / 15 minutes)
- Walking on a soft surface (e.g. on the beach or through the woods)
- Walking on an uneven surface (e.g. cobblestones, high sidewalks)
- Strolling / (window-)shopping
- Climbing up the stairs
- Climbing down the stairs
- Running (e.g. in order to catch the bus)
- Jumping

Self care

In the previous month, did you have any difficulty with:

- Drying your whole body
- Putting on a shirt, sweater etc.
- Putting on sock and shoes
- Putting on a tie or closing the top button of a shirt
- Going to the toilet

Leisure activities and sports

In the previous month, did you have any difficulty, due to hemophilia, with:

- Playing games (outdoors, e.g. with your children)
- Sports
- Going out (theatre / museum / movie theatre / bar)
- Hobbies
- Dancing
- Going on a holiday (active)
- Going on a holiday ("passive"; beach-/hotel holiday)

	n/a	Impossible	Always	Mostly	Sometimes	Rarely	Never
Playing games (outdoors, e.g. with your children)	<input type="checkbox"/>						
Sports	<input type="checkbox"/>						
Going out (theatre / museum / movie theatre / bar)	<input type="checkbox"/>						
Hobbies	<input type="checkbox"/>						
Dancing	<input type="checkbox"/>						
Going on a holiday (active)	<input type="checkbox"/>						
Going on a holiday ("passive"; beach-/hotel holiday)	<input type="checkbox"/>						

Pediatric HAL (PedHAL)

PedHAL

Sitting/kneeling/standing

Functions of the legs

Functions of the arms

Use of transportation

Self-care

Household tasks

Leisure activities and sports

Pediatric Haemophilia Activities List

Parents' version

An activities questionnaire for children aged 4-14 with haemophilia.

En proceso de validación

3. Valoración funcional

*

Health Assessment Questionnaire (HAQ)

	Durante la <u>última semana</u> , ¿ha sido usted capaz de...	Sin dificultad	Con alguna dificultad	Con mucha dificultad	Incapaz de hacerlo
Vestirse y asearse	1) Vestirse solo, incluyendo abrocharse los botones y atarse los cordones de los zapatos?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	2) Enjabonarse la cabeza?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Levantarse	3) Levantarse de una silla sin brazos?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	4) Acostarse y levantarse de la cama?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Comer	5) Cortar un filete de carne?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	6) Abrir un cartón de leche nuevo?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	7) Servirse la bebida?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Caminar	8) Caminar fuera de casa por un terreno llano?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	9) Subir cinco escalones?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Higiene	10) Lavarse y secarse todo el cuerpo?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	11) Sentarse y levantarse del retrete?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	12) Ducharse?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Alcanzar	13) Coger un paquete de azúcar de 1 Kg de una estantería colocada por encima de su cabeza?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	14) Agacharse y recoger ropa del suelo?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Prensión	15) Abrir la puerta de un coche?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	16) Abrir tarros cerrados que ya antes habían sido abiertos?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	17) Abrir y cerrar los grifos?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Otras	18) Hacer los recados y las compras?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	19) Entrar y salir de un coche?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	20) Hacer tareas de casa como barrer o lavar los platos?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Otras genéricas:
HAQ, I Katz, I.
Barthel, FIM

Calidad de vida

Table 1. Overview of QoL instruments for use in patients with haemophilia.

Type of instrument	Target age group	
	Children	Adults
Generic	KINDL [19]	Northingham Health Profile (NHP) [20]
	CHQ [21]	Quality of Well-being Index (QWB) [22]
	TACQOL [23]	Sickness Impact Profile (SIP) [24]
	PedsQL [25]	SF-36 Health Survey (SF-36) [26]
	-	EQ-5D [27]
	-	WHOQoL Questionnaire [28]
Haemophilia-specific*	Haemo-QoL [29]	Medtap [30]
	CHO-KLAT [31]	Haem-A-QoL [32]
	HemDax [33]	Haemofilia-QoL [34]
	QoL for young children [35]	Hemolatin-QoL [36]
	QUAL-Hemo [37]	QUAL-Hemo [37]

*Only two of the haemophilia-specific quality of life (QoL) instruments include a dimension to assess sports activities: the paediatric instrument Haemo-QoL and the adult instrument Haem-A-QoL.

Es una construcción multidimensional que incluye el bienestar físico, emocional y social

Table 11.1 Studies assessing HRQoL with disease-specific measures in hemophilia

Year	Authors	Country	Participants	Sample (n)	Measure
2000	Bullinger et al. [6]	6 European countries	Children/adolescents and parents	58*	Haemo-QoL
2004	v. Mackensen et al. [7]	6 European countries	Children/adolescents and parents	339#	Haemo-QoL
2004	Young et al. [8]	Canada	Children/adolescents and parents	50**	CHO-KLAT
2004	Arranz et al. [9]	Spain	Adults	73**	Hemofilia-QoL (version 1.0)
				35*	
2005	Remor et al. [5]	8 Latin-American countries	Adults	50**	Hemolatin-QoL
2005	Remor et al. [10]	Spain	Adults	121#	A36 Hemofilia-QoL
2005	v. Mackensen et al. [11]	Italy	Adults	233#	Hemo-A-QoL
2006	Guérois et al. [12]	France	Children/adolescents and parents, adults	70**	QUAL HEMO
2008	Rentz et al. [13]	Germany, Spain, USA, Canada	Adults	221#	Haemo-QoL-A

*Pilot testing, psychometric; **Development study; #Psychometric field study. CHO-KLAT (Canadian Haemophilia Outcomes – Kids Life Assessment Tool); Haemo-QoL (Children's Haemophilia Quality-of-life questionnaire); Haemo-QoL-A (Adults Haemophilia Quality-of-life questionnaire) A36 Hemofilia-QoL (Adults Haemophilia Quality of Life questionnaire); HemoLatin-QoL (Adults Haemophilia Quality of Life questionnaire); Hemo-A-QoL (Haemophilia QoL questionnaire for adults).

Table 11.2 HRQoL instruments for hemophilia available

Children (C/P version)	Age groups	Adults	Age focus
Cho-KLAT	4–7 (C/P), 8–12 (C/P), 13–17 (C/P)	A36 Hemofilia-QoL	> 17 years old
Haemo-QoL	4–7 (C/P), 8–12 (C/P), 13–17 (C/P)	Haemo-QoL-A	> 18 years old
QUAL HEMO	2–12 (C/P), 13–17	QUAL HEMO	> 18 years old
		Haem-A-QoL	> 18 years old
		HemoLatin-QoL	> 17 years old

C/P, Child/parents.

Tabla 3. Instrumentos utilizados en investigación para medir la CV en pacientes con hemofilias adultos

Instrumento	Autor(es)	Versiones y año de publicación	Objetivo	Población	Estructura	Específico para hemofilia	Confiabilidad y/o valides	Referencia o acceso
SF-36 (The Short Form Health Survey)	Ware y Sherbourne (1992)	Versión 1: 1992	Evaluar CV relacionada con la salud	Desde los 14 años en adelante	36 ítem y 8 dimensiones: 1) Función física; 2) rol físico; 3) dolor corporal; 4) salud general; 5) vitalidad; 6) funcionamiento social; 7) rol emocional y 8) salud mental	No	Consistencia interna= 0,76 para la dimensión de funcionamiento social y 0,8 para el resto de las dimensiones.	Ware, J.E., & Sherbourne, C.D. (1992). The MOS 36-Item Short-Form Health Survey (SF-36®): I. conceptual framework and item selection. <i>Med Care</i> , 30(6), 473-83.
		Versión 2: 1996						http://www.sf-36.org/tools/sf36.shtml#MODEL
	Alonso, Prieto & Antó (1995)	Adaptación española: 1995						Alonso, J., Prieto, L., y Antó, J.M. (1995). La versión española del 'SF-36® Health Survey' (Cuestionario de Salud SF-36®): un instrumento para la medida de los resultados clínicos. <i>Med Clin (Barc)</i> , 104(20), 771-6.
A36 Hemofilia-QoL	Arranz y Remor	Única versión: 2005	Evaluar la CV en adultos con hemofilia	Mayores de 17 años	36 ítems que cubren 9 dominios: salud física, actividades diarias, daño articular, dolor, satisfacción con el tratamiento, dificultades con el tratamiento, funcionamiento emocional, salud mental, relaciones y actividad social.	Sí	confiabilidad de 0,95 y valides con un rango entre 0,49 y 0,77 según la sub-escala	Referencias del instrumento original: Remor, E., Arranz, P., Quintana, M., Villar, A., Jiménez-Yuste, V., Díaz, J.L., ... Hemofilia-QoL Project Group. (2005). Psychometric field study of the new haemophilia quality of life questionnaire for adults: the Hemofilia-QoL. <i>Haemophilia</i> , 11(6), 603-10. Arranz, P., Remor, E., Quintana, M., Villar, A., Díaz, J.L., Moreno, M., ... Hemofilia-QoL Group. (2004). Development of a new disease-specific quality-of-life questionnaire to adults living with haemophilia. <i>Haemophilia</i> 10(4), 376-82
Hemolatin qol - Cuestionario Latinoamericano Para la Evaluación de la CV en Adultos con Hemofilia	Remor	2002	Evaluar la CV en adultos con hemofilia	Mayores de 18 años	47 ítems que evalúan: funcionamiento físico; funcionamiento emocional; apoyo social percibido; actividades y funcionamiento social; tratamiento médico; salud mental; satisfacción con las condiciones del entorno; bienestar general; salud general.	Sí	No hay datos	Remor, E. (2005). Desarrollo de una medida específica para la Evaluación de la CV en Pacientes Adultos Viviendo con Hemofilia en América-Latina: el Hemolatin-QoL. <i>Revista Interamericana de Psicología</i> , 39(2), 211-220. Proyecto de investigación en desarrollo. http://hemolatin-qol.info/

Table 2. Common domains of haemophilia-specific quality of life (QoL) questionnaires for adult patients.

Aspects	Specific domains			
	Medtap	Haem-A-QoL	Hemofilia-QoL	
Physical	Physical functioning	Physical health	Physical health	
	–	Sports and leisure	Joint damage	
	–	–	Pain	
Functional	Role functioning	Work and school	Daily functioning	
	Social	Psychosocial-related	Family planning	Relationship and social activities
–		Partnership and sexuality	–	
Emotional	Fear/worry	Feeling	Emotional functioning	
	Positive effect	View	–	
	–	Future	–	
Mental	–	–	Mental health	
	Treatment and disease	Treatment worry	Treatment	Treatment satisfaction
		–	Dealing	Treatment difficulties
No. of domains	6	10	9	
No. of items	46	46	36	



REVIEW ARTICLE

Assessments of outcome in haemophilia – what is the added value of QoL tools?

H. M. VAN DEN BERG,* B. M. FELDMAN,†‡ K. FISCHER,*§ V. BLANCHETTE,¶**
P. POONNOOSE†† and A. SRIVASTAVA‡‡

In conclusion, prospective systematic assessment of outcome of therapeutic interventions in haemophilia and related bleeding disorders is important. HTC's need to allocate resources to develop capacities to use appropriate tools that will provide relevant data. The usefulness or additional contribution of HRQoL data to those obtained by the more direct assessment of joint health, activities and participation is unclear at this time.

TRAS LA VALORACIÓN...

No lesiones / situaciones de riesgo → Prevención 1ª
→ Revaloración



TRAS LA VALORACIÓN...

No lesiones / situaciones de riesgo → Prevención 1ª

→ Revaloración

Detección de lesiones MSK → Prevención 2ª

→ Tratamiento

Prevención de lesiones

LA PREVENCIÓN

**de las alteraciones del aparato locomotor en el niño durante
la etapa del desarrollo osteo-articular**



Mejora la calidad de vida niño / familia

Prevención de lesiones

Uso profiláctico de factor deficitario

Evitar sobrepeso

Higiene postural

Reparto de cargas

Alineación de ejes

Consejos sobre calzado

Desarrollo psicomotor

Acondicionamiento físico

Actividad física y deporte



Prevención de lesiones

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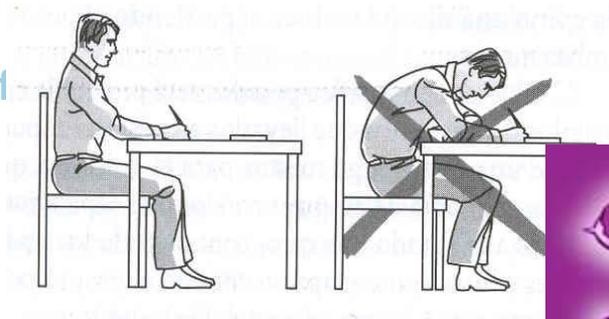
Alineación de ejes

Consejos sobre calzado

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Actividad física y deporte



Prevención de lesiones

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Evitar el sobrepeso

Higiene postural

Reparto de cargas

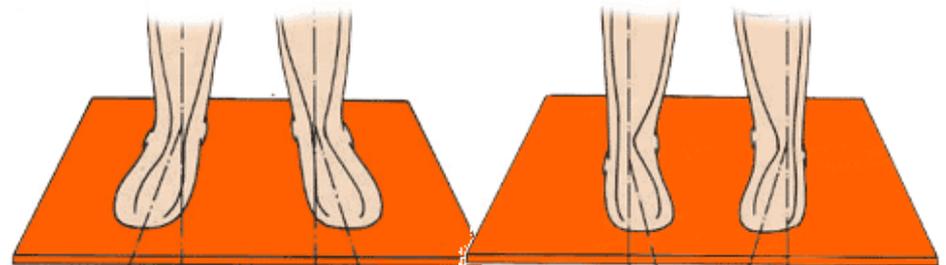
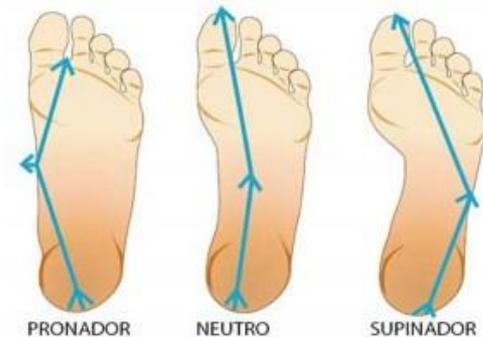
Alineación de ejes

Consejos sobre calzado

Desarrollo psicomotor

Acondicionamiento físico

Actividad física y deporte



Prevención de lesiones

Uso profiláctico de factor deficitario

Evitar el sobrepeso

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Reparto de cargas

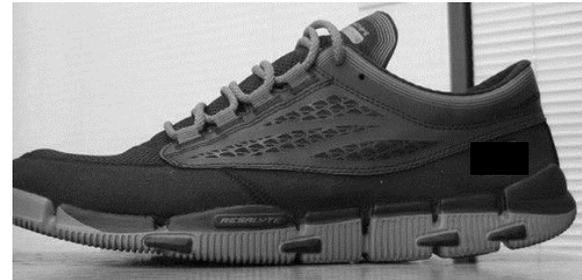
Alineación de ejes

Consejos sobre calzado

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Acondicionamiento físico

Actividad física y deporte



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Higiene postural

Reparto de cargas

Alineación de ejes

Consejos sobre calzado

Desarrollo psicomotor

Acondicionamiento físico

Actividad física y deporte



- En las últimas décadas, el incremento en la disponibilidad y seguridad de los concentrados de factor de la coagulación, ha permitido disminuir las restricciones físicas.

MODALIDAD PROFILÁCTICA CON FACTOR



Beneficios

- Existe un amplio reconocimiento de los beneficios que trae aparejada la actividad física y el ejercicio desde varios puntos de vista



Físico



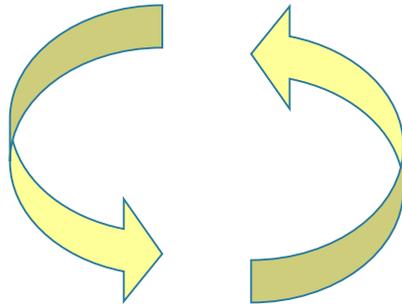
Socioafectivo



Psíquico

Parámetros usados para recomendar un determinado deporte en pacientes con hemofilia

Características del paciente



Peso
Edad
Modalidad tto hematológico
Condición física y habilidad
Gustos personales - Motivación
Práctica ejercicio anteriormente
Lesiones previas

Características del deporte

Aspectos biomecánicos del deporte
Nivel de dificultad para aprender la técnica
Riesgo de lesiones

Se debe aconsejar el tipo de ejercicio, la intensidad y duración del mismo así como la frecuencia y las precauciones a tener en cuenta

Tratamiento de lesiones

El equipo multidisciplinar aplicará el tratamiento más conveniente en cada caso:

Tto hematológico

Tto rehabilitador

Tto quirúrgico

Tratamiento rehabilitador

Tabla 4. Objetivos del tratamiento rehabilitador de las lesiones músculo-esqueléticas de los pacientes con hemofilia.

Aliviar el dolor

Recuperar el rango de movimiento

Prevenir la atrofia muscular

Mejorar la potencia y resistencia musculares

Recuperar la propiocepción

Prevenir las secuelas y deformidades

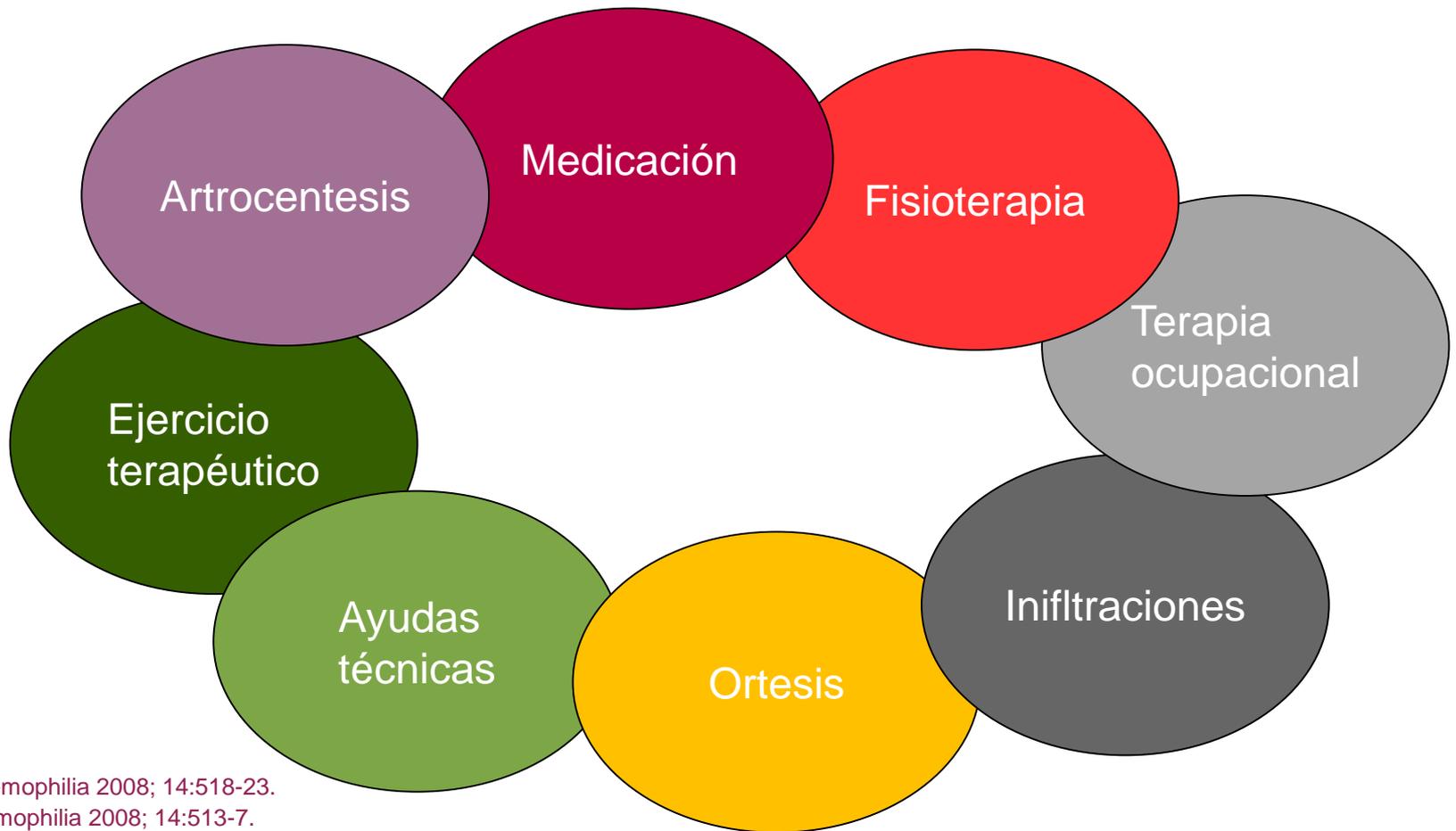
Mejorar las habilidades funcionales

Mantener un patrón de marcha adecuado

Reducir la frecuencia de sangrados articulares

En general, mejorar la calidad de vida

Tratamiento rehabilitador



Kavakli K et al. Haemophilia 2008; 14:518-23.

Brecelj J et al. Haemophilia 2008; 14:513-7.

De la Corte-Rodriguez H, et al. Blood Coagul Fibrinolysis.2013;24:1-19

Rodríguez-Merchán EC, Wiedel JD. Haemophilia 2001; 7 (Supp 2):6-10.

López-Cabarcos C et al. En: Recomendaciones sobre Rehabilitación en Hemofilia y otras Coagulopatías. 2009

Tratamiento rehabilitador



Kavakli K et al. Haemophilia 2008; 14:518-23.

Brecelj J et al. Haemophilia 2008; 14:513-7.

De la Corte-Rodriguez H, et al. Blood Coagul Fibrinolysis.2013;24:1-19

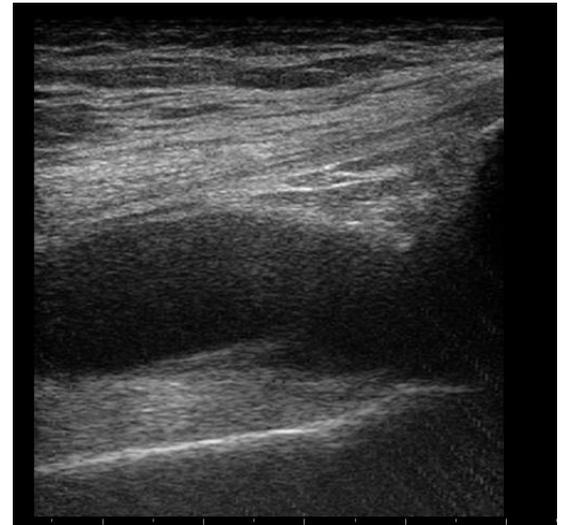
Rodríguez-Merchán EC, Wiedel JD. Haemophilia 2001; 7 (Supp 2):6-10.

López-Cabarcos C et al. En: Recomendaciones sobre Rehabilitación en Hemofilia y otras Coagulopatías. 2009

Ejemplos de tratamientos en diferentes patologías

**SIEMPRE TRATAMIENTOS INDIVIDUALIZADOS CON
OBJETIVOS TERAPÉUTICOS ESTABLECIDOS**

Ejm 1. **HEMARTROSIS de RODILLA. PAUTAS**



HEMARTROSIS en RODILLA. PAUTAS

Tratamiento Hematológico

Niveles terapéuticos de factor inicialmente \geq a 50 UI/dl.
Se valorará repetir dosis a las 12-24 h según clínica

DOMICILIO

Tratamiento Físico

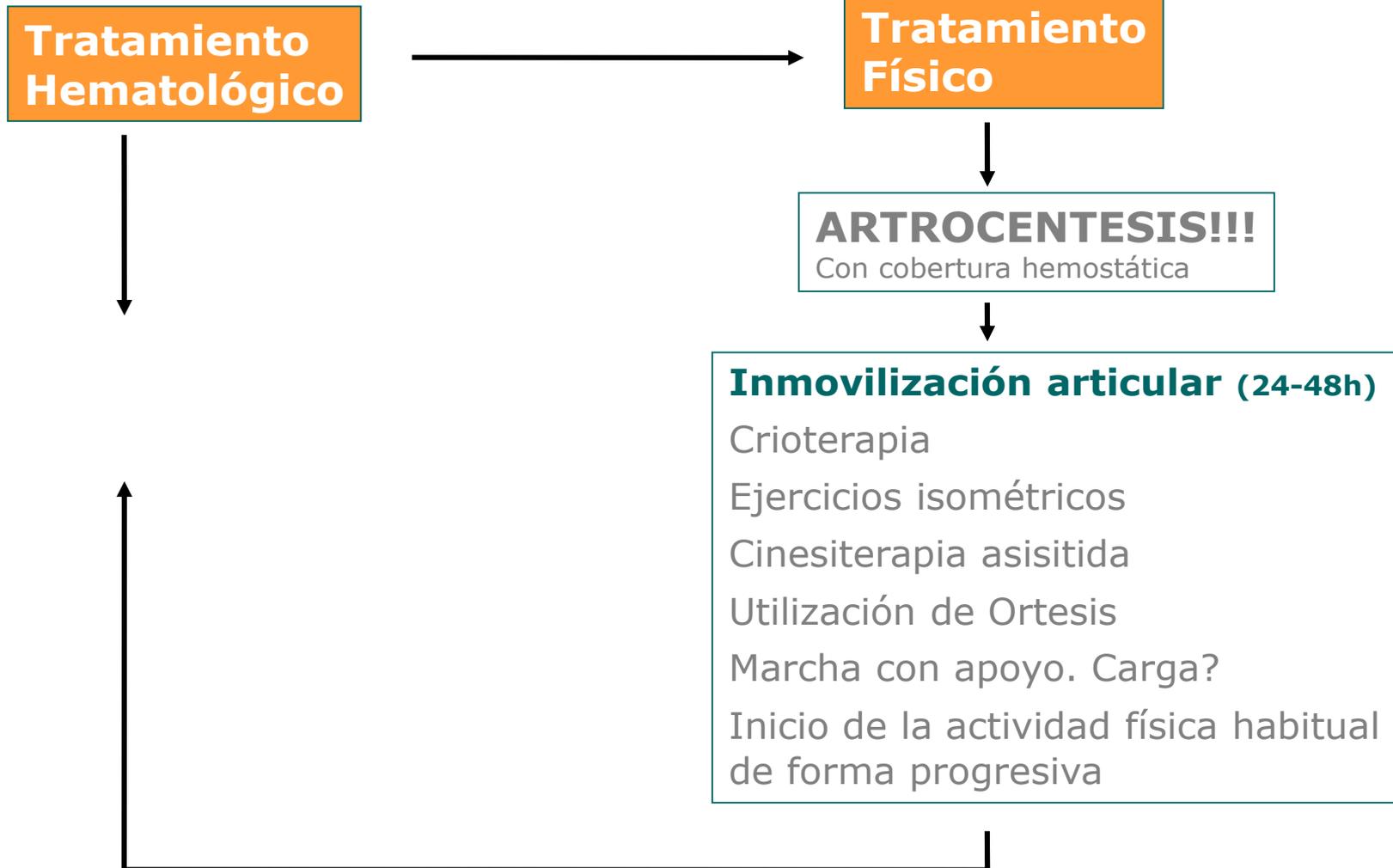
ARTROCENTESIS!!!

**Control evolutivo y
Prevención de recidiva**

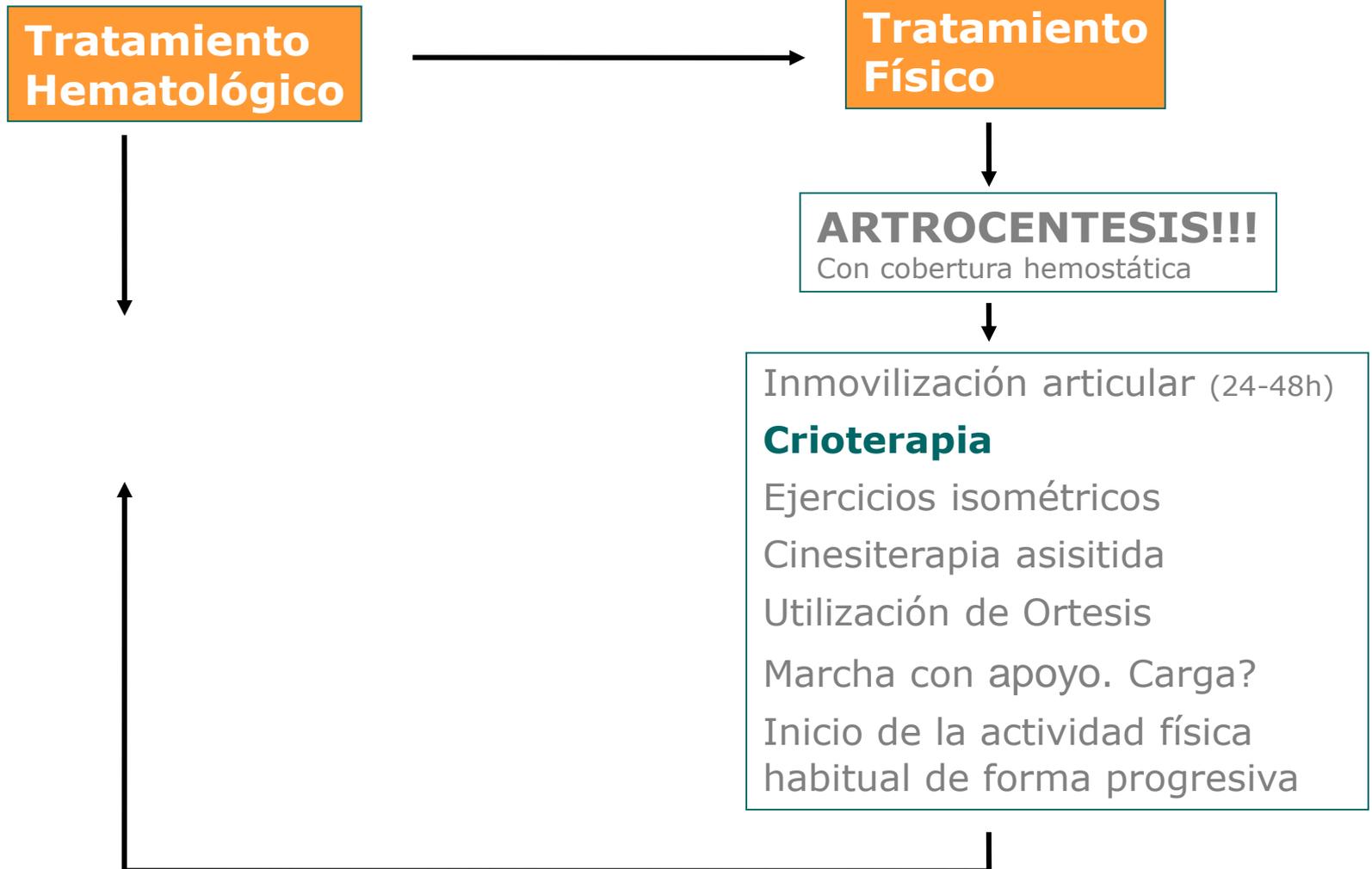


Marcha con apoyo. Carga?
Inicio de la actividad física
habitual de forma progresiva

HEMARTROSIS en RODILLA. PAUTAS



HEMARTROSIS en RODILLA. PAUTAS

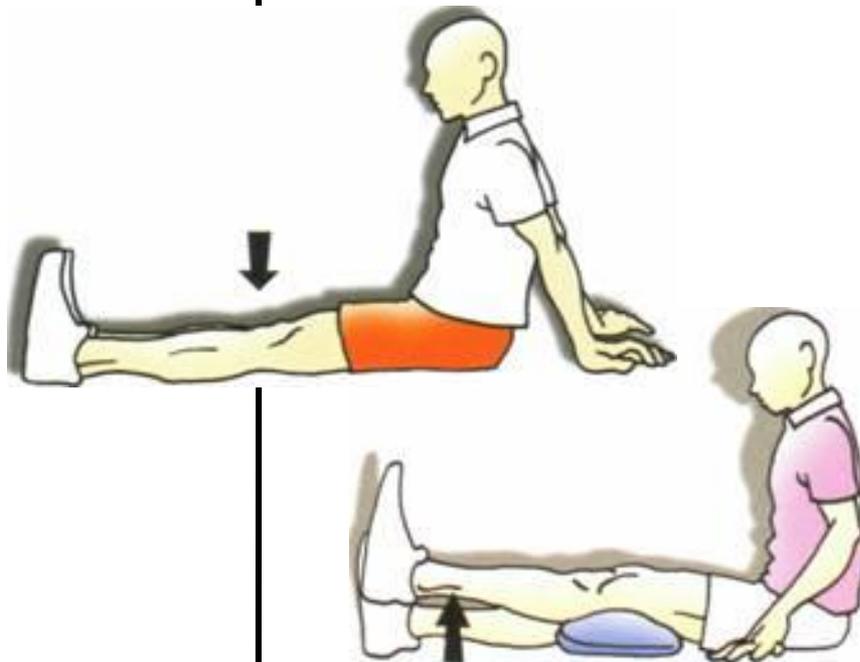


HEMARTROSIS en RODILLA. PAUTAS

Tratamiento Hematológico

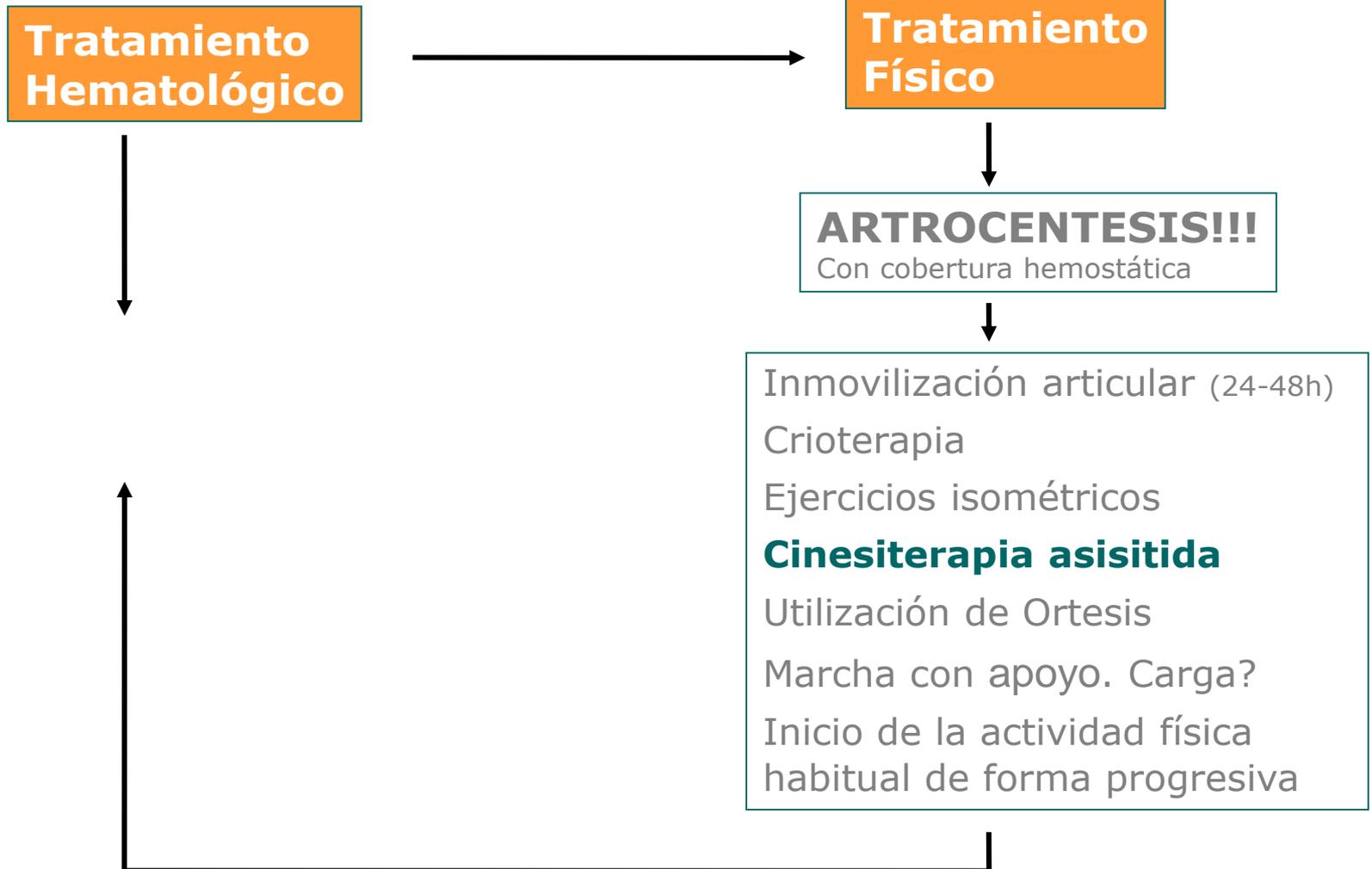
Tratamiento Físico

ARTROCENTESIS!!!
Con cobertura hemostática



Inmovilización articular (24-48h)
Crioterapia
Ejercicios isométricos/isot
Cinesiterapia asistida
Utilización de Ortesis
Marcha con apoyo. Carga?
Inicio de la actividad física habitual de forma progresiva

HEMARTROSIS en RODILLA. PAUTAS



HEMARTROSIS en RODILLA. PAUTAS

Tratamiento
Hematológico

Tratamiento
Físico

ARTROCENTESIS!!!
Con cobertura hemostática

Inmovilización articular (24-48h)

Crioterapia

Ejercicios isométricos

Cinesiterapia asistida

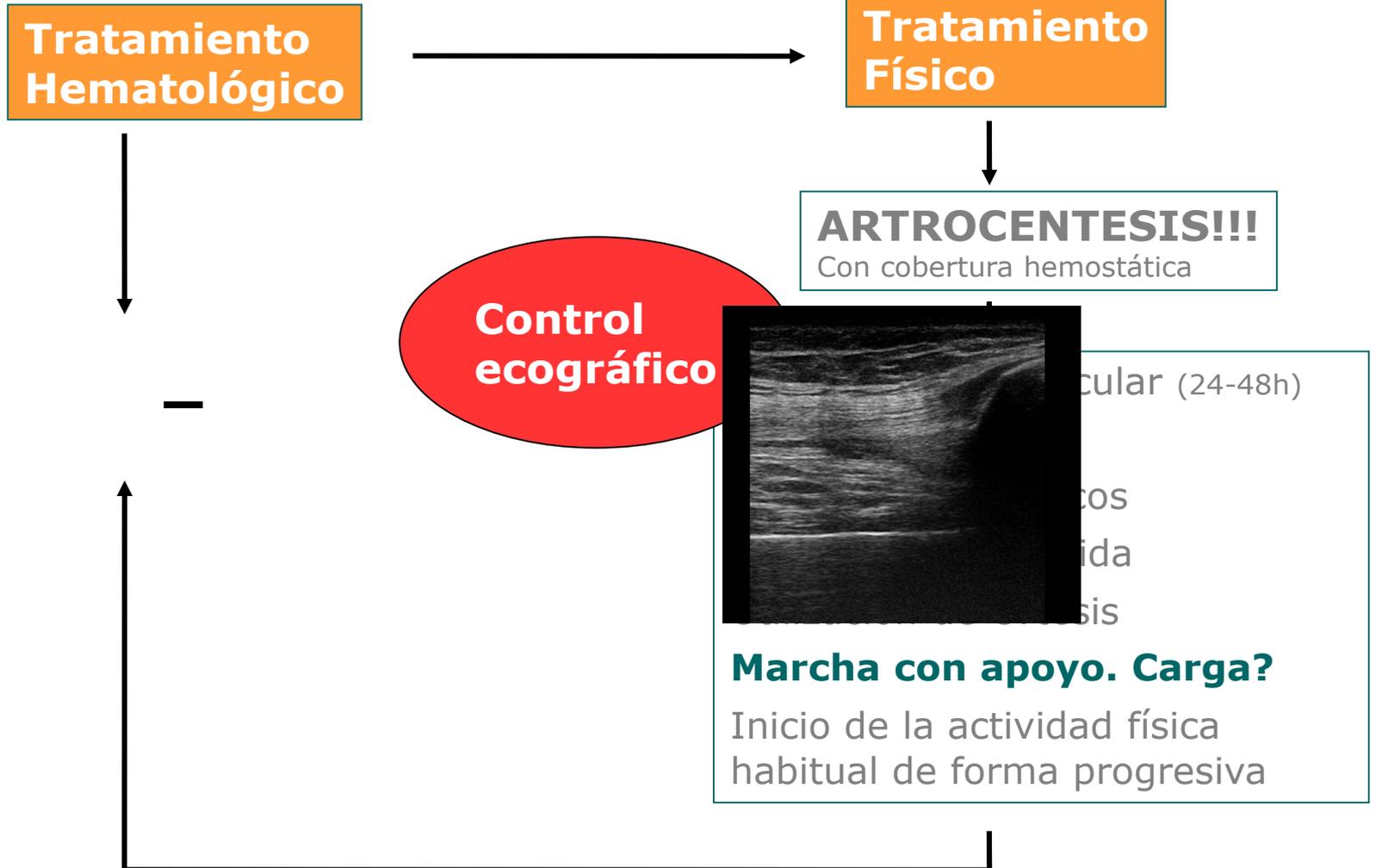
Utilización de Ortesis

Marcha con apoyo. Carga?

Inicio de la actividad física habitual de forma progresiva



HEMARTROSIS en RODILLA. PAUTAS



HEMARTROSIS en RODILLA. PAUTAS

Tratamiento
Hematológico

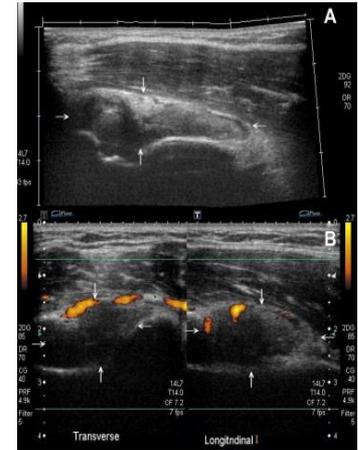
Tratamiento
Físico

ARTROCENTESIS!!!
Con cobertura hemostática



Inmovilización articular (24-48h)
Crioterapia
Ejercicios isométricos
Cinesiterapia asistida
Utilización de Ortesis
Marcha con bastones. Carga?
Inicio de la actividad física habitual progresiva

Ejm 2. SINOVITIS Y ARTROPATÍA de CODO. PAUTAS



SINOVITIS Y ARTROPATÍA de CODO. PAUTAS

Tratamiento Hematológico

3-6 m de terapia con factor profilactico
(FVIII 25-35 UI/kg, 3 d/sem; FIX 40-50 UI/kg, 2 d/sem)

AINES



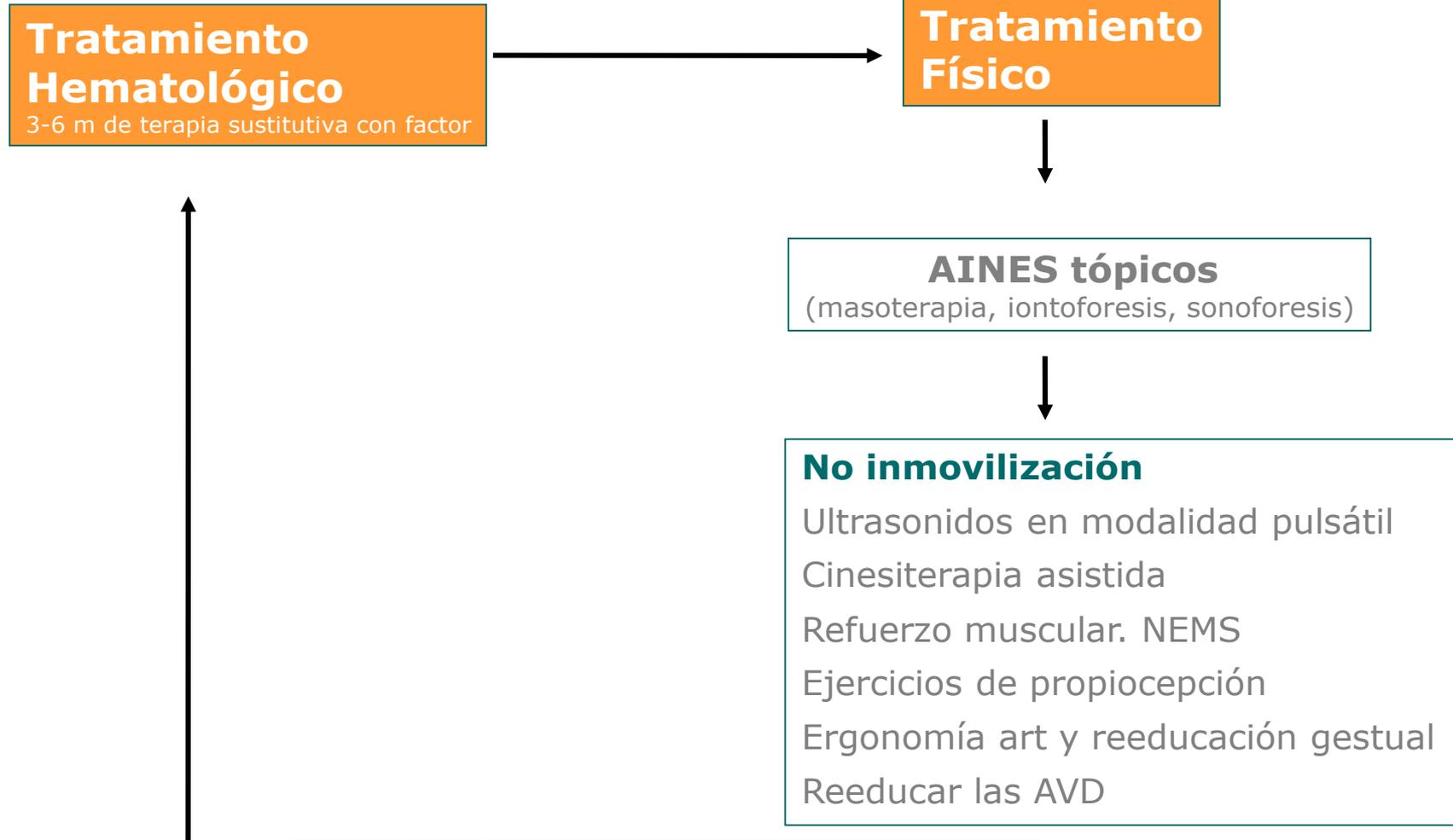
Tratamiento Físico

AINES tópicos

(iontoforesis, sonoforesis)

No inmovilización
Ultrasonidos en modalidad pulsátil
Cinesiterapia asistida
Refuerzo muscular. NEMS
Ejercicios de propiocepción
Ergonomía art y reeducación gestual
Reeducar las AVD

SINOVITIS Y ARTROPATÍA de CODO. PAUTAS



SINOVITIS Y ARTROPATÍA de CODO. PAUTAS

Tratamiento Hematológico

3-6 m de terapia sustitutiva con factor



Tratamiento Físico

AINES tópicos
(masoterapia, iontoforesis, sonoforesis)

No inmovilización
Ultrasonidos modalidad pulsátil
Cinesiterapia asistida
Refuerzo muscular. NEMS
Ejercicios de propiocepción
Ergonomía art y reeducación gestual
Reeducar las AVD

SINOVITIS Y ARTROPATÍA de CODO. PAUTAS

Tratamiento Hematológico

3-6 m de terapia sustitutiva con factor

Tratamiento Físico

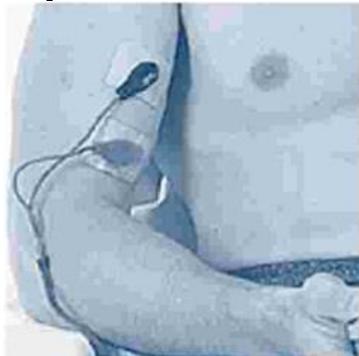
AINES tópicos
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Ultrasonidos en modalidad pulsátil
Cinesiterapia asistida
Refuerzo muscular. NEMS
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Ergonomía art y reeducación gestual
Reeducar las AVD

SINOVITIS Y ARTROPATÍA de CODO. PAUTAS

Tratamiento Hematológico

3-6 m de terapia sustitutiva con factor



Tratamiento Físico

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(masoterapia, iontoforesis, sonoforesis)

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SINOVITIS Y ARTROPATÍA de CODO. PAUTAS

Tratamiento Hematológico

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SINOVITIS Y ARTROPATÍA de CODO. PAUTAS

Tratamiento Hematológico

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AINES tópicos
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Refuerzo muscular. NEMS
Ejercicios de propiocepción
Ergonomía art y reeducación gestual
Reeducar las AVD

Si en 3-6 meses no mejora:
RADIOSINOVECTOMÍA
tratamiento de elección



Ejm 3. SECUELAS en MID. PAUTAS



Ejm 3. SECUELAS en MID. PAUTAS

Tratamiento
Hematológico

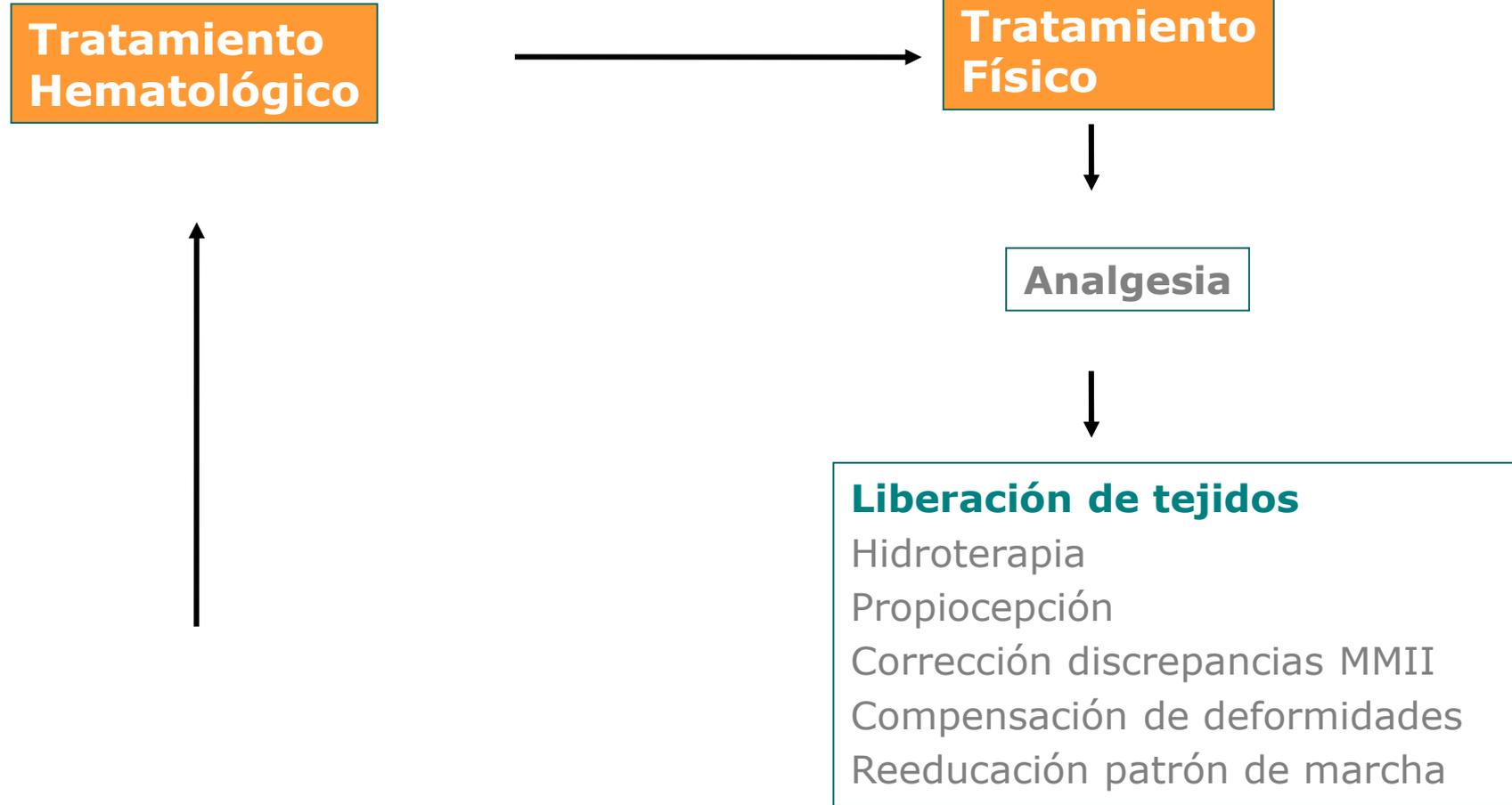
Tratamiento
Físico

Analgésia
TENS convencional
Infiltraciones

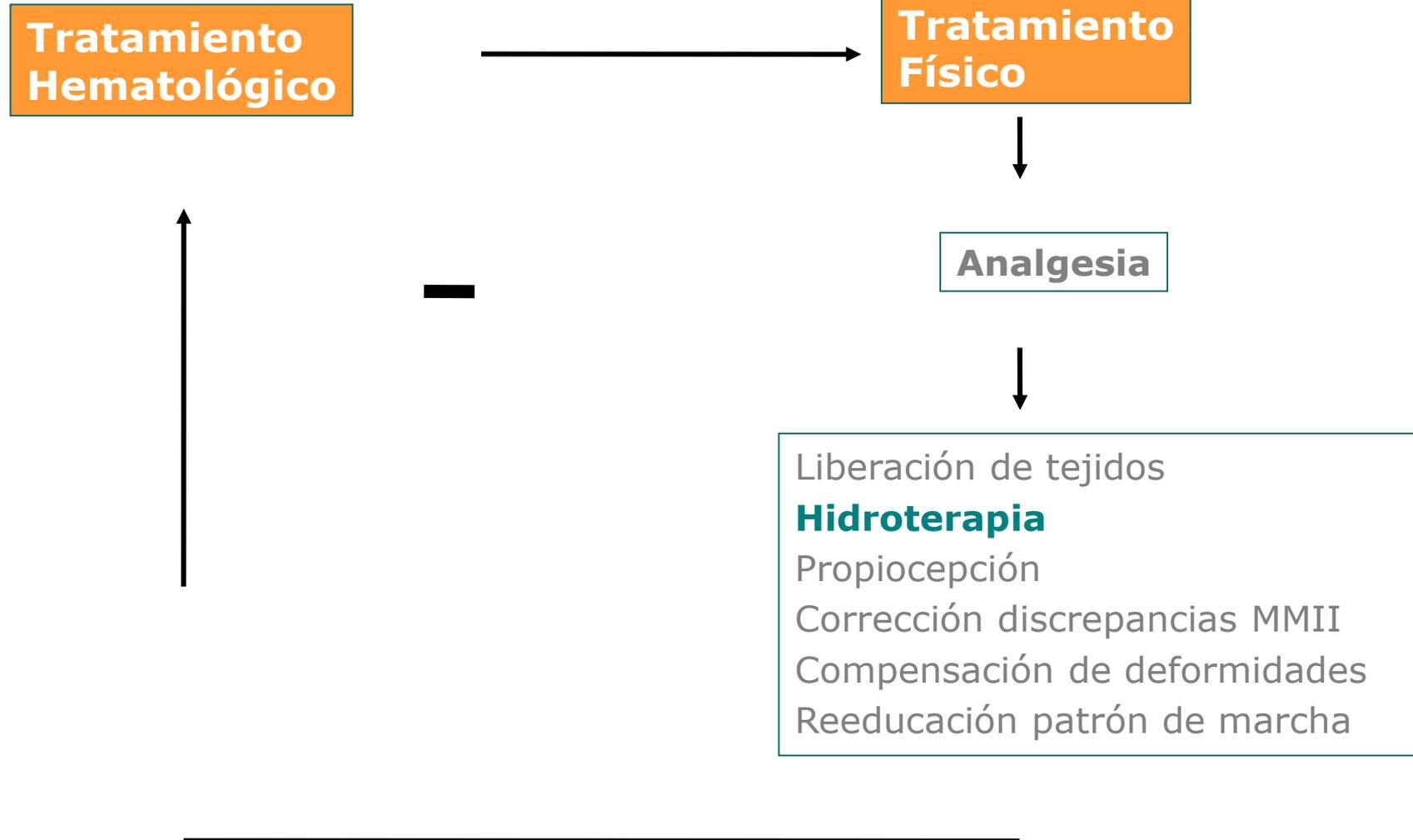
Liberación de tejidos
Hidroterapia
Propiocepción
Corrección discrepancias MMII
Compensación de deformidades
Reeducación patrón de marcha



Ejm 3. SECUELAS en MID. PAUTAS



Ejm 3. SECUELAS en MID. PAUTAS



Ejm 3. SECUELAS en MID. PAUTAS

Tratamiento
Hematológico



Tratamiento
Físico



Analgesia



Liberación de tejidos
Hidroterapia
Propiocepción
Corrección discrepancias MMII
Compensación de deformidades
Reeducación patrón de marcha



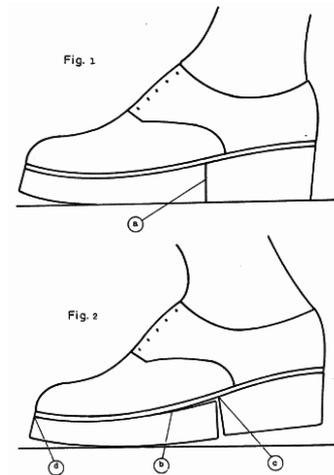
Ejm 3. SECUELAS en MID. PAUTAS

Tratamiento Hematológico

Tratamiento Físico

Analgesia

Liberación de tejidos
Hidroterapia
Propiocepción
Corrección postural y discrepanc
Compensación de deformidades
Reeducación patrón de marcha



Equilibrar pelvis.

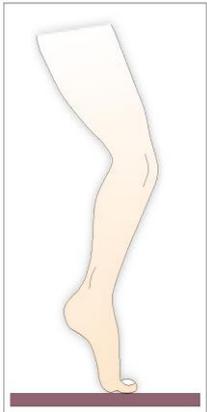
Ejm 3. SECUELAS en MID. PAUTAS

Tratamiento
Hematológico

Tratamiento
Físico

Analgesia

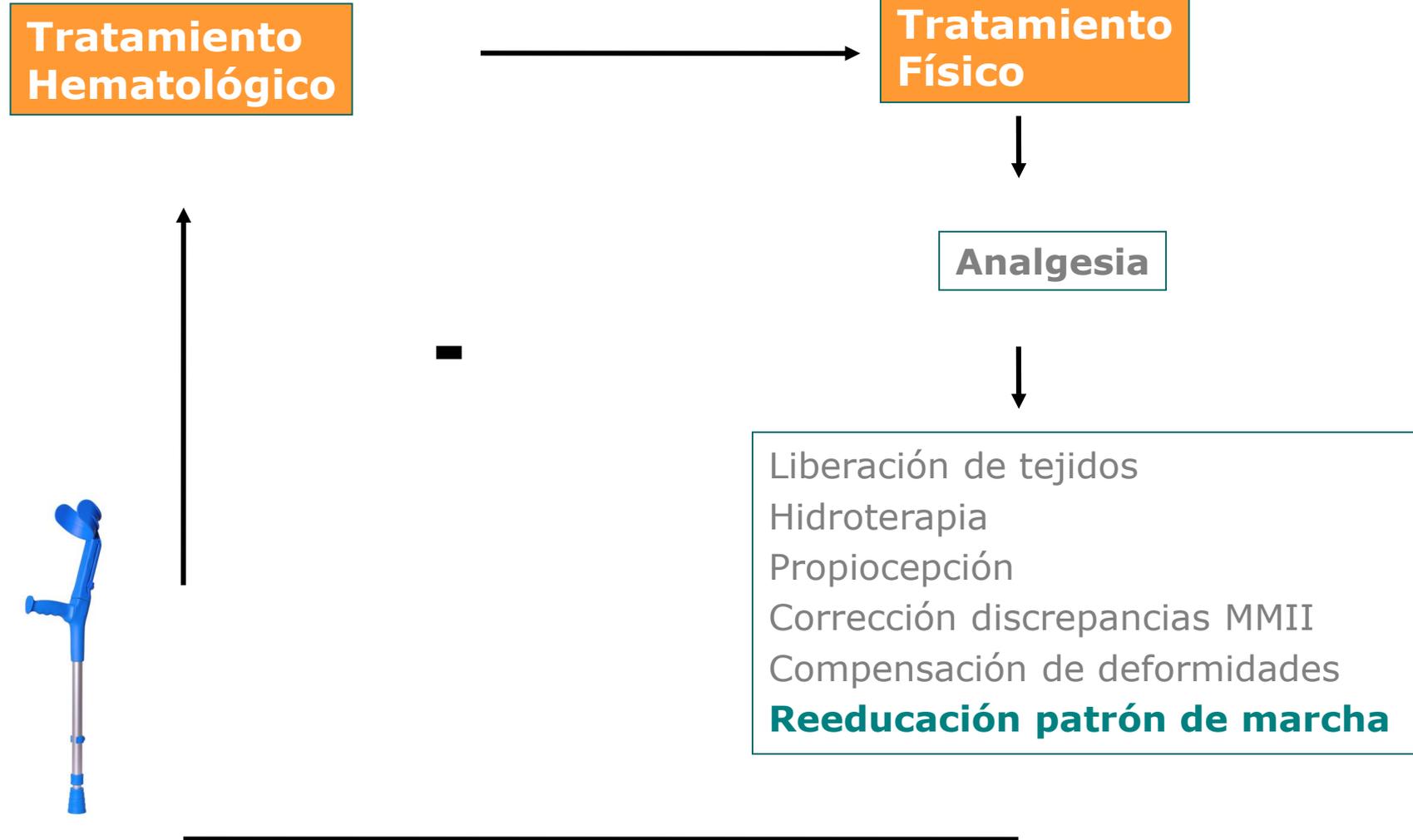
Liberación de tejidos
Hidroterapia
Propiocepción
Corrección discrepancias MMII
Compensación deformidades
Reeducación patrón de marcha



Descargar zonas de presión.



Ejm 3. SECUELAS en MID. PAUTAS



Ejm 3. SECUELAS en MID. PAUTAS

Tratamiento Hematológico

Tratamiento Físico

Analgesia

Intervención quirúrgica

Liberación de tejidos
Hidroterapia
Propiocepción
Corrección discrepancias MMII
Compensación de deformidades
Reeducación patrón de marcha

Tratamiento postquirúrgico

**Sinovitis
hipertrófica**



Sinovectomía artroscópica

Artropatías



Desbridamientos articulares

Osteotomías

Artroplastias (prótesis)

Artrodesis.

**Deformidades
articulares**

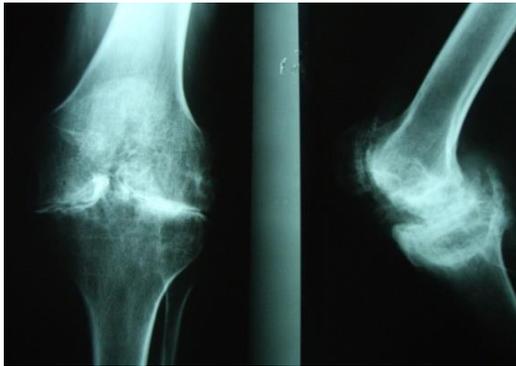


Alargamientos tendinosos

Osteotomías

Distracciones progresivas con
fijadores externos

Tratamiento postquirúrgico



Establecer un programa rehabilitador postquirúrgico inmediato, con el objetivo de alcanzar la máxima recuperación funcional

Es precisa la cobertura hemostática



CONCLUSIONES

1. Las lesiones del aparato locomotor son las que producen mayor morbilidad en las personas con hemofilia
2. La anamnesis, la exploración y las pruebas de imagen apoyan el diagnóstico y la toma de decisiones terapéuticas por parte del equipo multidisciplinar
3. El abordaje **rehabilitador** es complejo, debe hacerse de forma individualizada y con objetivos establecidos
4. El fin último es disminuir el impacto que las lesiones producen sobre la calidad de vida