Chronic pain in cryopyrin-associated periodic syndrome: A retrospective French study in 133 patients

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Objective.– The cryopyrin-associated periodic syndrome (CAPS) is a rare inherited inflammatory disease associated with genetic mutation. It includes 3 disorders of increasing severity: the familial cold autoinflammatory syndrome, the Muckle-Wells syndrome and the chronic infantile neurologic, cutaneous, and articular syndrome. Articular chronic pain is frequently described in CAPS but their frequency has been poorly investigated. Our objective was to describe the pain, and the medical care in a cohort of CAPS patients in France.

Method.– Retrospective, multicenter French study using a standardized questionnaire about articular pain, treatment and imagery in patients with CAPS.

Results.– One hundred and thirty-three patients (mean years 33.79 ± 18.68) were included among them 33 were children. During the follow-up of 124 patients, 109 patients (88%) had arthralgia most often localized at the knees (53%), ankles (48%), hands (31%) and wrists (29%). Seventy-two patients (58%) had synovitis. Tendinopathies (especially the Achilles tendon) occurred in 22% of patients, tender points (spine and pelvis) in 15% and myalgia in 33%. Three patients had typical arthropathy with bone abnormalities enlarged, deformed femora and patellae. Twenty percent have a limping frequently secondary to contracture at the knees. During the follow-up of 120 patients, 61% patients take regular analgesics and 42% NSAIDs. At the time of the study, 38% presented persistant arthralgia: 44% have no specific treatment and 28% are under anti-IL1 therapy. No patient has specifically physiotherapy. Only 33% of patients benefit from a radiography secondary to arthralgia or arthritis of whom 9% of patients highlight a destructive arthropathy.

Discussion.– Painful symptoms in patients with CAPS are very common and especially in the lower limbs. Most of the patients are treated with anti-IL1 therapy which allows a significant regression of clinical symptoms. However, the reported frequency of pain, presence of myalgia, joint limitations contrast with the low number of radiography or the use of physiotherapy. A check-up in medical rehabilitation could be suggested to this specific population.

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Volition and low back pain: What patients tell us

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Objective.– To explore, describe and understand volition of chronic low back pain (LBP) patients, in other words what is allowing them to initiate and maintain regular physical exercises.

Patients and method.– A content analysis of semi-structured interviews with 30 chronic LBP patients and 8 health care professionals regularly involved in the management of those patients was performed. Participants were asked about their physical capability, barriers and facilitators to regular exercises and finally the strategies implemented to achieve the program of exercises.

Results.– Patients often reported that they were motivated and that exercises had no negative effects on LBP. Many patients recognized to have difficulties to realize all their exercises regularly. The main barriers were: lack of time, fatigue, lack of visible results, pain and other daily priorities. The main facilitators were: to practice exercises in group, help from the therapist, strategic planning, favorable environment, pleasure associated with exercises, fear of recurrence of pain and pain itself.

Discussion.– Content analysis showed that stories allow patients to express their experience of LBP with their own words. It helped to explain why rehabilitation failed and inform healthcare professionals about therapeutic strategies useful for patients to improve compliance to home exercises programs. This work
provides a solid ground to develop a questionnaire assessing volitional competencies in CLBP patients and gives new insights for understanding kinesophobia and chronicity.

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Ehlers-Danlos syndrome: From sufferings to rehabilitation

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