

CO43-006-f

Évolution de l'espérance de vie des patients atteints de dystrophie musculaire de Duchenne au centre AFM Yolaine de Kepper entre 1981 et 2011

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Mots clés : Dystrophie musculaire de Duchenne ; Espérance de vie ; Assistance ventilatoire ; Trachéotomie

Objectifs.— Étude rétrospective sur 30 ans de l'espérance de vie des patients atteints de dystrophie musculaire de Duchenne (DMD). Analyse du rôle de la ventilation assistée et des causes de décès.

Patients et méthodes.— Cent dix-neuf patients adultes atteints de DMD ont séjourné de façon temporaire ou définitive au centre AFM Yolaine de Kepper, Saint-Georges-sur-Loire (France) entre 1981 et 2011. Le recrutement du centre a été national avec une prédominance régionale. L'espérance de vie des patients a été calculée en utilisant le modèle de Kaplan-Meier.

Résultats et discussion.— Sur les 119 patients, 55 étaient décédés, 28 perdus de vue et 36 vivants au 15 septembre 2011. Parmi ces derniers, six avaient plus de 40 ans et neuf autres entre 35 et 40 ans.

Les patients n'ont pas pu bénéficier avant 1980 d'une ventilation assistée non invasive par masque ou par trachéotomie, alors que celle-ci est devenue de plus en plus systématique à partir des années 1985 à 1990. L'âge moyen de mise en route de la ventilation non invasive (VNI) a été de 20,09 ans (Déviation standard [DS] \pm 4,05) et l'âge de la trachéotomie (pour les 77 patients trachéotomisés) de 21,66 ans (DS \pm 3,72).

L'espérance de vie des patients atteints de DMD sans ventilation assistée était de 22,16 ans et de 36,23 ans pour ceux qui en ont bénéficiée.

De la même façon, l'espérance de vie des patients nés à partir de 1970 (et ainsi le plus souvent ventilés) a augmenté de plus de 15 ans (25,77 ans avant 1970 et 40,95 ans après 1970).

Les causes de décès se sont également modifiées et depuis 1990, les causes respiratoires ont diminué de 92 % à 52 % alors que les causes cardiaques ont progressé de 8 % à 44 %.

Conclusion.— La ventilation assistée prolonge l'espérance de vie des patients atteints de Dystrophie musculaire de Duchenne de plus de 15 ans. La ventilation assistée non invasive avec relai par trachéotomie si nécessaire permet la conservation d'une qualité de vie satisfaisante et doit être systématiquement proposée.

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Efficacité des électrostimulation et de la péloïdothérapie en cas de parésie fibulaire chez des patients avec polyneuropathie diabétique

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Mots clés : Modalités physiques ; Électrostimulations ; Péloïdothérapie ; Électroneurographie

Introduction.— La polyneuropathie diabétique est la complication la plus fréquente chez les patients diabétiques.

Objectif.— Évaluation comparative entre deux programmes de médecine physique et de réadaptation.

Matériel et méthodes.— Pendant les dernières années, nous avons observé et investigué 68 patients souffrant de parésie fibulaire suite à une polyneuropathie diabétique.

Les patients ont été randomisés en deux groupes de traitement de 34 patients chacun.

L'investigation a été menée en accord avec les règles de protection des patients — selon la déclaration de Helsinki, et a été approuvée par les Commissions éthiques correspondantes. Tous les patients ont signé un accord de consentement avant chaque examen et procédure.

Le premier groupe a reçu une thérapie physique standard — exercices analytiques, massages, iontophorèse avec Nivalin. Dans le cas du groupe 2, nous avons ajouté l'électrostimulation et la péloïdothérapie (compresses de boue distales).

Pour l'évaluation statistique nous avons utilisé le *t* test (Anova) et le Wilcoxon rank test (analyse de corrélation non paramétrique), à l'aide du logiciel statistique SPSS. La différence a été considérée comme statistiquement significative pour un $p < 0,05$.

L'analyse comparative des résultats a montré une améliorations significative des symptômes de tous les patients, concernant la réduction de la douleur (visualisée par l'analyse des résultats de l'échelle visuelle analogique), de la polyneuropathie (sensibilité vibratoire, thermosensibilité, etc.), la parésie fibulaire (Manual Muscle Test, électroneurographie), de la dépression (échelle de Zung). Nous avons observé une meilleure efficacité dans le groupe 2 associant une combinaison de différentes modalités physiques.

Conclusion.— Nous recommandons notre programme complexe de MPR pour traiter la parésie fibulaire chez les patients souffrant de polyneuropathie diabétique.

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English version

CO43-001-e

Physical training and multiple sclerosis

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Keywords: Multiple sclerosis; Physical training

For a long time patients with multiple sclerosis were discouraged to practice physical activity for fear of worsening neurologic symptoms. The practice of physical activity depends on the possibilities of adaptation to stress, and also disability.

For high EDSS scores, abnormalities of cardiovascular adaptation and impairment of respiratory function can be observed.

Muscle weakness, impaired coordination can be a barrier to physical activity, then increasing the deconditioning resulting from the restriction of physical activity.

Various studies have underlined the interest of physical training with an improvement in VO₂ max, gait parameters and fatigability. A real impact on the quality of life is also observed.

Regular aerobic physical activity is required for maintaining the benefit of physical training programs.

The sport, more often as a leisure activity, must be recommended. It must be adapted to the disability and to the outcome of the disease.

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Effects of a 10-week passive cycling exercise on spasticity in high-level disability multiple sclerosis patients

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Keywords: Multiple sclerosis; Spasticity; Passive cycling exercise

Background.— Individuals with multiple sclerosis (MS) are largely inactive compared with non-diseased populations. Current studies demonstrate that physical activity in patients with MS improved several symptoms. No study explores physical activity in severely disabled MS patients. This study proposes to assess a supervised passive cycling exercise program in a population of non-ambulatory progressive MS patients (EDSS 6.5 to 7.5).

Methods.— This is a prospective pilot open cohort study. Passive cycling exercise program with a therapeutic exerciser (Motomed[®]) was proposed during 10 weeks (3 per week). Patients performed 20 minutes lower limbs passive cycling exercise. Lower limbs spasticity was assessed at baseline, 10 weeks, 3 and 6 months with the Modified Ashworth Score (MAS) bilaterally for the following muscles: triceps surae, tibialis posterior, quadriceps femoris, hamstring and adductor brevis, longus and magnus.

Results.— Forty MS patients (mean age 50, 4 ± 8,5 years, median EDSS: 6.71) completed the study. There was a significant decline in the MAS after training for the following muscles: right ($P = 0.0012$) and left ($P = 0.0128$) triceps surae, right ($P = 0.0147$) and left ($P = 0.0013$) tibialis posterior and left adductor ($P = 0.0055$). The positive effect of training can still be observed at 3 and 6 months for right ($P < 0.001$) and left triceps surae ($P < 0.0001$).

Discussion/Conclusion.— Some studies have examined effect of passive cycling exercise on spasticity in MS patients [1]. A Study [2] showed a significant effect of passive cycling exercise on spasticity on the soleus muscle after 20 minutes cycling (MAS 1.46 ± 0.96 vs 0.96 ± 0.93). Our study demonstrates that regular passive cycling exercise, even for persons with a severe handicap, can reduce lower limbs spasticity.

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Validation of the maximal frequency of small rapid alternating movements as a marker of functional impairment from upper limb tremor

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Keywords: Tremor; Rapid alternating movements; Functional impact

Introduction.— Apart from volumetric evaluations, there are no simple clinical tests to assess tremor-related functional impairment or to measure the efficacy of new treatments. We tested the hypothesis that the functional impact of hypermetric tremor (i.e. cerebellar type, essential or related to macroscopic lesions of the cerebellar pathways) could be measured by a simple test of rapid alternating movements of small amplitude performed in a clinic office.

Methods.— Nine consecutive patients with bilateral tremors (No. of visits/patient = 5 ± 3; mean follow-up duration = 22 ± 12 months) were continuously followed at the PM&R department of Créteil between 2009 and 2012 and were included in this retrospective study. The bilateral evaluations included four quantitative tests: maximum frequency of rapid alternating pronation/supination movements of small (20°, MFS) and large (90°, MFL) amplitudes around the neutral position for 15 seconds using a portable alternometer. Two volumetric tests measured the amount of spilled water: patient tries to hold a cup full to the brim steady for 30 seconds (V30, posture), and patient is asked to move the full cup of water from the sink to the lips five consecutive times (V5X, slow targeted action). For each patient, we calculated the mean performances from all visits and explored Pearson's correlations between MFS, MFL, V30, and V5X.

Results.— Tremor etiologies in the nine patients (3F, 64 ± 10 years, mean ± SD) comprised three with essential tremor and six with macroscopic cerebellar lesions. The characteristics of this cohort were: MFS = 1.5 ± 0.1 (Hz, mean ± SEM), MFL = 1.0 ± 0.1; V30 = 31 ± 9 mm, V5X = 36 ± 9 mm. Only MFS showed strong correlations with volumetric performances: MFS and V30 ($r = -0.80$; $P < 0.001$); MFS and V5X ($r = -0.86$; $P < 0.001$), MFL and V30 ($r = -0.46$; $P = 0.06$), MFL and V5X ($r = -0.54$; $P = 0.02$). The two volumetric performances were strongly correlated with each other ($r = 0.97$; $P < 0.001$).

Discussion.— The maximal frequency of small rapid alternating movements measured with an alternometer may be used a marker of tremor-related functional impact.

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Polio-survivors needs in France: Estimation from a specialized outpatient's department

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Keywords: Poliomyelitis; Post-polio syndrome

Introduction.— Polio survivors require health care depending on the sequelae, with their own consequences and impact on health, specially their impact on bone and joint systems. We need to have better knowledge of the national needs' extent for the future organization of care. The number of polio survivors is supposed to be 55,000 in France, from 400,000 to 1.1 million in Europe. The analysis of a specialized outpatient's department involved in a regional network is reported as a basis for a national study.

Method.— Retrospective study in a PRM out-patient's department since 2002 to 2011.

Results.— Among 217 patients examined, 200 files were enough informative to be studied. One hundred and forty-seven patients did not consult a PRM specialist since the initial event. They were 85 men, 115 women, mean age 55.2 years (20–86). Polio has been contracted in France for 114, out of France for 86, at a mean age of 4.2 years. The initial motor impairment involved: lower limb right/left 141/131, upper limb right/left 37/35, spine 37, and abdomen 19. Professional status: activity 43%, retired 22%, without work 20% (11% without information). Reason for consulting: global advice 54; functional impairment 135, pain 77, social difficulties five. Twenty (10%) had three symptoms (fatigue, loss of strength, musculo-arthritis pain) for a post-polio syndrome, 64 (32%) at least two. Ninety could walk without orthosis or assistive device. Orthopaedic disorders: limb inequality 106, hip flexum 12, knee recurvatum 29, knee flexum 41, equinus 36, varus foot six. Complementary test required: radiology 85, electromyography nine, respiratory function 11, sleep registration nine, RMI 9. Prescription: new orthosis 30, surgical advice 29, physiotherapy 106, dietary advice 20, social worker help 30.

Conclusion.— This analysis of a PRM out-patient's department dedicated to polio survivors, gives insight into the needs of this population. A national study is desirable because of the increasing need of these ageing subjects.

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Moral and conventional judgements in multiple sclerosis

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Keywords: Social norms; Sociocognition; Multiple sclerosis