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Why people with fibromyalgia persist in activity despite the increasing pain? A Delphi Study of the content of the Clinic Scale of Persistence in Activity in Fibromyalgia[☆]

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KEYWORDS

Fibromyalgia;
Behavioural pattern;
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Abstract

Background and objective: There is evidence of the relevance of fear, anxiety and avoidance of activity in the maintenance of pain in fibromyalgia. Recently, an opposite pattern based on the persistence in activity has been described. To date, the cognitions that impede modifying this pattern are unknown. Therefore, the aim of this study is to reach consensus on the content of an instrument that assesses those cognitions.

Material and methods: A Delphi method was applied to reach consensus on the content of the Clinic Scale of Persistence in Activity in Fibromyalgia (CCAP-FM).

Results: After three rounds of consultation, an acceptable consensus was reached. Those items that received an average rating of relevance lower than 5/10 and that at least the 75% of experts recommended removing were excluded. The preliminary questionnaire of persistence in activity was composed of 30 items.

Conclusions: The consensus on the content of the CCAP-FM will allow advancing towards the assessment of the relation between the modification of the cognitions responsible for the maintenance of the persistence in activity and the clinical improvement in people with fibromyalgia.

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PALABRAS CLAVE

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¿Por qué las personas con fibromialgia persisten en la actividad a pesar del dolor creciente?: estudio Delphi sobre el contenido del Cuestionario Clínic de Persistencia en la Actividad en Fibromialgia

Resumen

Introducción: Existen sólidas pruebas de la relevancia del miedo, la ansiedad y la evitación de la actividad en el mantenimiento del dolor en la fibromialgia. Recientemente se ha descrito un modelo opuesto basado en la persistencia en la actividad. Actualmente desconocemos las cogniciones que dificultan la modificación de este patrón de comportamiento. Por consiguiente, el objetivo del estudio es la definición consensuada del contenido de un instrumento que las evalúa.

Material y métodos: Mediante consulta prospectiva a expertos se consensuó el contenido del Cuestionario Clínic de Persistencia en la Actividad en la Fibromialgia (CCAP-FM).

Resultados: Tras 3 rondas de consulta se alcanzó un acuerdo aceptable. Se excluyeron los ítems que obtuvieron una valoración media consensuada de relevancia inferior a 5/10 y que al menos el 75% de los expertos recomendó eliminar. El cuestionario preliminar de persistencia en la actividad quedó compuesto por 30 ítems.

Conclusiones: La definición del contenido del CCAP-FM permitirá iniciar el proceso de evaluación de la relación entre la modificación de las cogniciones responsables del mantenimiento de la persistencia en la actividad y la mejoría clínica de las personas con fibromialgia.

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Introduction

Fibromyalgia is a disorder characterised by generalised pain and a low pain threshold detected in at least 11 of the 18 predefined areas where tendons join (tender points).¹ Even though its aetiology is unknown, there are tests suggesting that the somatic symptomatology observed in fibromyalgia is related to central sensitisation of the nociceptive system.^{2,3} Nociceptive system sensitisation is a protecting mechanism activated after potentially harmful peripheral stimulation either because of its repetition or intensity. This stimulation reduces the pain threshold and amplifies nerve conduction of subsequent peripheral stimulation, whether potentially harmful (hyperalgesia) or benign (allodynia). In the absence of a permanent lesion or repetitive peripheral stimulation, central nociceptive system sensitisation is resistant but reversible.⁴ One of the factors that may maintain central nociceptive system sensitisation is sustained peripheral stimulation.⁴ One of the factors potentially responsible for sustained peripheral stimulation is strenuous activity. In animal research, strenuous activity has been observed to increase generalised, but not peripheral, hyperalgesia, an effect that is gender dependent.⁵

In people with fibromyalgia, a behaviour pattern of brief alternating periods of strenuous activity followed by prolonged periods of inactivity has been observed.⁶⁻⁸ The same pattern has been observed in other pain disorders⁹ and in chronic fatigue syndrome.^{10,11} Modifying this pattern seems to reduce the intensity of the pain symptoms.^{12,13}

People with fibromyalgia are conscious of the negative effect that this behaviour pattern has on the intensity of their pain symptoms and relapses. Furthermore, their environment usually shows a negative attitude towards this type of behaviour.⁶ However, this behaviour pattern is resistant to change.

Two models have been described that attempt to explain this contradiction: first of all, the model based on the "Ergomania" concept¹⁴ maintains that hyperactivity is produced as overcompensation for unconscious dependency needs, body narcissism, masochism and excessive perfectionism. To date, it has not been possible to operationalise some of these constructs in order to submit them to experimental research. Secondly, the "avoidance-resistance" model¹⁵ argues that maintaining strenuous activity obeys a maladapted attentional coping pattern, consisting of minimising pain. To date, this model has only gotten empirical support for clinical pain in a lower back pain study.

From the beginning, multidisciplinary treatment programmes for fibromyalgia have included modifying the strenuous activity pattern, based on the balance between activity and pain (pacing). However, the definition of the concept of pacing continues to be controversial. It was initially defined by its function (adapting activity level to avoid increasing pain, ultimately reducing association between activity and pain and facilitating the progressive achievement of functional objectives); however, it has recently been defined only by behaviours that include slowing activity execution, taking breaks, maintaining a moderate pace or dividing activities into manageable portions, independently of the objective of those behaviours.¹⁶ This merely descriptive definition may bring about problems when assessing the therapeutic effect of this strategy, since some patients may use it as an avoidance strategy while others may apply it, with a progressive increase in activity, to improve their functional capacity.¹⁷ Measuring pacing and its relationship with clinical variables, such as functional incapacity, is not without its own problems as well. One of the instruments most used in assessing this behaviour pattern includes 6 items that explain a moderate but significant percentage for variance in functional disability.¹⁶ However, at least 2 of these 6 items presuppose, in the way that they are written, greater

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