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Separating emotions from consequences in muscle disease: Comparing beneficial and unhelpful illness schemata to inform intervention development☆

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ABSTRACT

Objective: Muscle diseases are currently untreatable and people with muscle disease experience reduced quality of life (QoL) and low mood. Patient's illness perceptions explain large proportions of the variance in QoL and mood, even after considering the impact of disease severity. Therefore a psychological intervention which helps patients modify their illness perceptions may improve QoL and mood even as the disease progresses. However, it is unknown which profile of illness perceptions (illness schema) an intervention should seek to promote. We aimed to fully describe and compare the illness schemata of clusters associated with better and worse outcomes.
Method: Following a cluster analysis of 217 people with muscle disease, a between-cluster comparison of QoL and mood identified the clusters associated with better and worse outcomes. Functional impairment was compared between-clusters to indicate if this could account for observed differences. Inter-correlations between the illness perceptions held within each cluster were examined across the clusters.
Results: Three stable clusters holding distinct illness schemata emerged. One cluster was characterised by greater functional impairment, worse QoL and mood than the other two clusters. The other two clusters did not differ in functional impairment but differed significantly in QoL and mood. The cluster associated with better outcomes was characterised by realistic views of timeline, greater coherence, reduced emotional representation and identity, and a lack of association between emotional representation and consequences.
Conclusion: Detailed comparison of beneficial and unhelpful illness schemata, taking into account disease-specific concerns, can help inform both the content and composition of an intervention.

Introduction

Muscle diseases are genetic or acquired primary disorders of muscle which are heterogeneous in their age of onset and speed of progression. They also vary in their pattern of weakness variously affecting ocular, bulbar or limb muscles. They are for the most part chronic long term conditions resulting in a range of impairments leading to varied disabilities. Upper limb weakness may reduce reach ability to do overhead tasks and hand grip whilst lower limb weakness affects ability to rise from sitting, climbing stairs, and walking. Alongside other unwanted outcomes, many people with muscle disease eventually require the use of a wheelchair.

Quality of life (QoL) is reduced [1,2], and mood disturbance may be increased, in muscle disease [3,4]. Unfortunately, at present, there are no available medical interventions which can affect disease progression for the majority of muscle diseases. Thus it is essential that we develop alternative methods for improving QoL and mood in this population.

There is considerable variation in QoL and mood between people with muscle disease, and encouragingly, the effect of disease severity on functioning provides an incomplete account of this variation [1,5]. Recent studies have also observed that large proportions of variance in QoL and mood score can be explained by illness perceptions, even after disease severity variables have been accounted for [6]. This suggests that a psychological intervention aimed at encouraging helpful illness perceptions may offer a way to improve QoL in muscle disease — even in the face of disease progression. Yet, to date there have been no reported psychological interventions trialled with muscle disease, let alone any which have addressed illness perceptions.

Illness perceptions or illness schemata

Illness perceptions are a component of Leventhal's Self-Regulatory Model (L-SRM) [7]. Taking the perspective that the patient is an active problem-solver, they are the cognitions formed in response to

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a health threat. In the L-SRM, illness perceptions allow individuals to make sense of the symptoms they experience and, along with the emotional response, determine which coping strategies are adopted. They include perceptions about: the time-course of the disease; its causes; its consequences; the symptoms involved; its emotional representation; its control or curability, alongside how understandable the illness itself is. Illness perceptions are predictors of adherence to medication, attendance at clinic and even mortality in other chronic disease groups (for a review, see Petrie and Weinman [8]).

Illness perceptions are usually measured with the Illness Perception Questionnaire Revised (IPQ-R) [9], which records these perceptions on nine domains. For this reason, most studies enter domains individually into regression analyses or use related techniques [10]. However L-SRM posits that illness perceptions form an inter-related framework of beliefs which are together used to make sense of a health threat, rather than individual perceptions in isolation from one another. This theoretical stance is supported by the occurrence of significant inter-correlations between illness perception domains, which may differ across disease groups [11–13].

A statistical technique called cluster analysis allows the profile of illness perceptions held by each individual (illness schema) to be maintained in the analysis and then groups together individuals based on the similarity of their illness schemata. As certain groups, or clusters, may be associated with better or worse patient outcomes, cluster analysis provides information on which illness schemata should be encouraged or discouraged by an intervention. For example, a cluster analysis of breast cancer patients [14] identified a group who reported less distress at six months post-diagnosis. These patients had stronger beliefs that their cancer had an acute and cyclical timeline, better treatment control, and lower perceived consequences.

There are different clustering techniques and, in a Monte-Carlo study, Clatworthy et al. [10] established the most appropriate way of clustering IPQ-R data. Yet, despite the availability of this method, only a small number of studies have used this optimum approach [12,14–17]. To add to this, whilst several studies have compared illness schemata between clusters associated with better and worse outcomes [12,14–17], to our knowledge no study has yet compared clusters based on their respective patterns of inter-correlations between illness perceptions. This is surprising since, as the pattern of inter-correlations may vary between clusters associated with better or worse outcome, this comparison may yield additional areas at which to target an intervention.

Therefore, to inform a future intervention, the present study applied the clustering method suggested by Clatworthy et al. [10] to the illness perceptions of a sample of people with muscle disease. The aims were to (a) establish if illness schemata associated with better or worse QoL and mood exist in the sample; (b) fully describe and compare (including patterns of inter-correlations) the illness schemata of these groups; and (c) discern if the impact of disease severity on functional impairment can account for any between-cluster differences in QoL, mood and illness perceptions.

Method

Procedure

Participants were recruited by convenience from muscle disease clinics based at several hospitals within the United Kingdom (King's College Hospital, London; Southern General Hospital, Glasgow; Institute of Neurology, Queen's Square, London; Queen's Medical Centre, Nottingham; Royal London Hospital, London; Yorkhill Hospital, Glasgow; Institute for Human Genetics, Newcastle; John Radcliffe Hospital, Oxford). Potential participants were identified by their clinician who then registered the potential participant's details onto a central web management system hosted by the lead centre (Kings College Hospital, London). From here clinicians were able to print off all the documents (covering letter, information sheet, consent form, questionnaire booklet, and a pre-paid envelope addressed to the lead centre) and administer these to the registered patient.

Second and third mailings of the questionnaire pack were sent from the lead centre to non-responders. Participants were required to complete the questionnaire booklet on one occasion. The study had ethics approval for the participating centres.

Participants

Potential participants were included if they were over 18 years of age and had muscle disease as confirmed by expert opinion, genetics, raised creatine kinase levels, neurophysiology, or muscle pathology of at least 6 months duration. They were excluded if they had cognitive impairment that prevented comprehension of the questionnaires; were unable to read English; had major active co-morbidities; or experienced symptomatic complications of muscle disease (e.g. respiratory weakness requiring non-invasive ventilation or symptomatic cardiomyopathy). Clinicians assessed participant's suitability against these inclusion/exclusion criteria from their knowledge of the patient and medical records. Participants later assessed themselves against these criteria; this information was included in the information sheet given to potential participants.

Measures

The following measures were used:

(i) A demographic questionnaire recorded diagnosis, gender, age, age at diagnosis and major co-morbidities unrelated to muscle disease.

(ii) The Individualised Neuromuscular Quality of Life Questionnaire (INQoL) [18], a validated [6,19], muscle disease specific questionnaire, was used to measure QoL. In the present study we assessed QoL on eight domains from the INQoL (INQoL symptom impact: weakness, fatigue, pain, locking; Cronbach's alpha 0.88–0.91. INQoL life areas: activities, independence, social functioning, emotional functioning; Cronbach's alpha 0.80–0.89). Higher scores on the INQoL questionnaire indicate poorer QoL.

(iii) The Stanford Health Assessment Questionnaire Disability Index (HAQ-DI) [20] was used to measure the effects of disease severity on functional impairment. It contains eight activity domains measuring, exclusively, physical functioning (dressing, arising, eating, walking, hygiene, reach, grip, and activities: Cronbach's alpha 0.76–0.89) and gives a total score out of three. Higher scores indicate greater functional impairment.

(iv) The Revised Illness Perception Questionnaire (IPQ-R) [9] (Cronbach's alpha 0.71–0.92) was used to measure patients' beliefs about their illness. In the present study illness perceptions were recorded in the following domains (eight of the nine possible domains of the IPQ-R). The identity domain concerns the number of symptoms the patient believes to result from their condition. The time-line acute/chronic and timeline cyclical domains are concerned with perceptions about the duration of the illness and whether it will be stable or fluctuating. The consequences domain captures beliefs about the negative outcomes, attributed by the patient, to their illness. Personal control and treatment control assess beliefs about whether one's own actions or medical treatment can influence the disease. The perceived emotional impact of the disease is also captured in the emotional representation domain. Illness coherence captures the patient's understanding of their disease and the extent to which it "makes sense" to them.

It should be noted that the cause domain of the IPQ-R (which records the strength of belief in potential causal factors) was excluded from the present analysis. For use in cluster analysis,