CLINICAL REHABILITATION

Clinical Rehabilitation
2014, Vol. 28(5) 508–519

DOI: 10.1177/0269215513511340
cre.sagepub.com
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A multicentre postal survey investigating the contribution of illness perceptions, coping and optimism to quality of life and mood in adults with muscle disease

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Abstract

Objective: To replicate the finding that illness perceptions influence quality of life in adults with muscle disease and to explore the additional influence of coping and optimism on quality of life and mood.
Design: A postal survey including questionnaires recording quality of life, mood, illness perceptions, optimism, coping and functional impairment.
Setting: National Health Service muscle clinics in the United Kingdom.
Participants: A convenience sample of adults with muscle disease.
Interventions: Not applicable.
Main outcome measures: Individualised Neuromuscular Quality of Life Questionnaire, Hospital Anxiety and Depression Scale.
Results: A total of 226 completed questionnaires were returned. Although functional impairment explained most of the variance in three out of eight quality of life domains, psychological factors explained greater amounts of variance (between 19% and 52% of variance) in all other quality of life domains and in both mood domains (between 45% and 48% of variance). Overall, illness perceptions explained much of

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the variance in quality of life and mood score (between 5% and 37% of variance), while coping (up to 8% of variance) and optimism (up to 15% of variance) explained smaller amounts of variance.

Conclusion: The results confirm that illness perceptions are associated with quality of life in muscle disease and suggest that they also influence mood. The addition of optimism and coping variables into the analysis yielded small increases in the proportions of variance in quality of life and mood which were explained. These results have implications for the composition of future psychological interventions.

Keywords

Coping, illness perceptions, mood, muscular diseases, muscle disease, neuromuscular, quality of life

Received: 18 January 2013; accepted: 8 October 2013

Introduction

Muscle diseases are a diverse group of acquired and inherited neuromuscular conditions that cause progressive muscle wasting and weakness, varying degrees of pain and fatigue and in some cases cardiac and respiratory complications. As a result, there is a decline in mobility leading to slowed walking, tripping and falls with some cases requiring walking aids or wheelchairs. Upper limb involvement can cause difficulties with reach and hand grip. Bulbar and ocular dysfunction are seen in some specific muscle diseases causing dysphagia, ptosis and ophthalmoparesis. Compared with healthy controls, those with muscle disease experience reduced quality of life[1,2] and can have increased symptoms of anxiety and depression.[3,4] Research into cures for muscle pathology is ongoing, but at present there are few effective treatments available for the majority of muscle disease and most management is supportive. This has prompted the search for additional methods for improving quality of life.[1,2]

Psychological interventions have shown encouraging efficacy for improving quality of life in other chronic diseases[5] and there exists a range of empirically supported methods for cognitive and behaviour change in chronic disease populations. These methods include cognitive behavioural therapy,[6] mindfulness-based cognitive therapy[7] and acceptance and commitment therapy.[8,9] However, to our knowledge there has been just one trial of a psychological intervention that has involved people with a muscle disease.[10] The absence of psychological interventions may reflect a poor understanding of how psychological factors relate to quality of life and mood in muscle disease and therefore which psychological processes should be targeted by an intervention. Thus, the present study aimed to investigate the relative contribution of selected psychological variables to quality of life and mood in adults with muscle disease after allowing for the effects of functional impairment and demographics.

We have focussed on psychological variables derived from Leventhal's Self-Regulatory Model[11] (see Figure 1), a well-validated model of patient response to illness.[12] This model posits that patient's beliefs about their illness (illness perceptions) inform the choice of behavioural and cognitive coping methods used to manage the illness and its emotional impact. The interaction of these processes in turn influences quality of life and mood.[13] Illness perceptions comprise patient beliefs about the timecourse of the disease; its cause and consequences; the symptoms involved and their emotional impact; its control or curability; and how understandable is the illness itself. So for example, if a patient believes that their illness can be well controlled by their own behaviour (illness perceptions) then they may be more likely to change their diet or use exercise as a way of controlling their symptoms (coping method) (see Leventhal et al.[13]).

Illness perceptions are believed to be formed by participant's experience of their illness, underlying personality factors and life experiences.[12,13] Of these personality factors, optimism represents an attributional style that may be related to illness

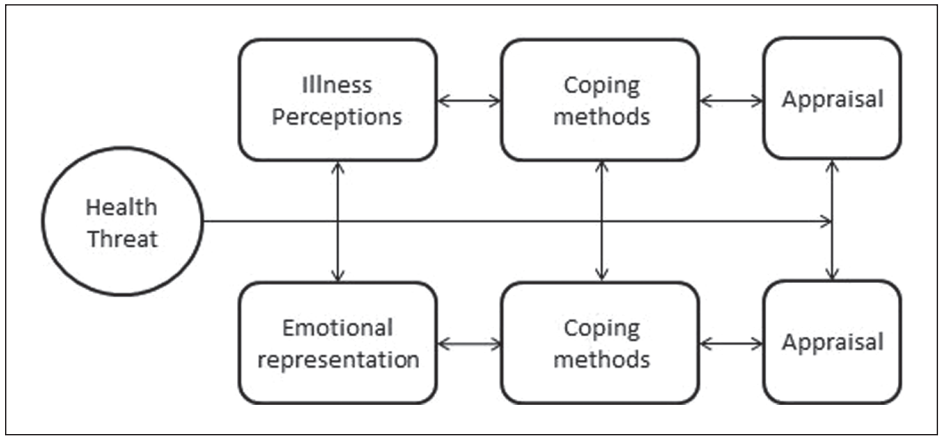

Figure 1. Leventhal's Self-Regulatory Model. Here a person's beliefs (illness perceptions) about a health threat and a parallel emotional response (emotional representation) inform the choice of coping methods used to remove or control the health threat. This model is dynamic and ongoing appraisals of the success or failure of coping methods continuously update later coping methods and illness perceptions.

perceptions and coping, and may impact on quality of life and mood. For example, someone who has greater optimism may hold more positive illness perceptions or choose more adaptive coping mechanisms. It has been documented that illness perceptions show associations with optimism[14] while a positive relationship between optimism and health-related outcomes has been observed in many chronic diseases.[15]

In a study of muscle disease patients in the United States of America,[16] illness perceptions were found to be strong predictors of many aspects of quality of life in muscle disease, even after accounting for functional impairment and demographics. In this study we wanted to replicate this United States study[16] with a United Kingdom population and to extend the study to: (1) explore the possible additional contribution of coping and optimism to quality of life and; (2) investigate how these psychological variables (illness perceptions, coping and optimism) also relate to mood.

Methods

National Health Service ethics approval was gained for this study (reference number: 08/H0907/118). Muscle specialists from British hospital muscle disease clinics recruited participants by convenience. Participants were identified by their clinician and their details were registered onto a central web management system. From here clinicians were able to print off all the documents, including the questionnaire booklet and the prepaid envelope (which was addressed to the main centre King's College Hospital) and administer this to the registered patient. Clinicians were paid nominal amounts for registering the patient and again upon receipt of the completed questionnaire.

Respondents 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 six months duration. They were excluded if their specialist doctor felt that they had cognitive impairment that prevented comprehension of the questionnaires; were unable to read English; had major active comorbidities; or experienced symptomatic complications of muscle disease (for example neuromuscular respiratory weakness requiring non-invasive ventilation or symptomatic cardiomyopathy).

Participants were sent or given a pack containing a covering letter, a study information sheet, a consent form, questionnaires and a prepaid envelope. A

second mailing of the questionnaire pack was sent to non-responders two weeks later and two weeks after that a reminder letter was sent to residual non-responders. The study had ethics approval for the participating centres.

The following measures were used:

1. A demographic questionnaire recorded diagnosis, sex, age, age at diagnosis and major comorbidities unrelated to muscle disease.
2. The Individualised Neuromuscular Quality of Life Questionnaire,[17] a 10-domain, validated,[16,18] muscle-disease-specific questionnaire was used to measure quality of life. In the present study we assessed quality of life on eight domains from this questionnaire: four domains capturing the impact of key muscle disease symptoms (symptom impact domains: weakness, fatigue, pain, locking) and four domains capturing the impact of muscle disease on particular life areas (life areas domains: activities, independence, social, emotional). Higher scores on all Individualised Neuromuscular Quality of Life Questionnaire domains indicate poorer quality of life.
3. The Stanford Health Assessment Questionnaire Disability Index[19] was used to measure functional impairment. It records impairments in eight specific areas of functioning (dressing, arising, eating, walking, hygiene, reach, grip and activities) to give a total score out of three, with higher scores indicating greater functional impairment.
4. The Revised Illness Perception Questionnaire[20] was used to measure patients' beliefs about their illness. Illness perceptions were measured in ten domains. The *identity* domain concerns the number of symptoms the patient believes to result from their condition. The *timeline acute/chronic* and *timeline cyclical* domains are concerned with perceptions about the duration of the illness and whether it will be stable or fluctuating, respectively. The *consequences* domain captures beliefs about the negative outcomes attributed by the patient to their illness. *Personal control* and *treatment control* domains 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. The *illness coherence* domain captures the patient's understanding of their disease and the extent to which it 'makes sense' to them. Higher scores on the identity domain indicates a greater number of symptoms attributed to the illness. Higher scores on the timeline acute/chronic domain and timeline cyclical domain indicate more strongly held beliefs that the illness is chronic and has a more fluctuating course, respectively. A higher emotional representation domain score suggests a greater perceived emotional impact of the illness. Similarly, greater perceived impact of an illness on one's life is implied by a high score on the consequences domain. Giving high personal and treatment control scores suggests that one perceives greater personal (one's own behaviour) and treatment (healthcare resources) control over illness, while a higher illness coherence score implies a better perceived understanding of the illness. Two additional illness perceptions domains were made from a checklist of possible causal attributions and were also included in the analysis; participants indicated if they endorsed (yes/no) *hereditary* factors as the cause of their muscle disease or if they endorsed *chance* or bad luck as the cause of their muscle disease.
5. The Hospital Anxiety and Depression scale,[21] a 14-item self-report questionnaire, was used to measure mood. Its gives scores that range from 0 to 21 and has two domains of anxiety and depression, with higher scores indicating greater mood disturbance.
6. The Brief COPE,[22] a self-report questionnaire with 28 items, was used to assess the extent to which 14 different coping methods were employed (self-distraction, active coping, denial, substance use, use of emotional support, use of instrumental support, behavioural disengagement, venting, positive reframing, planning, humour, acceptance, religion, self-blame). Higher scores indicate a greater tendency to use a particular coping style.

7. The Life Orientation Test–Revised,[23] a 6-item scale, was used to measure optimism in our respondents. Scores can range from 6 to 24, with higher scores indicating greater optimism. Data from the returned questionnaires were entered onto a computer database (Statistical Package for Social Scientists Version 15).

Statistical analysis

Our definitive statistical analysis methods were shaped by preliminary statistical analyses of the normality of the data and the psychometric performance of the outcome measures. The normality of the data was assessed using KS-Lilliefor's significance correction; multicollinearity was assessed by examining the variance inflation factor; while equality of variance was examined using Levene's test.

Multiple hierarchical regressions were then performed to examine the contribution of independent variables to the dependent variables (quality of life domains and mood). The independent variables were entered into the regression analysis in blocks. Demographic factors and functional impairment were entered in the first block, followed by optimism in the second block and illness perceptions variables in the third block. Coping variables were added in the fourth block.

Results

Descriptive data and preliminary analyses

Nine United Kingdom muscle clinics participated. From these centres, 451 participants were given questionnaires, of which 274 responded (response rate 61%). Of the 274 returned questionnaires, 48 were incomplete and were excluded. The final sample of 226 respondents had diagnoses of: limb-girdle muscular dystrophy 65/226 (29%); facioscapulohumeral muscular dystrophy 49/226 (22%); myotonic dystrophy 38/226 (17%); inclusion body myositis 16/226 (7%); inflammatory myopathies 9/226 (4%); and miscellaneous other muscle diseases 49/226 (22%).

Preliminary analysis observed acceptable levels of multicollinearity with variance inflation factor scores ranging from 1.01 to 2.17 (full correlation tables can be found in Graham, (2012)[24]). However, three variables had non-normal distributions (locking; negative coping; timeline acute/chronic) and these were transformed. Additionally, as the internal consistency among many of the subscales of the Brief COPE was poor, a Principal Component Analysis using a Varimax Rotation with Kaiser Normalisation was used to explore alternative factor structures. Factors with Eigen values greater than 1 and an examination of the scree plot determined the number of factors. Factor loadings of greater than 0.4 were used to decide which variables contributed to each new factor. Here 11 of the 14 subscales of the Brief COPE loaded onto four factors resulting in four subscales of conceptually similar items: the new negative coping domain comprised the denial, behavioural disengagement, venting and self-blame domains of the Brief COPE; the new active coping domain consisted of the active coping and planning domains of the Brief COPE; the new support-seeking domain comprised the emotional support and instrumental support domains of the Brief COPE; and the new positive reframing domain involved the positive reframing and religion domains of the Brief COPE. The substance use, humour and acceptance subscales of the Brief COPE did not load on to any one factor and were excluded.

Table 1 shows the characteristics of the sample and the overall scores on all questionnaires. Here there is evidence of considerable variation in all quality of life and mood domains and the average level of functional impairment was quite high. The role of the included independent variables in explaining this variance is now presented. Here the control variables comprised demographics (age, sex and years with muscle disease) and functional impairment.

Variance in quality of life score

Predictors of the symptom impact areas of the Individualised Neuromuscular Quality of Life Questionnaire are shown in Table 2. For the weakness

Table 1. Descriptive data for each included dependent or independent variable.

	Independent variables	Mean (SD)	Observed range	Possible range	Cronbach's α
Demographics and functional impairment	Age	47.48 (16.02)	18–79 years	—	—
	Sex	116 m /110 f	—	—	—
	Years with muscle disease	16.46 (11.67)	0–68 years	—	—
	Functional impairment (HAQ-DI)	1.51 (0.76)	0.13–3	0–3	0.76–0.89
LOT-R	Optimism	14.12 (4.76)	0–24	0–24	0.57
IPQ-R	Identity	4.96 (2.42)	0–13	0–14	—
	Consequences	3.94 (0.75)	1.17–5	0–5	0.82
	Personal control	2.63 (0.88)	1–5	0–5	0.82
	Treatment Control	2.05 (0.79)	1–4.6	0–5	0.82
	Timeline (acute/chronic)	5 (IQR 0.67)	3–5	0–5	0.71
	Timeline cyclical	2.54 (1.0)	0–5	0–5	0.83
	Illness coherence	3.48 (1.05)	0–5	0–5	0.92
	Emotional representation	3.24 (1.03)	0–5	0–5	0.91
	Cause: hereditary	152/226 endorsed	—	—	—
	Cause: chance	97/226 endorsed	—	—	—
Brief COPE	Negative coping	2.75 (IQR 1.25)	0–8	0–8	0.76
	Active coping	4.33 (1.60)	0–8	0–8	0.68
	Support seeking	3.78 (1.39)	0–8	0–8	0.65
	Positive reframing	3.24 (1.39)	0–8	0–8	0.55
Measure	Dependent variables	Mean (SD)	Observed range	Possible range	Cronbach's α
INQoL	Weakness	69.43 (24.57)	0–100	0–100	0.88
	Fatigue	50.83 (28.84)	0–100	0–100	0.91
	Pain	57.65 (27.41)	0–100	0–100	0.91
	Locking	0 (IQR 47.40)	0–100	0–100	0.90
	Independence	47.62 (30.69)	0–100	0–100	0.81
	Activities	57.65 (27.14)	0–100	0–100	0.80
	Social	29.31 (22.42)	0–92	0–100	0.91
	Emotional	40.35 (25.95)	0–100	0–100	0.89
HADs	Anxiety	6.88 (4.31)	0–18	0–21	0.68
	Depression	6.06 (3.90)	0–19	0–21	0.91

HADs, Hospital Anxiety and Depression Scale; HAQ-DI, Health Assessment Questionnaire Disability Index; INQoL, Individualised Neuromuscular Quality of Life Questionnaire; IQR, interquartile range; IPQ-R, Revised Illness Perceptions Questionnaire; LOT-R, Life Orientation Test Revised; SD, standard deviation.

domain, the control variables, in particular functional impairment, accounted for much of the explained variance ($\Delta R^2 = 0.48$), with illness perceptions adding moderately to the explanation of variance ($\Delta R^2 = 0.12$). Neither optimism nor coping added significantly to the proportion of explained variance. For the fatigue domain the control variables accounted for a modest amount of the variance ($\Delta R^2 = 0.10$) while optimism ($\Delta R^2 = 0.04$) and in particular illness perceptions ($\Delta R^2 = 0.25$) accounted for the majority of explained variance. Coping variables added minimally to the proportion of variance explained ($\Delta R^2 = 0.03$).

Similarly for the pain domain, a modest amount of the variance was explained by functional impairment and demographics ($\Delta R^2 = 0.09$) with optimism ($\Delta R^2 = 0.02$) and illness perceptions ($\Delta R^2 = 0.28$) explaining a significant proportion of additional variance. Here, coping variables did not add to the proportion of explained variance. Only a

Table 2. Multiple regressions results for each INQoL symptom impact domain: Table showing changes in variance with the addition of each block of variables.

Predictor	Quality of life domain							
	Weakness		Fatigue		Pain		Locking	
	ΔR^2	β	ΔR^2	β	ΔR^2	β	ΔR^2	β
Control variables	0.48		0.10		0.09		0.03	
Age		0.06		−0.02		−0.07		−0.02
Sex		0.10		−0.04		0.01		−0.05
Years with muscle disease		−0.03		−0.06		−0.02		−0.01
Functional impairment (HAQ-DI)		0.68**		0.31**		0.31**		0.16*
F	49.65**		5.65**		5.49**		1.56	
Personality	0.002		0.04		0.02		0.02	
Optimism		−0.05		−0.20**		−0.16*		−0.16*
F	0.92		9.18*		5.65*		5.34*	
Illness perceptions	0.12		0.25		0.28		0.14	
Identity		0.05		0.31**		0.44**		0.32**
Consequences		0.26**		0.16*		0.08		0.04
Timeline acute/chronic		−0.04		−0.07		0.07		0.05
Timeline cyclical		−0.03		0.09		0.03		0.08
Personal control		−0.14*		−0.10		−0.01		−0.03
Treatment control		0.03		−0.09		−0.06		−0.04
Illness coherence		−0.05		−0.07		−0.10		−0.11
Emotional representation		0.15*		0.14		0.17*		−0.02
Cause: chance		−0.02		−0.00		−0.02		−0.04
Cause: hereditary		−0.07		0.04		0.02		0.09
F	6.12**		8.10**		9.64**		3.66**	
Coping	0.006		0.03		0.03		0.03	
Negative coping		−0.01		0.14*		0.06		0.02
Active coping		0.07		0.13*		0.11		0.01
Support seeking		−0.01		−0.13*		−0.14*		0.11
Positive reframing		0.03		−0.04		−0.08		0.01
F	0.75		2.72*		2.33		1.60	
Total R^2	0.608		0.420		0.420		0.220	
Total *F*	16.30**		7.34**		7.82**		2.99**	

*Significant association at the $p < 0.05$ level.
**Significant association at the $p < 0.01$ level.
HAQ-DI, Health Assessment Questionnaire Disability Index.

small amount of the variance in the locking domain score could be explained ($\Delta R^2 = 0.22$); here illness perceptions ($\Delta R^2 = 0.14$), in particular IPQ-R identity, accounted for the majority of explained variance.

Table 3 shows the multiple regressions for Individualised Neuromuscular Quality of Life Questionnaire life areas domains. The vast majority of explained variance in the independence domain was accounted for by the control variables ($\Delta R^2 = 0.59$) with functional impairment the most important predictor. Neither optimism nor coping variables explained significant amounts of variance, but illness perceptions did explain additional variance ($\Delta R^2 = 0.05$). Similarly for the activities domain, much of the variance was explained by the control

Table 3. Multiple regressions for each INQoL life area domain: table showing changes in variance with the addition of each block of variables.

Predictor	Quality of life domain							
	Independence		Activities		Social		Emotional	
	ΔR^2	β	ΔR^2	β	ΔR^2	β	ΔR^2	β
Control variables	0.59		0.51		0.21		0.09	
Age		−0.04		−0.08		−0.03		−0.03
Sex		−0.03		0.08		0.12		0.05
Years with muscle disease		−0.02		−0.002		−0.17*		−0.11
Functional impairment (HAQ-DI)		0.76**		0.70**		0.44**		0.30**
F	77.13**		55.65**		14.10**		5.49**	
Personality	0.003		0.01		0.03		0.11	
Optimism		−0.06		−0.11*		−0.19*		−0.33**
F	1.81		4.81*		9.51*		28.50**	
Illness perceptions	0.05		0.12		0.15		0.37	
Identity		0.05		0.11*		0.14*		0.13*
Consequences		0.17*		0.15*		0.19*		0.16*
Timeline acute/chronic		0.01		−0.01		0.03		−0.05
Timeline cyclical		0.02		0.03		0.03		−0.06
Personal control		−0.08		−0.11*		−0.05		0.06
Treatment control		0.01		−0.05		−0.07		−0.13*
Illness coherence		−0.02		0.02		−0.04		−0.09
Emotional representation		0.07		0.20**		0.20*		0.53**
Cause: chance		0.01		0.04		0.04		0.08
Cause: hereditary		0.02		−0.03		−0.03		0.08
F	2.64*		7.04**		4.86**		17.41**	
Coping	0.008		0.01		0.05		0.04	
Negative coping		0.00		0.004		0.21*		0.25**
Active coping		−0.02		0.04		0.12*		0.11*
Support seeking		0.10*		−0.01		−0.04		0.05
Positive reframing		−0.01		−0.02		0.04		0.02
F	1.18		0.18		4.19*		6.71**	
Total R	0.651		0.65		0.440		0.610	
Total *F*	19.03**		20.27**		8.09**		17.009**	

*Significant association at the $p < 0.05$ level.
**Significant association at the $p < 0.01$ level.
HAQ-DI, Health Assessment Questionnaire Disability Index.

variables ($\Delta R^2 = 0.51$) with illness perceptions adding to the explanation of variance ($\Delta R^2 = 0.12$). For the social functioning domain, control variables ($\Delta R^2 = 0.21$) and psychological variables ($\Delta R^2 = 0.23$) explained similar amounts of variance. For the emotional functioning domain, psychological variables accounted for a large amount of the variance in score ($\Delta R^2 = 0.52$). Here, illness perceptions explained the vast majority of the variance ($\Delta R^2 = 0.37$), after optimism had accounted for a significant amount of variance ($\Delta R^2 = 0.11$), but before coping variables explained a small amount of additional variance ($\Delta R^2 = 0.04$).

Variance in mood score

Table 4 shows the multiple regressions for mood. Large amounts of variance in mood score were explained by psychological variables (depression $\Delta R^2 = 0.45$; anxiety $\Delta R^2 = 0.48$), after control variables, mainly functional impairment, had explained a small amount of the variance in mood (depression $\Delta R^2 = 014$; anxiety $\Delta R^2 = 0.08$). Here illness perceptions explained quite large amounts of variance in both areas (depression $\Delta R^2 = 0.25$; anxiety $\Delta R^2 = 0.25$). Optimism was also a significant predictor of both mood domains (depression $\Delta R^2 = 0.14$; anxiety $\Delta R^2 = 0.15$). Coping variables added minimally to the proportion of explained variance in depression ($\Delta R^2 = 0.06$) and anxiety ($\Delta R^2 = 0.08$).

Discussion

The present study built on an earlier study investigating role of illness perceptions in explaining quality of life in muscle disease[16] by assessing the additional role of optimism and coping in explaining both quality of life and mood. As in the earlier study, illness perceptions explained large amounts of the variance in most quality of life domains, ranging from 5% to 37% after controlling for the contributions of functional impairment and demographics. The addition of two psychological factors not previously studied, namely coping and optimism, generally explained little additional variance in quality of life domains. The contributors to mood had not previously been assessed in muscle disease. Here psychological variables explained most of the variance (48% anxiety; 45% of depression); while optimism (15% anxiety; 14% depression) and coping (8% anxiety; 6% depression) had more effect on mood than they did on quality of life; illness perceptions again showed the strongest associations (25% anxiety; 25% depression) with mood.

These findings add to the literature supporting the importance of illness perceptions in predicting quality of life and mood in chronic disease[12,13,25] and suggest that of the psychological variables investigated, illness perceptions may be the most appropriate target for a psychological intervention. The manipulation of illness perceptions using psycho-education or cognitive behavioural methods has shown efficacy for improving important outcomes in other patient groups. For example, an educational intervention with myocardial infarction patients showed postintervention changes in illness perceptions and a quicker return to work[26] and a family-based illness perceptions intervention with diabetes patients yielded greater improvements in glycated haemoglobin and well-being compared with controls.[27]

In contrast to some other studies,[28,29] the present study observed that coping variables added only modestly to the proportions of variance explained in quality of life and mood. It has been reported that the selection of appropriate coping methods has a lesser effect on outcomes in those with more severe symptoms.[30] This may be because those with more severe and less treatable symptoms may not see any improvement in their symptoms irrespective of which the coping strategy they employ. We therefore postulate that our finding showing lack of influence of coping on quality of life and mood, may be because our subjects with muscle disease had both high levels of functional impairment and lacked the means to alter the progression of their muscle disease symptoms.

Optimism has been found to have variable influence upon quality of life in various other chronic diseases. Some find a strong association,[15] but others,[31] as in the present study, have found more modest associations between optimism and self-rated overall health. Kreitler et al. (1993)[31] found that

Table 4. Multiple regressions for anxiety and depression: Table showing changes in variance with the addition of each block of variables.

Predictor	Mood			
	Anxiety		Depression	
	ΔR^2	β	ΔR^2	β
Control variables	0.08		0.14	
Age		−0.09		0.02
Sex		−0.04		0.11
Years with muscle disease		−0.15*		−0.09
Functional impairment (HAQ-DI)		0.24**		0.37**
F	4.75**		9.37**	
Personality	0.15		0.14	
Optimism		−0.40**		−0.38**
F	42.69**		41.53**	
Illness perceptions	0.25		0.25	
Identity		0.24**		0.13*
Consequences		−0.03		0.24**
Timeline acute/chronic		0.004		−0.14*
Timeline cyclical		−0.08		−0.05
Personal control		0.03		−0.04
Treatment control		0.03		−0.10
Illness coherence		−0.13*		−0.10
Emotional representation		0.43**		0.33**
Cause: chance		0.08		0.03
Cause: hereditary		0.11*		0.09
F	9.86**		11.11**	
Coping	0.08		0.06	
Negative coping		0.28**		0.31**
Active coping		0.15*		0.06
Support seeking		–0.10		−0.09
Positive reframing		0.04		−0.07
F	8.73**		8.09**	
Total R	0.560		0.590	
Total *F*	13.40**		15.94**	

*Significant association at the $p < 0.05$ level.
**Significant association at the $p < 0.01$ level.
HAQ-DI, Health Assessment Questionnaire Disability Index.

optimism had weaker associations with life satisfaction in head and neck cancer patients than it did in victims of accidents from which a full recovery was expected. Thus, in the face of a more serious health threat, a realistic acceptance of circumstance may be more influential on outcomes than either optimism or pessimism. Indeed, a study of those with multiple sclerosis observed a realistic acceptance of illness to be positively associated with well-being.[32] The benefit of realistic acceptance of symptoms has been consistently demonstrated in people experiencing chronic pain.[33,34]

A mis-match between level of disability and quality of life in has been observed in patients with diseases that greatly restrict functioning (e.g. Duchenne muscular dystrophy), where despite a high level of

disability, patients report a high quality of life.[35–37] This phenomenon has been termed the 'disability paradox'.[36] The present study observed that while functional impairment explained most of the variance in three of the eight quality of life domains (weakness, independence and activities), psychological variables explained larger amounts of the variance in all other quality of life domains and in both mood domains. Thus, the present findings suggest that psychological variables, especially illness perceptions, might explain this 'disability paradox'.[36]

The present study had the limitation of being cross-sectional using analysis based on correlation and so it is not possible to infer the direction of causality from these results. Thus, it is possible that quality of life and mood may also be influencing illness perceptions, coping and optimism. In addition, three included variables (locking, negative coping, and timeline acute/chronic) had non-normal distributions and required substantial transformation, so results relating to these variables should be interpreted with caution.

Though more concrete conclusions could be drawn from studies using experimental or longitudinal designs, the present study suggests that psychological factors do have a role in explaining quality of life and mood in people with muscle disease. Of the psychological variables under study, illness perceptions, as opposed to optimism and coping, appear to be most strongly associated with quality of life and mood. Thus a psychological intervention that aims to promote adaptive illness perceptions may be of benefit to those with muscle disease who experience low quality of life or low mood.

Clinical messages

- Psychological factors may be more important in explaining quality of life and mood in muscle disease than functional impairment and/or demographics.
- Of the psychological factors studied, illness perceptions appeared to be more strongly associated with quality of life and mood than coping or optimism.

Contributions

CDG prepared and analysed the data, and wrote the first draft. JW, MR and RS designed the study, recruited participants and commented on drafts. RP, MGH, CT, MP, PM, AR, CL, YR, KB, DH-J recruited participants, and assisted with the development of drafts. TC assisted with the statistical analysis and helped write and review drafts. All authors significantly contributed to the final draft.

Conflict of interest

All authors declare that they have no conflicts of interest.

Funding

This study was funded by the Muscular Dystrophy Campaign UK.

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