



UNIVERSITY OF LEEDS

This is a repository copy of *The influence of psychological flexibility on life satisfaction and mood in muscle disorders*.

White Rose Research Online URL for this paper:

<http://eprints.whiterose.ac.uk/97889/>

Version: Accepted Version

Article:

Graham, CD, Gouick, J, Ferreira, N et al. (1 more author) (2016) The influence of psychological flexibility on life satisfaction and mood in muscle disorders. *Rehabilitation Psychology*, 61 (2). pp. 210-217. ISSN 0090-5550

<https://doi.org/10.1037/rep0000092>

© 2016, American Psychological Association. This is an author produced version of a paper published in Rehabilitation Psychology. Uploaded in accordance with the publisher's self-archiving policy. This article may not exactly replicate the final version published in the APA journal. It is not the copy of record.

Reuse

Unless indicated otherwise, fulltext items are protected by copyright with all rights reserved. The copyright exception in section 29 of the Copyright, Designs and Patents Act 1988 allows the making of a single copy solely for the purpose of non-commercial research or private study within the limits of fair dealing. The publisher or other rights-holder may allow further reproduction and re-use of this version - refer to the White Rose Research Online record for this item. Where records identify the publisher as the copyright holder, users can verify any specific terms of use on the publisher's website.

Takedown

If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing eprints@whiterose.ac.uk including the URL of the record and the reason for the withdrawal request.



UNIVERSITY OF LEEDS

This is an author produced version of *The influence of psychological flexibility on life satisfaction and mood in muscle disorders*.

White Rose Research Online URL for this paper:

<http://eprints.whiterose.ac.uk/96680/>

Article:

Graham, CD, Gouick, J, Ferreira, N and Gillanders, D (2016) The influence of psychological flexibility on life satisfaction and mood in muscle disorders. *Rehabilitation Psychology*. ISSN 0090-5550 (In Press)



White Rose
university consortium
Universities of Leeds, Sheffield & York

*promoting access to
White Rose research papers*

eprints@whiterose.ac.uk
<http://eprints.whiterose.ac.uk/>

The influence of psychological flexibility on life satisfaction and mood in muscle disorders

Christopher D. Graham^{1,2}, Joanna Gouick², Nuno Ferreira³, David Gillanders³

1. Leeds Institute of Health Sciences, University of Leeds, 101 Clarendon Road, Leeds, UK,
LS2 9LJ, Tel: +44 (0)113 343 0839; e-mail: c.d.graham@leeds.ac.uk

2. NHS Lothian, Department of Clinical Neuropsychology, Astley Ainslie Hospital,
Edinburgh, UK, EH9 2HL Tel: +44 (0)131 537 900; e-mail:

Joanna.gouick@nhslothian.scot.nhs.uk

3. Department of Clinical Psychology, School of Health in Social Sciences, University of
Edinburgh, Teviot Place, Edinburgh, UK, EH8 9AG, 44 (0) 131 651 3946
david.gillanders@ed.ac.uk nuno.ferreira@ed.ac.uk

Correspondence to: Dr Christopher D. Graham, Leeds Institute of Health Sciences,
University of Leeds, 101 Clarendon Road, Leeds, LS2 9LJ; e-mail: c.d.graham@leeds.ac.uk

Accepted for publication in: Rehabilitation Psychology

Impact and Implications

- Psychological interventions offer a potential way to improve outcomes in MDs, which are progressive and mostly without disease modifying treatment. Yet, a dearth of a research using longitudinal designs means that we are unsure which psychological variables represent viable treatment targets in this context.
- In line with the theoretical assumptions implicit in Acceptance and Commitment Therapy (ACT), this study suggests that psychological flexibility is a distinct process, which influences life satisfaction and anxiety in muscle disorders.
- This provides evidence that ACT may have utility in the context of MDs. However, trials of ACT are now required to establish whether manipulation of psychological flexibility improves outcomes in muscle disorders.

Abstract

Purpose/Objective: Acceptance and Commitment Therapy (ACT), a newer type of behavior therapy which targets psychological flexibility, may have particular utility in the context of muscle disorders. However, there has been no formal investigation of psychological flexibility in this population. This longitudinal observational study investigated whether psychological flexibility is cross-sectionally related to, and prospectively influential on, life satisfaction and mood in muscle disorders.

Research Method/Design: Data were collected via online questionnaire batteries, completed at baseline then repeated four months later. Cross-sectional and prospective regression analyses examined relationships between validated measures of disability level, psychological flexibility (experiential avoidance, cognitive fusion and valued living) and illness perceptions (a psychological variable with known influence in muscle disorders), and outcomes (life satisfaction, anxiety and depression).

Results: A sample of 137 people with a range of muscle disorders participated. In cross-sectional analyses, psychological flexibility explained significant unique variance in addition to illness perceptions ($\Delta R^2 = 0.17-0.34$, $p = <.001$). In prospective analyses, psychological flexibility alone was predictive of change in life satisfaction ($\Delta R^2 = 0.04$, $p = .01$) and anxiety ($\Delta R^2 = 0.03$ $p = .04$) over four months. No independent variables were predictive of change in depression over four months, and disability level had no significant influence on outcomes.

Conclusions: Psychological flexibility influences important outcomes in muscle disorders. Experimental studies are required to establish if increased psychological flexibility leads to improved outcomes.

Key words: muscle disorders; muscular dystrophy; Acceptance and Commitment Therapy; illness perceptions; psychological flexibility

The influence of psychological flexibility on life satisfaction and mood in muscle disorders

Muscle disorders (MDs) are a group of genetic and acquired neuromuscular conditions the majority of which are progressive. Specific diagnoses include limb-girdle muscular dystrophy, facioscapulohumeral muscular dystrophy and inclusion body myositis. They principally affect muscle tissue, causing an insidious decline in physical functioning and mobility. Muscle weakness may also cause dysarthria, dysphagia, and ophthalmoparesis; while cardiac and respiratory symptoms, and pain and fatigue are often reported (Della Marca et al., 2013; Merrison & Hanna, 2009). MDs are associated with reduced quality of life and increased depression and anxiety (Bungener, Jouvent, & Delaporte, 1998; Burns, Graham, Rose, & Simmons, 2012; Graham, Rose, Grunfeld, Kyle, & Weinman, 2011).

Disease modifying treatments are unavailable for most MDs and there are no cures. Most interventions manage symptomatic complications to maintain quality of life, for example: physiotherapy and orthoses to maximise physical functioning, or medication for pain and fatigue (Merrison & Hanna, 2009). As evidenced in other chronic diseases (Astin, Beckner, Soeken, Hochberg, & Berman, 2002; Safren et al., 2014), psychological interventions may offer another way to improve outcomes in MDs (Graham, Simmons, Stuart, & Rose, 2015). Yet, to date, there has been just one such trial with an MD group – specifically aimed at reducing fatigue (Voet et al., 2014). There have been no trials of psychological interventions for improving quality of life/life satisfaction and mood in MD.

Psychological Flexibility

Of potentially applicable psychological interventions, Acceptance and Commitment Therapy (ACT) may be particularly suited to improving quality of life/life satisfaction and mood in MDs (Graham, Simmons, Stuart, & Rose, 2015). ACT is a “third wave” behavior

therapy which specifically aims to increase psychological flexibility (PF) (Hayes, Luoma, Bond, Masuda, & Lillis, 2006), defined as: being present in the here-and-now (present-moment focus), flexibly pursuing behaviours which are in line with deeply held values (valued-living), in acceptance of difficult thoughts and feelings, such as worries or fears (experiential acceptance); within this, being able to see thoughts as transient mental events (cognitive defusion) that are separate from the person who is doing the thinking (self-as-context) (Bond, Hayes, & Barnes-Holmes, 2006).

There are practical and theoretical reasons why ACT may be useful in MDs. Practically, given that MDs are progressive, exact significant functional impairment, and are without treatment, negative beliefs (about illness, self and future) are to be expected at times, and distress - although this can become problematic - may be a natural response to these challenges. Thus, ACT (i.e. increasing PF) may offer clinicians greater scope to improve outcomes than teaching participants to change negative beliefs or to control distress. On a theoretical level, PF is conceptualized to explain individuals' differential ability to undertake meaningful activity in the face of difficult circumstances – such as the challenges implicit in living with MDs and associated physical (pain, fatigue) and emotional (anxiety, fear, sadness) discomfort. Indeed, PF is predictive of meaningful outcomes in chronic pain (McCracken & Vowles, 2014), and other neuromuscular disease (Pakenham & Fleming, 2011). However, at present, we have only indirect evidence that PF is influential in MDs. This is mostly derived from the aforementioned studies with other chronic diseases, alongside one cross-sectional study with a small sub-sample of people with MDs, which showed that a willingness to experience pain, when this facilitated valued-activity, was negatively associated with depression (Kratz, Hirsh, Ehde, & Jensen, 2013).

The Present Study

We investigated the role of PF in explaining life satisfaction and mood in MDs. Since it is feasible that some aspects of PF may be more influential than others (Graham et al., 2014), we recorded key individual facets of psychological flexibility, which can be measured with existing questionnaires: experiential avoidance, valued-living, cognitive fusion. We also aimed to establish if PF explains unique variance in outcomes in addition to variables with known explanatory value in MDs. Thus, illness perceptions were included in the analysis; these are beliefs about the time-course of the health threat, its consequences and if it can be cured or controlled, amongst a range of other beliefs (Petrie & Weinman, 2012). Cross-sectional studies demonstrate that they explain between 5% and 37% of the variance in quality of life, and 25% of the variance in mood in this context (Graham et al., 2014; Rose et al., 2012; Sadjadi, Rose, & Group, 2010).

Therefore, we investigated the cross-sectional and prospective influence of PF (experiential avoidance, cognitive fusion and valued living) on life satisfaction and mood over the effects of disability level, and illness perceptions. We expected that PF would explain additional variance in life satisfaction and mood in both cross-sectional and prospective analyses.

Methods

Participants and Procedure

Participants were recruited via a news story on the Muscular Dystrophy Campaign (United Kingdom) website. A link directed participants to online information sheets, consent forms and the first questionnaire battery. Participants assessed themselves against inclusion/exclusion criteria. They were eligible if they had a diagnosis of MD with duration of greater than six months and were aged 18-75 years. They were ineligible if: they had major active co-morbidities unrelated to MD (such as stroke); experienced cognitive impairment or

myotonic dystrophy (which is associated with cognitive impairment [Minnerop et al., 2011]); were unable to read English; had major diagnosed active mental health co-morbidities, for example psychosis or major depressive disorder; or, were participating in treatment intervention studies. To help ensure that only the desired population participated: we recruited from a MD specific website, participants typed their exact diagnosis, and we kept secondary gain low – there were no rewards for participation. As an additional quality assurance step, only those who completed all questionnaires were included in the analyses.

The questionnaire battery contained measures of dependent and independent variables (listed below) and recorded demographics (MD diagnosis, age, gender, and years since they first noticed symptoms). Four months later, participants were e-mailed a link to the second questionnaire battery. This again recorded the dependent variables but omitted the independent variables, except disability level and illness perceptions (illness perceptions data collected at time 2 are not presented). Favorable ethical opinion was given by Department of Health in Social Sciences ethics committee at the University of Edinburgh.

Measures

Dependent variables.

The Satisfaction With Living Scale (SWLS) (Diener, Emmons, Larsen, & Griffin, 1985) is a five-item uni-dimensional measure of life satisfaction. Scores range from 0-35; higher scores indicate greater life satisfaction. Internal consistency in the present study was very good ($\alpha = .88$).

The Generalised Anxiety Disorder 7-item Scale (GAD-7) (Spitzer, Kroenke, Williams, & Lowe, 2006) is a seven-item measure of anxiety. Scores can range from 0-21, with higher scores indicating more severe anxiety. The cut-off indicating the possible presence of an anxiety disorder is a score of above 10 (Williams, 2014). Internal consistency in the present study was excellent ($\alpha = .90$).

The 9-item version of the Patient Health Questionnaire (PHQ-9) (Kroenke, Spitzer, & Williams, 2001) is a nine-item measure of depression. Scores can range from 0-27, with higher scores indicating more severe depression. The cut-off indicating the possible presence of major depressive disorder is between 8 and 11 (Manea, Gilbody, & McMillan, 2012). In the present study the internal consistency of the PHQ-9 was very good ($\alpha = .86$).

Independent variables.

The Stanford Health Assessment Questionnaire – Disability Index (HAQ-DI)

(Fries, Spitz, & Young, 1982) is a measure of impairment in physical functioning, or disability level, based on eight domains (dressing, arising, eating, walking, hygiene, reach, grip, and activities). There are various ways to score the HAQ-DI. As in previous studies with MD populations (Graham et al., 2014; Rose et al., 2012), to ensure that we assessed disability (as opposed to adaptation), we used the alternative scoring method which does not consider the use of mobility aides and averages the domains to give a total score (range 0 – 3) (Bruce & Fries, 2003). Higher scores indicate greater functional impairment. The internal consistency of the sub-scales ranged from $\alpha = .71$ to $\alpha = .89$.

The Brief Illness Perception Questionnaire (Brief IPQ) (Broadbent, Petrie, Main, & Weinman, 2006) was used to capture illness perceptions. Eight of nine possible domains were utilized (Cause domain excluded). Scores on each domain can range from 0 -10. Higher scores indicate a stronger belief that: MD has many symptoms (identity), it will be chronic as opposed to acute (timeline acute/chronic), it has many consequences (consequences), it can be controlled by ones behavior (personal control) or by treatment (treatment control), it is understandable (illness coherence), it is an emotive (emotional representation) or concerning experience (concern). These domains are summed to give a total score, which quantifies the extent to which the illness is viewed as threatening (Broadbent et al., 2006). The internal consistency for the combined score of the Brief IPQ was very poor. Thus exploratory factor

analyses were undertaken using principal components analysis (varimax rotation). The number of factors extracted was based on Kaiser's criterion (Kaiser, 1960) and inspection of the scree plot (Field, 2013). This yielded three latent variables; however, only one showed acceptable internal and conceptual consistency ($\alpha = .71$). This variable comprised the consequences, identity, emotional representation and concern domains; thus, it appears to capture the level of threat represented by MD - henceforth called IPQ Threat.

The Cognitive Fusion Questionnaire (CFQ) (Gillanders et al., 2014) recorded cognitive fusion: "the tendency for behaviour to be overly regulated and influenced by cognition, compared to other sources of behavioral influence" (Gillanders et al., 2014). With seven items, scores range from 7-49. Higher scores indicate more cognitive fusion. Means for multiple sclerosis and community samples are 22.22 (10.36) and 22.28 (8.30) respectively (Gillanders et al., 2014). Internal consistency in the present study was excellent ($\alpha = .95$).

The Acceptance and Action Questionnaire (AAQ)(Hayes et al., 2004) recorded experiential avoidance: a regulatory strategy comprising attempts to control or avoid unpleasant thoughts, feelings/or and bodily sensations (Machell, Goodman, & Kashdan, 2014). The AAQ consists of nine items. Scores can range from 9-63; higher scores indicating greater experiential avoidance. The internal consistency was acceptable ($\alpha = .73$). The average score in non-mental health populations is between 32-37 (Hayes et al., 2004).

The Engaged Living Scale (ELS) (Trompetter et al., 2013) is a 16 item measure of the ACT conceptualization of valued-living. Scores range from 16-80, and higher scores indicate greater valued-living. In a non-clinical sample the mean of the ELS is 60.80 (7.83), in those with chronic pain it is 50.90 (9.81) (Trompetter et al., 2013). Excellent internal consistency was apparent ($\alpha = .94$).

Data Analyses Plan and Statistics.

Multiple hierarchical regression analyses (enter method), conducted using SPSS version 21 (IBM, Released 2012), comprised the cross-sectional and prospective regression analyses. The cross-sectional regression analyses simply assessed the additive ability of independent variables to explain variance in each dependent variable at time 1. In the prospective analyses, the dependent variable was change in variance in the dependent variables over four months. This involved controlling for variance in the dependent variable measured at time 1. Thus, it can be inferred that variance in the T1 independent variable is antecedent to change in the dependent variable to T2 (Dalecki & Willits, 1991). In the analyses, independent variables were entered in the following steps: disability level (HAQ-DI), followed by illness perceptions (Brief IPQ), then facets of psychological flexibility (valued-living [ELS]; cognitive fusion [CFQ]; experiential avoidance [AAQ]). The time 1 dependent variable was entered as a preliminary first step in the prospective regressions.

Results

Description of Cohort

At time 1, 191 participants completed all items. Of this group, 137 (71.72%) completed the second questionnaire battery. The main MD diagnoses groups were: limb-girdle muscular dystrophy (N=42); facioscapulohumeral muscular dystrophy (N = 28); inclusion body myositis (N =20); Becker muscular dystrophy (N =13) polymyositis and dermatomyositis (N = 7). The remainder (N =27) had a range of MDs, including: oculopharyngeal muscular dystrophy and Emery-Dreifuss muscular dystrophy. The average age was 46.74 years (SD = 13.56); average years with MD was 23.19 years (SD = 14.00). More females (N = 80) than males (N=57) participated. Mann-Whitney U Tests and chi-square tests, corrected for multiple comparisons, revealed no significant differences between those who completed both questionnaires batteries and those who completed just battery one.

Preliminary Data Analyses

Paired t-tests and Wilcoxon tests showed that, over 4 months, life satisfaction worsened (T1 Mean: 18.54 [SD = 7.79], T2 Mean: 17.01 [SD = 7.52] $t[136] = 3.23; p < .01$) but no significant changes in anxiety ($Z = -.36, p = .72$), or depression ($Z = -.17, p = .86$) were observed (Table 1). Disability level increased slightly over this time-period ($Z = -2.38, p = .02$), (Median [SE] T1 = 2.13 [0.72], Mean [SD] T1 = 2.02[0.78]; Median [SE] T2 = 2.13 [0.60], Mean [SD] T2 = 2.08 [0.72]). Mean PF score appeared to be no higher than would be expected in a normal population, and PF was independent from disability level (Table 1).

Regression Analyses

The assumptions for regression were met, with some exceptions; HAQ-DI, CFQ, GAD 7 and PHQ-9 variables were skewed. These were transformed, which resulted in marked improved normality for just the CFQ and HAQ-DI. Thus, where GAD-7 and PHQ-9 were the dependent variables, robust regression procedures were employed (Field, 2013).

In the cross-sectional analyses illness perceptions explained significant proportions of variance ($\Delta R^2 = 0.26-0.27, p <.001$). However, PF ($\Delta R^2 = 0.17-0.43, p <.001$) explained significant additional proportions of variance in all dependent variables (Supplementary Tables 1-3). In the prospective analyses which controlled for time 1 variance in the dependent variable (i.e. where change over four months in the each respective outcome became the dependent variable) (Tables 2-4), most of the variance in each time 2 dependent variable was explained by the respective time 1 dependent variable ($\Delta R^2 = 0.52-0.68, p <.001$). Nonetheless, PF explained small but significant proportions of additional variance in life satisfaction ($\Delta R^2 = 0.04, p = .01$) and anxiety ($\Delta R^2 = 0.03 p = .04$). Experiential avoidance ($\beta = -0.22, p = .01$) was negatively associated with life satisfaction; while cognitive fusion ($\beta = 0.22, p =.01$) was positively associated with this outcome. No one facet of PF was a significant predictor of anxiety, rather a combination of the included variables predicted a significant proportion of variance. Illness perceptions were not predictive of variance in any

of these regressions ($\Delta R^2 = 0.00-0.01$, $p = .17-.99$) and no independent variables were predictive of changes in depression over time. Disability level did not explain a significant proportion of variance in any dependent variable ($\Delta R^2 = 0.00-0.01$, $p = .14-.86$).

Discussion

We investigated the cross-sectional and prospective influence of PF on life satisfaction and mood, after demographics, disability and illness perceptions were included in the analyses. As in previous studies (Graham et al., 2014; Rose et al., 2012; Sadjadi et al., 2010), in cross-sectional analyses illness perceptions explained large proportions of variance. Encouragingly, PF explained significant additional proportions of variance in each dependent variable. This suggests that PF makes a distinct contribution to explaining important outcomes in MDs - over, and above, a psychological variable with proven explanatory value (illness perceptions).

Since the direction of influence could not be ascertained from these cross-sectional analyses, and it is feasible that life satisfaction and mood may influence PF, prospective analyses were then undertaken. Baseline levels of each dependent variable explained large proportions of the variance in outcome variables (life satisfaction, anxiety and depression) over four months (52%-68% of the variance). This left little remaining free variance, making this a particularly tough test for the independent variables. Nonetheless, PF predicted small but significant additional proportions of variance in both change in life satisfaction and anxiety over four months. This is important because it suggests that PF is more than just an epi-phenomenon to change in these dependent variables, but rather it may influence their change over time. Interestingly, illness perceptions were not predictive of change over time. The clinical implication is that PF represents a meaningful treatment target that can influence outcomes, even in the face of high disability levels. Subsequent research should thus experimentally manipulate PF, perhaps in a trial of ACT, to establish if this leads to improved

outcomes. Similar intervention studies have returned encouraging results in other chronic diseases (Feros, Lane, Ciarrochi, & Blackledge, 2013; Gregg, Callaghan, Hayes, & Glenn-Lawson, 2007; Hawkes et al., 2013).

No independent variables predicted significant proportions of variance in change in depression over four months. This result is most plausibly explained by the lack of remaining free variance in the dependent variable, after time 1 depression had previously explained particularly large proportions of variance (68%).

Intriguing relationships between facets of PF and later outcomes were observed in the prospective analyses. In agreement with a study of pain in MDs (Kratz et al., 2013), later life satisfaction was negatively associated with experiential avoidance. Yet, surprisingly life satisfaction was also positively related to cognitive fusion. Cumulatively this suggests that life satisfaction benefits from a) viewing thoughts as real and literal (cognitive fusion), while b) being open to experiencing unpleasant private events, such as difficult thoughts and feelings (experiential acceptance). This combination of high cognitive fusion and low experiential avoidance may align with an attitude of ‘stoic’ acceptance – in other words, of ‘just getting on with it’ - which showed positive associations with quality of life in an earlier study with MDs (Ahlstrom & Sjoden, 1996). Another explanation is: since cognitive fusion regards thought process and not thought content, alongside having experiential acceptance, individuals with good outcomes hold salient positive thoughts which they see as factual.

In the present study, PF predicted significant proportions of variance in later anxiety. This adds to the literature which suggests that PF influences anxiety across populations (Masuda & Tully, 2012; McCracken, Gutiérrez-Martínez, & Smyth, 2013; White et al., 2013). However, no one facet of PF was significantly predictive of anxiety; rather it was the combination of all PF variables. Larger sample sizes may be required to tease out the individual relationships between these facets and outcomes.

Limitations and suggestions for future research

This study also used an observational design, thus experimental designs which manipulate independent variables are required to make stronger claims regarding causality. The demographic composition was very similar (age, years with MD, proportion of different MDs) to an earlier sample drawn from UK National Health Service clinics (Graham et al., 2014). Nonetheless, the exclusion criteria, which were used to help minimize the risk of someone without capacity to consent participating (e.g. cognitive impairment, severe psychiatric diagnoses), may limit the representativeness of the sample compared to a clinical sample. Indeed, our assumed self-awareness of psychiatric diagnosis may have been problematic because some participants may have been diagnosed with conditions that they do not remember or recognise (Marrie et al., 2009). Also, due to the somatic focus of some items on the mood questionnaires, conflation of MD symptoms with mood may have caused an overestimation of mood disturbance.

As half of the domains from the Brief IPQ were not used and only one measure of illness perceptions was included, compared to three measures of PF, direct comparison between the performances of these constructs is discouraged. Finally, given that PF includes processes implicit in other therapeutic modalities, such as mindfulness-based approaches (Pagnini, Phillips, Bosma, Reece, & Langer, 2015), the results infer that investigation of mindfulness processes may also be warranted.

Conclusion

PF explains unique variance in life satisfaction, depression and anxiety, and predicts change in life satisfaction and anxiety over four months. This suggests that PF is an influential process in MDs. Experimental studies are required to establish if manipulation of PF leads to improved outcomes.

References

- Ahlstrom, G., & Sjoden, P. O. (1996). Coping with illness-related problems and quality of life in adult individuals with muscular dystrophy. *Journal of Psychosomatic Research*, 41(4), 365-376. doi: 10.1016/s0022-3999(96)00191-2
- Astin, J. A., Beckner, W., Soeken, K., Hochberg, M. C., & Berman, B. (2002). Psychological interventions for rheumatoid arthritis: A meta-analysis of randomized controlled trials. *Arthritis care & research*, 47(3), 291-302.
- Broadbent, E., Petrie, K. J., Main, J., & Weinman, J. (2006). The brief illness perception questionnaire. *J Psychosom Res*, 60(6), 631-637. doi: 10.1016/j.jpsychores.2005.10.020
- Bruce, B., & Fries, J. (2003). The Stanford Health Assessment Questionnaire: Dimensions and Practical Applications. *Health and Quality of Life Outcomes*, 1(1), 20.
- Bungener, C., Jouvent, R., & Delaporte, C. (1998). Psychopathological and emotional deficits in myotonic dystrophy. *Journal of Neurology, Neurosurgery, and Psychiatry*, 65(3), 353-356.
- Burns, T. M., Graham, C. D., Rose, M. R., & Simmons, Z. (2012). Quality of life and measures of quality of life in patients with neuromuscular disorders. *Muscle & nerve*, 46(1), 9-25. doi: 10.1002/mus.23245
- Dalecki, M., & Willits, F. K. (1991). Examining change using regression analysis: Three approaches compared. *Sociological Spectrum*, 11(2), 127-145.
- Della Marca, G., Frusciante, R., Vollono, C., Iannaccone, E., Dittoni, S., Losurdo, A., . . . Ricci, E. (2013). Pain and the Alpha-Sleep Anomaly: A Mechanism of Sleep Disruption in Facioscapulohumeral Muscular Dystrophy. *Pain Medicine*, 14(4), 487-497. doi: 10.1111/pme.12054
- Diener, E., Emmons, R. A., Larsen, R. J., & Griffin, S. (1985). The Satisfaction with Life Scale. *Journal of Personality Assessment*, 49(1), 71-75. doi: citeulike-article-id:6447499
- Feros, D. L., Lane, L., Ciarrochi, J., & Blackledge, J. T. (2013). Acceptance and Commitment Therapy (ACT) for improving the lives of cancer patients: a preliminary study. *Psycho-Oncology*, 22(2), 459-464. doi: 10.1002/pon.2083
- Field, A. (2013). *Discovering statistics using IBM SPSS statistics*: Sage.
- Fries, J. F., Spitz, P. W., & Young, D. Y. (1982). The dimensions of health outcomes: the health assessment questionnaire, disability and pain scales. *The Journal of rheumatology*, 9(5), 789-793.
- Gillanders, D. T., Bolderston, H., Bond, F. W., Dempster, M., Flaxman, P. E., Campbell, L., . . . Ferenbach, C. (2014). The development and initial validation of the Cognitive Fusion Questionnaire. *Behavior therapy*, 45(1), 83-101.
- Graham, C. D., Rose, M. R., Grunfeld, E. A., Kyle, S. D., & Weinman, J. (2011). A systematic review of quality of life in adults with muscle disease. *Journal Of Neurology*, 258(9), 1581-1592. doi: 10.1007/s00415-011-6062-5
- Graham, C. D., Simmons, Z., Stuart, S. R., & Rose, M. R. (2015). The potential of psychological interventions to improve quality of life and mood in muscle disorders. *Muscle Nerve*, 52(1), 131-136. doi: 10.1002/mus.24487
- Graham, C. D., Weinman, J., Sadjadi, R., Chalder, T., Petty, R., Hanna, M. G., . . . Rose, M. R. (2014). A multicentre postal survey investigating the contribution of illness perceptions, coping and optimism to quality of life and mood in adults with muscle disease. *Clinical Rehabilitation*, 28(5), 508-519. doi: 10.1177/0269215513511340
- Gregg, J. A., Callaghan, G. M., Hayes, S. C., & Glenn-Lawson, J. L. (2007). Improving diabetes self-management through acceptance, mindfulness, and values: A randomized controlled trial. *Journal of Consulting and Clinical Psychology*, 75(2), 336-343. doi: <http://dx.doi.org/10.1037/0022-006X.75.2.336>
- Hawkes, A. L., Chambers, S. K., Pakenham, K. I., Patrao, T. A., Baade, P. D., Lynch, B. M., . . . Courneya, K. S. (2013). Effects of a telephone-delivered multiple health behavior change intervention (CanChange) on health and behavioral outcomes in survivors of colorectal cancer: a randomized controlled trial. *Journal of Clinical Oncology*, JCO. 2012.2045. 5873.

- Hayes, S. C., Luoma, J. B., Bond, F. W., Masuda, A., & Lillis, J. (2006). Acceptance and Commitment Therapy: Model, processes and outcomes. *Behaviour Research and Therapy*, 44(1), 1-25.
- Hayes, S. C., Strosahl, K., Wilson, K. G., Bissett, R. T., Pistorello, J., Toarmino, D., . . . Bergan, J. (2004). Measuring Experiential Avoidance: A Preliminary Test of a Working Model. *The Psychological Record*(54), 553-578.
- IBM. (Released 2012). IBM SPSS Statistics for Windows, Version 21.0. Armonk, NY.
- Kaiser, H. F. (1960). The application of electronic computers to factor analysis. *Educational and psychological measurement*.
- Kratz, A. L., Hirsh, A. T., Ehde, D. M., & Jensen, M. P. (2013). Acceptance of Pain in Neurological Disorders: Associations With Functioning and Psychosocial Well-Being. *Rehabilitation Psychology*, 58(1), 1-9.
- Kroenke, K., Spitzer, R. L., & Williams, J. B. W. (2001). The PHQ-9: Validity of a Brief Depression Severity Measure. *Journal of General Internal Medicine*, 16(9), 606-613. doi: 10.1046/j.1525-1497.2001.016009606.x
- Machell, K. A., Goodman, F. R., & Kashdan, T. B. (2014). Experiential avoidance and well-being: A daily diary analysis. *Cognition and Emotion*, 29(2), 351-359. doi: 10.1080/02699931.2014.911143
- Marrie, R. A., Horwitz, R., Cutter, G., Tyry, T., Campagnolo, D., & Vollmer, T. (2009). The burden of mental comorbidity in multiple sclerosis: frequent, underdiagnosed, and undertreated. *Mult Scler*, 15(3), 385-392. doi: 10.1177/1352458508099477
- Masuda, A., & Tully, E. C. (2012). The Role of Mindfulness and Psychological Flexibility in Somatization, Depression, Anxiety, and General Psychological Distress in a Nonclinical College Sample. *Journal of Evidence-Based Complementary & Alternative Medicine*, 17(1), 66-71. doi: 10.1177/2156587211423400
- McCracken, L. M., Gutiérrez-Martínez, O., & Smyth, C. (2013). "Decentering" reflects psychological flexibility in people with chronic pain and correlates with their quality of functioning. *Health Psychology*, 32(7), 820.
- McCracken, L. M., & Vowles, K. E. (2014). Acceptance and commitment therapy and mindfulness for chronic pain: model, process, and progress. *Am Psychol*, 69(2), 178-187. doi: 10.1037/a0035623
- Merrison, A. F. A., & Hanna, M. G. (2009). Muscle disease: THE BARE ESSENTIALS. *Practical Neurology*, 9(1), 54-65. doi: 10.1136/jnnp.2008.167171
- Minnerop, M., Weber, B., Schoene-Bake, J.-C., Roeske, S., Mirbach, S., Anspach, C., . . . Kornblum, C. (2011). The brain in myotonic dystrophy 1 and 2: evidence for a predominant white matter disease. *Brain*, 134(12), 3530-3546. doi: 10.1093/brain/awr299
- Pagnini, F., Phillips, D., Bosma, C. M., Reece, A., & Langer, E. (2015). Mindfulness, physical impairment and psychological well-being in people with amyotrophic lateral sclerosis. *Psychol Health*, 30(5), 503-517. doi: 10.1080/08870446.2014.982652
- Pakenham, K. I., & Fleming, M. (2011). Relations between acceptance of multiple sclerosis and positive and negative adjustments. *Psychology & Health*, 26(10), 1292-1309. doi: 10.1080/08870446.2010.517838
- Petrie, K. J., & Weinman, J. (2012). Patients' Perceptions of Their Illness: The Dynamo of Volition in Health Care. *Current Directions in Psychological Science*, 21(1), 60-65. doi: 10.1177/0963721411429456
- Rose, M. R., Sadjadi, R., Weinman, J., Akhtar, T., Pandya, S., Kissel, J. T., . . . the Muscle Study, G. (2012). Role of disease severity, illness perceptions, and mood on quality of life in muscle disease. *Muscle & nerve*, 46(3), 351-359. doi: 10.1002/mus.23320
- Sadjadi, R., Rose, M. R., & Group, M. S. (2010). What determines quality of life in inclusion body myositis? *Journal of Neurology, Neurosurgery & Psychiatry*, 81(10), 1164-1166. doi: 10.1136/jnnp.2009.183863
- Safren, S. A., Gonzalez, J. S., Wexler, D. J., Psaros, C., Delahanty, L. M., Blashill, A. J., . . . Cagliero, E. (2014). A randomized controlled trial of cognitive behavioral therapy for adherence and depression (CBT-AD) in patients with uncontrolled type 2 diabetes. *Diabetes Care*, 37(3), 625-633. doi: 10.2337/dc13-0816

- Spitzer, R. L., Kroenke, K., Williams, J. B., & Lowe, B. (2006). A brief measure for assessing generalized anxiety disorder: the GAD-7. *Arch Intern Med*, 166(10), 1092-1097. doi: 10.1001/archinte.166.10.1092
- Trompetter, H. R., Ten Klooster, P. M., Schreurs, K. M., Fledderus, M., Westerhof, G. J., & Bohlmeijer, E. T. (2013). Measuring values and committed action with the Engaged Living Scale (ELS): psychometric evaluation in a nonclinical sample and a chronic pain sample. *Psychol Assess*, 25(4), 1235-1246. doi: 10.1037/a0033813
- Voet, N., Bleijenberg, G., Hendriks, J., de Groot, I., Padberg, G., van Engelen, B., & Geurts, A. (2014). Both aerobic exercise and cognitive-behavioral therapy reduce chronic fatigue in FSHD: An RCT. *Neurology*, 83(21), 1914-1922. doi: 10.1212/wnl.00000000000001008
- White, R. G., Gumley, A. I., McTaggart, J., Rattrie, L., McConville, D., Cleare, S., & Mitchell, G. (2013). Depression and anxiety following psychosis: associations with mindfulness and psychological flexibility. *Behav Cogn Psychother*, 41(1), 34-51. doi: 10.1017/s1352465812000239
- Williams, N. (2014). The GAD-7 questionnaire. *Occupational Medicine*, 64(3), 224. doi: 10.1093/occmed/kqt161

Table & Figures**Table 1. Means (standard deviations) and inter-correlations (Pearson's r) between key study variables^a**

	M (SD)	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.	11.
1. SWLS T1	18.54 (7.79)		-.49**	-.52**	-.11	-.52**	-.57**	.38**	.74**	.72**	-.43**	-.40**
2. GAD-7 T1	4.31 (4.4)			.79**	.02	.50**	.53**	.60**	-.56**	-.38**	.75**	.67**
3. PHQ-9 T1	6.58 (5.36)				.08	.53**	.53**	.50**	-.56**	-.50**	.65**	.83**
4. HAQ-DI T1	2.02 (0.78)					.23*	.01	.06	.03	-.10	-.07	.06
5. IPQ Threat T1	26.73 (7.66)						.53**	.46**	-.44**	-.44**	.40**	.43**
6. AAQ T1	32.88 (8.90)							.58**	-.66**	-.51**	.50**	.48**
7. CFQ T1	19.96 (9.56)								-.53**	-.23**	.52**	.43**
8. ELS T1	54.50 (13.37)									.56**	.55**	-.45**
9. SWLS T2	17.01 (7.52)										-.34**	-.44**
10. GAD-7 T2	4.23 (4.28)											.68**
11. PHQ-9 T2	6.48 (5.36)											

^aSignificant association at less than or equal to p =.05.^{**}Significant association at less than or equal to p=.01.

^aWhere appropriate, transformed variables were used; presented means (SD) are for untransformed variables.
 AAQ = Acceptance and Action Questionnaire (experiential avoidance); CFQ = Cognitive Fusion Questionnaire (cognitive fusion); ELS = Engaged Living Scale (valued-living); GAD-7 = Generalized Anxiety Disorder 7 item Scale (anxiety); HAQ-DI = Health Assessment Questionnaire – Disability Index (disability level); IPQ Threat = Brief Illness Perception Questionnaire Threat Scale (illness perceptions); PHQ-9 = Patient Health Questionnaire 9 item Scale (depression); SWLS= Satisfaction with Life Scale (life satisfaction)

Table 2. Prospective hierarchical regression analyses showing the influence of baseline independent variables on change in life satisfaction (SWLS) over four months.

Step	Variable	β	t	p	R ²	ΔR^2	ΔF	p
1	T1 Life Satisfaction (SWLS)	.72	12.14	<.001	.52	.52	147.31	<.001
2	T1 Life Satisfaction (SWLS)	.72	11.99	<.001	.52	.00	0.72	.789
	Disability Level (HAQ-DI)	-.02	-.27	.79				
3	T1 Life Satisfaction (SWLS)	.67	9.61	<.001	.52	.01	1.95	.165
	Disability Level (HAQ-DI)	.00	0.02	.99				
	Illness Threat (IPQ-Threat)	-.10	-1.40	.17				
4	T1 Life Satisfaction (SWLS)	.59	6.33	<.001	.56	.04	3.65	.014
	Disability Level (HAQ-DI)	-.02	-0.30	.77				
	Illness Threat (IPQ-Threat)	-.10	-1.32	.19				
	Experiential Avoidance (AAQ)	-.22	-2.55	.01				
	Cognitive Fusion (CFQ)	.22	2.78	.01				
	Valued-living (ELS)	.06	0.58	.57				

Method: Enter

SWLS= Satisfaction with Life Scale; HAQ-DI = Health Assessment Questionnaire – Disability Index; IPQ Threat = Brief Illness Perception Questionnaire Threat Scale; AAQ = Acceptance and Action Questionnaire; CFQ = Cognitive Fusion Questionnaire; ELS = Engaged Living Scale.

Table 3. Prospective hierarchical regression analyses showing the influence of baseline independent variables on change in anxiety (GAD 7) over four months†

Step	Variable	β	t	p	R ²	ΔR^2	ΔF	p
1	T1 Anxiety (GAD-7)	.75	12.96	<.001	.56	.56	168.07	<.001
2	T1 Anxiety (GAD-7)	.75	13.05	<.001	.56	.01	2.20	.14
	Disability Level (HAQ-DI)	-.09	-1.48	.17				
3	T1 Anxiety (GAD-7)	.71	10.75	<.001	.57	.00	1.00	.32
	Disability Level (HAQ-DI)	-.10	-1.69	.11				
	Illness Threat (IPQ-Threat)	.07	1.00	.31				
4	T1 Anxiety (GAD-7)	.59	7.58	<.001	.59	.03	2.78	.04
	Disability Level (HAQ-DI)	-.08	-1.42	.17				
	Illness Threat (IPQ-Threat)	.00	-0.01	.99				
	Experiential Avoidance (AAQ)	.05	-0.53	.67				
	Cognitive Fusion (CFQ)	.08	1.03	.35				
	Valued-living (ELS)	-.14	-1.68	.11				

Method: Enter

GAD-7= General Health Questionnaire 7 item version; HAQ-DI = Health Assessment

Questionnaire – Disability Index; IPQ Threat = Brief Illness Perception Questionnaire Threat Scale; AAQ = Acceptance and Action Questionnaire; CFQ = Cognitive Fusion Questionnaire; ELS = Engaged Living Scale.

† Bootstrapped p-values reported

Table 4. Prospective hierarchical regression analyses showing the influence of baseline independent variables on change in depression (PHQ 9) over four months†.

Step	Variable	β	t	p	R ²	ΔR^2	ΔF	p
1	T1 Depression (PHQ-9)	.83	17.06	<.001	.68	.68	291.06	<.001
2	T1 Depression (PHQ-9)	.83	16.95	<.001	.68	.00	0.03	.86
	Disability Level (HAQ-DI)	-.01	-0.17	.88				
3	T1 Depression (PHQ-9)	.83	14.39	<.001	.68	.00	0.00	.99
	Disability Level (HAQ-DI)	-.01	-0.17	.87				
	Illness Threat (IPQ-Threat)	.00	0.00	.99				
4	T1 Depression (PHQ-9)	.82	12.56	<.001	.69	.01	0.84	.47
	Disability Level (HAQ-DI)	-.01	-0.11	.91				
	Illness Threat (IPQ-Threat)	-.02	-0.36	.70				
	Experiential Avoidance (AAQ)	.11	-1.50	.12				
	Cognitive Fusion (CFQ)	-.01	-0.07	.96				
	Valued-living (ELS)	.07	1.01	.37				

Method: Enter

PHQ-9= Patient Health Questionnaire 9-item version; HAQ-DI = Health Assessment

Questionnaire – Disability Index; IPQ Threat = Brief Illness Perception Questionnaire Threat

Scale; AAQ = Acceptance and Action Questionnaire; CFQ = Cognitive Fusion

Questionnaire; ELS = Engaged Living Scale.

† Bootstrapped p-values reported

Supplementary Table 1. Cross-sectional hierarchical regression analyses showing the contribution of baseline independent variables to baseline depression (PHQ 9).

Step	Variable	β	t	p	R ²	ΔR^2	ΔF	p
1	Disability Level (HAQ-DI)	-.11	-1.29	.20	.01	.01	1.68	.20
2	Disability Level (HAQ-DI)	.01	0.11	.92	.27	.26	47.92	<.001
	Illness Threat (IPQ-Threat)	-.52	-6.92	<.001				
3	Disability Level (HAQ-DI)	-.08	-1.47	.14	.62	.34	39.22	<.001
	Illness Threat (IPQ-Threat)	-.22	-3.27	.001				
	Experiential Avoidance (AAQ)	-.10	-1.22	.23				
	Cognitive Fusion (CFQ)	.13	1.81	.07				
	Valued-living (ELS)	.66	8.75	<.001				

Method: Enter

PHQ-9= Patient Health Questionnaire 9-item version; HAQ-DI = Health Assessment

Questionnaire – Disability Index; IPQ Threat = Brief Illness Perception Questionnaire Threat

Scale; AAQ = Acceptance and Action Questionnaire; CFQ = Cognitive Fusion

Questionnaire; ELS = Engaged Living Scale.

Supplementary Table 2. Cross-sectional hierarchical regression analyses showing the contribution of baseline independent variables to baseline anxiety (PHQ 9) †.

Step	Variable	β	t	p	R^2	ΔR^2	ΔF	p
1	Disability Level (HAQ-DI)	.02	0.25	.80	-.01	.00	0.06	.801
2	Disability Level (HAQ-DI)	-.10	-1.26	.25	.25	.26	46.18	<.001
	Illness Threat (IPQ-Threat)	.52	6.80	<.001				
3	Disability Level (HAQ-DI)	-.04	-0.59	.60	.47	.23	19.75	<.001
	Illness Threat (IPQ-Threat)	.20	-2.58	.02				
	Experiential Avoidance (AAQ)	.03	-0.35	.69				
	Cognitive Fusion (CFQ)	.38	4.50	<.001				
	Valued-living (ELS)	-.23	-2.67	.016				

Method: Enter

PHQ-9= Patient Health Questionnaire 9-item version; HAQ-DI = Health Assessment

Questionnaire – Disability Index; IPQ Threat = Brief Illness Perception Questionnaire Threat

Scale; AAQ = Acceptance and Action Questionnaire; CFQ = Cognitive Fusion

Questionnaire; ELS = Engaged Living Scale.

† Bootstrapped p-values reported

Supplementary Table 3. Cross-sectional hierarchical regression analyses showing the contribution of baseline independent variables to baseline depression (PHQ 9) †.

Step	Variable	β	t	p	R^2	ΔR^2	ΔF	p
1	Disability Level (HAQ-DI)	.08	0.97	.33	.01	.01	0.95	.332
2	Disability Level (HAQ-DI)	-.04	-0.50	.61	.28	.27	50.53	<.001
	Illness Threat (IPQ-Threat)	.54	7.11	<.001				
3	Disability Level (HAQ-DI)	.02	0.31	.77	.45	.17	13.06	<.001
	Illness Threat (IPQ-Threat)	.26	3.16	.02				
	Experiential Avoidance (AAQ)	.08	0.87	.34				
	Cognitive Fusion (CFQ)	.20	2.22	.09				
	Valued-living (ELS)	-.28	-3.10	<.01				

Method: Enter

PHQ-9= Patient Health Questionnaire 9-item version; HAQ-DI = Health Assessment

Questionnaire – Disability Index; IPQ Threat = Brief Illness Perception Questionnaire Threat

Scale; AAQ = Acceptance and Action Questionnaire; CFQ = Cognitive Fusion

Questionnaire; ELS = Engaged Living Scale.

† Bootstrapped p-values reported

Acknowledgements

We would like to acknowledge the Muscular Dystrophy Campaign for publicizing and promoting the study; and the B.Baggins Foundation, FSH-MD Support Group UK, The Neuromuscular Centre, Myositis UK, and the Myositis Support Group for further promotion. This study part-comprised Christopher Graham's Doctorate in Clinical Psychology, funded by NHS National Education for Scotland.