Relationships among alexithymia and pain intensity, pain interference, and vitality in persons with neuromuscular disease : Considering the effect of negative affectivity

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出版情報：Pain. 149 (2), pp.273-277, 2010-05-01. Elsevier
バージョン：

RELATIONSHIPS AMONG ALEXITHYMIA AND PAIN INTENSITY, PAIN INTERFERENCE, AND VITALITY IN PERSONS WITH NEUROMUSCULAR DISEASE: CONSIDERING THE EFFECT OF NEGATIVE AFFECTIVITY

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Keywords: Alexithymia, neuromuscular disease, chronic pain; TAS-20, SF-36

Running head: ALEXITHYMIA AND NMD

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Abstract

Alexithymia, the inability to identify or label emotions, has been shown to be associated with pain in patients with a number of chronic pain conditions. We sought to: (1) replicate this association in samples of persons with chronic pain secondary to neuromuscular disease; (2) extend this finding to other important pain-related measures, and (3) to determine whether relationships among alexithymia and study variables existed after controlling for negative affect. One hundred and twenty-nine individuals with muscular dystrophy and chronic pain were administered measures of alexithymia (Toronto Alexithymia Scale, TAS-20), pain intensity (0-10 NRS), pain interference (Brief Pain Inventory Interference scale), mental health (SF-36 Mental Health scale; as a proxy measure of negative affect) and vitality (SF-36 Vitality scale). Higher TAS scores were associated significantly with higher pain intensity and interference, and less vitality. Although the strengths of these associations were reduced when mental health was used as a control, the associations between the Difficulty Identifying Feelings scale and vitality, and the Externally Oriented Thinking and Total TAS scales and pain intensity remained statistically significant. The findings replicate and extend previous findings concerning the associations between alexithymia and important pain-related variables in a sample of persons with chronic pain and neuromuscular disease. Future research is needed to determine the extent to which the associations are due to (1) a possible causal effect of alexithymia on patient functioning that is mediated via its effects on negative affect or (2) the possibility that alexithymia/outcome relationships reflect response bias caused by general negative affectivity.

1. Introduction

The concept of alexithymia, a lack of emotional awareness and ability to describe feelings, was originally coined by Sifneos [33] to describe a common characteristic of patients with psychosomatic illness. Some authors have suggested that having alexithymia can contribute to the future development or maintenance of psychosomatic illness, that is, medical disorders thought to be primarily caused or maintained by psychological factors [1, 3]. Consistent with this hypothesis, research has supported the notion that patients with psychosomatic illnesses, such as asthma, hypertension, and functional bowel syndromes report higher levels of alexithymia than healthy controls [10]. Moreover, alexithymia has been shown to prospectively predict the maintenance of somatization over a period of two years [3].

Alexithymia has been shown to be associated with pain in patients with chronic myofascial pain [25], temporomandibular disorder [11], rheumatoid arthritis [24], migraine headaches [24], systemic lupus erythematosus [24], low back pain [28], fibromyalgia [15], and cancer pain [30]. Alexithymia has also been shown to predict depression [19, 25], anxiety [19], and physical impairment [25] in patients with various chronic pain conditions. The broad spectrum of conditions in which alexithymia predicts pain and functioning suggests that this concept may extend beyond patients with psychosomatic conditions to include populations with clear organic pathology.

Although alexithymia has been shown to be associated with a range of negative outcomes, some debate exists as to the mechanism of these associations, particularly when considering psychological outcomes such as negative affect. For example, it has been argued that alexithymia essentially *causes* depression due the direct effects of an inability to experience emotions leading to dysregulation of behavioral and biological systems, and to poor mood states [e.g., 34]. Others have proposed that the trait of negative affectivity (or neuroticism) creates a response bias that contributes to both a self-report of alexithymia and self-report of a negative outcome (pain interference, poor quality of life, etc) [20, 22].

The most common measure of alexithymia in the research literature is the Toronto Alexithymia Scale (TAS-20) [4, 5], which assesses three distinct components of alexithymia: (1) difficulty identifying feelings, (2) difficulty describing feelings, and (3) externally-oriented thinking. Research in pain populations has identified the Difficulty Identifying Feelings scale as the most consistent predictor of pain and pain-related dysfunction [15, 24, 27, 30, 32]. In the current study, we sought to determine if the associations among measures of alexithymia, pain and functioning (pain interference, mental health, and vitality) replicate in samples of persons with chronic pain and neuromuscular disease (NMD). We also sought to evaluate the extent to which any significant associations between alexithymia and various criterion measures change after controlling for psychological functioning, given possibility that negative affectivity may influence at least some of these relationships [15, 25]. Based on research that has been published to date, we hypothesized positive associations between the TAS-20 subscales, especially the Difficulty Identifying Feelings scale, and the measures of pain and dysfunction.

2. Methods

2.1. Participants

The participants in this study came from a population of 270 individuals who had responded to a previous survey on the nature and scope of pain in persons with neuromuscular disease, and who had agreed to participate in additional studies [17]. Of 270 surveys mailed, 32 were returned due to incorrect addresses, three individuals were deceased and one individual declined to participate. In total, 193 surveys were returned, for a response rate of 71%. Three of these were excluded due to participant ineligibility (unable to verify physician

diagnosis), yielding 190 completed and viable surveys. Of these, 144 individuals reported experiencing pain in the past three months and were included in the current study.

The vast majority of these 144 participants reported diagnoses of Facioscapulohumeral Muscular Dystrophy (FSHD; 54.1%) or Myotonic Muscular Dystrophy (MMD; 36.1%). Both conditions are genetic disorders that lead to progressive weakness and dystrophic changes in muscle. Although pain is a common secondary condition to these conditions, not all people with FSHD or MMD develop chronic pain [17]. For consistency with ongoing work in our group we limited the analyses to those participants with these two diagnoses, leaving a final sample size was 129 persons with FSHD or MMD and chronic pain. Nearly all respondents' diagnoses were made by a neurologist (92.4%) and were confirmed with DNA (59.0%), muscle biopsy (50.0%) and/or EMG (76.4%).

Individuals in the present study (n = 129) were primarily middle aged (age in years M = 52.0, SD = 12.4, range = 22-85). Seventy-two were female (56%) and 57 (44%) were male. The sample was predominantly Caucasian (98%) and married (67%). All but one participant reported a high school degree or GED (99%), with 33% reporting that they were college graduates. The most frequent pain sites for both diagnostic groups were the lower back (70.5% FSHD, 65.4% MMD), and legs (70.5% FSHD, 71.2% MMD).

2.2. Measures

2.2.1. *Demographic Information*. Participants provided information regarding their age, gender, level of education, current employment status, ethnicity/race, and marital status. Clinical variables included NMD diagnosis, the specialization of the diagnosing physician and nature of diagnosis confirmation (e.g., DNA testing, EMG testing).

2.2.2. *Alexithymia*. Alexithymia was assessed using the 20-Item Toronto Alexithymia Scale (TAS-20) [4, 5, 29]. The TAS-20 is a shortened version of the original Toronto Alexithymia Scale (TAS-26) [35]. As indicated above, the TAS-20 assesses three domains hypothesized to represent the primary alexithymia domains: (1) difficulty identifying feelings (example item, "I have feelings that I can't quite identify"), (2) difficulty describing feelings (example item, "I find it hard to describe how I feel about people"), and (3) externally-oriented thinking (example item, "I prefer to analyze problems rather than just describe them"). The TAS-20 has demonstrated strong psychometric properties including good test-retest reliability and external validity [4] and has been used in a variety of medical populations [4, 8, 13, 23, 26]. Possible responses to the TAS-20 items range from 1 ("Strongly disagree") to 5 ("Strongly agree"). In the current sample, the TAS-20 demonstrated adequate internal consistency as a total score (Cronbach's alpha = .70). Subscale reliability ranged from quite good (Difficulty Identifying Feelings scale, Cronbach's alpha = .80; Difficulty Describing Feelings scale, Cronbach's alpha = .76) to marginal (Externally-Oriented Thinking scale, Cronbach's alpha = .59). The relatively low internal consistency of the Externally-Oriented Thinking scale is typical and has been found in other studies [28].

2.2.3. Pain Intensity. Participants were asked to rate the average intensity of their pain in the past week on a 0 to 10 Numerical Rating Scale (NRS). Anchors were "no pain" (0) and "pain as bad as it could be" (10).

2.2.4. *Pain Interference*. The Brief Pain Inventory (BPI) [7, 9] was used to assess the extent to which pain interfered with normal daily activities during the past week. The original seven item version of this scale asked participants to rate the degree to which pain interfered with general activity, mood, walking ability, normal work, relations with other people, sleep, and enjoyment of life in the past week. Analogous to previous studies using the BPI to assess pain interference in populations with disabilities, several modifications were

made to the scale to accommodate the population [9, 37]. In the first of these, the "Walking ability" was modified to assess pain's interference with "Mobility, that is, your ability to get around" so that participants who do not walk due to their disability could respond to the item. Next, three questions pertaining to pain interference with self-care, recreational activities, and social activities were added, thus increasing the measure to 10 questions. Scale anchors to the BPI Interference items range from "Does not interfere" (0) to "Completely interferes" (10). The BPI score is calculated by computing the arithmetic mean of all, such that higher scores indicate greater pain interference. Like the original BPI scale, the modified 10-item version BPI has displayed excellent internal consistency (Cronbach's alphas = .89-.95) and validity in samples of persons with disabilities [12, 37]. In the current sample, internal consistency was also excellent (Cronbach's alpha = .95).

2.2.5. Mental health and vitality. Mental health and vitality were assessed using the Mental Health and Vitality subscales from the SF-36 [38], respectively. The Mental Health Scale is a 5-item scale commonly used as a measure of psychological functioning and has established internal consistency (Cronbach's alphas = .81-.95) and test-retest reliability (*rs* = .75-.80) (example items: "How much of the time during the past four weeks…have you felt downhearted and blue?"; "…. have you been a happy person?") [38]. The 4-item Vitality subscale assesses perceived energy versus general fatigue (example items: "How much of the time during the past four weeks…Did you feel full of pep?"; "…Did you have a lot of energy?"). Consistent with standard scoring for the SF-36, both subscales were transformed to a 0-100 scale, with higher scores indicating better functioning (that is, better psychological functioning and lower fatigue). Both scales demonstrated excellent internal consistency in the present sample (Mental Health: Cronbach's alpha = .86; Vitality: Cronbach's alpha = .80).

2.3. Procedures

All of the potential participants in the current sample had participated in a previous survey completed two years earlier, and had indicated that they would be interested in being contacted for further research opportunities. They were sent a second return by mail survey assessing clinical, demographic, and adjustment variables related to NMD and NMD associated pain, including the measures described above. The surveys took approximately one hour to complete, and participants were compensated $25 on survey return. In the case of missing or incomplete responses, research assistants followed up with survey respondents over the phone to obtain the most complete data set possible. The University of Washington Human Subjects Review committee approved all study procedures.

2.4. Data Analyses

Outcome variables of interest were average pain intensity, SF-36 Vitality and Mental Health scales, and the BPI mean score. Before analysis, the predictor and criterion measures were examined for outliers and for normality. These variables met requirements for analysis and no transformation was necessary. Zero-order relationships among TAS-20 scale scores and the criterion measures was established via Pearson correlation. We then computed partial correlations between the TAS-20 scale scores and all of the criterion variables, except the SF-36 MH scale, controlling for the SF-36 MH scale. SPSS 14.0 was used for all analyses.

3. Results

3.1. Study variable averages

Average scores for SF-36 Mental Health and Vitality outcomes were 63.29 (SD = 15.7) and 44.84 (SD = 16.6) respectively. These scores are consistent with scores taken from other populations with neuromuscular disease [2]. Average pain intensity over the past week was 4.6 (SD = 2.4) on a 0-10 scale, which is slightly lower than pain intensity averages reported in similar samples (e.g., 5.3-6.1 in [36]). Average pain interference (from the BPI) was 2.9 (SD = 2.2).

3.2. Correlation Analyses

The results of the correlation analyses are presented in Table 1. As can be seen, all three TAS-20 scales, as well as the total score, were significantly and moderately associated with pain intensity and pain interference. The total TAS-20 score and two of the scales (Difficulty Identifying Feelings and Difficulty Describing Feelings scales) were also significantly and moderately associated with vitality and mental health. The weakest associations were between the Externally Oriented Thinking scale and both vitality and mental health, although the significance of the differences between the coefficients was not tested.

In a series of partial correlations controlling for mental health, virtually all correlations among TAS-20 subscale scores and outcome variables dropped to non-significance, with only a few exceptions in which fairly weak associations remained [Difficulty Identifying Feelings remained significantly associated with Vitality ($r = -.20$, $p < .05$) and Externally Oriented Thinking remained significantly associated with pain intensity ($r = .21$, $p < .05$]. Consistent with these associations, the TAS-20 total score remained significantly correlated only with pain intensity ($r = .21$, $p < .05$) after including mental health as a control.

[Insert Table 1 about here]

4. Discussion

The current findings replicate and extend previous results concerning the associations between alexithymia and important pain-related variables in a sample of patients with chronic pain who have not yet been studied with respect to alexithymia (persons with neuromuscular disease). The results have implications for understanding the importance of the alexithymia construct across numerous illness conditions and the relationship between alexithymia and functioning in persons with chronic pain.

Consistent with the study hypothesis, higher TAS total and scales scores were significantly associated with higher pain intensity ratings, higher pain interference ratings, poorer psychological functioning and less vitality. All of the TAS-20 scales scores evidenced significant zero-order associations with pain intensity and pain interference, and the Difficulty Identifying Feelings (DIF), Difficulty Describing Feelings (DDF), and Total TAS-20 scores were also significantly associated with the measures of vitality and mental health. However, the Difficulty Identifying Feelings Scale tended to show the most consistent associations across outcomes. This is consistent with findings from other researchers [18, 24, 30, 32], although the reasons for this finding are not entirely evident. Perhaps difficulty identifying feelings, even more than difficulty describing feelings, is most indicative of dissociation between awareness and psychological functioning. In this way, the difficulty identifying feelings domain may be the most important component of alexithymia – at least with respect to pain and pain-related outcomes. It should also be noted that this particular subscale does contain some items with wording that directly addresses somatic symptoms (for example " I have physical sensations that even doctors don't understand" and "I am often puzzled by sensations in my body") and that this may in part explain the stronger associations of the DIF subscale with study outcomes.

Data from this study also indicate that the associations between alexithymia and pain intensity, pain interference, and vitality are greatly diminished when controlling for baseline mental health (which was used in this study as a proxy measure of negative affect). Of eight significant correlations among TAS-20 subscales

and outcomes, only two remained significant after controlling for the effect of mental health (the relationships between Externally Oriented Thinking [EOT] and pain intensity and between DIF and Vitality) and even these were substantially reduced. This is consistent with some previous work on alexithymia in patients with chronic pain [19]. Like other existing research in this area, and given the cross-sectional nature of our data, the findings are consistent with two competing hypotheses: (1) that alexithymia impacts psychological functioning (negative affect), which then contributes to higher levels of pain and dysfunction and (2) that negative affect produces a response bias that impacts both reports of alexithymia and dysfunction, and therefore accounts for the associations between these variables. In either case, however, it is important to note that although these relationships were weakened considerably after controlling for mental health, a significant (albeit weak) association did remain between the total TAS-20 score and pain intensity ($r = .21$, $p < .05$), suggesting that negative affect may not be "the whole story" in terms of explaining the impact of alexithymia on chronic pain. Further longitudinal work is needed to parse out these effects in chronic pain samples.

Early descriptions of the concept of alexithymia focused on its potential role in the somatization disorder, with the hypothesis that people who were unable to identify or express their feelings directly were likely to express those feelings indirectly by experiencing and communication about somatic symptoms. In fact, however, research findings tend to show weaker associations between measures of alexithymia and the sensory components of pain than between alexithymia and psychological functioning as well as the affective components of pain [19, 25]. Our findings are generally consistent with this view. Although we found a significant association between the TAS-20 total scores and pain intensity (even after controlling for mental health), we found even stronger associations between the TAS-20 scores and the SF-36 Mental Health scale. However, the SF-36 Mental Health Scale is not a direct measure of pain affect; confirmation of alexithymia's greater impact on pain's affective components versus sensory components will need to be determined in future research. Also consistent with this view, a research study examining cortical activation in persons with high

levels alexithymia indicate higher levels of processing in limbic cortical structures compared with sensory structures [18]. These investigators examined cortical responses to pain induced by colonic distension in patients with irritable bowel syndrome (IBS). They found that the IBS patients with higher total TAS-20 score (>61) showed more activation in the pregenual anterior cingulate cortex, right insula, midbrain and dorsolateral prefrontal cortex than those with lower TAS-20 total scores. These are brain sites that are implicated in the affective or unpleasantness component of pain [16]. Thus, it is possible that disruption and dysregulation in limbic system structures could potentially explain the effects that alexithymia has on pain and pain-related outcomes.

One important clinical implication of the findings concerns the potential treatment of alexithymia in persons with chronic pain. Although there is some question regarding whether alexithymia is a stable trait or a state that can change with treatment, one 5-year longitudinal study showed that alexithymia (as measured by the TAS-20) is about as stable as depression (with test-retest stability coefficients being .46 for the TAS-20 and .43 for the Beck Depression Inventory; BDI), and that both TAS-20 and BDI scores changed significantly over time [31]. Thus, both measures appear to be only moderately stable; like depression, alexithymia may respond to treatment. If so, then one potentially useful line of investigation would be to (1) develop and test an alexithymia intervention and then (2) examine the effects of this intervention on pain intensity and important pain-related variables such as pain interference.

What would a treatment for alexithymia look like? One possible intervention has been described, and includes treatment sessions that focus on developing specific skills and knowledge (e.g., increasing understanding of alexithymia, developing a vocabulary for emotions, learning to read the emotions of others, and practicing emotional self-awareness) that could result in a reduction in alexithymia [21]. If proven effective, such an intervention might increase the patient's ability to increase his or her emotional awareness and ability to describe this experience, and as a result, become better cope with and experience a decreased affective response

to pain. The current study suggests that a research program to test the possible benefits of such an intervention among patients with chronic pain is warranted. Moreover, if measures of negative affect and alexithymia (including both self-report and behavioral measures of alexithymia and pain) were included in a clinical trial, it would be possible to directly test hypotheses regarding the (possible) direct effect of alexithymia on pain and functioning using process analyses [6].

The limitations of the current study include the exclusive use of self-report measures as well as a limited representativeness of the sample. Using self-report measures alone may increase significant associations among variables due to shared method variance, producing over-estimates of true relationships. However, the fact that the TAS-20 scale scores were differentially predictive of the criterion variables (as opposed to universally predictive) argue against shared method variance as the primary explanation of the findings. Future research may wish to consider using one of the observer-rated measures of alexithymia that have been developed [14] to determine if the present findings replicate when such a measure is used. In addition, although we assessed global mental health as a proxy for negative affect, we did not measure negative affect directly in this study. Inclusion of validated measures of negative affect would have made these results more compelling.

Concerning generalizability, the current sample included only patients with neuromuscular disorders, and the sample was primarily Caucasian. Previous research suggests possible differences between Caucasians and African-Americans in levels of alexithymia, as well as the associations between alexithymia and key outcome variables [24]. Thus, we cannot conclude that the current findings necessarily generalize to other patient groups or groups that include other ethnicities. Additional research is needed to determine the reliability of the results.

Moreover, the cross-sectional nature of the analyses precludes direct interpretations of causality; it would be statistically possible to change the direction of influence or order of the variables in this model and still obtain significant results. Future researchers should consider using longitudinal designs to help understand

causal relationships and to test competing hypotheses regarding mechanisms of effects (e.g., if alexithymia has a direct negative impact on pain and functioning vs. the possibility that alexithymia and functioning are both influenced by a third confounding variable such as negative affect).

Despite the study's limitations, the findings confirm the importance of alexithymia as being associated with pain and other important pain-related variables a sample of persons with chronic pain and neuromuscular disease, thereby replicating and extending previous findings. Moreover, the results highlight the importance of negative affectivity on these relationships, although it is unclear from these data whether negative affect represents a mediating mechanism or is simply a cause of response bias. Results are also consistent with previous research suggesting (1) a greater importance of the difficulty identifying feelings component of alexithymia (in particular, as opposed to the externally-oriented thinking component) and (2) the possibility of a greater role of alexithymia for the affective components of pain and psychological functioning than for the sensory components of pain. Future research is needed to confirm these findings and determine the causal nature of these associations, and if modification of alexithymia has a beneficial impact on pain and its negative effects.

Acknowledgements

Supported by grants from Supported by the National Institutes of Health, National Institute of Child Health and Human Development, National Center for Rehabilitation Research (grant no. P01 HD33988), the National Registry of Myotonic Dystrophy and Facioscapulohumeral Muscular Dystrophy Patients and Family Members, and the National Institute for Disability Rehabilitation Research (grant no. H133B031118). IM has received research support in the past year from the US Department of Education; MPJ has received research support, consulting fees, or honoraria in the past year from Analgesic Research, Consultants in Behavioral Research, Endo, Fralex, Medtronic, Merck, Pfizer, US Department of Education, US Department of Veterans Affairs, and the US National Institutes of Health; DME has received research support from the US Department of Education and the US National Institutes of Health.

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Table 1. Zero-order and partial correlation matrix of the TAS-20 total score and subscales and the study dependent variables.

TAS-20 Scale	Pain Intensity (0-10 NRS)		Vitality (SF-36 Vitality)		Pain Interference (BPI Interference)		Mental Health (SF-36 Mental Health)
	Zero-order	Partial†	Zero-order	Partial†	Zero-order	Partial†	Zero-order
DIF	.28**	.14	-.41***	-.20*	.33***	.11	-.48***
DDF	.26**	.13	-.20**	.06	.25**	.04	-.42***
EOT	.25**	.21*	-.09	-.01	.18*	.13	-.15
Total Score	.34***	.21*	-.32***	-.08	.33***	.13	-.46***

† Controlling for SF-36 Mental Health

*p < .05; **p < .01; ***p < .001

Notes: (1): SF-36 Vitality and Mental Health composite scores are scored such that higher scores indicate more vitality and less negative affect, respectively. (2): NRS = Numerical Rating Scale; BPI = Brief Pain Inventory; DIF = Toronto Alexithymia Scale Difficulty Identifying Feelings scale; DDF = Toronto Alexithymia Scale Difficulty Describing Feelings scale; EOT = Toronto Alexithymia Scale Externally Oriented Thinking.