Relationship between the Perceived Burden of Suffering and the Observed Quality of ADL Task Performance before and after a 12-Week Pain Management Programme

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Background/objective: Constant pain causes suffering and affects performance of activities of daily living (ADL). In clients with chronic musculoskeletal pain, we wanted to determine (i) the relationship between the perceived burden of suffering (measured with the Pictorial Representation of Illness and Self Measure (PRISM)) and the observed quality of ADL task performance (measured with the Assessment of Motor and Process Skills (AMPS)); and (ii) the change in these assessments before and after a 12-week pain programme.

Methods: In this cross-sectional cohort study, we retrospectively collected data from participants in a Swiss pain management programme. We calculated the relationship, correlations and effect sizes for the PRISM and AMPS using non-parametric tests. We set the level of significance at α=0.05.

Results: Out of 138 clients, 74 participated. We found no significant correlations between the PRISM and AMPS (p=0.55-0.36), except for the PRISM and AMPS process ability measure after the pain management programme (p=0.023). Pre-post-correlations of the AMPS and PRISM were significant, with medium to strong effect sizes (-0.48--0.66).

Conclusion: Participation in this pain programme improved both, the PRISM and AMPS scores. The lack of correlation between these assessments in clients with chronic musculoskeletal pain, however, strongly argues for a thorough clinical assessment.

Keywords: activities of daily living, assessment, correlation, chronic musculoskeletal pain, occupational performance, occupational therapy

Introduction

Pain is a constant companion of persons with chronic musculoskeletal pain, affecting their activities of daily living (ADLs) [1], work activities [2, 3] and leisure activities [4, 5]. The consequences of long-term persistent pain go far beyond the individual and may negatively affect the social and economic environment [6, 7, 8, 9]. As chronic pain is a complex condition, evidence based practice recommends complex, interprofessional pain management programmes leading to improved client outcomes [10, 11, 12, 13, 14]. The focus of such programmes should be on the improvement of function, such as staying active, or return to work, rather than pain relief [14, 15]. Current evidence supports this focus, emphasizing that only slight changes in pain intensity were achieved after pain management programmes [16, 17].

Occupational therapists form a substantial part of interprofessional pain management programmes. They enable clients to perform meaningful occupations in daily life [18, 19] despite having chronic musculoskeletal pain. Amris et al. [20] concluded that assessments of functional ability in clients with chronic pain are less influenced by pain than are self-reported evaluations. Therefore, it is important to use both patient-reported and observational assessments for a holistic treatment evaluation. Nevertheless, only a few authors used observation-based assessments of ADLs in this population. Wæhrens and colleagues [1], for example, illustrated that quality of ADL task performance was lower in women with chronic widespread pain than in a healthy population as measured with the Assessment of Motor and Process Skills (AMPS), a valid observation-based assessment tool. Gantschnig et al. [21] evaluated the effectiveness of a pain management programme for clients with chronic musculoskeletal pain. They found significant changes over time for self-reported quality of and satisfaction with ADL task performance as measured with the Canadian Occupational Performance Measure (COPM). Simultaneously, the observed quality of ADL motor task

performance measured with the AMPS increased, while pain intensity did not change in a relevant matter [21].

Although pain intensity often changes only slightly after participation in a pain management programme, clients nevertheless expect pain to somehow be addressed during the course of the rehabilitation, as their burden of suffering is very high. Observational assessments of some individually relevant but isolated ADL tasks (as measured with the AMPS) cannot capture the individual burden of pain and suffering during a whole day or week. Moreover, there are clients with chronic musculoskeletal pain neglecting their pain until it exacerbates. These often called “over-users” struggle throughout the day as they often neglect their pain threshold (boom-bust, action-prone) [22, 23, 24]. They often perform daily activities while simultaneously perceiving an increase in pain [25]. In contrast, there are clients with chronic pain who strongly avoid performing daily life tasks due to their fear of pain (so called under-users) [25, 26, 27].

The burden of suffering represents much more than the plain constant pain alone. The burden of suffering reflects all the global influences a person perceives as emerging from the illness or its symptoms [28, 29], and to what extend the individual experiences the illness as a threat [30]. Thus, the burden of suffering through chronic pain is a very personal judgment and it can only be rated by the clients themselves, e.g., in illness narratives [31]. In outcome research, it is most often evaluated indirectly through instruments based on self-reporting like general health-questionnaires or assessments of the perceived level of quality of life. With the Pictorial Representation of Illness and Self Measure (PRISM) we found a valid, self-reported assessment for visualizing the burden of suffering [30], and therefore, a relevant complementation for occupational therapists when using the AMPS as an observational assessment.

There is evidence that the burden of suffering due to chronic pain decreased in the first 30 participants of a newly established Swiss pain management programme However, the primary outcome in that study was on return to work. To the best of our knowledge, no study compared the perceived burden of suffering and the observed ADL task performance in clients with chronic musculoskeletal pain before and after participating in a pain management programme. Therefore, the aim of the present study was twofold: to investigate before and after a 12-week pain management programme (i) the relationships between the individually perceived burden of suffering and the observed quality of ADL motor and ADL process task performance; (ii) to find out if there is a significant change over time in the PRISM and AMPS outcomes in clients with chronic musculoskeletal pain.

Materials and Methods

Research design

This study was a cross-sectional cohort study with two time points (baseline and 12-week follow-up). The Ethics Committee Bern (EK BE 2017-02088) approved the use of anonymized data from patient records at the University Hospital of Bern.

Participants

We collected the data for this study before and after a Swiss pain management programme, called “BAI-Reha programme”. In this admission process for the programme, we assessed clients using a standardized procedure in a stationary 48-hours-setting, which took place 1-2 months before the actual start of the BAI-Reha programme. Nurses, occupational therapists, physicians, physiotherapists, psychologists, and social workers used standardized tools to evaluate inclusion and exclusion criteria as a team by way of consensus. Participants who met

the following inclusion criteria were included in the study: 1) 18 - 75 years of age; 2) a diagnosis of chronic musculoskeletal pain syndrome according to ICD-10 criteria [20] with chronic pain either a) associated with actual or potential tissue damage or b) associated with tissue damage and a mental disorder; 3) indicators of significant impairment in psychosocial functions; 4) a dominance of somatic disease aspects over psychological/psychiatric problems such as depression; 5) a clearly expressed interest on the part of the client to participate in the BAI-Reha programme; and 6) rehabilitation potential defined using consensus by the interprofessional team. Exclusion criteria were: 1) a primary mental disorder; 2) refusal to participate in an interprofessional outpatient rehabilitation; 3) limited skills to actively participate in group discussions held in German; and 4) involvement in ongoing legal proceedings about health insurance benefits.

Detailed information about the content of the BAI-Reha programme is described elsewhere [21]. After the 12-week programme, all professions re-evaluated the participants at the last appointment of the programme with the same standardized tools.

Data collection

We retrospectively collected data from all clients who were enrolled in the BAI-Reha programme between March 2013 and March 2015 (n=138). We sent the request for informed consent in 2017 per mail.

Outcomes

The outcome measurements of this study were the PRISM and the AMPS.

The PRISM is a tool for visualizing the burden of suffering due to illness. The suffering due to illness is thought to be determined by the illness itself and the individual meaning in life, in the sense of experienced threat of illness, presence, or importance of illness in life [30]. With

the PRISM (see *Figure 1*), the client visualizes on a white plate (21x29,7cm) the distance between himself and his illness. The white plate represents the "whole life" of the client, in the right corner there is a yellow dot (7cm in diameter), representing the "self". For the current study, we asked the client, "Where would you put the pain (a red dot, 5cm in diameter) as the 'illness' in your life?", corresponding to the standard procedure of the PRISM [30]. The distance between the two central points of the dots is called the "Self-Illness-Separation" (SIS) and can be measured in centimetres (0-27cm). A smaller distance stands for a higher level of self-perceived burden of suffering. The PRISM has been validated and used in multiple clinical trials with different long lasting health problems, for example chronic pain [21, 32], orofacial pain [33], rheumatoid arthritis [30, 34], or systemic lupus erythematosus [29, 30].

The AMPS is an observational assessment of the quality of ADL task performance [35, 36]. First, in the AMPS interview, the client is asked to choose two ADL tasks from among a subset of 130 standardized tasks (e.g., washing dishes, changing the bed) which are meaningful for him and are currently presenting a challenge. Then, no matter which two tasks the client is performing, a trained and calibrated occupational therapist (AMPS rater) scores the quality of ADL task performance based on 36 ADL motor and ADL process skill items. The occupational therapist rates the client's performance on a four-point ordinal scale (4 = competent performance, 3 = questionable performance, 2 = ineffective performance, 1 = unacceptable performance) in relation to 1) physical effort, observable clumsiness and/or fatigue when moving the self and objects (=ADL motor skills), 2) efficiency when organizing and adapting actions (=ADL process skills), 3) safety, and 4) need for assistance [35]. The AMPS rater enters the data into special AMPS software, which computes the AMPS result report. This report presents the AMPS ADL motor ability measure and the AMPS ADL process ability measure in logits (logistically transformed probability units). Based on a

many-faceted Rasch measurement model, ordinal raw scores are converted into overall linear ADL motor ability measures and overall linear ADL process ability measures, which are adjusted for task challenge, skill item difficulty, a person's ability, and rater severity [35]. There is extensive international evidence to support the reliability and validity of the AMPS, including its validity for use with clients with chronic pain [37, 38] and its use in the Western European context [39].

Settings, staff and location

The study took place in Switzerland at the Department of Rheumatology and Immunology in the University Hospital Bern. This department provides interprofessional inpatient as well as outpatient medical and rehabilitation services for clients with various diagnoses, including clients with chronic musculoskeletal pain.

Standardization of the use of the PRISM was achieved through two occupational therapists from the team taking part in a two-day workshop led by the developer of the instrument himself. These therapists further instructed the rest of the team and supervised several of the interviews to guarantee quality. All occupational therapists had attended the obligatory one-week course and calibration-procedure of the AMPS, and had an average of 10 (range: 2-19) years of experience as occupational therapists by the end of data collection in March 2015. The first author was involved in the data collection as a member of the BAI-Reha team.

Statistical analysis

We performed descriptive statistics (frequencies and percentages) for demographic data. Then, we tested the variables for normal distribution. Based on results that showed that the variables were not normally distributed, we used non-parametric tests to calculate correlations. More specifically, we investigated the relationship between (i) the individually

perceived burden of suffering and the observed quality of ADL motor and ADL process task performance before and after the pain management programme using Spearman's Rho, and (ii) the PRISM and AMPS outcomes before and after the pain management programme, respectively, adopting Wilcoxon signed-rank tests for dependent samples. We set the level of significance at α=0.05. For the Spearman's Rho calculations, the strength of relationship was defined as: strong r>0.8, medium r>0.5, weak r>0.3 [40]. We calculated effect sizes for the dependent pre-post variable calculations using Cohen's classification: strong r>0.5, medium r>0.3, weak r>0.10 [41]. To give a visual impression of the results, we created scatterplots of the relationships. We performed all analyses with the IBM Statistical Package for Social Sciences (SPSS) version 25.0 software [42].

Results

Out of the first 138 clients qualifying for the BAI-Reha programme, 83 gave informed consent for participation. One client declined to take part in the study, 54 clients did not answer the request (see *Figure 2*). In total, we assessed 74 participants with the PRISM as well as with the AMPS. Only this data was included in the analysis. 49 participants (66.2%) were female, 25 (33.8%) were male. Participants were 45.1 (SD 12.2, min 20/ max 72) years old. We present more characteristics of the participants in Table 1 and their diverse chronic musculoskeletal pain diagnoses in Table 2.

There were no significant correlations between the perceived burden of suffering and the observed quality of ADL task performance before the BAI-Reha programme ($r_{s=}$0.07-0.13; p=0.55-0.36), nor between the perceived burden of suffering and the observed quality of ADL motor task performance after 12 weeks ($r_{s=}$-0.1; p=0.39) (see Table 3). The perceived burden of suffering significantly correlated with the observed quality of ADL process task performance after the 12-week pain management programme with r_s=0.311, p=0.023, n=53.

This corresponds to a weak effect [40]. The results are graphically displayed in Figures 3-6. The Wilcoxon sign-rank test showed significant correlations before and after the pain programme for both, the PRISM and AMPS assessments, with strong effect sizes for the PRISM and the observed quality of ADL motor task performance and a medium effect size for the observed quality of ADL process task performance of the AMPS (see Table 4).

Discussion

Our results showed that there is no relationship between the individually perceived burden of suffering and the observed quality of ADL motor and ADL process task performance neither before nor after a 12-week pain management programme in clients with chronic musculoskeletal pain. Only the burden of suffering and the observed quality of ADL process task performance showed a weak correlation at termination of the programme. Importantly, however, both outcome parameters showed significant and clinically relevant change over time. Thus, the 12-week pain management programme has a positive effect, which can be measured with the PRISM as well as with the AMPS by occupational therapists.

The present study results support findings from our earlier study [21] and are in line with the current state of evidence, which demonstrates that self-reported and observational assessments do not relate [20, 43, 44]. From a clinical perspective, however, it is counterintuitive that different assessments, which improve in parallel over time, are not correlated. Thus, in clinical practice one might intend to skip an assessment in order to save time. Our findings may be explained through the concept of suffering and the relationship to ADL task performance from an occupational therapy point of view, as we will explain in the following.

We assume that there is a relationship between better ADL task performance and a higher quality of life, wellbeing, and health [18, 19]. Our results might bring an additional aspect to

these theories. In clinical work and research, we often see variances in choice, and duration or frequencies of activity engagement in clients with chronic musculoskeletal pain. In the introduction, we showed that in clients with chronic musculoskeletal pain, there exist different strategies to overcome a day. Some bite their lips and neglect their pain threshold until the pain exacerbates (overusers). In contrast, others avoid many activities due to their fear of pain (underusers) [22, 23, 25, 26, 27]. Overall, both experience strong restrictions in their daily life task performance throughout a whole day or a whole week. Thus, we interpret our results as follows: although the observed quality of ADL task performance can be improved through rehabilitation [as shown in the present study and in 21], the direct observation of only two self-chosen ADL tasks, as it is usually done in the AMPS assessment, does not represent or sufficiently explain the suffering of this clientele. Relevant for clients with chronic pain are the struggles with the demands of the daily routine and the management of the day, as well as the flexibility to change ADL task performance [45]. These aspects support the interpretation of our results that the capability of the performance of ADL does not stand in direct relation to the individual perceived burden of suffering. Thus, we conclude that our results shed another light on the aforementioned professional occupational therapy perspective [18, 19]. We presume, in accordance with Furrer and colleagues [46], that the individual perception and the impact of chronic pain on several aspects of health are diverse and require further investigation into the causal associations within a broad array of aspects of pain.

Strengths and limitations of the study

An important strength of our study was the number of included persons. Unfortunately, only 53.6% of the clients who took part in our rehabilitation programme met the inclusion criteria (written informed consent; evaluated with PRISM and AMPS). As we sent out the request for informed consent per mail after the programme, we got no explanations of reasons of not giving consent. It was not possible to provide information about level of education, work

status or other socioeconomic factors. As oral communication was in German only, extrapolation of our results to persons of other languages has to be done with care.

Conclusion

The findings show no relationship between the individually perceived burden of suffering and the observed quality of ADL motor and ADL process task performance neither before nor after a 12-week pain management programme, except a weak correlation of perceived burden of suffering and observed quality of ADL process task performance after 12 weeks in clients with chronic musculoskeletal pain. In addition, we could show that this programme improved both used outcome measurements (PRISM and AMPS) significantly and clinically relevant. Therefore, we highly recommend evaluating both, the individual perceived burden of suffering and the observed quality of ADL task performance in clients with chronic musculoskeletal pain. We suggest further investigations into factors that might have the potential of increasing or decreasing the perceived burden of suffering of clients with chronic pain. A prospective study might identify variables influencing suffering and performance.

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Declaration of interest

We report no other potential conflict of interest relevant to this article.

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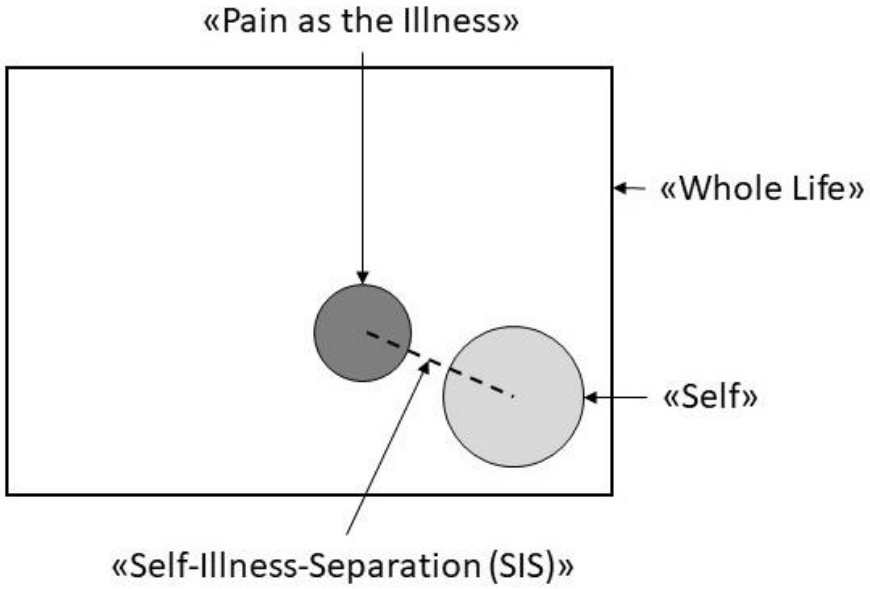
Figure 1

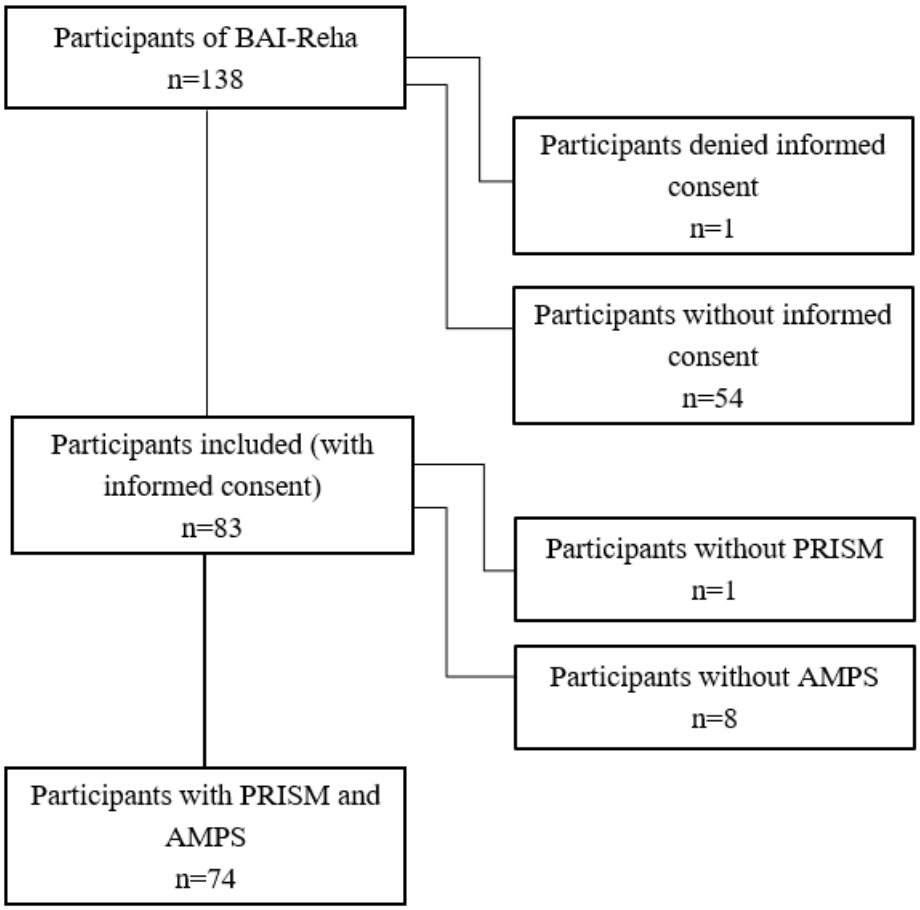
The PRISM Plate



Note. PRISM = Pictorial Representation of Illness and Self Measure (SIS=0-27cm, the smaller the distance the higher the level of self-perceived burden of suffering [30]).

Figure 2

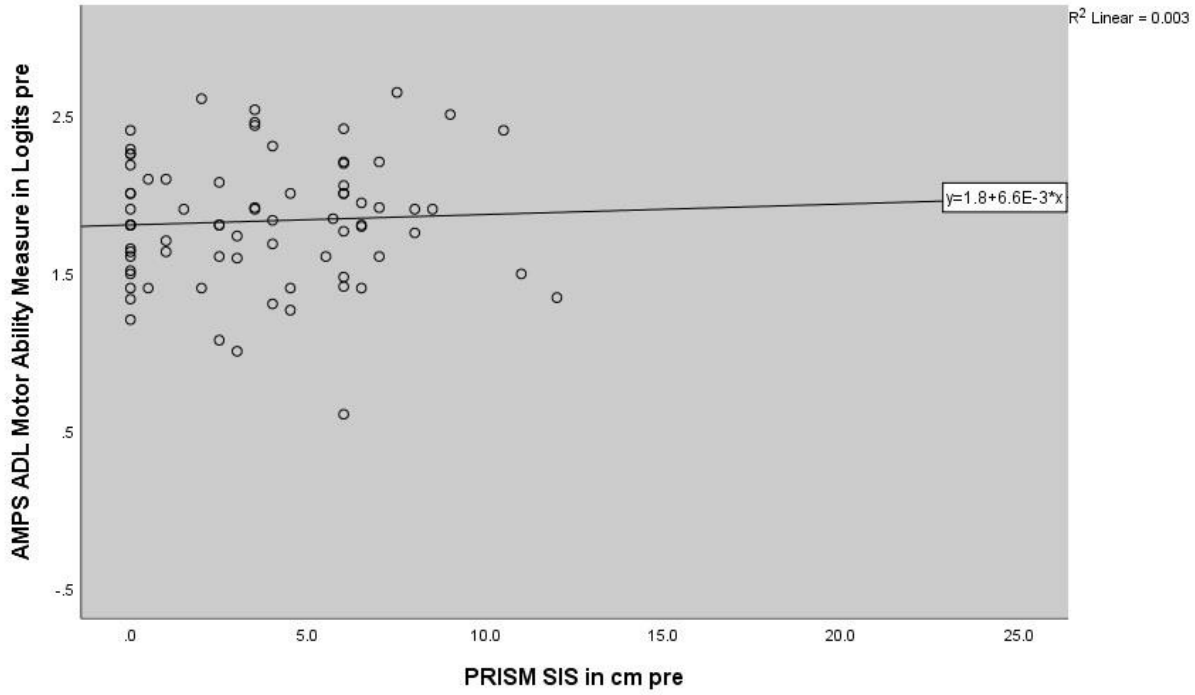
Study Flowchart of Participants

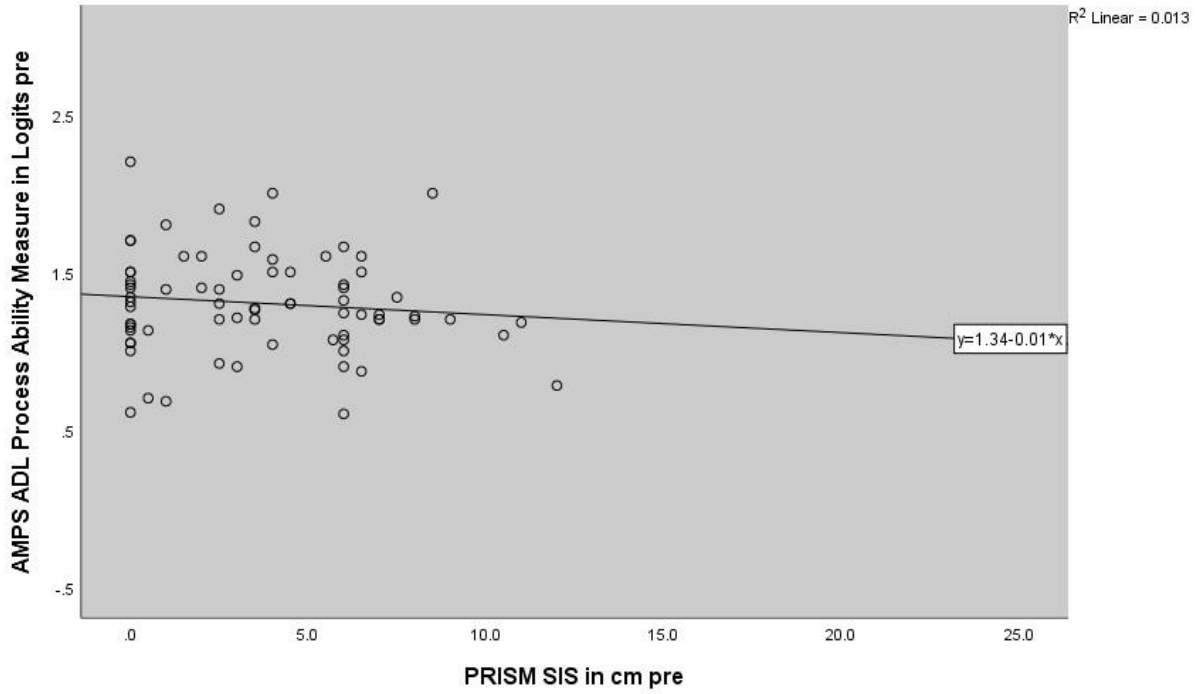


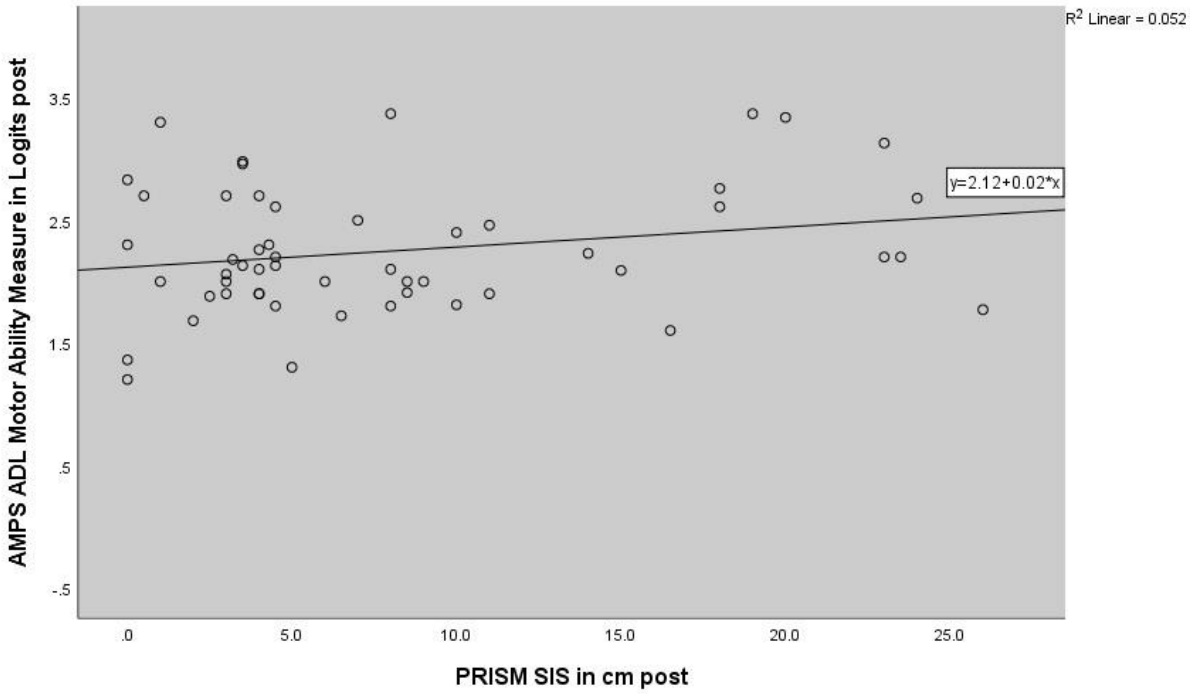
Note. PRISM = Pictorial Representation of Illness and Self Measure, AMPS = Assessment of Motor and Process Skills.

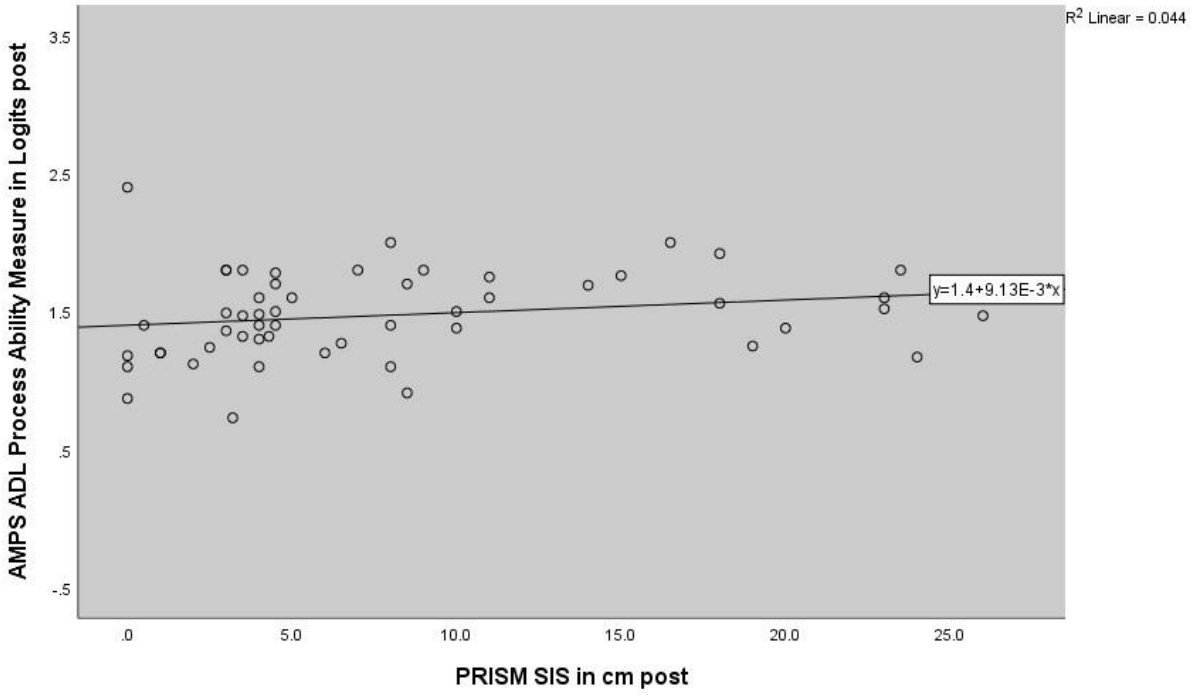
Figure 3 - 6

Relationships between Burden of Suffering and ADL Ability









Note. These figures represent graphically the relationships between the perceived burden of suffering and the observed quality of ADL motor, and ADL process ability measures, respectively. The reference line in the scatterplots shows the trends of the data.

PRISM = Pictorial Representation of Illness and Self-Measure, SIS = Self-Illness-Separation (operationalized in cm, the smaller the distance the higher the level of self-perceived burden

of suffering [30]), AMPS = Assessment of Motor and Process Skills (operationalized in Logits = Log odds probability units, a higher score indicates a higher ADL motor ability/ADL process ability [35]).

Table 1

Demographic Characteristics of the Participants regarding General Health Status, Pain, and Results of Assessments.

Characteristics (Scale)	**Mean**		**SD**		**Min-Max**		**n**	
	pre	**post**	**pre**	**post**	**pre**	**post**	**pre**	**post**
QoL, VAS (0-100mm)	46.2	54.3	16.4	17.0	10-75	25-90	50	30
Pain intensity NRS (0-10)	5.6	5.0	2.1	2.0	1-10	1-9	61	47
Numbers of pain areas (x)	5.9	5.3	2.8	3.1	2-12	0-14	56	40
PRISM, SIS (0-27cm)	3.7	8.3	3.1	6.9	0.0-12.0	0.0-26.0	74	61
AMPS motor (-3 - 4logits)	1.8	2.2	0.4	0.5	0.6-2.6	0.8-3.4	74	59
AMPS process (-4 - 3logits)	1.3	1.5	0.3	0.3	0.6-2.2	0.7-2.4	74	59

Note. QoL, VAS = Quality of Life, Visual Analogue Scale of the EuroQol Research Foundation EQ-5D™ Version 2009 (0 = the worst health you can imagine, 100 = the best health you can imagine), NRS = Numeric Rating Scale (0 = no pain, 10 = the worst pain imaginable), PRISM = Pictorial Representation of Illness and Self Measure, SIS = Self-Illness-Separation (operationalized in cm, the smaller the distance the higher the level of self-perceived burden of suffering [30]), AMPS = Assessment of Motor and Process Skills (operationalized in Logits = Log odds probability units, a higher score indicates a higher ADL motor ability/ADL process ability [35]).

Table 2

Characteristics of the Participants regarding Diagnoses.

Diagnoses (ICD-10, Version 2015)

Code	**Diagnosis**	**n**	**%**
M47	Spondylosis	14	18.9
M54	Back pain	11	14.8
M79	Other soft tissue disorders, e.g. Fibromyalgia	7	9.4
F45	Somatoform disorders	6	8.1
M25	Other joint disorders	3	4.1
M46	Other inflammatory spondylopathies	3	4.1
M53	Other dorsopathies	3	4.1
R52	Pain, not elsewhere classified	3	4.1
M11	Other crystal arthropathies	2	2.7
	Others (each diagnosis only once)	20	27.0
	Missing	2	2.7
	Total	**74**	**(100)**

Table 3

Correlations between PRISM and AMPS assessments at baseline and after the 12-week pain management programme.

Assessment	Spearman's rho	p-value	n
PRISM_pre & AMPS_motor_pre	0.071	0.548	74
PRISM_post & AMPS_motor_post	0.130	0.355	53
PRISM_pre & AMPS_process_pre	-0.102	0.389	74
PRISM_post & AMPS_process_post	0.311	0.023*	53

Note. PRISM = Pictorial Representation of Illness and Self Measure, AMPS = Assessment of Motor and Process Skills; significance level: $p \leq 0.05$; * = significant correlation.

Table 4

Correlations in the assessments at baseline and after the 12-week pain management programme.

Assessments	n	Median	p-values	Z-score	Effect size
PRISM_pre &		3.5			
	61		0.000*	-4.484	-0.57
PRISM_post		6.0			
AMPS_motor_pre &		1.8			
	59		0.000*	-5.106	-0.66
AMPS_motor_post		2.13			
AMPS_process_pre &		1.28			
	59		0.000*	-3.715	-0.48
AMPS_process_post		1.49			

Note. PRISM = Pictorial Representation of Illness and Self Measure, AMPS = Assessment of Motor and Process Skills; p-value: 2-tailed, asymptotic; * = significant correlation; effect size: $r = \left|\frac{z}{\sqrt{n}}\right|$.