# Prosjektoppgave Profesjonsstudiet i medisin





Expectations to treatment outcome in patients with neck- and back pain regarding improvement in pain and function. A cross sectional pilot study.

Sigrid Skatteboe

Veiledet av Lars-Petter Granan & Cecilie Røe

11. semester, høst 2013

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## **PREFACE**

Muscle and skeletal patients (MSP) is a vast and important group of diseases, both for the suffering individual, and for our society. This importance, combined with my interest for physical medicine, was the origin of this paper. Little is known about health expectations. It's noteworthy that the few existing articles on the field are suggesting important relation with health. There might be possible clinical benefits of addressing and utilize expectations. Expectations might be a clinical tool, but the topic lacks literature and evidence. This presented study looks into what is actually expected among neck/back patients, regarding improvement in pain and function. More literature is needed to understand, and eventually utilize, the possible relation between expectations and outcome.

I would like to thank my always helpful, inspiring and supportive supervisors Lars-Petter Granan and Cecilie Røe. They have thought me lots about the medical science world, which had been too enormous and unmanageable for me without their constant guiding. You both definitely serve as my role models, and I'm very grateful for all you're patience and help.

I should also thank my great family (Karoline, Anne And Rolf) who often tease and make fun of me, and this project, but always supports me. You three listen carefully, even though it might be longstanding and repetitive. I get helpful advises, support and cheering, and for that I'm very happy. Finally I would like to thank my great boyfriend Sindre, you help me better my best.

Parts of this text have been submitted to European Journal of Physical and Rehabilitation Medicine (September 2013). The authors on the submitted article where:

Sigrid Skatteboe<sup>1</sup>, Cecilie Røe<sup>1</sup>, Morten Wang Furuholmen<sup>2</sup>, Lars-Petter Granan<sup>1</sup>

<sup>&</sup>lt;sup>1</sup>Department of Physical Medicine and Rehabilitation, Oslo University Hospital, Norway

<sup>&</sup>lt;sup>2</sup>Unit of Biostatistics and Epidemiology, Oslo University Hospital, Norway

#### **ABSTRACT**

Literature suggests that patients' pre-treatment expectations can be clinically important for several reasons. Most interestingly has it been proposed influencing both prognoses and outcome. Expectations might therefore provide an intervention opportunity, and could perhaps be regarded as a prognostic tool. It is primarily necessary to investigate what is actually expected, to eventually explore these possible benefits. This study will look into neck/back patients' expectations for treatment outcomes (pain and functional improvement) prior to their first meetings with specialists in physical medicine and rehabilitation (PMR).

This study is a cross-sectional pilot study. Questionnaires were completed by patients prior to an appointment with a PMR specialist. Included patients were patients with neck/back pain and/or functional problems, referred for the first time to a PMR specialist. The forms consisted of one validated part (PSOE), and one self-constructed part with six 11-point numeric rating scales (11-NRS). Eligible patients were randomly selected between January and June 2012 at the PMR Neck/Back Outpatient Clinic, Oslo University Hospital.

Approximately 42 % of the patients expected their status to remain un-changed. A total of 17 % expected exacerbation of their status. No differences were found between expectations regarding pain and function. The patients did not expect full recovery. Highly educated patients, and those reporting high usage of analgesics, expected to improve more in pain and function. More elaborate studies are needed to confirm these results. These results are, to our opinion, surprisingly low, too pessimistic for this patients group. If the suggested results are trustworthy should one take notice in the potential relation between negative expectations and outcome.

#### INTRODUCTION

## Expectations

"Expectations" is an everyday word, commonly used. Our minds continuously consider the future, and thereby create expectations to help us prepare for it. Getting an illness will generate expectations toward the process, and the following outcome/prognosis. These expectations naturally show great variance among patients, two people with similar diagnosis do not necessarily expect the same. Expectations may also vary within a patient during life, or within a limited period. Expectations can be conscious or not, or a combination of both.

This paper will first give a summarized background of health expectations, more specifically pre-treatment expectations. Secondly will a clinical trial designed to map out neck/back patients pre-treatment expectations be described. Finally are the results the trial presented and discussed.

## Definition

"Expectations" is not a specific medically defined term (it is not even a MESHword). However, every field of medicine and psychology is involved with this, our health includes expectations. But, the term is difficult to define. Oxford English Dictionary describes expectations as "the action of mentally looking for some one to come, forecasting to happen, or anticipating something to be received; anticipation; a preconceived idea or opinion with regard to what will take place" (1). Several medical articles more shortly consider expectations as "a person's subjective opinion about an outcome" (2). Some contractions are necessary due to the heterogeneity of the term. Firstly is it important to distinguishing expectations, which is before an event, from satisfaction, which is a response after an event. It is essential that hope, wish or desire not are the same as expectations. The three first mentioned are more emotionally or motivationally motivated, where as expectations are thought to be more cognitive (3). A person can hope for something he/she knows is impossible, but he/she does not expect it. What a person thinks, believes, assumes, reflects or supposes all implies some kind of conscious reflections, where as expectations are thought to be both conscious and sub-conscious. Finally, an expectation is not a request (4), which in addition also differs from demands. When specified should it be mentioned that there are variations of expectations. Bialosky et al. (5) defines four types of expectations, and it is found useful since the term is wide. General can expectations be considered as a combination of these four groups':

- 1. Predicted expectations, or what the individual believes will occur.
- 2. Ideal expectations, or what the individual wants to occur.
- 3. Normative expectations, or what the individual believes should occur.
- 4. Unformed expectations, or the lack of a preconceived notion regarding a situation or intervention.

## Placebo = expectations?

Many people consider placebo as "an effect of expectations." Discussing precise definition of expectations therefore includes a consideration of the equality with

placebo. Placebo and expectations should be distinguished, even though there are similarities. The two terms firstly differ according their definitions. A common understanding of placebo from Oxford English dictionary is: "A substance with no therapeutic effect used as a control in testing new drugs, etc.; a blank sample in a test (1)." The understanding of the "placebo effect" should also be mentioned, even though these two terms often overlap. "A beneficial (or occasionally adverse) effect on health produced by a placebo that cannot be attributed to the properties of the placebo; (also) an instance of this (1)." According to the descriptions above is placebo a response to a specific (placebo-) intervention. It may be all sorts of interventions, from tablets to surgery, but it's a specific placebo-treatment. The patients may be aware of the actual placebo, or not (6). Of course the patients will have expectations to these interventions, but the term is not specifically towards this. Placebo is a "package," from an intervention, to a possible placebo effect. In addition is the term often including a non-placebo population. Placebo (and the placebo effect) surely includes expectations. Expectations have been described as the most important factor for the formation of the placebo (and nocebo) responses (7-9), but there is more than that included in the term. Pre-treatment expectations, on the other hand, are specifically the expectations you generate according your health condition. It does not specifically origin in a treatment/intervention. Everyone creates expectations about their symptoms, the possible meeting with the health care and generally how the situation may develop. The entire process will lead to expectations. This is not placebo, it is "just" the expectations you have to you're situation, and possible contact with the health care. We all have health expectations, also without placebo-treatments. It's earlier mentioned that pretreatment expectations are suggested to relate to the outcome as well, such as the placebo effect. This possible expectation influence should not be called a placebo effect; this is more a potential consequence of expectations.

## Historical background & original theories

It is doubtable if it actually exist any "origin" of the science around health expectations, it is at least less accessible. The research on placebo probably resulted in the awareness of expectations in the late 1950's. The search for a possible explanation for placebo led to attention around expectations. Premature studies showed relations between expectations and outcome, and theories about the possible links where generated (10). Expectations were for a long time, mainly independently investigated in psychiatry. The first major theory is probably Banduras "Social Learning Theory" (11). This defines the term "selfefficacy," which may be understood as expectations to personal participation, or involvement, in a treatment situation (11). Newer theories have also looked into the term, e.g. the "Health Belief Model (HBM)" and theory of locus of control (LOC) (3). It is also suggested that conditioning are of importance. Expectations are evolved in different parts of our cognitive system. The theories are therefore often wide, and approach various concepts. Few independent expectation explanations and theories exist. This might be because expectations are difficult to isolate, maybe impossible. It might also be due to the actual lack of insight in the field on the writing moment. But, the last decades have gained new interest to this, especially in medical research.

## *Individuality*

We know patients create expectations according to own health. It is known that these expectations are very individual, and depending on multiple factors. Patients with similar problems may expect completely different things. Literature suggests expectations relate to age, sex, education level (12), health status (13), ethnical background (14), nationality (15) socioeconomic status (16), marital status (17), social framework (18) and income rises (19). Expectations naturally also depends on the actual health problem, which varies according to the patient's earlier history of health problems (20), the intensity of the symptoms, the diagnosis (21), level of functional impairment, duration of problem, perceived seriousness, past experience with health care system, waiting time (22) and acquired knowledge. In these days are the Internet probably also create expectations. Finally, personality, emotional and cognitive functions will mot likely influence expectations.

### *Importance*

Expectations are interesting and important for several reasons. Expectations are a part of the patient the doctor meet. Meeting expectations produce better satisfaction with care (23, 24), less disappointment (25) and less misunderstanding (26). Clarifying of expectations will better the communication between doctor and patient, and patient's expectations may not be clear to the physician unless asked about it (27, 28). One should be aware of expectations if one wants to take care of the entire person (23).

Literature posts correlations between expectation and status development (29, 30). Expectations are found to be a predictor for chronic musculoskeletal pain patients' treatment outcome (31-34). If such a correlation exists may expectations be a possible intervention (33). Potentially can physicians' improve prognoses if they adjust pre-treatment expectations: both unrealistically high expectations and to low and pessimistic expectations may be altered. Literature suggests a connection between expectation, participation and outcome (35). Long lasting follow-ups and treatment-programs requires motivated and participating patients, and it is necessary with realistic expectations about this in advance. Expectations and motivation follow each other (31, 36). With all this in mind may also expectations potentially be used as a prognostic sign (31, 36), a predictor for individual prognoses.

If expectations actually matter in these suggested ways, why is it so? A theory often is referred to, is Flood and colleagues definition of five mechanisms about expectations' relations to the outcome (37):

- 1. Triggering a physiological response in the body
- 2. Increasing motivation to participate in treatment programs
- 3. Helping the patient to ignore certain symptoms and observe others
- 4. Changing the understanding of the disease
- 5. Acting together with anxiety to heighten or reduce symptoms

There is, as mentioned earlier, a lack of knowledge in this field. Expectations are not frequently investigated, and there are few existing explanations for its

potential effects. The placebo literature does as well lack reasonable descriptions of the suggested placebo effect. But, there are several interesting benefits related to expectations, noteworthy even thought the exact effects are unknown.

From a political point of view is expectation usable to learn more about what the population expect of our social health care system. Unrealistic expectations may increase healthcare utilization (38).

#### On the other side...

It should be mentioned that this posted relation between expectations and clinical outcome is discussable. It is said that the previously described relation between expectations and outcome is due to optimism (39), or other non-defined variables. Much doubt origin in the way expectations is measured, which is difficult. An evaluation after a treatment may mainly reflect satisfaction (40). Mannion et al. did not find any relation between expectations before, and the result after spinal surgery. One interesting article actually found an opposite relation, relating high expectations (too high?) and negative outcome (41). Sherman et al. found no significant relation between acupuncture and low back pain, which is in contrast to three earlier studies on the same field. It is difficult to state the reason for this variance in the literature. It's known that the field of expectations lacks standardizations, and few overviews and summaries exist. The complexity of the term added with the lack of specific literature challenge evidence.

## Why musculoskeletal patients?

Musculoskeletal diseases are a major group of conditions, they affects many peoples life and daily function. 19 % of European adults report musculoskeletal pain between modest and severe quality. (42) The situation is similar in Norway; about 75 % reported muscle and/or skeletal pain (MSP) the last month (43). When asked about chronicity did 51 % reports of MSP over minimum three months during the last year (44). Chronic musculoskeletal diseases caused 36 % of the disability pension in Norway in 2009 (45), and 30 % of the total new appliances in 2006. The most frequent issues for disability pension in Norway in 2008 were back (10,7 %), neck (3,8 %). Vos et al. presented last year that back pain were the leading, and neck pain the fourth, cause of years lost to disability (YLD) globally (46). This situation is reported to be quite stabile over years (47, 48). Vos et al. showed in the mentioned article that YLD in 2010 is equal to the status in 1990 (46). This group obviously consumes a vast portion of our healthcare budget. They patient also often have great health care costs themselves, due to long and frequent treatments.

Neck/back patients referred to PMR evaluation constitute a heterogeneously composed group. This group consists of both specific and more undefined conditions. They are often characterized by a protracted course of recovery and disability (49). A large number of doctor visits, followed by various treatments, often fail. Pain and functional problems often complicate the ability to work and daily living. Many patients lack an accurate diagnosis and require explanations for their problems. PMR patients do not share acute patient situations, but they

cannot be regarded as rehabilitation patients. All these factors can influence their expectations. These expectations might be clinically important.

The combination of expectations and PMR is insufficient. Only a few areas have been researched regarding neck/back patients: expectations regarding work return (17, 50, 51), expected interventions (52-54), expectations regarding general practitioner (GP) visits, and expectations regarding alternative therapies (30, 36, 55, 56). A couple of trials have presented pre-treatment expectations. The overall pre-treatment expectation tendency seems to be optimistic. Meng et al. reported in 2006 that 83 % of back rehabilitation patients expected to recover(57). Myers et al. reported in 2008 that more than 80 % of acute low back pain patients expected improvement (31). Boonstra et al. suggested in 2011 that 61 % of rehabilitation patients expected less pain, and 53 % expected more activity (58). Martins et al. demonstrated that pain expectations were correlated with the outcomes for chronic low back pain and fibromyalgia (59). Unfortunately, non-equivalent questionnaires were used in these different trials. The patient groups were differently composed; all these studies involved second-line special clinics, and the main focus varied.

#### Aim

The primary aim of the following project was to investigate neck/back PMR patients' overall expectations before meeting PMR specialists, regarding pain and functional improvement. We hypothesized that the patients would expect improvement in both pain and function.

#### **MATERIALS AND METHODS**

This research was designed as a cross-sectional pilot study. Information was derived from questionnaires completed by neck/back patients prior to their first appointment at the Oslo University Hospital (OUS) PMR ward.

#### *Inclusion and management*

Patients were included from the neck/back outpatient clinic at the Department of Physical Medicine and Rehabilitation (PMR) department at Oslo University Hospital (OUS). The clinic has both local and regional assignments, covering 0.5 and 2.6 million inhabitants, respectively. All referred patients > 15 years old were considered eligible for inclusion. The ward receives mainly neck/back patients with pain/functional problems; clear surgical referrals are not accepted. Patients with suspected chronic fatigue syndrome (ME), pain syndromes, fibromyalgia and similar conditions are not treated at the ward. The exclusion criteria were previous visits to the ward, patients not receiving a neck/back diagnosis, inability to understand the Norwegian language and non-consenting patients. A representative sample of patients was asked to participate, and the secretaries at the ward selected them randomly throughout the period. Patients were included if they signed a written informed consent letter. They were then provided with the expectations questionnaire and completed it prior to their appointments with the doctors. The physician in charge of each patient subsequently collected the form. The physicians at the ward were either PMR specialists or in specialization.

## The questionnaire

There is a lack of validated assessment tools for measuring expectations in musculoskeletal patients in general (60). The Patient Shoulder Outcome Expectancies (PSOE) was the validated assessment tool found to be most suitable for the present study(61). "The 3 PSOE items ask patients to consider their shoulder problem overall, their shoulder pain, and their ability to move and use their shoulder at the present time, and rate their expectancies regarding these 3 areas for the next month. Evidence for the unidimensionality of this measure was obtained from a confirmatory factor analysis in which one factor accounted for 89 % of the item variance, and the internal consistency of this measure, calculated using Cronbach's alpha was 0.94"(61). We substituted the word "shoulder" with "neck/back." The PSOE was translated into Norwegian and then back into English by professional translators with native Norwegian and English backgrounds, respectively. The final version was adapted after a consensus meeting. The PSOE was coded according to O'Malley et al. (61), except for reversing of the coding scale to harmonize the 11-NRS scale for pain applied in the present study (see below). The 3 questions were totaled and yielded a total maximum score of 18, where 9 points indicated no expected change in status. Less or more than 9 points was considered a positive or negative expectation, respectively.

A supplement to the original PSOE was developed. The intent was to categorize expectations with numbers, in addition to the verbal formulation of the PSOE. It was also expedient to obtain a specific measurement of expectations, compared to the current situation. This form consisted of six 11-point numerically rated scales (11-NRS). The 3 first items defined the present situation. The three subsequent scales were identical, defining the expected status after the doctor consultation. The 11-NRS assesses pain during both rest and activity and function. The items have 11 boxes between 0 and 10, with 0 indicating "no pain/no movement limitations" and 10 indicating "worst possible pain/no movement possible." The questionnaire can be found in the appendix (appendix 2). Expectations were measured according to the difference between expected and current status. As recommended by Farrar (62) and Childs (63), 2 boxes were considered the minimal clinically significant difference in the 11-NRS. Demographic information about the patients was collected from a questionnaire routinely sent to the home of every patient referred to the PMR ward, together with the appointment letter.

## Analysis and statistics

SPSS software, version 19.0 (64), was as used to analyze the data. Comparison of continuous variables was performed with t-tests, with a significance level (p) of 0.05. The ICD-10 diagnoses determined during the consultations and the number of days between referral and appointment were recorded. The patients' ICD-10 diagnoses were categorized in 2 groups for analysis. The first group included conditions with specific origins, and the second group was less specified, according to the suggested classification determined by the OUS musculoskeletal department (65) (appendix 1).

## **RESULTS**

## Patient characteristics

107 patients completed the forms. Approximately 52 % (56/107) were females. Patient characteristics are presented in Table 1.

Table 1 Sample characteristics and p-values (bold)

	(Amount) % / Mean (SD)
Total	(107) 100 %
Sex	
Female	(56) 52.3 %
Age (years)	
Mean	49.7 (15.0)
Min - max	16 - 80
Smokers (daily)	
Yes	(23) 21.7 %
Education (years)	
Educated 7 - 10 years (least educated group)	(12) 12.7 %
Higher education > 4 years (max. educated group)	(26) 25.5 %
Max education vr. min. Education	<b>0,04</b> *1
Painkilling drugs used daily (due to this problem)	<b>0,04</b> *2
Yes	(72) 69.9 %
Sick leave (due to this problem)	
Yes	(37) 42.5 %
Diagnosis *3	
Specified	(71) 65.7 %
Days of waiting between refferal and appointment	
Mean	63.4 (35.0)
Min - max	9 - 218
Primarily language	
Norwegian	(85) 88.5 %
Sivil condition	
Married or living with partner	(30) 71.4 %

<sup>\*1</sup> Maximum educated group vr. to minimum educated group

<sup>\*2</sup> Daily vr. rarely use of painkilling drugs, due to this neck/back problem

<sup>\*3</sup> Diagnosis: ICD-10, categorized as either specific pathology/origin or not, catego. **Bold** values: significant p-values

#### **Expectations**

The PSOE results are presented in Table 2. Patients with more education (> 4 years of higher education) had greater expectations for improvement compared to patients with minimal education (< 10 years in total) (p = 0.04, presented in Table 1). Patients reporting a high usage of pain-killing drugs (due to this PMR problem) expected more improvement compared with patients not reporting usage of pain-killing drugs (p = 0.04, Table 1).

Table 2, **PSOE** (Patient Shoulder Outcome Expectancies)

	1	2	3	1 +2 +3
	Total problem	Pain	Function	Total score
Mean	3,0	2,9	2,8	8,7
SD	1,1	1,0	1,0	2,8
Conf.int. min (95%)	0,8	0,9	0,8	3,2
Conf.int. max (95%)	5,16	4,86	4,76	14,19
Expected improvement (< 3, < 9)	33,0 %	31,8 %	38,7 %	40,6 %
No changes expected (3, 9)	49,5 %	53,3 %	50,0 %	42,5 %
Expected aggrevation (> 3, > 9)	17,4 %	14,9 %	11,3 %	16,9 %

Scoring: 1: Much better, 2: Better, 3: Unchanged, 4: A little worse, 5: Worse 6: Much Worse Total score: 3 (min) - 18 (max).

The results from the 11-NRS are presented in Table 3. The mean differences between current and expected scores on the 3 scales all indicated an expected reduction in pain or function; however, all the reductions were below 1 and were thus less than the pre-defined minimal clinically significant difference of 2.

Table 3, 11-NRS (11-Point Numeric Rating Scales)

	1. Pain in rest		2. Pain in activity		<b>/*1</b>	
	Now	Expected	Expected reduction	Now	Expected	Expected reduction
Mean (SD)	4,4 (2,3)	3,9 (2,2)	0,6 (1,9)	6,2 (2,1)	5,2 (2,5)	1,0 (2,0)
95% CI			-3,2 - 4,3			-3,0 - 4,9
	3. Function		SU	I <b>M</b> (1+2+3)		
	Now	Expected	<b>Expected reduction</b>	Now	Expected	Expected reduction
Mean (SD)	4,4 (2,3)	3,9 (2,4)	0,5 (1,5)	5 (1,8)	4,3 (2,0)	0,7 (1,6)
95% CI			-2,4 - 3,5			-2,4 - 3,9

<sup>11-</sup>NRS scoring: 0 = no pain/no movement limitaions, 10 = worst possible pain/no movement possible

### DISCUSSION

The presented results suggest that PMR neck/back patients have modest expectations for improvement when referred to PMR specialists. The two

<sup>\*1</sup> Activity: Activities of daily living and/or exercise

<sup>&</sup>quot;Now:" Reported status now, before appointment with PMR-doctor

<sup>&</sup>quot;Expected:" Expected status after appointment with PMR-doctor

<sup>&</sup>quot;Expected reduction:" Difference between reported status now, and expected status

Positive value = expected improvement

<sup>&</sup>quot;Significant difference" 11 NRS: 2 boxes -> "Clinical significant difference" 11 NRS: 2 boxes

presented instruments both showed expectations lying between expecting the status to remain unchanged towards anticipation a little improvement. On the PSOE did 42,5 % of the participants expect an unaltered status. The group mean value was 8.7, which was close to not expecting any alteration (score of 9). The six 11-NRS items all had different mean values (between current and expected status) of less than 2 boxes. This finding was not conclusive for clinically expected improvement. However, the differences were all positive, indicating expectations for slight improvement. The 2 instruments are therefore thought to present a similar tendency, although they were not especially enthusiastic overall. This study suggests no particular difference between expected improvement in pain and function. It was an overall finding that patients found it difficult to distinguish between these two; few neck/back conditions entail functional limitations only. Further, none of the patients expected full recovery.

Vague improvement expectations and lacking hope for recovery can have several causes, and they are most likely combinations of different factors. The primary reason might be the chronicity surrounding PMR neck/back problems. Prolonged duration can reduce expectations for recovery. Many of the patients had undergone multiple examinations, investigations and different treatments. It is likely that motivation and participation decrease with absent results. Worsening experiences with health care can also reduce expectations. Pain problems, combined with movement limitations, can challenge positive attitudes. In addition, the media, and especially the Internet, provide vast amounts of health information that is frequently negative.

Including all neck/back patients resulted in a vast number of diagnoses. Some conditions lack adequate explanations and accessible treatments. A few of these conditions are unfortunately less curable. Patients with pessimistic prognoses should realistically not be too expectant. However, in our opinion, the incurable patients with neck/back pain constituted less than 60 %. Many of the included patients might therefore expect too little. Everyone should perhaps not expect complete recovery, but the majority has the possibility to improve. The literature has suggested that expectations influence the process and outcome. If this relationship exists, one should take notice of unrealistic expectations. Negative expectations have been shown to reduce possible progression. The mechanism behind this relationship is unclear, but mental focus can affect both participation in follow-ups and rehabilitation. Attitude is also important for personal wellness, handling of challenges, work and personal situations, and surrounding oneself with friends and family. In addition to reducing possible improvement, negative expectations could perhaps prolong the course.

Other trials have presented greater outcome expectations, as mentioned earlier (31, 57-59). There are several possible explanations for these differences. The earlier mentioned studies all included different patients. Acute neck/back problems, GP visitors, first-time PMR-referred individuals and rehabilitation patients are in different phases of their problems. Dissimilar patients have unequivalent situations and therefore heterogeneous expectations. It is likely that pre-appointment expectations vary from expectations further along in the process. Pre-treatment expectations are thought to be more general, because the surroundings are less specified. This relationship is in contrast to, for example,

expectations regarding a particular treatment/surgery. In addition, the previous articles had different focuses. None of the trials investigated pre-treatment expectations primarily. It is also unfortunate that they all used different measurement tools. Overall, the existing literature was not found to be exactly comparable. In our opinion, generalized pre-treatment expectations among neck/back patients have been poorly investigated.

This study suggests that expectations distribute differently among certain variables. Less educated patients have greater expectations. Perhaps this finding is caused by more educated people having better health overall. They often show better coping skills and compliance with long-term treatment. Perhaps more education also results in increased skepticism and/or realism. This group might be under greater influence from the media's frequent negative perspectives on neck/back issues. In addition, many poorly educated patients do more physical work. They might therefore have greater requests of and expectations for improved function. Second, those reporting high use of analgesic drugs perhaps expect more. It is possible that medicated individuals have a greater belief in medical interventions (pharmacological or interventional). Well-medicated patients might be less influenced by pain and therefore be in better shape for rehabilitation. Perhaps the seriousness of the disorder is correlated with the use of analgesics, so more severe pain problems result in greater expectations. It is naturally possible that a significant difference does not reflect a clinical difference. The majority of the investigated factors seemed equal, except for the two above-mentioned factors. Perhaps expectations act in a general pattern. There might also have been confounding variables that were not investigated. However, if the patients mentioned above actually had different expectations, they might deserve special attention.

Pre-treatment expectations are naturally correlated with the individual situation. Expectations also depend on what the health-care system is believed to provide. Many patients encounter a chaotic system, with many different doctors, a lack of collaboration, long waiting times and an overall abundance of bureaucracy. These factors might reduce expectations for efficiency and results. It is impossible to state exactly the degree of negative expectations that are directly linked to the system and to the doctors. However, negative expectations might also be a sign of reduced belief in our system. One should bear this fact in mind and be aware that people can lose faith in public health care.

This study had several limitations. One was that a self-constructed, and therefore un-validated, form (11-NRS) was used, challenging its reliability. However, both the un-validated (11-NRS) and validated forms (PSOE) presented similar tendencies, which might be a sign of reliability. Perhaps the use of 2 questionnaires strengthened the total description of expectations. Potential patients were unfortunately omitted. Non-Norwegian-speaking patients were excluded due to problems with comprehension. This exclusion might challenge the generalization of our findings. Some included patients did not have sufficient time to complete the form, mostly due to late arrival. A few patients did not consent to participate. Some completed forms were deemed unusable because they lacked baseline information. Unfortunately, different losses of patients were not registered. However, except for the exclusion of non-Norwegian-speakers,

the included patients are thought to be representative. The overall method is considered favorable despite these limitations. The inclusion of approximately 100 patients might be small. This project was designed as a pilot study, so further studies should be prepared and optimized. Our suggested results should perhaps be considered prudently.

## **CONCLUSION**

Primarily referred neck/back PMR patients constitute a complex patient group. The cases in this study varied from recent and acute, to more long-term, difficult treatable situations. This study found that this group did not expect a vast improvement in either pain or function. Improvement was expected to lie somewhere between expecting an unchanged status and towards expecting a little improvement. In our opinion are these expectations too low for this group. Some cases might be incurable, but the majority has opportunities for improvement. These pessimistic results differ from the results of the existing literature, which has been more optimistic. The main reason for this difference is, to our opinion, that pre-treatment expectations in PMR patients have been poorly investigated. This pilot study was limited for 2 reasons. First, a single unvalidated questionnaire was utilized. Second, there was a loss of potential patients due to the management of the forms, and in addition were non-Norwegian-speaking patients excluded. More information is needed to specify these suggestions. If these propositions are trustworthy, the effects of negative expectations should be examined. The literature has suggested a potential relationship between expectations and outcomes. Expectations that are too negative might decrease possible improvement, so they should potentially be adjusted.

#### **ACKNOWLEDGEMENTS**

- Contributing physicians, secretaries, research coordinator Kathrine Hansen and the librarians at Oslo University Hospital

## **SUPPLEMETARY MATERIALS (appendix)**

1. Categorization of neck/back diagnoses according to specificity

ICD-10	1. Specific
	Neurogenic
	Other pathology (inflammation, cancer, trauma +)
40.09	Deforming backconditions
41.09	Scoliosis
42.09	Spinal osteochondrosis
43.09	Other deforming dorsopathies
45.09	Ankylosing spondylitis
46.09	Inflammatory conditions
47.0-9	Spondylosis
48.09	Other spondylopathies
49.09	Spondylopathies in diseases classified elsewhere
50.09	Cervical disk disorder
51.09	Other intervertebral dosc disorder
53.9	Dorsopathy, unspecified
54.0	Panniculitis affecting regions of neck and back
XIX	Injury, poisoning and other consequences of external causes
	2. Unspecific
	Unspecific back-pain
48.8	Other specified spondylopathies
50.9	Cervical disc disorder, unspecified
51.9	Intervertebral disc disorder, unspecified
53.0	Cervicocranial syndrome
53.1	Cervicobrachial syndrome
53.2	Spinal instabilities
53.3	Sacrococcygeal disorders, not elsewhere classified
53.8	Other specified dorsopathies
54.1	Radiculopathy
54.2	Cervicalgia
54.3	Sciatica
54.4	Lumbago with sciatica
54.5	Low back pain
54.6	Pain in thoracic spine
54.8	Other dorsalgia
54.9	Dorsalgia, unspecified
25.5	Pain in joint
79.1	Myalgia

### Comments:

<sup>-</sup> There is a code .9 in many chapters, which are considered specific. These diagnosis have a defined origin, since they are ordered in a chapter-"

- Diseases classified elsewhere" are considered the same way.

- In cases of doubt are the patient journal evaluated.

<sup>(65)</sup> 

#### 2. Questionnaire (English translation) 1. Compared with now, I think my **shoulder problem overall** next month will be: □ Much worse $\square$ Worse □ A little worse ☐ The same $\square$ Better □ Much better 2. Compared with now, I expect my **shoulder pain** next month will be: □ Much worse $\square$ Worse $\square$ A little worse ☐ The same □ Better □ Much better 3. Compared with now, I expect my ability to use and move my shoulder next month will $\square$ The same □ Much worse □ Worse □ A little worse □ Better □ Much better Describe your neck and/or back problem(s) as they are now: 4. Pain at rest: No □ 1 □ 3 □ 4 □ 5 □ 6 □ 7 □ 8 □ 9 Worst pain imaginable pain 5. Pain during activity (all activities, including daily activities and exercise): □ 2 □ 3 □ 4 □ 5 □ 6 No □ 1 Worst pain pain imaginable 6. Ability to use as well as move your neck and/or back: No move- $\Box$ 1 □ 2 □ 3 □ 4 □ 5 □ 6 7 □ 8 □ 9 $\ \square$ 10 No movement restrictions ment possible How do you expect your neck/back problem will be after seeing a doctor: 7. Pain at rest: No □ 1 □ 2 □ 3 □ 4 □ 5 □ 6 □ 7 □ 8 □ 9 □ 10 Worst possible pain pain 8. Pain during activity (all activities, including daily activities and exercise): No □ 1 $\Box$ 2 □ 3 □ 4 □ 5 □ 6 □ 7 □ 8 □ 9 □ 10 Worst possible

9. Ability to use as well as move your neck and/or back:

□ 4

□ 5

□ 6

□ 7

□ 8

□ 9

pain

No move-  $\Box$  1

ment restrictions

 $\Box$  2

□ 3

pain

No move-

ment possible

□ 10

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