Bridging troubled water - exploring improvement and patients' experiences using patient-reported outcome measures in physiotherapy: A mixed-method study

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Abstract

Background and Aims: Increased use of patient-reported outcomes in health care has been emphasized. Our aim was to use the Patient-Specific Functional Scale (PSFS) to examine improvement in neck pain patients' activity limitations during physiotherapy treatment, with the purpose to explore the patients' experiences of using PSFS. The study illuminates whether and how PSFS can be useful in clinical physiotherapy.

Methods: Six patients participated. A mixed-method study design was applied, triangulating ontological perspectives of realism and phenomenology, quantitative and qualitative methods. Single Subject Experimental Design with PSFS as outcome measure examined changes over time and phenomenological interviews examined its meaningfulness for patients. Patients defined their personal activity limitations due to neck pain and scored difficulties several times, during the physiotherapy treatment period, using PSFS. We used visual analyses of the quantitative data and thematic analyses of the qualitative data. Integration and combination of the results from the two designs are presented in the discussion.

Results: In the quantitative analyses, PSFS showed improvement in most activity limitations during treatment. The qualitative analyses revealed that using PSFS required the patient to engage in different bodily awareness processes and handle the dilemma of a possible double function of scoring chosen activities. The mixed findings revealed improved functionality and that the context and the interaction between patient and therapist have a significant influence on the assessment process.

Conclusions: To be able to improve the utilization of PSFS, communication between patients and physiotherapists is of vital importance. When using PSFS, physiotherapists should direct their attention to the importance of interaction as always present and vital in assessments.

KEYWORDS
clinical physiotherapy, evidence-based practice, phenomenology, PSFS, SSED
1 | INTRODUCTION

Health authorities across the European Union emphasized the need for patients’ experiences to be accorded greater prominence in health care.1 To this end, they recommend more use of Patient-Reported Outcome Measures (PROMs) and include the findings in patients’ records. The intention is 2-fold: to document the effectiveness of treatment and capture the patient’s own voice and specific experience. However, most PROMs are developed for research rather than for use in clinical practice. The growing demand for evidence-based practice (EBP) is also placing pressure on health practitioners to document the content and impact of treatment. In this paper, we explore the implications for physiotherapy of the growing emphasis on the use of PROMs in the context of EBP.

In primary health care in Norway, physiotherapy is mostly conducted on a face-to-face basis individually and/or group-based. In recent years, patient-centeredness has gained increased focus in medicine and health care.2–4 Patient-centered practice implies that each patient’s needs and priorities are taken into account during the framing and evaluation of treatment plans,4 and that patients should experience their treatment as useful.5,6 Hence, the PROMs should reflect patients’ individual experiences of benefit from physiotherapy.

With respect to PROMs, generic questionnaires have been designed to be applicable across diagnoses, conditions and populations and to address specific phenomena: for example, health-related quality of life.7 Disease- or condition-specific questionnaires have been developed to assess symptoms and functional problems regarded as typical for the specific disease/condition: for example the Neck Disability Index (NDI).8 Despite being specifically matched to a particular disease, these questionnaires may neither cover the purpose and expected outcome of treatment nor be important to the individual patient. Even if a disease-specific questionnaire includes some items of direct importance to the actual patient, changes in these items can be concealed in the sum score. Due to the heterogeneity among patients and diagnosis, physiotherapists need a variety of questionnaires. This implies that it is difficult to make use of generic or disease-oriented questionnaires to provide a feasible basis for evaluating patient-centered physiotherapy.

Other forms of patient-specific assessment have been developed to enable patients to define and score the severity of their specific problems. With a focus on the individual, such instruments can be used independently of diagnosis, illness, and age. Typical for patient-specific instruments is that the patient and the therapist determine the items and only the assessment scale is standardized. However, some of the available instruments are complicated, requiring detailed manuals and/or certification for use.9

In contrast, the Patient-Specific Functional Scale (PSFS), developed by PTs for use in clinical practice, is simple to use, needs no certification, and can be applied across diagnoses and conditions.3,10,11 For the purpose to assess activity limitations, patients are asked to identify several activities they find difficult to perform due to their health condition, and rate their difficulty with performing each activity.12

Our aim was to use the PSFS to examine improvement in neck pain patients’ activity limitations during physiotherapy treatment, with the purpose to explore the patients’ experiences of using PSFS. The study illuminates whether and how PSFS can be useful in clinical physiotherapy.

2 | METHODS

Data presented are from a sub-study within the Norwegian FYSIOPRIM (physiotherapy in primary health care) research program. For this study, we adopted an explorative mixed-method design13 in which we deployed a quantitative Single Subject Experimental Design (SSED) study examining outcomes of treatment using the PSFS, while also conducting qualitative interviews of the same patients to explore their experiences with using PSFS in their treatment process. The quantitative and qualitative data collection was performed separately and collected especially for the present study. The analysis is presented for each data set. The exploration across the two data sets is shown in the discussion.

Four PTs from the FYSIOPRIM network recruited the six patients with neck pain whose data are discussed in this article. There were no specific inclusion criteria despite being treated for neck pain by the actual physiotherapist.

Patient characteristics (age, sex, work status, pain duration, pain intensity) were assessed by a structured questionnaire, including the Norwegian version of the NDI14 and a Numeric Rating Scale (NRS) for current pain (from 0 = no pain to 10 = worst pain ever). NDI includes items evaluating to which degree neck pain interferes with 10 different daily activities, scored from 0 (best score) to 10 (worst score). A total score is calculated and considered to describe the patient’s degree of affliction.14

2.1 | The quantitative study

SSED is characterized by multiple assessments and each patient serves as their own control.15 Assessments conducted in periods when patients are not undergoing treatment (A) are used to control for day-to-day fluctuations, learning effects, and measurement variability. Assessments during the therapy period (B) indicate whether changes have taken place, and to what extent.16 However, our concern to carry out our research with minimal disturbance to everyday clinical practice meant that we were unable to have several assessments during A since the first consultation between patient and PT was immediately followed by a treatment period (B).

Using the PSFS, the patient is asked to list activities he/she finds difficult to perform. Before and during the treatment period, the patient assesses the severity of the problem on an 11-point numeric rating scale (NRS, 0 = cannot perform the activity, 10 = can perform without problems, or like before). PSFS has proved useful in both clinical practice and research11,17 and has good methodological properties when used with physiotherapy patients in primary health care.10,11,18
In our study, PTs themselves were responsible for the data collection. Oral and written information on how to use the PSFS was given to them by the main researcher (WSB). At least one measurement was to be done before treatment started. PSFS assessments were then repeated, with an interval of 1 to 6 weeks between assessments, as decided by the individual PT. For their first assessment, patients were asked to list 3-5 activities difficult to perform because of their neck problems. PTs were encouraged to ask patients not only about difficult activities but also activities where physiotherapy possibly could contribute or support improvement. The patients then scored the difficulty of performing each of the activities. In subsequent sessions, patients again scored their level of difficulty with each activity, but without access to previous scores. According to results from a previous study on the methodological quality of the PSFS,11 we used the first two activities with scoring from each patient in the analyses.

In accordance with methods developed for analyzing data of SSED studies, which also is appropriate to apply for clinicians, visual analysis was conducted to determine the change in each patients’ scores during the treatment process.15,16 We expressed the temporal changes in response for each patient as graphs. We also stipulated mean shift, trend, and overlap.16 Mean shift is the difference between the means for the treatment period and the value scored at baseline (or mean for baseline period, if more than one value was available). Trend relates to the direction of the curve and was registered as positive or negative in cases where at least two points indicated improvement or worsening. Assessments with the same value as a baseline were defined as overlap, and improvement or worsening was registered when at least half of the points, during treatment, differed from the baseline score.16

2.2 | The qualitative study

The first author observed one treatment session with each patient. Individual interviews, rooted in a phenomenological approach, took place in a separate room at the physiotherapy institute immediately after the observation. The focus was on the participants’ pre-reflective experiences19 of using PSFS and refers to how experiences are lived in the moment rather than how they subsequently have been theorized and conceptualized upon.20 The interviews were audio-recorded and transcribed verbatim.

The data were analyzed on an iterative basis involving moving back and forth between gathering and reflecting on experiential accounts.19 Phenomenological themes generated highlight, or exemplify, the eidos (essence) of the participants’ experiences. These themes can be seen to represent possible fragments of an experience that, while unique, are also shared or recognizable in terms of human experience.

2.3 | Exploration across and in-between qualitative and quantitative data sets

Much can be gained from bringing together the results of two parallel inquiries - one quantitative and one qualitative. This offers the possibility of gaining knowledge broader than the sum of the two parts. Inspired by the work of O’Cathain et al,21 in particular their suggested triangulation of research designs,21 we have sought to arrive at a more comprehensive portrayal of our findings. Triangulation in this context “moves researchers from thinking about findings related to each method” to “meta-themes” - themes that cut across the findings generated by the two different ontological positions and methods.21

The applied innovative method is also inspired by what Greenhalgh et al22 describe as a meta-narrative method. A method that goes across quantitative and qualitative studies, and adds value to the synthesis of findings in heterogeneous research where researchers have investigated the “same” phenomenon in various ways and produced differently, and maybe conflicting findings.22 Narrative research method is not a poor cousin of the quantitative method but a different and potentially complementary form23 and mixing research methods when studying the complex phenomenon, show promising potentials and should be explored further.22

2.4 | Ethical considerations

To guard against the risk of compromising the participants’ anonymity, we have avoided including any information that might identify either physiotherapists or patients. All participants received written and oral information and signed informed consents before inclusion.

3 | RESULTS

3.1 | Participants

Six patients of different ages and from varying social and work backgrounds participated. Four out of six (67%) were women (Table 1). All participants received physiotherapy treatment for their neck pain, and all reported activity limitations. The median (range) on NDI and current pain on NRS was 32 (26, 50) and 7 (4, 8) respectively, indicating moderate disability and high levels of pain. All six patients completed the PSFS on seven separate occasions: at the start of treatment, five times during treatment, and one at the end of treatment.

3.2 | Measured outcomes

Analyzing the SSED data, we found that the participants reported problems in different activities that mostly improved during treatment. The following activities were identified as problematic:
- Rotating one’s head while driving a car;
- Reading a book with head and neck bent forward;
- Turning one’s neck to the left;
- Knitting;
- Sewing;
- Performing household chores;
- Baking;
- Wiping one’s bottom;
- Sleeping;
- Working at the computer;
- Driving a car;
- Sleeping with head-on partner’s arm.

Figures 1 and 2 presents the visualized picture of the scores on PSFS on their two most prioritized activities.
The scores of four participants indicate an improved function in both their listed activities during the treatment period (visualized in Figures 1 and 2.), with mean shift, trend, and overlap all showing improvement. Participant 3 showed no improvement regarding activity 1 (turning head to the left) with 0 on mean shift, but showed improvement on activity 2 on mean shift overlap and trend. Participant 5 showed improvement on activity 1 on mean shift, overlap, and trend but no improvement on activity 2 (driving a car) (Table 2).

3.3 | Interviews

In the analysis, we aimed to explore the participants’ described experiences of filling in and scoring the PSFS. In the presentation below, excerpts from the empirical data are given in italics and our reflections in plain text. All interviews were in Norwegian and translated into English by the first author. Subsequently, we used the services of a professional English language editor.

3.3.1 | Extract 1: a turnaround of focus and awareness

It was actually difficult, sitting there writing down activities that are problematic for me. What is it that’s difficult? When driving my car, I can feel that certain movements are difficult for me. But when filling in the form -- it was at the very beginning and I thought, “Maybe I should have written that lying on my left side is problematic?” But there’s so much I could have written.

This excerpt shows how the patient became uncertain about what to include when writing down the activities he/she struggles with. When patients seek physiotherapy, their experiential focus does not necessarily appear to be on how their pain limits their activities.
Rather, it is their problematic body occupying the forefront of their attention. When the body is healthy and functions normally, the body disappears into the background and our attention is directed towards the activities and situations we are involved in. However, during illness or following an injury, the problematic body comes to the forefront of our attention as a dys-appearance. When our body dysappears, focus on activities and surroundings fades into the background. Patients can find it demanding to concentrate on directing
attention away from their problematic body towards the active body, and focus on what they do, have to do, cannot do and want to do in daily life. In this sense, completing the PSFS requires a restructuring of the individual's attention.

3.3.2 Extract 2: Realizing that “activity” means just “simple things”

When I was first asked to fill in the form my initial reaction was “Oh my God, what’s all this about?” But then the physiotherapist and I talked. The physiotherapist asked me, “What’s it’s like for you to do everyday things? What is it that bothers you?” Then I was able to come up with several things -- simple things that happen every day. For instance, being able to take my jumper off properly, rather than having to crawl out of it – that was very important to me.

The patient’s conversation with the PT proves a turning point, helping the patient move on from her initial experience of not knowing what filling in the PSFS is all about. It is through conversation that the concept of activity becomes “harmless,” and understood to involve just “simple things,” things one does daily. Filling in the PSFS demands the patients read and try to understand the meaning inhabiting the written words. In the contemporary world, the concept of activity encompasses a variety of meanings and multiple connotations. The way activity as a concept is predominantly understood and talked about involves “ready-made-meanings”: meanings constituting a kind of general understanding in a given society. A focus on activity related to an individual’s own bodily ailments and physiotherapy has the potential to open up different ways of understanding the concept. In Western societies, the considerable emphasis continues to be placed on the need for everyone to be more active, raising the possibility that such ready-made meanings may influence how patients perceive the process of filling in the PSFS. Nancy argues: “there is no meaning if the meaning is not shared.” Implying that, to be sure what activity means in this context, it is necessary to clarify this between the patient, the therapist, and the questionnaire.

3.3.3 Extract 3: Gaining insight into one’s own capacity, or non-capacity

I think it’s very positive. Having to write down those activities made me much more aware, it really did! Filling in the form made me aware of things I have not been able to do lately. I think it’s quite brilliant to be asked about activities that are problematic to perform... in a way I became conscious through the questions. Writing down these activities and situations made me think about the situations in which I do experience pain.

Thinking about which activities one struggles with or provokes pain can prove to be a revelation. Since participants had hardly considered this before, being asked these questions seemed to facilitate greater awareness of their individual capacity (or non-capacity) to act in daily life. Living with a problematic, perhaps painful body for a long period, he or she seems to adapt or become familiar with their bodily situation. The problematic body appears to find alternative ways to perform necessary activities. However, the individuals themselves do not necessarily register these changes. Rather, the individual seems to adapt to the reality of the body, as it currently exists, even if it is perceived as problematic.

The body constitutes “an element in the system” of an individual’s world, and the tasks to be performed elicit the necessary movements from us without any conscious calculation on our part. Our body establishes the most effective balance between motor reactions, actual activity, and our situation now. Even when experiencing our body as problematic or painful, we try to get the maximum grip of the present situation and act in order to accomplish our everyday tasks. Our basic motor-intentionality or pre-reflective consciousness grasps and understands our situation and guides our actions. Accordingly, we adjust our behavior in terms of what is unconsciously grasped. Beyond this basic level of consciousness, there exist several layers bringing our perceptions (eg, of carrying out a particular movement) to the forefront of our awareness. It is when our attention is directed towards what we unconsciously perceive in daily life, we arrive at a new and explicit awareness.

Completing the PSFS required the participants to focus on their bodies in an explicit way. Aspects that they may have been aware of at a pre-reflective level now come to their attention. Awareness turns towards their own body and the experiences of performing certain actions. Participants reflect on how their body functions by scoring the difficulties in performing activities. Physiotherapy may be described as a body discipline: one which uses bodily reflections to improve and retrain bodies that are problematic or painful. Filling in the PSFS seems to facilitate this by focusing awareness, if only temporarily, on which activities you struggle with. It helps patients reflect on what they can do, have difficulties with, and cannot do.

3.3.4 Extract 4: A revelation of the body’s past experiences

You know what? I actually realized that some things had become a lot better! Yes, they had - and very quickly, too! But other things were taking a long time, and I’ll have to struggle a bit more with those. Scoring activities during the course of treatment puts things in perspective. It also helps you identify the problems that remain and how to move forward. It places a greater focus on finding a way ahead.

One of my activities was housework. Well, it’s speeded up - my ability to do it has actually improved! Yes, it’s become easier – it’s easier now for me to get right inside corners!

Scoring the difficulty in performing specific activities seems to work as an act of disclosure. As we always exist “now” and never can become “past,” the memory of our own former performance of a certain activity is not necessarily something we are explicitly aware of. A veil of oblivion always shrouds our past. This gap in memory between past and present expresses the temporal structure of our being.
The space and time we inhabit “are always in their different ways indeterminate horizons which contain other points of view,” and this “synthesis of both time and space is a task that always has to be performed afresh.”20,p162 Scoring the PSFS might help patients perceive the gap between their past and present perceptions of performing an activity. Since focusing during treatment often is on reducing pain, it can be difficult to remember what activities were problematic previously and how difficult they were to perform. Blinded scores can then be useful to highlight improvement and refresh goals for treatment. However, it depends on how the physiotherapist uses the results and urges the patient to think back on former functioning that the individual may become aware of changes that more or less have happened unnoticed.

3.3.5 | Extract 5: Becoming aware of a “double function”

I found scoring very difficult. All depended on how I was feeling that particular day and at that particular moment. If I’d come for physiotherapy at a different time that same day, the score would have been different. I remember last time when everything was just great! A good day in a way. But if I’d done the scoring a couple of days earlier, the score would have been quite different. In my experience, the way I perform my chosen activities does vary. It can often change in the space of one day. It might have something to do with what I’ve done that day… it might not have anything to do with what the therapist has done.

When the recovery process is an experience of alternation between improvement and deterioration, scoring the PSFS can be challenging. It is difficult to find the “right” or the appropriate score. It appears that the patient’s sense of solidarity with the therapist intertwines in the scoring process. Difficulty and dilemma linked to scoring indicating no progress bother the patient. In physiotherapy, inter-affectivity is jointly created between the participants.28,p127 When a patient’s situation varies considerably from day to day and during one single day, the patient perceives it as unfair to set scores indicating a lack of progress - as it might be understood as a failure of the therapy. When experiencing a lack of progress, the patients perceive a sort of dilemma. They understand how their scoring can be about their own functioning, as well as about the success of the therapy.

4 | DISCUSSION

Here we draw together and integrate the findings from both parts of our study performed in, and not on, clinical physiotherapy practice. The focus in the interviews has been on the patients’ experience of filling in and scoring PSFS, and the quantitative data are the activities and scores the patients actually have filled in. We would argue that the interview data extend the findings from the quantitative part and the analysis of this dataset represent the integration between the two methodological approaches. Results from the quantitative analysis show that we were able to identify the improvement of selected activities for patients with neck pain, although having no information about the content of the physiotherapy. Hence, the study provides some clear-cut results and shows how using PSFS in physiotherapy requires the patient to engage with different bodily awareness processes and handle the dilemma of becoming aware of a possible double function of scoring difficulties with the chosen activities. Our combined findings showed that communication between patient and therapist became important for the patient's understanding of PSFS, and thus of significance for completing the form. This has implications for clinical practice and the request for more use of PROMs.

We have searched for convergence, complementarity, and discrepancy21 and asked ourselves; what do the overall results tell about the use of PROMs and about the evidence of the outcomes? We became specifically interested in how and whether self-reported data like activities filled in on the PSFS can be understood as purely subjective, and whether the outcomes, can be understood as purely objective. Initially, we pointed to the requirement that health services should both relate to the principles of EBP and be person-centered. Our ambition was to explore how the growing emphasis on the use of PROMS has implications for physiotherapy. We, therefore, continue to discuss our two meta-questions related to whether the activities completed on PSFS can be understood as purely subjective and whether scoring these activities, understood as measured effect, can be seen as purely objective data.

An understanding of the activities filled in on the PSFS, as purely subjectively determined, represents an idea that overlooks how we by the mere fact of our existence, always are part of the society. Our existence is both personal and relational because we exist in co-existence.20,p421 In a process of therapy, our intersubjectivity and co-existence create a shared social world. A shared world of meaningful engagement between patient and therapist and their participatory sense-making in the encounters. As subjects, the patients and therapist transcend towards each other in the situation and the activities they share.20,p419 In every interaction we both push and are pushed as we seek to make sense of one another’s sense-making and the situation we inhabit.28,p127 Sharing a situation, like using the PSFS, implies interaction as well as inter-affect. For example, we mutually affect one another when sharing our appreciation of progress or disappointment of no progress in therapy.28,p125 Therefore, it seems impossible to say that the patient selected activities are neither purely subjective nor objective. Regardless of whether or how the physiotherapist and the patient interact in the situation when the patient is to fill in the PSFS, the chosen activities will be both personal, relational, and contextually based. Accordingly, it is not a question of how the physiotherapist can avoid influencing the patient’s choice of activities; rather it raises an important question of how the interaction between them may influence the chosen activities, the scoring, and possibly the improvement.

Focusing on interaction is not only a question of how the patient and the therapist interact but also how the PSFS form act and affects the interaction between them. Things in use, like the PSFS, do prescribe specific forms of action from both patient and therapist. Artifacts are not passive, but actively co-shape what actors do.29-31 Related to this, we cannot speak of anything purely subjective or purely objective, as both choosing and scoring activities provide data
that have to be seen as created in the relationship and interaction between the three actors and their common situation. However, this does not mean that the activities and the scoring are not the patients’ own, or even false. They are real, but not purely subjective as both interaction and context affect all actors. Phenomenology, therefore, challenges both the understanding of EBP as based on objective knowledge with a potential to produce objective data and the idea of PROMs as personal and subjective data. Goldenberg describes the combination of EBP and person-centered care as a current competing medical discourse.\(^3\) Focusing on a first-person perspective may help to rediscover what is beginning to lose its authority when bodily examinations in medicine and health care become more technical.\(^3\) Despite medicine and health care’s undeniable diagnostic and therapeutic successes, there is a question whether personal consideration of the individual, in particular, can exist in light of the ongoing silence of the patient in modern medicine and health care.\(^3\)

Our study has revealed that the context, interaction, and sense-making between patient and therapist have a significant influence on the entire process using the PSFS. Instead of thinking that the therapist should avoid influencing the patient’s choices and scores, we would direct the attention to interaction as always present and vital. Therefore, we should pay attention to how the therapist uses the PSFS in collaboration with the patient. The attention on interaction and collaboration emphasizes not only a first-person perspective but also the dialogue between the first and third-person perspective and EBP. Focusing on both the first- and third-person perspective implies paying attention to the lived body and adding this to the science of the objective body.\(^2\)

When using PSFS, physiotherapists need to be aware of the importance of communication with patients. For patients, the conversation seems to be crucial. Patients may need help to understand the meaning of the terms activity and “functional problem” to identify examples reflecting their situation. Furthermore, the identified problems should be in the focus of the treatment. Not having this in mind might reduce the possibility to measure improvement and deterioration. Physiotherapists also need to be aware that filling in and scoring the PSFS can be an ambiguous process for some patients, particularly evident in situations without improvement, where an “eager to please” response arises from patients. In such cases, a dialogue between the patient and physiotherapist might be clarifying. It is likewise important for the physiotherapist to gain knowledge about the treatment effect to be able to adjust the therapy.

The focus of our research, in clinical physiotherapy, was on the patients’ experiences. Hence, in a way, we have ignored both the physiotherapists and the therapy. That said our findings would also be of interest and relevance to physiotherapists with the PSFS integrated into practice.

5 | CONCLUSIONS

In order to conduct PSFS assessments based on strong relationships with patients, physiotherapists require the ability to compare alternative solutions. When interpreting responses together with the patient, therapists need to be able to navigate individual circumstances and contexts with tact and sensitivity. It is important that patient-determined items on the PSFS should “match” the purpose of treatment. Communication should be vital - at every stage of the process. Furthermore, it is vital to understand the importance of interaction. We would argue that our mixed findings significantly enriched our understanding of the processes at work when applying an outcome measure like PSFS in the physiotherapy encounter.

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CONFLICT OF INTEREST

The authors declare no conflict of interest.

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DATA AVAILABILITY STATEMENT

The data is stored on a research server at the University of Oslo. The informed consent from the participants do not include permission for data to be shared publicly.

ETHICS STATEMENT

The Ethical Committee for Medical Research Norway approved the FYSIOPRIM research program (2013/2030); the approval covers the present study. All participants received written and oral information and signed informed consents before inclusion.
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