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To cite this article: Anne Marit Mengshoel, Wenche Schrøder Bjorbækmo, Merja Sallinen & Astrid Klopstad Wahl (2019): ‘It takes time, but recovering makes it worthwhile’- A qualitative study of long-term users’ experiences of physiotherapy in primary health care, Physiotherapy Theory and Practice, DOI: 10.1080/09593985.2019.1616343

To link to this article: https://doi.org/10.1080/09593985.2019.1616343

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Published online: 13 May 2019.

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‘It takes time, but recovering makes it worthwhile’- A qualitative study of long-term users’ experiences of physiotherapy in primary health care

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ABSTRACT
In several European countries, patients with chronic pain conditions are high consumers of physicians’ and physiotherapists’ health services in primary health care. This study aimed to explore how patients in a Norwegian context make sense of their long-term use of physiotherapy. Narrative interviews were conducted with six long-term users. The data material was subjected to a narrative analysis with a focus on the stories’ content and how health professionals and informants were inscribed in the stories. The stories provide rich and varied information about the informants’ experiences with prior and present health services inscribed in their experiences of illness and recovery. The narrative’s introduction portrays a shared illness narrative, centered around negative experiences as illustrated by the theme ‘A long time searching for explanations and solutions to recover’. The narrative’s plot describes a gradually ascending story of recovery where abilities overshadowed disabilities, as the informants are ‘Learning their own meaningful ways to proceed’. The narrative has no definite ending, but instead depicts an ‘Uncertainty about future and own ability to reverse relapse’. The shared narrative’s storyline is that ‘It takes time, but recovering makes it worthwhile’.

Introduction
In Europe, the high prevalence of chronic musculoskeletal problems is of great concern, and chronic musculoskeletal problems are common reasons for seeking physiotherapy in primary health care (Breivik, Collett, Cohen, and Gallacher, 2006). In Norway, physiotherapy services in primary health care are funded partly by patients and partly under the Public Health Scheme; however, when they reach a certain level of costs, they are fully covered by health authorities. Physiotherapy services are supposed to reduce costs that accrue through sick-leave or disability pensions. Accordingly, physiotherapists (PTs) are obliged to critically appraise the patients’ benefits from therapy in terms of both health benefits and costs. In other words, their therapies should be efficient and time-limited. However, in a previous survey conducted in Norway, we found that about half of the total sample had received physiotherapy regularly for several months and even years, frequently consulted several general practitioners (GPs) and medical specialists, and undergone advanced medical investigations (Opseth, Wahl, Bjørke, and Mengshoel, 2018). The physiotherapists engaged in this survey expressed concern about these high public health costs, and they questioned whether they over-treated their patients. As outsiders, however, we questioned why patients are willing to spend such a long time in physiotherapy if they do not experience any gain.

Patients’ long-term use of physiotherapy in primary health care is scarcely addressed in the scientific literature, but Dutch studies, together with our prior study, suggest that the users of physiotherapy services often suffer from chronic musculoskeletal pain (Hendriks et al., 2003; Opseth, Wahl, Bjørke, and Mengshoel, 2018; Swinkels et al., 2014). Research has, however, addressed frequent consultation with GPs. For example, a systematic literature review showed that individuals who frequently saw GPs suffered from various musculoskeletal disorders, headaches, or combinations of musculoskeletal, psychological and social problems (Vedsted and Christensen, 2005). GPs may call these patients ‘heart sink’ patients and often refer them to physiotherapy (Clemence and Seamark, 2003). This may align with prior findings that regular users of physiotherapy tended to report more negative health beliefs (Opseth, Wahl, Bjørke, and Mengshoel, 2018), perceive more emotional distress, and have less trust in their own ability to improve their health.
compared with patients with similar complaints who did not frequently attend physiotherapy (Wahl et al., 2018). Accordingly, frequent use of PTs’ and GPs’ services may relate to chronicity, mood, negative health beliefs, and poor self-management.

In physiotherapy, the particular interest is the body and movement, and PTs have tended to adopt a biomedical understanding of the body by relating altered movements to biological changes within the body (Nicholls and Gibson, 2010). Accordingly, the body’s typical malfunctioning is to be repaired or normalized by various physiotherapy modalities, for example tailored exercises (Mengshoel, 2007). However, patients with persistent musculoskeletal disorders do not necessarily present any distinct, typical pattern of physical malfunctions, and therefore for several musculoskeletal pain conditions, clinical guidelines recommend conditioning exercises and education in self-management, but why and what is the best to do remain unclear (Barbatunde et al., 2017). It is also perceived as challenging when patients do not comply well with their exercise programs (Peek, Carey, Mackenzie, and Sanson-Fisher, 2018). If patients do not adhere to their therapy or improve, they can be accused of not doing their best to recover (Mengshoel, Sim, Ahlsen, and Madden, 2018) and thereby a patient’s moral agency is questioned (Frank, 1997). Patients may also experience health professionals thinking that they are malingering (Åsbring, 2001), thus challenging their legitimacy as patients (Werner and Malterud, 2003). Doctors express uncertainty about how to communicate and manage these patients (Yon et al., 2015), and this is likely to occur among PTs as well. As such, for both patients and PTs, a lot is at stake during consultations, and the ways in which those involved make sense of what happens may impact their actions.

In the present paper, we take as our point of departure the understanding that long-term use of physiotherapy is found meaningful by patients in some way. Our theoretical underpinnings are that the ways people make sense of and relate to each other and are involved in therapy sessions are intertwined and inseparable. Accordingly, what is experienced and found meaningful by participants is considered to be socially constructed (Burr, 2003). Presently, our purpose was to examine how patients create meaning of their long-term use of physiotherapy.

Methods

Design and theoretical framework

This study is part of a larger study about physiotherapy in primary health care which includes a survey about health service use and individual interviews of patients’ experiences. The interview part utilizes narrative methods which implies focusing on the stories being told (Riessman, 2008). According to narrative theory, storytelling is a fundamental way for people to make sense of life experiences (Frank, 1995; Kleinman, 1988; Mattingly, 1998; Polkinhorne, 1995). When people tell stories about what happens to them, they create meaning by weaving together the experiences of past and present events with expectations for the future (Mattingly and Garro, 1994). Riessman and Speedy (2007) emphasized that personal narratives can be differentiated from other forms of discourse in terms of sequence and consequence, through which the events are selected, connected and evaluated as meaningful for the specific audience. Moreover, the characters involved in the narrated events may play particular roles in a story. For example, the story’s protagonist can have an antagonist, and thus the story can express tensions and drama. By analysing how actors and events are portrayed and interconnected throughout a narrative, the meaning or the storyline of the whole narrative can be developed (Squire et al., 2014).

Research team

Four women, all senior researchers, were involved in the present study. During the last 10 to 20 years they have been engaged in research and as lecturers in master programs in health sciences or rehabilitation. Three have their professional background in physiotherapy (AMM, WSB, MS); specialized respectively in manual therapy, paediatrics or mental health, and one in nursing (AKW) specialized in dermatology and internal medicine. Also, the researchers hold various competencies in qualitative methods; narrative methods, phenomenology and grounded theory. The research team’s various backgrounds and competencies enhanced our reflexivity. We had no specific pre-understanding why the participants continued to attend physiotherapy for a long time, but were curious to learn about it as such practice seems to be found inappropriate by both PTs and health authorities.

Ethical considerations

The survey and individual interviews were approved by the South-East Regional Ethical Committee of Medical Research (Ref.no. 2009/1238). The participants were informed both orally and in writing about the purpose of the study and about their right to withdraw from the study at any time. A consent form was signed, and no one withdrew after the interviews were performed. In the paper, the participants’ anonymity is secured by
avoiding detailed descriptions of age and other personal characteristics. To illustrate that the presented narrative is based on what is told by the whole sample, the accounts are referred to the various participants by identification numbers.

Recruitment of participants

The participants for the interviews were recruited after the results of the survey were available. The participants were recruited by physiotherapists at an outpatient physiotherapy clinic organized within Norway’s primary health care service. The clinic employs about 30 PTs, most of whom have a specialty in manual therapy. The inclusion criteria for the participants were rather open: participants needed to have had musculoskeletal problems for at least one year and have consulted the same PT regularly for at least six months; i.e. a convenience sampling procedure. Potential participants were informed by the PTs about the study and asked if they were willing to participate. We do not know how many PTs asked their patients to volunteer for the study and how many declined. The recruitment was performed in two periods with about one year in between because of the researchers’ busy time schedules. Eight patients volunteered and were contacted by phone, and additional information about the study was provided. Two patients could not be reached, but the others were interviewed. The interviewed participants were seeing two female manual therapists with several years of clinical experiences who are highly approved for their expertise by their colleagues.

Interviews

The interviews were performed by the first author (AMM). She presented herself as a researcher in the health sciences, thereby creating some distance between herself and the participants’ PTs. All but one interview – which was conducted in a meeting room at the university – took place at the physiotherapy clinic immediately after the participants had completed a physiotherapy session. In accord with narrative research tradition, few overarching questions were asked in order to facilitate the participants’ to tell stories as freely as possible (Riessman, 2008): Can you please tell me about yourself and what happened when you became ill; Can you tell me about your illness and the help you have received for it; Can you tell me about your experiences with physiotherapy; and What are your outcome expectations for the future? The interviewer listened carefully to what was told and asked for more in-depth information by asking: Can you give some examples of that; What happened then; and What do you think about what happened? The interviews lasted from 50 minutes to 1.5 hours, and were tape recorded and then transcribed verbatim. The interviewer’s reflections about what had happened and been heard during the interviews were written down immediately afterwards.

Data analysis

The tape recordings, transcribed texts and the interviewer’s notes constituted the data for analysis. Initially, the tape recordings were carefully listened to and the transcribed texts were read several times to get an overall impression and become familiar with the content. The initial impression was that the narratives addressed the debut and progression of illness, a lengthy process of trying to find adequate help, rather positive, experiences of current physiotherapy, and ambiguous expectations about the future.

Each interview was closely read and analysed in detail by the first author (AMM). In accord with narrative, thematic analysis, accounts about events were identified and ordered temporally to examine how events related to each other (Riessman, 2008). Then, the accounts of each interview were coded, often with contradictory codes (e.g. ‘not taken seriously/taken seriously’ and ‘not making sense/making sense’) and next the codes were compared across the interviews. Despite their variation in details across the interviews, they could be ordered under categories (e.g. ‘treated according to a book/as a unique person’ and ‘no evaluations/importance of noticing improvements’). The rather negative and positive experiences coalesced into respectively the narrative’s stable, illness introductory part and an ascending, recovery middle part, and a last part without a definite ending point. Next, the ways in which characters were portrayed and positioned differently in the stories of past, present and future were examined. Finally, a shared narrative based on the participants’ stories was developed. During the analysis and writing up the findings, the research team provided critical questions to the analysis and interpretations, and thereby enhanced the credibility of the study.

Findings

Presentation of the participants

One man and five women, from 27 to 52 years of age, were interviewed. One participant had a disability pension, one was a student, and the others were full- or part-time employees. Some participants were single or divorced and lived alone, while others lived with their
spouses and/or families, with small or grown-up children. Four participants had college or university degrees. At the time of the interviews, three participants were attending physiotherapy regularly because of several years of pelvic girdle pain, spine and hip pain, or temporomandibular pain. Three participants were symptom-free after having had headaches for years, related either to prior trauma or a probable congenital torticollis. Of these, one participant consulted the PT every second week to prevent relapse, another consulted the PT if a relapse occurred, and the third one had recently stopped seeing the PT. All participants had been seeing their present PT regularly for more than one year.

**A long time searching for explanations and solutions to recover**

The participants begin their story-telling by going back in time and speaking about how their illness started and developed. The debut of symptoms is ascribed by some to significant events, such as being diagnosed with cancer, getting pregnant, or having recurrent head injuries. Other participants speak about their symptoms as not having a clear point of onset, but rather a gradual development. This was interpreted by the participants as resulting from long-time overload due to bodily malfunction (e.g. a tilted neck due to torticollis or of stooping forward when walking because of a stiff back following surgery for idiopathic scoliosis in childhood). Despite the range of onsets, interpretations and progressions of the complaints, the participants describe a shared history of a long time spent consulting different physicians and PTs to find explanations and solutions for their problems. They speak vividly about bad experiences from such consultations, where they are 'not taken seriously' and 'not listened to', and they hold the opinion that they have been offered inappropriate advices and therapies. Anger and indignation colours the narrative when talking about the past, as exemplified by this quote:

*I don’t trust doctors much when it comes to head injuries – or light head injuries at any rate – they don’t have a clue, they haven’t. It’s like when they don’t know what it is, and it’s sort of a little out of the ordinary, and perhaps the patient starts to have wishes of their own and such – then it fails. The pain isn’t very diffuse for the patient, isn’t it? It’s very present and quite concrete and specific and easy to locate. It’s there, but the fewer objective findings there are for conditions where objective findings no longer are relevant, because the examination methods don’t exist, the more the doctors need to be willing to empower the patients and listen to them.*  
(No. 2)

The participants also tell about disappointing consultations with various PTs, who neither examine them nor take the time to listen to them to find out what the problem was. Dialogs with these PTs are described as rather challenging or absent, and nothing in the participants’ stories reflect any kind of personal relationship with these PTs. Typically, the PTs are portrayed as acting as experts who know what to do without involving the participants or asking them about their opinions. Further, they offer conditioning exercise programs that, the participants say, are determined by the diagnosis but do not take into account any problems they may have performing these exercises. They emphasize that ‘one size fits all’ programs cannot work. The participants expect that a PT’s expertise is to design exercise programs tailored to an individual’s particular movement problems, but this expectation is not met. They do not become better and often even become worse. Thus, they feel it does not make any sense to continue seeing the PTs. However, the participants have no other option than to continue to search for someone to help them:

*I have constantly changed physiotherapists – many of them in the city centre – jumped from this to that to find a physiotherapist who could treat me for the illness I had and not just by a book that they learn by rote. That’s what I felt the physios whom I used were like. They had learned a type of job, and that’s what they used on me. And I just got worse and worse. And I still mean that this is no way to treat a patient […] I think, like, what they’re saying and the way they do it – everything, like, everything is affected.*  
(No. 1)

In this part of the participants’ narrative, the physicians and the PTs are described as people concerned with following procedures ‘by the book’ and who act accordingly, while the participants consider themselves ‘not to fit into this terrain’. However, some also talk about PTs who try to adjust exercises to the participants’ motion problems, but are unsuccessful in their efforts. Such examples, together with encounters where health professionals do not critically evaluate whether their therapies lead to any benefits for the participants, lead them to question whether these health professionals have the expertise needed to help them:

*Because I remember that once I went to a chiropractor, and he treated and treated and treated me, and all for diddly-squat. And, clearly, it was like you come in there with a referral and he goes, ‘yeah, we’ll fix it’. And then there were these cracking noises, once on each side, and then it went ‘yeah, you have a new appointment at such-and-such a time’. […] And he kept doing exactly the same. It didn’t work. […] He should have looked up and asked himself ‘hmm – why isn’t this working, what’s the reason?’*  
(No. 4)
The shared narrative’s introductory part provides a great deal of varied information about the period when participants searched for explanations and solutions for recovery. However, there is no progression in this part of the narrative, and the participants continue to ask questions about why they are ill and what they should do about it. Here, the health professionals are the main characters, with expertise that falls short and who act as antagonists opposing the participants’ efforts to recover. The participants portray themselves as passive recipients of health services and objects being acted upon, but at the same time they also display agency in continuing their search to find more appropriate solutions. In this way, a number of tensions can be noticed in the stories participants told about the past, which serves as an important back-shadowing to what is told about the present.

Learning their own meaningful ways to proceed

The story-telling about present experiences takes an ascending turn and, gradually, more positive experiences come to the fore. Again, physicians and PTs are included, but now they are inscribed in meaningful events, together with the participants. In these events, health professionals provide meaningful explanations to the participants for why they feel ill:

"I came to a neurologist who was really quite good. First I had – I felt that she took me seriously. That is, she listened carefully to what I had to say. And she related to that story – to the symptoms that I described. And then I was given good information on why it might be like that, and why I was so knackered. She had some hypotheses about it […]. She described how the impact of the injuries from a concussion increases and becomes more serious with each new incident – that their effects accumulate. (No. 3)"

At this stage in the shared narrative, in contrast to their previous experiences, the participants now speak about how the PTs invite them to engage in a discovery process to find out what might help. The PTs listen to what they have to say, ask relevant questions, examine their movement problems, try out movements and exercises together with them, and make sense of the whole. Exercise programs are tailored to their movement problems and in accordance with what they can tolerate to do:

"She started from the basics and taught me that at first, there should be no large strides – take small steps – and see what we can do (to avoid pelvic pain). And it started out really small-small, and now I have stepped it up. Encouragement and support all the way, perhaps not so much motion, but it has all helped me to where I am today. [...] She has sort of seen what I can do and cannot do. And she has started from the basics. Oh, my oh my, the exercises I did when I came here – today, I can do them with no problems at all. (No. 1)"

The participants’ stories include several events illustrating how they had felt trapped by an unfamiliar, aching and resistant body. However, when the PTs tailor exercises to their problems in daily life, exercising becomes meaningful to the participants, who gradually learn what they are capable of doing. In this way, they re-familiarize themselves with their bodies. For example, one participant, who had been more or less bedridden for several years, relates how she and her PT have an agreement that she comes to the clinic on a daily basis. This has made her realize that it is possible for her to participate in life outside her house. The participants describe their current PTs as skilled people – and the participants feel safe in their hands, both practically and metaphorically, as illustrated by this quote:

"I felt that she (the physiotherapist) knew what she was doing. And it felt as she had eyes in her fingertips. Because she found exactly the right spots. And that’s a completely magical feeling, really. I also felt as though she treated me so that the pain was lessened and that my mobility gradually increased. […] Yeah, I actually felt that I had to learn to be in the world in a totally new way. I have been used to being really, really quick – nearly as if my head has been half a meter ahead of the body. So I think that what I needed to learn was sort of to get into my body and be present in my body. […] So now I can feel it when I’m going faster than myself. (No. 3)"

The participants describe how the PTs engage in the participants’ ups and downs, and know what to do in order to get the process back on track and to get them to move further along. The participants’ recovery occurs so slowly, however, that advances are barely noticeable. The PTs identify and make them aware of these small steps of progress for example pointing out their ability to do more repetitions of an exercise or more advanced exercises, or reminding them about how things had been before. By attaching improvements to the participants’ performance, the participants recognize their own advancements. The improvements also validate that they are on the right track, which in turn motivate the participants to move ahead:

"It’s really motivating to work with her, because she is so good at pointing out the progress made. Because I don’t always see that – she can say ‘gee, now you’re able to do this one and that’, so she is really good. Today, then – I have been unable to put on my socks until now – and so I told her that I was fed up with it. So then we tried, and I found a way to reach (down to my feet) with her help and I could put my sock on. And that was, sort of, like a – yes! […] I do feel now that it feels really
meaningful to go to her. It’s not only me going alone to exercise, because I don’t see the progress in the same way. So when she has noticed something it makes me really happy. I go out, and feel really happy. Once she said something, can’t remember what, then I called my boyfriend right away and said ‘you know what she told me? That I was, and that she could see that I was’. So I can feel that it means really a lot. (No. 5) When the shared narrative shifts to the present, the health professionals and the participants both inhabit active roles; they are collaborating in exploring and discovering how the participants can manage the situation. Here, the participants portray themselves as the main character in their narratives, but the health professionals are still presented as important characters that actively engage and respond to what the participants tell and do. The health professionals provide plausible explanations and solutions from which participants learn about the relationship between their body and life experiences. The participants present themselves, in turn, as active, resourceful learners able to re-familiarize themselves with their body and take charge of their life situation.

Uncertainty about future and own ability to reverse relapse

After the narrative’s ascending section, in which the participants’ stories convey a path to recovery, the narrative’s ending about the future is more ambiguous and uncertain. They all believe that they will either experience increasing wellness or will mostly remain well in the future. Those who are not symptom-free believe they are on the right track and that they will reach a future state of increased wellness, but at the same time they are uncertain how far it is possible for them to reach. Those who are symptom-free, for the most part, are rather certain that they will continue to stay well.

However, the narrative’s ending displays that for all informants, even those who are symptom-free, previous experiences about illness and search for appropriate help still reside in the background. Worries about what will happen if they get worse again is explicitly articulated. Relapse of illness are expressed as set-backs – in terms of something that make them take a step backwards in their recovery process or as an acute new event where they fall ill again. In both cases, relapses mean starting the process of recovering over again:

As I said, it’s been a rollercoaster ride for me. One day I can get out of bed in a good mood and have just a little pain, and such minor pain is no big deal for me any longer. It’s sort of these bouts that scare me. [...] I’m afraid of having such bouts, because I know how I felt when I was at rock bottom, and I don’t want to fall back there. If I do, it’s hard to get back up. (No. 1)

Only the participant who just had stopped seeing her PT feels certain that she eventually will manage a relapse at her own. She is confident that her body awareness competence will enable her to take action before a relapse occurs. The other participants, however, find their recovery achievements to be rather fragile. Thus, some wish to continue consulting PTs to enhance further progression, while those being symptom-free focus on avoiding or reversing relapse by either continuing with physiotherapy regularly to maintain their gains and prevent relapse or trusting their PTs to provide immediate help if needed. It is not only to avoid restarting a recovery process they find important, but also to avoid a new search to find appropriate help. The narrative’s description of a recovery process with up and downs without a definite endpoint and the role of a PT is well captured by this informant:

I have hit rock bottom – into a black hole. It was hopeless there, and when you’re there you’re not motivated to do anything. Getting back up from there has been a long and laborious process. I was totally knocked out by the treatment given by the PT and cried a lot, but now I can take more. It’s a good sign. Now I can feel it when things start to go wrong, I’m more aware – and then I go to my physiotherapist for help at once. I don’t want to have to start anew. This has not been a quick fix, but I’ve been patient and slowly worked my way back out of the hole, but I’m still sitting with my legs dangling over the edge and I’m a little afraid of falling back in. So I need a little more time to get onto firmer ground. I believe that I’ll be there soon. (No. 6)

The above quote shows how a recovery trajectory can include prevention and reversals of future relapses. Thus, the roles of the doctors and PTs in the future are somewhat ambiguous, depending on how far it is possible for the participants to ‘climb up the ladder’ or get ‘safe ground under their feet’. In this part of the narrative, the participants display themselves as responsible main characters who have the necessary competence to know when a relapse arises and who they will ask for help, if needed. In this ending part of the narrative, the health professionals’ roles is fading into the background.

Discussion

The participants’ experiences of long-term use of physiotherapy include variability with respect to details, but nevertheless their experiences can be expressed in a shared narrative constituted by three themes: ‘A
long time searching for explanations and solutions to recover’ describes the participants’ when ill, ‘Learning their own meaningful ways to proceed’ portrays their recovery process, and ‘Uncertainty about future and own ability to reverse relapse’ depicts a recovery process without any definitive ending and an ambiguity regarding the need of future help. The narrative’s storyline is expressing that for the participants ‘it takes time, but recovering makes it worthwhile’.

People with chronic illnesses are found to share a concern that illnesses limit functional abilities and disturb ordinary lives (Bury, 2005). When people cannot perform habitual tasks and roles anymore, a coherent sense of self can be lost (Charmaz, 1999). These theoretical understandings communicate well with the first theme, ‘A long time searching for explanations and solutions to recover’, which displays an illness narrative describing how an unfamiliar body restricts and disturbs the participants’ daily life. Ordinary daily life is disrupted and perceived as rather chaotic (Bullington, Nordemar, Nordemar, and Sjöström-Flanagan, 2003). The merry-go-round with diagnostics and standardized exercise programs did not help the participants come to terms with their illness and regain control over the situation.

In the narrative’s opening theme, here seems to be a mismatch between health professionals’ dedication to delivering services ‘by the book’ and the participants’ concerns about their individual life situation. Accordingly, the participants’ experience was that they were treated as objects upon which health professionals acted instead of people with unique problems and needs. Similar findings have been reported among patients with illnesses without any objective medical signs of disease (Mengshoel, Sim, Ahlsen, and Madden, 2018; Nettleton, Watt, O’Malley, and Duffey, 2005); however, the present study extends this notion as both patients with and without objective medically-confirmed diagnoses related that they had not received explanations or solutions they found meaningful. Greenfield (2006) has stated that health professionals are moral practitioners if they consider their patients as people and as worthy of receiving their best care, and if they have a moral orientation to connect with others based on a process of receptivity and reciprocity. As such, in the present study, the health professionals depicted in the opening of the narrative would not be considered ‘moral practitioners’. The patients ultimately were agential in their search elsewhere for more appropriate help; this can be a time-consuming and frustrating process, however, in which a personal recovery process can be postponed. Moreover, it may become more challenging and take time for health professionals to turn such a negative process into a more positive one.

In contrast to the narrative’s opening part where the participants reach no further, the narrative’s middle part or plot ‘Learning their own meaningful ways to proceed’ shows forward motion. Gradually, what the participants could not do was replaced by what they were able to do, depicting how illness was gradually replaced by more wellness. This part parallels theoretically with the patient’s personal recovery or healing process expressed in terms of learning and personal growth. As seen presently, personal recovery includes complex processes of making sense of illness experiences, and adjusting life and oneself to these experiences (Radley, 2004). In the recovery literature, it has been found that creating a meaningful coherence between one’s self and one’s own way of living (Antonovsky, 2000) and creating order in one’s new daily life (Kralik, Koch, Price, and Howard, 2004) is key to enhancing personal recovery in terms of more wellness (Lucy, 2017).

A personal recovery trajectory can be eventful, made up of small and/or major events acting as turning points and drivers of the personal process (Mattingly, 1998). In the present study, such turning points are illustrated by the participants consulting physicians who gave explanations appropriate to the participants’ experiences and concerns, and PTs who made sense of the relationship between the body and the activities of daily life. The PTs’ reminders about the participants’ improvements, however small, can also be interpreted as important turning points that empowered the participants to move forward. This individualized approach aligns well with a patient-centered model of care emphasizing the importance of listening carefully to a patient’s story and relating therapy to a patient’s individual needs (Gluyas, 2015; Sacristan, 2013).

Hope for a better future is an active ingredient in a recovery process, as it motivates people to move forward (Repper and Perkins, 2003). However, patients may hang in the balance between hope and resignation (Afrell, Biguet, and Rudebeck, 2007). This was the case during the illness and recovery process for the participants in this study, but hope gradually came to the fore in the recovery part and held a dominant place in the expectations for the future. In the recovery process, steps forward were hardly noticeable for the participants, and relapses moved the process in the wrong direction; the participants at times felt resigned and hopeless. Thus, being reminded by their PT about advancements was important for feeding into the participants’ belief in their own success and hopes for future progress. The improvements were concretized
through the PTs pointing out their ability to do more repetitions, more advanced exercises, and perform daily activities they previously could not do. Such statements were compared and validated through the participants’ own experiences. In this way, creating hope was not a part of a structured evaluation of whether predefined goals were reached, but was embedded in the learning process. Thus, our findings contrast the finding that PTs, in order to avoid raising false hopes, are more concerned with setting realistic, attainable goals than with creating hope (Mudge, Stretton, and Kayes, 2014).

Theories of personal recovery have mainly been developed by social scientists (Antonovsky, 2000; Bury, 2005; Mattingly, 1998; Radley, 2004) or by people working within psychiatry (Ralph and Corrigan, 2002; Repper and Perkins, 2003; Roberts, Davenport, Holloway, and Tattan, 2006). Here, the role of the body in the recovery process is rarely discussed. Our study, however, reveals a recovery narrative that is closely linked with making sense of the ill body through performing movements that, in turn, helped the patients adjust daily activities. Obviously, this body work meant more than merely doing exercises as expressed by one of the participants, ‘I had to learn how to be in the world again’. In other words, the participants were creating coherence between themselves, their bodies and their lives through a concrete, practical way of moving in everyday life (i.e. a process of learning by doing). This kind of re-familiarization with the body contrasts with reports from a previous study that patients considered their body an unreliable enemy to which they had to surrender (Afrell, Biguet, and Rudebeck, 2007). Our findings are in accord, however, with prior studies showing that patients want PTs to explain and discuss their problems with them and to design individually tailored exercise programs (Bernhardsson, Larsson, Johansson, and Öberg, 2017; Calner, Isaksson, and Michaelson, 2017). However, our study adds to this notion by pointing out that exercises can be a ‘tool’ to reconnect with an unfamiliar body and subsequently create the potential to adjust daily life. We have seen earlier that such a connection may depend on PTs’ embodied ability to get in touch, communicate and interact with the unique person seeking help (Bjorbækmo and Mengshoel, 2016).

In the present study, the shared narrative’s ending shows that the recovery process is not brought to a definitive end. The participants still thought their body might defeat them through flare-ups or new episodes of illness. They felt uncertain if and when such a set-back could happen, and they monitored their bodies to prevent such events from occurring. This worry about relapse is in line with findings from a study on patients who have recovered from fibromyalgia (Grape, Solbrakke, Kirkevold, and Mengshoel, 2015). Previous illness experiences thus continue to be a part of future life. Such uncertainty should be acknowledged and addressed by health professionals, as this might support and help the patient to end a trajectory of regular health service use due simply to uncertainty. In the present study, the participants underlined that they had developed a bodily awareness enabling them to recognize an upcoming relapse, and they grew to understand the right time to ask for help. Having such competence is important for patients, and knowing that they can get adequate help if needed can make them safer and reduce their dependency on health professionals’ regular support.

In the narrative about the past and present experiences, the roles and actions of health professionals were portrayed rather differently. In stories about the past, health professionals delivered standardized regimes of diagnostics and exercise therapy. As such, they were seen as experts delivering evidence-based practice (EBP) (Sackett et al., 1996). In the present, however, the health professionals were portrayed as experts engaging with the participants’ concerns and taking the patients’ perspective as a point of departure for their actions. These different kinds of actions can be linked with different perspectives on what counts as knowledge in clinical decision-making. EBP follows rational thought, valuing factual knowledge about what is found effective in modifying a disease condition (Anjum, Kerry, and Mumford, 2015). In contrast, health professionals who are engaged in the personal recovery process seem to draw on an amalgam of factual knowledge, their personal knowledge, and patients’ experiential knowledge. The latter aligns with Gabbay and le May (2004) concept of ‘mindlines’, which are ‘guidelines in the head, in which evidence from a wide range of sources has been melded with tacit knowledge through experience and continual learning to become internalized as a clinician’s personal guide to practicing in various context’. In our study, what Gabbay and le May (2016) call ‘knowledge in practice and context’ expertise seems to have been successful. These PTs might be good role models from whom others can learn. However, there will always be a risk that personal mindlines is inappropriate (Gabbay and le May, 2016). Mindlines can express wisdom, as evidenced by the present study, but not all personal mindlines are wise. We would argue that the same holds true for evidence-based guidelines. What is right to do in a clinical setting relates to how knowledgeable a clinician is, and the wisdom of applying relevant knowledge in the actual setting. This can be particularly important in
encounters with patients’ with long-lasting illnesses who have failed to improve; patients whom some health professionals deem ‘difficult’ (Koekkoek, Hutschemaekers, van Meijel, and Schene, 2011).

The trustworthiness of the present study relies on several issues, for example the interviewee’s role in co-authoring and analysing the participants’ narration. Overarching questions were asked to invite the participants to tell their stories without much interruption from the interviewer. The quotes of the participants presented above reflect the fact that the participants told lengthy stories. Nevertheless, stories cannot be considered facts about an existing reality, but neither are they fiction, as they relate to events happening in people’s lives (Mattingly, 1998). However, which events and experiences that are found relevant to talk about and how the story is told is contextual. In the present study, the participants told a health scientist about what they deemed bad and good experiences. By contrasting past and present experiences, the participants clarified their points in a convincing way.

Trustworthiness also relates to whether the researchers’ interpretations are credible. The first author performed the analysis, and no member checking of the coding was performed. However, the narrative methodology, and the co-authors’ critical reading enhanced the reflexivity and accordingly the credibility of the analysis. We expect that some will criticize our small sample size. However, we agree with Malterud, Siersma, and Guassora (2016) that the power of qualitative studies is the richness of the data rather than the sample size. This is especially true with respect to narrative methods which concerns relate to whether the data is rich and detailed enough to make up stories, and if fulfilled, even one narrator may contribute to new insights (Riessman, 2008).

In narrative methods, it is taken for granted that a study’s finding do not include all possible circulating narratives about a phenomenon. However, as people’s stories to a great extent are socially and culturally influenced, it is likely that the narrative described presently is one plausible narrative among other narratives about long-term use of physiotherapy in primary health care heard in clinical practice. Our informants were well educated and resourceful, but nevertheless their rather complex, but still successful narrative can probably appear among less well educated people as well. It also seems likely that the findings about the importance to find out what an ill body tolerates in order to manage daily life, as well as worries of relapse are transferable to several other patient groups than those having musculoskeletal pain conditions, and thereby provide relevant information for clinicians.

In Norway, PTs in primary health are allowed to treat patients without any referrals from physicians. Thus, they have to make decisions about who needs physiotherapy and when physiotherapy should be terminated. Our findings show a slow and strenuous recovery process that might be worthwhile when patients become significantly better or symptom-free. At the other hand, our findings raise relevant questions for future research such as; who are likely to become much better or not, how to identity an (un)successful recovery path, when is it appropriate to terminate physiotherapy, and who is the best to take such decisions.

In conclusion, the patients in our study were long-term users of health services, both in terms of seeking help that turned out to be ineffective and utilizing health services promoting personal recovery work. Their shared narrative illustrates how complex and strenuous a recovery process can be for patients with long-lasting musculoskeletal pain. The patients found the long time they had spent seeking appropriate care to be worthwhile overall, because of what they had learnt and the progress they had made.

**Declaration of Interest**

The authors declare no conflict of interest.

**References**


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