



## Experiences of shifts in physiotherapy for rheumatoid arthritis over time – an autoethnography

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To cite this article: Anne Marit Mengshoel (2023): Experiences of shifts in physiotherapy for rheumatoid arthritis over time – an autoethnography, *Physiotherapy Theory and Practice*, DOI: [10.1080/09593985.2023.2169061](https://doi.org/10.1080/09593985.2023.2169061)

To link to this article: <https://doi.org/10.1080/09593985.2023.2169061>

## ABSTRACT

Several shifts in physiotherapy treatment of patients with rheumatoid arthritis (RA) have occurred over time. This paper aims to identify shifts in physiotherapy practice for patients with RA based on the author's work experiences from the 1980s until today at two Norwegian rheumatism hospitals, and to explore why shifts may have happened. A narrative was developed by describing events making a difference, categorizing, and ordering them with the help of narrative analysis and a sensitising analytic lens on discourses. The storyline from the 1980s to approximately the turn of the millennium is called 'Shifts determined mainly by clinical context-driven events' which occurred in response to medical advances and physiotherapists' clinical experiences. These shifts were later justified by physiotherapists' research in the clinical context. The other storyline covers mainly the 2000s and is called 'Shifts increasingly determined by events beyond clinical physiotherapy context'. They include adjustments to further medical advances and implementation of biopsychosocial understanding of disease at the hospital, and to external research-based recommendations, health reforms and economy. These processes have moved physiotherapy practice at the hospital from mainly providing individualized remedial and rehabilitative physiotherapy for the purpose to normalize physical function to an increasing focus on generic health measures for the purposes of health promotion and cardiovascular disease prevention. However, this shift may not fully match the complex needs presented by patients in disease remission with unrelenting fatigue and work inability and those who have multiple functional challenges and comorbidities.

**Keywords:** Physiotherapy – rheumatology – clinical practice – evidence-based practice – narrative – discourse

## **Introduction**

A characteristic feature of systemic inflammatory autoimmune diseases (SIADs) is that the immune system reacts against the body's own cells. The aetiologies of the diseases are not fully understood, and their symptoms and courses vary. Without adequate treatment, SIADs can cause significantly impaired body functions and limit daily functioning (Helby-Petersen, et al., 1986). Among the SIADs is rheumatoid arthritis (RA), which is characterized by inflamed synovial membranes within the joint capsules leading to swollen joints, impaired joint mobility, reduced muscle strength, and activity-induced pain. When the inflammation persists over time, inflamed tissues may weaken joint capsules, cartilage, and bone tissues. Joint contractures, laxity and malalignments of joints may occur and influence mobility, thus limiting activities and restricting a patient's participation in society (Dziedzic and Hammond, 2010). There is also an increased risk of cardiovascular comorbidity (Hollan et al., 2013). Drugs and physiotherapeutic modalities are used to modify activity of the immune system, to relieve symptoms, and to prevent or reduce impaired functioning (David, 1998; Lindahl, 1998). Major advances in medical treatment of SIADs have taken place during the last decades, and today, several patients with SIADs, for example patients with RA, experience no or minor disability, a trend that will hopefully continue.

For decades, physiotherapy has been central for the treatment and rehabilitation in rheumatology (Dziedzic and Hammond, 2010), particularly for patients with rheumatoid arthritis (RA). However, significant changes in physiotherapy practice have taken place over time. In a recent work aimed to describe the physiotherapy services at a rheumatism hospital in Norway, physiotherapists expressed concerns that today, the delivery of services to outpatients with RA has taken priority above the rehabilitation services for hospitalized patients, and they questioned whether their expertise may have become more blurred by shifting from 'repairing' specific disease-induced function deficits to strengthening health by advocating a non-sedentary lifestyle and prescribing general conditioning training (Mengshoel et al., 2021). To understand the present situation, Brockmeier (2000) argues that it is important to understand how events in the past, present and future are interconnected. Thus, the aim of this paper is to examine the shifts that have taken place in clinical physiotherapy from the 1980s to the present, and what prompted the changes. Inspired by narrative analysis and autoethnography, which systematically describes and analyses personal experience in order to understand practice (Ellis, Adams and Bochner 2011), a narrative about clinical physiotherapy for patients with RA was

constructed based on the author's varied work experiences at two Norwegian rheumatism hospitals.

## **Theoretical framework and methodology**

The core interests of physiotherapy are the body, movements, and function (Nicholls, 2018). Recently, Nicholls (2022) demonstrated how physiotherapy has developed to address medical challenges in our society, but he also showed how physiotherapy is shaped by external forces, like evidence-based practice (EBP), organisational structures, health politics, and economy. Accordingly, in rheumatology, physiotherapists need to know how to meet patients' needs, the impacts of various institutional and societal claims for health services, and political and economic regulations (Praestegaard, Gard, and Glasdam, 2015). In other words, shifts in physiotherapy practice can be contingent to concrete events related to clinical experiential and research-driven knowledge as well as socio-political regulations of healthcare. Minor shifts may occur over time and can thus remain unnoticed and inexplicable if events are considered separately instead of interconnected.

Presently, the shifts in clinical practice are explored inspired by autoethnography. Autoethnography is a research approach seeking to inspect own experiences to identify events after which life does not seem to be quite the same anymore, and systematically analyse the experiences to make sense of what happened. In autoethnography, the researcher's subjective experiences are found tenable for analysis. Therefore, writing autoethnography is an explorative process. A researcher retroactively and selectively writes about own past experiences from being part of a culture, consults others and documents to recall, and looks at the experiences analytically to detect facets of the experiences to reach an overall meaning of what happened (Ellis, Adams, and Bochner, 2011). According to Bochner (2012), autoethnography implies narrative inquiry and acts of meaning.

People tell stories to make sense of what happen to them. A storyteller chooses experiences among past events to make sense of the present and create expectations for the future (Hurwitz, Greenhalgh, and Skultans, 2004). Hence, a circularity between the past, present and future occurs by looking backwards to find what matters for the present (Brockmeier, 2000). Storytelling is based on personal and contextual experiences, but at the same time, what is told is also informed by shared knowledge, in this case about physiotherapy, clinical context

and society. Therefore, a story may seem familiar and make sense to others (Mattingly and Garro, 2000). Presently, narrative inquiry and analysis were conducted by selecting events, appraising and organizing them to develop coherent, meaningful storylines (Riessman, 2008). The ‘narrative turn’ in the human and social sciences emerged as an opposition to the positivist mode of inquiry (Riessman, 2005). The positivist’s objective is to develop knowledge about a reality existing independent to human beings and culture. In contrast, a narrative analysis is based on an ontological view acknowledging that there are many ‘realities’, and these are created through persons’ engagement in the social world and shaped by what is made possible to happen in a cultural context (Burr, 2003).

Presently, the author is the storyteller, and what is told about physiotherapy practice is based on the author’s clinical experiences, observations of others’ practice, and conversations with health professionals in two rheumatism hospitals in Norway from the 1980s to the present. During this time, the author has inhabited roles as a clinician, practice teacher for physiotherapy students, scientist, advisor for allied health professionals in rheumatology, and as an academic at a university. A narrative was constructed by identifying relevant events, what Mattingly and Garro (2000) call ‘telling moments’ making a difference, and critically appraise their relevance to reach a more comprehensive meaning of shifts happening over time. Initially, the relevance of events was discussed with two physiotherapists with long experiences within rheumatology: a clinician at the hospital and a scientist at a university. My purpose was not to test the events’ truth, but rather to find out whether the events were recognizable to others.

In addition to ‘what’ to tell, a narrative analysis focus on ‘how’ to tell (Riessman, 2008). In developing a coherent narrative about work experiences, the descriptions of the events’ ‘what’ was told to clarify the point of the events (abstract), orientation to time, characters, and situation, identifying turning points (complicating action), consequences of events (resolution), and an ending bringing action back to the present (Riessman, 2005, p.3). The events were also structured temporally. Temporality in narrative analysis implies an understanding that subjective experiences are not necessarily expressed chronologically, and neither do events always have an exact start and ending. Rather temporality is understood as events happen before or after others in the unfolding of a story (Hurwitz, 2004). Thus, developing the presented narrative was an explorative and interpretive process which was nurtured by knowledge from multiple sources. In this process, the text was critically assessed and refined multiple times to create and express the meaning as storylines. Underpinning my analysis were a broad set of

theories about physiotherapy, disease, illness, health, and methodology, and the following analytical questions: what physiotherapy was/what it might have been, what physiotherapy became/what it might have become, and who were the actors/what roles did they play in the becoming of physiotherapy practice?

An ‘effective’ narrative gives meaning to others through its structural order. This structure also enabled me to discover how events were interrelated and shaped by mutual discourses, i.e., a particular set of assumptions and understandings. For example, biomedical disease is characterised by understanding disease and physical function in relation to a causal logic starting in biology, with psychological and social consequences. Biopsychosocial disease implies to understand disease and physical function resulting from reciprocal relationships between biological, psychological and social issues (Cormack et al., 2022). These understandings form a disease discourse paying interest in the cause(s), diagnosis, classification, and effects based on objectivity according to a positivist ontology and epistemology (Lupton, 2012). Health services are also influenced by health politics, often in concert with socioeconomic discourse based on the principles of market economy, where health services are considered in terms of commodities, efficiency and productivity. Furthermore, governmental health reforms and laws impact health institutions and those working there, and health reforms may encapsulate cultural discourses of what is considered good and bad in society. For example, today, people in our culture are expected to actively take responsibility for their own health, and therapies should be cost-effective (Lian, 2007).

## **Historical contextualization of rheumatology and physiotherapy**

SIADs are old diseases, and for example RA and ankylosing spondylitis (AS) can be traced back to ancient times, with archaeological findings showing joint changes in skeletons similar to those observed in these arthritic conditions. For example, a 3,000-year-old Egyptian mummy showed ossified spinal joints indicative of AS. Later European painters, e.g., Rubens (1577–1640), portrayed persons with swollen and misaligned joints in the fingers and hands as seen in RA. During the 1600s, Sydenham began to divide diseases into separate diagnostic classifications, for example infectious diseases. However, a landmark break-through in rheumatology occurred just after World War II with the discovery of antinuclear and rheumatoid factors, resulting in the development of serological diagnostic tests. This also

resulted in a shift in the understanding of SIADs as autoimmune instead of infectious diseases. Consequently, medical research was set out to better understand the immune process, the influence of genetics, to develop more accurate diagnostic classification criteria and better disease-modifying drugs, for review see Shrikant (2014). For a long time, however, physiotherapy modalities took precedence over drug management because there was an uncertainty about the drugs' safety and effects.

Already in ancient Greece, diets, spa therapy (e.g., mudpacks, baths, massage, recreational activities) and 'bed-cure' were treatments used for patients with rheumatic diseases. Such measures were also central in the spa resorts that appeared in Norway in the mid-1800s. At that time, the first Norwegians were educated as medical gymnasts (later called physiotherapists) in a school established by Ling in Sweden (Haugen, 1997). A central feature in Ling's school was medical gymnastics, in the form of specific remedial movements (specific exercises) aimed at healing the function of various organs, and whole-body gymnastics (general training) to promote physical upbringing, discipline and health (Haugen, 1997; Ottosson, 2011). The students were predominantly men, often with a military or medical background (Ottosson, 2011). Physicians developed Ling's school further (Ottosson, 2010), and in physiotherapy, exercising came to be linked with medicine rather than sports (Langaas and Middelthon, 2021). From the 1880s, the medical gymnasts were educated in specific remedial exercises, massage, bathing, infrared light, general gymnastics, and electrotherapy (Ottosson, 2010). Their focus was on disease-related changes in body posture and movements, understood with the help of biomedicine and biomechanics. Thus, physiotherapy was based on an understanding of the 'body-as-machine' (Nicholls, 2018), which aligns with a biomedical understanding of disease.

After completing the education in Sweden, female physiotherapists with no medical background became central in integrating physiotherapy into the Norwegian public health services. They collaborated with physicians to legitimise their practice, and these physicians played a significant role in establishing and developing physiotherapy in Norway. For example, orthopaedists introduced physiotherapists to specific self-straightening exercises for spinal scoliosis (including spinal traction, active and passive exercises), use of corsets and mechanical training aids (Langaas and Middelthon, 2021). Physicians were also heading the Norwegian physiotherapy education from its onset in 1897 until 1974. The close collaboration with physicians resulted in continuing the development of physiotherapy in adherence to medicine and a biomedical understanding of disease.

In 1938, the first Nordic rheumatism hospital was established in Oslo, Norway's capital city. At the beginning, the staff had professional backgrounds in medicine, nursing, physiotherapy, and social work whereas occupational therapists were included in the 'combined unit' in the 1950s (Eriksen, 1988; Munthe, 1987). The physiotherapists' therapeutic modalities and knowledge of medical terminology, musculoskeletal system, orthopaedic conditions, anatomy and physiology (Nicholls, 2018) aligned well with the interests of the new hospital's physician, who was recruited from a spa resort (Eriksen, 1988). The physiotherapists also incorporated warm baths, mudpacks, and pool exercises from the spa tradition into their practice (Munthe, 1987). The physiotherapists provided specific passive remedial movements to maintain and restore flexibility of the joints, and additionally, the physiotherapists provided heated baths, massage, relaxation, thermotherapies, and electrotherapy for symptom relief (Munthe, 1987). These modalities continued to be used for decades, and 'bed-cure' was a therapeutic option up till the 1970s. Patients were also told how to protect their joints by avoiding injurious compression of the afflicted joints. Thus, treatments of SIADs to a great extent remained unchanged until the late 1970s.

## **A narrative about shifts in physiotherapy practice for patients with RA**

### Shifts determined mainly by clinical context-driven events

#### *From joint protective non-weight-bearing to cautious weight-bearing exercises*

In the 1970s and 1980s, more active and efficient treatment with disease-modifying anti-rheumatic drugs (DMARDs) improved the disease control of RA. Additionally, synovectomy delayed the progression of joint damage (Meijers, Valkenburg, and Cats, 1983), and damaged joints were replaced by better arthroplasties than before. At the hospital, the physiotherapists responded to this change by replacing prior passive range-of-motion and active assisted movements in non-weight-bearing positions with more active movements in the 1980s. Initially, muscle capacity of specific muscles in terms of strength, endurance and stabilising joints was trained mainly with isometric exercises against physiotherapist-provided resistance, but in the 1980s, isometric exercises became accompanied by dynamic resisted exercises. From the middle of the 1980s, contracture in joints without malalignment was targeted by active stretching movements and physiotherapists' manual traction and intra-articular gliding movements of specific joints (Kaltenborn, 2003). At that time, physiotherapists also started to



try out and carefully incorporate specific exercises in weight-bearing positions in their repertoire, but they also continued to instruct patients to perform exercises in suspension slings and heated pools. Both non-weight-bearing and weight-bearing specific exercises were tailored to normalise or 'repair' reduced capacity in specific joints and muscles. However, at the hospital, there was still uncertainty among the physiotherapists and rheumatologists as to how much weight load the afflicted joints could tolerate.

For the purpose of reducing pain and stiffness, thermotherapy (mud and hot packs, heated baths, infrared lamps) and electrotherapy (ultrasound, diadynamic current therapy, transcutaneous nerve stimulation (TNS), histamine enhanced by galvanic current) continued to be applied at the hospital. Additionally, the multidisciplinary team started classes to educate patients about the disease and self-management techniques. The uncertainty about the safety of weight load to arthritic joints resulted in physiotherapists and occupational therapists, for the purpose of joint protection, taught patients how to perform daily activities so as to minimise compression of joints, to use orthoses and aids, as well as to modify load from everyday activities by balancing activity and rest. The focus was on the disease and consequences of activities for the body's structure and function. In accordance with Nicholls' terms (2018), the body was understood as a 'moving machine' that needed protection, maintenance, and repair. Thus, physiotherapy practice continued to align with a biomedical understanding of disease.

### ***From cautious weight-bearing exercises to safe physical activity and general training***

During the late 1980s, physiotherapists in rheumatology entered the research arena in Scandinavia. The physiotherapists' research focused on themes such as examining the joints' tolerance for weight load in patients with RA (Ekdahl, Ekman, Petersson, and Svensson, 1994; Stenström, 1994a; Stenström, Arge, and Sundbom, 1996; Stenström, et al., 1992), exercise-induced pain and fatigue in soft tissue rheumatic disorders (Mengshoel, Førre, and Komnæs, 1990; Mengshoel, Saugen, Førre, and Vøllestad, 1995; Mengshoel, Vøllestad, and Førre, 1995), developing relevant and valid assessment methods to evaluate function capacities in muscles and joints (Boström, Harms-Ringdahl, and Nordemar, 1991; Ekdahl, 1989, 1992), and designing and evaluating the safety and benefit of group exercise programmes for patients with RA (Ekdahl, Andersson, Moritz, and Svensson, 1990; Stenström, 1994b; Stenström et al., 1991). In the 1980s and early 1990s, Swedish studies demonstrated that patients with RA who had been physically active, had less radiological joint changes, less disease activity and were less disabled than sedentary patients (Nordemar, 1981; Nordemar, Ekblom, Zachrisson, and

Lundquist, 1981; Stenström, 1994a). During the 1990s, physiotherapists also demonstrated that land-based general training was safe and resulted in better functioning than pool-based training (Stenström, et al., 1991). Furthermore, home-based dynamic exercise programmes improved aerobic capacity, muscle strength, muscle endurance, and capacity for daily activities more than static exercises (Ekdahl et al., 1990), and dynamic exercises increased the levels of beta-endorphin and modified pain (Ekdahl et al., 1994). Thus, these studies demonstrated that weight-bearing general aerobic conditioning and dynamic resistance muscle training did not harm the joints of patients with RA; on the contrary, training improved patients' functioning and mood. Safe weight-bearing activity also brought attention to patients' movement patterns when performing activities; for example, in walking, and exercises were prescribed to restore capacities to coordinate movements, stabilise joints and maintain body balance (Ekdahl and Andersson, 1989; Mengshoel, Clarke-Jenssen, Fredriksen, and Paulsen, 2000).

In parallel with the physiotherapists' research endeavour at the rheumatism hospitals, Scandinavian physiotherapy researchers and clinicians met regularly to present and discuss ideas and research findings. Thus, land-based general training, individually and in groups, was soon implemented as an adjunct to group training in heated pools in the rheumatism hospital. In parallel, physiotherapists continued to examine and tailor exercises to patients' specific impairments in muscles and joints, and they prescribed specific home exercise programmes to restore optimal functioning, and thermo- and electrotherapies (except histamine treatment) continued to be a part of physiotherapy. For multidisciplinary patient education, the new knowledge meant a shift of focus for the physiotherapists from joint protection towards advice on regular home exercise to maintain or increase specific movement capacities and daily function. In Nicholls' terms (2018), the understanding was now extended to a 'body-as-functioning-machine' in need of restoring specifically lost functional capacity and improving functional capacity in general.

In summary, this storyline displays that the development of physiotherapy occurred as a response to medical advances implying an increased tolerance for weightbearing activities, and the shifts in physiotherapy to weight-bearing exercises were supported by evidence provided by researchers in the clinical context.

## Shifts increasingly determined by events beyond clinical physiotherapy context

### *Physiotherapy practice adjusted to changes in the hospital context*

In the late 1990s, major medical advances once again radically improved the treatment of SIADs. The new biological DMARDs are highly effective in stopping the inflammation. In this vein, new medical assessment methods and diagnostic criteria were gradually developed, and today, rheumatologists can identify the need for and start early pharmacological treatment (Shrikant, 2014). This means that if RA is discovered before any tissue damage has occurred and if the individual patient tolerates and responds effectively to the drugs, the disease induces no or minor limitations in joint and muscle capacities. In Norway, the number of patients with RA treated with biological DMARDs increased from about 1,000 in 2010 with a disease remission rate of 42% to more than 4,000 treated in 2019 with 67% successfully brought to remission (Brkic et al., 2022). In response to this shift, more services gradually came to be delivered in the hospital's outpatient clinic, and today, only a small number of beds is reserved for specialized rehabilitation. Hence, two kinds of patients were gradually seen in the rheumatism hospital. Patients who are identified early, treated efficiently with drugs and have minor disease-induced physical impairments, are expected to continue to live as before and are mainly seen in the hospital's outpatient clinic. Here, physiotherapists focus mainly on patients' physical activity habits and general conditioning training plans for the purposes to promote health and prevent cardiovascular diseases. The other group comprises patients, often with comorbidities, with unrelenting fatigue, body deficits, impaired specific and general capacities for function. These patients may not be working and may have low incomes and poor education. Such patients are often referred to the rehabilitation unit at the rheumatism hospital. Here, physiotherapists provide individualized approaches including primarily specific exercises, cardiovascular condition and muscle strength training plans, and if needed, joint traction, massage and hot packs. Additionally, physiotherapists deliver conditioning, muscle strength and relaxation training for groups. Electrotherapy and exercise in heated pool, however, are not provided any longer.

Another driver for a shift at the rheumatism hospital came from the World Health Organization (WHO)'s International Classification of Functioning (ICF) (2001). ICF was found applicable to frame an overall vision for multidisciplinary health services at the hospital and thereby, conceptualise a mutual biopsychosocial understanding of disease, health, and functioning. The ICF was embraced by physiotherapists as the ICF conceptualises the complexity of physical function, and in particular psychological concepts, such as self-efficacy,

motivation, coping and fear-avoidance beliefs were adopted to explain limited functioning and non-adherence to training programmes. Thus, a shift from a biomedical to a biopsychosocial understanding of disease took place at the hospital, as well as in physiotherapy. This means that the focus continued to be on disease, but today, the physiotherapists' concerns and interpretation also include mental issues.

### ***Shifts driven by forces beyond the rheumatism hospital***

At the turn of the new millennium, the Norwegian health authorities established a National Competency Centre of Rehabilitation in Rheumatology to initiate a more uniform, updated and effective clinical practice across specialized rheumatology clinics. The new competency centre became a strong driver for the implementation of EBP at the rheumatism hospital. The EBP model advocates that clinical decisions should be based on research evidence (Newham, 1997) and favours interventions that have been proven effective by systematic meta-analysis (Sackett et al, 2007). In the 2000s, enough effect studies were available to perform systematic literature reviews on physiotherapy. Thermotherapies were found effective in reducing pain and stiffness; in particular, wax bath of hands, and electrotherapy in forms of laser, ultrasound and TENS were effective in modifying pain and tenderness (Brosseau et al, 2004a), and a systematic review more recently demonstrated that massage had some pain-relieving effects (Nelson and Churilla, 2017). However, several of these therapeutic modalities were gradually disappearing or getting a reduced priority at the hospital.

Evidence was also found in favour of general training in relieving symptoms and improving the capacity for daily functioning (Brosseau et al, 2004b, Van den Ende, Vliet, Munneke, and Hazes, 2008), but there was and still is, a lack of studies examining effects of specific exercises (Brosseau et al, 2004b). Over the years, physiotherapists at the hospital have increasingly adapted practice to what they have learnt from researchers and EBP guidelines, and the National Competency Centre of Rehabilitation in Rheumatology have strongly been advocating general conditioning and muscle strength training, as well as education in healthy lifestyles. Today, the European Alliance of Associations for Rheumatology (EULAR) strongly recommends the importance of intensive general training and patient education (Rausch Osthoff et al., 2018, Nikiphorou et al., 2021). Thus, there has been a radical shift from providing a variety of physiotherapeutic modalities to a great emphasis on general training and patient education at the hospital, and recently, the heated pool was closed and replaced by a gymnasium

equipped with modern treadmills and weights. This shift endorses a present cultural discourse that patients should self-manage, take responsibility for own health, and stay independent of health services.

In 2002, a governmental health reform in Norway transferred the responsibility for specialized health services in hospitals from local health authorities to the State through health trusts. This implied that a prior predetermined yearly budget was partly replaced by a performance-based financing, and the health trust buys specialized rheumatological services from the rheumatism hospital. Thus, the hospital's budget depends to some extent on documentation of the efficacy and productivity of their services. In this way, the employees gradually became accountable for the institution's economy through documenting what they do and the significance it has. In 2009, another governmental health reform was launched, aimed at reducing the costs of specialized health services by transferring the responsibility for rehabilitation to primary health care. Today, this places extra pressure on documenting the need for delivering rehabilitation services in the hospital setting instead of in primary health care. This has also raised a debate in the hospital about what is specialized rheumatological rehabilitation. A study conducted at the hospital demonstrated that an advantage at the hospital is that the services of multiple professionals complement each other in a way not applicable in primary health care (Mengshoel and Skarbø, 2017). However, it is not obvious what is the difference between physiotherapy delivered by specialists in physiotherapy at the rheumatism hospital and physiotherapists in primary health services.

In 2006, the Norwegian Ministry of Health decided to launch a programme aimed to reduce the societal costs of work absence by supporting an establishment of 'Return to work' programmes. The hospital adapted its existing multidisciplinary diagnosis-specific 'Education and coping' programme to include management of occupational life. The new programme received external funding and was delivered in an outpatient clinic, and gradually, the patient education programmes for both in- and outpatients included education in self-management in daily and occupational life, as well as generic healthy lifestyle recommendations and training. Recently, the week-long courses for hospitalized patients were terminated, and the 'Return to work' programme was replaced by short format courses in the outpatient clinic. Here, the physiotherapists advice patients how to maintain physical activity and perform intensive general training.

In summary, this storyline demonstrates that physiotherapists at the rheumatism hospital continue to adjust their practice to medical advances and to interpret their practice in line with

a disease discourse. Their practice aligns with international research recommendations deriving from effect studies and is adjusted to socio-political and economic discourses.

## **Reflections on present dilemmas and possibilities for future advances**

The present narrative analysis about physiotherapy portrays a consistent focus on movement and function in physiotherapy over time and in the interpretation of the phenomena related to a disease discourse. This has successfully nested the shifts in physiotherapy into medicine. Over the last twenty years, physiotherapy practice has increasingly been shaped by multiple discourses external to the hospital context, leading to a gradual shift from identifying and targeting an individual's function problem by individualized remedial treatments and restorative rehabilitation to an increasing focus on generic health promotion and disease-preventive approaches. This shift in purpose increasingly separates physiotherapists from their prior expertise in rheumatological rehabilitation.

One dilemma for the physiotherapists at the rheumatism hospital today is whether physiotherapy should be delivered by physiotherapists in specialized rheumatology clinics or in primary health care. An advantage of the hospital is the multidisciplinary 'combined unit' and their broad evaluation and set of approaches which are not available in primary health care. However, generic health measures in form of general conditioning training and healthy lifestyles can be provided outside a hospital for less costs. In line with this, the recent EULAR guideline for the implementation of self-management strategies for patients with SIADs (Nikiphorou et al., 2021) describes self-management in a generic, non-disease specific form. The guideline advocates that patients should 'receive support to adopt healthy behaviours, including guidance on what constitutes a healthy balanced diet, the benefits of exercising and stop smoking, among others'. Moreover, the EULAR task force recommends referring patients to self-management resources outside specialized institutions, such as patient organisations' self-help groups and information provided on websites. In a similar vein, the EULAR 2018 guideline on physical activity for patients with inflammatory arthritis and osteoarthritis (Rausch Osthoff et al., 2018) recommends that patients, including RA, should follow the WHO recommendations for the public on 'physical activity for general health' and intensive general conditioning training sessions according to the principles recommended by the American College of Sports Medicine (Garber et al., 2011). These recommendations mean that adverse

effects from high-intensity training are no longer a concern; on the contrary, high-intensity training is found effective in reducing risk factors of cardiovascular disease (Hernández-Hernández and Díaz-González, 2017). Since healthy physical activity and training are performed in the patients' daily environment and not in hospitals, physiotherapists are now supposed to educate patients in the use of tools for the adoption and maintenance of healthy physical activity and training behaviour, such as goal setting, self-monitoring, feedback and action planning (Nessen, Opava, Martin, and Demmelmaier, 2019). However, this is not necessarily a specialized service and may be supported by physiotherapists outside the hospital.

Despite a higher remission rate among patients with RA, it is a dilemma in rheumatology that the increased remission rates in Norway are not accompanied by an increased rate of employed patients (63% employed in 2009 and 59% in 2019) among those treated with biological DMARDs (Brkic et al, 2022). Recently, another Norwegian study demonstrated that despite successful disease remission, several patients still experience unrelenting fatigue that is not associated to disease parameters (Hammer, Agular, and Terslev, 2022). Thus, fatigue and patients' restrictions in social functioning are not explained by a disease discourse and not likely to be fully addressed by general health measures. Thus, physiotherapists may need to find out how to address the lack of functioning by understanding a patient's illness and life situation.

From a patient point of view, movement, body, function, exercise and training have personal and social meanings; however, theories that help to understand this are surprisingly absent from physiotherapy (Nicholls, 2022). During the last decade, it has also become increasingly popular to systematically synthesise qualitative studies, but evidence from qualitative studies might be considered more theoretically than practically applicable by physiotherapists (Mengshoel et al., 2021). Nevertheless, qualitative studies can promote new ideas about physiotherapy. For example, recently, a mega-ethnography of nine prior qualitative systematic literature reviews revealed the challenges experienced by patients with RA (Toye, Seers, and Barker, 2019). This illustrates that RA makes a taken-for-granted body unpredictable and unreliable, thus disturbing or controlling the patient. For the individual, it is difficult to make sense of what is happening, social relationships are disturbed, and it might be challenging to balance personal and work life roles. Accordingly, the individual's self and life are disrupted and need to be reframed (Toye, Seers, and Barker, 2019). The person enters unfamiliar terrain where old road maps and navigating compass no longer function appropriately (Frank, 1995), and patients with RA may have to navigate in between the 'kingdoms' of health and illness (Sontag, 1990). Patients may need time to reorient themselves, find out how to get back some

control over their body and life, and to re-establish the self and remake a well life (Van der Elst et al., 2020; Landgren et al., 2020). Because RA has a fluctuating course, this healing work is an ongoing endeavour, involving prevention of flares and taking care of health issues along with managing the disease's various implications for living an ordinary life. Such insights may facilitate a development of a specialized patient-centred, illness-focused physiotherapy that also incorporates an understanding of disease. As pointed out by McPherson, Gibson and Leplège (2015, pp.3-20), political and economic drivers may have overwhelmed humanistic drivers in clinical practice.

Another dilemma at the hospital is that the patients referred to rehabilitation services at the hospital may suffer from complex illness and functioning problems, often in combination with comorbidities like osteoarthritis and fibromyalgia. However, there is a lack of evidence about how to best address patients with multimorbidity and their diverse limitations in functioning. This is also likely to continue as the reasons are inherent to the design of randomised controlled trials. In effect studies, patients with comorbidities are excluded to obtain a homogenous sample. The effects of an approach tailored to a specific function problem are almost impossible to examine by randomised controlled studies since enough patients with a similar problem are seldom available, and thus, the generalisability of findings is hampered by small sample size. Moreover, with respect to training, only those willing and motivated to practice training are included in effect studies. Thus, it seems that physiotherapists at the hospital must engage in laborious critical rethinking to understand and approach the diverse problems presented by the patients with complex problems in their clinical context.

In recent years, coproducing knowledge together with patients has become common among researchers in European rheumatology. However, the researchers in rheumatology have to recognize that health professionals who provide services are also knowledge users and should be invited to define their needs of knowledge. Today, some scientists argue that services are working better if they are coproduced through collaboration between researchers, service providers, service users, and stakeholders (Vindrola-Padros et al., 2019). Others have criticised a view that interventions are understood as stable units, and they instead suggest that interventions should be seen as 'in-the-making' and a matter of becoming. 'This means that evidencing makes intervention at the same time as intervening makes evidence' (Rhodes and Lancaster, 2019, p. 1). This is an option for scientists doing practice-bound research to address complex issues within a clinical context.



Physiotherapy practice has adapted to multiple internal and external forces aligning mostly with a positivistic ontology and epistemology without critically elaborating on what do the changes mean to physiotherapy, and to ask if practice can become otherwise. Theoretically, physiotherapy is based on a solid platform of understanding movement and function, outlined as, for example, movement science (Carr and Shephard, 1987), movement control (Shumway-Cook and Woollacott, 1995), and the ‘movement continuum model’ (Cott et al., 1995). However, during the 2000s, an increasing number of scholars with background in physiotherapy have promoted broadening our understanding of the body, movement and function. For example, Slatman (2014) addresses personal and existential meanings of the body inspired by phenomenological philosophy. The body can be understood as a complex phenomenon comprising something we have (biology), something we are (existential), and something through which we act, shape and are shaped (sociocultural). This implies, for example, that movement and exercises, in addition to relating to biology, also relate to internal processes of connecting a person to their own body and self, and furthermore, through movements and exercises a person engages and interacts with and relates to others and the surrounding world (Wikström-Grotell and Eriksson, 2012). Furthermore, almost all physiotherapy research in rheumatology has examined recovery as an outcome, i.e., the effects of particular physiotherapy methods and protocolled approaches for groups of patients. However, recovery can also be understood as a personal healing process where it is essential for the individual to come to terms with disease and reframe oneself and one’s life situation within the boundaries set by an altered body and fluctuating, life-long disease (Mengshoel and Feiring, 2020). A desirable outcome of such a personal healing process is a person’s ability to place well-being in the fore and ill-being in the background (Paterson, 2001). Furthermore, Nicholls (2022) applies theories from social sciences to understand how sociocultural issues, such as capitalism, are shaping our understanding of health and health services in contemporary health care and physiotherapy practices. Thus, several theories are available for physiotherapists that may help to critically rethink physiotherapy to eventually create a rethought specialized clinical practice.

## **Conclusive remarks**

The present narrative illuminates that the development of physiotherapy practice has moved from having a purpose to relieve symptoms and ‘normalize’ disease-related physical function

to increasingly aiming to promote health and prevent cardiovascular diseases. However, this shift may not fully match the needs of patients in remission who have disabling fatigue and are unable to work and those patients with comorbidities and multiple functional challenges. Even if details differ, this narrative plot is likely to be recognisable for physiotherapists beyond a Norwegian rheumatological clinical context and may facilitate discussion and awareness in other practices. Such discussions seem necessary to encourage clinicians and researchers to engage in developing an eventual future avenue for physiotherapy in the field of rheumatology. To maintain a speciality in rheumatology for physiotherapy, physiotherapists seem to have reached a moment where considerable rethinking of practice is needed.

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