

SPECIAL REPORT

PHYSICAL AND REHABILITATION MEDICINE AND SELF-MANAGEMENT EDUCATION: A COMPARATIVE ANALYSIS OF TWO APPROACHES

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Background: Discussion surrounds the publication *The White Book on Physical and Rehabilitation Medicine in Europe* as to whether the medical specialty termed “physical and rehabilitation medicine” is in fact a reality.

Objective: To disclose previously undiscussed issues related to *The White Book on Physical and Rehabilitation Medicine in Europe* by juxtaposing its content with a body of work from a related healthcare approach termed “self-management education”.

Methods: Inspired by discourse analysis and actor network theory, texts on both approaches were contrasted as having vocabularies of their own expressed under certain material conditions.

Issues: Four issues arose: (i) the difference in illness trajectories between a sudden transition from an able to disabled person after a disease with acute onset and the indefinite and unpredictable course of a chronic disease; (ii) the different material and social set-up of clinical and community rehabilitation settings; (iii) the influence of these different implementation environments on goal-setting; and (iv) the relative neglect of social theory in physical and rehabilitation medicine.

Conclusion: If a bio-psycho-social functional approach to patients with acute and chronic conditions is regarded as essential for the identity of physical and rehabilitation medicine, the discourse on chronic illness should be paid more explicit attention.

Key words: rehabilitation; chronic disease; qualitative research; goals; self-efficacy; problem-solving.

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INTRODUCTION

The White Book on Physical and Rehabilitation Medicine (WB) describes the specialty of physical and rehabilitation medicine (PRM) in Europe (1, 2). The publication of the WB was a catalyst for lively discussion of the identity, position and foundation of PRM. Some researchers made the discussion worldwide by

arguing that its content deserved to be examined across European boundaries (3, 4). Others still did not consider the specialty of PRM to be a reality, thereby questioning the increased value it should have over other medical specialties and health professionals involved in rehabilitation. They suggested that the shaping of PRM specialists’ self-concept and identity in the WB would profit from interdisciplinary dialogue with other specialties (5, 6). The editors of the WB, in their turn, did not see a specialty with an identity problem, but instead the reality of a thriving PRM profession both inside and outside Europe (7).

Incorrect use of language was another issue discussed. Participants in debate were called to account for not using the core concepts of PRM’s underlying conceptual framework – the International Classification of Functioning, Disability and Health (ICF) – according to accepted definitions (8, 9). Interested readers were invited to engage in a discussion to determine a universally accepted conceptual description for PRM (8). A common approach to complex terminology in medicine is indeed to try to define its key words unambiguously. Conversely, that a single language suffices to describe, in a unifying way, all processes in medicine has been questioned in social studies of science and medicine (10–12).

Thus we aim to contribute to the discussion from a somewhat different angle, thereby gratefully embarking on the actual and comprehensive description of PRM in the WB. Instead of trying to define away all ambiguity in terminology, we took the language in the WB as the starting point for further analysis. The language in which the WB describes the content of PRM, was therefore juxtaposed with that of a body of work from a related healthcare approach, termed self-management education (SME). Therefore what we say about PRM and SME is not new *per se*. What is new is the comparison of the two fields. Both approaches are significant for people’s opportunities to have a good quality of life despite injury or disease. Both also focus on the consequences of injuries and diseases as were set out in ICF’s predecessor, the International Classification of Impairments, Disabilities and Handicaps. At the same time the two approaches are not synonymous. By pinpointing differences in approach, we hope to enrich the discussion surrounding the PRM specialty.

METHODS

Our comparative analytical work draws on discourse analysis and actor network theory (13–16). In some types of discourse analysis and

all actor network theory, the meanings of words within a discourse inform each other and are part and parcel of a material network. Rather than applying predetermined definitions of terminology, language is thereby analysed as something that is expressed under certain material conditions (17). We explored PRM- and SME-texts as if these were written in different languages and compared their key words in order to determine similarities and differences in knowledge practices. In Law's words, we unravelled how PRM and SME are performed, embodied and related in different material environments (14).

The WB was chosen as primary document on PRM (1, 2), as it is a thorough and up-to-date discussion document on PRM (3–9). To this we added articles on rehabilitation that addressed issues of significance to the study (18–28). From the overwhelming volume of literature on SME we restricted our comparative study to the work of Kate Lorig (29–41), because she is one of the founders of SME and has played a considerable role in the SME debate to date. Her work served as source of inspiration for many other self-management programmes, such as the Expert Patient Programme in the UK (42), although there is also some concern about the effectiveness of her programmes; for example, the Chronic Disease Self-Management Programme (43). With respect to SME we added some literature that helps to explain its conceptual underpinnings (44–46).

The PRM- and SME-texts were analysed as a set of juxtaposed grids, each of which was considered to have a history and momentum of its own (15). This resulted in several readings with a different focus. Our first reading focused on current definitions, problems and related goals in PRM- and SME-texts in order to build up an image of the target group. To further open up the content of PRM and SME, we searched in a second reading for predecessors to PRM and SME, analysing the arguments for and against these earlier practices. In a third reading text fragments about the material and social set-up of both approaches were compared in order to explore how they are embodied and related to these environments. In the final reading, the principles and practices were the object of comparative analysis as they also give each other content in a discourse. This form of triangulation provided a detailed picture of both discourses.

FIRST READING

What problems do PRM and SME wish to address? What do they endeavour to achieve? Our first reading was focused on text fragments that portrayed the target group and desired outcomes of both approaches.

Optimal physical, mental and social potential

According to the WB, the definition of rehabilitation is: "An active process by which those disabled by injury or disease achieve full recovery, or if full recovery is not possible, realize their optimal physical, mental and social potential and are integrated into their most appropriate environment." (1, p. 39). "The person's well-being and their social and vocational participation" are described as fundamental outcomes (1, p. 7). PRM's overall aim is articulated as: "To enable people with disabilities to lead the life that they would wish, given any restriction imposed on their activities by impairments resulting from illness or injury as well as from their personal context." (1, p. 7). In short, the WB construes the target group of PRM in terms of "disabling conditions" and "impairments" caused by injury or disease and regards functional recovery or optimal physical, mental and social function as desired outcome.

Greatest physical capability and pleasure from life

Lorig defined SME as "programmes that are built on patients perceived disease-related problems and assist patients with

problem solving and gaining self-efficacy or the confidence to deal with these problems" (37, p. 699). The main purpose is "learning and practicing skills necessary to carry on an active and emotionally satisfying life in the face of a chronic condition" (29, p. 11) with, as main outcome: "the greatest possible physical capability and pleasure from life" (33, p. 1). According to Lorig: "a healthy way to live with a chronic illness is to work at overcoming the physical and emotional problems caused by the disease" (33, p. 1). Thus, Lorig speaks about the target group of SME in terms of patients with chronic illnesses, with the intention of making them as active, confident and physically capable as possible in order to live a meaningful and pleasurable life as desired outcome.

Reflection

The quotes above reveal that the respective problems the two approaches wish to address are not very different. Whether patients with "impairments and disabling conditions" differ from patients with "chronic illness" is not very clear. This is also the case with respect to desired outcomes, for example, "optimal physical, mental and social potential" or "functional recovery", compared with "the greatest physical capability and pleasure from life".

SECOND READING

New approaches arise as reactions to previous endeavours to counter particular problems. Tracing these predecessors and analysing the arguments advanced for and against them in terms of their different wordings, is another way of opening up the content of PRM and SME.

Restoring disabling consequences of injuries and diseases with acute onset

Physical rehabilitation arose to counter the problems faced by victims of a worldwide polio epidemic in the first half of the 20th century and the wounded of the Second World War. Injured soldiers entered rehabilitation programmes aimed at restoring the disabling consequences of the damage caused by gunfire and other acts of war (18). Following the experiences of the war and polio epidemic, PRM was increasingly used to assist traffic accident victims and people with central neurological diseases, such as stroke survivors. Thus, the target group of rehabilitation in the past comprised people with disabling conditions due to injury and disease with acute onset.

Its rehabilitative programmes were directed at making the "attitudes, habits, and values compatible with the normal behaviour patterns that war had disrupted and distorted" (18, p. 271). This was achieved through a progressive and graduated programme of calisthenics (cardiovascular exercise), active recreation, competitive team-play, and vocational training. Thereby "the patient learned not only what he liked to do but what he was able to do, both in terms of ability and in terms of any handicap he had" (18, p. 271). Those with disabilities had to be approached as being "able"; that is, by highlighting their potential rather than their limitations. This would help

patients not only to readjust to everyday life but also to aid the process of post-war social reconstruction.

Similarly, the WB designates traditional medicine as a predecessor, arguing that it is “not directed at curing single pathologies, but instead is targeted at treating a multitude of disabling consequences of different pathologies”. Its aim “is to bring benefits no matter what the underlying diagnosis is” (1, p. 23). PRM is presented in the WB as “a holistic approach to people with acute and chronic conditions” (1, p. 10). Thus, PRM has further expanded its field.

The WB speaks of the bio-psycho-social approach to disability, incorporating key terms, such as impairment, activity and participation, from the ICF. But the terms in which the WB describes the outcomes of rehabilitation, “the person’s well-being and their social and vocational participation”, are similar to those that explain the psychosocial and economic aspects of rehabilitation in the past, as described by Rusk (1946). Although present-day PRM-texts express greater freedom of choice, “to enable people with disabilities to lead the life that they would wish”, changing the behavioural patterns of people with respect to their (dis)abilities still appears to be PRM’s core business. The historical text thus reveals that rehabilitation discourse has always had a bio-psycho-social line of thought.

Accessing psychological possibilities in chronic illness

SME arose in the second half of the 20th century as a reaction to the failure of the medical world to deal with chronic diseases (30, 39). Traditional medicine was also a predecessor of SME. With its primary focus on curing acute diseases, medicine did not do justice to non-curable chronic diseases. Lorig emphasized that “the lack of a regular or predictable pattern in chronic illness is a major characteristic in most chronic illnesses”. And that “unlike most acute diseases where full recovery is to be expected, chronic diseases usually lead to persistent loss of physical conditioning” (33, p. 3). Chronically ill people were forced to give up activities they were used to carrying out, which lead to emotional distress “such as frustration, anger and depression” (38, p. 1).

This brings us to a second predecessor of SME: biomedical-oriented medicine *within* the healthcare programme of chronically ill people. Novel therapeutic and surgical techniques, such as insulin regulation in diabetes or bypass operations, meant that patients survived diseases that in former days were fatal. However, medical specialists neglected the psychological impact of the long-term consequences of chronic illness. An advantage of SME is expressed in terms of its helping patients with chronic disease “to maintain wellness in their psychological foreground perspective”, rather than becoming overwhelmed by the unpredictable physiological course of their chronic illness (38, p. 1). Therefore, living in a healthy way with a chronic disease means, in the long-term, that self-management aims to improve the health status of chronically ill patients by teaching them the “psychological skills” required to deal with the physiological waxing and waning aspects of their chronic disease.

A third predecessor detected is the healthcare system itself, which failed to address the long-term problems of chronically ill patients. Discontinuity and the fragmentation of healthcare became widespread. In order to cope with their chronic disease, patients constantly had to attend different healthcare practices, and this was experienced as a burden for patients and their proxies as well as for society (39). The healthcare system lacked organization and could not provide chronically ill people with the benefits resulting from the efficient use of time, funds and resources. SME was therefore supposed to be directed towards encouraging them to make appropriate use of healthcare resources.

Reflection

Both PRM and SME emerged as responses to the limitations of the traditional biomedical focus on “curing acute single diseases”. Both shifted their focus of attention to the shared, multifaceted problems of people with “different pathologies”, for whom the disabling condition was often not “fully curable” (PRM) or had an “unpredictable course” (SME). Nevertheless, PRM had a primary focus on restoring the physical or functional limitations of diseases with an acute onset, while SME’s emphasis was more on accessing the psychological possibilities available to patients with a “chronic illness”.

THIRD READING

PRM and SME not only have histories of their own; they are also performed and discussed in other environments, including different buildings, providers and equipment.

Multidisciplinary teams in a clinical setting

The material environment of PRM is traditionally a hospital in which the physical structure is designed to offer patients with disabling conditions the possibility to undertake intensive physical exercise, daily activity training and vocational education, and to engage in social interaction. PRM is currently delivered in various facilities, ranging from specialized rehabilitation centres and departments in hospitals to outpatient and community settings (1, 2). The provider is a team of rehabilitation professionals with different disciplinary backgrounds. Coordination occurs through structured team communication and regular team conferences led by a physiatrist (1, 2). Functioning and participation are enhanced by offering “a coordinated source of information, advice and treatment for the person with disabilities and the family, with the team acting as provider and catalyst” (1, p. 18).

The WB states that rehabilitation should be delivered in “an organized goal-oriented, patient-centred manner” (1, p. 7). It argues that “the team works with the person with disabilities and family to set appropriate, realistic and timely treatment goals within an overall coordinated rehabilitation programme” (1, p. 18). The setting of “treatment goals” implies that they must be adjusted over time according to the progress of the patient. “Patient-centred” means that treatment goals should

be owned by the patients and their proxies rather than be set on a discipline-by-discipline basis. The multi-professional approach has to enable patients “to make informed choices of treatment” (1, 2).

Nevertheless, the literature reports difficulties associated with setting treatment goals in rehabilitation. Patients were not in the habit of setting themselves explicit goals and found it difficult to learn such skills (24, 27). Moreover, treatment goals are set for a future situation that may require activities that clash with the specificities of the present situation (22). Furthermore, professionals also develop goals for an environment that differs from that found in centres where people train to accomplish set goals (25). Despite the best intentions, many treatment goals are owned by the team, according to the literature (22).

Peer leaders in a community setting

SME started at the point where there was no further recovery to be gained according to the medical world. Lorig's SME began where hospital care stopped. Patients were sent home with, at best, the message that they must learn to live with their condition. SME aimed to help with that assignment: “Rather than telling people to ‘learn to live with it’, let us help them learn to self-manage” (37, p. 701). Lorig's SME-programmes are group practices provided in community centres, such as public libraries and healthcare facilities (32). The provider is often a volunteer, usually a lay person who, preferably, has been diagnosed with a chronic disease. This is because successful self-managing peers show how active self-management works and fellow sufferers may want to copy that behaviour to achieve similar results (34). In SME leaders act more as facilitators than lecturers. “Rather than prescribing behaviour changes, they assist participants in making management choices and achieving success in reaching self-selected goals” (32, p. 7). In this way peer leaders act as role models.

“Goal-setting” or “action planning” is an important skill offered in SME too (35). An assumption is that patients can learn to take responsibility for the day-to-day management of their chronic disease (32). Three self-management tasks are thereby distinguished: (i) medical management, such as taking medication and exercising; (ii) role management, maintaining and adapting important life roles, such as those of mother or worker; (iii) emotional management, dealing with anger, fear, frustration and depression that come with having an uncertain future (33, 38, 45). Self-selected goals can vary from “I will make an action plan to eat sweets no more than 4 times a week” to “I want to go to my daughter's birthday who lives 500 miles from here”. Goal-setting in SME is about life goals. The patient and provider negotiate a specific action plan that assists in the attainment of a life goal (33). The initiative for the plan lies with the patient. “The action must be something you want to do, that you feel you can do realistically, a step on the way to your long-term goal” (33, p. 19).

Reflection

Both approaches describe goal setting and active participation of patients as being crucial. Nevertheless, there are differences

to consider. In PRM there is a “multidisciplinary team”, which needs to attune the interventions of the disciplines involved in a treatment plan that has to be agreed on by the patients and their families. In SME a peer leader assists patients in making action plans to achieve self-selected goals in order to be able to deal with the unpredictable course of their chronic condition. PRM-texts speak of “treatment goals”, while SME-texts are focused on “life goals”. The multi-disciplinary team can be considered to be experts in the disabling consequences of chronic conditions and the patients to be experts of their own lives.

FOURTH READING

The final reading focused on the principles and practices discussed in PRM and SME, for it is not only words and materials that interdefine each other; theories can also play such a role.

Motor learning principles and practices

The WB portrayed PRM specialists as teachers, especially when new concepts of plasticity and motor learning are required to support rehabilitation programmes: “Effective modern concepts of motor learning and recovery are developed with the aim of inducing skill-acquisition relevant to the patient daily life” (1, p. 18). It is argued that such an approach is beneficial, preventing “learned non-use phenomenon” and avoiding “mal-adaptation”. Although “motor learning” is presented as a basic principle of PRM, the WB does not specify how rehabilitation professionals can bring such motor learning principles into practice. That is why we searched for answers in other rehabilitation texts dealing with “learned non-use” and “mal-adaptation”.

“Learned non-use” is a phenomenon that is widely referred to in relation to stroke rehabilitation (28). Patients with stroke-induced hemiplegia can choose a variety of treatments to prevent “learned non-use” of their affected side, such as “constrained induced movement therapy” (20) and “task- and context-specific training” (21). “Avoidance” and “maladaptation” are frequently used terms in chronic pain rehabilitation. The consequences of long-lasting pain are thereby described in terms of “avoidance behaviour” and “maladaptive cognitions”, resulting in decreased activity levels. A diverse range of cognitive behavioural treatments is delivered, all of which aim to increase patients' physical activity level despite the pain, e.g. “graded activity” (19) “exposure *in vivo*” (26) and “cognitive treatment of illness perceptions” (28).

Social learning principles and practices

Teaching and learning are also important ingredients of SME. However, self-management is more about “social learning”, as expressed in Bandura's social cognitive theory (44). Bandura (44) asserted that most human behaviour is learned observationally by modelling. By observing others one forms an idea of how a new behaviour is performed, and on later occasions this coded behaviour serves as a guide for action (44). Inspired by Bandura's social cognitive theory, Lorig & Holman (38) considered

“self-efficacy” as a hallmark of SME: “the teaching processes must be structured to include the four ingredients of efficacy enhancement: performance mastery; modelling; interpretation of symptoms; and social persuasion” (38, p. 4). Self-efficacy was defined as the individual’s personal confidence beliefs about his or her capacity to undertake behaviour that may lead to desired outcomes such as improved health (40, 41). Watching people similar to oneself succeed through sustained effort may strengthen patients’ belief in their own capabilities.

“Problem-solving” is considered to be a core self-management skill. However, “this does not mean that people are taught solutions to their problems. Rather they are taught basic problem-solving skills” (38, p. 2). In Lorig’s self-management programmes the problem-solving steps are: “problem definition, generation of possible solutions including the solicitation of suggestions from friends and healthcare professionals, solution implementation, and evaluation of results” (38, p. 2). These resemble the problem-solving skills that D’Zurilla developed for patients with depression (46).

Reflection

Both PRM- and SME-texts discuss learning principles and teaching skills. The focus of PRM is, however, on motor learning, neural plasticity and functional recovery, while the emphasis in SME is on social learning, problem-solving and self-efficacy. PRM-specialists attempt to prevent learned non-use and mal-adaptation with the help of a great variety of physical and cognitive behavioural treatments, while SME-teachers attempt to strengthen patients’ self-efficacy by teaching them to apply basic problem-solving skills in managing life goals.

DISCUSSION

The aim of this paper was to contribute to the WB discussion by means of comparative analysis of rehabilitation- and self-management texts. The different contents of the texts were approached as having a vocabulary of their own, each ordering a characteristic set of problems, principles and practices expressed under certain material conditions. In doing so, we dissociated ourselves from the idea that in order to clarify the relationship between both knowledge practices we should give key terms a clear meaning in advance. Despite the restricted number of texts scrutinized, this comparative analytical style was a fruitful way of tracing similarities and differences between the two knowledge practices.

At first glance there was much common ground. Both PRM and SME were based on the premise that people with disabling or chronic conditions should be offered the opportunity to be able to function at the maximum of their potential. The idea of offering tools to develop to full potential stems from a shared discontent with the healthcare system at the time that both approaches originated. Both were responses to the limitations of traditional medicine, which focused on curing single diseases, thereby neglecting the disabling and long-lasting consequences of a multitude of conditions that were not yet fully curable. Closer examination of the language, however, made it apparent

that PRM and SME use different wordings that are entwined with different material and organizational environments (see Table I). This helped us to discover the different logics at work and gave words to silenced issues in the WB.

A first issue that deserves to be attended to is the difference in illness trajectories between a sudden transition from an able to a disabled person after a disease with an acute onset (such as in stroke rehabilitation) and the indefinite and often unpredictable physiological course of a chronic disease (such as in pulmonary or diabetes rehabilitation). Although PRM is presented in the WB as a holistic approach to patients with acute and chronic conditions, it is still predominantly articulated in recovery-oriented terms (see first column Table I). It thereby silences issues that are important for people who have to deal with the waxing and waning of chronic conditions.

A second issue has to do with the different material and social set-up (see second column Table I) of a clinical and a community rehabilitation setting. Although present-day rehabilitation attempts to strengthen community-based rehabilitation, the transition from the clinical to the community setting after discharge is still experienced as difficult (47, 48). The introduction of peer leaders in clinical as well as community settings, who teach patients basic problem-solving skills, is an intervention that may assist PRM in equipping patients to cope more confidently with the transition after discharge.

A third issue concerns the importance of distinguishing treatment goals from life goals (23). Within PRM, a multi-professional team sets “treatment goals” with the patient and their proxies in order to streamline the functional recovery process. In SME, a peer leader facilitates the self-efficacy of patients in setting “life goals” to enhance a meaningful life. There is little doubt that patients need both sets of goals in order to grow to full potential. Nevertheless, treatment and life goals can be at odds with one another. To promote functional recovery, rehabilitation professionals, as experts of the disabling medical conditions, may make patients as independent as possible of others in all activities of daily living. This, however, reveals little about the extent to which patients, as experts of their lives, experience such independent living as meaningful in real life. For instance, if getting dressed in the morning exhausts a patient’s energy for the day, it may be desirable for him/her to accept the assistance of caregivers in order to save energy for going to work (49).

Table I. *The differences in language used in the two discourses*

Physical and rehabilitation medicine discourse	Self-management education discourse
Disabling conditions	Unpredictable course of illness
Diseases and injuries with acute onset	Chronic diseases
Impairments	Emotional distress
Physical limitations	Psychological skills
Functional recovery	Self-efficacy
Hospital setting	Community setting
Multi-disciplinary team	Lay person/successful peers
Treatment goals	Life goals
Motor learning	Social learning
Neural plasticity	Problem-solving, modelling

This brings us to a fourth issue: the lack of attention on social theory in PRM. The historical text revealed that rehabilitation discourse has always had a bio-psycho-social line of thought. Nevertheless, analysis of the WB and related texts showed that PRM is more about motor learning and cognitive behavioural principles than about social ones. Bandura's social cognitive learning theory was revealed as an issue that was not covered in the WB discussion. Why not profit from other social learning theories too? Social theory is about individuals, groups and organizations that reflect on the values, assumptions, policy that drive their actions and their efforts to change them. Thus, there is much to learn from social studies, particularly when the aim of PRM is to bring rehabilitation closer to real-life settings.

PRM and SME can thus mutually benefit, as can be illustrated by the analogy of a relay race in which professionals and patients pass the baton from one to the other. Both have to know when to grasp the baton and when to pass it on. The "responsibility" for, or "expertise" in, the condition can shift back and forth between patients and rehabilitation professionals depending on the status of a patient's disabling or chronic condition. When the condition is beyond the control of the patient – beyond self-management – rehabilitation professionals step in and provide the required expertise. The moment the disease or condition is regulated again, the patient, as self-manager, takes over. Coaching patients to carry the baton skilfully and with the necessary self-efficacy may give self-management a considered place in the rehabilitation process. Therefore patients also need to be taught to rely on the expertise of professionals when the responsibility of carrying the baton becomes too demanding.

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