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Rethinking recovery

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Abstract

In this chapter, we explore recovery as knowledge and practices. In health sciences, clinical practice and public debates, the understanding of recovery relates to various interpretations of disease, illness and health. Our analytical perspective is inspired by theories of knowledge production; in particular, Jasanoff's work on co-production of knowledge. In the present chapter, we unpack two ideal-typical understandings of recovery. According to the first understanding, recovery is disease-oriented and relates to the treatment's curative effects (recovery as outcome), and knowledge production is separated from the persons and situations involved. The second, meanwhile, sees recovery in terms of a personal experiential process focusing on illness experience and the process of overcoming or coming to terms with illness in real-life situations (recovery as experience). Here, knowledge production integrates persons, contexts and culture.

Recovery as outcome concerns health professionals' responsibility to choose the most effective treatment for patients, informed by quantitative effect studies. Recovery as experience embraces the process undertaken and valued by the individual person in the act of living that can be informed by qualitative interview studies. In the third section, we elaborate on how these two understandings of recovery are integrated into contemporary clinical practice (recovery as co-production).

Keywords: Recovery, outcome, personal experiences, co-production, knowledge production, clinical practice

Introduction

The term 'recovery' frequently occurs in medical and in public settings. For example, in medical care, people can recover from a disease, such as bronchitis or cancer, and are said to be in recovery when they learn how to cope with symptoms and manage practical everyday tasks despite limitations set by chronic illness. While laypeople often say they have recovered from a cold, mental illness or cancer, drug addicts will describe themselves as being in recovery when they become sober or abstinent. Recovery may encompass becoming better or being cured, returning or arriving at a healthy state or life as it used to be, regaining something that was lost, or recreating a meaningful or well life.

Inspired by Jacobson (2004), we refer to different meanings and uses of the term recovery. These include *recovery as outcome* (evidence), which was first used in mental hospital services in the mid-nineteenth century, and *recovery as experience* (personal healing process), an understanding that was constituted as a response to the former by the voices of mental health survivors and ex-patients during the 1930s. In addition, *recovery as co-production* covers the new public emphasis on partnerships as well as people's accountability for their own health and the reduction of health costs (Jasanoff 2004, Jacobson 2004). In the sociology of science, the concept 'co-production of knowledge' is applied on a new combined approach, analysing the social structure and cultural meanings, integrating theory and practice, macro and micro, objects and subjects as well as historical and contemporary studies (Jasanoff, 2004). In our society today, in both mental and somatic health care systems and in research, political documents emphasize evidence-based practice and consumers' or users' expertise. In these contexts, recovery is an umbrella term with various interpretations and meanings.

A search of scientific databases, using the term recovery alone or in combination with health professions including physiotherapy, results in thousands of hits. Often, studies by health professionals refer to treatment outcomes in terms of their effectiveness in minimizing symptoms and disease-related limitations in functioning. Less frequently, studies address how people experience illness or, even less commonly, illuminate people's recovery experiences. However, since the 1980s, the disease-oriented quantitative studies on recovery outcome have been complemented by qualitative studies of ill people's experiences (Jacobson, 2004). We characterize the quantitative studies as disease-oriented, outcome-based research, defining recovery as a dimension of pathology or disease-related deficits and a real event represented by the nonappearance of certain disease indicators. On the other hand, the qualitative studies focus on personal experiential processes where recovery is constructed in the process of learning how to live a safe, dignified and self-determined life.

The disease-oriented recovery outcome is informed by evidence from quantitative studies aiming to produce knowledge that can be valid for groups of patients across contexts and cultures, and the qualitative and mixed studies consider recovery experiences as contextual and occurring in an interplay between individuals, their clinical treatment and their social surroundings. We refer to the first approaches as a disease-oriented recovery outcome and the second as a personal experiential recovery process. Our aim is to unpack these two applications of the term recovery, analysed as different ways of producing knowledge, first, in terms of curing disease and second, in the language of a person's process of overcoming or coming to terms with disruptions from illness. Third, we discuss how it is possible to critically integrate recovery as outcome and recovery as experience in professional health practices into what Jasanoff (2004) has referred to as co-production of knowledge.

Disease-oriented recovery outcome

Disease is the problem from the practitioner's perspective. In the narrow biological terms of the biomedical model, this means that disease is reconfigured only as an alteration in biological structure or functioning. (Kleinman, 1988, p. 5)

For centuries, physicians were committed to understanding people's suffering based on information from interviews of individuals and their own observations through gaze, smell and taste (Johannisson, 2004). Treatment was a product of the physician's skill at

interpreting what people told them, as well as the meanings of their conversations with patients and their own observations. But when the nature of disease and the idea of specific disease aetiology emerged, the physician's task became to translate what ill persons told them into a classification of symptoms to be used to further trace the cause of disease (Bury, 2005, Chap 1). Accordingly, the focus of medical practice shifted from subjective experiences to objective measures of pathology and from personalized and symptom-oriented logics to disease-oriented ones.

The disease-oriented perspective is based on a biomedical understanding wherein disease is defined in terms of deviance from statistical norms of organ functioning in healthy populations (Boorse, 1977). The deviances or signs of disease that are hidden inside the body become visible through technological measures, for example, radiological imaging and blood tests. The aim of treatment becomes to 'normalize' what is wrong by targeting abnormal organ structures and functioning with appropriate treatment. In order to make decisions concerning treatment or therapy, health professionals translate patients' illness experiences into symptoms, which in turn serve as clues to guide further testing for plausible diseases (Eriksen & Risør, 2014). In the International Classification of Diseases (ICD), clusters of typical symptoms and bodily malfunctioning create criteria for diagnosis, and if clinical findings match these criteria, a disease is named by a diagnostic label (Jutel, 2011). In other words, a person's perceptions and bodily changes are translated into nomenclature and disease taxonomy that constitutes an objective 'it' that exists beyond the particular patient (Kleinman, 1988). From this point, the disease becomes a real 'thing' that justifies a person's suffering and legitimizes a need for help (Lian, 2007). A similar logic can be found in physiotherapy, for example, in physiotherapists' attempts to develop a pathokinesiological classification system of limitations in physical functioning (Rose, 1988), as well as in the importance they place on arriving at a function diagnosis and connect treatment to this diagnosis (Rose, 1989; Sahrman, 1988).

What is similar should be treated similarly

At the beginning of the 1900s, medicine became enchanted by the idea that the nature of diseases could be discovered and their specific causes and treatment found, and the hunt for precision in diagnosis and treatment continues to this day (Cassell, 2004). According to this view, each disease is believed to have a particular cause that can be revealed by observing changes in inner organs' function and structure, and in turn, treatment should

target such disease-specific changes and normalize them to recover health. Physicians should act upon a particular disease with specific treatments, for example, a targeting drug should destroy bacteria that cause disease. During the last couple of decades, medical treatment has become even more specific by targeting specific disease mechanisms within a diagnostic category. For example, patients with prostate cancer receive various medical therapies specifically designed to target different pathological patterns. Thus, in some areas of medicine, personalized medicine has become an alternative. In this context, personalization means that each person's specific disease pathology within a diagnostic category should be acted on, and those with similar pathology should be treated similarly in order to become better or be cured.

The idea of classification and using targeted therapy to help patients recover their health can be traced to early in the history of physiotherapy. At the beginning of the 1800s, Per Henrik Ling, the founder of physiotherapy in Scandinavia, developed an exercise system tailored to promote healing of musculoskeletal pain (Haugen, 1997). This was carried further, for example, during the poliomyelitis epidemic in the 1950s, physiotherapists developed a method for assessing the strength of specific muscles (Kendall, 1983). The aim was to identify which muscles were affected by poliomyelitis and tailor specific exercises to revitalize the affected muscles. Treatment modalities have also been developed to normalize the functioning of other organs, for example, joint mobilization techniques aim to reduce stiffness in joints capsules (Kaltenborn, 2002). The idea that similar problems should be treated similarly can also be seen in the model of evidence-based practice (EBP), in which treatment recommendations are grouped according to diagnosis (Herbert et al., 2005).

Recovery as absence of disease, deficits or dysfunctions

Within biomedicine, health is defined as the absence of disease (Hofmann, 2001). Health and disease are understood as dichotomous phenomena, and recovery is usually understood as an endpoint or a treatment outcome where the disease is absent, and a cure is reached. Recovery results from either a natural biological healing process or an effective curative treatment. In addition to cures, recovery outcomes can also be expressed as partial recovery (less disease-related deficits and dysfunctions) or remission (normalized biology, but not the absence of disease).

In 1948, the World Health Organization (WHO) expanded the biomedical definition of health to include not merely absence of disease or infirmity, but also a state

of complete physical, mental and social well-being (Larson, 1996). Later, Engel (1977) argued that disease should be understood as complex, dynamic, interacting processes between biological, psychological and social phenomena. He coined the concept 'biopsychosocial' and expanded the biomedical understanding of disease (White, 2005). This was followed up by the WHO's (1980) introduction of a supplement to the biomedical classification of disease (the ICD), launching the International Classification of Impairments, Disabilities and Handicaps (ICIDH) which included a theoretical model describing that disease-related bodily impairments could lead to disabilities and handicaps, and secondly, a classification of multiple factors under the terms impairments, disabilities and handicaps. In the years that followed, the ICIDH was criticized, first for its biomedical understanding by indicating a causal chain from biological impairments to disability and handicap, and second for labelling people with impairment as disabled and handicapped.

The ICIDH was revised several times, leading to the present International Classification of Health and Functioning, ICF (WHO, 2001). The ICF model shows reciprocal interrelationships between body function (previously impairment) and personal limitations in functioning under activities and participation (previously disability and handicap). Accordingly, the ICF model now reflects a biopsychosocial understanding of disease, and it still includes a classification system. However, in contrast to the biomedical understanding of disease, the present ICF model of reciprocal interactions suggests that a person's health can be targeted in multiple ways. The ICF has been embraced within the field of rehabilitation, including among physiotherapists. In clinical practice and research, the ICF and the biopsychosocial model are presented as a more comprehensive and complex understanding of disease and health than the biomedical model. But the ICF can still be criticized for having an individualistic perspective and not taking into account social and political barriers to a person's health, functioning or well-being. Also, the ICF follows the biomedical principle of objectivity and value-neutrality. Thus, Hammel (2006) argues that the application of this classification tool does not have any benefit for the persons being objectified and coded; rather, classification systems are tools for health professionals. The use of classification tools, such as the ICF, is also criticized by Leplege et al. (2015) and by Gibson (2016).

Recovery determined by measured treatment outcomes

Recovery outcomes, in terms of treatment effects, are determined by evaluating the extent to which disease-related measures approximate statistically based or socially determined norms, as well as by the disappearance of symptoms. In physiotherapy, body function is assessed by measures such as aerobic capacity, muscle strength, and range of motion. Limitations in activities and participation are assessed by patient self-report questionnaires. Questionnaires can be generic instruments developed to assess what is normal in a general population, such as quality of life and presence at work. Alternatively, in physiotherapy research, disease-specific questionnaires are often used to assess the reduction of typical disease-related symptoms and limitations in daily functioning. In both cases, recovery is determined by external criteria for what is considered normal among healthy people or within a society. However, norms determined by statistics or social values of functioning do not always match what is important in the treatment of an individual patient. In particular occupational therapists and physiotherapists within the field of rehabilitation have expressed concerns that generic and disease-specific instruments do not capture the effects of therapies tailored to patients' specific activity problems. To address this, they have developed patient-specific instruments that allow clinicians, in collaboration with their patients, to specify the problem to be approached by treatment. The severity of a problem is assessed by scales, and recovery outcome is measured in terms of the amelioration of the problem. Accordingly, improvements are evaluated with respect to self-defined treatment goals and norms for success (Stevens et al., 2013; Stratford et al., 1995).

A personal experiential recovery process

Illness refers to how a sick person and the members of the family or wider social network perceive, live with, and respond to symptoms and disability experience [...] Illness is always culturally shaped. Paradoxical as it sounds, then, there are normal ways of being ill (ways that our society regards as appropriate) as well as anomalous ways. (Kleinman, 1988, pp. 3, 5)

A social movement promoting personal recovery

As a critical response to disease-oriented approaches, consumer communities in the 1930s showed how recovery was related to individuals' experiences of illness (Jacobson, 2004).

Anonymous Alcoholics (AA) is an early example of recovery as experience (Feiring, 2013), and Ralph and Corrigan (2005) consider these communities ‘historical backdrops’ to modern mental health services. In the 1970s and 1980s, people experiencing mental health problems started to oppose the focus within psychiatry on diagnosis, psychopathology and biological treatments and claimed that it was possible to achieve a life of personal value by focusing on personal experiences and resources. According to Roberts and Boardman (2013), the recovery movement in psychiatry arose as a product of critique, emerging from the writings of survivors and ex-patients.

During the 1980s and 1990s, a social movement also emerged among people with physical disabilities who objected to the ‘normalization’ of functioning within the field of rehabilitation and claimed their human right to participate in society alongside able-bodied people on equal terms (Oliver, 1990). For example, constructions of public transport and buildings excluded access for people with physical disabilities. Instead, a society accepting and adjusting to diversity among citizens was envisaged as a means to achieving a more inclusive society.

Jacobson (2004) associates recovery as experience with this type of social rights movement. Publicly driven campaigns challenged medical views on people with mental illnesses and physical disabilities, resulting in health reforms highlighting human rights and individuals’ possession of the expertise and resources necessary to live well despite illness or disability, as well as changes within health services, including the introduction of patient- or person-centred practice. Over the last couple of decades, a personal resource-oriented approach to recovery in mental health care has gradually gained ground with the aim of empowering individuals to take action and create a life worth living despite mental illness (Roberts & Wolfson, 2006).

Following Deegan (1997, 2003), who was diagnosed with schizophrenia during adolescence, it is possible for people to actively bring wellness into their lives, but a disease-oriented practice may hamper such a process. For example, Deegan (2003) was told by physicians that schizophrenia was chronic and non-responsive to treatment. This type of message, she argues, sentences patients to a life-long disease and leaves little hope for the future. Ralph and Corrigan (2005, Chap. 2) argue that hope is crucial to motivate personal recovery processes as a way of living, an attitude, and a way of approaching daily challenges. For a person in recovery, making life meaningful is a complex process that includes healing personally and socially by developing new ways of living, adopting new social roles, and rebuilding a life around changed priorities and a new sense of self

(Jacobson, 2004). A person in recovery engages in self-discovery, self-renewal and transformation (Ralph & Corrigan, 2005); being in recovery is a personal process that cannot be separated from life itself (Kleinman, 1988). This process involves learning and personal growth and lacks a definite endpoint; the subject is in constant change, with various transformations occurring over time.

Studies on personal recovery experiences

Scientific studies on personal accounts of recovery see illness as a subjective experience of how disease and its consequences are perceived (Bury, 2005; Nettleton, 2006). According to Bury (2005), health is a taken for granted form of wellness, which, paradoxically, is first detected through its absence. When a person is incapacitated by illness or disability, they can experience alienation from their own body, be removed from social roles and obligations, or lose connections to family, colleagues, and friends (Lupton, 2012). Personal recovery implies a process of discovering how to bring wellness back into life – in terms of either overcoming illness or reclaiming wellness despite illness (Davidson & Dinzeo, 2009).

Kleinman (1988) has long urged that health professionals and researchers must address not only symptoms and diseases but also the meaning of illness and the practical problems illness creates in a person's life. Since the 1990s, inspired by theories from the social, cultural and humanistic sciences based on interpretative logics, researchers have been increasingly interested in examining people's illness experiences and what they do to cope and self-manage. To explore recovery as a personal experience, based on qualitative empirical studies, we address the following themes: The meaning of wellness, developing self-knowledge, recovery as an ongoing process, and recovery identified in people's storytelling.

Wellness and meaning

The meaning of wellness is seen in relation to the concept of illness and what illness entails. In accordance with Lupton (2012, Chap. 4), several studies describe falling ill as a process whereby people either suddenly or gradually perceive changes in an otherwise 'silent body' or disturbances in the taken-for-granted performance of daily activities. Thus, illness separates a person from his or her own body and also disrupts ordinary daily routines, social relationships and roles (Njølstad et al., 2019). Changes in the social self (Charmaz, 1991) and disruption of a person's biography (Bury, 1982) can also occur,

particularly in long-term illnesses. The future may become uncertain, and according to Mattingly (2010, p.161), a person may 'lack a hopeful picture of her future self'. In this way, illness disturbs a person's lifeworld (Kleinman, 1988).

Studies of personal recovery illuminate how people replace illness with wellness by accepting and adapting to their changed situation, adjusting their life situation, and adopting alternative social roles while still living a meaningful life (Kearney, 1999). For example, people with schizophrenia, an incurable mental illness from a disease perspective, may feel recovered when they have secured a safe, meaningful social life (Ralph & Corrigan, 2005). Alternatively, for women who had previously suffered from fibromyalgia (a contested, medically incurable musculoskeletal illness), recovery or wellness meant being free from symptoms or having tolerable, manageable symptoms (Grape et al., 2015). These two examples illuminate that wellness can imply living well despite being ill and struggling, as well as overcoming an illness, and at the same time, including new meaning for life.

Kleinman (1988) argues that it is important for people to make sense of their symptoms and suffering, as well as to figure out how to manage the implications of their illness. This means that a type of self-knowledge is considered crucial to recovery. Ill people want answers to many questions, such as, 'What is causing my illness?', 'What does the illness do to my body?', 'What can I expect from treatment?', 'What can I do to manage the illness, its exacerbations and consequences?', and 'What can be expected in the future?' (Kleinman, 1988, p. 43). Many people with chronic illnesses strive to make sense of their illness experiences (Aronowitz, 1998). For example, women who had recovered from fibromyalgia reported that they made sense of their experiences through a mundane, daily exploration of the relationship between their symptoms and their way of living (Grape et al., 2017).

Developing personal expertise

According to Kearney (1999), a recovery trajectory includes learning to endure the altered situation and grieving over experienced losses, accepting the situation as it presently is, creating hope for a better future, reckoning one's own resources and the possibility of overcoming losses and making choices about how to adapt and adjust to a new situation. The process of learning how to come to terms with an illness is not linear, and it includes possible setbacks. However, relapses are not necessarily considered a failure but rather events from which a person can learn. Personal knowledge and engagement also include

the capacity to build relationships with other people and take part in meaningful activities that create a feeling of connectedness and social belonging (Halding et al., 2010) that may lead to new, valued social identities (Lau & van Niekerk, 2011). Thus, the personal recovery process includes expanding competence by developing practical skills, adjusting activities, identities and social roles, and creating new meaning and purpose in life.

People with chronic illnesses are often engaged in an ongoing recovery process to maintain what they have achieved and continue to adjust and adapt to their illness, which can fluctuate or progress. Arthritis, for example, often has a fluctuating course, and for people with arthritis, this means that in addition to reclaiming a life despite illness, they have to take action to prevent exacerbations (Tollefsrud & Mengshoel, 2019). A person diagnosed with ankylosing spondylitis portrayed this through the following allegory: Life with arthritis is like living in a spider's web; it is impossible to escape, but there are still many roads to follow to live well. But if strings in the web break, they have to be knit together, and this limits the space (Mengshoel, 2008).

The fluctuations of experiences illustrate that illness and wellness are coexisting rather than dichotomous phenomena, shifting positions between the fore- and background (Paterson et al., 2003). Hope serves as fuel for not giving up, motivating the ongoing recovery process and taking action, and the hope is nurtured by success and belief in further progress (Mengshoel et al., 2019). Accordingly, hope is not merely a feeling but an incorporated part of a recovery practice (Mattingly, 2010).

Noticing a personal recovery process

A person's recovery process is an integrated part of their daily life and can be identified in personal stories. Mattingly (1998, 2000) argues that ill persons' recovery narratives include moments that make a difference, turning points that display a break-through where new insight and activities make new recovery routes possible. Such narratives may portray a shift from withdrawal to active engagement, from loneliness to reconnection with others, from passive adaptation to active coping, from low self-esteem to a positive sense of self, or from alienation to a sense of meaning, purpose and belonging, as well as the awakening of hope.

Recovering is mirrored by moments or events but can also become evident through the storyline in a person's narrative (Squire et al., 2014). Storylines can be interpreted according to the narrative typologies developed by Frank (1995). A restitution narrative describes falling ill, getting a diagnosis, receiving appropriate treatment, and

being cured. In contrast, a chaos narrative is an illness storyline that portrays a lack of understanding of what is happening in which everyday life is chaotic, and there is no obvious prospect for the future. Such stories are often fragmented, broken, hesitant and difficult to listen to and understand (Bülow, 2008). A quest storyline, Frank claims, captures a personal recovery process in which a person trusts their own experiences, arrives at new insights and moments that affect the situation positively, and expresses hope for an optimistic future. Frank's typology thus shows that storylines, like the personal recovery process, display complex interactions between impairment, illness, experience, contexts and culture.

Co-production of recovery

As discussed by Arthur Kleinman et al. (1997), we need to think of suffering as social and not merely personal [...] because health problems are intertwined with political, economic, and institutional conditions, with the way power is structured and wielded. (Mattingly, 2010, p. 41)

Standardization and differentiation in clinical practice

Nowotny et al. (2001) characterize knowledge production based on a 'cool' rational logic which is technically rather than culturally determined. This corresponds to knowledge production in a disease-oriented recovery outcome perspective that aims to *explain reality*, and it is essential to operationalize and classify deviances, 'normalize' them through treatment, and evaluate whether treatment produced successful outcomes. This orthodoxy is seen in clinical practices following classification schemes, standardized tools and treatments. Thus, clinical practice is determined by, what Rose (2006) calls political technologies, in forms of protocols, EBP guidelines and standardized reporting tools, which separate professionals and ill persons from their treatment and healing practices.

Ill persons criticize disease and deficit-oriented practice for depersonalizing them by reducing them to a disease or failure (Deegan, 2003) or reducing their illness experiences into scores on questionnaires (Gibson et al., 2019). Physiotherapists can devalue a person's illness experiences by asking closed, factual questions when taking patient histories (Ahlsen et al., 2019) or by stereotyping the delivery of physiotherapy according to 'cookbook recipes' (Mengshoel et al., 2019). Studies show that ill persons wish to be at the centre of physiotherapists' concern, preferring the latter to shift their

focus away from techniques to providing information they find meaningful (Wijma et al., 2017). To reduce depersonalization in clinical practice, policy documents, as well as users of health services and health professionals have spoken of person-centred practice that is characterized by clinicians' valuing the autonomy of ill persons and treating people in a respectful way, as well as meeting individuals' particular needs (Gluyas, 2015; Sacristan, 2013). We argue that human rights-based, person-centred practice demands a non-standardized, differentiated clinical approach that has the potential to enhance more than human rights by backing a person's healing practice. However, attending to individuals' needs, personal experiences and wishes are not straightforward, and complex negotiations between the persons involved and what is possible in a particular context may take place (Gibson et al. (2019). We will, however, argue that knowledge production of personal and socio-cultural issues, aligning with a personal experiential recovery process, is helpful for *understanding* what is at stake for an ill person.

Disease-oriented recovery practice is concerned with the effectiveness of a treatment to 'repair' disease-related deviances or deficits. Patients are victimized by injury or disease, and physiotherapists have been trained to act on disease- or injury-induced changes and are responsible for providing the best available treatment. For example, in cases of ankle sprain, physiotherapists follow a certain procedure in the acute phase, cooling down the bleeding tissues, elevating the leg to reduce oedema, and afterwards gradually introducing specific exercises to restore range of motion and muscle control with the goal of re-establishing former functioning. This type of storyline corresponds well with Frank's (1995) restitution narrative typology and a traditional disease-oriented recovery orthodoxy. Likewise, in lung physiotherapy, procedures are followed to remove mucus from the lungs to improve lung malfunctioning, and both the ill person and the physiotherapist notice an immediate improvement in respiration if the treatment works. These examples illustrate how physiotherapists act on knowledge about the body's biological mechanisms and follow a standardized, 'one-size-fits-all' physiotherapy procedure. Thus, in these examples, a view of recovery focusing on objective and predictable knowledge is applicable.

Contemporary societies worldwide face great concerns and costs related to chronic diseases, illnesses and disabilities without any known curative or restorative treatment. In such cases, recovery cannot be limited to disease parts and specific functional impairments but should involve the whole person and her or his life project (Cassel, 2004). A personal recovery process differs from protocol-based 'one-size-fits-

all' education defined by professionals teaching ill people how to 'live with their illness', for example in the form of self-management, lifestyle or standardized conditioning training programmes. Living with a chronic condition is more complex and intruding than fixed by practising defined techniques as being ill is fundamentally a social state of affairs. An individualized and differentiated clinical approach is needed, tailored to each person's strengths and opportunities to find a way to come to terms with illness and remake a meaningful life. Such practice calls for information from a scientific knowledge production that is particular, contextual and situational (Nowotny et al., 2003) and aligned to an interpretive epistemology. Following one of Nicholls' (2018) positions for future education in physiotherapy, we argue for a critical integration of biomedical, psychological, socio-cultural, lay and political knowledge in the curricula of health professions.

Nicholls and Gibson (2010) have argued that an expanded understanding of the body beyond biological deficits is needed. The personal experiential recovery process includes reconnecting with the alienated body. Lupton (2012, Chap. 2) describes the body along two dimensions, as a body-organ object (aligning with disease-oriented recovery) and as a body-self subject (relevant to personal experiential recovery). Accordingly, a body constitutes a duality of being and having (Crossley, 2006). The mind-body dualism can be overridden through understanding the body as a site of disease, embodied life experiences and a sense of social self (Lupton, 2012). By discovering the relationship between movements, activities and daily life, it is possible to make sense of own experiences and reconnect with one's own body and life, as well as to draw new road maps, both for a person's life and for a physiotherapist's understanding. During such an adventurous, often laborious, journey towards a life worth living, a physiotherapist may inhabit the role of co-adventurer and supporter.

In sum, we will argue that disease-oriented and experiential recovery operate in conjunction with each other; the disease-oriented recovery perspective will be privileged for acute or short-term conditions with specific, well-defined problems, where standardized treatment protocols are more likely to work. In contrast, with respect to incurable, long-term conditions that people live with, the personal experiential recovery process will probably take precedence and offer a differentiated treatment approach to meet the complexity of healing a person's suffering or recovery as co-production. Further, supporting a personal experiential recovery process is promoted in the recommended policies of person-centredness, user involvement, self-care and self-management.

However, we worry that the personalization may be veiled by new upcoming technologies aimed to secure human rights through a homogeneous, standardized practice.

Predictability and uncertainty in clinical practice

In the final section, we will explore the interaction of the different understandings of recovery and their positions within evidence-based practice (EBP), first in relation to the hierarchical ordering of evidence and then in relation to the logic underpinning EBP.

Originally, the purpose of EBP was to fill a gap between research and clinical practice, thereby reducing clinical malpractice. Today, a kind of ‘industry’ has been established in order to synthesize randomized controlled trial (RCT) studies to conclude which treatments are on average the most effective (Greenhalgh, 2014). This research has been translated into evidence-based clinical guidelines by expert panels and based on meta-analysis of effect studies explicit statements are provided to assist practitioners and patients in making decisions about treatment (Scalzitti et al., 2001, Feiring et al., 2019). We argue that results from meta-analysis cannot dictate professionals what to do in particular cases, but meta-analysis informs clinicians about what the research has to say about effects of interventions.

Research evidence is *hierarchically ordered* according to its design with the meta-analysis of RCTs at the top; this research aims at unbiased measured effects of standardized treatment by controlling for the influences from persons and context to arrive at generalizable results. The hierarchical order of evidence places knowledge production of particular, contextual, and situational experiences at the bottom of the hierarchy, and sometimes they are excluded entirely. Following our earlier argument that both disease-oriented and personal experiential recovery are likely to operate together, disease-oriented treatment may be more successful in clinical practice if a person finds a treatment meaningful. But according to our argument that standardized treatment is not likely to address the complexity of chronic or long-term conditions, we question whether RCTs can actually tell which treatment is the best. Thus, treatment solutions cannot merely be tied to evidence from RCTs but must be related to a bricolage of various types of knowledge (Shaw & DeForge, 2012).

We argue that disease-oriented recovery practice has a hegemonic position in our society, including in physiotherapy. For example, physiotherapists in clinical practice may ask for appropriate ‘tools’ developed for research purposes to structure their practice of taking patient histories and for evaluating the outcomes of their practice. As we see it,

this is a way to position and legitimize physiotherapy practice within a hegemonic knowledge system in our society. The standardization of practice follows the rational logic illuminating an ordered form of practice that produces predictable results. However, clinical practices are highly social and better understood by interpretative logic. Since clinical practice embraces relationships between people and particularities embedded in clinical meetings, as well as institutional and political contexts (recovery as co-production), practice is social, unstable and uncertain and may disrupt the stability and predictability of rational logic. Ignoring this may downplay the uniqueness embedded in clinical practice, for example, the healing roles of therapeutic alliances and personal communication as shown by Hall et al. (2010).

Paradoxically, placebo studies within a disease-oriented paradigm have shown that disease measures are influenced by a person's thoughts, attitudes, beliefs, expectations and social relationships (Mestre & Lang, 2017), and thus that the healing power of people's experiences and relationships cannot be ignored. Brun-Cottan et al. (2018) argue that some essential components of physiotherapy practice remain a personal tacit 'art'. This artistry should be given a language and incorporated into the body of physiotherapy knowledge. In sum, we argue that treating people in a clinical practice context is an experiential, political, complex, uncertain, and often diffuse endeavour of co-production. It is certainly understandable that people are searching for concretization and predictability. However, in so doing, tensions and ambiguities are likely to occur and need to be understood and managed to create person-centred clinical practice.

Concluding remarks

In this chapter, we first outlined how two ideal-typical understandings of recovery – recovery as outcome and recovery as experience – have merged into a third type, namely recovery as co-production, promoting both person-centred and evidence-based practice. Disease-oriented recovery builds on a rational, explanatory logic wherein classifications, standardizations, EBP, 'repairing' disease-related deficits are essential, and recovery outcomes provide measured evidence of effective treatment. On the other hand, a personal recovery process is based on meaning, embracing complexity, diversity, individuality and humanism, and recovery is seen as a personal healing process relying on an interpretative logic to understand phenomena. Today these two understandings of recovery operate in conjunction, but orthodox physiotherapy approaches have primarily focused on the former while the latter, heterodox practices seem to be regarded as a kind of personal,

tacit knowledge of the ‘art’ of physiotherapy. We have outlined how health professions, exemplified by physiotherapy, produce different types of knowledge, and we call for a critically reflected integration of the disease-orientated approaches to recovery with the personal, social and cultural approaches to recovery. We argue that person-centredness and evidence-based practices are drawing on different understandings of the term ‘recovery’. We call for a critical rethink of recovery in clinical practice, educational curricula and political documents, which we have called co-production of recovery.

References

- Ahlsen, B., Engebretsen, E., Nicholls, D., & Mengshoel, A. M. (2019). The singular patient in patient-centred care: Physiotherapists’ accounts of treatment of patients with chronic muscle pain. *Medical Humanities*. doi:10.1136/medhum-2018-011603
- Ahlsen, B., Mengshoel, A. M., Bondevik, H., & Engebretsen, E. (2018). Physiotherapists as detectives: Investigating clues and plots in the clinical encounter. *Medical Humanities*, 44(1), 40-45.
- Aronowitz, R. A. (1998). *Making sense of illness: Science, society, and disease*. Cambridge: Cambridge University Press.
- Boorse, C. (1977). Health as a theoretical concept. *Philosophy of Science*, 44, 542-573.
- Brun-Cottan, N., McMillian, D., & Hastings, J. (2018). Defending the art of physical therapy: Expanding inquiry and crafting culture in support of therapeutic alliance. *Physiotherapy Theory and Practice*, 1. doi:10.1080/09593985.2018.1492656
- Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of Health and Illness*, 4(2), 167-182.
- Bury, M. (2005). *Health and illness* (1 ed.). Cambridge: Polity Press.
- Bülow, P. (2008). "You have to ask a little": Troublesome storytelling about contested illness. In L.-C. Hydén & J. Brockmeier (Eds.), *Health, illness and culture. Broken narratives*. (131-153). NY: Routledge.
- Cassell, E. J. (2004). *The nature of suffering* (2 ed.): Oxford University Press.
- Charmaz, K. (1991). *Good days, bad days: The self in chronic illness and time*. New Brunswick, N.J: Rutgers University Press.
- Crossley, N. (2006). *Reflexive embodiment in contemporary society*. Maidenhead: Open University Press.
- Davidson, L., Drake, R., Schmutte, T., Dinzeo, T., & Andres-Hyman, R. (2009). Oil and water or oil and vinegar? Evidence-based medicine meets recovery. *Community Mental Health Journal*, 45(5), 323-332.
- Deegan, P. (1997). Recovery as a journey of the heart. In L. Spaniol, C. Gagne, & M. Koehler (Eds.), *Psychological and social aspects of psychiatric disability*. (pp. 74-83). Boston: Boston University.
- Deegan, P. (2003). Recovering our sense of value after being labeled. In L. Spaniol, C. Gagne, & M. Koehler (Eds.), *Psychological and social aspects of psychiatric disability*. (pp. 370-376). Boston: Boston University.
- Engel, G. L. (1977). The need for a new medical model: A challenge for biomedicine. *Science*, 196, 129-136.

- Eriksen, T. E., & Risor, M. B. (2014). What is called symptom? *Medicine, Health Care & Philosophy*, 17(1), 89-102.
- Feiring, M. (2013). Politicisation of self-help in Norway. In: Nicolaou-Smokoviti, L., Sünker, H, Rozanova, J., & Pekka Economou, V. (Eds.), *Citizenship and Social Development. Citizen Participation and Community Involvement in Social Welfare and Social Policy*. pp. 207-220, Frankfurt am Main: Peter Lang Publishing Group.
- Feiring, M., Bonfils, I.S. (2019). The redesigning of neurorehabilitation in Denmark and Norway. In: Harsløf, I., Poulsen, I., Larsen, K. (Eds.). *New dynamics of disability and rehabilitation: Interdisciplinary perspectives*. Chapter 5. Palgrave Macmillan.
- Frank, A. F. (1995). *The wounded storyteller. Body, illness, and ethics*. Chicago: The University Press of Chicago Press.
- Gibson, B. E. (2016). *Rehabilitation: A post-critical approach*: Boca Raton: CRC Press, Taylor & Francis Group.
- Gibson, B. E., Terry, G., Setchell, J., Bright, F. A. S., Cummins, C., & Kayes, N. M. (2019). The micro-politics of caring: Tinkering with person-centered rehabilitation. *Disability and Rehabilitation*, 1-10.
doi:10.1080/09638288.2019.1587793
- Gluyas, H. (2015). Patient-centred care: Improving healthcare outcomes. *Nursing Standard*, 30(4), 50-57.
- Grape, H. E., Solbrække, K. N., Kirkevold, M., & Mengshoel, A. M. (2015). Staying healthy from fibromyalgia is ongoing hard work. *Qualitative Health Research*, 25(5), 679-688.
- Grape, H. E., Solbrække, K. N., Kirkevold, M., & Mengshoel, A. M. (2017). Tiredness and fatigue during processes of illness and recovery: A qualitative study of women recovered from fibromyalgia syndrome. *Physiotherapy Theory and Practice*, 33(1), 31-40.
- Greenhalgh, T. (2014). Evidence based medicine: A movement in crisis? *British Medical Journal*, 348.
- Halding, A. G., Wahl, A., & Heggdal, K. (2010). 'Belonging'. Patients' experiences of social relationships during pulmonary rehabilitation. *Disability and Rehabilitation*, 32(15), 1272-1280.
- Hall, A. M., Ferreira, P. H., Maher, C. G., Latimer, J., & Ferreira, M. L. (2010). The influence of the therapist-patient relationship on treatment outcome in physical rehabilitation: A systematic review. *Physical Therapy*, 90(8), 1099-1110.
- Hammell, K. W. (2006). *Perspectives on disability and rehabilitation: contesting assumptions. Challenging practice*. Edinburgh: Churchill Livingstone/Elsevier.
- Haugen, K. H. (1997). *En utdanning i bevegelse - 100 år med fysioterapiutdanning i Norge*. (An education in motion – 100 years of physiotherapy education in Norway). Oslo: Universitetsforlaget.
- Herbert, R., Jamtvedt, G., Mead, J., & Hagen, K. B. (2005). *Practical evidence-based physiotherapy*. Edinburgh: Elsevier.
- Hofmann, B. (2001). Complexity of the concept of disease as shown through theoretical frameworks. *Theoretical Medicine*, 22, 211-236.
- Jacobson, N. (2004). *In recovery: The making of mental health policy*. Nashville, Tenn, London: Vanderbilt University Press.
- Jasanoff, S. (2004). States of knowledge: the co-production of science and social order. London: Routledge.

- Johannisson, K. (2004). *Tecknen: Läkaren och konsten att läsa kroppar (Signs: The physician and the art of interpreting bodies)*. Stockholm: Norstedt.
- Jutel, A. (2011). *Putting a name to it: diagnosis in contemporary society*. Baltimore: John Hopkins University Press.
- Kaltenborn, F. (2003). *Manual mobilization of the joints. The Kaltenborn method of joint. Examination and treatment. The spine.* (4 ed. Vol. 2). Oslo: Nordli.
- Kearney, M. H. (1999). *Understanding women's recovery from illness and trauma*. Thousand Oaks: Sage Publications.
- Kendall, F. P. (1983). *Muscles: Testing and function* (3rd ed. ed.). Baltimore: Williams & Wilkins.
- Kleinman, A. (1988). *The illness narratives*. Cambridge, Massachusetts: Basic Book.
- Larson, J. S. (1996). The World Health Organization's definition of health: Social versus spiritual health. *Social Indicators Research*, 38(2), 181-192.
- Lau, U., & van Niekerk, A. (2011). Restorying the self: An exploration of young burn survivors' narratives of resilience. *Qualitative Health Research*, 21(9), 1165-1181.
- Leplège, A., Barral, C., & McPherson, K. (2015). *Conceptualising disability to inform rehabilitation: Historical and epistemological perspectives*. In K. McPherson, B. E. Gibson, & A. Leplège (Eds.), *Rethinking rehabilitation: Theory and practice*. Chap. 2. Boca Raton: CRC Press Taylor & Francis group.
- Lian, O. S. (2007). *Når helse blir en vare: Medikalisering og markedsorientering i helsetjenesten (When health becomes a commodity: medicalization and market orientation in health services* (2. utg. ed.). Kristiansand: Høyskoleforlaget.
- Lupton, D. (2012). *Medicine as culture. Illness, disease and the body.* (3 ed.). London: Sage.
- Mattingly, C. (2010). *The Paradox of hope: Journeys through a clinical borderland*. Berkeley: University of California Press.
- Mattingly, C. (1998). *Healing dramas and clinical plots. The narrative structure of experience*. Cambridge: Cambridge University Press.
- Mattingly, C., & Garro, L. C. (2000). *Narrative and the cultural construction of illness and healing*. Berkeley, Calif: University of California Press.
- Mengshoel, A. (2008). Living with a fluctuating illness of ankylosing spondylitis: A qualitative study. *Arthritis Rheumatism (Arthritis Care and Research)*., 59(10), 1439-1444.
- Mengshoel, A. M., BJORBAECKMO, W. S., SALLINEN, M., & WAHL, A. K. (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*, 1-11. doi:10.1080/09593985.2019.1616343
- Mestre, T., & Lang, A. (2017). Placebos in clinical trials: Unravelling a complex phenomenon. *The Lancet Neurology*, 16(1), 28-29.
- Nettleton, S. (2006). *The sociology of health and illness*. (2 ed.). Malden: Policy Press.
- Nicholls, D. A., & Gibson, B. E. (2010). The body and physiotherapy. *Physiotherapy Theory and Practice*, 26(8), 497-509.
- Nicholls, D. A. (2018). Aged care as a bellwether of future physiotherapy. *Physiotherapy Theory and Practice*, 1-13. doi:10.1080/09593985.2018.1513105
- Nicholls, D. A. (2018). *The end of physiotherapy*. Abingdon, Oxon, New York, NY: Routledge.
- Njølstad, B. W., Mengshoel, A. M., & Sveen, U. (2019). 'It's like being a slave to your own body in a way': A qualitative study of adolescents with chronic fatigue syndrome. *Scandinavian Journal of Occupational Therapy*, 26(7), 505-5014.

- Nowotny, H., Scott, P., & Gibbons, M. (2001). *Re-thinking science. Knowledge and the public in an age of uncertainty*. Cambridge: Polity Press.
- Nowotny, H., Scott, P., & Gibbons, M. (2003). Introduction: 'Mode 2' revisited: The new production of knowledge. *A Review of Science, Learning and Policy*, 41(3), 179-194.
- Oliver, M. (1990). *The politics of disablement*. Basingstoke: Macmillan.
- Paterson, B. L. (2003). The koala has claws: Applications of the shifting perspectives model in research of chronic illness. *Qualitative Health Research*, 13(7), 987-994.
- Ralph, R. O., & Corrigan, P. W. (2005). *Recovery in mental illness: Broadening our understanding of wellness*. Washington, D.C: American Psychological Association.
- Roberts, G., & Boardman, J. (2013). Understanding recovery. *Advances in Psychiatric Treatment*, 19(6), 400-409.
- Roberts, G., & Wolfson, P. (2006). New directions in rehabilitation: Learning from the recovery movement. In G. Roberts, M. Davenport, F. Holloway, & T. Tattan (Eds.), *Enabling recovery: The principles and practice of rehabilitation psychiatry*. (1 ed., pp. 18-37). Trowbridge: Gaskell.
- Rose, S. J. (1988). Description and classification. The cornerstone of pathokinesiologial research. *Physical Therapy*, 66(3), 379-386.
- Rose, S. J. (1989). Physical therapy diagnosis: Role and function. *Physical Therapy*, 69(7), 535-537.
- Rose, N. (2006). Governing "advanced" liberal democracies. In A. Sharma & A. Gupta (Eds.), *The anthropology of the state: A reader* (pp. 19). Malden, Mass.: Blackwell.
- Sacristan, J. A. (2013). Patient-centred medicine and patient-oriented research: Improving health outcomes for individual patients. *BMC Medical Informatics and Decision Making*, 13, 6.
- Sahrman, S. A. (1988). Diagnosis by the physical therapist - a prerequisite for treatment: a special communication. *Physical Therapy*, 68, 1703-1706.
- Scalzitti, D. A. (2001). Evidence-based guidelines: Application to clinical practice. *Physical Therapy*, 81(10), 1622-1628.
- Shaw, A., & DeForge, R. T. (2012). Physiotherapy as bricolage: Theoretizing expert practice. *Physiotherapy Theory and Practice*, 28(6), 420-427.
- Squire, C., Davis, M., Esin, C., Andrews, M., Harrison, B., Hydén, L.-C., & Hydén, M. (2014). *What is narrative research?* London: Bloomsbury Academic.
- Stevens, A., Beurskens, A., & Köke, A. (2013). The use of patient-specific measurement instruments in the process of goal-setting: A systematic review of available instruments and their feasibility. *Clinical Rehabilitation*, 27(11), 1005-1019.
- Stratford, P. W., Gill, C., Westaway, M., & Binkley, J. M. (1995). Assessing disability and change on individual patients: A report of a patient-specific measure. *Physiotherapy Canada*, 47, 258-263.
- Tollefsrud, I., & Mengshoel, A. M. (2019). A fragile normality - illness experiences of working-age individuals with osteoarthritis in knees or hips. *Disability and Rehabilitation*, 1-7. doi:10.1080/09638288.2019.1573930
- White, P. (2005). *Biopsychosocial medicine - an integrated approach to understanding illness*. Oxford: Oxford University Press.
- World Health Organization (1980). *International classification of impairments, disabilities, and handicaps*. Geneva.

World Health Organization *The International Classification of functioning, disability and health (ICF)*. (2001). Genova.

Wijma, A. J., Bletterman, A. N., Clark, J. R., Vervoort, S., Beetsma, A., Keizer, D., Van Wilgen, C. P. (2017). Patient-centeredness in physiotherapy: What does it entail? A systematic review of qualitative studies. *Physiotherapy Theory and Practice*, 33(11), 825-840.