Cognitive treatment of illness perceptions
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CHAPTER 1

Introduction
As a young Dutch physiotherapist I worked in a rehabilitation centre in Germany. I was impressed by therapists’ passionate application of specific treatments. Helping patients to master essential skills like walking, getting dressed or doing the shopping was very satisfying for me. I did not feel the same degree of desire in mastering a specific treatment approach or in becoming a dedicated follower of certain treatment developers. This kept bothering me. I asked my colleagues why these techniques were used and what made them more effective than others. The answers were unsatisfactory. Over time my desire to know more about rehabilitation treatment and its background proved to be stronger than the desire to become a master in applying them. Consequently, I returned to the Netherlands to study Human Movement Science in Groningen.

Studying Human Movement Science I discovered why it was hard for my colleagues to answer my questions on the background of treatments: many rehabilitation treatments have gradually grown and developed, often incorporating new ideas in quite implicit ways. Treatments have branched out in new derivative forms without settling the arguments with its predecessors. This seemed one of the reasons why this so-called tacit knowledge was difficult to articulate for insiders. However, not only therapists but also researchers had difficulties in specifying content and assumed working mechanism, when they were called in to investigate which treatment produced the best effect. This caused them to produce misleading conclusions. Indeed, when researchers have little knowledge of similarities and differences in the treatments they aim to compare, they run the risk of comparing apples and oranges.

In the methodology classes I was disappointed by the strict quantitative procedures that seemed perfect for answering some questions, but did not seem to accommodate the more clinical questions. Questions such as ‘why, for whom, and under what circumstances treatments are effective’ could not be answered satisfactorily. Moreover, the requirement of highly controlled research environments did not match my experience of clinical settings. Most researchers appeared to behave in a similar manner to the clinicians I had met, like the dedicated followers of a specific method(ology). However, in the more senior years of education theory-driven methodology stole my heart. It seemed the perfect tool for clinical relevant research, as it highlighted the need for a thorough understanding of the content of treatment before attempting to examine it. It also kept a close eye on implementation problems. In addition, theory-driven methods made use of the combination of knowledge that led to a theory so that this knowledge could be profitable for both clinical and research purposes.
Therefore, theory-driven research seemed important enough to devote my thesis to.

Theory-driven programme evaluation was well-known in social sciences (Chen, 1990; Lipsey, 1990), but still a rather novel approach in the field of rehabilitation science (Keith & Lipsey, 1993). So it was obvious that answers had to be conquered rather than found. One of the obstacles to theory-driven programme evaluations was the diversity of meaning and usage of theory in rehabilitation medicine. Not just biomedical theories gave shape to multidisciplinary rehabilitation treatments but also psychosocial theories. By taking two competing rehabilitation treatments in stroke rehabilitation as the object of study for my master thesis [i.e. the generally applied neurodevelopmental treatment (NDT) and the more novel motor relearning programme (MRP)], I had the opportunity to explore the different ways in which theoretical principles had found a place in and given shape to the content of both rehabilitation treatments (Siemonsma, Lettinga et al., 1994; Lettinga & Siemonsma, 1997; Lettinga, Siemonsma et al., 1999). This comparative analysis revealed that theoretical principles are not located ‘down below’ in the foundation underlying rehabilitation treatments, nor are they located ‘up above’, outside the construction of treatments operating as judges passing sentence on the validity of a treatment. The analysis appeared to conclude that theoretical principles got a place in treatments after many transformations. Consequently, they play an informing role within treatment constructions by elaborating on the content of treatment (Lettinga et al., 1999).

Having studied the motor relearning handbook (Carr & Shepherd, 1982) and related literature, I was curious to know about its application and implementation in clinical practice. I became a research fellow at the Nottingham Stroke Research Unit where a comparative trial on the two treatments was being performed. I learned how to perform and implement trials in real life, a very useful extension to the theoretical knowledge of Human Movement Science (Siemonsma & Walker, 1997). At the same time my esteem of theory-driven methodology was strengthened: it seemed to me that many of the implementation problems and trial limitations could have been avoided with a more theory-driven approach and systematic incorporation of detailed knowledge of similarities and differences between the treatments in their study design.

I started working in (chronic) pain rehabilitation and planned to make use of past experiences: I wanted to help develop rehabilitation treatments in a theory-driven way. Based on experience I knew that implementing a new treatment is hard and even harder if it involves unlearning old practice. The start
of a new low back pain team was a good opportunity to put my ideas to the test. Two commonly used treatments for chronic low back pain rehabilitation are Graded Activity and Gradual Exposure in Vivo. Graded Activity is a treatment focusing on the role of behavioural factors in the continuation of pain. Gradually increasing the activities despite the experienced pain is an important feature of this treatment. In Gradual Exposure in Vivo activities are also increased according to plan. However, this plan is not set by time and amount of activity but the activities are increased by the level of emotion (anxiety) they cause the patient. The first treatment is characterized as focusing on behaviour, the second as focusing on emotion.

As there was no treatment focusing primarily on the patient's thoughts, these so-called illness perceptions (the patient's personal thoughts about their illness) seemed an innovative target for treatment. Leventhal’s Common sense Self Regulation Model (CSRM) (Leventhal, Brissette et al., 2003) appeared to be a good theory to guide the development of such an illness perceptions focused treatment. A large number of predictive studies have resulted in the CSRM being an established theory by which it was shown that illness perceptions are related to a number of illness behaviours in a variety of diseases. CSRM is a theory that is intuitively easy to comprehend as well as having clear focus on the illness. Therefore, CSRM seemed to have the potential to help paramedics to focus on the patient’s perceptions without the immediate risk of entering the psychologist's territory. A further factor that added to the excitement, was that the application of CSRM in interventions was in its early stages. Having convinced the Dutch Organisation for Health Care Research (ZonMw) that it was worth testing the value of theory-driven methodology in clinical practice, the basis of this thesis was secured.

The field of rehabilitation includes a wide variety of professions and treatments. Therefore, some explanation on what I understand by ‘rehabilitation’ is necessary. The verb ‘to rehabilitate’ is defined in the Oxford Dictionaries Online (Oxford Dictionaries Online, 2011) as: to restore (someone) to health or normal life by training and therapy after imprisonment, addiction, or illness. In this thesis ‘rehabilitation’ is used in the context of illness and, therefore, training and therapy refers to actions taken in a medical context. For chronic pain rehabilitation the focus is not so much on restoring health but on restoring normal life. Having narrowed down rehabilitation in this way, a vast field of specialists and actions are still included. To me this is no surprise, as according to Wade (Wade, 2005) ‘Rehabilitation is perhaps the archetypal complex intervention’. Much of this thesis is about specifying what is meant by words such as
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'rehabilitation' or 'treatment'. It is important to know that when I refer to rehabilitation I refer to actions taken by a dedicated treatment team of rehabilitation physicians, paramedics and psychologists to restore someone to normal functioning as far as this is possible in daily life. This is also called multidisciplinary rehabilitation.

In this thesis I have explored the effects of Cognitive Treatment of Illness Perceptions (CTIP), a rehabilitation treatment for patients suffering from chronic low back pain (CLBP), in a theory-driven way. Theory-driven outcome research makes use of treatment theories and contextual factors to collate an optimal research design for treatment improvement. In the 1980s programme-theorists in social sciences opted for explicit use of theory to broaden the evidence base and enhance the understanding and usefulness of research results. Therewith, they reacted to disappointing results of many outcome studies, in particular small effects and little information for improvement of clinical practice. It was argued that outcome research is not just a matter of technical and methodological expertise. To gain knowledge on how to improve treatment programmes, the theoretical implications of programme (treatment) content, participants and context should also be studied. Theory, thus, has a role in explaining the supposed working mechanism of a treatment as well as in selecting the most relevant variables to be studied in research (Campbell, Fitzpatrick et al., 2000; Whyte, 2006).

In rehabilitation outcome research similar concerns are now voiced. Rehabilitation research is challenged to broaden its evidence base. This requires more precise and more consistent conceptualisation and measurement of treatment ingredients (Whyte & Hart, 2003; Fuhrer, 2003). Treatment theories can help narrow the scope of possible active ingredients by specifying how the treatment is thought to work. They need to be distinguished from theories of dysfunction. Theory-driven outcome studies do not only assist in assessing the clinical value of the treatment, but also advance theory development. In addition, treatment theories shape inclusion and exclusion criteria as well as informing the choice of outcome measures for clinical trials by suggesting what types of patients may benefit from the specified treatment and where the treatment impact should be expected (Whyte, 2006). Furthermore, treatment theory is necessary in the process of assessing treatment fidelity, which is the extent to which interventions are delivered and received as intended in the trial (Fuhrer, 2003; Hart, 2009).

In this thesis I have taken on the challenge of integrating theoretical, methodological and clinical considerations into the design of our outcome study on CTIP. Chapter two is dedicated to detailed description of the multidisciplinary
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rehabilitation treatment of chronic low back pain, which was the object of the study: cognitive treatment of illness perceptions (CTIP). Its aims, process of change, outcome, theoretical underpinnings and contextual factors were described using a conceptual framework inspired by the work of Chen, Fuhrer and co-workers. In chapter three this knowledge is used to develop an optimal research design to study the effects of and the best candidates for CTIP. The choices and decisions that led to the final design are made explicit. In chapter four the content of CTIP is contrasted with that of Graded Activity and Gradual Exposure in Vivo and similarities and differences of these three treatments for chronic low back pain are specified.

In chapter five the question whether CTIP is effective is answered by means of a randomized controlled trial (RCT). In this clinical trial patients with chronic low back pain were randomly assigned to CTIP or a waiting list condition. The theory-driven approach evoked a further study, which is reported in chapter six: which patients with CLBP are the best candidates for CTIP? In this study theory-derived treatment relevant predictors are assessed. In order to interpret the results of chapters five and six correctly, the fidelity to treatment protocol is assessed and reported in chapter seven. This study determines to what degree the essential parts of the treatment are provided, because the treatment-as-provided might differ from the treatment-as-planned, thereby possibly influencing the results. The gains of this theory-driven approach and its benefits for rehabilitation in general are reflected upon in chapter eight, the discussion section of this thesis.

REFERENCE LIST


Chapter 1