DEALING WITH DISABILITY

INQUIRIES INTO A CLINICAL CRAFT

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Dr. T.E. Swierstra

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for my mother and
my sister Veronika

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Introduction

Inquiries into Clinical Rehabilitation

> It was in early spring in 1994 when I was an advanced student of physiotherapy and prepared myself for the last part of my education, the practical training. I was eager to put into practice what I had learned during my training; I wanted to help people who were ill, make them feel better. I was going to listen carefully to patients and respect what they wanted with their bodies and lives; I was going to make proper examinations, develop treatment plans and assess whether the treatment was effective. Equipped with high expectations and nervous agitation, I set off to see the first patients. But very soon I found myself in puzzlement and disappointment. People had been ill for many years and compared to my expectations, my ability to help them was very limited. I felt that my treatment was somehow important to patients, at least that's what they told me, but the results hardly fit into the evaluation schemes from my training. I did examinations and made plans like I had learned at school, but very often, my treatment goals started to shift and many were never achieved.

What went wrong? Why was it such a disappointing experience? My straightforward conclusion was that I was a bad physiotherapist. However, my trainers did not quite agree. They said that many novice therapists had this experience; according to them, there was a gap between what was written in the textbooks we read at school and what happened in treatment practice. I was not really convinced, but I decided that if books and treatment practice were two different matters, I would turn to the books.

The book you have started to read is not a book about the adventures of young physiotherapists. But my short story gives some clues about the subject of this thesis, which is the tensions between what we tend to read in books and what we encounter in clinical practice.

Speaking about the Quality of Care

The introduction above touches upon issues that are often part of debates concerning the quality of health care. Scientists, policy makers, prominent health care professionals, or ethicists extensively elaborate on the chaos, inefficiencies, and failures of contemporary Western health care. The problems are well-known: the world population has grown older and technological and scientific advances in medicine have contributed to a larger proportion of people surviving formerly fatal diseases. As the incidence of chronic conditions increases, demands on the health care system proliferate, health care costs explode and care delivery is increasingly complex and difficult to control. Given these reports about the serious challenges health care is facing it comes as no surprise, but it is still alarming, that young physiotherapists are disappointed about what they experience in clinical practice. Analysts argue that in order to meet these challenges, clinical practice has to improve its services, organisation and results. Their suggested solutions cover a wide range, as do problem definitions. Improvement strategies extend from standardisation, the use of guidelines and information technologies via transparent and efficient service provision, to patient emancipation and more possibilities for choice. In this range of quality improvements, two positions are particularly important. Many health care analysts emphasise that in order to improve the results of health care, it is essential that only those services are delivered that are really *effective*. Health care professionals are encouraged to apply treatments with proven efficacy and thus they seek to investigate the effectiveness of their interventions. In addition, it is widely acknowledged that health services should be organised and integrated around the patients' needs in order to make care more *patient-centred*. Treatment and care should be geared towards individual clients, whose needs should be respected and who are educated and supported to make informed decisions concerning their treatment and care. Arguments such as these shape the public image of care as well as the expectations and demands with which young professionals, patients, policy makers or lay people enter treatment practices. Such arguments are also influential in health care policy and in the textbooks health care students read. So, what is written in these books?

Effectiveness Research

One of the leading trends in Western health care during the past decade has been evidence-based medicine, or more broadly, evidence-based practice, which emerged in the late 1980s[1]. Evidence-based practice is defined as 'the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients.' (Sackett et al. 1996). Sackett and others started to develop evidence based practice, because they felt that it was increasingly hard to master what they called 'clinical entropy'. Advances in medical technologies and in diagnostic and therapeutic possibilities contributed to a growing complexity in health care, which often left clinicians with a growing difficulty to identify and apply an intervention for individual patients. The complexities of modern health care have resulted in striking variations in medical interventions that clinicians provide to their patients: a patient who consults a doctor in hospital X may be given a different treatment than someone with the same condition who is treated in hospital Y. In addition to the problem of making decisions about the best therapy, clinicians face difficulties keeping informed of medical advances reported in scientific journals. As a way out of this, in evidence-based practice professionals are to make use of external evidence that is obtained from research into the effectiveness and efficacy of diagnoses and treatments. Or, as Sackett and his colleagues summarise: 'Without current best external evidence, practice risks becoming rapidly out of date, to the detriment of patients.' ((Sackett et al. 1997), p. 2). External evidence increases the standards of current medical practices and is preferably produced by 'patient-centred clinical research into the accuracy and precision of diagnostic tests […], the power of prognostic markers, and the efficacy and safety of therapeutic, rehabilitative, and preventive regimes.' By means of clinical research, among which clinical trials are the golden standard, researchers judge whether a therapy does more good than harm or compare the risks and benefits of alternative interventions. In evidence-based practice, effectiveness research is regarded as critical to improving the day-to-day practice of medicine. Hence, practitioners are not only trained to become clinical professionals, but they are also expected to track down the best evidence, appraise and incorporate it into clinical practice, and measure outcomes that are valid and well-documented (Pollock 2002).

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[1] For an analysis of the history and politics of evidence-based medicine in contemporary health care see (Timmermans and Berg 2003).

Client Orientation

The lack of external evidence from effectiveness research is only one of the alleged concerns of contemporary health care. Another one is that health care is not sufficiently patient-centred. The issue of patient-centred health care is discussed in a variety of disciplines, most particularly in ethics. Among the most important moral values of contemporary Western ethics, especially in its liberal version, is respect of a person's autonomy regarding his or her health, body, treatment, and life. This moral principle emphasises the rights of patients to be protected in situations where they are in a comparably weak position vis-à-vis the professional. This protective concern in relation to medicine became strong after the Second World War, when people with mental disabilities and prisoners were enrolled in medical experiments without their consent. After these practices had been disclosed, critics made a strong claim for self-determination and respect of a person's autonomy and bodily integrity in medical experimentation. Formulated first in the Neuremberg Code in 1947, these principles were acknowledged as fundamental human rights and formally endorsed in the declaration of Helsinki in 1964[2]. In the decades after the declaration, the principle of personal autonomy developed into one of the key moral ideals of medicine and health care. Respecting a person's self-determination was not only important to protect patients from unwanted interference in experimentation, but also in regular treatment practice. Partly as a result of major improvements in medical knowledge and the expansion of medical technology, treatment possibilities grew excessively in the 1960s. Medical treatment could be maintained much longer than before, even though it was not always clear whether patients wanted this treatment. As a consequence, the principle of informed consent, with which a person gives or withholds consent for medical treatment, became the ethical and legal standard of good clinical practice.

Efforts to make health care more client-centred did not stop with the principle of patient autonomy, they persist until today. Policy makers claim that health care still has to make a shift towards profound client orientation. In client-oriented health care, patients are treated as emancipated citizens who have the right to speak up for themselves and who are treated on an equal basis. Citizens can assert their interests, either individually in situations of treatment and care, or collectively through the

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[2] See for this history (Ten Have et al. 1998). And for the history of medical ethics and medical law in the Netherlands see (Kater 2002).

influence of patient organisations. Some politicians and policy planners extend this emancipating move towards a model of health care as a market. In a health care market, patients operate as consumers of care when they are given the opportunity to choose those services of treatment and care that fit them best[3].

Gap

Students of physiotherapy and others read the kinds of books presented above and they are illustrative for a discourse that is much more widely available in health care. We can all imagine 'clinical entropy' and come to recognise the necessity to measure results, document findings, and incorporate the evidence from up-to-date research. Most of us know stories about awkwardly paternalistic professionals and would agree that respect of a patient's autonomy is a basic requirement for good treatment practices.

However, despite the generally shared belief that health care is in need for amelioration and despite the nobility of the aims of those who propose improvement strategies, practice tends to be more difficult to control than the reformers seem to hope for. How to make sense of this frequently made experience that my physiotherapy trainers called a *gap* between what is written in books and what happens in practice? During my physiotherapy training, I had a simple explanation: clinical practice plainly *fails* to meet the standards that both clinicians and scholars agree upon. Practitioners are not *good enough*. This, however, might be an all too quick conclusion. The problem may well be more fundamental. My trainers indicated a different answer when they talked about the *gap* between books and practice. A gap, after all, may be due to the books as well as to the practice. Maybe my trainers' line of reasoning is a fruitful one. It abandons harsh judgements and premature conclusions and invites instead to *take seriously* the reality of clinical practice and to *investigate* the exact nature of this often felt gap between clinical practice on the one hand and improvement strategies, theoretical notions, requirements and expectations being raised about this practice on the other. What happens when improvement strategies meet clinical practice? How do they relate to the creativity and complexity of clinical practice? How do they relate to the activities, routines, technologies, and materialities that are constitutive parts of clinical practice?

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[3] In the Netherlands this ideal of people purchasing their own services has already been realised in the particular case of the so called personal budgets. Chronically ill and disabled people are provided with money to employ, for example, their own assistants. See for a critical discussion of this system and other arrangements which are intended to orient health care towards the market model (Tonkens 2003).

These are the questions central to this book. In order to address them, reading books is not enough. These questions call for something else. Something different.

View from Within

Health care debates, theories, requirements for effectiveness, outcome evaluations, client orientation, and consumer choices create a specific image of health care and bring about high expectations. But are these expectations appropriate? The approach of the present study is to start out from a different perspective, that is from *clinical practice itself* and to explore its characteristics, strength and weakness from within. The book presents an ethnographic examination of what happens in clinical treatment and care, analysed against the background of public debates, research and policy, concerned with the quality of these practices. The book explores issues such as outcome measurement, effectiveness, patient autonomy, or client orientation as they appear in the day-to-day activities of clinical work. At the same time, this study traces issues that are silenced in public debate, but that are crucial for an adequate understanding of clinical practice.

The theoretical and methodological inspiration for this approach comes from Science and Technology Studies and ethnographic studies in medical practice. In these studies, day-to-day practices with their activities, routines, technologies and material design are the starting point of investigation. In explorations of day-to-day clinical work from within, complexity and contingency do not appear as chaos, but as a characteristic trait of clinical work, as creating development, robustness, and creativity, and as being necessary for anticipating different situations[4]. Complexity, multiplicity, and contingency are part and parcel of practical activities and routines of clinical work and this study follows these activities and routines in order to grasp diverse, unexpected, and hardly visible effects of treatment and care, which tend to be missed by regular outcome research[5]. The issue is not *whether* a treatment is effective, but rather what *different kinds of effects* are being generated in clinical treatment and care[6]. By investigating the

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[4] For explorations of complexities and multiplicity in the day-to-day routines of large organizations see (Law 1994), in technical design see (Bijker et al. 1987; Law 2002), and in clinical work see (Mol 1998; Mol 2002). For overviews, see (Law and Mol 2002a) or (Berg and Mol 1998).

[5] For studies in the field of Science and Technology Studies that moved from plans or results to activities and processes see (Berg 1997a; Hirschauer 1991; Latour and Woolgar 1979; Star and Strauss 1999; Suchman 1987; Timmermans and Berg 2003).

[6] See for a similar shift (Berg 1997b; Epstein 1996; Lettinga 2000).

activities and routines of clinical practice, this book moves away from single moments of patient care, for example situations of decision-making, and follows instead the entire organisation of treatment and care, which is to a large extent materially and technically shaped. Contemporary health care is essentially technological care and without a sense of the materialities and technologies of care, it seems impossible to understand the specific character of clinical work, its potentials and its weaknesses[7]. An ethnographic study of clinical care also articulates the disruptions, failures and fragility of the care for people who are ill or disabled[8]. It raises issues that have so far been neglected in public debate, such as how loss and failure are dealt with in clinical practice.

Drawing on an empirical study of clinical practice, this book compares the resourcefulness, creativity, challenges and failures of clinical health care with the notions circulating, arguments employed, expectations created, judgements made, and improvement strategies developed in public health care debate, health care research, education, and policy. With this ethnographic contrast, I invite clinical practitioners to critically reflect on their practices, activities and routines. At the same time, I hope to calibrate the notions, judgements, expectations and improvement strategies developed elsewhere to the specificities of clinical practice.

Clinical Rehabilitation

This book draws on ethnographic research carried out on a ward for people with extensive physical disabilities, such as spinal cord injury or multiple sclerosis (MS), in a Dutch rehabilitation clinic[9]. Rehabilitation care is a good site for this study, since it starts out by adding complexity to all too simple notions many hold about medicine and health care. One of the most straightforward outcomes allegedly pursued in health care, cure or recovery from a disease or injury, is impossible in rehabilitation. Rehabilitation practitioners treat people with diseases or disabilities that are chronic, often irreversible, and rarely curable. Residual disability may well persist throughout a

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[7] Scholars from Science and Technology Studies have been influential with their analyses of our world as a material and technological world. See for example (Akrich 1992; Callon 1986; Haraway 1991; Latour 1992; Latour 1999; Law 1987). And in health care and medicine see (Benschop 2001; Hendriks 1998; M'charek 2000b; Mol 2000; Mol and Elsman 1996; Pasveer 1988; Pasveer 1989; Willems 1995). This view is still up-to-date, as is indicated by a recent article by Jozef Keulartz and his colleagues, who argued that the moral significance of technological artefacts is still insufficiently acknowledged in contemporary applied ethics (Keulartz et al. 2004).

[8] For related studies, see (Baart 2002; Mesman 2002; Moser 2003; Pols forthcoming; The 2002).

[9] See for further details the subsequent chapters.

person's life: a person with paralysed legs may never be able to walk again. As a consequence, rehabilitation medicine has been making great efforts to establish alternative aims that direct treatment and care. In general terms, rehabilitation scholars agree that rehabilitation aims to support a person with disabilities to mobilise resources to maximise physical, psychological, and social functioning[10]. As the lack of unequivocal results makes it more difficult for rehabilitation professionals, patients and scholars to identify the specific effects of rehabilitation, the pressure to demonstrate its added value is all the more urgent in this field, where chronic illness, persisting disabilities and deteriorating conditions frustrate impressive results.

The establishment of evidence for the effectiveness of rehabilitation programmes is not the only challenge rehabilitation medicine has to face; client orientation is another one. Rehabilitation has increasingly moved from a medical model towards more client-centred models of treatment and care[11]. In the medical model, the professional 'knows best' and the disabled person is in a passive and dependent position. In client-centred models of rehabilitation, by contrast, the disabled person establishes the goals of the treatment process and the outcomes of therapy that are most important to his or her life situation. Professionals give adequate information, advice, and support in this trajectory, but 'the destination is defined by the client' ((Pollock 2002), p. 34).

My ethnographic inquiry into rehabilitation care is lead by four major topics, *independence*, *patient autonomy*, *goal setting*, and *suffering*, which are analysed in the four subsequent chapters of this book. On the one hand, the elaboration of these themes helps to grasp the characteristics of rehabilitation care, to work out its specificity. On the other hand, all four topics make it possible to discuss and make contrast to improvement strategies, quality instruments, or theoretical notions from contemporary health care debate. In the chapters that follow, I explore the results professionals and disabled people on the ward for spinal cord injury or MS seek to achieve, their ambitions and their methods, but also the losses and failures they have to bear.

Chapter 1 deals with independence, which is one of the possible outcomes of rehabilitation treatment: someone with a severe physical disability seeks to function as independently as possible in day-to-day life. Independence is one of the indicators that provide evidence for the effectiveness of rehabilitation. The chapter examines the ways in which independence is realised in the rehabilitation centre and relates these to the

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[10] Many rehabilitation scholars defined rehabilitation medicine. See for a discussion (Van Dijk 2001).
[11] See for the different models and for the shift in rehabilitation (Barnes and Ward 2000; Pollock 2002).

assessment of independence in outcome measures.

Chapter 2 shifts away from effects and focuses instead on the way patient autonomy - one of the central ideals in the ethics of health care - is dealt with in rehabilitation care. Unlike liberal ethical theory, this chapter does not seek patient autonomy in situations of self-determined decision-making, but introduces instead a view on patient autonomy as it is *done* rather than respected: a view from the kitchen.

The two issues central to quality discussions about health care, effectiveness and autonomy, which are taken up in chapter 1 and 2, come together in a method of rehabilitation medicine that I explore in chapter 3: goal setting. In the rehabilitation clinic disabled people are encouraged to establish the desired results of their individual rehabilitation programme and to set treatment goals. Despite the general acceptance of goal setting, it is far from straightforward in actual treatment practice: goals are often adjusted over time or never achieved, people sometimes disagree about goals, and some find it difficult to establish goals for themselves. This chapter argues that the difficulties of goal setting are not necessarily a failure of clinical practice, but result from a set of assumptions.

Chapter 4 concerns an issue that pervades clinical rehabilitation, but that is remarkably absent in public debate: the pain and suffering that tend to come along with chronic illness and disability. The chapter articulates the ways in which suffering is dealt with in clinical rehabilitation and discusses the silence of suffering outside clinical care.

In the conclusions I elaborate on the question of what ethnographic inquiries into clinical rehabilitation may yield. Such inquiries are important, I suggest, because clinical practice differs in a variety of ways from the strategies that seek to improve this practice. By portraying clinical rehabilitation as a creative craft and by articulating its creativity and richness, I seek to speak up for the specificities of clinical practices in order to protect them against all too easy invasions from elsewhere.

> As a novice physiotherapist, I was disappointed by the realities of therapeutic work. My expectations were shaped by what I had read in the textbooks during my education and maybe my view was shaped in such a way that I could only be left in disappointment. But what if I had a second, more sensitive and closer look at clinical practice? What would that show?

Chapter 1

More or Less? Or What? Assessment of Independence[1]

Over the past thirty years, researchers in the field of Science and Technology Studies (STS) have opened the black box of scientific knowledge production and demonstrated that science is a practice just like assembling a machine[2]. They have argued that scientific practices have their own language, instruments, rites of passage, sociological and cultural features[3]. Meanwhile, scientific tools and techniques are becoming increasingly influential in practices outside science[4]. Take for example medicine, which has recently been making great efforts to become more *evidence-based.* With the explosive growth of treatment possibilities in health care as well as with their increasing complexity, the great variation of interventions was felt to result in intolerable "clinical entropy", which could only be overcome by the explicit use of scientific evidence ((Sackett et al. 1997), p. 10) [5]. Implicit, non-verbal reasoning, professional knowledge, clinical expertise, or prevailing routines are no longer deemed to be sufficient sources for sound clinical judgment. Clinical decision-making, or so advocates of evidence-based medicine maintain, lacks external evidence, produced by scientific research regarding 'the accuracy and precision of diagnostic tests [...], the power of prognostic markers, and

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[1] This chapter was submitted for publication in *Science, Technology and Human Values*.

[2] For early examples of laboratory studies which unravelled the specificities of the practices in which scientific knowledge is produced, see (Latour and Woolgar 1979) or (Knorr-Cetina 1981). More recent laboratory studies are those by (Tchalakov 2004) or (M'charek 2000a).

[3] See for example (Kuhn 1962), (Knorr-Cetina 1999) and (Latour 1988).

[4] Some STS researchers have followed scientific facts on their way out of the laboratory as they were translated into – and thus co-constituted with - the world outside the laboratory. See for example (Latour 1987), (Singleton and Michael 1993) or (Jordan and Lynch 1998).

[5] See for a definition of evidence-based medicine and a brief introduction (Sackett et al. 1996), but also (Gross 2001) and (Friedland 1998). For an exploration of the history and politics of standardization and evidence-based medicine in contemporary health care, see (Timmermans and Berg 2003).

the efficacy and safety of therapeutic, rehabilitative, and preventive regimes.' ((Sackett et al. 1996), p. 72). But what kinds of evidence does this scientific research produce? And maybe more importantly, what kinds of evidence does it not produce? Especially since scientific evidence is considered to be essential for decisions that get at the core of medical work, it is surprising to notice that few questions about the precise nature of this evidence have been raised so far.

In their analysis of classification systems, Bowker and Star have demonstrated that classifications are never neutral: 'Each standard and each category valorizes some point of view and silences another.' ((Bowker and Star 1999), p. 5). Drawing on Bowker and Star's moral agenda, this paper mobilizes their argument in an analysis of the production of scientific evidence in medical practices. In order to do so, I take up the case of rehabilitation for people with a physical disability[6]. One of the overall aims of rehabilitation programmes is to make people more independent in their day-to-day life. As a consequence, scientific research in rehabilitation often focuses on the question as to whether rehabilitation programmes improve a person's independence in day-to-day activities. As an assessment is always an abstraction from the complex practices under study, the measurement instruments being used in these kinds of scientific studies give a specific interpretation of what independence entails. What counts as meaningful independence? What contributes to it and what reduces it? This paper tries to reveal what is exactly assessed by existing measurement instruments of independence as well as what falls beyond their scope.

Rehabilitation Outcome Measures

Most people who train in centres of physical rehabilitation suffer from extensive, incurable disabilities. Rehabilitation participants seek to move beyond cure and pursue overall treatment aims such as improved function and independence in day-to-day life, a

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[6] The argument developed here is based on an ethnographic study, which I conducted between 2000 and 2003 in a rehabilitation centre for people with severe physical disabilities. I observed the daily routines on a neurological ward for people with spinal cord injuries or multiple sclerosis (MS), where I also held open ended in-depth interviews with health professionals and with disabled people, some of whom I visited later in their own home environment. The original field notes and interviews were taken in Dutch, but have been translated for this paper into English by myself. All names used in this paper are fictitious. First and last names are used according to the customs on the ward.

higher life satisfaction, self-esteem and quality of life[7]. The establishment of these aims is often followed by the question as to whether these goals are achieved. And this is no surprise: patients, practitioners, as well as administrators and managers of health care seek to know whether rehabilitation programmes actually make a contribution to people's independence and to their quality of life. Outcome assessment as a means to establish scientific evidence for the effectiveness of one's interventions has thus become a hot issue in rehabilitation medicine: most rehabilitation handbooks devote a chapter to it[8]. Rehabilitation outcomes are assessed at two different levels: at the individual level and at the group level. At the level of individual patients, rehabilitation assessment may assist in intervention and discharge planning by documenting patients' current abilities and monitoring changes (Christiansen and Ottenbacher 1998). In addition, regular clinical assessment should improve communication with other members of the rehabilitation team or with managers. Aggregated data at the group level is used for scientific research on the effectiveness and efficiency of rehabilitation programmes[9].

Assessment at the individual level as well as at the group level is an important method in the pursuit to make rehabilitation more evidence-based. But what then counts as evidence[10]? Within physical rehabilitation, functional independence in self-care and mobility has always been a central treatment goal (Christiansen and Ottenbacher 1998). After having become paralyzed in an accident, people start by training basic skills, such as grooming, dressing, eating, or moving. It is thus not surprising that some of the most important indicators in rehabilitation document functional *independence* in day-to-day life (Kelly-Hayes 1996). One of the most often employed measures of functional independence in North America is the Functional Independence Measure

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[7] Among the authors who gave a set of general rehabilitation goals are (Kottke and Lehmann 1990) and (Kelly-Hayes 1996).

[8] From the wide collection of rehabilitation handbooks, see for example (Braddom 1996), (DeLisa and Gans 1998) or (Barnes and Ward 2000). And more specifically for the rehabilitation of people with neurological diseases (Greenwood et al. 1997).

[9] See recent programme evaluations in rehabilitation, for example by (Hershkovitz et al. 2003), (Cifu et al. 2003), or (Chen et al. 2002).

[10] Most rehabilitation scholars refer to the International Classification of Functioning, Disability and Health (ICF) (WHO 2001), which is the revised version of the International Classification of Impairment, Disability, and Handicap (ICIDH) (WHO 1980), as the conceptual basis of rehabilitation assessment. The ICF seeks to provide a comprehensive framework for health and health-related states that may or may not induce medical intervention or professional support. Rehabilitation medicine formulates its overall aims primarily at the level of activities and participation, rather than at the level of body functions and structures. For an analysis of a similar disease classification, see (Bowker and Star 1999).

(FIM), which assesses basic activities of daily life as well as cognitive functioning[11]. It was designed to indicate a person's suitability for discharge, the ability to live alone and the need for additional support[12]. The current use of the FIM, however, reaches far beyond the individual level, also establishing criteria for admission and discharge, and monitoring progress (Kelly-Hayes 1996; Wade 1997; Ward and McIntosh 1997). As Granger and his colleagues state: 'Improved FIM ratings indicate decreased support time and it follows that they have a relationship to the cost-effectiveness of the treatment program.' ((Granger et al. 1996), p. 244). Aggregates of FIM-data have regularly been employed as one of the outcome indicators in effectiveness studies in rehabilitation[13]. Hence, the FIM is an important instrument in physical rehabilitation and thus worth having a closer look at. Figure 1 shows a print of the FIM[14].

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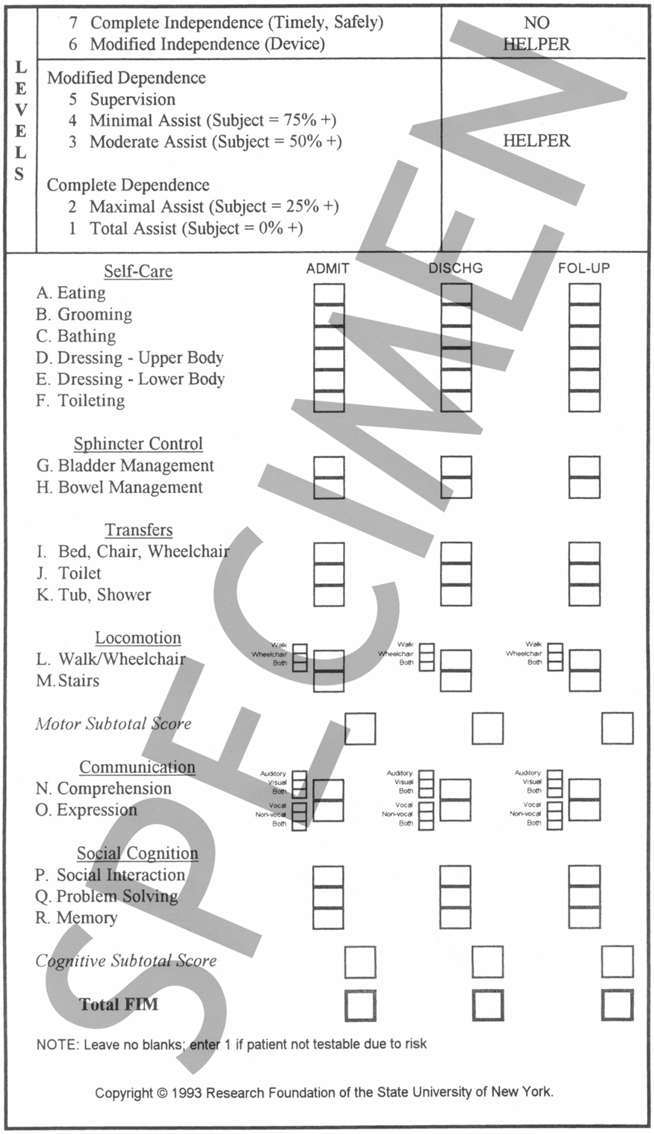
[11] The FIM-scale is a more elaborate version of one of the oldest measures for functional independence, the Barthel Index, which measures performance ability in mobility, self-care and continence (Mahony and Barthel 1965). Independence scales such as the Barthel Index and the FIM are designed to determine the degree of disability people experience and the progress they make through programmes of medical rehabilitation (Granger et al. 1993).

[12] The designers of the FIM give some more information about the usability of the instrument: 'The FIM, for instance, predicts the approximate help in minutes per day that a person with a certain level of disability needs. It is a valid measure of physical assistance or substituted effort from one person to another.' ((Granger et al. 1996), p. 244).

[13] In the research field of neurological rehabilitation, see for recent examples of effectiveness studies (Parsch et al. 2003), (Patti et al. 2003), (Macciocchi et al. 2004). Both the Barthel Index and the FIM are popular measures in effectiveness research in rehabilitation because of their established psychometric qualities, such as reliability, validity, and precision (Kelly-Hayes 1996).

[14] The print given here is the English version. In my fieldwork in the Dutch rehabilitation centre, rehabilitation participants used the Dutch translation of this original version. Due to the popularity of the FIM in North America and its established qualities, a growing number of Dutch rehabilitation centres have implemented the Dutch FIM.



LEVELS		
	7 Complete Independence (Timely, Safely) 6 Modified Independence (Device)	NO HELPER
	Modified Dependence 5 Supervision 4 Minimal Assist (Subject = 75% +) 3 Moderate Assist (Subject = 50% +) Complete Dependence 2 Maximal Assist (Subject = 25% +) 1 Total Assist (Subject = 0% +)	HELPER

	ADMIT	DISCHG	FOL-UP
Self-Care			
A. Eating	☐	☐	☐
B. Grooming	☐	☐	☐
C. Bathing	☐	☐	☐
D. Dressing - Upper Body	☐	☐	☐
E. Dressing - Lower Body	☐	☐	☐
F. Toileting	☐	☐	☐
Sphincter Control			
G. Bladder Management	☐	☐	☐
H. Bowel Management	☐	☐	☐
Transfers			
I. Bed, Chair, Wheelchair	☐	☐	☐
J. Toilet	☐	☐	☐
K. Tub, Shower	☐	☐	☐
Locomotion			
L. Walk/Wheelchair	Walk ☐ Wheelchair ☐ Both ☐ ☐	Walk ☐ Wheelchair ☐ Both ☐ ☐	Walk ☐ Wheelchair ☐ Both ☐ ☐
M. Stairs	☐	☐	☐
Motor Subtotal Score	☐	☐	☐
Communication			
N. Comprehension	Auditory ☐ Visual ☐ Both ☐ ☐	Auditory ☐ Visual ☐ Both ☐ ☐	Auditory ☐ Visual ☐ Both ☐ ☐
O. Expression	Vocal ☐ Non-vocal ☐ Both ☐ ☐	Vocal ☐ Non-vocal ☐ Both ☐ ☐	Vocal ☐ Non-vocal ☐ Both ☐ ☐
Social Cognition			
P. Social Interaction	☐	☐	☐
Q. Problem Solving	☐	☐	☐
R. Memory	☐	☐	☐
Cognitive Subtotal Score	☐	☐	☐
Total FIM	☐	☐	☐

NOTE: Leave no blanks; enter 1 if patient not testable due to risk

Figure 1: Functional Independence Measure (FIM) by Uniform Data System for Medical Rehabilitation (Granger et al. 1996).

The FIM measures a person's level of functional independence in eighteen performance categories, combined in five areas, ranging from self-care and transfers to communication. Making use of a seven-level ordinal scale, a FIM score ranges from a maximum of 126 points, representing complete independence in all performance areas, to a minimal score of 18, representing dependence in all areas evaluated. Independence scales such as the FIM are not the only indicators for the quality and effectiveness of rehabilitation interventions[15]. Most programme evaluations also seek to measure emotional, social, or vocational functioning. However, assessment instruments for these areas are much less developed, especially for the target groups of rehabilitation (Keith and Lipsey 1993). So, despite their limitations, measurement scales of functional independence such as the FIM are ubiquitous in rehabilitation assessment and key instruments to measure disability, monitor progress, enhance communication, measure the effectiveness of treatment, and document the benefits of rehabilitation interventions.

We have got an impression of the kinds of issues that outcome measures like the FIM focus on. But what does this say about the independence of a concrete person who lives with an extensive disability? And what does it say about the clinical practice of rehabilitation, where people are trained to become more independent?

Device and Help

Independence scales were designed to assess the assistance a person with a disability required after the clinical rehabilitation period. The basic idea was to indicate the burden of care or the cost of not being functionally independent (Kelly-Hayes 1996). In order to give such an indication, independence scales quantify the relationship between independence on the one hand, and the use of a technological device or assistance by a helper on the other. The independence score is highest for a person able to perform activities without making use of a device and without being assisted. And it is low if a person needs total assistance for activities of daily living (see figure 1).

In their one-dimensionality, independence scores do not provide information about the multiple entanglements of independence, technology, and care that tend to shape

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[15] Keith and Lipsey criticised the frequent use of independence scales in rehabilitation research. They held that functional independence is an important parameter in reducing dependence on others, but the repertoire of behaviours required to lead a meaningful life is much broader (Keith and Lipsey 1993). See for a similar argument (Kelly-Hayes 1996).

the daily lives of people with disabilities and their carers.

> Mr Smith's spinal cord was injured in an accident a couple of years ago. He is wheelchair-dependent and was discharged from the rehabilitation centre to return to home, where he lives with his wife. In spite of the fact that he is dependent on a wheelchair, Mr Smith performs walking exercises three times a week. A so-called walkabout, a special kind of corset, fixes his paralysed legs, and so he is able to walk from the bedroom to the living room and back. Mr Smith: 'I put on the walkabout myself, though it always takes me some effort. I call my wife to help me raise myself up, but I carry on walking alone. I don't want her to go too far away, I mean, just in case. I can always get spasms, but if she is around, everything is fine. Last week I did my walking and she was working in the front garden. She left the door and the bathroom window open, so she could hear me.'

Walking with disabled legs is a tough and sometimes risky business and Mr Smith would not be able to walk without assistance by his wife and medical technology. But what *kind of assistance* does Mrs Smith provide? She *is around* when her husband does his exercises, but she can go on with her own activities. She does not support him with each step, which would take much more of her time. Since Mr Smith only needs a push up, it is no heavy physical burden for Mrs Smith to help her husband, nor does she need specific professional competence nor does she give therapeutic instructions.

To give an indication about what consequences a physical disability has for people and their caretakers, these kinds of issues are crucial. If a measure only indicates *whether* a person needs help, rather than *what kind of help* exactly, it leaves out the most valuable information. Rehabilitation researchers, however, deliberately exclude this information from their assessments: 'From the point of view of the carers, the main consideration is whether or not the patient needs any help; the precise nature of that help is often of secondary nature,' ((Wade 1997), p. 152). But in clinical rehabilitation, professionals as well as the patients and their carers are concerned with the precise nature of help.

> A physiotherapist: 'We go into each aspect of an activity. How is it exactly done? What do you need to get it realized? If you want to walk, but you can't put on the walkabout, it's useless.'

People may walk in many different ways and assistance in walking exercises may adopt multiple forms. Dependence is accepted as a matter of fact in disabled living and rehabilitation practitioners try out different chains of dependency that produce different types of independence[16]. This is a qualitative question rather than a quantitative one.

In the example of Mr Smith, personal assistance comes in different ways. And so do technological devices. In their multiplicity, they make major differences.

> When Petra Brand enters the physiotherapist's room in a hand-propelled wheelchair, I am astonished, as she usually sits in an electric wheelchair. She tries to negotiate a bend, which takes her quite a long time. She makes an effort to propel the left wheel while the right one is standing almost still. She leans forward with her shoulders and trunk to reinforce the power in her arm, and her left hand gets almost stuck between the door and the wheelchair. Petra has difficulties getting over thresholds or doorsills, even small ones, in her manual chair and when she has finally arrived, she is exhausted: 'It took me almost ten minutes to wheel down from the ward to the physiotherapists' gym. It's very tiring and my shoulders hurt. With my powered wheelchair, it hardly takes me a couple of minutes.' But in spite of the pain and the fatigue, she seems happy: 'It's strange, but I feel less disabled in the manual wheelchair. A powered chair looks so… bad; it's big and clumsy. When I'm having dinner with my family, for example, I sit at a distance, a bit separated.'

Petra Brand needs a wheelchair for moving around, but she has two different ones. She takes the powered chair if she wants to go quickly from one place to the next, if she has to negotiate doorsills and rough terrain, if she wants to cover long distances and seeks to avoid pain and exhaustion. But that one also makes her feel more disabled and awkward in social interaction. Whereas a powered wheelchair may get Petra Brand far into town, it limits her in the sitting room. So, it does not make sense to compare the two wheelchairs by arguing that one makes her more – or less – independent than the other. Each one has its own drawbacks and advantages.

People with a disability often pass beyond the question whether or not to employ a

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[16] Winance described some of these chains of dependency for people with muscular dystrophies (Winance 2001). In a different setting, that of giving birth, Akrich and Pasveer analyse the qualitative differences between the kinds of dependencies in giving birth in two different countries, France and the Netherlands (Akrich and Pasveer 2000).

technical device to carry out a particular activity. Being dependent on a wheelchair – or any other technical device – has become a matter of fact[17]. People seek to know which activities are exactly made possible by an assistive technology and which not. And *how* these activities are made possible, at what costs: each technology has a variety of consequences for the people who use it: it may interfere in existing social and other relationships, it may influence one's self image, it may go along with certain risks, with inconvenience, and with side effects[18]. Rather than being a passive means in the achievement of independence, medical technology is an actant, along with other human and non-human actants, in the socio-technical network from which a person living with his or her disability emerges[19]. Actants have multiple effects in the network in which they are embedded. The most important questions, then, are to analyse the crucial nodes in the network, the weak connections, as well as the various effects being generated.

Professionals, disabled people and carers work along with medical technologies in these ways – as parts of a network that creates useful, pleasant, painful, beautiful, risky, burdensome or whatever ways of living one's own life. The thickness, complexity, and multiplicity of the relations between people and assistive technology, created through ongoing rehabilitation work in a fragile network, lies beyond the scope of independence outcome measures.

More or Less? Or What?

Outcome measures are not able to grasp the qualities of multiple independences as results of socio-technical relationships. As the plural of independence already indicates, concepts such as independence or quality of life do not entail one issue or activity, but a

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[17] Scholars from STS have convincingly demonstrated how each person, not only people with disabilities, relies on technology in day-to-day living. As Donna Haraway stated: 'We're all cyborgs!' (Haraway 1991). Haraway has claimed that it is a politically relevant question what cyborgs exactly do in our technological worlds, rather than embracing or disapproving technology *per se* (Haraway 1997).

[18] Different authors investigated the ways in which medical technologies work in everyday medical practice. See for overviews the special issues in *Science, Technology and Human Values* (Casper and Berg 1995) and in *Theoretical Medicine and Bioethics* (Vos and Willems 2000). For an analysis of articulations that speaking aids make im/possible in people with speech disabilities, see (Moser and Law 2003).

[19] In their semiotic analyses of the effects different kinds of entities produce, Michel Callon, Bruno Latour, and Madeleine Akrich were the first to introduce the concept of actant, and thus shift the attention from human *actors* and *intentional activity* towards the performative forces of different kinds of acting. See for example (Akrich and Latour 1992; Callon 1986; Latour 1988).

whole range of different ones. Most outcome scales address this problem by distinguishing different dimensions or categories. In the FIM, independence was devided into eighteen performance categories, combined in five dimensions: self-care, continence, mobility, communication and social cognition. The core aspects of being independent are thus *a priori* identified. In clinical practice, however, each person is independent in a different way.

> After almost ten months of rehabilitation at the spinal cord unit, Mrs Van Dijk will return to home, where she lives with her husband. She has been training to groom, dress, and transfer herself from the bed to the wheelchair without help of her husband. She also plans to do tasks in the household such as ironing, dusting, and preparing meals. According to Mrs Van Dijk, her husband is a great help to her, and he takes care of her devotedly. He has always managed the administrative affairs of their household and he organises everything: appointments and arrangements with care providers as well as phone calls with the insurance company, the wheelchair service, or other health institutions. Mrs Van Dijk: 'My husband is very good at that, he knows all the names of the people there and he can be very persisting.'

While Mrs Van Dijk trained extensively in rehabilitation to put on her shoes, she never cared about filling in forms, making applications for refunds, or negotiating with wheelchair companies. It has simply never been her business and unless her husband changes his mind, it will not be in the future. By contrast, others are eager to manage their own business and do not care about ironing or dusting. People tend to find some parts of their day-to-day life more important than others[20].

Independence is multiple and individuals have their own interpretation of what makes up an independent life. Rehabilitation assessment measures a person's progress in a set of pre-defined categories, but rehabilitation practice is already several steps ahead when only those categories relevant to the person are included in treatment. As rehabilitation scholars Barnes and Ward claimed: 'It may be better for a young man to have a goal of opening a can of lager rather than making a cup of tea!' ((Barnes and Ward 2000), p. 9). But people with disabilities not only *wish to* determine the activities

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[20] Rehabilitation teams try to tailor rehabilitation programmes towards individual preferences in treatment plans and in goal setting procedures. See for an analysis of goal setting and the assumptions that are underlying this (Struhkamp forthcoming).

of daily life being most important, they often *have to* as they simply cannot do all. Many disabled people are not able to do their personal hygiene in the morning, go to work after that, care for their children and do the shopping. They are worn out after *one* of these activities; doing them *all* is out of question. If they try to do all, they overburden themselves and wind up lying in bed for the next couple of days, unable to do anything at all. In living with a disability, 'more' is not always 'better'[21]. While independence measures aggregate different aspects to an outcome as *high* as possible, this aggregation of different tasks in daily life may lead to a general decrease in independence. In addition, independence scales count each category of independence as equal, whereas people often carefully balance different activities in a relative weight.

Independence is multiple, different aspects have relative weights and some elements are not important at all. Rehabilitation is all about dealing with multiple ways of being independent and balancing different activities. Multiplicity is often frustrating because aspects of independent living may clash.

> Mr Emerson arrives for an outpatient treatment with Marc Jansen, the occupational therapist of the neurology unit of the rehabilitation centre. Recently, he went through a period of exacerbation of his Multiple Sclerosis: he was able to walk in the past, but now he needs a wheelchair to cover greater distances. He is still able to drive, but has difficulties lifting the wheelchair into his car. Marc Jansen gives some instructions about folding and lifting a wheelchair and Mr. Emerson tries to push a couple of buttons, fold the chair, and lift the heavy wheels on to a table. When Mr. Emerson grows noticeably fatigued, Marc fetches a chair and Mr. Emerson is relieved to be able to sit down. Marc seems slightly concerned: 'You're quickly exhausted and lifting this heavy stuff is very bad for your back.' Mr. Emerson has complained about back pain in the past, and Marc says: 'A good lifting technique is really important and you may put a small stool in the back of your car, which you can use when you are exhausted.' Mr. Emerson nods: 'Yes, I know. Sometimes, I can't do anything because of the pain in my back.'

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[21] Different studies into living with a disability or with a chronic disease support this argument, demonstrating how living with a disability is often a matter of allocating the limited energy to the key activities of that day (Charmaz 1991; Pols et al. 1998). In addition, disability advocates criticised the bias towards independence in self-care apparent in physical rehabilitation and rehabilitation assessment: 'If a person can get dressed in 15 minutes with human assistance and then be off for a day of work, that person is more independent than the person who takes 2 hours to dress and remains homebound.' ((DeJong 1979), p. 444).

Mr Emerson lives alone and is able to perform the necessary activities of daily life without assistance. Setting his own pace, he does the laundry and the shopping and all the other tasks in his household. But these jobs are exhausting and when his back aches, he is not able to do them. He wants to drive, too, but lifting the wheelchair into the car is heavy and makes his back hurt. So, driving and housekeeping tend to clash here. Yet, Mr Emerson does not choose either one of the two activities, he tries to do both. How to coordinate the different and sometimes conflicting aspects of independent functioning in rehabilitation therapy? The occupational therapist provides instructions about lifting the wheelchair and sparing the back; he thinks of medical technologies that may give additional support. And a physiotherapist prescribes exercises for the back.

Measurement instruments that aggregate multiple aspects of independent functioning are designed to offer a comprehensive assessment of pre-defined activities that are considered to be relevant to the lives of people with disabilities. Aggregation means ‘the more, the better’: *each* activity is assessed for everybody in the same way. And each activity is *better* if it is carried out at a maximum level. Contrary to this logic of aggregation, clinical rehabilitation practice knows another way of dealing with multiplicity, which is coordination[22]. Coordinating the multiplicity of independence implies that people work out which activities of daily life are more relevant than others, ignoring those activities that are not important at all. In addition, coordinating multiplicity requires balancing relative weights as well as actual training to realise what is really meaningful. But the most challenging job of coordinating multiple ways of being independent in day-to-day life is gearing conflicting activities to one another. In clinical rehabilitation, people with disabilities do not gain as much independence as possible in an accumulation of pre-defined activities. Rather, disabled people and professionals seek an optimally fine-tuned and balanced independence, which is tailored to a person’s specific characteristics and situation.

Time

Rehabilitation assessment distracts evaluations from the complexities and particularities of clinical practice. By doing so, it ignores the qualities of the socio-technical networks that tend to produce multiple ways of being in/dependent. This multiplicity, however, is

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[22] Annemarie Mol described another form of coordination in clinical practice, which is the coordination of multiple enactments of a disease (Mol 2002). Apart from coordination, she unravelled two other clinical styles of dealing with multiplicity: distribution and inclusion.

crucial in day-to-day practice, where coordination rather than aggregation is the predominant strategy. Rehabilitation assessment also monitors the development of a person's functioning in time by subsequent measurements during the rehabilitation trajectory, for example at admission, discharge and after some follow-up time. Assessments at regular time intervals give an indication of improvement or regression of a person's condition in relation to time. In clinical practice, information about the development of a person's condition is indeed useful, but time does much more.

> Hans Faber is in his forties and lives together with his wife and their 14-year-old daughter. His spinal cord was injured in a traffic accident many years ago and he is paralysed from his stomach downwards. In the years following his spinal cord injury, one of the most annoying and difficult to handle symptoms were the spasms he had in his limbs. He recounts: 'I used to lie in bed or take a shower and then – wham! – my legs would fly into the air. I had to strap them to the wheelchair, because I ended up in awkward situations at work; I would be helping a customer and suddenly my legs would just shoot up without warning! And when I started to drive, I also had to fasten my legs.' The spasms decreased tremendously after a small pump that exudes medication was implanted in his body four years ago. His muscles are weak now and sitting in the wheelchair and working is much more pleasant now. However, Hans was recently admitted to the spinal cord unit because he had developed several pressure sores. He tells about the possible cause of the skin breakdown: 'I haven't had that ever before. I think it's related to the pump [which inhibits spasms]. The doctors say that it's good to have some spasms, because if you don't have any muscle tone you get bad blood circulation and the risk of sores increases. And my muscles have been very weak since I got the pump.'

Hans Faber's spasms were awkward in working, driving, or taking a shower. But without any spasm, the muscles are weak; he develops pressure sores and ends up with extended treatment, operations and weeks of bed rest, which also prevents him from working or driving. As we have seen before, different aspects of living with a disability often do not go together very smoothly. Yet, Hans Faber's story illustrates another complication: multiple aspects of a person's functioning do not clash at one particular point in time, but extend over different time frames in the past and present[23]. After Hans was freed from spasms in the past, he was able to work and drive well, but the low muscle tone and poor blood circulation also may have contributed to the sores. So, an intervention at one point in time may have negative consequences for another activity later[24]. How to deal with this? The spasm medication was slightly brought down so that Hans Faber got some spasms back, but at an acceptable level. He had to fasten his legs again and did some relaxation exercises. His muscles thus became more active and this reduced the risks of pressure sores.

The difficulty of coordinating conflicting activities over different time frames is that problems may or may not occur. A future time frame introduces uncertainty and risk[25]. And the coordination of potential events is much more difficult than the coordination of real ones.

> Mrs Breeveld has been wheelchair-dependent for more than ten years, but it's the severe pain in her lower back that has been particularly disabling in the last couple of years. Mrs Breeveld: 'I would like to go out more often, to do more, but I'm often in too much pain. Sometimes, when I'm in pain, I get help with dressing, though I can usually manage it myself.' When I ask her what she does to relieve the pain, she responds: 'I've got medication, but it has many side effects and I need increasingly higher doses. I try to change positions as often as I can. Sitting up in the wheelchair a whole day is very painful, and so I go and lie down for a while, or I sit in a comfortable chair with some cushions in my back.' 'Do you transfer yourself from the wheelchair to that chair?' 'Yes. But each transfer is hard. I've just had surgery in my right wrist and I often think that I should spare my arms, because I can't use my legs and I use my arms a lot. The transfers are doing no good, I'm overtaxing my arms, but it's also very unpleasant to be in the wheelchair all day long.'

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[23] Time is an important factor in chronic disease and disability and has been analysed extensively. For a classical sociological study of the ways in which time structures medical treatment and hospital routines, see the ethnography of tuberculosis treatment by (Roth 1963).

[24] Annemarie Mol and John Law analysed the disruption of time frames in dealing with a chronic disease, diabetes, and the difficulty of managing decisions that extend over a person's present situation as well as over the long term future (Mol and Law submitted).

[25] Uncertainty and risk are often said to become the most poignant issues of present-day health care, in which cure and care gradually shift towards prevention of illness and long-term risk management. These issues have been discussed extensively in the area of genetics. See for example (Baird 1990; Horstman 2001; Nelis 2000).

Nobody can exactly predict how Mrs Breeveld will be able to make use of her arms in five or ten years. And how much better her arms might be if she skipped one transfer each day. And how much more back pain that might bring her. These kinds of probabilities are almost impossible to calculate as there is no instrument that balances pain against the possibility of making less use of arms[26]. Time thus does not only imply linearity, movement, or development, but rather uncertainty, instability, disruption, and the pressure to make decisions that are almost impossible to make[27]. And yet, this is the pressing way in which time enters into clinical practice[28]. Rehabilitation practitioners and patients deal with the uncertainties of disabled living not by calculating risks, but by drawing on experiences of day-to-day life with a disability of themselves or others. Mrs Breeveld tries to experience what a whole day in a wheelchair does to her, and whether the pain remains the same each day or not. She tries to reduce the pain by different means, rehabilitation therapists train sound transfer techniques with her and they seek to notice early signs of physical strain. Participants in clinical rehabilitation thus make the most demanding, but also the most valuable practical synchronizations of multiple ways of living with a disability that stretch to the past, present and future.

To Conclude

The descriptions of clinical practice in this paper have revealed the thickness, complexity, and creative craftsmanship that characterises rehabilitation work. However, outcome measures that are employed in assessment and evaluation of clinical practice are hardly able to recognise multiplicity, coordinations, and complexities in clinical work. Since assessments are growing increasingly important in quality judgements of clinical rehabilitation, whether this may be in effectiveness research, as part of evidence-based medicine or as management instrument, they are far from innocent.

This paper has illustrated those aspects of clinical practice which tend to gain little

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[26] The difficulty to balance incomparable entities in living with a disability was also analysed in (Struhkamp submitted).

[27] Rayna Rapp studied the difficulty to deal with calculated scientific health risks in the context of prenatal diagnosis. She argues how pregnant women, who have to decide about prenatal testing, do not calculate probabilities and risks, but draw on a wide range of moral and social experiences (Rapp 1998; Rapp 2000).

[28] Also in contexts other than prenatal screening or rehabilitation, linearity of time has been shown to offer a limited perspective on clinical practice. In his study on neurosurgery, Tiago Moreira ethnographically demonstrated how medical or surgical trajectories are often complexified (Moreira 2001).

attention in outcome measurement. First, outcome scales give a *quantitative, one-dimensional* assessment of the relationship between independence, assistance by a carer, and medical technology. The most important aim of independence measures is to give an indication of the amount of care a disabled people is supposed to require; the nature of this care is of marginal importance and is not a part of the assessment. In clinical rehabilitation, by contrast, the *nature* of support is much more important than the support *per se.* Rehabilitation professionals, people with disabilities and their carers establish multiple and qualitatively different chains of dependency between bodies, carers and technologies in order to perform activities in day-to-day life. Independence emerges from socio-technical networks and the nature of each single node in the network is of crucial importance for the people involved. Whereas independence measures assess *whether* a person is dependent, rehabilitation participants ask *how* this dependence actually is shaped.

Second, independence is measured in *a priori* established dimensions, which attach equal weights to all dimensions of independence. The sub scores are then aggregated to a maximum level. In clinical practice, the multiplicity of independence is not aggregated, but coordinated. Coordination implies that disabled individuals give more weight to some aspects of independence, leaving aside others. Rehabilitation professionals welcome personal preferences and do not work at all possible aspects of independence. When multiple ways of independent living clash, for example when being able to drive may reduce a person's ability to do household tasks, rehabilitation practitioners seek to coordinate the clashing activities towards do-able situations. More often than not, this is not a maximum level of independence at all dimensions, but an optimal level of some selected dimensions of independence, carefully adjusted to a person's specific situation.

And finally, outcome scales monitor the linear development of a person's independence by comparing overall scores at different points in time. But rehabilitation participants have to deal with time in more complex ways. As multiple aspects of a person's functioning tend to extend over different time frames in the past, present, and future, participants have to coordinate conflicting requirements over different time frames. Disabled living and rehabilitation do not follow a linear development in time; rather, people are confronted with time disruptions, uncertainty, and risk. Tensions between an activity now and a probable outcome in the future are not quantitatively calculated, but rather managed in a creative way by drawing on experiences of living with a long-term disability.

So, existing instruments of rehabilitation assessment fail to notice the clinical specificity, local complexity, multiplicity and creative coordination of rehabilitation work. Is that a problem? It might be. It depends on what rehabilitation assessment is used for. We can read in rehabilitation handbooks that most assessment scales are employed to document a patient's progress in rehabilitation. But the progress as described by participants in day-to-day situations is often much more multifaceted, complex and specific than outcome measures tend to report. So, if these outcome measures are employed to give an indication about the contributions rehabilitation programmes may make to a person's independence in day-to-day life, this indication gives a limited view[29].

In addition, outcome measures are not only used for clinical evaluations, but also in effectiveness research and evidence-based medicine[30]. Evidence about the effectiveness of rehabilitation programmes is gained from research into the results of therapeutic or rehabilitative interventions. As I have argued in this paper, the data produced by independence measurements only offer a specific and limited perspective on the gains, losses, and potential effectiveness of rehabilitation programmes. Carefulness is thus recommended in the use of this kind of data. If the specificity and thus the confined significance of the evidence produced in this research is insufficiently recognised, and if the potential conclusions from this evidence are used to judge the quality of clinical work, the creativity of this work is not only in danger of being misjudged, but also of being eroded.

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[29] Ant Lettinga and Annemarie Mol identified a similar problem in outcome research of rehabilitation practices. They demonstrated how the parameters for success in stroke rehabilitation programmes often do not correspond with the aims of the various therapy interventions. They suggest that rehabilitation research should pay more attention to the specificities of the therapeutic interventions under study (Lettinga and Mol 1999).

[30] Theodore Porter convincingly demonstrated the mechanisms of the power that statistically produced numerical evidence is able to generate (Porter 1995).

Chapter 2

Patient Autonomy: A View from the Kitchen[1]

> A patient sits face to face to his doctor in a consultation room and presents his health problem. He sits in a wheelchair after having become paralysed in an accident and he has come to see the doctor because he has difficulties with urination. The doctor listens carefully and asks detailed questions about when the patient urinates, how often, how much he drinks, etc. She glances through the patient's case history, checks some numbers and arranges for additional diagnostic tests. Then the doctor describes some mechanisms of urination and explains her view of the problem. She gives some general advice and asks the patient to come back for a second appointment to discuss the test results and the therapy options. When the patient visits the doctor again ten days later, she tells him what she has found, based on which she explains a possible treatment: medication to be taken twice a day. She tries to give adequate and relevant information about the expected results of the therapy, the possible side-effects and the risks involved. After considering the information carefully, and discussing his ideas with the doctor, the patient decides to start the treatment.

The situation described above is the textbook version of the way in which patient autonomy is respected in medical practice: giving or withholding informed consent. This model is the frame of reference for discussions on patient autonomy in medical ethics, law, or health care policy (Beauchamp and Childress 1979; De Beaufort and Dupuis 1988). And it demonstrates the mainstream interpretation of patient autonomy in

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[1] This chapter will appear in a slightly different version in *Health Care, Medicine and Philosophy*.

contemporary liberal bioethics: giving the patient the right to self-determination in order to protect him from unwanted interference.

In the past decades, a growing number of ethicists and moral philosophers has criticised the liberal model of informed consent and the interpretation of patient autonomy as a right to self-determination. Scholars from feminist ethics, ethics of care, virtue ethics, or hermeneutical ethics argued that the liberal understanding of autonomy implies an atomistic model of human agency, which refers to individuals as existing apart from social relationships and being self-sufficient (Donchin 1995; MacIntyre 1981; Tronto 1993; Verkerk 2001; Widdershoven 2000)[2]. They developed alternatives for the liberal interpretation of autonomy, in which relationality, interdependence, and the vulnerability of human beings are emphasised, as well as alternative moral values, such as dignity, trust, authenticity, and integrity (Baier 1994; Dahl Rendtorff 2002; Schermer 2002). In the ethics of care, specifically, there is a growing appreciation of the moral qualities of concrete activities in day-to-day care (Smits 2004). In her book *Moral Boundaries*, Tronto interpreted the ethic of care as a practice, rather than as a set of rules or principles (Tronto 1993). She worked out four elements of care, among which is the competence of actual care-giving. The practice of care, she argued, 'involves particular acts of caring and a general "habit of mind" to care that should inform all aspects of a practitioner's moral life' (p. 127). Tronto elaborates on the moral qualities of practice, in which people carry out concrete activities. In this paper, the appreciation of the morality of concrete practices is adopted to reconsider patient autonomy.

This paper intends to enrich current discussions on patient autonomy with a perspective on the concrete activities that take place in day-to-day practices of health care. The scope is broadened from a focus on individual or interactive decision-making in the consultation room to actually performed activities. The move towards the day-to-day work in health care draws the attention towards the ways in which autonomy is *practiced*: patient autonomy, or so I will show, unfolds in the activities of care, in institutional arrangements, in the materiality of high- or low-technical objects, in the actual and embodied training of people with disabilities, as well as in interaction with professional and non-professional carers who do not only talk about, but also *do* the actual work of taking care. With this analysis, I take seriously what some authors claim

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[2] Among these ethicists and moral philosophers, there is a great variety of views that are elaborated and compared elsewhere. See for an overview in English (Schermer 2002) or in Dutch (Swierstra 2000; Widdershoven 2000). An exploration of the similarities and differences of these critiques, however, reaches beyond the scope of this paper.

to be an important aspect in the constitution of autonomy: the empirical reality of medical care (Conradi et al. 2003; Ten Have 1998).

In order to explore the realisation of patient autonomy in health care activities, I undertook an exploratory, qualitative study in the day-to-day practice of rehabilitation care[3]. I gathered ethnographic material about the practicalities of food and eating in order to examine the activities in which patient autonomy is practiced.

Menu Cards and Food Containers: Organisation and Materialisation of Autonomy

One way in which health care professionals seek to respect autonomy is by giving people with disabilities choices about their treatment and care. In the consultation room example from the introduction, a person is asked to make a decision about his treatment. But making decisions goes beyond the consultation room; professionals in health care also attempt to give people choices about other elements of care.

One example of this is the organisation of meals. People with disabilities choose their dinner from a menu card (see figure 1).

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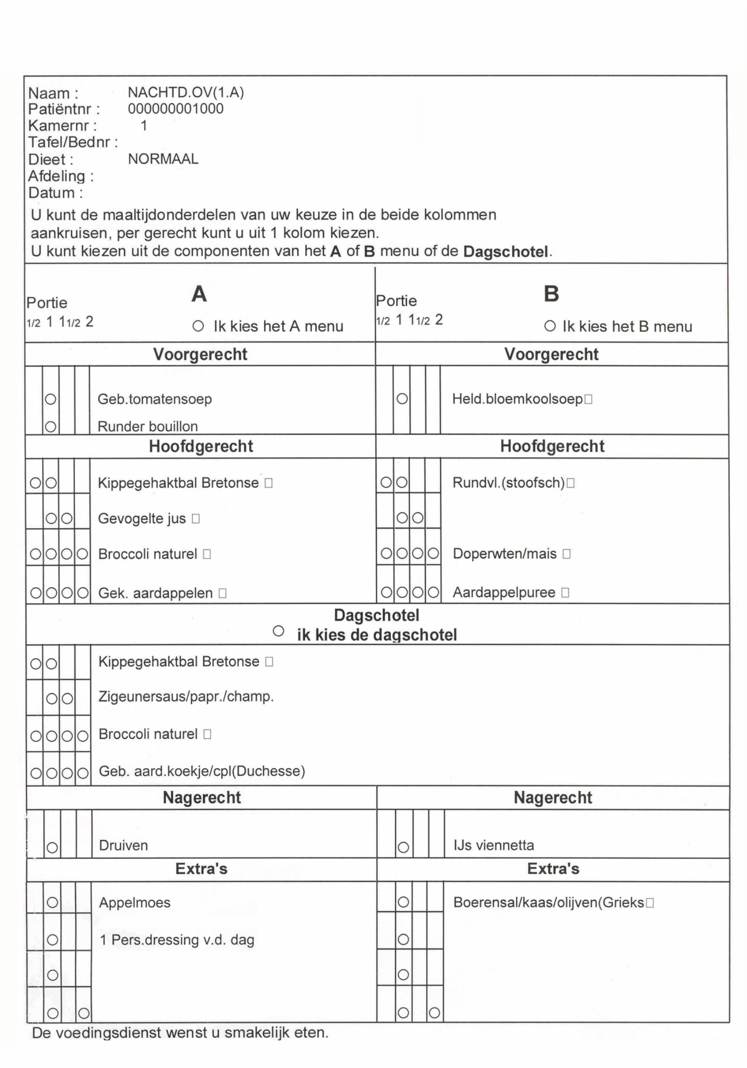
[3] Between March 2000 and December 2001 I did ethnographic research in a Dutch centre of physical rehabilitation. I conducted participant observations on a ward for people with spinal cord injury or advanced multiple sclerosis (MS), held semi-structured interviews with health professionals and with disabled individuals, some of whom I visited in their own home environment after they had been discharged from the rehabilitation centre. The field notes and interview fragments I use in this paper were translated from Dutch into English and all names are invented; in the usage of first or last names, I follow the conventions of the ward.



Naam : NACHTD.OV(1.A)
Patiëntnr : 000000001000
Kamernr : 1
Tafel/Bednr :
Dieet : NORMAAL
Afdeling :
Datum :

U kunt de maaltijdonderdelen van uw keuze in de beide kolommen aankruisen, per gerecht kunt u uit 1 kolom kiezen.
U kunt kiezen uit de componenten van het **A** of **B** menu of de **Dagschotel**.

A

○ Ik kies het A menu

Portie ½	1	1½	2	
				Voorgerecht
	○			Geb.tomatensoep
	○			Runder bouillon
				Hoofdgerecht
○	○			Kippegehaktbal Bretonse ☐
	○	○		Gevogelte jus ☐
○	○	○	○	Broccoli naturel ☐
○	○	○	○	Gek. aardappelen ☐

B

○ Ik kies het B menu

Portie ½	1	1½	2	
				Voorgerecht
	○			Held.bloemkoolsoep☐
				Hoofdgerecht
○	○			Rundvl.(stoofsch)☐
	○	○		
○	○	○	○	Doperwten/mais ☐
○	○	○	○	Aardappelpuree ☐

Dagschotel

○ **ik kies de dagschotel**

○	○			Kippegehaktbal Bretonse ☐
	○	○		Zigeunersaus/papr./champ.
○	○	○	○	Broccoli naturel ☐
○	○	○	○	Geb. aard.koekje/cpl(Duchesse)

A

				Nagerecht
	○			Druiven
				Extra's
	○			Appelmoes
	○			1 Pers.dressing v.d. dag
	○			
	○		○	

B

				Nagerecht
	○			IJs viennetta
				Extra's
	○			Boerensal/kaas/olijven(Grieks☐
	○			
	○			
	○		○	

De voedingsdienst wenst u smakelijk eten.

Figure 1: Menu card[4]

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[4] The menu card presented here is written in Dutch and only the key elements will be explained in the text. It is presented here to give the reader an impression of the way in which an instrument of choice is actually designed.

In the rehabilitation centre people indicate whether they prefer for example broccoli over peas, chicken over beef stew, grapes over ice cream. And they specify the size of the portion or order some extra salad. People with particular diets get special cards. So, people may make a choice between various kinds of meals, but what lies beyond dinner choices?

> It is 11.45 a.m. at the spinal cord unit and the dinner is about to be served. The dinners come on dinner trays which are stacked on food trolleys and labelled with each person's name. Hours before, the personnel in the general kitchen downstairs prepared the food, which was then put onto plates and into bowls that are kept warm by stainless steel covers. After the trolleys have arrived at the ward, nurses and aides deliver the trays to the bedrooms and to the tables in the dining room, where people have their meal.

In large institutions such as the rehabilitation centre, food choices are only possible if those who work there carry out a range of activities such as preparing and delivering food. These activities are dependent on a whole set of material conditions, which often shapes the kinds of dinner choices people make. Convenient one-pan meals appear more often on the menu than difficult-to-prepare dishes that require many different ingredients. Oven dishes are no option at all, because they require too many ovens in the general kitchen to bake them. And only if the soup is kept in suitable containers and travels efficiently, arrives nice and hot, then people tend to choose soup, which they would rather refuse if their soup arrived lukewarm. Without the people who prepare and deliver the food, but also without menu cards, computer systems, food trolleys, dinner trays, name plates and covers that keep the food warm, the system of food choice as it is practised in many health care institutions would be impossible. Individual reflexive action, such as choice, is only possible in a heterogeneous collective network (cf. (Callon and Law 1997; Gomart and Hennion 1999)).

So, food choices are dependent on care activities and their material conditions. In addition to this, choices are shaped by the organisational setting of the rehabilitation centre.

> I ask nurse Sarah: 'Does everybody have their dinner at noon? Because at home, most people would have a light lunch and then dinner in the evening.' 'I think that a dinner at night would be impossible here; although I believe that they discuss variations of the

> system. They make plans to offer a real menu à la carte or a dinner at night, and I know of some experiments in which they offer different kinds of desserts on dessert trolleys after dinner. You're right,' Sarah continues, 'some people have a poor appetite at noon and prefer a sandwich or something light. But having dinner at noon is easier for us, there are fewer nurses on the late shift, it would be impossible to serve the meals then.'

The times at which meals are prepared and served correspond with the availability of staff in the main shift, which in most institutions is roughly between 7 a.m. and 3 p.m. People cannot choose to have their lunch at midday and their main meal in the evening, like most Dutch people do. The complex organisation of the relevant care activities is important to understand the possibilities and limitations of the practical realisation of individual choices.

The material and organisational setting of health care is often practically discussed, but much less frequently from a moral point of view. However, the material and organisational realisation is one way to practice patient autonomy. And there are more ways.

Pasta Bolognese: Corporeality of Autonomy

Patient autonomy is embedded in day-to-day activities that take place in the material and organisational context of care. As we have seen in the example of food choice, individual decision-making is important in rehabilitation practice.

> Alice Brinkman is a young woman who has been at the spinal cord unit of the rehabilitation centre since her car accident one year ago. Alice is what rehab participants call a tetraplegic: both her legs and her arms are paralyzed. Although she propels her own wheelchair manually, her arms, hands and fingers are not very strong. She is impaired in many things people tend to do in everyday life: grasp a cup of coffee, put on clothes, hold a pen, and write a few words. Alice has been in rehabilitation for one year now and after having discussed the possibilities of independent living with her therapists, she plans to move to a purpose-designed accommodation where she will be supported by her family and by professional carers.

A physical handicap tends to change a person's life. For a young woman such as Alice, the spinal cord injury brings about major decisions about how she may continue to live her life. This fits in with ethical theory in which patient autonomy is often illustrated with examples about dilemma's or decisions that concern a person's general life plan (Dupuis et al. 1994). In rehabilitation, however, a patient's autonomy is not only an issue when people make major decisions, such as where and how to live, but also in ordinary situations of care:

> Susan Bos, one of the occupational therapists in the rehabilitation centre, is planning a therapy session with Alice Brinkman. She asks: 'Alice, how do you feel about a therapy session in which you prepare a meal?' Alice replies: 'Cooking? Yes, why not?' 'What would you like to make?' 'Well, what about Pasta Bolognese?' 'That's fine,' Susan says, 'what do you need for the pasta?' 'Ehm… about one pound of pasta and minced meat, and an instant tomato sauce-mix. You know the kind you can buy in the supermarket? And a small tin of tomato purée. That's it.'

The situation does not seem to imply a major dilemma, but Susan Bos asks Alice for her consent to practice cooking. Creating spaces for choices about what to eat, what to wear and how to proceed during training are ways in which a patient's autonomy is respected (Lelie 1999; Schermer 2002).

But however important such choices are, focussing on the ways in which decisions are being made, distracts from those parts of rehabilitation treatment and care that do not involve decisions, but are important for a patient's autonomy all the same.

> One week later, Alice arrives at the kitchen in the occupational therapy department, where she finds the ingredients for Pasta Bolognese. Susan greets her: 'Hi Alice, how are you today? It's our cooking day, isn't it?' Alice starts straight ahead and wheels to the middle of the kitchen unit, somewhere between the sink and the cooker, where she puts the wheelchair on the brakes and presses a button that moves the specially adapted kitchen unit downwards[5]. In order to fill a pan with water, she clasps the pan between her fists, slides it to the sink and lets it slip into it. She turns on the tap, which reaches far to the front. Alice slides the pan with water to the electric

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[5] See figure 2 for an example of such an adjusted kitchen unit.

cooker, where she has difficulties to move the pan onto the burner. Susan explains: ‘This cooker is not very practical, those with a flat surface are much better, because you can slide pans more easily.’ After Alice has managed to put the pan on the cooker, she is figuring out how to switch on the heat. She tries to turn the button around, first with one hand, then with two hands, in different positions and with various techniques. Susan comments: ‘You see how important it is to have a well-equipped kitchen? These buttons are hard to manage. Well-adapted cookers have electronic touch control buttons, which are much easier to turn on and off.’ The session is progressing, the water starts to boil and Alice fries the meat in a frying pan. The mince is more or less one big block of meat and Alice barely manages to scrape little bits from the lump. Susan does not make any attempt to help, she restricts herself to some suggestions: ‘Maybe you can try to turn the piece around?’ Alice gives it a try, but cannot turn her hand and forearm. Susan comments: ‘It’ll get better when the meat starts to get done.’

Figure 2: Wheelchair-adjusted kitchen unit

Making the decision to cook one's own meal depends on one's capacity to actually do the cooking. Rehabilitation treatment tries to train such capacities and thereby works on the conditions of the practical realisation of autonomy rather than on the conditions of decision-making. The theory of informed consent deals with the question when and under which conditions a decision is truly autonomous (Faden and Beauchamp 1986). Rehabilitation practitioners train the physical capacities and create adequate material conditions that make activities one might opt for possible. Without the capacity to turn on the cooker, making the decision to prepare your own meal is futile.

Susan takes Alice' physical situation seriously when she withholds her own active intervention. Alice has to train her arms and hands if she wants to realise her plan to do her own cooking at home. But the material environment in which Alice cooks her meal also makes a major difference in the realisation of her autonomy[6]. Adjustable kitchen cabinets, taps and cookers facilitate or restrict the way in which Alice is able to live and cook at home.

Physical training and technical adjustment of the physical environment are not only important in a therapeutic sense, but also with respect to a person's autonomy. Rehabilitation practice shows the embodied and material realisation of autonomy in practical training and thus demonstrates that the dualism between the practical, material or corporeal on the one hand, and the moral on the other hand does not make much sense (Mol and Mesman 1996; Moser and Law 1999).

Meals-on-wheels: Relationships and Activities

Patient autonomy, or so the practice of rehabilitation shows, is realised in organisational and material arrangements and in concrete physical training. But not only these activities help to realise autonomy, the actual care-giving of professional and non-professional carers do so as well. To illustrate this, I will enter yet another kitchen, not in the clinic this time, nor in the department of occupational therapy, but in a person's home.

> Mrs Verhagen is in her sixties and has been sitting in a wheelchair since she broke her neck eighteen months ago. I first met her in the rehabilitation centre, where she had therapies and received training

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[6] This links up to an important argument of the disability activist movement, which is that the problem of disability is not situated in the impaired body, but in the mismatch between the physical environment and the bodily situation of disabled people. See for overviews of the work that has been done in the field of disability studies (Albrecht et al. 2001).

> for more than a year. About six months ago, she moved from the rehabilitation clinic to a wheelchair-accessible apartment in a sheltered accommodation in her home town. I visit Mrs Verhagen for an interview in her new apartment, and after our first cup of coffee, we start talking about preparing meals. I ask: 'How do you get your meals?' She answers: 'Well, I don't do my own cooking, that's impossible. But I can manage my own meals if I get prepared food from one of my sisters or from Lisa [her daughter]. Sometimes I order my meals from meals-on-wheels.'

Mrs Verhagen is dependent on her sisters, daughter and on the professional meals-on-wheels service for her warm meals[7]. To a large extend, others decide what Mrs Verhagen is going to eat and when she gets the meals. But interestingly, in these dependencies Mrs Verhagen's autonomy is not just bypassed, but also respected. Her daughter Lisa, for instance, anticipates her mother's preferences and brings her favourite traditional dish with potatoes, meat and vegetables. She respects and maintains the way her mother used to live her life. Or, to put it differently, Lisa respects her mother's autonomy by supporting the continuity of her biography and her authentic life style (Agich 1993; Schermer 2002).

Mrs Verhagens story illustrates that one assumption of the liberal model of autonomy, complete independence from others, is problematic (Dworkin 1988). Mrs Verhagen does not live in complete independence from others; she has never lived in such a way, nor does she pursue such a life in the future.

> Mrs Verhagen: "I've lived all my life in Bosheuvel. Most of my large family still lives there and we come to see each other almost daily."

In order to incorporate relationality into ethical theory, ethics of care held that relationships, interdependence and vulnerability are resources of a person's autonomy rather than limitations to it (Keller 1997; Manschot 1994; Verkerk 2001).

Mrs Verhagen would agree that the actual care-giving by others, the concrete practice of cooking and delivering meals, constitute her autonomy.

> After her spinal cord injury, Mrs Verhagen found out that she was not able to move back to her own house, where she had lived alone

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[7] The possible differences and similarities between formal and informal care deserve a more thorough analysis than I can provide in this paper. See for a more detailed study (Potting 2001).

> since her husband's death some years before. She did not like the idea of moving to a nursing home, since there she would have to live among people much older and sicker than she is; and she would not have her own apartment but only one room, probably shared with others. And maybe worst of all, as there is no nursing home in Bosheuvel, she would have to move to another town. So, she moved to a wheelchair-accessible apartment in a sheltered accommodation, where she lives independently with some basic professional help with grooming, toileting and dressing.

Mrs Verhagen is able to live in her own apartment and in the town she prefers most, because others *actually and actively* take care of her. Other people assist with dressing and toileting, they do the shopping, prepare food, and bring it along. These activities enable Mrs Verhagen to live the kind of life she pursues. Important for Mrs Verhagen's autonomy is not only the respect of her decisions and life style, but also the assistance and care provision that help realising it.

Microwave Oven, Chocolate Taste, and Adjustable Kitchen Units: New Perspectives on Autonomy

Patient autonomy is an important ideal in rehabilitation care. As a moral norm it informs discussion about how to improve the quality of care. Policy makers, managers, patient organisations as well as professional groups seek to strengthen the patient's position, but often it is unclear where and how people's autonomy is at stake.

Patient autonomy, or so I argue here, is practiced in day-to-day health care as a part of the usual routines of care-giving and during a variety of therapy activities. What kinds of insights does this broad view on patient autonomy yield?

> Dr Helen de Groot is seeing Fred Moss, a young man with a spinal cord injury who sits in a wheelchair. They are talking about the skin problems Fred Moss has suffered from regularly in the last couple of weeks. Yesterday, a nurse detected a red spot of irritated skin on Fred's backside, which is often the first sign of developing skin breakdown or decubitus. Fred is frustrated and discouraged. Skin breakdown is a nasty thing to have, because these tiny little wounds tend to heal very slowly and if nothing is done against it, they may grow bigger. With the spot on his backside, Fred has to take more bed rest. In the course of the conversation, Fred says that he has

> lost much weight during the last weeks. Helen is visibly concerned and says: 'Such a major weight loss may have serious consequences. If you're not in a good physical condition, you'll be liable to further skin breakdown. And if there's not enough subcutaneous fat tissue on your prominent bones, your skin will get irritated.' And then she adds: 'But how is it possible that you've lost so much weight? What do you eat each day?' Fred seems to find this an awkward question: 'Ehrr… well, I don't eat much. I know I should eat better, but the problem is that they serve dinner at noon here. You see, I don't feel like having my hot meal just in the middle of the day! And then sandwiches at 5 p.m., that's also much too early. I don't feel hungry at that time.' 'You could keep the sandwiches and have them later at night?' the doctor suggests. 'Yeah, possibly…' He doesn't sound convinced, 'It's much easier at home,' he continues 'At home I can have something to eat whenever I fancy it.'

Helen de Groot listens carefully to Fred's complaints and frustrations. She is a doctor who respects the patient's autonomy in a broad sense: she shows respect for the person, even if his story is not straightforward (Schermer 2002). But still, there is a problem. Fred Moss is in a bad condition and there is not one best treatment strategy, nor a set of options to choose between. A perspective on patient autonomy that moves away from this decision-making to the activities and practicalities of treatment and care may help to understand the situation of Fred Moss, as well as the strategies to tackle the problem.

Fred's health problem seems to be connected to the organisation of meals in the rehabilitation centre. Dr De Groot seeks to intervene into this organisation when she suggests that Fred could have his sandwich later at night, so that the time of eating is better attuned to his appetite. In addition, Fred's situation is tied to the material conditions of rehabilitation care.

> Nurse Sarah is cleaning the tables in the dining room at the spinal cord unit. In one corner, there is a small kitchen unit, where crockery and cutlery is stored and where a large fridge and a microwave oven are installed. I wonder what this kitchen is for and Sarah explains: 'Patients may use the fridge and the microwave oven if they want to store their own drinks or warm some food.'

Helen de Groot suggested that Fred might heat up his dinner in the microwave oven. It can be stored in the fridge from noon to whenever he fancies it. Thus, not only Fred's problem, but also the solutions the doctor comes up with, are embedded in organisational arrangements, as well as in material devices.

Some difficulties people with disabilities encounter in the realisation of their autonomy have to do with their specific corporeality. Let's look again at the story of Fred Moss:

> The conversation between Dr De Groot and Fred Moss about his skin problem and his weight loss continues. Fred says: 'I don't understand this. Before the accident, I never had any problems with my weight.' Helen de Groot: 'So, what did you eat then?' 'Pizza,' is his prompt answer. Helen laughs and suggests that Fred should see the dietician, but Fred does not seem to like this idea: 'Oh, she'll give me these horrible nutritious drinks, which I really hate. They're simply disgusting and they turn my stomach. I'm not going to take them!' The nutritious drinks Fred tells about are rich in proteins and carbohydrates and often given to people who suffer from pressure sores or malnutrition. Helen responds: 'Well, you can tell her and she might have different flavours. She'll work out your diet and if pizzas are part of it while nutritious drinks are not – that's all right with me!'

In rehabilitation practice, professionals attempt to be sensitive to the taste and texture of food and not just to the nutritional value of it (cf. (Harbers et al. 2002)). Hence, the dietician has drinks in different flavours and why not have a pizza sometimes? Different aspects of food are fine-tuned: Fred's physical problems as well as his peculiar preferences are taken seriously in a creative way. The realisation of autonomy goes beyond deliberation and decisions and includes practical tinkering with food values and different tastes.

In the following part of Fred Moss' story, we see how autonomy is also tied to actual caring activities. Or not.

> When Fred Moss had an accident, he was still living at his parent's home, but he was about to move to a place of his own. After some months of rehabilitation, he reconsidered his situation: moving back to his parents would imply a massive rebuilding of their house to make it wheelchair accessible and so he decided to look for a place of his own that could be adapted to his special needs. He found a

> pleasant apartment not too far from his parents' house, which required some adaptations to make it wheelchair-accessible. Fred needs a lower kitchen unit that fits a wheelchair, but other people who do not sit in a wheelchair, like Fred's friends or his mother, will also use his kitchen. So, the kitchen unit needs to be adjustable in height rather than fixed at wheelchair height. Adjustable units are much more expensive than those with a fixed height and the local authority that pays for this adaptation argued that this extra feature was unnecessary since Fred would be living alone in his flat and would be the sole user of the kitchen[8].

The reasoning of the local authority shows the practical consequences of a liberal interpretation of patient autonomy that does not include practical activities done by others. Fred is seen as autonomous in the sense of being completely independent and self-supportive, without others actually providing care for him. But Fred has never lived alone, his mother and friends may drop by and cook for him or with him. By doing so, they might, if the kitchen allows it, become crucial in the realisation of Fred's autonomy.

The case of Fred Moss reveals how professionals in health care creatively deal with cases in which no straightforward solution is at hand and in which respect for a person's autonomy is a complicated matter. With a broad view on the practice of patient autonomy, this practical strength can be articulated and the morality embedded in care practices can be appreciated. A view on patient autonomy as realised in practical activities may also contribute to a practitioner's moral self-image. Professionals regard their own day-to-day activities as being as moral valuably as consultation room situations in which patients make informed decisions. In addition, an understanding of patient autonomy as unfolding in different kinds of activities in health care is important for the distribution of money as well as in policy decisions concerning health care. Touch control buttons and adjustable kitchen units are expensive, as is occupational therapy, but they may contribute to the realisation of a person's autonomy. Only if actual activities in the practice of patient autonomy are taken seriously, the relevance of therapy activities in rehabilitation care can be adequately assessed.

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[8] In the Netherlands, every physically disabled person should be allowed to live in a personal environment that is adjusted to his or her specific needs. People have to apply for these adaptations at a special department of the local authority.

To Conclude

This paper intends to broaden the discussion of patient autonomy by moving away from individual or interactional decision-making to practices of rehabilitation care. This move to the practice of patient autonomy has two implications. First, patient autonomy is not only at stake in the consultation room where people may or may not make treatment decisions. Rather, patient autonomy is practiced at *different locations*, ranging from the general kitchen of the rehabilitation centre, the dining room, the therapy department to a person's own apartment. These locations, secondly, offer a view on the *activities* of health care that shape a person's autonomy and that reach beyond the discursive interaction that takes place in the consultation room. A description of the activities of health care in which patient autonomy is practiced illustrates that autonomy is partly realised in and through organisational and material arrangements of care. In therapy settings, the embodied activities of a disabled person as well as the material environment in which they take place are considered necessary for a practical and actual realisation of autonomy. Moreover, the practice of patient autonomy demonstrates the importance of actual care-giving by others for the realisation of a person's autonomy.

This view on autonomy allows a careful understanding and appreciation of the participant's creativity in practicing a person's autonomy. Professionals in health care are often very inventive in their response to a disabled person's situation. However, this practical creativity tends not to be recognized as being valuable from a moral perspective by outsiders. The installation of a microwave oven at the ward's dining room is a solution for a problem that has to do with the organisation of care, a person's physical condition, material resources in an institution, and moral considerations. Rehabilitation practice thus makes disappear clear-cut boundaries between different domains. This paper is an attempt to articulate the normativity of medical practice to make it available for recognition, appreciation, and assessment, as well as for critical reflection and discussion.

In addition, the description of the practice of patient autonomy may stimulate creative innovations in health care at places where the ideal of patient autonomy so far has been of minor importance or where it has been subject to misinterpretation. Patient autonomy, or so I have argued, partly lies in the often less visible but pervasive routines of health care. Not only the doctor's information influences a patient's autonomy, but also what happens on the management floor, in the therapy kitchen, in the technical services department, or at the local authority.

An exploration of the practice of patient autonomy may help to gain a better understanding of key issues in current health care and possible innovations, but only if we abandon the one-sided interest in giving consent or making decisions in discursive interaction in the consultation room, and adopt instead the idea of patient autonomy as being practiced. Organisational arrangements, material devices, physical training and actual care-giving all help to constitute patient autonomy in the day-to-day activities of practical care.

Chapter 3

Goals in their Setting[1]

In a practical field such as the rehabilitation of people with a severe disability, the complicated process of treatment and care is often structured by the method of goal setting (Barnes and Ward 2000) (McPeak 1996). Especially in the management of chronic problems and disabilities, goal setting is regarded as one of the key means to help organise care in a more patient-centred way (Bauman et al. 2003). Despite the general acknowledgement of the method, the practice of goal setting is not straightforward, especially not in the rehabilitation of chronically ill and severely disabled people. It often turns out that goals are not achieved in the course of rehabilitation, goals tend to be modified over time, people sometimes disagree about how realistic certain goals are, and people with disabilities appear to find it difficult to establish goals for themselves (Hasler and Schnyder 2002) (Kirschner et al. 2001).

Some authors address the problem of goal setting by suggesting an improvement of the procedure of goal setting: goals require particular criteria and they should be formalised, monitored, documented, and assessed (Barnes and Ward 2000). Others argue for better patient and therapist education, which would improve the compliance of goal setting in practice (Baker et al. 2001). In these discussions, the assumptions behind goal setting have rarely been questioned. These notions mask the complexities of targeting goals in a medical setting. Some of these assumptions have been unravelled earlier, such as the idea that practical actions are purposeful, goal-directed and instrumental, and the associated goals are supposed to be relatively stable over time and place (Suchman 1987). When goals are turned into practice, the assumptions appear to be much more problematic than the model suggests. The assumptions of goal setting may be perceived as the implicit normativity of one of the key instruments that support the management and rationalisation of a complex practice in health care (Berg et al.

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[1] A slightly different version of this chapter was accepted for publication in *Health Care Analysis.*

2001) (Berg 1997b) (Molewijk et al. 2003).

In order to understand the normativity of goal setting in actual health care practice and the difficulties of this method, I undertook an explorative, qualitative study of the intricacies of goal setting in the day-to-day routines of rehabilitation care[2]. In this paper, I articulate a set of tensions that are inherent in goal setting in practice. In addition, I demonstrate how practitioners do not seek to solve these tensions of goal setting, but attempt to deal with them in a dynamic way.

Goals in a Rehabilitation Team Meeting

> Every Monday just after lunchtime the rehabilitation team gathers for a patient meeting in Dr Braakman's room on the first floor of the rehabilitation centre. Team members come into the room, pour themselves a cup of coffee and strike up a chat with a colleague. Eight people take a seat at the table: a rehabilitation physician, a registrar, a physiotherapist, an occupational therapist, a nurse, a social worker, a psychologist, and I, the ethnographic observer. After a while, the registrar Helen De Groot opens the meeting: 'Shall we start, I guess everybody's in now?' People stop their conversations and start shuffling through their papers. Dr De Groot reads from her notes: 'We're going to discuss the situation of Mrs De Waard, born November 16th, 1940, incomplete spinal cord injury after trauma in August 1999, re-admission into the centre after discharge September 2001.' She looks up: 'Uhm, we all know Mrs De Waard, but what are we going to work at the next few weeks?' Paul, the physiotherapist, is the first to respond: 'She says that being able to walk is very important to her, so we've intensified walking exercises and we've started to walk with her with a rollator.' The doctor nods: 'She told me that it went pretty well.'

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[2] The argument I develop in this paper is based on ethnographic research in a rehabilitation centre for people with physical disabilities in the Netherlands. Between March 2000 and December 2001 I conducted several months of participant observations on a ward for people suffering from spinal cord injury or advanced multiple sclerosis (MS). In addition to taking field notes I held semi-structured interviews with health professionals and with disabled individuals, some of whom I visited in their own home environment after they had been discharged from the rehabilitation centre. The field notes and interview fragments I use in this paper were translated from Dutch into English and all names I use in this paper are invented; in the usage of first or last names, I followed the conventions of the ward.

> The social worker is more sceptical: 'Will she be able to walk independently with a rollator at home? That's what she trains for after all.' 'I don't know,' the physiotherapist replies, 'she'll always need a rollator and one person for assistance. Her legs tend to give way unexpectedly every now and then, which makes her very insecure. Still, she often walks a couple of hundred metres, so it should just be possible.' The occupational therapist Susan goes on: 'She told me that she's so insecure, because she can't firmly grip the rollator brakes. Her hand function is fairly limited, but I promised to see if I can fix another kind of grip.' She briefly pauses. 'This rollator, by the way, is not her own. If she walks at home she'll need one of her own. Shall we apply for one?' She looks at her colleagues. Some people nod in approval and Susan accepts that as an acknowledgement: 'Alright, I'll go over this matter with her.' Paul, the physiotherapist then asks: 'I have the impression that she should walk more often, twice a day at least. What if the nurses walked with her from her room to the dining room on the ward?' he looks at nurse Annette: 'Walking might become more of a daily routine and we could spend more time at training her hand function.' Annette: 'Uhm, yes, why not? We could start by once a day, just after the lunch nap. Does she need any special help?' 'No, not really.' Paul replies, 'But I'll come to the ward later today in order to check if all goes well.' 'Good, I'll write a note in the record for the other nurses.' Helen de Groot summarises the discussion: 'So, we'll intensify Mrs De Waard's walking exercise programme. Susan will adjust the rollator and apply for one. Anything else? What about the home living situation? Any news?' The social worker responds: 'No, nothing new. The request for an adapted apartment in her home place has been filed quite some time ago. It's under consideration. I'll give them a ring and ask about it.' The registrar winds up the discussion: 'No more questions then? To conclude: ambulation with assistance is the first priority for the next six weeks and we'll keep in touch with the local authorities about the apartment, right?'

Many of us are not very experienced with the kind of complex processes that take place in the rehabilitation of somebody who is severely disabled or chronically ill. Rehabilitation trajectories are complex in various ways. The list of physical problems is long for people with spinal cord injuries or advanced MS, ranging from paralysis of the limbs, which often makes people sit in a wheelchair, via bowel and bladder dysfunction and bed sores to extensive fatigue. However, it is not just the seriousness of the physical disorder that often makes rehabilitation so complicated, but rather the many ways in which these physical problems tend to get entangled with almost every aspect of a person's day-to-day life (Charmaz 1983) (Winance 2001). People with spinal cord injury or MS have to develop new strategies of being mobile, of dressing and toileting, of household, leisure, and vocational activities. In addition to this, rehabilitation is complicated because the course of a chronic condition is to a large extent uncertain. It is often difficult to predict how much disablement a physical impairment will cause after an extensive period of rehabilitation. Chronic diseases or physical disabilities often result in gradual deterioration of one's physical condition, but the time frame and the extent to which this happens are uncertain.

As a way to tackle the complexity of rehabilitation problems, their entanglement with everyday life activities and their uncertainty, rehabilitation professionals set goals and develop plans. As we can see from the field note, professionals approach the complexity of rehabilitation in a management style. The rehabilitation team identifies the patient's most important medical and rehabilitation problems, formulates a problem list, develops treatment options for these problems, documents the treatment time, and periodically evaluates the patient's progress (McPeak 1996).

Goal setting is a reasonable answer to the complexity of rehabilitation after a severe disability, but as it is precisely that, a *reasonable* answer, there are also other answers.

Fate

> The registrar Dr Helen de Groot goes to see Mrs Smit, a semi-paraplegic woman who steers a self-propelled wheelchair. Helen de Groot opens the consultation, 'Mrs Smit, I want to talk to you about your condition and about the treatment you get here in our centre. Have you thought about your health problem and about what that means for your future?' Mrs Smit smiles at the doctor and replies, 'No doctor, I never worry about my future. Everything will be fine. God will take care of me.' Helen de Groot continues, 'Well, if I had to give a prognosis, I'd say that I don't see how you could make it without a wheelchair.' Contrary to the way in which most patients react to such news, Mrs Smit does not seem to be impressed, 'I'm always very optimistic about the future, I trust in God. Many people just sit here and brood. But that's not how I see it; I have faith in the future.' There are signs of irritation in the doctor's voice when she

> goes on, ‘Look, we can teach you lots of things, but you might not need all these things. How can I know what you do and do not need? That’s what you have to tell me. You’ve got to think about that and you’ve got to decide about what you want and what you don’t want.’ Mrs Smit does not seem to follow this reasoning. She says that she enjoys the therapies and that she finds everything she does here very pleasant and useful. But that’s not what the doctor is after. ‘We can train you to wheel really fast, for example, but you might say I don’t need to go fast.’ In her immediate response, Mrs Smit is enthusiastic: ‘Oh, they’ve taught me how to use the wheelchair and that was really good. I had no idea how to steer it and so on. And then they showed me how to do it and now I know. No… I never go fast.’ ‘That’s exactly what I want you to think about. We can teach you how to cook your meals from a wheelchair. But it’s of course possible that you are not interested in cooking at all. Maybe you’ve always detested cooking!’ ‘Oh no, quite the opposite! I love cooking. I have several cook books and I can spend hours in my kitchen!’ ‘See!’ the doctor exclaims, ‘That’s important information for me! I want you to think more about those kinds of things!’ Mrs Smit does not agree with Dr de Groot as her answer is firm: ‘Oh no, I cannot do that. I could write my plans on a piece paper and then present that to the Lord. [She raises her hand as if she held a written paper]. But that’s not how it works! My life is in his hand, it’s not me who determines my fate. I might be dead tomorrow. I don’t know my future and I trust in God.’ Helen de Groots makes a desperate attempt to explain her position: ‘That’s not how it works here, it’s necessary to think about the future. Our system requires that, because you have to apply for services you might need in the future. There are waiting lists for many things, it often takes a long time to get the provisions you might need and you have to count on delays.’ She pauses. ‘So you have to make decisions about what you need and what you want.’

Mrs Smit’s response appears unusual in the decisiveness of her rejection and in the religious motivation of her objection, which is uncommon in the secular environment of the Netherlands. But with her persistence, she just makes clear what others put forward only in fragments.

Mrs Smit’s resistance concentrates on three different assumptions of goal setting. First, although the doctor tried to make her think about the future, Mrs Smit persistently stuck to a time frame of the present. Dr De Groot thought ahead when she talked about a prognosis and long waiting lists. For Mrs Smit, by contrast, the future was irrelevant, because she knew that she would be alright. Second, in the same way as she was not bothered about her future, Mrs Smit was not much interested in the world outside her current environment, the rehabilitation centre. Her immediate setting, such as the wheelchair training she had been doing, was important for her; it was much more important than the imaginary world outside. Finally, Mrs Smit refused the idea of active actorship that goal setting implies. The doctor asked her to make up her mind about her preferences, about activities she might want to train and goals she might want to achieve. Instead, in Mrs Smit's view, her future life is not up to her, but up to God's will. One's life is not subject to one's individual will, but to God. Mrs Smit rejects steering her life actively, in favour of the open attitude of accepting her destiny.

These tensions between two opposing positions in goal setting, which Mrs Smit's cheerful stubbornness illustrates, beg the question how elsewhere in rehabilitation, in interaction with other patients, goal setting works. As it turns out, or so I would like to argue, goal setting in day-to-day rehabilitation practice exhibits three sets of tensions for health care professionals. These tensions resonate with three themes that we have seen in Mrs Smit's resistance. First, there is a tension between the future and the present situation. The second tension is that between the home environment and the environment in the rehabilitation centre. Finally, there is a tension between active interference in one's life and the acceptance of one's fate. How are these seemingly irreconcilable tensions between setting goals and letting go dealt with in day-to-day practice of rehabilitation? There, or so I will attempt to show, creative strategies are often more helpful than the fixed positions that goals and plans seem to imply.

Time

The professionals who discussed Mrs De Waard's case in the team meeting on the one hand and Mrs Smit in her conversation with the doctor, on the other hand, seem to live in two different time frames. Health care workers talked about actions that were going to take place at points or periods of time in the future, while Mrs Smit focussed on the present.

An important tool in the time management of a rehabilitation team is a rehabilitation plan. It is sequenced into successive steps from an appraisal of the patient's medical and rehabilitation history, an extensive account of the current status, and a range of therapeutic interventions that should help to achieve treatment goals in the future (McPeak 1996). Such a plan describes a linear movement, spanning from the past to the present, in which one step initiates the next.

The team meeting I attended in the Dutch rehabilitation centre was structured by treatment plans of the individual team members. Figure 1 shows the physiotherapist's plan for the meeting of Mrs De Waard's case[3].

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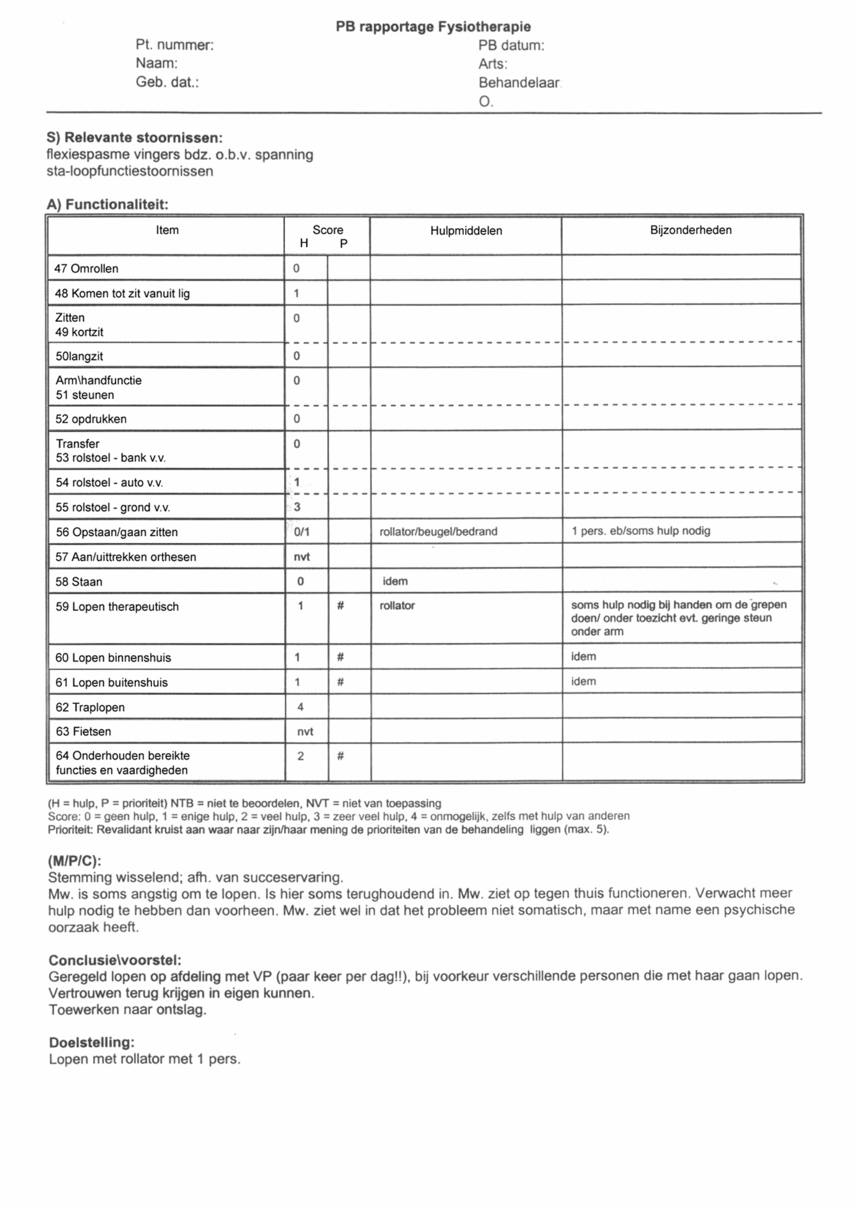
[3] The plan is written in Dutch. It is presented here to give the reader an impression of the formal lay-out of rehabilitation plans rather than to provide a detailed analysis. Hence I will only summarise the key issues in English.



PB rapportage Fysiotherapie

Pt. nummer:
Naam:
Geb. dat.:

PB datum:
Arts:
Behandelaar
O.

S) Relevante stoornissen:
flexiespasme vingers bdz. o.b.v. spanning
sta-loopfunctiestoornissen

A) Functionaliteit:

Item	Score H	P	Hulpmiddelen	Bijzonderheden
47 Omrollen	0			
48 Komen tot zit vanuit lig	1			
Zitten 49 kortzit	0			
50langzit	0			
Arm\handfunctie 51 steunen	0			
52 opdrukken	0			
Transfer 53 rolstoel - bank v.v.	0			
54 rolstoel - auto v.v.	1			
55 rolstoel - grond v.v.	3			
56 Opstaan/gaan zitten	0/1		rollator/beugel/bedrand	1 pers. eb/soms hulp nodig
57 Aan/uittrekken orthesen	nvt			
58 Staan	0		idem	
59 Lopen therapeutisch	1	#	rollator	soms hulp nodig bij handen om de grepen doen/ onder toezicht evt. geringe steun onder arm
60 Lopen binnenshuis	1	#		idem
61 Lopen buitenshuis	1	#		idem
62 Traplopen	4			
63 Fietsen	nvt			
64 Onderhouden bereikte functies en vaardigheden	2	#		

(H = hulp, P = prioriteit) NTB = niet te beoordelen, NVT = niet van toepassing
Score: 0 = geen hulp, 1 = enige hulp, 2 = veel hulp, 3 = zeer veel hulp, 4 = onmogelijk, zelfs met hulp van anderen
Prioriteit: Revalidant kruist aan waar naar zijn/haar mening de prioriteiten van de behandeling liggen (max. 5).

(M/P/C):
Stemming wisselend; afh. van succeservaring.
Mw. is soms angstig om te lopen. Is hier soms terughoudend in. Mw. ziet op tegen thuis functioneren. Verwacht meer hulp nodig te hebben dan voorheen. Mw. ziet wel in dat het probleem niet somatisch, maar met name een psychische oorzaak heeft.

Conclusie\voorstel:
Geregeld lopen op afdeling met VP (paar keer per dag!!), bij voorkeur verschillende personen die met haar gaan lopen.
Vertrouwen terug krijgen in eigen kunnen.
Toewerken naar ontslag.

Doelstelling:
Lopen met rollator met 1 pers.

Figure 1: A physiotherapist's treatment plan

The plan is divided into three categories: S) contains information about the patient's impairment; A) includes a list of functional activities such as rolling over, transferring oneself, or ambulation; (M/P/C) gives an indication of the patient's psychosocial functioning as well as her communication. These three areas summarise the patient's current status, mainly aimed at functional activities. In addition to this, the physiotherapist draws a conclusion and proposes a treatment. The plan concludes with the treatment goal: 'Walking with rollator with 1 person'.

The physiotherapist's assessment of Mrs De Waard's current situation and the treatment proposal referred to the present and was taken as an agreed basis for the meeting rather than an issue of discussion. By contrast, treatment goals as well as the future situation towards which the plan should lead were extensively discussed during the meeting. The doctor, for example, asked about the planned therapy activities for the next few weeks and the social worker wondered about how Mrs De Waard would manage after leaving the centre and returning home. Professionals who develop a rehabilitation plan mainly refer to the future time frame. When goals have to be set, they distract their discussion from the irregularities and variations of day-to-day rehabilitation and create a point of view in which mainly the future counts.

Mrs Smit lives in a different time frame. In her conversation with Helen de Groot, she was not engaged in the future, the only relevant time for her was the present. As Mrs Smit seemed to be absorbed by her experiences of that particular day, she did not get worried by the unfavourable prognosis the doctor gave her; the future is of limited relevance to her. Her actions were an immediate response to demands posed by the therapists, as I saw her excitedly participating in the wheelchair training or the cooking session that had been proposed. Mrs Smit seems to embrace and be embraced by the present, remote from the past and the future.

In contrast to the separation of future and present in both the team meeting and Mrs Smit's position, the two time frames tend to get re-connected in day-to-day rehabilitation practice. Having developed a rehabilitation plan in the patient meeting, health care workers return to their individual treatments in which they cannot only make plans for the future, but have to respond to the present situation.

For Mrs De Waard, the woman with spinal cord injury, the plan is to train walking with some help. But then there is a problem:

> Two doctors enter Mrs De Waard's bed room during their morning round. Earlier that morning, the senior nurse reported a tiny sore on Mrs De Waard's right toe. The doctors turn to Mrs De Waard, who is sitting in her wheelchair, her bare right foot on the foot rest. They sit down on their heels in front of her, lift up her leg and gaze at the wounded toe. Dr Helen De Groot: 'It doesn't look like decubitus, more like a minor wound.' She looks up at Mrs De Waard 'Did you get injured when you were barefoot? In the shower perhaps?' Mrs De Waard: 'I don't know, I can't feel anything that happens to my feet, can I?' Dr Braakman turns to the nurse who is sitting next to him: 'Could you put a small bandage with [brand name of a medication cream] on it? It has to be changed each day.' Helen de Groot adds: 'You shouldn't go for walking exercises the next few days, Mrs De Waard. The wound has to heal first and you can't wear your shoes. We'll have another look at your toe on Thursday.' Mrs De Waard is disappointed: 'No therapy today? I always enjoy it very much.' 'I can imagine,' Helen de Groot replies 'But we can't let you go. The wound may grow into a severe decubitus that is difficult to cure.'

Mrs De Waard is very motivated to train walking and so she goes for walking therapy twice a day. However, the sore renders the goal unachievable. Future goals and present situation may call for opposite actions in rehabilitation. The imperative of the present restricts striving towards the future goal. Walking is put off, at least for a while. If the sore does not heal and even grows into decubitus, which is the major threat the doctor worries about, the future goal may need reconsideration. The present situation delineates the future.

Rather than separating the future and the present in daily care, professionals seek to make practical connections between the future and the present. Future goals may be temporarily set aside or finally adjusted to the present condition. Patients along with their therapists find themselves caught up in various trade-offs between relevant and often clashing requirements.

Other authors have demonstrated that living with a chronic disease is characterised by a permanent struggle to balance present needs and long-term effects (Charmaz 1995) (Murphy 1987). People with diabetes may find themselves entangled in trade-offs between the temptation of a cream pastry on a birthday party and the risk of blindness as a result of excessively high blood sugar levels. Balancing food intake, exercise and insulin injections has become for many of them a daily practice (Mol and

Law submitted). Managing conflicting time frames implies, as in the situation of Mrs De Waard's toe, that present activities that may cause future harm are weighed off against their potential pleasure at present. But the opposite situation in which present inconvenience is accepted as an investment for future advantage is also quite common. Here is another account from my field work.

> Mr Mans is lying in his bed when Dr De Groot and Dr Braakman enter his room. A bleeding around the spine high in his neck has paralysed his four limbs. When Dr De Groot sees him lying in a somewhat crooked position, she asks: 'Don't you wear the arm splints we made for you? If you lie in bed like this your fingers will get contracted and your shoulders will soon start hurting.' The doctor looks around and finds two long-shaped splints beside the bed. Mr Mans looks contrite: 'Uhm, it's just so uncomfortable with the splints. It becomes painful after just a few minutes.' Both doctors start to fit the splints on his arms, each on one side. Dr Braakman: 'Your body has to adjust to the new position, that's always painful. You could try to start wearing them for one hour and then increase the time each day.' The man replies: 'The nights are awful 'cause I can't fall asleep with these things.' 'I can imagine,' says the doctor 'But try to carry on. I'll ask the nurse to help you work out a schedule.'

The doctors held to the long-term goal of keeping Mr Mans' limbs loose-jointed and pain free, though they also took the patient's present inconvenience seriously. They proposed to adjust the amount of time the splints were worn in favour of more comfort and pleasant sleeping. Mr Mans agreed with the long-term goal and followed the doctor's suggestions, though only half-heartedly, as he had different preferences.

While in Mrs De Waard's case the future goal of walking was adjusted to the current requirements, Mr Mans' present situation is mainly arranged with the future benefit in mind. A successful arrangement of future and present implies that exclusive standpoints have to be abandoned. Professionals as well as patients elaborate a tinkering approach in which they search for a composition of future benefit and present inconvenience. With practical creativity and a sense for diverse requirements they deal with incompatible goals locked up in different time frames. The approach of day-to-day rehabilitation treatment is one of tinkering towards some acceptable outcome (cf. (Law and Mol 2002b)).

Place

Linked up with the two time frames discussed in the previous section, there are two kinds of locations: the rehabilitation centre and the place people go to after they have left the centre.

In the team meeting, the professionals examine Mrs De Waard's ability to walk at home rather than in the physiotherapist's gym. Goals are often formulated for locations which the disabled person returns to or moves to after discharge. During the last decades, it has been argued that people with disabilities should – as much as possible - get the opportunity to live in local communities rather than in care institutions (DeJong 1983). Although much care has been moved to community-based health care workers, in-patient rehabilitation care in specialised institutions is still provided for severely disabled individuals in the period between acute treatment in the hospital and the less resource-intense community-based care. In-patient rehabilitation programmes are carried out in an institution, yet the goals formulated in these programmes are directed towards locations outside that institution. The places that matter in a rehabilitation plan are people's own home environments, the homes of family members or friends, the supermarket where people will do their shopping, or the office building where they work. In contrast to the goal setting in team meetings and rehabilitation plans that is mainly oriented towards locations outside the clinic, Mrs Smit was primarily concerned about her most direct environment. She was triggered by what people around her were doing and saying. She felt sorry for people 'sitting here brooding'. She did not seem to visualise new environments or other places than the ones she encounters in her current life.

Instead of keeping the two kinds of localities that are relevant to rehabilitation separated, professionals and people with disabilities somehow relate them in everyday treatment. They face the difficulty of being located in an institution while attempting to master an environment that differs from this institution in various ways. Living in one world, they train to manage another world.

In their training sessions, professionals attempt to bridge the distant locations by moving between close by and distant in order to manage ever more and ever distant places.

> Several months ago Mr Porter fell down the stairs and broke his neck. He is now able to sit in a wheelchair and this allows him to start

> with exercises and training sessions. The physiotherapist Paul is going to teach Mr Porter how to transfer himself from the wheelchair to a special exercise table. He shows him how to remove the arm of the wheelchair and to then put one end of the sliding board, a polished long-shaped piece of wood, on the table and the other end under Mr Porter's right buttock. Mr Porter places his right hand on the table, the left one on the seat of the wheelchair, raises his body a little and tries to shift his weight via the sliding board to the table. Paul is standing in front of him, supporting him with his hands around the backside, and very carefully though somewhat awkwardly, Mr Porter moves onto the table.

After the first transfer from the wheelchair to the exercise table, Mr Porter gained more experience in transferring himself to the table and then he continued to make transfers in a growing number of different places. First, he went from the wheelchair to the exercise table, then to his bed, to the toilet, and eventually to a car seat.

> Some months later, Paul and Mr Porter meet at the car park next to the rehabilitation centre, Mr Porter in his wheelchair in front of a car, a sliding board next to him. He is now able to transfer himself from the chair to the exercise table, to his own bed or to the toilet, and he is going to train the transfer from the wheelchair to a car seat. Paul opens the passenger door and gives some instructions. Then he asks: 'OK, shall we try?'

Step by step, Mr Porter masters new locations; he and Paul start at places that are related to the institution, such as the exercise table. Then they move on to environments that are more related to Mr Porter's life outside the rehabilitation centre, such as the toilet or a car.

The training of activities meant to take place elsewhere requires that patients are willing to acquire capacities that are not relevant to their direct environment. When Mr Porter started to train the car transfer he still travelled by wheelchair bus so he did not need to transfer himself yet. The training is ahead of the daily routines and Mr Porter is willing to make a connection with the world outside the centre. As the training becomes more ahead of the here and now, the exercises may become increasingly straining for a patient. The training only pays back in other locations, not in the environment of that moment. People train to make coffee while they do not need to make coffee in the clinic, where coffee is supplied. Making coffee is only useful when people come home, which makes it more difficult to become motivated for the therapy. It is easier to invest if rewards are immediate.

In order to overcome the distance between the centre and the home environment, people try to imagine themselves within their environment at home. Professionals ask people about the life they used to live, the activities they used to do, the setting in which these activities took place and the way in which this could be done again. In addition, people go home for weekend leaves and there they experience what they find difficult to do at home and what they would like to train in the rehabilitation centre. They start to make coffee in the weekends and, thus, experience the difficulties of handling a hot and heavy coffee pot while sitting in the wheelchair. With the knowledge from a person's visualisation of the home or from actual experience, professionals attempt to imitate the distant environment. A car transfer is practiced at the car park in a car that has the same characteristics as the one that will be used later. People train a toilet transfer in the bathroom and make coffee in a therapy kitchen; the institution copies environments that are elsewhere.

Actorship

Rehabilitation professionals in a patient meeting on the one hand and Mrs Smit on the other hand not only relate to different time frames and different locations, they also seem to perceive the individual's role in the rehabilitation process differently. When it comes to goal setting, professionals attribute a pro-active and self-determined attitude to disabled individuals, while Mrs Smit seems to refuse such a position. Instead, she displays a position in which she lets things take their course.

Actorship is important in goal setting. Whose goals are we talking about? Professionals often emphasise that goals should not be set by *themselves* but rather by the *disabled individual*. When Mrs De Waard's case was discussed in the patient meeting, the professionals sought to set rehabilitation goals according to what they understood to be Mrs De Waard's preferences. The physiotherapist motivated his suggestion for an intensive walking programme with the argument that 'walking is very important to her' and other team members shared his impression. In addition to this, people's goals are documented more formally. The physiotherapist's treatment plan (see figure 1) showed a list of functional problems the physiotherapist had identified. Out of this list Mrs De Waard was asked to indicate up to five problems that matter most for her.

In patient interviews, rehabilitation workers ask their patients to make their preferences explicit.

> Vocational counsellor: Usually we start with an interview [in which we ask about] training, employment history, the development of the symptoms, the course of the sickness absence, and the patient's expectation: 'What do you think yourself, what do you want to achieve, what are your capacities, do you have an idea about this?'

The question of actorship in goal setting is also discussed in rehabilitation handbooks. Like professionals, these books emphasise that rehabilitation goals should be set by the individual rather than by the team. McPeak explains that if this attitude is disregarded, the consequences are negative:

> It is tempting to set goals without inquiring about the patient's specific goals. Goal attainment depends on patient motivation and cooperation. The history should document the specific wishes or goals of the patient. If the physician fails to ask the patient about goals, it might not be noted that the patient has unrealistic goals. These problems can be avoided with careful assessment of the patient's personal goals or wishes. (McPeak 1996) (p. 8)

In addition to the risk of unrealistic goals, undesired goals may frustrate the disabled individual and cause ineffective rehabilitation, as Barnes and Ward express quite graphically.

> It may be better for a young man to have a goal of opening a can of lager rather than making a cup of tea! (Barnes and Ward 2000) (p. 9)

But actorship does not only concern the question whose goals are set, but also the degree of participation in the entire rehabilitation trajectory. Professionals stimulate individuals to take a pro-active role in the process. They find an explicit anti-position in the 'passive patient' who has become dependent on the autocratic, though caring rehabilitation team:

> The so-called 'medical model of disability' can be characterized by the disabled person taking or being forced into a dependent and passive position and having goals and strategies imposed on them by the rehabilitation team. It is an autocratic, 'we know best' system

> which may be caring but does nothing to promote independence, enablement, and self-esteem. (Barnes and Ward 2000) (p. 6)

Barnes and Ward describe the medical model in which the rehabilitation teams rather than the individual sets goals and in which the team controls the process and, thus, forces the patient into a passive position, as outdated and harmful for successful rehabilitation. Professionals seek to avoid such a paternalistic attitude and they are, as a way to respect a person's autonomy, very keen on a pro-active involvement of the individual in his or her rehabilitation process (cf. (Schermer 2002)).

In contrast to what professionals in the patient meeting expect from people with disabilities, Mrs Smit did not want to set her own goals. In her conversation with Dr De Groot, Mrs Smit emphasised that she commended herself to God. Whereas therapists wanted her to train pro-actively, she was re-active in therapy situations. She happily followed the instructions during the wheelchair training, as she reported in the interview with Dr De Groot, while a physiotherapist complained in another team meeting that Mrs Smit never tried out a different move or brought up a problem she had encountered. She would start a therapy session by asking the therapist: 'What do you want me to do today?', while therapist expected a more active role in which she would think for herself about what she would need to improve her functioning. In Mrs Smit's view on rehabilitation and medical treatment, the rehabilitation team is responsible for the therapy and the patient follows instructions.

So far there seem to be two opposing positions concerning the question of actorship in rehabilitation: either the individual or the team sets goals and determines the course of the rehabilitation trajectory. The disabled individual either participates pro-actively in rehabilitation and tries to control its course or she displays a re-active attitude of acceptance of how events take their course. In positions the roles of disabled individual and team are separated and thus, to a certain extent, exclusive; it is *either* the team *or* the disabled individual who sets goals. And the person may take *either* a pro-active *or* a passive role in rehabilitation.

In contrast to these two fixed positions, in day-to-day treatment various forms of actorship are distributed among professionals and patients in a more complex and dynamic way. Goals tend to go back and forth between both the patient and the care provider.

> Mr Porter is wheeling in his hand-propelled wheelchair to the occupational therapy department, where he is welcomed by therapist

Susan: ‘Hey Mr Porter, how are you today? I’d suggest trying out a ride with a handbike[4], what do you think?’ Mr Porter nods and they make their way to another wheelchair that has a long device with one wheel attached to it, which turns the wheelchair into a hand-driven bike called a handbike. Susan explains: ‘You know how it works, don’t you? You might have seen Hans Faber with his bike around here. You may use it for transportation outside, but it’s also a good device to train your upper body parts.’ After quite some time of instruction, wheelchair adjustment and safety checks, Mr Porter gets into the handbike-wheelchair and starts biking towards the other end of the ward. Mr Porter stops at the end of the corridor and Susan shouts out her encouragement: ‘Splendid! This was great! How did you like it?’ Mr Porter replies, in a more reserved matter: ‘Uh, it’s difficult and rather straining, I hadn’t thought that my arms were so weak.’ Susan: ‘You’ve got to practice and to train your arms, of course, but I really think you were great. Shall we continue that way?’ Mr Porter disagrees: ‘No, I’m exhausted, I’d prefer to go back and stop.’ ‘Alright, no problem, it’s good that you set your limits.’

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[4] Figure 2 shows a handbike such as the one Mr Porter used.

Figure 2: Handbike

In this handbike session therapist and disabled individual are in ever changing ways actively involved. Initiative for a new exercise or a new step in the treatment is often, though not always, taken by professionals. Based on their routines and their professional expertise they bring up new therapy goals. However, the suggestions they make for new treatment activities are not only shaped by the patient's physical constitution, but also by the financial and institutional possibilities. A handbike session only makes sense if the centre has handbikes available and if people get the possibility to continue riding a handbike after they have returned to their home environments[5].

Although the goal of riding a handbike is initiated by the professional, the case of

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[5] This point shows that goal setting is not simply a personal, inter-personal or even institutional matter. The political, organisational, financial framing of which goals are seen as realistic is highly relevant for a discussion of goal setting, but exceeds the scope of this paper. A good source for disability politics is (Davis 1997) and (Albrecht et al. 2001).

Mr Porter demonstrates that such a goal is suggested to the patient rather than imposed on him. In the ordinary course of events, rehabilitation workers informally check if their goal matches with the patient's expectations, such as: 'What do you think?' The individual agrees in a similar way by nodding or just starting with the exercise. This insignificant moment may be identified as solidification in the interaction that results in the patient's goal; it demonstrates that actorship is often weak rather than pro-active and resolute (Gomart and Hennion 1999).

The therapy goal to ride a handbike is inevitably shaped by the entire rehabilitation setting. As the occupational therapist suggested, people often get interested in particular devices after they have shared experiences with their fellows ('You might have seen Hans Faber with his bike around here.'). In addition, the patient's goals are likely to be affected by the enthusiasm with which a therapist presents a new treatment approach.

Mr Porter agreed with riding a handbike. If, however, people refuse to do an exercise, the therapists often hold back, as did Susan when she agreed to return to the ward rather than taking another round. In day-to-day rehabilitation, a patient's insistence on an unrealistic goal is rare, as is the strict refusal of a recommended treatment. Much more frequent and more interesting for investigation are those innumerable moments of hesitation, fear, or weariness to set a new goal; moments of impetuosity or enthusiasm; of laziness or unfamiliarity with a new situation. Which modes of activity and passivity, which interactive modes of stimulation and reluctance do professionals and disabled people employ in the process of rehabilitation?

Anecdotally, physiotherapists and other rehabilitation workers are said to urge people to treatment and shout out instructions and encouragement in order to make them try harder and not give up (Murphy 1987) (Reeve 1998). From the fieldwork I did in the Dutch rehabilitation centre, I cannot confirm these accounts, which raises the question how to understand this difference[6]. Nonetheless, therapists in my field did encourage their patients verbally and physically, though they also seemed to think that a therapy goal and the motivation to attain it should come from the person herself. If a person is only motivated by a therapist, they think, the therapy is limited to the

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[6] It is interesting to explore in greater detail the difference between the rehabilitation centre where I was observer and the rehabilitation settings described by other authors. There may be a time difference: therapy approaches have changed during the last two decades. In addition, cultural and other differences between the Netherlands and the US may contribute to these observations. A comparison of different treatment settings is highly relevant, but was not part of my research. For an example of a study in which two different practices of giving birth in two different countries, the Netherlands and France, were investigated, see (Akrich and Pasveer 2000).

rehabilitation centre, while they want people to develop activities outside the rehabilitation centre, at home.

> Vocational counsellor: The ultimate goal is that people continue with it. You jump on the bandwagon for a short time only, and then the train continues and we leave the train again and they [people with disabilities] have to carry on.

However, even if professionals hesitate to push people to engage in treatment, they think that some form of support is necessary.

> A physiotherapist: Everybody has his own responsibility [for the rehabilitation]. But we also have our own professional responsibility. Someone may have gone through a lot, especially those who've experienced a large trauma. It may be necessary to stimulate someone just for a while in order to help him over this threshold.

In order to deal with the tension of support versus the disabled person's own responsibility, professionals develop modes of stimulation in many varieties, depending on individual characteristics of the professional and the patient, as well as on the kind of encouragement professionals think someone may need. Health care workers provide people with spinal cord injuries with information about a potential therapy goal, about the advantages or disadvantages, the chances for success, the types of investment, the financial costs etc. Much information, both verbally as well as on paper, is provided to patients in order to help them make up their minds. In the Dutch rehabilitation centre people with spinal cord injuries are invited to participate in an education programme, called 'Spinal Cord Injury Education', which includes a series of meetings educating people with spinal cord injuries as well as their partners or family members about diverse topics relevant to spinal cord rehabilitation. Some people gather this information eagerly, completing it with loads of other stuff collected from the internet, brochures, journals and books, while using all this as an input for their rehabilitation trajectory. A person may for example ask about the advantages of a special kind of handbike she has read about elsewhere. By contrast, others are hardly interested in the education they are offered; they feel compelled to attend the meetings, but they do not see how this knowledge could be of any use in their rehabilitation. One man with an incomplete spinal cord injury first refused to participate in the programme, because he insisted that his spinal cord was not permanently injured and that he would recover from his injuries after some time[7].

In addition to gathering knowledge, individuals tend to get involved in their rehabilitation by physical experience of various activities.

> A physiotherapist: "Somebody enters our centre and doesn't know what he may be able to do and what it takes to put on your trousers yourself. Only by doing things people experience the possibilities."

The physical experience of an activity may create enthusiasm and motivation to perform what is still possible with a disabled body, while it may cut down unrealistic goals. Some disabled people are excited by new physical experiences and they are eager to extend the range of situations in which they explore new skills. Others are much more reluctant and anxious, even if they are supported by a therapist who guides them through a new exercise. They do not tend to apply the therapy skills to situations of everyday life and rarely try out something completely new, either within or outside the therapy setting.

In addition to knowledge and embodied experience, experiences of fellow patients help people with disabilities to explore their goals. A spouse of a man with spinal injury recounted how she was first very depressed about the kind of life she and her husband were going to live after he had become wheelchair-dependent. The stories of another couple gave her new hope for the future:

> "You just think, holidays and so on, your world completely breaks down, so you just think, it's all impossible. But they [a couple, both wheelchair-dependent] were very optimistic and [said to us:] 'Why shouldn't that [going on holidays] be possible?'"

Lively accounts by experienced people who have gone through extended rehabilitation appear to be very stimulating for many people in rehabilitation, because it helps to get an idea of what it means to live with a spinal cord injury. The contact among fellows with similar experiences and comparable daily hassles is important in several respects,

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[7] This is a situation in which the man's ideas about his rehabilitation were accepted by the professionals, while they did not match their goals. He did not attend the spinal cord education, nor did he initially go to wheelchair training sessions, because he thought he would only temporally need a wheelchair. After some time, he changed his mind and started to attend the wheelchair training.

but the woman in the quote above emphasises that it was important for her in order to be able to think about new goals rather than to see ‘your world’ breaking down.

Both professionals imposing goals upon patients and individuals setting self-determined goals without interference are rare in day-to-day practice. Instead, subtle and complex entanglements of various contributions lead to an activity such as riding a handbike. Setting goals is part of small-scale activities, distributed among professionals as well as people with disabilities, which are often not identified as purposeful actions. While goal setting assumes that goals precede and determine people’s activities, rehabilitation practice indicates that goals unfold *simultaneously* with and as a part of actual and embodied action. This argument adds a temporal dimension to Lucy Suchman’s exploration of the relationship between plans and concrete action (Suchman 1987). She argued that plans fail to determine our actions, because all activity is fundamentally concrete and embodied. ‘Plans’, Suchman stated, ‘are at best viewed as a weak resource for what is primarily *ad hoc* activity.’ (p. IX). Rehabilitation practice shows that plans not only fail to *determine*, but also do not necessarily *precede* our actions.

I have described three different ways in which goal setting is enacted in the interaction of professionals and disabled people within the situated context of rehabilitation. Via education, embodied experience of activities, and exchange with fellows, professionals and disabled people continually constitute ways of involvement in rehabilitation activities and the establishment of rehabilitation goals.

Mr Porter’s handbike story continues and we learn something else about actorship and goal setting.

> One year later, I visit Mr Porter at his own house for an interview. His condition has massively improved: he is on his feet now; he does not use a wheelchair and walks with a cane. For outdoors, he walks short distances with a rollator and takes a scooter[8] for longer distances. A handbike is not mentioned during the whole interview.

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[8] A scooter is particular kind of motorised vehicle often used by people with walking disabilities for transportation outside their home. See figure 3 for an example.

Figure 3: Scooter

Mr Porter's tremendous physical progress rendered a wheelchair and a handbike superfluous. Goal setting, distributed among various actors, happens all along the rehabilitation trajectory, and yet end results are sometimes much less determined by goals than by unforeseen developments of the disease. This resonates with what Mrs Smit in her rejection of goal setting seemed to express: she embraced the uncertainty of life.

Articulation of Difficulties

I have explored the tensions that come along with goal setting in rehabilitation care and have unravelled how therapists and patients in day-to-day rehabilitation tinker along with different time frames, separated locations and different forms of actorship. An understanding of goal setting in terms of time, place, and actorship enables me to articulate now the specificities of some difficulties that appear in setting rehabilitation goals.

Time: Assessment of Technological Aids

In daily rehabilitation, professionals attempt to escape the separation of future and present by weighing off future goals against the present condition. However, sometimes the two time frames cannot get connected.

> Mrs Blom is about halfway her in-patient rehabilitation trajectory and intends to apply for a scooter. She tells me about that scooter in an interview.
>
> RS: You said you applied for a scooter. Do you use it to go outside?
>
> Mrs Blom: Yes. We used to cycle a lot [before the injury] and my husband can still use his bike; I can ride next to him with the scooter.
>
> RS: Have you done it yet?
>
> Mrs Blom: Yes, I went down this neighborhood and into town with the therapist. We entered a shop, this supermarket down there, it went very well.

Applications for rehabilitation services, assistive technology, special housing or professional care for people with physical disabilities take a lot of time. Many of these services are scarce in the Netherlands as well as in other countries and people wait for them for months, in some cases years. Wheelchairs or scooters are personally fitted and require long trajectories of try outs, fittings, adjustments, and re-adjustments before being assembled. Consequently, people start assessments as soon as possible in rehabilitation. Mrs Blom's scooter was prescribed halfway through her in-patient rehabilitation for her situation at home. Her condition was assessed at a particular point in time and projected to a situation that was months ahead. For somebody with a severe disability this is problematic, since the development of the disease is uncertain.

> It is almost a year later when I visit Mrs Blom in her own house.
> Again, she tells me about the scooter.
>
> Mrs Blom: I'll return the scooter to the centre.
>
> RS: You haven't used it?

> Mrs Blom: No, I can't get on the seat, I can't make it. The seat is too high, it's a difficult position for [using] the sliding board, it's too much for me. And it's too much for Ed [her husband] as well. So we don't go by scooter and by bike. Ed also loves to walk. […] I'll send the scooter back to the rehab, it might do someone else a favor; such things are wasted on me.

While Mrs Blom was able to get on the scooter at the centre, she could not manage it some months later at home. The reasons for this change are diverse, which makes them difficult to anticipate in the clinical stage. A sudden or gradual deterioration of a person's condition, as in the case of Mrs Blom, is not uncommon in people with chronic disabilities, especially after they return home. But it also happens that a person's situation improves considerably, as happened to Mr Porter. These changes have to be re-connected to referral procedures that are caught in another time frame. In lengthy assessments, in which not only the therapist and the patient are involved, but external authorities as well, it is hard to re-negotiate changes in a person's situation to goals such as riding a scooter. In the case of Mrs Blom, this re-negotiation did not happen, which is why she ended up with a scooter she could not use.

My analysis of time frames in goal setting may help to understand why the long-term goals required by lengthy and inflexible application procedures are potentially problematic for the rehabilitation of people with chronic diseases or severe disabilities. A regular re-balance of present and future in complex and lengthy assessment procedures is difficult, but important if one wants to prevent unachieved goals and unused technical aids. How to do this?

One may re-connect goals to present situations by regular check-ups during the application in which relevant changes of the patient's situation are reported to the executing company. In addition, goals can be adjusted to the patient's needs if devices are designed in such a way that devices can be adjusted after they have been brought into use.

Place: Imitation and Transportation

An analysis of goal setting in terms of time frames helps to articulate the difficulty of re-connecting gradual changes to far-away goals in lengthy assessment procedures. What can we learn if we focus on significant differences between the clinical environment and the home environment?

> Mrs Blom: I can't vacuum my home. […] I did all these things in rehab, but it's quite a difference to do it at home.
>
> Interviewer: How is it different?
>
> Mrs Blom: 'We'll teach you vacuuming' [said the therapists], alright, I was in my wheelchair and took the vacuum cleaner and in these large rooms with nothing around it's not a big deal. But here at home I've got to put the stuff aside and I can't make it.

The main professional strategy for bridging the differences between centre and home is imitation. With Mr Porter, the therapist went to a car parc and practiced at a car that resembled the one Mr Porter's wife drives while Mrs Blom vacuum cleaned one the rooms in the rehabilitation centre as if she were at home. But the rehabilitation centre will always be an imperfect simulation of the home. The differences concern not only the material environment, but also the amount, quality and availability of professional care, as well as changes in the social environment of the person. People with disabilities will always get into situations that they have never mastered before and that are hard to live through.

If clinic and home are geographically separated and if an imitation of people's homes will always be imperfect, what other ways of overcoming the differences can one think of? Mrs Blom was not able to *transfer* what she had learned in the clinic to her home. Training the capacity to transfer acquired knowledge and capacities from the clinic to locations outside the centre means that differences between places are not reduced by imitation, but rather that patients are encouraged to explore as many different situations as possible in order to learn from the differences (cf. (De Laet and Mol 2000)). People are then supported to confront unknown problems, to cope with unfamiliar settings, and to explore their adaptive potential. Yet, one has to keep in mind that the possibility to adjust to an unknown setting is much more limited for a person with physical impairments than for an able-bodied person.

In addition to the approach of imitation, in-patient rehabilitation has recently developed initiatives with the aim to train people's creativity. As I have noted earlier, professionals stimulate disabled people to explore unfamiliar environments at home in the weekends while they still return for clinical rehabilitation during weekdays. In addition, professionals sometimes confront people with disabilities with unexpected changes that force them to find productive solutions. However, this type of treatment that attempts to practice a patient's adaptability is demanding for both the therapist and the patient as such an exercise-into-the-unexpected is counter-intuitive. A professional has to *organise* an *unexpected* situation and she has to follow the person's struggles to manage the situation without early interference. The disabled person, in her turn, has to accept the challenge of the experiment and must try to deal with the situation without giving up too easily.

However difficult such a training of creativity and adaptability might be, it is important to acknowledge that one of the problems of goal setting in rehabilitation is the separation of places for which goals are set. My analysis of goal setting is an attempt to help unravel these problems and describe different strategies – imitation or transfer - of dealing with them.

Actorship: The Burden of Independent Living

Different time frames and separate locations are challenges in clinical rehabilitation, as are the different forms of actorship. I have argued that goal setting is a dynamic interaction of professionals and patients with different modes of involvement in the rehabilitation process. What happens if this dynamic interaction is challenged? To explore this question, I return to Mrs De Waard, the woman whose situation was discussed in the patient meeting with which I opened this paper.

> Mrs De Waard eventually left the rehabilitation centre in 2000 after more than a year of clinical rehabilitation. She was in a hand-propelled wheelchair and her hands and arms were somewhat impaired when she left the centre. Moreover, she was able to walk short distances with a rollator. Aged 60, she moved to a home for elderly people where some degree of nursing care was available. She very much looked forward to getting back to a place of her own after such a long time in health institutions.
>
> But much went wrong after her move. Her attendants were inexperienced with the care for people with spinal cord injury, so that she had to give exact instructions. The assistance was limited to personal care every morning and night, and assistance with going to the toilet. As a consequence, she had to manage her day-to-day living at home, her household tasks and errands, her meals, the mobility in and outside home etc. with limited professional support.

> She could hardly make it. And the next consultation with her rehabilitation physician was still weeks ahead.

It appears that some people collapse under the burden of the management of their own disability at home. Rather than the complex interaction between different actors that characterizes in-patient rehabilitation, the situation at home depends to a large extend on Mrs De Waard's direction. In order to live independently, instruct personal attendants, and organize necessary support, she has to become a strong manager. After returning to her home environment, a person is separated from the professional network that supported her. Self-maintenance is a valued goal for many disabled individuals and professionals, but the consequence of isolated actorship implies costs that are high, sometimes too high.

How can a more distributed and interactive actorship be developed at home, even if people live independently and self-supporting?

> It is one year later, 2001, and Mrs De Waard was re-admitted to the rehabilitation centre after various setbacks. When the day of her new release is approaching, professionals seem to be much more aware of their responsibility in the process at home. Dr Braakman: 'You'll go home again, but I hope we're better prepared than last year. I'll make an appointment with you just two weeks from now.' 'And what about physiotherapy?' Mrs De Waard asks. 'We'll contact your physiotherapist at home and discuss the state of affairs, as well as your attendants in the home. We'll check if everything is prepared and everybody is up-to-date.'

A move from the centre to home often implies a re-distribution of responsibilities; hence an intermediate phase of professional stand-by may help many people to re-arrange activities of day-to-day living. Recent initiatives of community-based rehabilitation teams, such as outpatient rehabilitation and case management are important developments in this respect (Barnes and Ward 2000). Another example of re-arranged actorship is a project where specialist nurses from regional rehabilitation clinics in the Netherlands have set up consultation services for people living at home after an extended period of hospitalisation in a rehabilitation centre. These forms of treatment and care, though not intended to outsource clinical care in the community, could be an effective arena in which ways of active disability management as well as professional support are re-negotiated after a period of hospitalization. My analysis of actorship in goal setting may help to understand the intricacies of such re-negotiations.

To Conclude

Goal setting is an important professional method, and it is one of the key concepts that structure the field of rehabilitation medicine in theoretical discussions as well as in the daily routine. However, the actual use of goals in rehabilitation practice is much less straightforward than the general acceptance of the method suggests. In order to understand the difficulties of goal setting in day-to-day practice, I have explored the normative assumptions of goal setting, that is a set of tensions linked up with goal setting. First, goals are set for a future situation that may require activities that clash with specificities of the present situation. Second, professionals in clinical rehabilitation develop goals for an environment that differs from the environment in the centre, where people train for the accomplishment of goals. Finally, goal setting requires active patient participation and individual control that sometimes appears impossible, unrealistic, and undesirable.

The rehabilitation approach for people with a spinal cord injury, which I have described in this paper, deals with these tensions of goal setting in a pragmatic, flexible, and dynamic way. Goal setting is turned into a practical tool, despite its contradictory assumptions, because in practice professionals are able to juggle its various elements. Rather than striving after fixed goals, rehabilitation practice is oriented towards a specific person with particular problems that require local assessments. Thus goals become helpful resources rather than rigid conditions in the process of rehabilitation. Goals are, in short, *situated* in the particular, local, individual context of rehabilitation.

This paper is an articulation of the intricacies, practicalities, and tensions that come along with the key concept ‘goal’ in physical rehabilitation. Its approach is not critical. I do not state that goal setting is too inflexible a strategy to be used in the erratic practice of rehabilitation[9]. Neither do I criticise the practice studied for not living up to the ideals implied in goal setting - not being planned and determined enough (Barnes and Ward 2000). I have not even found a misfit between the theoretical demands of

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[9] For such an approach see for example (Engelhardt 1996) and (Tauber 2001), who argue that the Kantian reading of the principle of autonomy is inappropriate in the clinical setting of health care.

goal setting and the demands set by day-to-day rehabilitation practice that induces me to suggest some new or refined concept[10].

Instead, I have explored a different style of theorizing. Equipped with theoretical background from philosophy, sociology, anthropology, and science and technology studies, trained in methods of ethnography, and drawing on some professional experience in health care, I went out into a rehabilitation centre and followed the notion 'goal' to the various locations where it was brought into use (cf. (Timmermans and Berg 2003)). This allowed me to see goal setting demonstrating its strengths in a patient meeting where goals and plans enable coordinated action in the complexity of a severe disability. I also encountered goal setting's weaknesses in attending to the uncertainty, unpredictability, and instability of a chronic disease or disability. If taken too rigidly, goals and plans are difficult to adjust to the erratic flux of life with a disability. However, in day-to-day practice, rehabilitation practitioners and people with disabilities appeared to have much expertise in the management of goal setting. They had found ways of making goals more flexible and adaptive by connecting different time frames. They applied different strategies for linking the different places goals are set for. And they interactively involved different actors in different ways in the process of rehabilitation.

An articulation of the tensions coming along with goal setting, the tensions between different time frames, places, and various forms of actorship, is, or so I would like to argue, a normative analysis of current practice and as such more fruitful than a judgement about the appropriateness of goal setting in rehabilitation (Molewijk et al. 2003). It helps to understand why goal setting is often so appealing, even if so much effort has to be made to link it to the practicalities of day-to-day life. It also helps to make the tensions coming along with goal setting, as well as the creative ways these are dealt with, more readily available in professional and academic discussions. With the articulation of the tensions of goal setting I pursue two – yes – goals. The first is to open the possibility for an exploration of unquestioned routines as well as experienced difficulties, such as waiting lists or patient involvement in rehabilitation, from a different angle, e.g., as connected to issues of time frames, place and actorship. My re-description

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[10] Ruth Benschop and colleagues took such a stance in their research of the concept of voice in public debate about genetics. They argued that voice was often narrowed in public debate to giving individuals a choice about developments in genetics. Instead of voice, they suggest a refined concept, 'hesitant voice', which is much better equipped to articulate important issues of genetics and predictive medicine (Benschop et al. 2003).

of goal setting in rehabilitation should provide new opportunities for reflecting upon current practice. It should support and inspire self-reflection of rehabilitation practitioners.

The second goal of my articulation is to invite theorists to further analyse the concept of 'goal' and explore its implicit normativity, such as the tensions, strengths, limitations, as well as the effects of goal setting in contexts other than clinical rehabilitation. Goal setting is mobilised in many professional and non-professional settings and it touches upon issues such as individuality, control, and uncertainty (Morris and Fitz-Gibbon 1978). Hence, a study of goal setting in physical rehabilitation is not so much an analysis of a local concept, as well as an examination of assumptions and routines that are much more widely available and for which goal setting in rehabilitation may serve as an example. It will be intriguing to explore how the tensions of goal setting evolve in other medical or non-medical sites and situations, which of these tensions is more or rather less important elsewhere, what other strategies are developed to deal with them; what and how to learn from the tensions that unfold in goal setting?

Hence, I invite professionals to take advantage of my re-descriptions of goal setting in rehabilitation practice for their self-reflection and I invite theorists to relate to the example of rehabilitation medicine as they explore goal setting and its tensions elsewhere. By doing so, I also argue for a style of academic research that does not assess either theoretical notions in the light of empirical evidence or judge the practice in terms of the theory. Instead, I propose *articulation* and *re-description* of a concept-in-practice in order to learn from the intricacies of its usage.

Chapter 4

Wordless Pain: Dealing with Suffering[1]

Current health care discussions deal with issues such as self-determination, consumer orientation, and patient autonomy, leaving aside other aspects of living with a disability or disease, such as pain or suffering. The European Disability Forum for example states: '[Our] mission is to ensure disabled citizens' full access to fundamental rights through their active involvement in policy development and implementation in the European Union' (Forum 2004). The Forum stands up for civil rights, it does not talk about pain and suffering. Instead, full citizenship and choices for people with disabilities are high on the agenda of disability activists, as the following quote illustrates: 'The Independent Living Institute offers resources for persons with extensive disabilities and develops consumer-driven policies for self-determination, self-respect and dignity' (Institute 2004).

The avoidance of suffering in the vocabulary of disability advocates resonates with the criticism that was raised several decades ago by medical sociologists and disability researchers concerning the public stigma of people with disabilities as being dependent, childlike, incompetent, and deprived individuals[2]. Shifting from a medical model of disability towards a social model, disability activists saw disability not as a physical or mental impairment, but rather as a social construction, resulting from social and political discrimination[3]. These scholars tried to overcome the reduction of disabled people to their physical condition: 'We must free ourselves from the "physicality" of our

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[1] An earlier draft of this chapter was published in Dutch in *Krisis: Tijdschrift voor empirische filosofie.* See (Struhkamp et al. 2004). A slightly revised draft of this English chapter was submitted in *Cultural Studies.*

[2] See for some early examples (Becker 1963; Goffman 1963).

[3] See for example (Davis 2001; Oliver 1990)

conditions and the dominance of our lives by the medical world.' ((Zola 1979), p. 455)[4]. They criticized the normalization and medicalization of the impaired body in medical institutions, which was believed to result into the materialization of impairment as 'unitary and universal attributes of subjects' ((Tremain 2002), p. 42).

The language of *self-determination* and *civil rights* does not accidentally skip over pain and suffering, but is being used in a deliberate attempt to avoid the portrayal of people with a disability as passive victims of their tragic fate. It represents people with disabilities as active and empowered citizens instead. However great the gain of this shift - there is a problem with this, too. For while they are no longer foregrounded, pain and suffering risk to be silenced altogether. And what ensues may be a cultural void of gestures and words that communicate suffering and pain[5]. The anthropologist Arthur Kleinman and his colleagues wrote: 'A major preoccupation in the Western tradition has to do with the incommunicability of pain, its capacity to isolate sufferers and strip them of cultural resources, including especially the resource of language' ((Kleinman et al. 1996) p. XIII)[6]. We all seem to avoid talking about suffering, because we fear the erratic regimes of our potentially sick, disabled and painful bodies [7].

Recently, therefore, various scholars and activists try to bring the reality of pain and suffering back into the public domain. They seek to reintroduce bodily experiences as well as the identities and subjectivities that go with them, into the discourses around disability (Thomas 1999). This paper is a part of that endeavor. More specifically, it challenges the idea that suffering inevitably renders disabled people into passive captives of their physicality. Instead, it empirically explores how people actually *do* suffering[8]. By

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[4] See also (Illich 1975).

[5] Contrary to health care and disability discussions, there is an increasing representation of suffering in the popular media. See Luc Boltanki for an elaborate analysis of the relationships between suffering, media and politics (Boltanski 1999).

[6] Many scholars signalled the difficulty to express and articulate pain or suffering. Elaine Scarry aptly wrote in her influential analysis of the political consequences of the inexpressibility of physical pain: 'Physical pain has no voice.' ((Scarry 1985), p. 3). Various contributions to the special issue on 'Social Suffering' in *Daedalus* formulate questions of social suffering in relation to language (Kleinman et al. 1996). See also Virginia Woolf's impressive literary search for words to describe embodied experiences of illness: 'English, which can express the thoughts of Hamlet and the tragedy of Lear has no words for the shiver of the headache.' ((Woolf 1967), p. 194).

[7] Richard Sennett elaborated on these fears, which he called the 'shame of dependence': in western societies, people feel it is demeaning to publicly expose weakness, dependency and suffering. He demonstrated the liberal roots of this shame and developed a theory in which respect and inequality can go hand in hand (Sennett 2003).

[8] This question resonates with the quest for suffering in contemporary theology. Theologians encourage the acceptance of human suffering in a mystic embrace of reality (Sölle 1984). Hence, they support the idea that suffering requires some form of active engagement. However,

framing that question, the paper hopes to demonstrate how people *actively* deal with suffering in the day-to-day embodied practices of living with a disability without passively sinking into it. At the same time, the analysis searches for a possible language to communicate its findings. It does not attempt to explain what people in everyday practices already know; instead, it articulates what is, often without so many words, already being done[9]. If it is hard to face and to speak of human suffering in living with disabilities, this paper is a modest contribution to find words that help to articulate these experiences. Rather than searching for an answer to the question *how to live*, I suggest investigating and describing *how one lives*.

In the search for words that articulate what is being done, I do not pursue empirical completeness, but seek illuminating examples. This article therefore does not provide a *comprehensive* empirical answer to the question how people actively deal with suffering. Instead, I hope to provide illustrations of concrete empirical practices of suffering, building on the rich tradition of articulations of lived experiences of disability in autobiographic writing, anthropological and participatory research[10]. Hence, the empirical research material was collected at a site that suits the question of this paper: a center for rehabilitation of people with a physical disability[11]. People do not enter rehabilitation centers to passively undergo medical treatment, but to actively engage in an individual and dynamic rehabilitation process. Rehabilitation programs emphasize education, teaching people to take an active role in living their own life with their disability. In this active approach, suffering is given shape in multiple ways. First, people deal with suffering by making *translations*, which implies a transformation as well as a transfer of the difficulties they encounter. Second, people discover in physical rehabilitation how to *manage* their suffering. And finally, rehabilitation participants stop trying to combat suffering and *create a space* where suffering is allowed to exist.

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theologians often deal with Suffering in general rather than with the lived experiences of concrete people, who engage with their suffering in concrete situations of day-to-day life.

[9] The ethnographic study by Carolin Länger is another example of an investigation of a cultural phenomenon, in her case blindness, in social practices (Länger 2002).

[10] For accounts of their own disabled embodiment, see for example (Murphy 1987) or (Toombs 1992). For an overview of studies that articulate experiences of disabled living, see (Gill 2001).

[11] This paper is based on ethnographic research in a Dutch rehabilitation center. During several months in 2000 and 2001, I conducted participant observations on a ward for people with spinal cord injuries or extended multiple sclerosis (MS). I also held semi-structured interviews with health professionals and with disabled people, some of whom I later visited in their own home environment after they had moved to their home. All field notes and interviews have been translated from Dutch into English and all names are invented; in the usage of first or last names, I follow the conventions of the ward.

‘The wheelchair is your legs’: Translations

What kind of problems can we come across at the spinal cord unit? What do people suffer from?

> The physician Dr Petra Klein introduces me to Mr Van der Laan, whose spinal cord got injured in a traffic accident more than ten years ago. I ask: “You came here last week because of bedsores?” “Yes, and because of my bad condition, my health was zero point zero. […] I’m listless, this last six months I didn’t do anything at all. I lay in bed for twelve weeks. When I sit in a chair for an hour now, I think: ‘Well, glad I can lie down again.’ Can you imagine? […] I want to go home, leave the hospital, just have a nice life, quit the doctoring, get into a better shape, just live!”

What is it that Mr Van der Laan suffers from? He does not mention his spinal cord injury, because it is a matter of fact. He does not seem to suffer from the impossibility of feeling any sensations, pain, temperature or touch below the injury level. He does not complain about his erratic bladder and bowel movements or about his muscles, which are paralysed, but contract in uncontrollable spasms. His disabilities are serious, but they have moved to the background. Mr Van der Laan came to the rehabilitation clinic because of the bedsores, which form when one lies or sits in one position too long. The open wound at his skin is not physically painful, because Mr Van der Laan does not have any sensation. But a tiny sore can expand into an ugly, gaping, and difficult to heal ulcer. This is the reason why Mr Van der Laan was in bed for twelve weeks. It was terrible. He became listless and apathic by not being able to do anything or to go anywhere. He wants to get in shape again, he just wants ‘to live’.

Misery does not seem to sit in exact locations: it moves from the spine via bedsores to life: Mr Van der Laan does not suffer from the paralysis or from the sores. Rather, his bad condition, the isolation, and the powerlessness make him feel really unhappy. Despite the dissolving volatility of suffering, rehabilitation professionals try to treat the diffusive consequences of extensive disabilities.

> I walk down the corridor together with the rehabilitation physician when we meet Mr Van der Laan, lying on a special kind of stretcher with large wheels and rings, just like those on wheelchairs. Mr Van der Laan is lying flat on his stomach and pushes the stretcher to

> move himself to the dayroom. Petra Klein explains: “It’s a stretcher-wheelchair for people who are not allowed to sit. It gives them the opportunity to move around independently.” Mr Van der Laan greets us and pushes the stretcher ahead.

The wheelchairbed enables Mr Van der Laan to train his arms and general condition. He can leave his bedroom, drink coffee and chat in the dayroom. Professionals try to move beyond the incurable spinal cord disease. They don’t become fixated on the slow sore treatment even though it is still important to them[12]. Rather, they *translate* the difficulties people tend to encounter[13]. Mr Van der Laan suffers from a condition that can be treated by a stretcher with large wheels: it enlarges his sphere of action, offers an opportunity to meet others, and helps him keep fit. The wheelchair stretcher helps to translate an unsolvable problem, the hard-to-treat sores, into a problem that can be solved, which is that beds are not very mobile[14]. Therapists start by training weak legs immediately after a neurological lesion, but for most people with paralysed legs, clinical rehabilitation has no possibility whatsoever to make legs work again. Hence, rehabilitation practitioners shift their attention from the weak leg towards the difficulty to walk, to get from one place to another, to go to work, or to do the shopping[15].

Assistive technologies such as wheelchairs are enrolled to make these kinds of translations. A physiotherapist illustrates the translation from body to technology in a provocative, but straightforward way:

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[12] Moving beyond the physical disease towards the functional consequences of a physical impairment is the basic philosophy of rehabilitation (Barnes and Ward 2000). This philosophy was formally established in the International Classification of Functioning and Disability (ICF) by the World Health Organization (WHO 2001), which is a revision of the International Classification of Impairments, Disabilities and Handicaps (ICIDH) (WHO 1980). The ICF seeks to provide a comprehensive framework for health and health-related states that may or may not induce medical intervention or professional support. Rehabilitation medicine formulates its overall aims primarily at the level of activities and participation, rather than at the level of body functions and structures.

[13] Bruno Latour introduced the notion of translation in his studies on the production of scientific facts and technological artifacts (Latour 1988) (Latour 1987). He worked out the two different meanings of the word translation, which are also relevant for an understanding of suffering. Translation means transformation in a linguistic and transfer in a geographic sense.

[14] A few decades ago, critics of medicine regarded medical technologies as the most important *sources* of human suffering, rather than as means to deal with it (Illich 1975). However, more recent approaches in the philosophy of technology assume that technology is part of our daily life. Its consequences, or so these scholars argue, are to be assessed in the concrete situations of its use. See for an overview (Achterhuis 2001)

[15] Contrary to clinical rehabilitation, rehabilitation research does attempt to find interventions into the bodily impairment in spinal cord injury, for example research on nerve regrowth or electric nerve stimulation of paralysed muscles (Holsheimer 2001) and (Kenney et al. 2001).

> "I always say: your wheelchair, that's your legs."

Professional distance is not required for making these translations. After some time of adjustment, many people with a disability make a similar argument:

> "It may sound strange, but I don't really miss my legs; one can live well without legs and use the wheelchair instead. I can go anywhere with the chair."

Translations are attractive, because they offer possibilities for action. *I can go anywhere with the chair.* If the problem is framed in terms of cut nerves and weak muscles, a spinal cord injury is characterized by loss and lack. However, as soon as the problem is reframed into mobility, into how to push a wheelchair, the situation is still tough but not a dead end. There is perspective, challenge, possibility for action. Beyond lack there is hope, and hope mobilizes positive energy.

Translating is not a resigned, but an active way of dealing with suffering. People *actively* transfer their difficulties into locations and translate them into languages in which they can be dealt with. And yet, each translation is incomplete, there is always something lacking[16]. Most wheelchairs do not negotiate stairs; our built environment is much more adapted to legs than to wheels[17]. Walking does not cause bedsores, but sitting in a wheelchair does. Each translation is the source of new trouble. In addition, some problems are hard to translate.

> Mr Sonsbeek had a spinal cord injury five years ago, which made him wheelchair dependent. He was treated at the spinal cord unit for a broken foot, but he will soon return home. The physician Petra Klein: "Mr Sonsbeek, you're doing very well and we have the impression that you're on the same level as you used to be." Mr Sonsbeek: "Well, I feel that I've lost something. With a spinal cord injury, each time you give something up." Dr Klein: "Can you tell what you've given up?" "My feet are more clubfooted, the muscles aren't supple, everything is more difficult than it used to be." The

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[16] Bruno Latour indicated that each translation is always a transformation: 'We cannot speak properly, moving from the *same* to the *same*, but only roughly, moving from the same to the *other*. […] If a message is transported, then it is transformed.' ((Latour 1988) p. 181)

[17] From their very early beginning, the disability movement has strongly emphasized the distinction between impairment and disability. While impairment is a biological condition, disability is a social construction, situated within the larger social, political, and economic context, including our built environment. See for example (Oliver 1990) and (Davis 1997).

> physician responds: “And what about your functioning? Can you do everything that you did earlier, I mean before you broke your foot? Can you dress, groom and move independently?” Mr Sonsbeek: “Yes, I can, but it’s more difficult.” The doctor asks: “So, it takes you more time?” “No, that’s not the point, it’s… more difficult.” Some time later, Petra Klein tells me: “Mr Sonsbeek says that he has lost something, but we think that he functions at his former level. He complains about the clubfoot, but that doesn’t hamper him. He describes it as ‘more difficult’, but that’s no use to me. What is ‘more difficult’?”

Petra Klein finds it hard to understand Mr Sonsbeek’s loss, because she usually translates physical complaints to activities of daily life. Problems with dressing or moving can be managed in rehabilitation, but Mr Sonsbeek’s difficulties are ‘no use’ to her. Lost suppleness, a lack of quality in moving and a changed corporeality by a clubfoot: these are Mr Sonsbeek’s untranslatable losses. He struggles with this lack, he searches for words to express it, but rehabilitation medicine does not know not what to *do* with. These untranslatable losses are not exactly silenced, but they cannot be dealt with.

Translating encounters its limits. It is one way to approach suffering, but it is no *solution*. Some forms of misery are difficult to translate into do-able problems, which is also illustrated by the story of Mrs Witte. We can sympathize with her loss, but it is very hard to handle:

> Interviewer: “If you could get back one thing, what would you want back?” Mrs Witte: “That’s a very hard question, because there are so many things. But I don’t feel warmth and cold, and I wish I could feel warmth. If you go to bed at night and you feel pleasantly warm. I don’t even feel cold, but snuggling down, you know, so lovely and warm. I miss that. People often think that I wished I could walk again, but that’s not the most important thing for me.”

Mrs Witte became severely injured in a work accident. She sits in a wheelchair and she is not able to feel any sensations from her chest downwards. She cannot walk, neither can she groom or dress herself, eat and drink without help or hold a book. There are many things that she has lost. Nevertheless, she does not talk about these activities when she thinks of what she misses most. She tries to talk about something that is difficult to find words for. She misses warmth, while she does not even feel cold. When she seeks for the right words to express her loss, she illustrates the limitation of what I have called translations.

How Much Bed Rest Makes up for a Wedding Day? Management

Translations are impossible when the problem appears to be untranslatable in day-to-day rehabilitation. Yet, even if problems are not translated, rehabilitation practitioners continue to actively deal with suffering. Although there is often no *solution,* some ways of living are more difficult than others. For example in the story of Mr Altena, what counts most?

> Mr Altena's spinal cord is injured from his shoulders downwards and he has developed major bedsores that have made him lie in bed for weeks. His brother's marriage is approaching and Mr Altena is looking forward to it: "This is once in a lifetime, it's an important day". But the sores are healing very slowly and the practitioners discuss what to do. Doctor Klein says to the occupational therapist: "The wedding is very special to Mr Altena, he has to be able to sit. Could we cut a hole in the wheelchair seat?" The therapist tinkers with the seat in order to reduce the pressure, but he says: "The hole in the wheelchair is only one part of the problem. If Mr Altena sits up all day long, the sores will be open up again." Dr Klein: "I see, but I have the impression that Mr Altena is prepared to sacrifice a lot for that day. He would accept two weeks of bedrest."

There was no best solution for Mr Altena, not even a hole in the wheelchair seat. Without a single way out the question was raised what is worst: two weeks of complete bedrest yet again or missing from the wedding party? One loss is weighed against another. The professionals have the impression that Mr Altena would not want to miss the party, even if it implied weeks of bed rest. They will check with him if their impression is right. The people involved seek to prevent that Mr Altena's life is reduced to his impairment, even when they treat sores. Practitioners attempt to create a discretionary space in order to prevent people being immersed by suffering. It is a narrow space, but it allows one to decide what kind of suffering is hardest to bear.

Still, the kinds of balances Mr Altena and the rehabilitation practioners try to make here are very complicated. After an endless frustrating day in bed and having got the message of a growing sore, Mr Altena may hesitate to go to the wedding. By contrast, he may be very willing to go and accept the burdens of treatment after having had a long talk with his brother on the phone. Scenarios differ from one day to the next, but more stability is achieved by taking your time. It opens the possibility to carefully consider the different options, to live through different outcomes, to gather different perspectives and to make preferences less dependent on a temporary mood[18].

Some decisions, however, return each day or each week. People have to make them over and over again.

> Liesbeth Verstraten: "[I would] want to go out more often and meet others, but that's exactly the problem." Interviewer: "Your disabilities are too restricting?" Liesbeth: "That's right. I have this pain in my back, one day it's OK, the other I can do nothing. We've got a puppy, that's so much fun. We went to a puppy course and although it took me great effort to finish it, I'm very happy I did it. [It] was once a week in the evening, so my bowels were OK, but my back was … sometimes I was…" Interviewer: "… in pain?" "Yes. And sometimes I couldn't make it, but I really wanted to do this. […] It was much fun, and I really love the dog, so I really enjoyed it and I met people."

Liesbeth Verstraten sits in a wheelchair, has a difficult bowel movement, and often suffers from great pains in her back. Yet, she pushed to attend the puppy course. She did not surrender to her situation. And so she went, sometimes in pain, and sometimes she had to cancel. Rather than making a decision once and for all, managing a disability consists of ongoing decision-making in countless situations of everyday life: how are the bowels today, what about the pain? How does this weigh against the fun at the course and a well-behaving little dog? Reviews like this, over and over again, are difficult and burdensome. But decision-making is an activity that prevents people from becoming a prey of their disability. People may *do* something, being in an active position of going out, meeting others, and enjoying the time with the puppy. Even the decision to stay at home is an active engagement with one's situation.

But there is also a limit to management. Balancing two weeks of bedrest and a wedding party is difficult, because the options do not belong to a uniform scale. The

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[18] The instability of preferences in decision making processes is very problematic in ultimate decisions such as in euthanasia, which is legal in the Netherlands. The participants also address this problem by taking time and consulting a second physician. See Robert Pool for a worthwhile and vivid ethnography of euthanasia in a Dutch hospital (Pool 2000).

different options are poignantly incomparable[19]. In addition, management is often hard, because the consequences of a decision are unpredictable. Some events are *unique*.

> I arrive at the Harmsen's apartment and Mr Harmsen is letting me in. When he takes my coat, he explains that I have to see his wife in the bed room, because she was not able to get up that day. He says apologetically: "Our first granddaughter was born last Wednesday and that was more than she could take." I greet Mrs Harmsen whom I met several times during her treatment in the rehabilitation clinic. She starts the conversation by telling about the birth of her granddaughter. She is full of the event and shows me pictures. I ask: "So, you went to the hospital on Wednesday?" Mrs Harmsen: "Sure! But when we came home that night, oh, I was terribly exhausted. I have to pay for everything extra."

The birth of her grandchild meant so much to Mrs Harmsen and it was such a unique experience that it seems ridiculous to calculate how much energy she would be willing to put into the visit. She went to see her daughter and the baby, her mind and body were completely occupied by it. Later, however, she realized how much the visit took from her and she had to stay in bed for several days. Unique experiences cannot be cut down to calculable proportions.

Furthermore, managing is an exhausting activity and people are encumbered by it.

> Mrs Van Wijk: "I can never do anything spontaneously, everything is planned, I have arrangements for everything, nothing happens spontaneously. That's OK, but sometimes, you just want…"

Managing, anticipating, planning your life and pleasure do not meet the wish to… Mrs Van Wijk does not finish her sentence. The exact nature of her loss appears to be difficult to articulate, but it is connected to a lack of space for impulse: *sometimes, you just want*…. Doing something all of a sudden, on the spur of the moment, *un*planned and *un*controlled. Management is an active way of dealing with suffering, but sometimes people pursue neither activity nor calculation. Sometimes, one just wants to let go.

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[19] In their analysis of train accidents, John Law and Annemarie Mol emphasize that managers often deal with more than two interests (Law and Mol 2002b). Management-in-action goes beyond the classic management style of balancing good against bad, and can be better described as *tinkering* along with a series of different and often clashing 'goods' and 'bads', which are tailored together.

Creating Space for Suffering

Health care professionals provide treatment and support, and so they do in rehabilitation clinics. They translate problems into a manageable form and they support people in identifying and weighing different options. They mobilize action. Even, or maybe just, in the face of deep despair.

> Two doctors come to see Mr Blankenstein on their morning round. He has been distressed and short of breath for a couple of days and he has not slept well. It's his birthday tomorrow and he is having a hard time. His wife died a year ago and he misses her very much. The doctors patiently listen to his story and after a while, Petra Klein says: "It's very difficult, Mr Blankenstein, it's quite something. In the past, you went to see a psychiatrist and you use medication, so I suggest that he comes to see you again. You shouldn't get into a downward spiral, don't you think?" Mr Blankenstein agrees: "Yes, that's alright, doctor." Shortly after, the doctors meet the psychologist, who questions the strategy: "Considering his circumstances, it's normal that Mr Blankenstein is somewhat downcast and depressed. I don't think that we should suppress this with medication. Only if he slides down further, we've got to intervene." The doctor replies: "But I think that we've reached that point."

Mr Blankenstein does not only suffer from his physical complaints, but also from the loss of his wife, from being paralysed and maybe from more. The doctors sympathised with him, they took time to listen to his story, and they took his emotions seriously: *It's quite something*. They continued by searching for a strategy to deal with the situation and suggested a psychiatric consult. The psychologist, however, had a different approach and argued that one should not 'suppress' each depressive mood. She suggested to give space to Mr Blankenstein's suffering - unless he 'slides down further'. Giving space to suffering implies that nothing can be done. And it also implies actively stopping one's activity[20]. And this is, indeed, hard to *do*.

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[20] The difficulty to let oneself go was also described by Emilie Gomart and Antoine Hennion in their excellent analysis of the 'active passions' music amateurs and drug users pass through (Gomart and Hennion 1999). The authors seek to go beyond oppositions like agent/structure, subject/object, active/passive, or free/determined by investigating the attachments from which subjects emerge as part of a 'dispositif'.

> A practitioner: “It touches upon the way in which professionals deal with their own feelings of powerlessness. If a doctor sat quietly by the patient and asked: ‘What would you like to do?’ […] Then there is a good chance that the patient wants something in which the doctor had nothing to do. He has got nothing to do. The same goes for the nursing staff. […] Nurses would have to loaf around with their hands in their pockets. They feel useless straight away.”

Creating a space for suffering might be very hard to do as it does not give a sense of power. By contrast, it makes one feel powerless. How to create a space for suffering? In the rehabilitation center, professionals seem to accept their powerlessness with respect to erratic bodies:

> Nurse Carla goes for a walk with Mrs Bremer, who sits in a wheelchair, but is able to walk short distances with a walking aid. Mrs Bremer gets to her feet, leans heavily on the walker and starts to set a step. She complains: “Oh, it’s so difficult today, last week I walked much more easily. It’s nothing today!” Carla stays with her at each step and stimulates her: “You’re doing fantastic, this is just fine!” But Mrs Bremer’s steps are already getting more and more unstable. She sighs: “I’m tired today, it’s not my day.” She seems to get shaky and when she sits down in her wheelchair with relief, she is almost in tears: “It was terrible!” Carla takes a seat next to her and tries to calm her down: “Never mind, Mrs Bremer, it’s OK, you did very well and tried hard, but there’re always better and lesser days. Tomorrow will be much better.”

Mrs Bremer was able to walk smoothely the week before, but not that day. Carla could not help and accepted the situation. She did not stimulate Mrs Bremer to push further. If legs do not carry one, the best thing to do is to accept it. When Mrs Bremer became desperate and frustrated about her unwilling legs, Carla tried to stop her suffering. She tried to console and reassure her: *you did very well.*

People tend to train hard in rehabilitation and bodies, especially disabled bodies, are sometimes hard to control. And so, people often reach their personal limits and end up deeply frustrated[21]. The responses of professionals in these kinds of situations are often just being there, remaining calm, taking time, listening, reassuring or resting a hand

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[21] See (Murphy 1987) for a description of his first session with the physical therapist that was a tremendously exhausting, challenging, and shocking experience of reaching your own limits.

on one's arm[22]. They share the pain. But Carla's compassion also confirmed the asymmetry of her relationship with Mrs Bremer. Carla provided care and Mrs Bremer received care. It was Mrs Bremer who walked just a few steps and Carla said that she was doing well[23].

The fixed division of roles between professionals and people with disabilities particularly struck me when it was suddenly disturbed. One day during the ethnographic fieldwork, a major fire broke out within walking distance from the rehabilitation clinic. It damaged several houses in that neighborhood and hurt some people. Some practitioners and patients from the rehabilitation center lived in that area and the days and weeks after the fire were filled with the incident.

> I accompany the physiotherapist to the main hall of the rehabilitation center, which is crammed with people. People with crutches or in wheelchairs are standing next to doctors in their white coats and kitchen personnel with their white hats. People are talking to each other about what has happened when the general manager walks to a microphone and says a few words of consolation, addressing us as if we were one community.

The fire did not affect everybody in the same way, but everybody, field worker, nurse or patient, was stricken. People gathered in the main hall to share their grief. Some were more distressed than others, but the difference between those who suffered and those who consoled did not necessarily correspond with the roles of patient and professional. Mrs Bremer said some comforting words to Carla. After the fire, conversations did not attempt to settle the situation.

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[22] In a nursing rehabilitation handbook, Mary Ann Solimine and Shirley Hoeman explored how nurses can deal with suffering in clinical rehabilitation. They indicated that rehabilitation nurses try to listen carefully, reassure, or be sympathethic in situations of despair (Solimine and Hoeman 1996).

[23] Asymmetry in patient-professional relationships has been a major concern in medical anthropology and medical sociology for several decades. One of the scholars who analyzed and criticized unequal power relations in medical practices was Arthur Kleinman (Kleinman 1981). More recently, the general criticism has been replaced by a growing acceptance of differences between patients and practitioners as an inevitable reality of medical practice. Some researchers have raised questions such as how these differences take shape in concrete medical practices, when this difference becomes important, what its consequences are and for whom. See for these some of these studies (Akrich and Pasveer 1996; Casper 1998; Cussins 1998; Singleton 1996).

> The physiotherapist Karin Vos arrives at Erwin Kopers bed in the morning. He's lying flat on his back when she starts to practice his legs. The conversation quickly turns to the fire; the house of Erwins family was struck. "They estimated the damage at 30,000 euro. But we can stay in the house." I know Erwin as a silent person, but today he is talkative. Karin listens carefully; sometimes, though not often, she asks a question. In a quiet voice, Erwin tells about the things that have kept him busy the past weekend. Karin is working through the exercises without stopping to listen to Erwins story. At the end of the session, Erwin says: "But I'm coming along." Karin smiles at him, nods briefly, and says: "Chin up, I'll see you tomorrow."

The conversation ended with a brief encouragement, *chin up*, but apart from that, it was not a talk between care provider and care seeker. It resembled a talk between neighbors who share in each other's worries. Erwin knew that Karin could do nothing about his damaged home and she did not suggest otherwise. While she went through the exercise program as usual, she listened to the misery that had happened to Erwin. And so the hardship remained what it used to be: hardship. Karin Vos seemed to be able to accept her powerlessness and this opened up the space for Erwin, a close-lipped man, to articulate his suffering. Abstinence from a helping mode helped him. Erwin said at the end that he was 'coming along'. Putting his grief into words relieved him. There was space for suffering.

To Conclude

I have not avoided pain and suffering in my text and language, I have written about it. I have not addressed suffering in general, but unravelled actual situations in day-to-day practice in which suffering unfolds. This way of writing about suffering does not pretend to offer solutions. Articulating suffering is yet another way of facing human suffering rather than dispelling and silencing it.

People do not endure their pain and suffering passively in the rehabilitation clinic, but they actively deal with them in multiple ways. They mould suffering in interaction with the day-to-day realities of disabled embodiment. In order to articulate the activities taking place in concrete practices, I have distinguished three different ways of dealing with suffering.

First, translations transform problems from one language into another and transfer them from one location to another. Interrupted nerves in the spine and difficult to heal sores are translated into new questions, such as how to move from one place to the next or how to escape from social isolation. This transformation induces a transfer of the locus of intervention: practitioners not only treat bedsores, but also train a person's arms that push a wheelchair. When situations appear despairingly hopeless, translations offer new perspectives and generate hope. Problems are being dealt with and sometimes even solved. But translations are always incomplete. Intangible suffering continues to exist and there is no answer to it.

Second, suffering and pain are managed by balancing different types of misery. Which scenario is hardest to endure? Management is demanding, but it prevents one from sinking down into agony. Balancing different options deprives suffering from its amorphous and overpowering character. One route seems slightly less unattractive than the other one. Management encounters its limits in unstable desires, unpredictability, and in the uniqueness of certain events. Managing is active, but it is also exhausting. One gets tired of it and one just wants to let go.

Third, a space is created where suffering is allowed to exist. Practitioners tend to find it hard to step back and tolerate the full dimension of suffering, because they cannot do what they understand as their task: provide help and relieve the pain and suffering caused by disease and disability. The paradox of creating space for suffering is that it is an active way of letting go. In its paradoxical nature, it is hard to realise. Similar to the other styles of dealing with suffering, this style requires active participation: people listen carefully and resist the temptation of offering solutions. Professionals 'keep their hands in their pockets', even when their fingers itch. Dealing with one's own suffering also entails activities: talking about it and articulating one's grief, in order to make it available and share it with others.

As it turns out, giving space to suffering also encounters its limits. Take this paper. It attempts to create a space for suffering by portraying, articulating, and evoking suffering as it is revealed in concrete practices of day-to-day rehabilitation. It seeks the right words to speak up for the silenced conditions of lived human pain. It tries to help filling the cultural void with a language that talks about translations, management and spaces of suffering. It challenges the idea that suffering turns people into passive victims of their disability, succumbing to their physical impairment. It describes how people actively deal with suffering by moulding it into different shapes. The limit of all these attempts is suffering itself. It is the powerlessness of those who, actively, but yet, suffer. It is the pain being felt at the moment that everything falls apart. It is inescapable and it goes beyond papers and words. Wordless pain.

Conclusions

Dealing with Disability

> Some ten years ago, I was eager to treat patients as a therapist, but I was left in puzzlement and disappointment about what happened in treatment practice. Several years later, I set off for clinical practice a second time. Less impatient I was, though I felt a similar nervous agitation at my first days in the field. But this time, I would not have to prove that physiotherapy was able to generate impressive effects. Rather, I was curious to see what happened in a field where people did their best to learn how to live with their disability and where professionals tried to support them in that pursuit.

Was this second enterprise worth the effort? I think it was. Let me try to explain.

Tensions

The ethnographic stories in this book have revealed parts of the richness, complexity and difficulties of the care and treatment of people who try to re-adjust to day-to-day life with a severe physical disability. My inquiries into clinical rehabilitation have been lead by four topics – independence, patient autonomy, goal setting and suffering - that help to grasp the characteristics of rehabilitation. This view on day-to-day care may be unexpected for those who are closely involved in this care, the professionals and people with disabilities. It may surprise them as their daily routines are re-described in the light of public health care debate or quality improvements, such as outcome measurement, ethical practices of choice, or rehabilitation plans. My analysis of clinical rehabilitation may not only surprise practitioners, but also rehabilitation theorists, philosophers, ethicists, or policy makers, because it gives insights into treatment and care that diverge in a variety of ways from the images and instruments that usually circulate.

The tensions between clinical practice on the one hand and theoretical practices, their techniques and requirements on the other hand have been the main concerns of this book. In the previous chapters, I have demonstrated that outcome assessment, self-determined decision-making, treatment plans, and public debates about health care differ from clinical practice in various ways. However, these tensions all centre around two issues: multiplicity and materiality.

Multiplicity, Frictions, Loss

The first theme with which the differences can be understood is that of *multiplicity*. Rehabilitation outcomes are often not straightforward, treatment goals diverge, and therapy approaches come in multiple varieties. This multiplicity is often felt as a threat: which treatment effect is the *best*? Which goal to pursue? Which is the *best* way to approach a certain problem? A common answer to this threat is to aggregate it scientifically: if independence appears in multiple shapes, it is aggregated to one overall measure in order to assess it in its comprehensiveness. For example in questionnaires that are widely used in quantitative research, various dimensions of a concept such as independence are aggregated and the highest outcome indicates the best result. Another answer to multiplicity is to sort out differences rather than to accumulate them. If there are various goals for rehabilitation, disabled people make an *informed choice* for the goal that is most attractive to them. And when professionals and disabled people happen to disagree about various possibilities, the preferences of the disabled person should be respected[1]. With aggregation or choice the conflicts multiplicity often induces are blotted out and the perplexing amount of possibilities is reduced.

By contrast, participants of clinical rehabilitation practice do not seek to tame multiplicity, but take it as starting point for rehabilitation. In chapter 1 we have seen how people may be independent in their day-to-day life in various ways. Some people with disabilities train to wash and dress themselves each day while others seek assistance for such self-care in order to be able to work. Aggregating these differences disregards that disabled people attach a different meaning to different activities. Moreover, accumulating activities of daily living does not result in a *maximum* of independence. When people with a severe physical disability or a chronic disease try to do independently *as many* activities *as possible*, they overburden themselves and eventually they are just exhausted and not independent at all. Yet, sure enough, multiplicity is not easy to handle. It leads to perplexing situations, especially when

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[1] This position is very common in the ethics of rehabilitation medicine. See for example (Haas 1998) or (Saunders 1997).

multiple forms of being independent, multiple goals, or multiple activities clash. And this happens, as the cases in the chapters of this book show, all too often. A person with MS wants to drive in order to be mobile, do the shopping and visit friends. But this may lead to heavy back pains that make it impossible to run the necessary tasks in the household. In cases such as this one, people do not choose either one goal; *both* are too important to give up. When a person has sores on the skin, he stays in bed, sometimes for weeks and months, to get these sores closed. This is already a depressing experience, but it becomes absolutely hopeless when this person wants to get up to go to a wedding party. Multiplicity is often complex in a sense that it induces a series of problems: conflicts, tensions, frictions.

The frictions between different forms of being independent or multiple goals are neither aggregated nor sorted out in clinical practice, but they are *coordinated*[2]. Coordination is not the same thing as giving people a choice between different goals. People hardly ever create priorities in such a way that one goal is pursued and another is set aside. One example from chapter 3 was the story of a man who wears arm splints in bed that help to prevent painful muscle contractions. These splints are so uncomfortable that they keep him out of sleep a whole night. But neither the goal of pain reduction, nor that of sleep, is given up in favour of the other. Instead, these two goals are not taken as fixed entities, but they are adjusted, shifted, tinkered with. Rehabilitation work implies tailoring together multiple goals and possibilities in a patchwork of activities to be put into practice in actual settings and situations. Multiple and often conflicting goals merge into a meaningful and rich, even if still perplexing and demanding day-to-day living with physical disabilities.

A focus on clinical rehabilitation practice has not only shown how to appreciate multiplicity and how to deal with it rather than tame it. It has also demonstrated that the coordination of multiple and contradicting goals, treatment results, and activities does not go without loss. Independence in *all* possible ways at a *maximum* level is utopian in day-to-day living – either with or without disability - as is the achievement of *each* goal in its most desirable form. Reducing complexity implies that one turns one's back to the losses and suffering that are an inescapable reality of life. Aggregating

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[2] Annemarie Mol described the mechanisms of multiplicity of a disease-in-practice in day-to-day clinical work (Mol 2002). Drawing on ethnographic fieldwork, she illustrated that coordination is, along with distribution and inclusion, a way to make a multiple disease such as atherosclerosis cohere. And for some questions about the political *consequences* of the multiplicity of reality, see (Mol 1999).

different activities of disabled living wears people out. And the right to choose between different goals does not help much when people are puzzled by the complex tensions goals tend to bring about. Goals sometimes clash in such a way that each attempt to make them go together fails. But even in such a case clinical work does not stop. Participants keep tinkering, adapting and shifting goals, cutting holes in wheelchairs, managing different options, and eventually bearing the loss that comes along with it. The suffering that living with a physical disability sometimes produces is endured.

The stories in this book have demonstrated how to appreciate and actually approach the perplexing and often threatening disorder of reality. Unlike aggregation or choice, clinical rehabilitation does not try to reduce complexity away. But this does not mean that there is chaos all around. Clinical practice, in this study rehabilitation practice, demonstrates the crafted, creative, pragmatic, and careful moulding of inescapable multiplicities into the realities of life, suffering included.

Materiality, Realisation, Failure

The second issue that cuts through the various tensions between diverging practices described in this book concerns the *materialisation* of independence, patient autonomy, goals, and suffering. In rehabilitation research, the level of a person's independence is *assessed;* ethicists and policy makers *advocate* patient autonomy and self-determined decisions as fundamental human rights; and rehabilitation theorists and administrators *argue for* transparent treatment plans and goal setting. However, the concrete technologies, material design, and professional activities that help to constitute these ambitions are hardly considered. If mentioned at all, the technologies, materialities, and activities which help to shape disabled living, are depicted as passive means, subordinate to deliberate decisions, intentional actions, and self-determined goals, which are seen as backbones of rehabilitation medicine.

The chapters of this book, however, have drawn a different picture. Medical technologies and material environments are not the decorative background against which treatment results, ideals, and goals are realised. Instead, patient autonomy, as chapter 2 has demonstrated, only emerges in and through the institutional routines, materialities, and caring activities of dinner trolleys, microwave ovens, and daughters who bring along pre-cooked meals. Patient autonomy is not only respected in interpersonal interaction and by the possibilities of self-determined decision-making, but also emerges from institutional arrangements, material conditions, and actual care that enable a person to cook her own meal.

Clinical rehabilitation is a craft in which participants tinker with the material, organisational and embodied possibilities and impossibilities. Measurements, arguments, and plans do exist in clinical practice, but eventually actions and realisation make the difference. The exact *setting* of goals in patient meetings is important, but these meeting are pointless without the creative *realisation* of goals. Chapter 3 has illustrated the tensions between goal setting in team meetings and working at goals in day-to-day treatment. Professionals deal with these tensions concerning time frames, place, and actorship in a creative and pragmatic way: they do not hold on to the exact treatment plan, but rather adjust it to the necessities of the situation. A woman, for example, was supposed to do exercises twice a day, but when she had a wounded toe, the exercises were temporarily put off, because walking with a wounded toe might be harmful. Health carers do not establish and evaluate goals as precisely as possible, they rather turn towards a specific person with particular problems that require local assessment, adjustments, and responsive trial-and-error. The craft of clinical rehabilitation is to tinker along with the technologies at hand and explore the material and physical possibilities.

Rehabilitation participants draw our view towards the practical and material realisation of treatment results, ideals, and goals given the difficulties of day-to-day living with a disability. But professionals and people with disabilities also have to tolerate the frustration of not being able to overcome all difficulties. In trial-and-error, there is error. Goals imply the frustration of unrealised goals, and striving for a better living means that it does not always work out. It may turn out to be impossible to go for a ride on a scooter and walking exercises may end up in exhaustion. Realisations do not go without disruptions. Failures are part of clinical rehabilitation and the participants face them. And they do so in a material world: in chapter 4, I have described how professionals install large wheels under a bed so that people can move themselves around. In a chain of translations, patients' difficulties are shifted from the body towards a larger environment. Translating problems, trying out a new approach, cutting a hole in a wheelchair cushion, adjusting an arm splint to a more comfortable size: working with the materialities at hand is - also in situations of suffering - practical care. Hope in rehabilitation is crafted hope. But this materiality may – again - fall apart.

The Politics of Care

The differences between the ways in which independence, patient autonomy, goal setting, and suffering are dealt with in public debate on the one hand and in clinical practice on the other hand have far-reaching consequences for discussions concerning the quality of health care. As I have noted already in the introduction, the quality of care is a hot issue, extensively discussed in the field itself, in public discourse, and national policy.

Interventions from outside clinical practice with the goal to improve this practice risk being insufficiently geared to the specificities of clinical care, because little attention is paid to the fact that each practice has its own peculiarity, strengths and weaknesses, which call for specific approaches and fine-tuned improvement strategies. Possibilities of choice and the right to self-determination protect people from unwanted interference, but ask for a different interpretation in a rehabilitation practice where people face the complex entanglement of multiple, interdependent and yet often conflicting goals that frustrate the possibility of a choice between alternative options. Quantifications of therapy results allow the comparison of these results across different locations, but at the same time they are blind, and maybe even disruptive, for the selectivity and inventiveness with which rehabilitation practitioners seek to generate effects. This book attempts to enlarge the perceptiveness among clinicians, theorists and policy makers for the specific character of clinical practice and its strengths and weaknesses. Because this practice does not only face difficulties, it also has much to offer.

A Clinical Craft

Much of the practical creativity of contemporary health care practices tends to get trapped between the developments that compel health care practices towards more effectiveness, efficacy, standardisation, or consumer orientation[3]. But much of the quality of health care precisely unfolds in the activities that escape measurement, that go beyond treatment plans, and that precede or follow decisions. This does not imply that it is impossible to improve care, but seeking improvement in measurable results and

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[3] Evelien Tonkens explored the limitations of the free-market model and consumerism for the public sector and health care. She offered an alternative to this trend in strengthening a process of democracy, in which citizens and professionals communicate on an equal basis. See (Tonkens 2003).

decision-making is too limited and might be disruptive for the qualities of clinical rehabilitation. The ethnographic accounts in this book have portrayed rehabilitation work as a creative craft and thus hope to contribute to a movement that thinks and improves quality of care in a different way.

Craftswomen and -men, whether they live with a disability or professionally support others, go along with the local necessities of the situation they try to master. They skilfully deal with the dynamics, ambiguity, and frictions that characterise rehabilitation. But the creativity and resourcefulness are difficult to grasp in a measurement that requires comparable and homogeneous results, reproducible and reliable effects, and transportable and fairly standardised activities[4]. And choices require a set of unambiguous and well-to-compare options that people may choose from. The appreciation of clinical practice as being unfit for these requirements and the articulation of clinical practice as having a quality and logic of its own may be the first step in the quest for more situated strategies for the improvement of care.

Craftswomen and -men also cannot do without their tools, without their embodied skills and tacit knowledge, without the materiality of the situation in which they work. Their work cannot be distracted from the material conditions in which it takes place and craftswomen and -men take these realities as seriously as arguments, ambitions, and goals. This material heterogeneity is not a sign of chaos in clinical practice, it is part of its quality, robustness and resourcefulness. Intervening by means of ideals and arguments ignores the material forces and medical technologies as constituting layers of health care. Appreciating them, by contrast, may shift the attention towards the ways in which health care is made durable, and it may open new perspectives to make care better[5].

Craftswomen and -men do not only draw things together, they also face the fragility of life. They are do-ers and get frustrated by things falling apart. But loss is so much part of their day-to-day reality that they do not turn away from it. They face their losses and deal with them. When we focus on independence, autonomy, self-determination, effects, and results, we lose our capacity to put into words and to deal with the fragility of life. Health care practitioners seek to eliminate or prevent the

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[4] Ant Lettinga and Rita Struhkamp analysed the effects of effectiveness research in physiotherapy and demonstrated how this research and other strategies to make physiotherapy more homogeneous are often counterproductive to therapy settings. See (Lettinga and Struhkamp 2001).

[5] Bruno Latour introduced the idea that technology is 'society made durable' (Latour 1991). See also for the continuation of this idea his 'Parliament of Things' (Latour 1993).

suffering that sickening and aging bodies sometimes generate. They want to help rather than 'keep their hands in their pockets'. But the impossibility to eliminate suffering is no failure; it is the confrontation with the volatility of life[6]. The quality of rehabilitation medicine is not only to work *against* loss, but also to *bear* it.

Wheelchair Articulations

Attempts to contribute to quality improvements in health care show a variety of styles. In many of these styles, the attempt is to adjust the instruments used in effectiveness research, ethical principles, or caring standards to the specificities of clinical practice. For example, assessment scales are refined and adjusted to grasp the treatment effects of rehabilitation programmes[7]. A similar kind of development can be seen in ethics and philosophy, where scholars discuss new conceptualisations of patient autonomy and broaden it towards more diverse situations of the interaction between professional and patient during the continuing illness trajectory[8]. A specific development in this respect is empirical ethics, which is an important recent trend in medical ethics in the Netherlands and which seeks to work out its key moral norms and values in permanent interaction with concrete cases in medical practice[9]. So, epidemiologists refine their measures and ethicists think through their concepts, but rehabilitation scholars work at the improvement of their methods. This means, for example, that goal setting procedures are adjusted in such a way that the frequent adaptation of goals in an ongoing rehabilitation trajectory is possible. And treatment plans are modified so that they do not contain a list of pre-defined goals, but that each patient is able to design his or her own plan. Another style of quality improvement is the development of guidelines for those situations of clinical practice that professionals and patients find particularly hard to deal with, for example situations of miserable suffering[10].

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[6] Karin Spaink illustratively talked about the 'capriciousness of bodies': illness and disability are cruel reminders of the fact that our bodies may become rebellious and unreliable (Spaink 1999).

[7] The research of Marcel Post and his colleagues is only one example of this large field. They compared two different questionnaires concerning their utility in patients with stroke. See (Post et al. 2002).

[8] In chapter 2 of this thesis, I elaborated on the work of philosophers of and ethicists who seek to broaden the concept of patient autonomy. See there for a range of references, but see for an overview (Schermer 2002). For an attempt to think and move current medical ethics beyond the issue of patient autonomy, see (Willems 2003).

[9] See for a discussion (Swierstra 2002).

[10] See for the entire process of guideline development, implementation, and evaluation the thesis of Bekkering (Bekkering 2004).

In this thesis, I have developed yet another style of addressing quality issues in health care, which is the style of *articulation*[11]. I have articulated the craftsmanship of clinical rehabilitation with its richness and losses against the background of theories, notions, expectations and instruments that come from elsewhere and that enter clinical rehabilitation in order to improve it. Articulations do not describe what is already there; rather, they make audible, perceptible, or visible, they put into words, what is usually invisible or silent. I take quality instruments, outcome measures, informed consent doctrines, treatment plans, and goal setting practices, seriously as they are part of the realities of health care. These instruments are designed in a certain context, resting on particular assumptions to achieve particular goals. Yet, these quality instruments tend to move into the clinical setting, which is a setting that differs from the practices in which these instruments have been developed in a variety of ways. Without unravelling these differences, the effects for the quality of care may be damaging. The ethnographic articulations in this book speak up for the specificities of clinical practices to strengthen them in times when the health service is in turmoil. Articulations put accounts from situated clinical practices in a broader framework and make them available in settings such as health care policy, rehabilitation research or medical ethics. As soon as we realise that the use of theoretical notions and instruments is not innocent, it does *not* become easier to improve health care. Improving practices, or so the stories in this book have illustrated, is *difficult*. But we can build on the craftsmanship in clinical practice.

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[11] See for more examples of articulation as style of analysis (Pols forthcoming) and (Moser 2003).

Sources

Chapter 1

Figure 1:
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Chapter 2

Figure 1:
Fieldwork material from the rehabilitation centre

Figure 2:
Pronk Ergo BV, the Netherlands, www.pronkergo.nl

Chapter 3

Figure 1:
Fieldwork material from the rehabilitation centre

Figure 2:
Speedy Reha-Technik, Germany, www.speedy-reha-technik.de

Figure 3:
Revatak BV, the Netherlands, www.revatak.nl

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Samenvatting

Omgaan met handicaps: Een onderzoek naar een klinisch ambacht

De kwaliteit van de gezondheidszorg kan beter. We horen en lezen dit bijna dagelijks in krantenberichten, politieke debatten, beleidsvoorstellen en wetenschappelijke analyses. Over wat precies de problemen in de zorg zijn lopen de meningen uiteen en ook de aangedragen oplossingen verschillen fors. Twee benaderingen zijn echter vooral belangrijk. Ten eerste probeert men de gezondheidszorg meer *evidence-based* te maken door systematisch onderzoek te doen naar de effecten van de verschillende behandelingen. Ten tweede probeert men om de gezondheidszorg meer cliëntgericht te maken door de behoeften van zorgvragers centraal te stellen. In dit boek worden kanttekeningen geplaatst bij deze pogingen om de kwaliteit van de zorg te verbeteren. Dit gebeurt aan de hand van een etnografische studie die werd uitgevoerd op een afdeling van een Nederlands revalidatiecentrum voor mensen met een dwarslaesie of multiple sclerose (MS). De beschrijvingen van de alledaagse revalidatiepraktijk in dit boek maken de kracht en creativiteit, maar ook het lijden en falen binnen de dagelijkse zorg zichtbaar en thematiseren zo de kwaliteit van de hedendaagse gezondheidszorg vanuit de klinische praktijk. Die klinische praktijk komt door verbeterstrategieën als resultaatgerichtheid en marktdenken intussen steeds meer onder druk te staan.

Dit boek behandelt de manieren waarop thema's als effectiviteit of patiëntenemancipatie in de revalidatiepraktijk een rol spelen. Hulpverleners helpen revalidanten om na een ongeluk of ziekteperiode de draad weer op te pakken, ondanks hun blijvende lichamelijke beperkingen. De vier hoofdstukken bieden een blik op de dagelijkse activiteiten van beide partijen, alsmede op de context van de revalidatiezorg. Dit gebeurt aan de hand van vier verschillende onderwerpen: *zelfstandigheid*, *autonomie van patiënten*, *doelen stellen* en *lijden*.

In hoofdstuk 1 staat het meten van zelfstandigheid centraal. Om te kunnen beoordelen of revalidatieprogramma's effectief zijn, worden de resultaten van revalidatiebehandelingen regelmatig met behulp van epidemiologisch onderzoek in kaart gebracht. Hoofdstuk 1 draait om de vraag wat de meetinstrumenten die in dit soort onderzoek worden gebruikt precies meten en welke aspecten van de klinische revalidatie buiten de meting vallen.

Zelfstandigheid is een belangrijke parameter voor het succes van revalidatiebehandelingen. Aan de hand van drie voorbeelden laat ik zien dat de gehanteerde vragenlijsten verschillende alledaagse aspecten van zelfstandigheid buiten beschouwing laten. Ten eerste gaan deze vragenlijsten uit van een kwantitatieve relatie tussen zelfstandigheid, technologie en hulp van anderen. Iemand scoort *hoger* voor zelfstandigheid naarmate zij *minder* hulpmiddelen en verzorging van anderen nodig heeft. In de revalidatiepraktijk blijkt een dergelijk verband echter veel te simpel. Daar telt namelijk niet de vraag *of* iemand voor een activiteit technologie of hulp nodig heeft, maar *op welke manier* daaraan behoefte bestaat. In de revalidatie gaat het om de kwalitatieve aspecten van het gebruik van technologie, bijvoorbeeld om hoeveel moeite het een revalidant kost om haar te gebruiken. Voor mensen met een handicap blijkt zelfstandigheid te ontstaan in een netwerk waarin lichaam, technologische hulpmiddelen en zorg van anderen op elkaar ingrijpen. Het precieze karakter van de verbindingen binnen dat netwerk zijn essentieel voor iemands zelfstandigheid, iets dat niet wordt meegenomen in bestaande meetinstrumenten.

Ten tweede meten vragenlijsten zelfstandigheid in algemeen gedefinieerde dimensies, zoals kunnen eten of zichzelf kunnen wassen. Als ideaal daarbij geldt om zo hoog mogelijk te scoren op al deze dimensies: *hoe meer hoe beter*. Dit sluit echter niet goed aan bij de revalidatiepraktijk. Daar geldt immers veeleer dat iedere revalidant probeert op een eigen manier zelfstandig te worden. Veel mensen met een chronische ziekte of handicap geven aan dat het streven naar zo veel mogelijk zelfstandig uitgevoerde activiteiten tot overbelasting leidt. Zij zijn gedwongen selectief te werk gaan. Dat betekent dat ze voortdurend verschillende activiteiten tegen elkaar af wegen: autorijden en het huishouden doen zijn beide dimensies van zelfstandigheid, maar wat te doen wanneer autorijden tot uitputting en rugpijn leidt en daardoor het huishoudelijk werk onmogelijk maakt? In de revalidatiepraktijk gaat het minder om *maximeren* dan om *coördineren*, waarbij in een specifieke situatie verschillende activiteiten met creativiteit en aanpassingsvermogen op elkaar worden afgestemd. Juist deze opbrengst van de revalidatie blijft bij de meeste meetinstrumenten onzichtbaar.

Aan de hand van een derde voorbeeld laat ik zien hoe ook de tijd in de klinische praktijk een andere rol speelt dan in meetinstrumenten wordt geïmpliceerd. Zelfstandigheid wordt op verschillende momenten in het revalidatietraject gemeten. Op deze manier beoogt men de ontwikkeling van de revalidant in de tijd te volgen. In de klinische praktijk gaat tijd echter niet alleen gepaard met een ontwikkeling, maar ook met botsingen tussen korte- en langetermijneffecten. Deze laatste brengen altijd onzekerheid en twijfel met zich mee en dat maakt risico-inschattingen noodzakelijk. De bestaande meetinstrumenten brengen het verloop van de tijd lineair in kaart. Zo onttrekken ze aan het zicht hoe revalidanten en hulpverleners het zelfstandig uitvoeren van activiteiten in het heden voortdurend betrekken op de gevolgen die dat kan hebben in de toekomst en hoe zij omgaan met de onzekerheid die daarmee samenhangt.

Er is dus een spanningsveld tussen zelfstandigheid zoals deze wordt geëvalueerd in effectmetingen en zelfstandigheid zoals deze figureert in de revalidatiepraktijk. Dat verschil wordt een probleem, zo concludeer ik in hoofdstuk 1, wanneer aan die metingen belangrijke conclusies worden verbonden, bijvoorbeeld dat een revalidatieprogramma moet worden gestaakt omdat het onvoldoende resultaat zou boeken. Effectmetingen geven een geheel eigen en smalle invulling van wat telt als effect. Wanneer men deze beperking uit het oog verliest, dreigen de specifieke kwaliteiten van de zorgpraktijk niet alleen buiten beeld te verdwijnen, maar uiteindelijk ook teloor te gaan.

Waar het in hoofdstuk 1 draait om de effectiviteit van de zorg, daar gaat het in hoofdstuk 2 om de autonomie van patiënten. Respect voor autonomie is de laatste decennia uitgegroeid tot een van de belangrijkste ethische normen in de gezondheidszorg. In de liberale medische ethiek wordt deze norm vooral ingevuld als het recht van de patiënt op zelfbeschikking. De laatste jaren hebben verschillende ethici en filosofen, bijvoorbeeld vanuit de zorgethiek of de deugdethiek, kritiek geuit op deze interpretatie van het principe van autonomie. Hoofdstuk 2 sluit bij deze kritieken aan door zich niet op de spreekkamer en de interactie tussen arts en patiënt te richten, waarin behandelingsbesluiten worden genomen, maar door de blik te richten op handelingen, routines en de materialiteit van de zorg. Daarmee verschuift de blik naar andere locaties dan de spreekkamer, omdat ook daar de autonomie van revalidanten vorm krijgt. Als voorbeeld is gekozen voor locaties die te maken hebben met een van de cruciale activiteiten uit het dagelijks leven: eten.

In het revalidatiecentrum kiezen revalidanten met behulp van een menukaart hun dagelijkse warme maaltijd. Op het eerste oog vormt deze keuzemogelijkheid een gaaf voorbeeld van autonome besluitvorming door revalidanten zelf. Hun keuzen blijken echter alleen mogelijk te zijn dankzij het bestaan van een uitgebreide materiële en organisatorische infrastructuur. Bovendien blijkt dat het maken van een keuze voor de autonomie van revalidanten helemaal niet zo belangrijk is. Wat vooral telt is dat gemaakte keuzen dankzij lichamelijke training en een aangepaste omgeving praktisch kunnen worden gerealiseerd. Als je bijvoorbeeld het fornuis niet kunt aanzetten, dan is de keuze om zelfstandig te koken zinloos. Naast deze fysieke en materiële voorwaarden is voor de autonomie van revalidanten ook de zorg van derden belangrijk. Ingebed zijn in een zorgnetwerk betekent geen aantasting van iemands autonomie, maar maakt die juist mogelijk.

Momenteel wordt autonomie vooral (h)erkend in de vorm van het recht op zelfbeschikking. Door echter te onderzoeken op welke andere manieren autonomie in de praktijk nog meer gestalte krijgt, wordt het mogelijk om de creativiteit daarvan te waarderen. Of het gebrek daaraan zo nodig kritisch aan de orde te stellen. Een a priori onderscheid tussen praktische, organisatorische of therapeutische zaken aan de ene kant versus morele of ethische zaken aan de andere kant, is in dit verband weinig vruchtbaar. Een blik vanuit de keuken kent dergelijke verschillen niet, maar biedt wel nieuwe perspectieven op belangrijke noties in de debatten over verbetering van de zorg, zoals autonomie.

De twee centrale thema's in kwaliteitsdiscussies in de zorg, effectiviteit en autonomie, komen in de kliniek samen in één methode: revalidanten wordt gevraagd om zelf duidelijke revalidatiedoelen te stellen. Op deze manier beoogt men de gewenste resultaten van een revalidatieprogramma duidelijker vast te stellen zodat achteraf te evalueren valt of ze ook gehaald zijn. Dat moet uiteindelijk de revalidatiezorg transparanter, resultaatgerichter én cliëntgerichter te maken. Deze methode vormt het onderwerp van hoofdstuk 3.

Het stellen van doelen blijkt in de praktijk echter niet tot de beoogde transparantie te leiden. Doelen worden immers permanent bijgesteld, uitgesteld of nooit gehaald. Sommige auteurs zoeken de oorzaken hiervan bij de betrokkenen zelf. Deze zouden zich onvoldoende aan de afgesproken procedures houden. Hier betoog ik dat het zinvoller is de gesignaleerde problemen te begrijpen als het resultaat van spanningen die eigen zijn aan het proces van doelen stellen. Drie van zulke spanningen werk ik uit aan de hand van concrete voorbeelden.

Ten eerste moeten hulpverleners en revalidanten verschillende *tijdsassen* zien te overbruggen. Doelen liggen per definitie in de toekomst, in de concrete behandelsituatie zijn mensen echter gebonden aan het heden. De vaak tegenstrijdige eisen van nu en later doen een voortdurend appèl op de creativiteit en het improvisatievermogen van de betrokkenen. Op de een of andere manier moeten ze die strijdige eisen immers met elkaar in overeenstemming zien te brengen. Ten tweede moet in het doelen stellen het spanningsveld tussen verschillende *plaatsen* overbrugd worden. Doelen worden gesteld voor een situatie buiten het revalidatiecentrum. Voor de meeste revalidanten is dat de thuissituatie. Maar de therapie vindt plaats binnen het revalidatiecentrum. Hulpverleners doen hun best om dit spanningsveld tussen buiten en binnen te overbruggen door de situatie thuis te imiteren, bijvoorbeeld in een therapiekeuken. Maar dergelijke imitaties stuiten al gauw op hun grenzen. Daarom leren mensen ook om hun kennis en vaardigheden te verplaatsen, te vertalen naar nieuwe situaties. Op deze manier kunnen doelen mee verhuizen naar een nieuwe plek in plaats van daar te stranden. Het derde spanningsveld ligt tussen verschillende vormen van *actorschap*. Een centrale vraag bij het stellen van doelen is om wiens doelen het eigenlijk gaat. In revalidatiehandboeken wordt benadrukt dat de doelen van de revalidant bepalend horen te zijn en niet de doelen van hulpverleners. Revalidanten zouden dus zelf hun doelen moeten bepalen en hulpverleners ondersteunen hen slechts. Maar vaak blijkt deze scherpe rolverdeling onwenselijk, onhaalbaar of onrealistisch. Zowel de revalidant als de hulpverleners zijn op verschillende, soms meer actieve en soms meer reagerende, manieren betrokken bij het stellen van doelen. Doelen worden niet zozeer vastgelegd via een duidelijk en bewust keuzemoment, maar ontstaan uit een reeks van gebeurtenissen, toestemmingen en aarzelingen die gaandeweg tot doelen uitkristalliseren. Doelen gaan niet vooraf aan revalidatieactiviteiten, maar ontwikkelen zich gelijktijdig.

Het stellen van revalidatiedoelen kent belangrijke voordelen, bijvoorbeeld de mogelijkheid van gecoördineerde actie in een complex behandelproces. Maar het blijft moeilijk om in te spelen op de onzekerheid, instabiliteit en veranderlijkheid van een chronische ziekte of handicap. Wil dit soort methoden de praktijk werkelijk ondersteunen, dan kan dat alleen als men er niet naar streeft plannen exact na te volgen. Beter is het om flexibel en creatief om te gaan met de spanningsvelden die eigen zijn aan het praktisch realiseren van doelen.

Hiervoor heb ik een aantal opvallende verschillen in kaart gebracht tussen de klinische praktijk aan de ene kant en wat publieke zorgdebatten daarvan (willen) maken aan de andere kant. In beide domeinen wordt op verschillende manieren naar resultaten, autonomie en doelen gestreefd. In hoofdstuk 4 komt een verschil aan de orde dat minder in het oog springt, maar minstens zo wezenlijk is als de voorgaande. Dit verschil betreft de manier waarop met lijden wordt omgegaan. In de publieke taal over de gezondheids- en gehandicaptenzorg wordt over lijden meestal gezwegen. Daarmee wordt lijden iets zwijgzaams, iets dat de persoon die lijdt tot een passief slachtoffer van zijn ziekte maakt. Uit de klinische revalidatiepraktijk valt lijden daarentegen niet te weren. Het is soms schrijnend aanwezig. Maar mensen ondergaan lijden niet passief of zwijgzaam, maar geven daar juist actief vorm aan.

Ik onderscheid drie verschillende manieren waarop mensen in de alledaagse revalidatie praktijk actief omgaan met het lijden. Ten eerste de translatie: hulpverleners en revalidanten vertalen een probleem vaak naar een ander, beter op te lossen, probleem. Een slecht genezende doorligwond verandert in het probleem dat je niet kunt voortbewegen in een bed. Die vertaling gaat gepaard met een verplaatsing van het probleem van het lichaam naar elders: men behandelt niet alleen de wond op de rug, maar monteert ook wielen onder een bed. Dankzij translaties valt ook de situatie van iemand met een ongeneeslijke ziekte nog te verbeteren. Helaas laten niet alle problemen zich transleren. Voor wie geen koude of warmte meer voelt en daardoor niet meer ‘lekker warm onder de deken kan kruipen’, is eenvoudigweg geen oplossing voorhanden.

Een tweede manier om actief met lijden om te gaan is om het lijden te ‘managen’. Verschillende vormen van ellende worden in dit geval tegen elkaar afgewogen. Wat weegt het zwaarst in een situatie waarin je óf niet naar de bruiloft van je broer kunt gaan óf als gevolg van die bruiloft wekenlang op bed moet blijven? Dit soort afwegingen zijn lastig om te maken, maar zij voorkomen dat mensen door lijden overspoeld raken omdat ze niets kunnen doen. Management ontdoet lijden van zijn overweldigende karakter, maar het heeft ook een grens. Verlangens zijn soms niet constant en dan kunnen zij ook niet goed worden afgewogen. Daarnaast is het managen problematisch wanneer de gevolgen van handelingen moeilijk te voorspellen zijn. Bovendien heeft lang niet iedere revalidant voldoende energie om voortdurend dit type afwegingen te maken.

Een derde manier om met lijden om te gaan is het te laten bestaan en er ruimte voor te creëren. Dit blijkt lastig voor hulpverleners omdat ze hiervoor hun hulp – actief - uit moeten stellen. Zij luisteren, wachten geduldig af, komen niet gelijk met oplossingen en staan ‘met de handen in de zakken’, ook wanneer hun handen jeuken om te troosten of naar oplossingen te zoeken. En ook van revalidanten vereist deze stijl activiteit: ze geven woorden aan het lijden om het met anderen te delen. Maar ook het laten bestaan en het woorden geven aan lijden kent haar grenzen. De grens ervan is het lijden zelf, de onmacht die het oproept, de woordenloze pijn.

In de conclusie ga ik in op de opbrengst van deze etnografische studie van de klinische revalidatie tegen de achtergrond van publieke zorgdebatten en de daarin aangedragen interventiestrategieën, noties, verwachtingen en eisen. In elk hoofdstuk zag het verschil tussen klinische praktijk en publiek debat er anders uit, maar twee belangrijke filosofische thema’s keren in alle hoofdstukken terug, namelijk meervoudigheid en materialiteit.

De dagelijkse realiteit van het revalideren, zo blijkt in dit boek, is vaak meervoudig: resultaten zijn niet eenduidig, behandeldoelen lopen uiteen en behandelingen verschillen. Een antwoord op deze meervoudigheid is om haar tot één maat te reduceren, bijvoorbeeld in effectmetingen. Een andere aanpak is om tussen verschillende opties te kiezen. Maar beide antwoorden op het probleem van meervoudigheid lopen in de klinische praktijk spaak. Daar hebben verschillende activiteiten een ander gewicht in iemands leven en deze verschillen kunnen niet worden gehomogeniseerd en bij elkaar worden opgeteld. Ze moeten in plaats daarvan zorgvuldig op elkaar worden afgestemd. Vooral wanneer verschillende doelen botsen is het zaak meervoudigheid te *coördineren* in plaats van haar door optelling of keuze onzichtbaar te maken. Bij de coördinatie van botsende doelen treedt altijd verlies. De praktijk leert ons hoe dit verlies te erkennen en te dragen.

De dagelijkse realiteit, zo concludeer ik verder, is niet alleen meervoudig, maar ook materieel. In de dagelijkse praktijk gaat het vaak niet zozeer om het nauwkeurig *meten* van resultaten, het *bepleiten* van idealen of het *beargumenteren* van doelen. Het gaat vooral om het *realiseren* van effecten, idealen en doelen in de weerbarstigheid van het dagelijks leven. Materialiteit is niet slechts het decor voor ambities en argumenten, maar een volwaardig constituerend element van de revalidatiepraktijk.

Een uitwerking van de spanningsvelden tussen klinische praktijk enerzijds en de idealen die in het publieke debat circuleren anderzijds is vooral van belang om kwaliteitsdiscussies in de zorg aan te scherpen. De momenteel in het publieke debat gepropageerde interventiestrategieën en instrumenten zijn in een bepaalde context ontstaan, stellen specifieke eisen en scheppen bepaalde verwachtingen. Deze sluiten niet zonder meer aan bij de karakteristieken en eigenheden van de klinische praktijk. Dit boek tracht de kracht van de klinische praktijk te articuleren: haar gelaagdheid en materiële robuustheid, haar creativiteit en ambachtelijkheid, maar ook haar vermogen om te gaan met de kwetsbaarheid van het bestaan. Deze kwaliteiten van de klinische revalidatie verdienen het gehoord, gezien en gewaardeerd te worden. Zeker nu zij bekneld dreigen te raken onder de druk om steeds resultaatgerichter, efficiënter en consumentgerichter te werken.

Curriculum Vitae

Rita Struhkamp was born in 1971 in Herbern, Germany. Aged 20, she moved to the Netherlands to study Physiotherapy in Utrecht and Health Sciences in Maastricht. After her graduation, she worked part-time as a physiotherapist and as a junior researcher at the department of Health Ethics and Philosophy at the University of Maastricht. From September 1999 to March 2004, she conducted her PhD research at the department of Philosophy at the University of Twente. She was also a student representative on the executive board of the research school of Science, Technology and Modern Culture (WTMC), and an editor of the Dutch journal *Versie: Tijdschrift voor Gezondheid, Burgerschap en Politiek.* In 2002, she spent three months as a visiting student at the Centre of Science Studies at the University of Lancaster, UK. She now works at the department for research policy at the Erasmus Medical Centre in Rotterdam.