

Linking scientific and clinical knowledge practices

Innovation for prosthetic rehabilitation



Sacha van Twillert

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Linking scientific and clinical knowledge practices

Innovation for prosthetic rehabilitation

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1

Introduction

This thesis reflects a shift from a more biomedical perspective to a more sociological perspective with regard to innovation and implementation research in the field of rehabilitation. With a background in physical therapy (1997) and human movement sciences (2001), my personal incentive has always been to link rehabilitation practice with new scientific insights. The question was how to address this link in meaningful ways.

Research-practice gap

Most researchers and practitioners tend to experience the link between rehabilitation practice and research as a gap.^{1,2} Interestingly, they hold each other responsible for the existence of this research-practice gap.³ Researchers blame practitioners for being unable or unwilling to adopt interventions that have been proven effective. Practitioners, in their turn, blame researchers for not taking them seriously, because the evidence, which takes years to obtain, is often not attuned to the problems they encounter in clinical practice. This blaming of the other party is an all too simple way of reasoning and it would be more helpful to reflect on the contribution of both parties. In this thesis, we investigate possible ways of overcoming this gap felt between research and practice, by conducting a case study in the field of prosthetic rehabilitation. The theoretical notions, methodological requirements and practical implications raised in this study may help point to ways of improving rehabilitation practice with research knowledge, as well as indicate advanced ways of conducting research relevant to rehabilitation practice.

To prove or to improve

The shift made here has a historical context. As a physical therapist, I was passionate about working in a rehabilitation centre, as it enabled me to be part of the patient process of gaining optimal function in all aspects of life. During my study of human movement sciences I learned to be critical of the effectiveness of given treatments (rehabilitation or other) in general, and of the methods used to demonstrate their effectiveness in particular. The treatment programmes that physical therapists use to treat their patients, which I had unquestioningly adopted during my training in physical therapy, were now placed in a scientific light. Were these treatments evidence-based? And if not, how should we conduct research to prove their effectiveness? We were taught several research designs aimed at proving the effectiveness of treatments with randomized clinical trials at the top of the design hierarchy, as the best method to tackle threats to internal validity. However, we also learned to be cautious about the methods and the related design hierarchy promoted in evidence-based medicine (EBM) because of their limitations. To address these limitations we were taught to make a shift from method-driven to more theory-driven evaluation research. Method-driven research characterized traditional evaluation research in terms of merely

applying technical and methodological expertise, that tends to result in a simple 'input-output' or 'black box' type of evaluation research. Most clinical trials in the field of rehabilitation appeared to be method-driven rather than theory-driven. In other words, the majority of rehabilitation programmes were evaluated without specification of the treatment ingredients and theories about how these ingredients were supposed to lead to desired outcomes. Most trials focused on the question of whether or not treatments were effective, providing no information on how and why a rehabilitation programme succeeded or failed. This makes it difficult to improve the programme content, including the conditions under which the programme works best.

Therefore, we learned to value the use of treatment theory in outcome evaluations. Treatment theory identifies the target, the supposed working mechanism and the active ingredients of the treatments under evaluation.^{4,6} Specification of treatment theory facilitates the selection of the optimal research design, including potential relevant outcome measures and inclusion and exclusion criteria for treatments in rehabilitation practice.^{7,8} Exemplary for me was an intern student project which was a theory-driven study of McConnell taping. The desired outcome - pain relief - could be proven, however, the supposed working mechanism - changing the alignment of the patella and the function of the quadriceps – could not be confirmed. This lack of knowledge about the working mechanism made it difficult to give recommendations to therapists about, for example, the correct placement of the tape.

Integrating the scientific and stakeholder perspective

Social scientists developed a theory-driven perspective on programme evaluation because they observed that little had been learned from evaluation research on social programmes and issues that were not of interest to the stakeholders were often addressed.⁷ They emphasized the need to combine the stakeholders' perspective and the scientific perspective in an evaluation to increase the applicability of evaluation research.⁷ They thereby focused on both internal validity and external validity issues. They urged researchers to assist stakeholders in specifying the input, output and supposed working mechanism of a programme, and explore with them the circumstances under which the programme might work best.⁸ They required this kind of substantive knowledge to choose the most appropriate research design that would produce findings of interest to the stakeholders.⁹ According to these programme theorists, there is no such thing as one single best design that can be universally applied to any evaluation situation.⁷ The use of a design depends on contextual conditions, such as the evaluation goals, the maturity of the treatment programme, stakeholder and evaluator values, and the political and organizational environment of a programme.⁷ These programme theorists encouraged me to broaden my own perspective on evaluation.

Explicating treatment theory with stakeholders

The theory-driven perspective inspired me in several of my research activities. In particular, the importance of involving stakeholders in the design of the research and specifying the treatment theory with them assisted me in my goal of improving rehabilitation programmes. For my thesis in human movement sciences, I analysed and specified a treatment theory for a behavioural treatment programme for patients with chronic back pain in the rehabilitation centre where I worked. Two research questions guided the specification process: (1) What is the content and supposed working mechanism of the treatment according to the rehabilitation professionals (stakeholders perspective), and (2) How can scientific knowledge help to specify this treatment under study (scientific perspective)? I learned from this content analysis that the treatment programme was rather eclectic. It consisted of three different approaches - an operant, cognitive and respondent approach - with different, sometimes opposing, treatment theories. We recommended that the local rehabilitation professionals should not offer the three approaches simultaneously in an eclectic rehabilitation programme, but instead reason from a theoretical perspective by addressing the question, 'Which patients with what characteristics might be the best candidates for which (combination of) approach(es)?' In other words, what should be done for who should be made more explicit.

Bringing about change

This PhD project builds on the knowledge and learning experiences I gathered during my study of the human movement sciences. The starting point of this PhD project was a request from the prosthetic rehabilitation team to update their treatment programme with new scientific insights. This request was based on their concern that skills learned by patients in the clinical setting were not preserved after discharge from the rehabilitation centre. Again, we started with a content analysis of the programme. Subsequently, we searched for scientific knowledge on rehabilitation, and prosthetic rehabilitation in particular, to identify relevant knowledge that might help improve the prosthetic rehabilitation programme. This time, however, we continued the innovation research by also attempting to put the 'newly' discovered knowledge into action. In close collaboration with team members and their patients, we worked on the integration of 'new' scientific principles and related practices into the programme specified for patients with a lower-limb amputation (LLA), and implemented the programme in the local setting.

This innovation and implementation work draws on a sociologically informed conception of science that considers scientific and clinical knowledge practices as distinct but of equal value.^{10,11} In such a conception of science, it is assumed that researchers do not produce bare facts, but rather that scientific facts are co-constituted by the materials, methods and measurement tools used in

local experimental contexts.¹² In so doing, it acknowledges that scientific facts (or evidence) that are produced within one context need to be transformed and translated when applied to another context, for instance a clinical context.¹³ In other words, both science and clinical practice produce different knowledge practices and neither should be privileged over the other.¹¹

Change management principles and practices,^{14,15} participatory action research^{16,17} and an integrated Knowledge-To-Action (KTA) framework¹⁸⁻²⁰ appeared to be other valuable sources of inspiration for this innovation and implementation project. Change management principles and practices were of value because of the guidance they offered when encouraging change in organizations, in this case a Dutch prosthetic rehabilitation setting.^{14,15} Participatory action research methodology (PAR) was used as we wanted to conduct research *with* and *for* people rather than *on* people.^{16,17} Advocates of PAR argue for mutual respect of both kinds of knowledge practices, which leads to bidirectional learning by both.^{16,17} For the translation and implementation of research knowledge into the local prosthetic setting we used an integrated KTA framework to guide the knowledge *co*-creation and *bi*-directional learning process. In so doing, this PhD thesis assumes that the research-practice gap does not result from a knowledge transfer problem (for instance, because of resistance from knowledge users), but rather from a knowledge production problem (researchers fail to address the most important problems encountered by professionals, managers and decision-makers).¹⁹ Therefore, much emphasis is placed on the partnerships between researchers, professionals and patients within integrated KTA processes.¹⁹

We started this innovation and implementation project with all of these assumptions and methodologies in mind, but did not know in advance precisely how things would work in practice. This thesis is thus rather explorative in character. It illustrates *how* this alternative, sociologically informed way of working – aimed at addressing the perceived research-practice gap – actually functioned in a local prosthetic rehabilitation setting in the Netherlands. The issues addressed in this PhD thesis can therefore be read on two different levels: (1) on a practical level, addressing the question “How to improve a prosthetic rehabilitation programme with scientific knowledge from ‘within’ a local setting?”, and (2) on a theoretical, methodological and implementation level, addressing the question “What are the implications of a more sociological way of *thinking* and *doing* research in relation to reducing the research-practice gap in general, and improving rehabilitation programmes in particular?”

OUTLINE OF THE THESIS

This thesis presents the sociologically informed exploration process from different angles. After this introduction, Chapter 2 illustrates how this innovation project developed in response to a request from the prosthetic rehabilitation team to improve their rehabilitation programme with up-to-date scientific knowledge. Participatory research methodology was used as a tool to explore the content and conceptual underpinnings of the treatment programme in close collaboration with rehabilitation professionals and patients. Thereby, we tackled a vital issue: the feared decline in outcome of patients after discharge and the struggle of professionals to encourage patients to be active learners. This might have to do with a primary focus on biomedical and biomechanical principles and practices and a lack of focus on social learning principles and practices. A literature study provided theoretical knowledge about how to give content to active learning, as discussed in self-management literature. This raised the question of how to incorporate self-management principles and practices into a primarily biomedically and biomechanically based prosthetic rehabilitation programme?

Before we tackled this issue, we investigated this feared decline in outcome of patients with LLA (Chapter 3). The question was not only whether or not a decline could be objectified, but also what personal and environmental conditions affected outcome after discharge. We therefore chose a mixed methods design to study the functioning, participation and autonomy of patients with LLA at discharge and then three and six months later, and the barriers and facilitators affecting these outcomes. The results of this study confirmed our earlier line of reasoning that a self-management programme could help prepare patients for the post-discharge period. In relation to integrating self-management into prosthetic rehabilitation, the question arose: In what way does physical rehabilitation medicine differ from self-management education?

In Chapter 4, a comparative text analysis was used to trace differences and similarities in knowledge practices between physical rehabilitation medicine (PRM) and self-management education (SME). Inspired by discourse analysis, texts on both approaches were contrasted as having vocabularies of their own, expressed under certain material conditions. In doing this, a better understanding was provided of how self-management could be given a considered place within the rehabilitation process.

In Chapter 5, the knowledge from Chapters 2 to 4 was brought together, in order to develop and implement the self-management intervention. The integrated KTA framework served as a guide for integrating the research knowledge and the practical contextual knowledge of the local team, and subsequently putting the co-created knowledge into action. The roles of the researcher and professionals in the local team, working collaboratively in genuine partnership, were thereby made explicit.

Chapter 6 discusses the complexities faced by both researchers and professionals in the field of rehabilitation when aiming to work in an evidence-based manner. Four themes that came to the fore in evidence-based practice in prosthetic rehabilitation were addressed: (1) the methodological complexity in research on elderly patients with amputations, (2) the impact of technological advancements on evidence-based prescription, (3) diverging classification systems in prosthetic prescription, and (4) additional modifying factors in the transfer to individual patients. Ways of dealing with these complexities and a reorientation of the use of evidence in clinical practice are suggested.

In the general discussion in Chapter 7, I return to the question of what these studies can teach us about innovation and implementation research in healthcare and about improving rehabilitation practice in a rapidly changing healthcare and research system. More specifically, I will consider what this move from a biomedical towards a sociological perspective on innovation and implementation research in rehabilitation practice taught us about the role of theory, engaged partnerships, the methodologies and tools to use, as well as the role of the researcher.

REFERENCES

1. Dijkers MP, Murphy SL, Krellman J. Evidence-based practice for rehabilitation professionals: concepts and controversies. *Arch Phys Med Rehabil* 2012; 93 (8 Suppl 2): 164-176.
2. Sackett DL, Strauss SE, Richardson WS, Rosenberg W, Haynes RB. *Evidence-based medicine: how to practice and teach EBM*. 2nd ed. Edinburgh: Churchill Livingstone; 2000.
3. Green LW. Making research relevant: if it is an evidence-based practice, where's the practice-based evidence? *Fam Pract* 2008; 25: i20-124.
4. Whyte J. Contributions of treatment theory and enablement theory to rehabilitation research and practice. *Arch Phys Med Rehabil* 2014, 95 (1 Suppl 1): S17-23.
5. Keith RA. The role of treatment theory. In Fuhrer MJ ed. *Assessing medical rehabilitation practices: the promise of outcomes researched*. Brookes Publishing, 1997: 257-274.
6. Lipsey MW. Theory as method: small theories of treatments. In Sechrest L, Perrin E, Bunker J eds. *Conference proceedings: research methodology: strengthening causal interpretations of non-experimental data*. Rockville US, 1990: 33-52.
7. Chen H-T. *Theory driven evaluations*. London: SAGE Publications, 1990.
8. Lettinga AT. Chen and the art of bridging gaps. About the foundations and pillars of theory-driven evaluation. In: *Looking back and forward*. Groningen, Stichting Kinderstudies, 1995.
9. Siemonsma PC, Schroder CD, Roorda LD, Lettinga AT. Benefits of treatment theory of explanatory trials: cognitive treatment of illness perceptions in chronic low back pain rehabilitation as an illustrative example. *J Rehabil Med* 2010; 42: 111-116.
10. Lettinga AT, Mol A. Clinical specificity and the non-generalities of science: on innovation strategies in neurological physical therapy. *Theo Med Bioeth* 1999; 20: 517-535.
11. Kitto SC, Sargeant J, Reves S, Silver I. Towards a sociology of knowledge translation: the importance of being dis-interested in knowledge translation. *Adv in Health Sci Edu* 2012; 17: 289-299.
12. Law J, Mol A. *Complexities: social studies of knowledge practices*. Durham and London: Duke University Press, 2002.
13. Gherardi S, Nicolini D. To transfer is to transform: the circulation of safety knowledge. *Organization* 2000; 7: 329-348.
14. Wierdsma A. *Co-creatie van verandering*. Delft: Eburon, 2003.
15. Van der Zouwen T. *Building an evidence based practical guide to Large Scale Interventions. Towards sustainable organizational change with the whole system*. Delft: Eburon, 2011.
16. Cornwall A, Jewkes R. What is participatory research? *Soc Sci Med* 1995; 41(12): 1667-1676.
17. White GW, Suchowierska M, Campbell M. Developing and systematically implementing participatory action research. *Arch Phys Med Rehabil* 2004; 85, (Suppl 2): S3-S12.
18. Graham ID, Logan J, Harrison MB, et al. Lost in knowledge translation: time for a map? *J Contin Educ Health Prof* 2006; 26: 13-24.
19. Straus SE, Tetroe J, Graham ID. Introduction: knowledge translation- what it is and what it isn't. In: Straus SE, Tetroe J, Graham ID eds. *Knowledge translation in health care: moving from evidence to practice*. Chichester, United Kingdom: John, Wiley & Sons Ltd; 2013
20. Bowen SJ, Graham ID. From knowledge translation to engaged scholarship: promoting research relevance and utilization. *Arch Phys Med Rehabil* 2013; 94 (1 Suppl 1): S3-S8.

2

Improving rehabilitation treatment in a local setting: a case study of prosthetic rehabilitation

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ABSTRACT

Objective: To contribute to the discussion on the research-practice gap by illustrating obstacles and opportunities that arise in an evidence-informed improvement process of prosthetic rehabilitation in a local setting.

Setting: Dutch rehabilitation centre.

Presupposition: The improvement process was considered as a two-way translation process rather than a unidirectional process of knowledge transfer between science and practice.

Method: Case study and participatory research methods comprising documentary analysis, treatment observations, individual and focus groups interviews, and literature studies. A qualitative software program (Atlas-ti) was used to triangulate the collected data.

Results: The main concern of local practitioners was identified to be the post-discharge decline in functional capacity in elderly people with amputations. This was related to a predominantly biomedical and biomechanical approach, and accompanying traditional therapist-patient interactions. The content and underpinnings of prosthetic treatments were scarcely specified in either the scientific literature or the local setting. Generic principles and practices from other fields were useful for treatment innovation for post-discharge problems, such as task- and context-specific training and self-management education. A circuit training focused on motor learning and a problem-solving training focused on social learning were developed by integrating amputation-specific knowledge.

Conclusion: Improving rehabilitation practice with the use of available evidence is a heterogeneous and multifaceted scientific enterprise. Such an enterprise requires as much self-reflexivity from researchers as from practitioners.

INTRODUCTION

Clinical research should be aimed at improving treatments delivered rather than at just proving their effectiveness.¹ It is commonly accepted that improvements in clinical practice have to be based on available evidence. Most research findings are, however, not ready-made for straightforward application in clinical practice.^{2,3} For instance, the population of subjects used in research may differ markedly from the clinical population to which the results are to be applied. Besides, it is very difficult to synthesize the body of evidence available into a coherent piece of advice on how to manage a particular situation.⁴ What is more, such an advice needs to be incorporated into an existing practice. Indeed, a practitioner is far from empty with respect to knowledge, concerns, demands on time and resources, and other contextual considerations.² The question then is how to bridge the gap between general research results and a local clinical practice.

Usual solutions for this research-practice gap tend to investigate ways to communicate available evidence to practitioners as an intervention to overcome barriers to change in clinical practice.^{2,5} Quality improvement interventions, for instance, try to enhance the uptake of evidence-based guidelines by creating a dialogue between researchers, content experts, front line staff members and managers.^{3,6,7} Advocates of so-called practice-based research on the other hand attempt to include practitioners at the very beginning in the research process.^{2,8} Another remedy is found in bringing researchers into action as knowledge translators between research and practice. Improvement of clinical practice is thereby not regarded as a linear, unidirectional process of knowledge transfer, but as an iterative and interactive process focused on actively translating evidence into usable interventions for local settings.⁹

This paper presents a case study in which the obstacles and opportunities of an iterative and interactive translation process are illustrated with the example of a rehabilitation treatment for patients with a lower-limb amputation in a Dutch rehabilitation centre. We not only took up the challenge of translating scientific knowledge into a useable form relevant for this local practice, but also added an extra element. Inspired by recent ethnographical work^{1,10,11} we chose first to explore the implicit knowledge, concerns and lacunas of practitioners in the local setting under study, and then searched for relevant knowledge in the scientific literature that could be useful in improving their rehabilitation treatment. The aim of this case study is twofold: (1) to provide details of a concrete, evidence-informed improvement process of prosthetic rehabilitation, and (2) to enrich the more abstract discussion on the research-practice gap.

METHOD

A combination of case study and participatory research methodology was used comprising documentary study, treatment observations, individual and focus group interviews with practitioners and patients, and literature study. The collected knowledge was analysed with help of the qualitative software program Atlas-ti. Atlas-ti is valuable for triangulation. It assists in extracting, coding and comparing meaningful fragments out of the texts, transcribed interviews, and noted observations. Information from one data source can thereby supplement, refine or provide background information for other data sources.

The local setting under study was a Dutch rehabilitation centre to which patients with disabling conditions due to acute and chronic conditions are admitted for multidisciplinary rehabilitation treatment. The case study was focused on the prosthetic rehabilitation team consisting of physiatrists, physiotherapists, occupational therapists, nurses, a prosthetist, a psychologist and a social worker.

The study started with a request from the multidisciplinary team to update their treatment programme. The resulting improvement process consisted of an iterative and interactive approach between the team and the first author. The first author (SvT) took the role of participatory researcher and knowledge translator. The last author (AL) acted as an outsider by critically reflecting on the steps in the improvement process. Each step followed from the results of the step before and thus served a different purpose.

The first improvement step was aimed at specifying the explicit and implicit knowledge of the multidisciplinary team under study by focusing on the content and conceptual underpinnings of their prosthetic rehabilitation treatment. All the written material that the team had produced to explain their treatment to other stakeholders was analysed, including a description of the rehabilitation programme, a patient leaflet and two chapters from a Dutch textbook in which physiotherapists and occupational therapists clarified their part of the treatment.¹² Subsequently treatment observations and semi-structured interviews with team members were employed to elucidate the written material and to identify gaps in their treatment descriptions.

The second step consisted of a search into the scientific literature on prosthetic rehabilitation in order to find evidence and new scientific insights that could be used to improve the prosthetic treatment under study. No attempt was made to perform a full systematic review. As the aim was improvement of the content and conceptual underpinnings of the local treatment, the focus of attention was more on treatment research than on dysfunction research.^{13,14} Dysfunction theory conceptualizes how a particular problem comes about - for instance, phantom pain or a motor problem - how it is maintained, how it ends or reappears and so on. Treatment theory refers to

the conceptual underpinnings of the process of change during treatment; the assumed working mechanism of prosthetic training.

In a third step a wider search into rehabilitation literature was conducted to seek promising generic rehabilitation principles and practices that might resolve the critical issues at stake in the local treatment under study.

The focus of the fourth step was on gathering amputation-specific knowledge in order to translate the generic principles and practices to prosthetic rehabilitation treatment. Individual and focus group interviews were held to obtain data about patient's needs on the one hand and to collect knowledge of practitioners on patient's motor problems on the other hand.

In the fifth step the generic principles and practices were translated into two treatment modules for the local prosthetic rehabilitation programme. An overview of these steps is presented in a flow diagram in Figure 1.

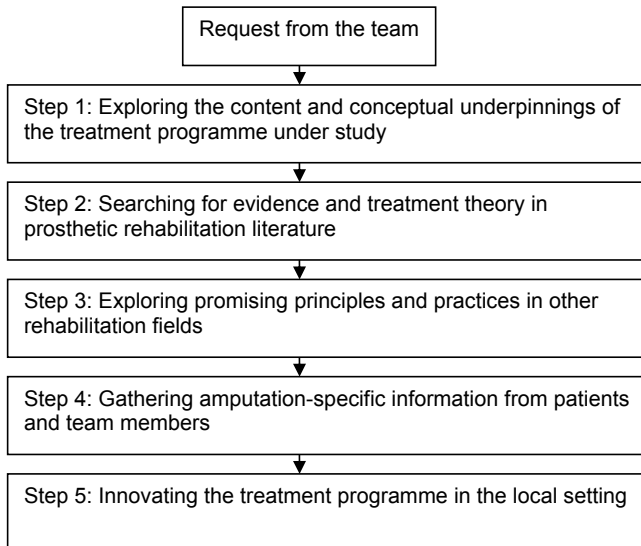


Figure 1 Iterative and interactive translation process.

Request from the team

The request from the prosthetic rehabilitation team to update their treatment programme was primarily based on the concern that the skills learned in the clinical setting were not preserved after discharge from the rehabilitation centre. All team members worried about the decline in functional outcome experienced especially by the elderly patients with a lower-limb amputation. Take the following interview quote:

I'm not really worried about the younger patient with a lower limb amputation; he or she will probably be inclined to move. My worries concern the elderly patient with an amputation based on vascular problems. He or she will not be able to walk long distances in bad weather; won't do any shopping. The level of his/her condition will therefore slowly decline after discharge and he/she starts functioning worse.

Step 1: Exploring the treatment content and its conceptual underpinnings

With this carry-over problem in mind we started to explore the content and conceptual underpinnings of the prosthetic treatment in the local setting.

Documentary study

The documentary study provided information on the programme's content in terms of *which* discipline had to do *what* part of the treatment. The treatment protocol, for example, stated that physiotherapists were responsible for prosthetic gait training and sport activities, whereas occupational therapists had to train patients to use a wheelchair or to perform activities of daily living with a prosthesis. But the documents hardly gave any information on *how* therapists delivered their part of the treatment, and *why* they choose to do so in that specific manner. The content and conceptual underpinnings of the treatment could thus not be specified sufficiently with the help of the team's manuscripts.

Semi-structured interviews

The team members were therefore asked to address the 'how' and 'why' questions in semi-structured interviews. They depicted their treatment in terms of treatment goals such as reducing oedema of the stump, preventing contractures and skin defects, optimizing strength and general condition, providing optimal prosthetic prescription or balance and mobility training in functions of daily living. However, they still had difficulties in explaining *how* they attempted to produce therapeutic change, and *why* it was supposed to work. Take the following quotes:

What the treatment is based on? No, I can't answer that question right now.

and

It is hard to articulate. Normally you don't dwell on that.

Analysis of interview transcriptions

Analysis of the transcribed interview material revealed that the underpinnings of prosthetic treatment were presumably biomedical and biomechanical of character. Implicitly, therapists referred to principles of exercise physiology and physical training when talking about strength and condition training:

When the patient has set his goal on unlimited walking indoors and walking small distances outdoors, as a physiotherapist you translate this goal to an optimal condition of the stump, sufficient mobility, adequate muscle force, optimal balance and enough condition to achieve this goal.

In addition, they used biomechanical terms when prosthetic training was the topic of conversation:

With respect to prosthetic training I especially think about the technical aspects of dealing with a particular type of prosthesis. A patient with a knee ex-articulation, for instance, does have more possibilities to use his hip musculature in an adequate and efficient manner than a patient with a transfemoral amputation..... It is also quite a difference when you train somebody with a free swinging knee or locked prosthetic knee joint. The first needs far more time to learn to control the knee mechanism before starting gait training.

Treatment observations

We got more insight into *how* content was given to prosthetic rehabilitation by watching various treatments, thereby focusing on the delivery form, instructions, exercises and the context of the treatment. Noticeable in these observations was that predominantly elderly patients relied heavily on the knowledge and expertise of the therapists. Most therapists thereby did little to encourage patients to be active learners. Often the therapist had the role of the expert: they prescribed patients how to deal with problems in ambulation. Instead of teaching patients actively how to perform their daily tasks with a prosthesis, patients were approached as more passive recipients of therapeutic intervention.

Synthesizing data with the help of Atlas-ti

By integrating the data from the different method sources with Atlas-ti, we not only indicated a critical issue in the knowledge and skills of the team but also a possible way out. Namely, the team's concern - the patients' decline in functional capacity after discharge - could be related to the traditional roles of the therapists and patients. This traditional interaction between therapist and patient seemed to be indirectly derived from a treatment programme primarily based on biomedical and biomechanical principles in which therapists are the technical, and therefore, training experts and patients have to be compliant. The application of more up-to-date learning theories in which patients actively participate in prosthetic training could be a solution to this carry-over problem.

Step 2: Searching for evidence and treatment theory in prosthetic rehabilitation literature

We searched in the scientific literature on prosthetic rehabilitation for evidence and conceptual underpinnings that supported or refuted our solution.

An overwhelming volume of articles on dysfunction research

An overwhelming volume of articles on a great variety of topics emerged when we searched the database PubMed for terms such as '(lower limb) amputation', '(prosthetic) rehabilitation', '(lower limb) amputees', and combined that search with terms such as 'treatment' and 'theory'. This urged us to delineate our search dramatically. A main focus on reviews appeared to be helpful. Most reviews, however, summarized research findings that could be labelled as dysfunction research. They focused on topics related to the onset, incidence, nature, maintenance or reappearance of problems patients with a lower limb amputation are confronted with such as phantom pain,¹⁵ gait analysis,¹⁶ amputation surgery,^{17,18} physical capacity and walking ability,¹⁹ sexuality and amputation,^{20,21} and skin problems.²² Most reviews concluded that the available evidence had implications for clinical practice but few concrete suggestions on how research results could be used for treatment innovation were offered. Above all, these topics were not relevant for our improvement question.

Little evidence available in scarce articles on treatment research

Literature about treatment research appeared to be scarcer. In a 10-year review of rehabilitation prosthetics literature (1990-2000) it was concluded that no articles were found with new aspects regarding para-medical treatment.²³ Another review suggested that an interdisciplinary team approach with active participation of the patient should be implemented early in the pre-amputation period, as it might facilitate short hospital stay and earlier return to productivity with associated cost savings.²⁴ But *how* the prosthetic rehabilitation team should give content to active participation of patients and *which* learning principles should be applied, was not made explicit.

Most reviews summarizing treatment research focused particularly on the technical advances of prosthetics.²⁵⁻³⁰ We found one Cochrane review synthesizing the effectiveness of prosthetic rehabilitation for older dysvascular people following a unilateral transfemoral amputation.³¹ As just one clinical trial satisfied the methodological criteria, it was concluded that there was inadequate evidence to inform the choice of prosthetic rehabilitation, including the optimum weight of the prosthesis. Furthermore we detected one elegant clinical perspective study that entered in length into the biomechanical principles and practices of a new treatment called 'OrthoTherapy', a name selected by the author to define comprehensive biomechanical treatment that integrates physical therapy and prosthetic and orthotic technology.³²

Step 3: Exploring promising principles and practices in other rehabilitation fields

As the content and underpinnings of prosthetic rehabilitation were insufficiently described and there was little evidence available to inform treatment choice, we conducted a wider search into the literature to find interventions that encouraged active participation of patients in the rehabilitation process. We chose for two interventions: task- and context-specific training^{33,34} and self-management education,³⁵ as their content and conceptual underpinnings were analysed in a thorough way.^{36,37}

Task- and context-specific training

There is evidence that task- and context-specific training is successful in stroke rehabilitation.^{38,39} In addition, elderly patients may benefit from such training as it showed promising results compared to a resistance exercise programme.³⁴ The content analysis revealed that task- and context-specific training is informed by a mixture of biomechanical, cognitive, motor learning, and muscle physiological principles.³⁶ Biomechanical analyses of functional tasks by healthy subjects - such as sit-to-stand and walking - were used as a standard for identifying essential components that are missing when individuals with stroke-induced hemiplegia executed such tasks.⁴⁰ The early stage of motor relearning is thereby cognitive of character. It requires verbal cues and feedback, visual input and explanations concerning missing/essential components which may help patients to think things through.⁴¹ So, task- and context-specific training appealed to patients' problem-solving capacities rather than relying on practitioners' prescriptions.

Self-management education

There is some evidence that self-management education can improve the health status of a heterogeneous group of chronic disease patients while reducing hospitalization.⁴² Self-management also makes a strong appeal to patients' problem solving capacities.³⁵

Four basic problem-solving skills are taught: (1) problem definition and formulation, (2) generation of alternative solutions, (3) decision making and (4) solution implementation and verification.⁴³ Self-management education is aimed at enhancing the patients' self-efficacy through interventions such as mastering of skills, modelling, interpretation of symptoms and social persuasion.³⁵ Self-efficacy is derived from social cognitive learning theory and is defined as the belief in one's capabilities to organize and execute the courses of action required to produce given attainments.⁴⁴

Contrasting task- and context-specific training and self-management education

So both task- and context-specific training and self-management education focused on active participation of patients in the rehabilitation process in order to enhance the transition from the clinical to the home setting. In task- and context-specific training, however, patients' problem-solving capacities were deployed to teach them the necessary *motor* skills after a stroke with an acute onset,³⁶ whereas in self-management education such capacities were appealed to in order to provide patients with the *psychological* skills to deal with the unpredictable course of a chronic illness.³⁷ We argued that both skills could be valuable in assisting patients with a lower limb amputation to cope more confidently with the carry-over problem.

Step 4: Gathering amputation-specific information

To be able to translate the promising principles and practices in concrete interventions relevant for elderly patients with amputations we needed amputation-specific information to: (1) specify essential components of motor tasks in prosthetic training; (2) identify post-discharge problems of people with an amputation.

Focus group discussion on essential components of motor tasks

In a focus group physiotherapists were invited to discuss prosthetic training in terms of missing and essential components. Several motor tasks such as walking, sit-to-stand, getting up from the floor, picking up an object and crossing obstacles were specified into essential components in functioning with a prosthesis. According to the therapists such components had in particular to do with that part of the movement pattern where the patient needed to place weight on their prosthesis or had to cope with the working mechanism and restrictions of the prosthetic knee and foot. For example, patients with an above-knee amputation needed to shift weight on their forefoot to unlock the knee before sitting down. And the restrictive mobility of a prosthetic ankle needed to be dealt with when stepping down from a stair or in kneeling down.

Individual and focus group interview on post-discharge problems

Individual interviews with therapists from several disciplines provided information about post-discharge problems such as lack of space or rough carpet in the home setting compared with the large ceiled rooms and extended passages in the rehabilitation setting, influence of the weather on outside activities and shortage of attention for stump wounds. In a patient focus group interview the transition from the rehabilitation centre to their home was recounted in terms of

I have a feeling of doing nothing at all

or

You have to be aware of falling into a sort of limbo; it is quite a transition.

Patients clarified their feelings as a loss of supervision, not receiving encouragement of peers anymore and lack of therapy structure. Examples of problems they had to face at home were provided such as getting downstairs with a laundry basket or preparing dinner in a poorly adapted kitchen.

Step 5: Innovating the treatment programme in the local setting

With the help of this domain-specific knowledge two new group modules were developed: (1) a circuit training in which patients actively learn to deal with the essential components in functioning with a prosthesis, and (2) a problem-solving training in which patients actively learn to cope with post-discharge problems.

Circuit training

The circuit training consists of several working stations in which therapists have to create a challenging motor learning environment. The missing components that are relevant for patients with a lower limb amputation are trained at these stations, varying from basic motor skills as walking and getting up from a chair to more advanced activities such as getting up from the floor or crossing obstacles. Verbal instructions on the essential components of the task are presented on the wall combined with visual cues on the floor, so patients know exactly what to do and how to monitor their own performances. Instructions and feedback are provided by therapists in a manner that stimulates mental practice of the patient and offers patients options to critical reflect upon their own performances. In addition, patients have to form couples so one patient can monitor the results of the performances of the other and register the progress graphically. The same skill is also trained within a working station in different contexts, for example sit-to-stand from chairs of different heights.

Problem-solving training

In the problem-solving training the four basic problem-solving skills are taught and applied to two main amputation-related items: mobility and limb care. Each item encompasses several subitems. Mobility, for instance, is related to contextual constraints such as differences in material environment between the home and the rehabilitation setting, the impact of the weather, the loss of supervision of the therapist, encouragement of peers and lack of therapy structure. Limb care is divided into subitems such as stump care, hygienic actions, dressing, wound management and stump volume changes. The required knowledge on these items is presented and discussed in interactive classes. Patients not only get the opportunity to practise skills such as stump dressing with each other, they are also invited to bring in real life scenarios with respect to experienced

problems. Each session ends with the construction of an individual action plan on how to act on a chosen aspect of the discussed item during the days at the rehabilitation centre as well as during weekend leaves. The action plans are evaluated in the next group session.

DISCUSSION

The challenges of translating research evidence into a usable form that is relevant to local practice are rarely discussed.⁹ Most solutions for the research-practice gap are mainly discussed in terms of research dissemination and utilization, thereby explaining difficulties in uptake of evidence and related clinical guidelines in terms of resistance of practitioners.^{2,5} In this case study on prosthetic rehabilitation we started our explorative research with another set of orienting presuppositions of which the theoretical and practical implications will be touched on in this discussion section. In doing so, we hope to enrich the discussion on the research-practice gap in rehabilitation.

Presuppositions regarding the research-practice gap

Inspired by sociologically informed conceptions of science we regarded clinical research and clinical practice as two complex knowledge practices, the appropriateness of which is open for further analysis and comparison.^{1,11,36} Accordingly the evidence-informed improvement process was considered as a two-way translation process between clinical and scientific knowledge practices rather than as a unidirectional process of knowledge transfer from the heights of science to a local clinical setting. This implied that researchers should not just act as evidence producers, summarizers, disseminators or resistance removers, but also take the role of knowledge translators and reflective questioners.

We did not know, however, at least not in a strong sense, how - within these presuppositions - our knowledge translation and reflection efforts would work out in practice. Nevertheless it led us to gather different kind of material including treatment descriptions, transcriptions of interviews, field notes as well as scientific literature. By analysing and comparing the clinical and scientific material - and raking through what had been written, told and noticed - we generated a sense of pattern, and with that, made a series of 'decisions' about what (or what not) counted as warrantable translations within this local setting. Although the decisions and collected data are above all pertinent to the local setting under study - and therefore can be questioned for generalization to prosthetic rehabilitation in other settings - the strategies used can be challenging and inspiring for all researchers and practitioners who want to collaboratively work on the improvement of rehabilitation treatments.

Challenges for local practices

Most of the knowledge in the local practice as well as the scientific literature on prosthetic rehabilitation appeared to be predominantly biomedical and biomechanical of character. It was also noticeable that both insufficiently described how prosthetic rehabilitation produced therapeutic change, and why it was supposed to work. However, by limiting our scope on scientific literature, we may possibly have neglected a body of potential useful information on prosthetic rehabilitation such as that in text books. By identifying the main concern of the local practitioners as a post-discharge decline in functional capacity of elderly people with an amputation, we could focus our search on promising principles and practices in other rehabilitation fields to address the functional carry-over problem, such as task- and context-specific training and self-management education. With help of amputation-specific knowledge the more generic principles and practices could be translated in two novel prosthetic rehabilitation modules: a circuit training focused on motor learning and a problem-solving training focused on social learning. The identified knowledge lacunas, concern and opportunities in prosthetic rehabilitation of this particular local setting may be recognizable, and therefore also challenging for other settings.

We do realize that this iterative and interactive translation process has been just a first step in the improvement process. Several other steps need to be taken. Our next challenge is to integrate and implement the treatment modules in the local setting. Thereby we can take advantage from the ethnographical material of the local setting by addressing the question which of the existing interventions are still critical, and which might be superfluous when integrating the new modules. As the novel modules try to tackle the main concern experienced by the local practitioners, they are sincere and driven to implement the novel modules. Indeed, it is important that practitioners feel the need for change. This may be a better guarantee for actual change than regulating it by external rules or applying generic guidelines.¹⁰ The last and future challenge is to design an effectiveness study that can examine the supposed superior value of the novel modules in an appropriate way. We have already started an explorative cohort study to examine and objectify the perceived decline in functional capacity after discharge from the rehabilitation centre.

CONCLUSIONS

This case study on prosthetic rehabilitation in a Dutch rehabilitation centre demonstrated that the nature of the questions that arise when attempting to use evidence for improvement of a rehabilitation treatment in a local setting are far more complex than assumed in unidirectional knowledge transfer conceptualizations. It shows that improving rehabilitation practice with the

use of available evidence is a heterogeneous and multifaceted scientific enterprise. It suggests that rather than trying to strengthen rehabilitation treatments by subjecting them to evidence-based rules, improvement strategies can be more successful when the clinical knowledge in the local setting is also seriously dealt with. Improving rehabilitation practice thus requires as much self-reflexivity from researchers as from practitioners. Only then can researchers and practitioners make optimal use of each other strengths.

Clinical messages

- Improving rehabilitation practice will be more promising when evidence-based as well as clinical knowledge is analysed and compared.
- Self-management and task- and context-specific training principles can be integrated in prosthetic rehabilitation to enhance the functional carry-over from the clinical to the home setting.

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REFERENCES

1. Mol A. Proving or improving: on health care research as a form of self-reflection. *Qual Health Res* 2006; 16: 405 - 414.
2. Green LW. Making research relevant: if it is an evidence-based practice, where's the practice-based evidence? *Fam Pract* 2008; 25: i20-i24.
3. Parker LE, Kirchner JE, Bonner LM, et al. Creating a quality-improvement dialogue: utilizing knowledge from frontline staff, managers, and experts to foster health care quality improvement. *Qual Health Res* 2009; 19: 229-242.
4. Wade DT. Editorial *Clin Rehabil* 2006; 20: 93-96.
5. Grol R, Grimshaw J. From best evidence to best practice: effective implementation of change in patients' care. *Lancet* 2003; 362: 1225-1230.
6. Ogrinc G, Mooney SE, Estrada C, et al. The SQUIRE (Standards for Quality Improvement Reporting Excellence) guidelines for quality improvement reporting: explanation and elaboration. *Qual Saf Health Care* 2008; 17 (Suppl 1): i13-i32.
7. Rubenstein LV, Hempel S, Farmer MM, et al. Finding order in heterogeneity: types of quality-improvement interventions publications. *Qual Saf Health Care* 2008; 17: 403-408.
8. Demers L, Poissant L. Connecting with clinicians: opportunities to strengthen rehabilitation research. *Disabil Rehabil* 2009; 31: 152-159.
9. Scott NA, Moga C, Barton P, et al. Creating clinically relevant knowledge from systematic reviews: the challenges of knowledge translation. *J Eval Clin Pract* 2007; 13: 681-688.
10. Pols J. *Good care. Enacting a complex ideal in long-term psychiatry*. PhD thesis, 2004.
11. Struhkamp R, Mol A, Swierstra T. Dealing with independence: doctoring in physical rehabilitation practice. *Sci Technol Human Values* 2009; 34: 55-76.
12. Geertzen JHB, Rietman JS. *Amputatie en prothesiologie*. Utrecht: LEMMA, 2002, p.169-196.
13. Kazdin AE. A model for developing effective treatments: progression and interplay of theory, research, and practice. *J Clin Child Psychol* 1997; 26: 114-129.
14. Lettinga AT, van Twillert S, Poels BJJ, Postema K. Distinguishing theories of dysfunction, treatment and care. Reflections on 'Describing rehabilitation interventions'. *Clin Rehabil* 2006; 20: 369-374.
15. Halbert J, Crotty M, Cameron ID. Evidence for the optimal management of acute and chronic phantom pain: a systematic review. *Clin J Pain* 2002; 18: 84-92.
16. Rietman JS, Postema K, Geertzen JHB. Gait analysis in prosthetics: opinions, ideas and conclusions. *Prosthet Orthot Int* 2002; 26: 50-57.
17. Pinzur MS, Pinto MA, Schon LC, Smith DG. Controversies in amputation surgery. *Instr Course Lect* 2003; 52: 445-451.
18. Blanc CH, Borens O. Amputations of the lower limb - an overview on technical aspects. *Acta Chir Belg* 2004; 104: 388-392.
19. Van Velzen JM, van Bennekom CAM, Polomski W, Sloopman JR, van der Woude LHV, Houdijk H. Physical capacity and walking ability after lower limb amputation: a systematic review. *Clin Rehabil* 2006; 20: 999-1016.
20. Ide M. Sexuality in persons with limb amputation: a meaningful discussion of re-integration. *Disabil Rehabil* 2004; 26: 939-943.
21. Geertzen JHB, Van Es CG, Dijkstra PU. Sexuality and amputation: a systematic literature review. *Disabil Rehabil* 2009; 31: 522-527.
22. Meulenbelt HEJ, Geertzen JHB, Dijkstra PU, Jonkman MF. Skin problems in lower limb amputees: an overview by case reports. *J Eur Acad Dermatol Venereol* 2007; 21: 147-155.
23. Geertzen JHB, Martina JD, Rietman HS. Lower limb amputation Part 2: rehabilitation – a 10 year literature review. *Prosthet Orthot Int* 2001; 25: 14-20.
24. Pandian G, Kowalske K. Daily functioning of patients with an amputated lower extremity. *Clin Orthop Relat Res* 1999; 361: 91-97.
25. Dillingham TR. Musculoskeletal rehabilitation: current understandings and future directions. *Am J Phys Med Rehabil* 2007; 86: S19-S28.

26. Aaron RK, Herr HM, Ciombor DM, et al. Horizons in prosthesis development for the restoration of limb function. *J Am Acad Orthop Surg* 2006; 14 (10): S198-S204.
27. Berry D. Microprocessor prosthetic knees. *Phys Med Rehabil Clin N Am* 2006; 17: 91-113.
28. Pasquina PF, Bryant PR, Huang ME, Roberts TL, Nelson VS, Flood KM. Advances in amputee care. *Arch Phys Med Rehabil* 2006; 87: s34-s43.
29. Esquenazi A. Amputation rehabilitation and prosthetic restoration. From surgery to community reintegration. *Disabil Rehabil* 2004; 26: 831-836.
30. Marks LJ, Michael JW. Science, medicine, and the future: Artificial limbs. *BMJ* 2001; 323: 732-735.
31. Cumming JC, Barr S, Howe TE. Prosthetic rehabilitation for older dysvascular people following a unilateral transfemoral amputation. *Cochrane Database Syst Rev* 2006; 18: CD005260.
32. Bedotto RA. Biomechanical assessment and treatment in lower extremity prosthetics and orthotics: a clinical perspective. *Phys Med Rehabil Clin N Am* 2006; 17: 203-243.
33. Carr JH, Shepherd RB. A motor learning model for stroke rehabilitation. *Physiotherapy* 1989; 7: 372-380.
34. de Vreede PL, Samson MM, van Meeteren NLU, Duursma SA, Verhaar HJJ. Functional-task exercise versus resistance strength exercise to improve daily function in older women: a randomized, controlled trial. *J Am Geriatr Soc* 2005; 53: 2-10.
35. Lorig KR, Holman, HR. Self-management education: history, definition, outcomes, and mechanisms. *Ann Behav Med* 2003; 26: 1-7.
36. Lettinga AT, Siemonsma PC, van Veen M. Entwinement of theory and practice in physiotherapy: a comparative analysis of two approaches to hemiplegia in physiotherapy. *Physiotherapy* 1999; 85: 476-490.
37. Jansma FFI, van Twillert S, Postema K, Sanderman R, Lettinga AT. Physical and rehabilitation medicine and self-management education: a comparative analysis of two approaches. *J Rehabil Med* 2010; 42: 808-814.
38. Peppen RPS, Kwakkel G, Wood-Dauphinee S, Hendriks HJM, van der Wees Ph J, Dekker J. The impact of physical therapy on functional outcomes after stroke: what's the evidence? *Clin Rehabil* 2004; 18: 833-862.
39. Saunders DH, Greig CA, Young A, Maed GE. Physical fitness training for stroke patients. *Cochrane Database Syst Rev* 2004; 1: CD003316.
40. Carr JH, Shepherd RB. *A motor relearning program for stroke*, second edition. Oxford: Butterworth-Heinemann, 1987.
41. Carr JH, Shepherd RB. Motor training following stroke. In Banks MA. ed. *Stroke international perspectives in physical therapy 2*. Edinburgh: Churchill Livingstone, 1986, p. 48-79.
42. Lorig, KR, Sobel DS, Stewart AL, et al. Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization: a randomized trial. *Med Care* 1999; 37: 5-14.
43. D'Zurilla TJ, Sheedy CF. Relation between social problem-solving ability and subsequent level of psychological stress in college students. *J Pers Soc Psych* 1991; 61: 841-846.
44. Bandura A. The nature and structure of self-efficacy. In Bandura A. ed. *Self-efficacy: the exercise of control*. New York: WH Freeman and Co., 1997.

3

Functional performance, participation and autonomy after discharge from prosthetic rehabilitation: barriers, facilitators and outcomes

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ABSTRACT

Objective: To examine functional performance, participation and autonomy after discharge from prosthetic rehabilitation and to identify the barriers and facilitators affecting these outcomes.

Design: Concurrent mixed-methods design. Quantitative and qualitative data were collected at discharge from rehabilitation, and 3 and 6 months later. The data were integrated during analysis.

Subjects: Thirteen patients with a unilateral lower limb amputation participating for the first time in prosthetic rehabilitation in a Dutch rehabilitation centre.

Methods: Functional performance was measured using the Two-Minute Walk Test and L test, and participation and autonomy using the Impact on Participation and Autonomy questionnaire. Barriers and facilitators were identified in semi-structured interviews.

Results: After discharge, 9 out of 13 patients declined in functional performance. The principal problems in participation were observed in the "autonomy outdoors" and "family role" domains. Many factors affected functioning and participation and many differences were observed in the way that factors acted as barriers or facilitators for individual patients. No time patterns were found for barriers and facilitators.

Conclusion: Post-discharge, distinctive fluctuations were observed in functional performance and participation and autonomy in patients with lower limb amputation. It is recommended that patients are educated about these fluctuations and the barriers and facilitators identified in the environmental, personal and medical contexts.

INTRODUCTION

Prosthetic rehabilitation is complex and multifaceted, involving both physical and psychosocial challenges for the patient.¹ It aims to optimize health, function, independence and quality of life.² After discharge from rehabilitation, a long-term adaptation phase begins, during which the harsh realities of the disability are felt by the patient with an amputation in their own living environment without the direct support of the multidisciplinary rehabilitation team.^{3,4} Clinicians have called for more insight into this phase, as they are concerned that the functional performance achieved in rehabilitation, especially of elderly patients with an amputation, declines after discharge.⁵ However, little is known about possible changes in functional performance post-discharge and how patients perceive their participation and autonomy in their own living environment. More information is required about the factors that affect these outcomes, so that the content of current rehabilitation programmes can be improved and patients with an amputation can be optimally prepared for the post-rehabilitation period.

To our knowledge, there have been only 4 follow-up studies after discharge from rehabilitation that have assessed the stability of certain rehabilitation outcomes.⁶⁻⁹ The studies found stability or improvement in examined outcomes, contrary to the decline expected by clinicians. More specifically, the studies found stability in functional status and prosthetic use after 2 months,⁶ and, after 3 months, sustained low balance confidence scores and improvements in walking ability,⁷ relative stability in quality of life,⁸ and improvements in prosthetic wear and locomotor capabilities with the prosthesis and stability in the performance of life habits.⁹ A variety of outcome measurements and follow-up periods were used, and thus it was difficult to make comparisons. Furthermore, little attention has been paid to autonomy within participation, which is the extent to which patients can determine which activities they participate in and how they participate.

Other studies have attempted to identify the factors that predict functional outcome¹⁰ or quality of life (QoL)^{11,12} of patients with lower limb amputation (LLA). Age at amputation, one-leg balance on the unaffected limb, comorbidity and cognitive impairment were detected in one study as patient factors that forecast functional outcome.¹⁰ Many diverse factors, such as perceived prosthetic mobility, prosthesis use and problems, use of an assistive device, phantom limb pain, residual limb pain, depression, social support, social activity participation, employment status, comorbidity and age, were identified as predictors of QoL in 2 other studies.^{11,12} A study using secondary data analysis provided preliminary knowledge of the environmental barriers, activity limitations and participation restrictions experienced by patients with a major limb amputation.¹³ Climate, physical environment and income were pinpointed as the most common environmental barriers encountered by patients with LLA.

Therefore, some studies have provided insight into the sustainability of functional performance post-discharge. Others have indicated *which* patient and environmental factors might influence their outcome. A more integrated picture of the complexities inherent in functional performance, participation and autonomy after discharge is, however, lacking.

The aim of this study is to provide a better understanding of the impact of barriers and facilitators on functional performance and participation and autonomy post-discharge. Combining both topics in a single study could provide answers as to *which* factors impact these outcomes post-discharge, as well as to *how* they affect them. We therefore conducted a mixed-methods study that enabled us to combine the outcome measurements and experiences of these concepts for patients with LLA.

METHODS

For this explorative study a concurrent mixed-methods design was used, integrating both quantitative and qualitative research methodologies in the context of a single study.¹⁴ Quantitative and qualitative data were collected concurrently at rehabilitation discharge (T0), at 3 months (T1) and 6 months (T2) after discharge, and then integrated during data analysis. The study protocol was approved by the ethics committee of the local University Medical Center.

Patients with LLA participating in prosthetic rehabilitation (inpatient and outpatient service) at a Dutch rehabilitation centre were recruited between June 2009 and September 2010. Inclusion criteria were: (i) the patient has a LLA above Syme level; (ii) the rehabilitation team expects that the patient will function at home with a prosthesis; and (iii) the patient has a good understanding of Dutch language. Exclusion criteria were: (i) the patient has a bilateral LLA; and (ii) the patient was re-admitted for prosthetic rehabilitation. Fifteen participants were initially included. One person did not finish the rehabilitation programme and one person died post-discharge, leaving 13 participants who completed the study. All participants provided written informed consent.

Quantitative methodology

Data on sociodemographic characteristics and diagnosis were extracted from medical records and obtained using a brief self-constructed questionnaire. To assess functional performance, patients performed the Two-Minute Walk Test (2MWT)^{15,16} and the L test.^{17,18} The 2MWT objectifies the distance a person can walk within 2 min. The reliability of the test is good: intra-rater reliability 0.90-0.96 and inter-rater reliability 0.98-0.99.¹⁵ The 2MWT has proved responsive to changes in rehabilitation in patients with LLA.¹⁶ The L test is a modified version of the Timed Up & Go test

(TUG), developed to overcome ceiling effects and insufficient challenge, and to provide a more realistic simulation of the minimal mobility required for older adults to function at home.^{17,18} The L test is a walk test in which the seconds are registered to make 2 transfers (get up and sit down) and walk a 20 m L-shaped trail requiring turns to both the right and left.¹⁷ The L test has excellent intra-rater and inter-rater reliability; 0.97 and 1.00, respectively.¹⁸ Both a higher score on the 2MWT and a lower score on the L test indicate progress. A minimum detectable change of 34.4 m in the 2MWT is considered a relevant change.¹⁹ To assess participation and autonomy, patients completed a generic questionnaire on the Impact on Participation and Autonomy (IPA).^{20,21} The IPA measures participation and autonomy in 5 domains: autonomy indoors, family role, autonomy outdoors, social life and relationships, and work and education. Patients can score: 0= very good, 1= good, 2= fair, 3= poor, 4= very poor. Therefore, a higher score on the IPA domains indicates more perceived limitations in participation and autonomy. The IPA has been validated for persons older than 18 year with several chronic conditions within rehabilitation practice,²¹ but, to our knowledge, has not been used in patients with LLA. Chronbach's α for each of the domains varies between 0.81 and 0.91.²¹ The responsiveness of the IPA is good.²⁰ Due to a difference in scoring of the IPA questionnaire and no available data on subjects with LLA, we had no indication of the minimal detectable change or standard error of measurement. Therefore, the extent of possible changes in outcome on the IPA is difficult to judge.

Qualitative methodology

Semi-structured interviews were used to explore the patients' individual perceptions and experiences on factors affecting their functioning. The first interview at T0 focused on their perceptions of functioning at that time, on perceived problems in functioning at home, and on their expectations of functional performance and participation post-discharge. At T1 and T2, patients were asked to elaborate on their experiences, to reflect on their previously mentioned expectations, and to indicate barriers and facilitators in post-discharge functioning and participation. Paraphrasing and reflective listening were used at all the interviews. All the interviews were tape-recorded and transcribed verbatim.

Quantitative analysis

Descriptive statistics were used to analyse the quantitative data, including sociodemographic data and measurements of functional performance and participation and autonomy. Data were analysed using SPSS version 16.0. The sociodemographic data of all individual cases are presented in Table I. Scores for functional performance and IPA domains were calculated separately for T0, T1 and T2 for each case. As described in the IPA-manual, the domain scores were calculated if

75% of the items were completed. The mean domain score was calculated by dividing the sum score by the number of completed items.²¹

Cases were categorized into 3 groups: those that showed an increase or decrease in outcome from T0 to T2 and those retaining their baseline levels.

Qualitative analysis

Interview transcripts from each individual case were analysed by the first author (SvT) using Atlas.ti, a qualitative software package. A code list was prepared based on the ICF classification constructs, to provide codes for external factors, personal factors and for body functions and structures.^{22,23} As the ICF does not categorize personal factors, we followed the Dutch translation of the ICF, in which personal factors are defined as: aspects of the individual that are no part of the functional health status of the patient.²³ Examples are: gender, race, age, coping-behaviour, social background, education and former life experiences. The interviews were coded using the code list. In addition, the quotations grouped within the "external factors", "personal factors" and "body functions and structures" codes were analysed to identify overall issues. The last author (AL) took the position of reflective questioner to critically assess the coding and analysis. The original transcripts were re-read for renewed analysis in case of disagreement or lack of clarity.

Integration of data

All findings were recorded in a single table to provide an overview (Table II). A maximum of 3 most prominent affecting factors selected for T0, T1 and T2 were combined with an indication of improvement or deterioration over T0 to T2 for the 2MWT and the IPA domains. Data were analysed horizontally within the table at an individual level, which permitted discussion of the quantitative findings with the qualitative findings on barriers and facilitators. Data on affecting factors at T0, T1 and T2 were analysed vertically within this table, which permitted exploration for time patterns in factors. Factors affecting patients who improved were contrasted with factors affecting those who deteriorated.

RESULTS

Population characteristics of the 13 participants are described in Table I.

Functional performance

The L test revealed a range of 16-61 at T0, 16-45 at T1 and 15-45 at T2. The individual scores on the L test and 2MWT showed virtually identical patterns. Due to high Spearman's rho correlations between the 2 tests for the difference scores at T1-T0, T2-T1 and T2-T0 of -0.94, -0.88 and -0.93, respectively, graphs are presented only for the 2MWT. In total, 9/13 (69.2 %) of the patients showed a decline in functional performance (i.e. those who showed a decrease in outcome and those who were not able to perform the performance test on T1 and/or T2). Figs 1a-c illustrate the developments in functional performance: 4 individuals showed an increase (Fig. 1a), 4 showed a decrease in outcome (Fig. 1b) and 5 were unable to perform the performance test on T1 and/or T2 as they were not able to walk (Fig. 1c).

The cases with an increase in outcome showed quite a linear progress, whereas the cases with a decrease showed a more variable pattern. Of the cases able to perform the test at all time points, a clinically relevant change in the 2MWT of 34.4 m was observed only in case 3 between T0 and T1 (decrease), in case 13 between T0 and T2 (decrease) and in case 10 between T0 and T2 (increase).

Table 1: Sociodemographic data of all individual cases.

Cases	Age (yr)	Gender	Marital status	Living accommodation	Work status	Duration of rehabilitation (days)	Type of treatment*	Level of amputation	Side of amputation	Cause of amputation	Walking aids
1	73,7	Male	Living together	At home	No	114	A	Transibial	Left	Vascular	Handstick
2	51,8	Male	Living together	At home	No	105	A	Transibial	Left	Vascular	None
3	72,3	Male	Living together	Sheltered housing	No	94	A	Transibial	Left	Vascular	One crutch
4	36,4	Male	Living together	At home	Yes	207	A	Knee disarticulation	Right	Trauma	None
5	55,1	Female	No partner	At home	No	112	A	Transibial	Left	Vascular	None
6	68,7	Male	No partner	At home	No	102	A	Transfemoral	Left	Vascular	Wheeled walker
7	57,7	Female	Living together	At home	Yes	137	B	Transibial	Right	Trauma	One crutch
8	38,3	Male	Living separate	At home	No	87	B	Transibial	Left	Trauma	None
9	61,8	Male	Living together	At home	No	170	A	Knee disarticulation	Right	Vascular	One crutch
10	55,0	Male	Living together	At home	Yes	240	A	Transibial	Right	Vascular	One crutch
11	54,5	Male	No partner	At home	No	119	A	Transibial	Left	Vascular	None
12	46,9	Female	Living together	At home	No	214	A	Transibial	Left	Other	One crutch
13	29,7	Female	Living separate	At home	Yes	132	A	Transibial	Left	Trauma	None

*Type of treatment: A= inpatient service followed by outpatient service; B= outpatient service

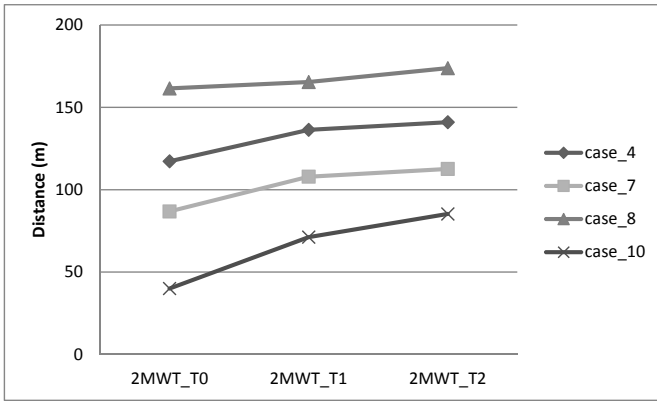


Fig 1a. Increase in outcome Two-Minute Walk Test

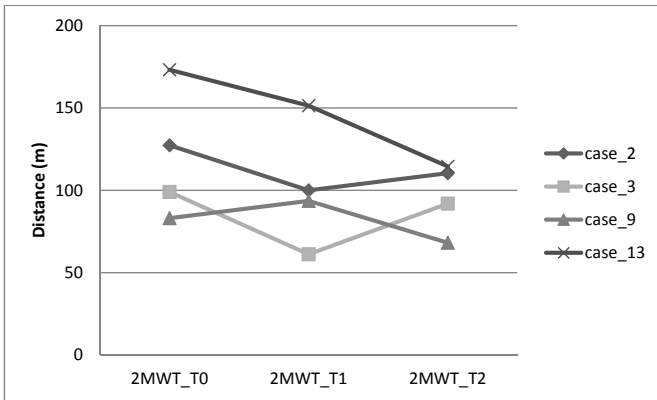


Fig 1b. Decrease in outcome Two-Minute Walk Test

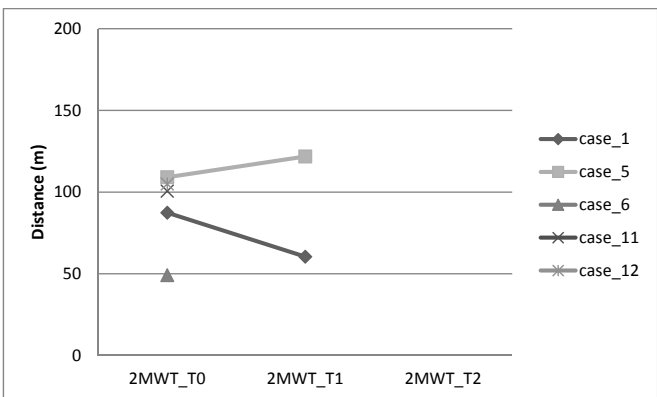


Fig 1c. Outcome 2MWT for cases unable to perform Two-Minute Walk Test at T1 and/or T2

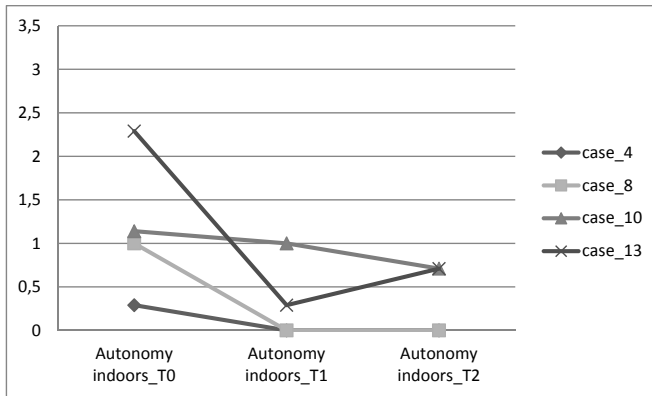


Fig 2a. Decrease in outcome Impact on Participation and Autonomy domain Autonomy indoors

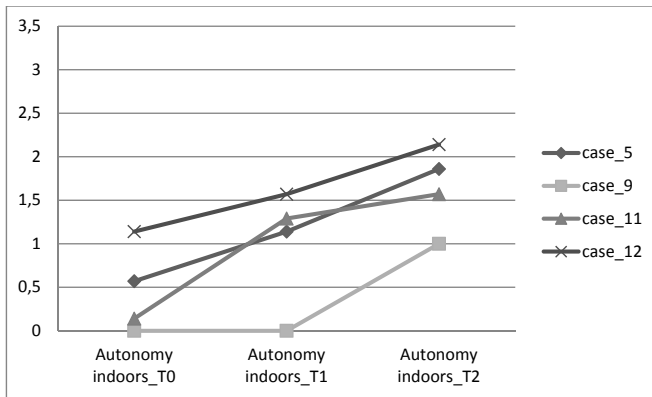


Fig 2b. Increase in outcome in Impact on Participation and Autonomy domain Autonomy indoors

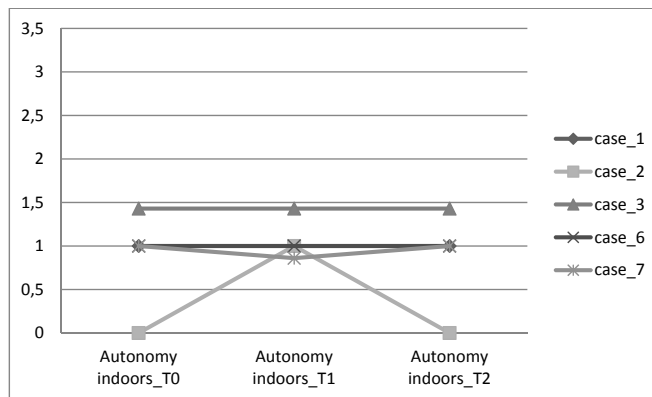


Fig 2c. Outcome in Impact on Participation and Autonomy domain Autonomy indoors T0=T2

Participation and autonomy

The main limitations in participation and autonomy were observed in the “autonomy outdoors” and “family role” domains, with scores of fair to poor. Figs 2-6 illustrate all individual data on the 5 IPA domains. Autonomy indoors: 4 cases showed a decrease (Fig. 2a), 4 showed an increase (Fig. 2b) and 5 had the same scores at T2 as at T0 (Fig. 2c). Family role: 6 cases showed a decrease (Fig. 3a) and 7 showed an increase (Fig. 3b). Autonomy outdoors: 4 cases showed a decrease (Fig. 4a) and 8 showed an increase (Fig. 4b). Fig. 4c presents the one case in which T2 equals T0. Social life and relationships: 6 cases showed a decrease (Fig. 5a) and 7 showed an increase (Fig. 5b). Of the domain “work and education” (Fig. 6) those 5 cases are presented for whom work was relevant during the study. Case 10 showed a small decrease over T0 to T1 and case 4 showed a decrease over T1 to T2. For case 13, work became an issue at T2, at which point the patient scored high for problems in autonomy. Case 8 showed a temporary decrease at T0 to T1, but an increase from T1 to T2 and case 7 showed an increase, indicating more limitations in autonomy at work.

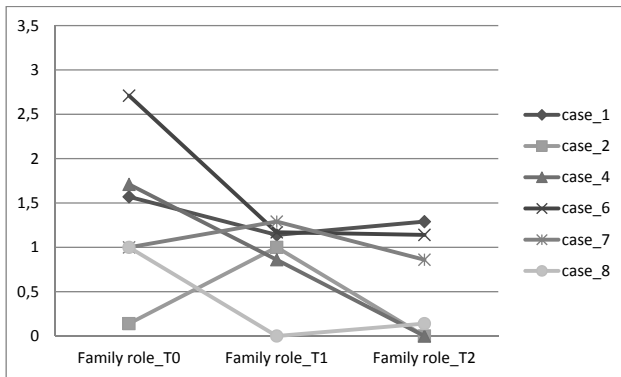


Fig 3a. Decrease in outcome Impact on Participation and Autonomy domain Family role

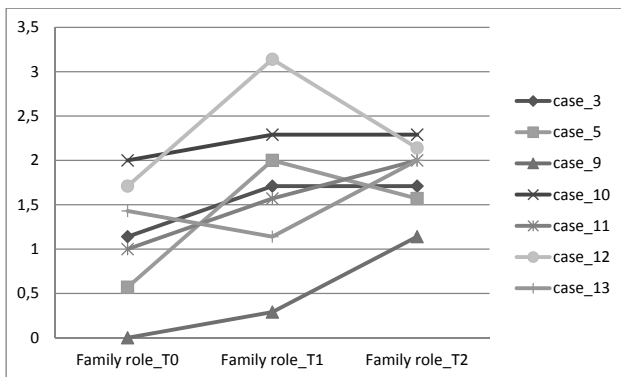


Fig 3b. Increase in outcome Impact on Participation and Autonomy domain Family role

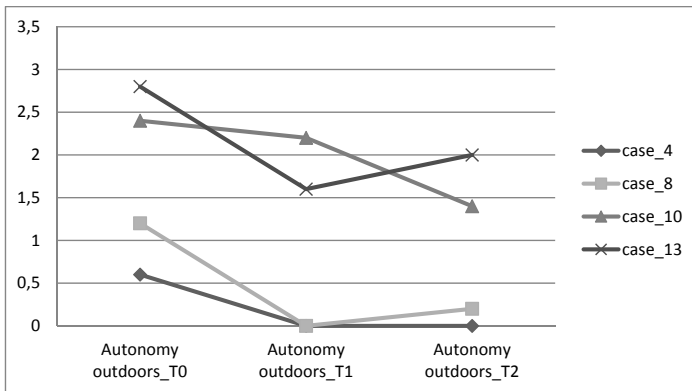


Fig 4a. Decrease in outcome Impact on Participation and Autonomy domain Autonomy outdoors

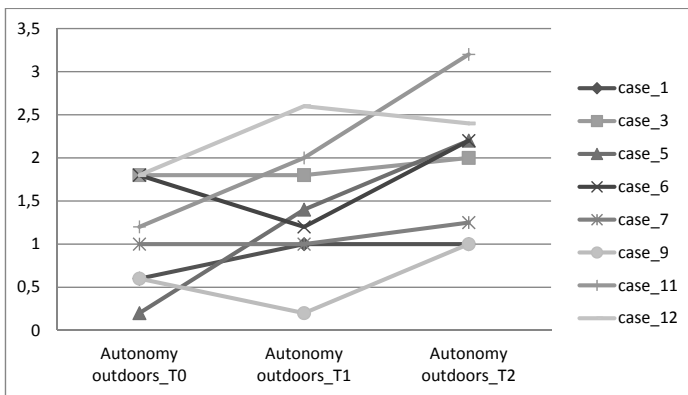


Fig 4b. Increase in outcome Impact on Participation and Autonomy domain Autonomy outdoors

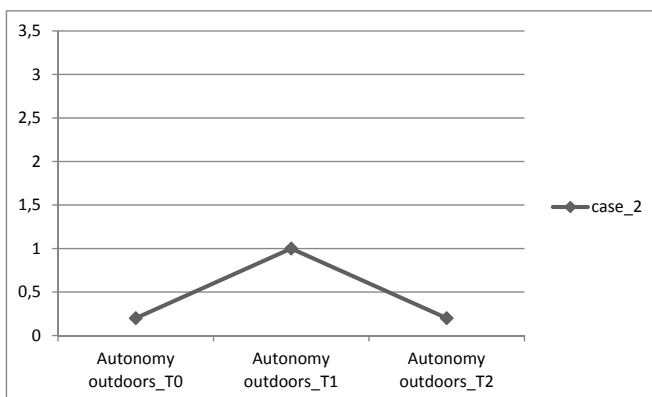


Fig 4c. Outcome in Impact on Participation and Autonomy domain Autonomy outdoors T0=T2

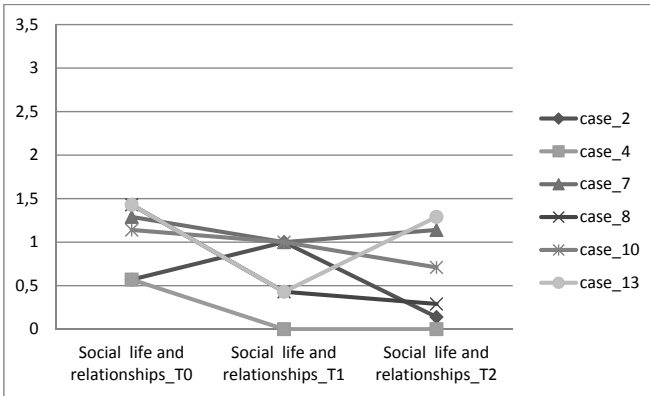


Fig 5a. Decrease in outcome Impact on Participation and Autonomy domain Social life and relationships

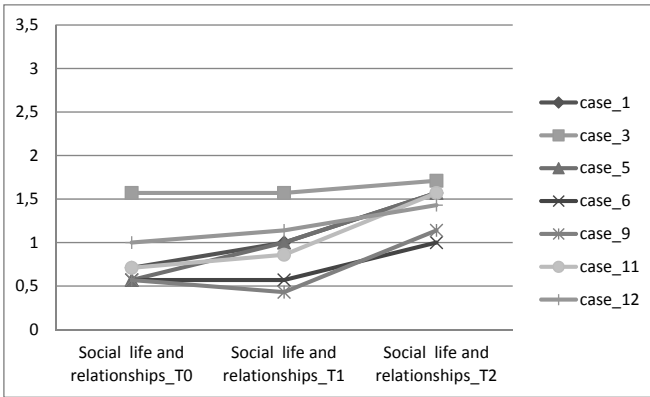


Fig 5b. Increase in outcome Impact on Participation and Autonomy domain Social life and relationships

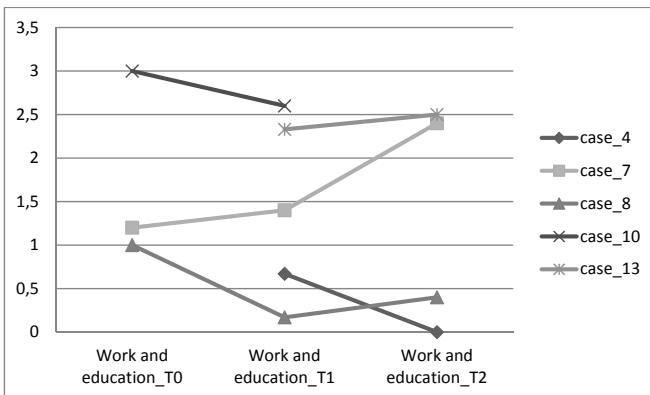


Fig 6. Outcome Impact on Participation and Autonomy domain Work and education

External factors

With regard to the external factors, the *Products and technology* item stood out as the most frequently mentioned factor in both a positive (facilitator) and a negative sense (barrier). This item centred on 2 topics: prosthetic-related issues, such as fitting problems due to decreased stump volume, and outdoors mobility-related issues, such as adapted bicycles, cars or hand-bikes. The fitting problems led to reduced activity in some patients, while others actively sought help and talked about the adjustments required instead of problems. Many patients expressed an experience of freedom when regaining outdoors mobility; to be able to go outdoors, without being dependent on others, was highly valued. The *natural environment* and, more specifically, the inevitable consequences of the Dutch climate, was a barrier for many patients. A long snowy winter and slippery surfaces hindered many in functioning, although warm weather was also indicated as negative as it led to sweating and irritated skin when wearing the prosthesis. *Support* from partners, family, friends and personal care providers was most often seen as a facilitating factor. The support of peers was especially prominent as a valued factor during rehabilitation, and was accordingly experienced as a loss post-discharge. Support was also mentioned by some patients as a barrier: the unsought support from family members or partners, overprotective spouses and loss of support from health professionals were perceived as hindering independent functioning. With regard to *services, systems and policies*, many patients experienced problems in their housing situation: for instance, narrow areas and stairs complicated functioning at home, especially when patients did not wear their prostheses. Few patients mentioned labour and employment services. One patient experienced no cooperation in his desire to return to work, others were declared unfit to work or were advised to look for other jobs.

Personal factors

At discharge, many patients were positively orientated and appreciative of the goals they had reached during rehabilitation, and they expected to continue to improve. The personal factors mentioned at all time-points were diverse. Coping strategies and attitude were often indicated as positive. A positive attitude, confidence, perseverance, goal-orientation, internal motivation, and a solution-focused attitude were personal characteristics that helped many of the patients to deal with the amputation and their changed reality in daily life. Personal factors that were perceived more negatively often referred to personal characteristics and lifestyle, such as perceived feelings of aversion towards asking for help or fear about undertaking certain activities. Some patients indicated a lack of motivation that hindered them from maintaining the physically active lifestyle they had experienced during rehabilitation.

Body functions and structures

The most common barriers to functioning were factors of body functions and structures. Only two individuals (both improvers) reported no physical problems. Most of these factors were related to the amputation, such as wounds on the stump, skin problems or related conditions, such as vascular diseases, which impacted their non-amputated leg. One patient received a transfemoral amputation after the initial transtibial amputation, one person was re-operated on the stump, two were operated on their non-amputated leg and one had the non-amputated leg amputated shortly after T2. Co-morbidity in general also impacted functioning negatively. The emotional impact of the amputation was often referred to negatively: depression, worries, the process of acceptance and the feeling of being observed in the real world. Factors of body functions and structures were, however, also positively articulated: pain relief owing to the amputation, gaining renewed physical possibilities, the experience of more automatism in walking and the perception of having a better physical condition. It is important to note that some of the abovementioned operations initially acted as barriers, but ended up as facilitator through the removal of underlying physical problems.

Integrating functional outcomes and barriers and facilitators

Table II presents an overview of all individual data. The horizontal analysis of Table II, which integrates quantitative and qualitative data, resulted in 13 different individual stories, in which in some cases qualitative findings provided an explanation for the quantitative findings. Consider case 2: a deterioration in physical performance and a temporary decline in perceived autonomy indoors and outdoors could be directly ascribed to a fall at home, which led to a wound on the stump. The overall high incidence of medical conditions was very apparent in the patients who declined in functional performance. Four of the 5 patients who were unable to carry out the performance tests at T1 and/or at T2 had severe medical conditions, the other patient experienced prosthetic problems.

The horizontal analysis also illustrated how multifaceted individual functioning is. Consider case 10: although this patient improved in functional performance and in several IPA domains, he experienced a decline in emotional well-being. Case 13 illustrates, in contrast, a decline in functional performance over time along with improvements in autonomy indoors and outdoors and in social life and relationships in the IPA. This patient indicated that improved emotional well-being and acceptance was attained after an initial moment of emotional distress post-discharge.

Vertical analysis of Table II provided insight into which barriers and facilitators were most prominent at which time. It revealed that, although many patients indicated similar barriers and facilitators after discharge (for example, outdoor mobility, prosthetic problems and housing situation issues), a collective time pattern could not be discerned.

Table II. Individual representation of barriers and facilitators on T0, T1, T2 and developments on Two-Minute Walk Test (2MWT) and IPA over T0 to T2.

Cases	Factors T0	Factors T1	Factors T2	2MWT	IPA				
					AI	FR	AO	SR	W
Case 1	Housing situation – Support + Vascular problems non-amputated leg –	Climate – Support + Medical condition general –	Medical condition general – Mood – Prosthetic problems –	↓ T0 to T1	↔	↑	↓	↓	X
Case 2	Support + Personal factor attitude + Climate –	Wound stump – Support + Prosthesis +	Support + Personal factor confidence + Prosthesis+	↓	↔	↑	↔	↑	X
Case 3	Climate – Housing situation – Support –	Housing situation – Prosthetic problems – Support –	Prosthetic problems – Support + Personal factor attitude +	↓	↔	↓	↓	↓	X
Case 4	Adapted bicycle/car- Personal factor attitude +	Adapted car/bicycle + Personal factor attitude + Physical condition +	Personal factor attitude + Automatism + Climate –	↑	↑	↑	↑	↑	↑T1 to T2
Case 5	Housing situation – Vascular problems non-amputated leg – Support-	Housing situation – Operated on non-amputated leg + Stump problems –	Operated on stump – Prosthetic problems – Housing situation +	↑T0 to T1	↓	↓	↓	↓	X
Case 6	Personal factor attitude+ Assistive devices + Support +	Prosthetic problems – Inactive coping – Personal factor attitude +	Climate – Physical condition -	Measurements only at T0	↔	↑	↓	↓	X
Case 7	Pain free functioning due to amputation + Stump problem – Housing situation +	Outdoor mobility – Prosthetic problems -	Outdoor mobility + Stump problems –	↑	↔	↑	↓	↑	↓

Cases	Factors T0		Factors T1		Factors T2		2MWT	AI	FR	IPA			W
										AO	SR		
Case 8	Personal factor attitude+ Pain free functioning due to amputation+ amputation +	Pain free functioning due to amputation+ Employment services – Personal factor attitude +	Personal factor attitude + Prosthesis + Employment services -	↑	↑	↑	↑	↑	↑	↑	↑	↑	
Case 9	Housing situation – Pain free functioning due to amputation + Personal factor attitude +	Stump problems – Climate – Personal factor attitude +	Transfemoral amputation – Pain free due to amputation +	↓	↓	↓	↓	↓	↓	↓	↓	X	
Case 10	Personal factor attitude + Physical condition – Housing situation -	Climate – Medical condition general – Personal factor attitude +	Mood – Employment service: declared unfit to work -	↑	↓	↓	↑	↑	↑	↑	↑	↑T0 to T1	
Case 11	Medical condition general – Personal factor attitude + Outdoor mobility -	Medical condition non-amputated leg – Outdoor mobility + Housing amputated)– situation-	Medical condition non-amputated leg (will be amputated)	Measurements only at T0	↓	↓	↓	↓	↓	↓	↓	X	
Case 12	Housing situation – Outdoor mobility + No automatism -	Medical condition non-amputated leg – Prosthetic problems – Physical condition -	Medical condition non-amputated leg - Prosthetic problems -	Measurements only at T0	↓	↓	↓	↓	↓	↓	↓	X	
Case 13	Medical condition general – Housing situation – Acceptance -	Medical condition general – Acceptance – Personal factor attitude +	Acceptance + Medical condition: operated on non-amputated leg + Personal factor attitude +	↓	↓	↓	↑	↑	↑	↑	↑	↓T1 to T2	

+ : positive influence, – : negative influence, X: not applicable, ↔ : stable from T0 to T2, ↑: improvement T0 to T2 (i.e. increase Two-Minute Walk Test (2MWT) and decrease IPA domain), ↓: deterioration T0 to T2 (i.e. decrease 2MWT and increase IPA domain), IPA: impact on participation and autonomy; AI: autonomy indoors, FR: family role, AO: autonomy outdoors, SR: social life and relationships, W: work and education.

Personal factors were particularly prominent within the group of patients who showed improvement in functional performance and participation and autonomy. They noted being strong-willed, persevering, goal-oriented, confident and highly motivated.

DISCUSSION

The integration of quantitative and qualitative methodology in a single study provided us with in-depth information on the post-rehabilitation period for patients with LLA. This study showed that 9 of our 13 patients declined in functional performance after discharge. The main participation limitations were perceived in the “autonomy outdoors” and “family role” domains. Changes in outcomes on functional performance were, however, not always in line with those observed in participation and autonomy. Many diverse factors were found to affect functional performance and participation post-discharge, acting sometimes as barriers for some individuals and as facilitators for others. We realize that our sample size was small and consisted of a convenience sample of participants from a single rehabilitation centre. Our results are therefore not generalizable to all patients with LLA and to all rehabilitation settings.

The large percentage of patients that declined in functional performance in our study contrasts with results for stability or improvement in functional outcomes post-discharge seen in previous studies.^{6,7,9} Our study design provided insight into the factors that explained the individual decline, such as medical complications and prosthesis problems. It is also important to note that 3 of the 4 patients who decreased from T0 to T2 started at very high 2MWT levels at discharge and deteriorated to a level that can still be considered high compared with the outcomes of Brooks et al.¹⁶ When we relate our ranges on the L test to the mean score and standard deviation of the study by Miller & Deathe,⁷ we can conclude that our subgroup, that performed the test at T0, T1 and T2, performed better as our maximum score equals their mean score. Both groups show a large variability in outcome.

With regard to participation, the IPA was chosen to identify person-perceived participation and autonomy rather than just measuring functional independence.²¹ Many patients experienced more limitations in autonomy outdoors, and are somehow restricted in their family role. “Getting heavy tasks done”, “Getting minor repairs done”, “Fulfilling my role at home”, “Going on trips and holidays” and “Living the life I want” were thereby items that scored fair to poor. Individual fluctuations over time were also observed for these outcomes. The outcomes on the IPA gave insight into which items were of importance and/or changing over time for each individual. Thus, this questionnaire is of great value for clinicians. In order to measure effect, there is need for

comparable data measured in groups with different diagnoses, analysed as prescribed in the IPA manual.

With respect to barriers and facilitators, our study did not detect new factors affecting functional performance and participation, but provided a better understanding of *how* factors influenced the functioning of patients, and the individual diversity in these interactions. Factors such as a changing stump volume, climate and environmental factors caused problems for some patients, while others coped adequately with these circumstances. The presence of barriers and facilitators also appeared to fluctuate over time. No clear collective time pattern became apparent.

Our analysis of outcomes at an *individual* level revealed distinguishing fluctuations in functional performance, in IPA domains and in the presence of barriers and facilitators over time. This is in striking contrast with the stability and improvements in outcomes outlined in previous studies, in which individual patterns were averaged out. This pattern of fluctuations is an extremely important insight for rehabilitation professionals. We believe it is up to these professionals to prepare patients for the distinctive fluctuations in functioning post-discharge and the upcoming barriers patients can encounter. Our studied patients were confident they would continue to improve after discharge, however, the reality was different. It is inevitable that patients will encounter barriers; climate conditions are foreseeable and a changing stump volume is a known phenomenon.²⁴ Due to the great diversity in individual reactions to perceived barriers, it would be helpful to teach patients a generic approach to dealing with problematic situations.

In a previous study we already proposed integrating self-management principles and task and context-specific training principles to teach patients problem-solving to enhance functional carry-over from the clinical to the home setting.⁵ Others have also emphasized the need for self-management interventions for this diagnosis group.²⁵ The results of this study confirm our previous line of reasoning and provide concrete issues that patients need to cope with. Integrating problem-solving principles and techniques in the rehabilitation phase to enhance the patients' confidence in their own capacities in problem-solving could prepare patients for the post-rehabilitation phase and, it is hoped, will contribute to less decline in outcome. In addition to changes in clinical practice during prosthetic rehabilitation, we propose that regular follow-ups are carried out after discharge, as recommended in guidelines.² The focus should then be on perceived barriers and the patients' capacity for coping with these barriers.

With respect to future research, we hope that the added value of mixed methods that emerged in this study will inspire researchers to combine quantitative and qualitative methodology, despite the resulting length of publications. In our study we distinguished which quantitative outcomes were most pertinent to our research question, in order to have sufficient article length to present the integration findings, given that this is the key reason for conducting mixed-methods

research.²⁶⁻²⁸ The justification for undertaking mixed-methods studies is to engage with the complexity of health(care) by adopting a more comprehensive approach than a single set of methods would allow.²⁶ Therefore our results contribute to a better understanding of the post-discharge phase of patients with LLA, providing professionals with insights and tools to prepare patients for the challenges they will face in everyday life.

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REFERENCES

1. Schaffalitzky E, Gallagher P, MacLachlan M, Ryall N. Understanding the benefits of prosthetic prescription: exploring the experiences of practitioners and lower limb users. *Disabil Rehabil* 2011; 33: 1314-1323.
2. Department of Veterans Affairs and Department of Defense. *VA/DoD Clinical practice guideline for rehabilitation of lower limb amputation. Version 1.0-2007*. Washington, (DC): Department of Veterans Affairs, Department of Defense, 2007.
3. Horgan O, MacLachlan M. Psychosocial adjustment to lower-limb amputation: a review. *Disabil Rehabil* 2004; 26: 837-850.
4. Bradway JK, Malone JM, Racy J, Leal JM, Poole J. Psychological adaptation to amputation; an overview. *Orthot Prosthet* 1984; 38: 46-50.
5. van Twillert S, Postema K, Geertzen JHB, Hemminga T, Lettinga AT. Improving rehabilitation treatment in a local setting: a case study of prosthetic rehabilitation. *Clin Rehabil* 2009; 23: 938-947.
6. Streppel KRM, de Vries J, Harten van WH. Functional status and prosthetic use in amputees, measured with the prosthetic profile of the amputee (PPA) and the short version of the Sickness Impact Profile (SIP68). *Int J Rehabil Res* 2001; 24: 251-256.
7. Miller WC, Deathe AB. The influence of balance confidence on social activity after discharge from prosthetic rehabilitation for first lower limb amputation. *Prosthet Orthot Int* 2011; 35: 379-385.
8. Zidarov D, Swaine B, Gauthier-Gagnon C. Quality of life of persons with lower-limb amputation during rehabilitation and at 3-month follow-up. *Arch Phys Med Rehabil* 2009; 90: 634-645.
9. Zidarov D, Swaine B, Gauthier-Gagnon C. Life habits and prosthetic profile of persons with lower-limb amputation during rehabilitation and at 3-month follow-up. *Arch Phys Med Rehabil* 2009; 90: 1953-1959.
10. Schoppen T, Boonstra A, Groothoff JW, de Vries J, Göeken LN, Eisma WH. Physical, mental and social predictors of functional outcome in unilateral lower-limb amputees. *Arch Phys Med Rehabil* 2003; 84: 803-811.
11. Sinha R, van den Heuvel WJA, Arokiasamy P. Factors affecting quality of life in lower limb amputees. *Prosthet Orthot Int* 2011; 35: 90-96.
12. Asano M, Rushton P, Miller WC, Deathe BA. Predictors of quality of life among individuals who have a lower limb amputation. *Prosthet Orthot Int* 2008; 32: 231-243.
13. Gallagher P, O'Donovan M-A, Doyle A, Desmond D. Environmental barriers, activity limitations and participation restrictions experienced by people with major limb amputation. *Prosthet Orthot Int* 2011; 35: 278- 284.
14. Kroll T, Morris J. Challenges and opportunities in using mixed method designs in rehabilitation research. *Arch Phys Med Rehabil* 2009; 90 (Suppl 1): S11-S16.
15. Brooks D, Hunter JP, Parsons J, et al. Reliability of the two-minute walk test in individuals with transtibial amputation. *Arch Phys Med Rehabil* 2002; 83: 1562-1565.
16. Brooks D, Parsons J, Hunter JP, Devlin M, Walker J. The 2-minute walk test as a measure of functional improvement in persons with lower limb amputation. *Arch Phys Med Rehabil* 2001; 82: 1478-1483.
17. Deathe AB, Miller WC. The L test of functional mobility: measurement properties of a modified version of the Timed "Up & Go" test designed for people with lower-limb amputations. *Phys Ther* 2005; 85: 626-635.
18. Nguyen VC, Miller WC, Ason M, Wong RY. Measurement properties of the L test for gait in hospitalized elderly. *Am J Phys Med Rehabil* 2007; 86: 463-468.
19. Resnik L, Borgia M. Reliability of outcome measures for people with lower limb amputations: distinguishing true change from statistical error. *Phys Ther* 2011; 91: 555-565.
20. Cardol M, Beelen A, van den Bos GAM, de Jong BA, de Groot IJ, de Haan RJ. Responsiveness of the Impact on Participation and Autonomy Questionnaire. *Arch Phys Med Rehabil* 2002; 83: 1524-1529.
21. Cardol, M. *[Impact on Participation and Autonomy (IPA). Manual and questionnaire]* Amsterdam: Afdeling Revalidatie, Academisch Medisch Centrum, 2005. Available from: www.nivel.nl. (In Dutch)
22. World Health Organization (WHO). *Towards a common language for functioning, disability and health ICF*. Geneva: WHO; 2002. Available from: www.who.int/classifications/icf/training/icfbeginnersguide.pdf

23. WHO FIC Collaborating centre in the Netherlands, RIVM. *[Dutch translation of the ICF.]* Bohn Stafleu van Loghum: Houten; 2002. Available from: www.rivm.nl/who-fic/in/ICFwebuitgave.pdf
24. Sanders JE, Fatone S. Residual limb volume change: systematic review of measurement and management. *JRRD* 2011; 48; 949-986.
25. Wegener ST, Mackenzie EJ, Ephraim P, Ehde D, Williams R. Self-management improves outcomes in persons with limb loss. *Arch Phys Med Rehabil* 2009; 90: 373-380.
26. O’Cathain A, Murphy E, Nicholl J. Integration and publications as indicators of “yield” from mixed methods studies. *J Mix Method Res* 2007; 1: 147-163.
27. O’Cathain A, Nicholl J, Murphy E. Structural issues affecting mixed methods studies in health research: a qualitative study. *BMC Med Res Methodol* 2009; 9: 82
28. Bryman A. Barriers to integrating quantitative and qualitative research. *J Mix Method Res* 2007; 1: 8-22.

4

Physical and rehabilitation medicine and self-management education: a comparative analysis of two approaches

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ABSTRACT

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

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

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

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

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

INTRODUCTION

The White Book on Physical and Rehabilitation Medicine (WB) describes the speciality of physical and rehabilitation medicine (PRM) in Europe.^{1,2} The publication of the WB was a catalyst for lively discussion of the identity, position and foundation of PRM. Some researchers made the discussion worldwide by arguing that its content deserved to be examined across European boundaries.^{3,4} Others still did not consider the speciality of PRM to be reality, thereby questioning the increased value it should have over other medical specialties and health professionals involved in rehabilitation. They suggested that the shaping of PRM-specialists' self-concept and identity in the WB would profit from interdisciplinary dialogue with other specialties.^{5,6} The editors of the WB, in their turn, did not see a speciality with an identity problem, but instead the reality of a thriving PRM profession both inside and outside Europe.⁷

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

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

METHODS

Our comparative analytical work draws on discourse analysis and actor network theory.¹³⁻¹⁶ In some types of discourse analysis and all actor network theory, the meanings of words within a discourse inform each other and are part and parcel of a material network. Rather than applying predetermined definitions of terminology, language is thereby analysed as something that is expressed under certain material conditions.¹⁷ We explored PRM- and SME-texts as if these were written in different languages and compared their key words in order to determine similarities and differences in knowledge practices. In Law's words, we unravelled how PRM and SME are performed, embodied and related in different material environments.¹⁴

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

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

First reading

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

Optimal physical, mental and social potential

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

Greatest physical capability and pleasure from life

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

Reflection

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

Second reading

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

Restoring disabling consequences of injuries and diseases with acute onset

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

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

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

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

Accessing psychological possibilities in chronic illness

SME arose in the second half of the 20th century as a reaction to the failure of the medical world to deal with chronic diseases.^{30,39} Traditional medicine was also a predecessor of SME.

With its primary focus on curing acute diseases, medicine did not do justice to non-curable chronic diseases. Lorig emphasized that “the lack of a regular or predictable pattern in chronic illness is major characteristic in most chronic illnesses”. And that “unlike most acute diseases where full recovery is to be expected, chronic diseases usually lead to persistent loss of physical conditioning”.^{33(p.3)} Chronically ill people were forced to give up activities they were used to carrying out, which lead to emotional distress “such as frustration, anger and depression”.^{38(p.1)}

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

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

Reflection

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

Third reading

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

Multidisciplinary teams in a clinical setting

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

The WB states that rehabilitation should be delivered in “an organized goal-oriented, patient-centered manner”.^{1(p.7)} It argues that “the team works with the person with disabilities and family to set appropriate, realistic and timely treatment goals within an overall coordinated rehabilitation programme”.^{1(p.18)} The setting of “treatment goals” implies that they must be adjusted over time according to the progress of the patient. “Patient-centred” means that treatment goals should be owned by the patients and their proxies rather than be set on a discipline-by-discipline basis. The multi-professional approach has to enable patients “to make informed choices of treatment”.^{1,2}

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

Peer leaders in a community setting

SME started at the point where there was no further recovery to be gained according to the medical world. Lorig's SME began where hospital care stopped. Patients were sent home with, at best, the message that they must learn to live with their condition. SME aimed to help with that assignment: “Rather than telling people to ‘learn to live with it’, let us help them learn to

self-manage” .^{37(p.701)} Lorig’s SME-programmes are group practices provided in community centres, such as public libraries and healthcare facilities.³² The provider is often a volunteer, usually a lay person who, preferably, has been diagnosed with a chronic disease. This is because successful self-managing peers show how active self-management works and fellow sufferers may want to copy that behaviour to achieve similar results.³⁴ In SME leaders act more as facilitators than lecturers. “Rather than prescribing behaviour changes, they assist participants in making management choices and achieving success in reaching self-selected goals” .^{32(p.7)} In this way peer leaders act as role models.

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

Reflection

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

Fourth reading

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

Motor learning principles and practices

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

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

Social learning principles and practices

Teaching and learning are also important ingredients of SME. However, self-management is more about “social learning”, as expressed in Bandura’s social cognitive theory.⁴⁴ Bandura⁴⁴ asserted that most human behaviour is learned observationally by modelling. By observing others one forms an idea of how a new behaviour is performed, and on later occasions this coded behaviour serves as a guide for action.⁴⁴ Inspired by Bandura’s social cognitive theory, Lorig & Holman³⁸ considered “self-efficacy” as a hallmark of SME: “the teaching processes must be structured to include the four ingredients of efficacy enhancement: performance mastery; modelling; interpretation of symptoms; and social persuasion”.^{38(p.4)} Self-efficacy was defined as the individual’s personal confidence beliefs about his or her capacity to undertake behaviour that may lead to desired outcomes such as improved health.^{40,41} Watching people similar to oneself succeed through sustained effort may strengthen patients’ belief in their own capabilities.

“Problem-solving” is considered to be a core self-management skill. However, “this does not mean that people are taught solutions to their problems. Rather they are taught basic problem-solving skills”.^{38(p.2)} In Lorig’s self-management programmes the problem-solving steps are: “problem definition, generation of possible solutions including the solicitation of suggestions from

friends and healthcare professionals, solution implementation, and evaluation of results".^{38(p.2)} These resemble the problem-solving skills that D'Zurilla developed for patients with depression.⁴⁶

Reflection

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

DISCUSSION

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

At first glance there was much common ground. Both PRM and SME were based on the premise that people with disabling or chronic conditions should be offered the opportunity to be able to function at the maximum of their potential. The idea of offering tools to develop to full potential stems from a shared discontent with the healthcare system at the time that both approaches originated. Both were responses to the limitations of traditional medicine, which focused on curing single diseases, thereby neglecting the disabling and long-lasting consequences of a multitude of conditions that were not yet fully curable. Closer examination of the language, however, made it apparent that PRM and SME use different wordings that are entwined with different material and organizational environments (see Table I). This helped us to discover the different logics at work and gave words to silenced issues in the WB.

Table 1: The differences in language used in the two discourses

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

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

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

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

it may be desirable for him/her to accept the assistance of caregivers in order to save energy for going to work.⁴⁹

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

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

REFERENCES

1. Gutenbrunner C, Ward AB, Chamberlain MA, editors. White Book on Physical and Rehabilitation Medicine in Europe. *J Rehabil Med* 2007; 39 Suppl 45: 1-48.
2. Gutenbrunner C, Ward AB, Chamberlain MA, editors. White Book on Physical and Rehabilitation Medicine in Europe. *Eura Medicophys* 2006; 42: 292-332.
3. Negrini S, Ceravolo MG. The White Book on Physical and Rehabilitation Medicine in Europe: a contribution to the growth of our specialty with no boundaries. *Am J Phys Med Rehabil* 2008; 87: 601-606.
4. Melvin JL. Physical and rehabilitation medicine: comments related to the White Book on Physical and Rehabilitation Medicine in Europe. *Eur J Phys Rehabil Med* 2008; 44: 117-119.
5. Ebenbichler G, Resch KL. The dream of a medical specialty named physical and rehabilitation medicine: a commentary on the European White Book of Physical and Rehabilitation Medicine. *Am J Phys Med Rehabil* 2009; 88: 165-167.
6. Resch KL, Ebenbichler G. Re: the dream of a medical specialty named physical and rehabilitation medicine: a commentary on the European White Book of Physical and Rehabilitation Medicine. *Am J Phys Med Rehabil* 2009; 88: 1039.
7. Gutenbrunner C, Ward AB, Chamberlain MA. Re: the dream of a medical specialty named physical and rehabilitation medicine: a commentary on the European White Book of Physical and Rehabilitation Medicine. *Am J Phys Med Rehabil* 2009; 88: 1037-1039.
8. Stucki G, Reinhardt JD, Gutenbrunner C, Bickenbach JE. Re: the dream of a medical specialty named physical and rehabilitation medicine: a commentary on the European White Book of Physical and Rehabilitation Medicine. *Am J Phys Med Rehabil* 2009; 88: 1039-1042.
9. Ebenbichler G, Resch KL. Re: the dream of a medical specialty named physical and rehabilitation medicine: a commentary on the European White Book of Physical and Rehabilitation Medicine. *Am J Phys Med Rehabil* 2009; 88: 1042-1043.
10. Berg M, Mol A. *Differences in medicine, unraveling practices, techniques, and bodies*. Durham and London: Duke University Press, 1998.
11. Lettinga AT, Mol A. Clinical specificity and the non-generalities of science: on innovation strategies for neurological physical therapy. *Theor Med Bioeth* 1999; 20: 517-535.
12. Law J, Mol A. *Complexities: social studies of knowledge practices*. Durham and London: Duke University Press, 2002.
13. Foucault M. *The order of things: an archaeology of the human sciences*. London: Tavistock Publication, 1973.
14. Law J. *Organizing modernity*. Oxford: Blackwell, 1994.
15. Mol A, Mesman J. Neonatal food and the politics of theory: some questions of methods. *Soc Stud Sci* 1996; 26: 419-444.
16. Mol A. *The body multiple*. Durham: Duke University Press; 2005.
17. Lettinga AT. Diversity in neurological physiotherapy: a content analysis of the Brunnstrom/Bobath controversy. *Adv Physiother* 2002; 4: 23-36.
18. Rusk HA, editor. Convalescence and rehabilitation. *Proc Americ Philosoph Soc* 1946, p.271-274.
19. Fordyce WE. *Behavioural methods for chronic pain and illness*. St Louis: Mosby; 1976.
20. Taub E, Crago JE, Uswatte G. Constraint-induced movement therapy: a new approach to treatment in physical rehabilitation. *Rehabil Psychol* 1998; 43: 152-170.
21. Lettinga AT, Siemonsma PC, van Veen M. Entwinement of theory and practice in physiotherapy: a comparative analysis of two approaches to hemiplegia in physiotherapy. *Physiotherapy* 1999; 85: 476-490.
22. Playford ED, Dawson L, Limbert V, Smith M, Ward CD, Wells R. Goal-setting in rehabilitation: report of a workshop to explore professionals' perceptions of goal-setting. *Clin Rehabil* 2000; 14: 491-496.
23. Sivaraman Nair KP. Life goals: the concept and its relevance to rehabilitation. *Clin Rehabil* 2003; 17: 192-202.
24. Siegert RJ, McPherson KM, Taylor WJ. Toward a cognitive-affective model of goal-setting in rehabilitation: is self-regulation theory a key step? *Disabil Rehabil* 2004; 20: 1175-1183.

25. Struhkamp R. Goals in their setting: a normative analysis of goal setting in physical rehabilitation. *Health Care Anal* 2004; 12: 131-155.
26. Leeuw M, Houben RMA, Severeijns R, Picavet HJS, Schouten EGW, Vlaeyen JWS. Pain-related fear in low back pain: a prospective study in the general population. *Eur J Pain* 2007; 11: 256-266.
27. Young CA, Manmathan GP, Ward JCR. Perceptions of goal setting in a neurological rehabilitation unit: a qualitative study of patients, carers and staff. *J Rehabil Med* 2008; 40: 190-194.
28. Siemonsma PC, Schröder CD, Dekker JHM, Lettinga AT. The benefits of theory for clinical practice: cognitive treatment for chronic low back pain patients as an illustrative example. *Disabil Rehabil* 2008; 30: 1309-1317.
29. Lorig KR. Self-management of chronic illness: a model for the future. *Generations* 1993; 17: 11-14.
30. Lorig KR. Chronic disease self-management: a model for tertiary prevention. *Am Behav Sci* 1996; 39: 676-678.
31. Lorig KR, Stewart AL, Ritter PL, Gonzalez VM, Laurent DD, Lynch J. *Outcome measures for health education and other health care interventions*. Thousand Oaks: Sage Publications, 1996.
32. Lorig KR, Sobel DS, Stewart AL, et al. Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization: a randomized trial. *Med Care* 1999; 37: 5-14.
33. Lorig KR, Holman HR, Sobel DS, Laurent D, Gonzalez VM, Minor M. *Living a healthy life with chronic conditions. Self-management of heart disease, arthritis, diabetes, asthma, bronchitis, emphysema and others*. Boulder, Co: Bull Publishing Co, 2000.
34. Lorig KR, Sobel DS, Ritter PL, Laurent DD, Hobbs M. Effect of a self-management program on patients with a chronic disease. *Eff Clin Pract* 2001; 4: 256-262.
35. Lorig KR. Partnerships between expert patients and physicians. *Lancet* 2002; 359: 814-815.
36. Bodenheimer T, Lorig K, Holman H, Grumbach K. Patient self-management of chronic disease in primary care. *JAMA* 2002; 288: 2469-2474.
37. Lorig K. Self-management education. More than a nice extra. *Med Care* 2003; 41: 699-701.
38. Lorig KR, Holman HR. Self-management education: history, definition, outcomes, and mechanisms. *Ann Behav Med* 2003; 26: 1-7.
39. Holman H, Lorig K. Patient self-management: a key to effectiveness and efficiency in care of chronic disease. *Public Health Rep* 2004; 119: 239-243.
40. Marks R, Allegrante JP, Lorig K. A review and synthesis of research evidence for self-efficacy-enhancing interventions for reducing chronic disability: implications for health education practice (Part I). *Health Promot Pract* 2005; 6: 37-43.
41. Marks R, Allegrante JP, Lorig K. A review and synthesis of research evidence for self-efficacy-enhancing interventions for reducing chronic disability: implications for health education practice (Part II). *Health Promot Pract* 2005; 6: 148-156.
42. Donaldson L. Expert patients usher in a new era of opportunity for the NHS. *BMJ* 2003; 326: 1279-1280.
43. Bury M, Newbould J, Taylor D. *A rapid review of the current state of knowledge regarding lay-led self-management of chronic illness. Evidence review*. London: National Institute for Health and Clinical Excellence, 2005.
44. Bandura A. Self-efficacy: toward a unifying theory of behavioural change. *Psychol Rev* 1977; 84: 191-215.
45. Corbin J, Strauss A. Managing chronic illness at home: three lines of work. *Qual Sociol* 1985; 8: 224-247.
46. D'Zurilla T. *Problem-Solving Therapy. A social competence approach to clinical intervention*. New York: Springer, 1986.
47. Pringle J, Hendry C, McLafferty E. A review of early discharge experiences in stroke survivors and their carers. *J Clin Nurs* 2008; 17: 2384-2397.
48. Cameron JJ, Tsoi C, Marsella A. Optimizing stroke systems of care by enhancing transitions across care environments. *Stroke* 2008; 39: 2637-2643.
49. Struhkamp R, Mol A, Swierstra T. Dealing with in/dependence: doctoring in physical rehabilitation practice. *Sci Technol Human Values* 2009; 34: 55-76.

5

Incorporating self-management in prosthetic rehabilitation: case report of an integrated knowledge-to-action process

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ABSTRACT

Background: In improvement of clinical practice, unidirectional approaches of translating evidence into clinical practice have been pinpointed as main obstacles. The concept of engaged scholarship has been introduced to guide knowledge-to-action (KTA) processes, in which research knowledge and practical knowledge derived from therapists, patients, and organizational structures mutually inform each other. Accordingly, KTA experts should engage end-users earlier in the knowledge translation and work in companionship with them on both knowledge creation and knowledge implementation.

Purpose: The purposes of this case report are: (1) to provide an illustrative example of an evidence-informed improvement process in prosthetic rehabilitation in a local setting and (2) to articulate the bidirectional translation work incorporated into an integrated KTA process.

Case description: A KTA expert translated research knowledge on self-management and task- and context-specific training into a functional prosthetic training program for patients with a lower limb amputation. Therapists contributed as co-creators to the translation process with practical knowledge of the specificities of the target group and local organizational context. The KTA expert moved the co-created knowledge into action in iterative and interactive steps with local therapists, patients, and managers.

Outcome: This bidirectional KTA translation process led to shared ownership of the functional prosthetic training program, in which self-management and task- and context-specific training principles and practices were integrated.

Discussion: Bidirectional knowledge translation builds on explicating and integrating the different knowledge practices of researchers, therapists and their patients. Knowledge-to-action experts and end-users have their own roles and activities in such knowledge translation processes. Appreciating these different roles in genuine partnerships and acknowledging the distinct but equally valued knowledge practices can help in effectively translating evidence into action.

INTRODUCTION

Despite strong support for evidence-based practice in physical therapy and other health care fields, the application of available evidence to local practices continues to have modest success.¹⁻³ Researchers and policy makers easily point toward practicing therapists for not being compliant with evidence summarized in reviews and evidence-based clinical practice guidelines.³ In doing so, they implicitly frame the limited use of evidence in clinical practice as a knowledge transfer problem.⁴⁻⁷ They thereby assume that evidence produced in clinical trials is ready-made knowledge, is easy to access, and is simple to implement in local practices as long as therapists are willing to act upon that proven knowledge.^{4,5}

There is growing recognition, however, that a problem in knowledge production rather than in knowledge transfer hinders the knowledge-to-action (KTA) translation process.^{4,8,9} Most knowledge transfer approaches value objective knowledge gained in clinical trials over subjective knowledge from, for example, therapist and patient experiences.^{8,9} Such a unidirectional approach has been pinpointed as one of the main obstacles hindering improvement of clinical practice with available research knowledge.^{3,4,8,9} This finding has prompted a need to reconsider the evidence and assumptions that underlie our current knowledge translation approaches.^{4,8-10}

To prevent knowledge production problems, the concept of engaged scholarships has been introduced, emphasizing the importance of collaborative inquiry and meaningful interaction of researchers and end-users from the very beginning of the research.^{4,9} In engaged scholarship, it is recognized that researchers and therapists bring their own expertise in providing multidirectional learning.^{4,9} It is thereby acknowledged that research and practical knowledge are 2 distinct but equally valued types of knowledge that can provide complementary insights for understanding reality.^{8,9} The concept of engaged scholarship in KTA efforts has social science roots. It draws on participatory action research rather than on clinical epidemiological research promoted by evidence-based medicine.^{4,10} Moving towards a sociology of knowledge translation may help to reduce the research-practice gap.⁹

The purpose of this case report is to provide an illustrative example of an integrated KTA process in which an engaged scholarship was formed to translate self-management and task- and context-specific training principles into functional prosthetic training. A well-known KTA framework was used as guide in the translation process.⁷(Figure 1)

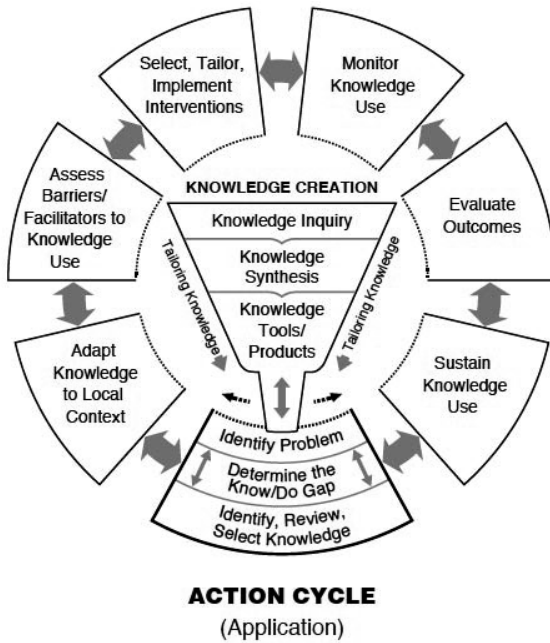


Figure 1: The knowledge-to-action cycle.⁷ Reprinted with permission from John Wiley & Sons Inc.

This framework distinguishes 2 concepts in KTA processes: (1) the knowledge creation funnel and (2) the action cycle.⁷ Each concept encompasses ideal phases. Knowledge creation includes several types of research that can be used to distill and refine the knowledge so that it becomes more useful to stakeholders. The action cycle represents all steps that can be taken to facilitate the use of knowledge. Although the 2 concepts are distinguished in this framework, in reality the process is complex and dynamic, and boundaries are fluid and permeable.⁷ The phases of the action cycle may occur consecutively or concurrently, and the phases of the knowledge creation may influence the phases of the action cycle.⁷ This case report describes the dynamic and fluid nature of a bidirectional knowledge translation process. The various roles and activities of the KTA expert, therapists, patients and medical manager, and their shared effort for a genuine partnership are thereby made explicit.

Case description

The target setting was a Dutch rehabilitation center providing multidisciplinary inpatient and outpatient rehabilitation for people with disabilities, injury or disease to regain optimal functioning in all facets of life. The target population of this KTA process was adults with a lower limb amputation (LLA). Each year, approximately 52 patients with LLA visit the center for inpatient

or outpatient prosthetic rehabilitation. During this rehabilitation period, a multidisciplinary team including physiatrists, physical therapists, occupational therapists, prosthetists, psychologists and social workers collaborate with patients to regain the level of functioning they aim for. The scope of this case report is limited to the interventions of physical therapists and occupational therapists. Creating optimal conditions for prosthesis use and teaching how to regain mobility with the prosthesis are the main focuses of the physical therapists. The main focus of the occupational therapists is integrating the use of the prosthesis in activities of daily living.

This case report is part of a larger research project in which participatory action research methodology is used to engage the multidisciplinary team in the evidence-informed improvement process.^{5,10,11} Two problems were leading motives at the start of this bidirectional KTA process, as was described in a previous article.⁵ First, therapists were concerned about a possible decline in outcome after rehabilitation discharge in elderly people with amputations. Second, therapists struggled with encouraging patients to be active learners (ie, they experienced difficulties in translating principles and practices of active learning to their target population). A literature study in the field of prosthetic rehabilitation provided no insight into useful principles and practices and how they should be applied to give content to active learning.⁵

Literature on rehabilitation of chronic diseases and on neurological and geriatric rehabilitation provided information on effective interventions encouraging active learning (ie, self-management education¹²⁻¹⁵ and task- and context-specific training,¹⁶⁻¹⁹ respectively). Integrating these interventions into prosthetic training could be a solution to the experienced carry-over problem.⁵ The problem then identified was how to translate these principles and practices into prosthetic rehabilitation? Together with the multidisciplinary team, it was decided to develop 2 training interventions - psycho-educational training intervention and motor skill training – to encourage active participation of patients with LLA.⁵ In this case report, the focus is on the development and implementation of the motor skill training in which principles and practices of task- and context-specific training and self-management education were incorporated.

The engaged scholarship for this translation process was formed by several stakeholders. The KTA expert (first author and a former physical therapist and human movement scientist) reflected with a research project group (other authors) on the entire KTA translation process. Three physical therapists, 3 occupational therapists, and the medical manager participated as co-creators in the development of the training. Patients with LLA were engaged by sharing their experiences with the newly developed training in individual interviews. All stakeholders had a share in the different phases of the KTA process.

The KTA process

The leading question in this integrated KTA process was: How can self-management education and task -and context-specific training principles and practices be translated and integrated into prosthetic rehabilitation in the local setting?⁵

Knowledge creation: tailoring knowledge

In previous studies, a first exploration of self-management education and task -and context-specific training was conducted.^{5,20} To enable translation and implementation of these interventions to patients with LLA, we needed a more detailed description. Thus, a first activity of the KTA expert was to map the principles and practices described in the scientific literature on self-management education and task- and context-specific training. A brief summary of the explicated principles and practices revealed that often self-management education programs are informed by social cognitive theory.²⁰⁻²² The self-efficacy of patients to perform self-management skills is thereby explicated as a mediating principle between the self-management behaviors and outcomes.²¹ The practices that therapists can use to enhance patients' self-efficacy are based on exposure to 4 sources: performance mastery, modeling (learning from peers), verbal persuasion, and interpretation of symptoms.^{12,13,21,22} Of all self-management skills, problem-solving skills are regarded as the most important skills needed to self-manage.^{13,20,23} According to Hill-Briggs "Effective disease problem-solving would follow from the use of a rational problem-solving approach, a positive problem-solving orientation, adequate disease-specific knowledge, and ability to transfer knowledge and experience to new disease-related problem situations."^{23(p188)} Practices that therapists can use are: (1) teaching patients how to find knowledge, (2) stimulating a positive problem-solving orientation and, (3) teaching patients the 4 steps of problem-solving (ie, problem definition, brainstorming for solutions, decision making, and implementation and evaluation).^{24,25}

The task- and context-specific training is informed by muscle physiological, biomechanical, cognitive, and motor learning principles.²⁶ From a physiological and biomechanical point of view, it has been argued that training of functional tasks is remedial in itself because muscles are activated on the same length they are activated during these functions in daily life.²⁷ Practices concerning instructions, feedback, and delivery mode follow from cognitive and motor learning principles. That is, because of the cognitive nature of the first phase in learning activities, much emphasis is placed on mental practice of the patient and on the way the therapist provides instruction (short and clear, with focus on the aim of the task) and feedback (with cues on knowledge of performance).^{27,28} Often task- and context-specific training is given content by the use of workstations, providing an individually tailored treatment in a group training.^{16,17,29,30}

The use of workstations also enables the practice of including variation in the context, thereby stimulating as closely as possible the condition of daily tasks, so that problem solving of patients is stimulated.^{17,26,31}

Adapt knowledge to local context

The KTA expert subsequently educated the physical therapists and occupational therapists in the explicated self-management education and task-and context-specific training principles and practices. Afterward, she asked them to reflect on these principles and practices and to outline the possibilities and obstacles they saw in translating the principles and practices to patients with LLA. The therapists appreciated the task-oriented focus of the training and recognized the importance of communication and interaction for enhancing self-efficacy. However, they foresaw many obstacles on an organizational level in putting the workstations together, and they had a hard time visualizing how the workstations should look.

The actual translation of the principles and practices into the new motor skill training consisted of 2 phases: tailoring of principles and practices to the target group (ie, patients with LLA) and a more generic translation of the principles and practices. For tailoring of principles and practices to their target group, the therapist were asked to share information on which tasks were important and challenging for patients with LLA. They mentioned tasks in which patients: need to make transfers, have to deal with the specific instructions of their prosthesis, have a lack of visual feedback, or have to maneuver in a small place. This practical knowledge led, for example, to a workstation in which patients have to transfer with a laundry basket or a tray with coffee cups from one room to another when passing a threshold. In addition, the therapists were asked to specify which patients would or would not be indicated for this new training. This process led to the formulation of inclusion and exclusion criteria, such as excluding patients with a vulnerable foot or wound problems on the non-amputated limb.

The KTA expert then refined, in close collaboration with the therapists, the design of the functional prosthetic training with a further translation of the generic principles and practices. The principles on variation led to a broad selection of tasks and in the context of the workstations to create challenges ('motor problems') for the patients. The principles on problem solving resulted in concrete instructions and feedback given by the therapist. In that way, therapists can stimulate mental practice (ie, problem solving) of patients and teach them how to deal with the variety in tasks and context. The training was designed to be group training in order to enable modeling and thereby enhance self-efficacy. To enhance self-efficacy, instructions were given to enable positive skills mastery for patients and create a positive atmosphere during training sessions in which verbal persuasion of therapists and other patients can be stimulated. All of this was written down by the KTA expert in a concept protocol for therapists.

Assess barriers to knowledge use

The KTA expert anticipated, in close collaboration with all stakeholders, possible barriers hindering good implementation of the training. Possible barriers were identified on 3 levels: (1) the organizational level: several organizational aspects (eg, how and when to include patients, scheduling of the training, availability of therapists and of facilities and materials) needed to be taken care of; (2) the professional level: therapists needed to be able to let go of their usual routines and had to act more in a problem-solving manner; and (3) the target group level: the new training should be appealing and identifiable for patients with LLA.

Select, tailor and implement interventions

The identified barriers led to several activities intended to facilitate the actual use of the new training. On the organizational level, barriers were tackled by the KTA expert, in close collaboration with therapists and staff, in making a script for who was responsible for inclusion of patients, scheduling of the training and usability of facilities such as the room where the training was provided. The script also described on which items the training would be evaluated, when and by whom (Table 1).

Table 1. Items to evaluate of the concept of motor skills training

Issue	Method	Issue	Method	Issue	Method	Issue	Method
Content of the training		Material/ training		Practical implementation		Patients' experiences	
Applicability of problem-solving concept	Focus group therapists	Usefulness of training before implementation	Focus group therapists (and feedback after sessions)	Experiences with size of the group	Focus group therapists (and feedback after sessions)	Added value/ usefulness/ satisfaction	Evaluation with patients
Adaptations to the content	Diary of the training	Usefulness of training on the job	Focus group therapists (and feedback after sessions)	Experiences with frequency of sessions	Focus group therapists (and feedback after sessions)	Delivery mode / need of additional material / organizational context	Evaluation with patients
Adaptations to inclusion and exclusion criteria	Focus group therapists	Completeness of provided material	Focus group therapists (and feedback after sessions)	Experience of combining patients with and without prosthesis in the functional training	Focus group therapists (and feedback after sessions)	Need for attendance of partner	Evaluation with patients
Suitability of workstations	Feedback after sessions	Clarity of instructions for therapists	Feedback after sessions	Problems with scheduling the training	Focus group therapists (and feedback after sessions)	Complementary issues for improvement	Evaluation with patients

On a professional level, the KTA expert anticipated identified barriers by training therapists on 3 training aspects: (1) giving instruction and feedback on how to enable problem solving by patients instead of reaching out with solutions for how to deal with the challenging task, (2) integrating variety in tasks and contexts, and (3) applying techniques for enhancing self-efficacy of patients.

Barriers regarding the target group level were addressed during a meeting in which the KTA expert presented the training for feedback to 3 delegates of 2 national associations for patients with amputations. They reflected positively on the training and brought points of attention forward, such as providing tailored individual care within group training and the role of partners in this training.

Monitor knowledge use

To refine the design of the training and monitor knowledge use, the KTA expert organized a pilot implementation. For this pilot implementation, a time period of 7 months was scheduled. During this period, the therapists trained 20 patients, 2 times a week, in 2 stages during their prosthetic rehabilitation: (1) when they did not have a prosthesis yet and (2) when they had learned the basics of how to deal with their own individual prosthesis. As the number of training sessions was tailored to the individual needs of the patient, they varied from 1 to 16 sessions. In most sessions, the KTA expert provided on-the-job training for therapists when they had difficulty carrying out the principles and practices of self-management education and task- and context-specific training.

As the KTA expert observed most sessions, instant feedback and experienced inadequacies from therapists and patients were easily communicated. This approach enabled direct adaptations to the training where needed. Several deviations from the planned training were regarded to be necessary and drew attention to information on what missed in the planned training, without doing harm to the underlying essential principles and practices. Thus, in this iterative and interactive process, the training was continuously refined and brought into practice, which led to a training that was optimized for the local context.

Evaluate outcomes

To evaluate outcomes, the KTA expert conducted a focus group with all therapists and the medical manager of the team in which the training itself and the KTA process were evaluated. With regard to the training, therapists emphasized that providing this training in a group was seen as an important added value. On the other hand, they pointed out a limitation of group training: the group process can be hindered by a negative contribution of a single participant. The vulnerability

of group training also came to the fore when few patients attended prosthetic rehabilitation at the rehabilitation center or when participants canceled their training, leaving their co-participants alone, which negatively affected the opportunity for learning from modeling. In the opinion of the therapists, therefore, guiding the group process was still a point of attention for them.

With regard to the KTA process, therapists experienced the participatory presence of the KTA expert as very constructive and enabling for direct and low-level communication, which was reflected in quick responses where adaptations and organizational interferences were needed. This co-creation process led to an ongoing refinement of the training, tailored to the specific target population and to the local setting. Therapists appreciated the involvement of the KTA expert from the start of the improvement process. They felt they were listened to and that the training on the job gave them the opportunity to truly master the training principles. The KTA expert also evaluated the training in individual interviews with 5 patients. The patients emphasized the usefulness of the training. They explained that they not only learned from doing the challenging tasks themselves but also had learned from their co-participants in how they solved the challenges in their own manner. Patients felt left alone when co-participants did not attend the training and proposed to make the training compulsory.

Sustain knowledge use

Several activities were initiated to sustain knowledge use. The KTA expert described the final training in a booklet for therapist.³² Regular meetings of the KTA expert with the therapists were planned and are still part of the ongoing process. In these meetings, the training is discussed as are the successes and barriers experienced by therapists. These meetings keep all participants focused on why the training was originally developed and on how to keep the problem-solving principles active in the functional prosthetic training.

DISCUSSION

In this case report - focused on improving the transition from the clinical setting to the home setting in prosthetic rehabilitation - both research knowledge described in the literature (in this case, on principles and practices of self-management education and task- and context-specific training) and practical knowledge and contextual knowledge (in this case, therapist and patient knowledge about LLA in a Dutch rehabilitation center) were represented as distinct but equally valued knowledge practices.^{8,9} In doing so, complementary insights were provided for bridging the experienced research-practice gap. Self-management and task-and context-specific training

principles and practices developed for other target groups in physical rehabilitation were translated and incorporated into a functional prosthetic training for patients with LLA. Therapists and the medical manager provided the amputation-specific information and knowledge on the organizational context, and the KTA expert with skills in participatory action research conducted the articulation, translation, and integration work. This form of genuine partnership led to shared ownership of the improved functional prosthetic training focused on active learning of patients with LLA, which now has become part of usual care.

Despite this genuine partnership, therapists had to overcome several difficulties in putting the principles and practices into action. During knowledge creation, it turned out that therapists had a hard time in shifting from their daily practice and routines to the abstract level of the presented principles. During the pilot implementation, therapists experienced difficulties in letting their own routines go and continuing to act in a problem-solving manner. They also had to deal with barriers that are common in usual practice such as work pressure, a sudden reduction in number of patients, fewer staff during holidays, and so on. Nevertheless, the translation of knowledge into action was experienced by those involved as effective and successful. Conditions known from partnerships with patients, such as mutual respect, clear communication, flexibility, and sufficient time to deal with foreseen and unforeseen barriers, contributed to a fruitful KTA process.^{9,33,34}

This case report elucidates the concept of engaged scholarship, departing from a sociologically informed way of conceiving of what sciences are and do.^{4,8,35} Instead of holding on to the contrast between clinical practice and science in terms of subjective versus objective, as they are explicated in positivist conceptions of science, both therapeutic and scientific work are regarded as different but equally valued knowledge practices in the integrated KTA process.^{8,35} The KTA expert played the roles of searcher, observer, articulator, translator and integrator of both research knowledge reported in scientific literature and tacit practical knowledge possessed by therapists and their patients. Such an expert needs conceptual analytic skills to integrate the different knowledge practices, and ethnographic skills to assist therapists and patients to give words to their know-how.^{35,36} Therapists are then well prepared to critically reflect on the designed intervention during pilot implementations. The different roles of the researcher and physical therapists are summarized in Table 2.

Table 2: Roles of Knowledge-to-action (KTA) expert and physical therapists in an integrated KTA process

Phases of KTA project	Roles of KTA Expert	Roles of Therapists
Knowledge creation	-Collector and translator of promising principles and practices	
Adapt to local context	-Educator of principles and practices -Integrator of research and practical knowledge practices -Co-creator of concrete protocol	-Providers of disease-specific knowledge -Co-creators of concrete protocol
Assess barriers	- Integrator of aspects from different stakeholders and contexts	-Providers of knowledge on local organizational context
Select, tailor, and implement interventions	-Trainer -Facilitator -Co-organizer -Negotiator of all stakeholders	-Co-organizers
Monitor knowledge use/pilot implementation	-Observer -Receiver of feedback -Adapter -Trainer on the job	-Performer -Critical reflector -Reporter of feedback and adjustments
Evaluation of content and process	-Receiver of feedback -Translator of comments for refinement of final training	-Providers of feedback
Sustain knowledge use	-Writer of final handbook -Discusser of successes of and barriers to final training	-Discusser of successes of and barriers to final training

A limitation of this iterative and reflective KTA approach is that the quality of the improvement was not evaluated quantitatively, for instance, by measuring functional performance, participation and autonomy.¹¹ A previous study, however, revealed that many diverse factors affected functioning and participation of patients with LLA in the clinic and community, acting sometimes as barriers for some individuals and as facilitators for others.¹¹ To address this complexity, we advocate the use of mixed method designs in future evaluation research. By using both quantitative and qualitative methods and data in combination in a single study, or set of related studies, the interactions among physical, personal, and environmental factors can be better understood.³⁷

This case report is part of a larger research project in which participatory action research methodology is used to relate to and build on knowledge that already exists in rehabilitation practice and research. It is about localized and generalized knowledge that needs to be put into words, translated to other target groups and contexts, and integrated in recognized and owned capacities for improvement. The focus of this case report was on the development of motor skills training in which physical therapists and occupational therapists encouraged active learning of patients with LLA. In complementary psychoeducative training, psychologists conduct group sessions to teach patients with LLA problem-solving skills to prepare them for possible postdischarge problems such as skin conditions, bad weather issues, and loss of supervision, therapy structure and encouragement of peers.³²

To summarize, shared ownership and genuine partnership between therapists and the KTA expert are of great importance for changing and enriching therapeutic knowledge practices with new insights and moving therapists away from their comfort zone. A KTA expert needs conceptual analytical skills to integrate scientific and therapeutic knowledge practices and ethnographic skills to give words to the know-how of therapists and their patients.³⁶ In this process, it is essential to value scientific and therapeutic knowledge equally. A next step in this integrated KTA process is to translate the motor skill training and related know-how to and from other target groups and settings. Some insights may be generic; others need to be tailored to the specificities of the target group or target setting under study. Currently, not much is known about how co-created knowledge and lessons learned by doing in one setting might benefit others. We address this challenge and hope that others will join us.

REFERENCES

1. Jette DU, Bacon K, Batty C, et al. Evidence-based practice: beliefs, attitudes, knowledge, and behaviors of physical therapists. *Phys Ther* 2003; 83: 786-805.
2. Salbach NM, Jaglal SB, Korner-Bitensky N, et al. Practitioner and organizational barriers to evidence-based practice of physical therapists for people with stroke. *Phys Ther* 2007; 87: 1284-1303.
3. Green LW. Making research relevant: if it is an evidence-based practice, where's the practice-based evidence? *Fam Pract* 2008; 25: i20-i24.
4. Bowen SJ, Graham ID. From knowledge translation to engaged scholarship: promoting research relevance and utilization. *Arch Phys Med Rehabil* 2013; 94 (1 Suppl 1): S3-S8.
5. van Twillert S, Postema K, Geertzen JHB, Hemminga T, Lettinga AT. Improving rehabilitation treatment in a local setting: a case study of prosthetic rehabilitation. *Clin Rehabil* 2009; 23: 938-947.
6. Kerner JF. Integrating research, practice, and policy: what we see depends on where we stand. *J Public Health Manag Pract* 2008; 14: 193-198.
7. Straus SE, Tetroe J, Graham ID. Introduction: knowledge translation- what it is and what it isn't. In: Straus SE, Tetroe J, Graham ID eds. *Knowledge translation in health care: moving from evidence to practice*. Chichester, United Kingdom: John Wiley & Sons Ltd; 2013.
8. Kitto SC, Sargeant J, Reeves S, Silver I. Towards a sociology of knowledge translation: the importance of being disinterested in knowledge translation. *Adv in Health Sci Educ* 2012; 17: 289-299.
9. Van de Ven AH. *Engaged scholarship, a guide for organizational and social research*. New York, NY: Oxford University Press; 2007.
10. Van Twillert S, Geertzen JHB, Hemminga T, Postema K, Lettinga AT. Reconsidering evidence-based practice in prosthetic rehabilitation: a shared enterprise. *Prosthet Orthot Int* 2013; 37: 203-211.
11. Van Twillert S, Stuijve I, Geertzen JHB, Postema K, Lettinga AT. Functional performance, participation and autonomy after discharge from prosthetic rehabilitation: barriers, facilitators and outcomes. *J Rehabil Med* 2014; 46: 915-923.
12. Lorig KR, Sobel DS, Stewart AL, et al. Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization; a randomized trial. *Med Care* 1999; 37: 5-14.
13. Lorig KR, Holman HR. Self-management education: history, definition, outcomes, and mechanisms. *Ann Behav Med* 2003; 26: 1-7.
14. Scheurs KMG, Colland VT, Kuijter RG, de Ridder DT, van Elderen T. Development, content and process evaluation of a short self-management intervention in patients with chronic diseases requiring self-care behaviours. *Pat Educ Couns* 2003; 51: 133-141.
15. Newman S, Steed L, Mulligan K. Self-management interventions for chronic illness. *Lancet* 2004; 364: 1523-1537.
16. Wevers L, van de Port I, Vermue M, Mead G, Kwakkel G. Effects of task-oriented circuit class training on walking competency after stroke; a systematic review. *Stroke* 2009; 40: 2450-2459.
17. de Vreede PL, Samson MM, van Meeteren NLU, Duursma SA, Verhaar HJ. Functional-task exercise versus resistance strength exercise to improve daily function in older woman: a randomized controlled trial. *J Am Geriatr Soc* 2005; 53: 2-10.
18. Saunders DH, Greig CA, Young A, Mead G. Physical fitness training for stroke patients. *Cochrane Database Syst Rev* 2004; 1: CD003316.
19. Carr JH, Shepherd RB. A motor relearning model for stroke rehabilitation. *Physiotherapy* 1989; 75: 372-380.
20. Jansma FFI, van Twillert S, Postema K, Sanderman R, Lettinga AT. Physical and rehabilitation medicine and self-management education: a comparative analysis of two approaches. *J Rehabil Med* 2010; 42: 808-814.
21. Jones F. Strategies to enhance chronic disease self-management: how can we apply this to stroke? *Disabil Rehabil* 2006; 28: 841-847.
22. Bandura A. *Self-efficacy: the exercise of control*. New York, NY: WH Freeman and Co, 1997.
23. Hill-Briggs F. Problem solving in diabetes self-management: a model of chronic illness self-management behavior. *Ann Behav Med* 2003; 25: 182-193.

24. D'Zurilla TJ, Goldfried MR. Problem solving and behavior modification. *J Abnorm Psychol* 1971; 78: 107-126.
25. Nezu AM, Nezu CM, Friedman SH, et al. *Helping cancer patients cope: a problem solving approach*. Washington DC: American Psychological Association, 1998.
26. Lettinga AT, Siemonsma PC, van Veen M. Entwinement of theory and practice in physiotherapy. A comparative analysis of two approaches to hemiplegia in physiotherapy. *Physiotherapy* 1999; 85: 476-490.
27. Carr JH, Shepherd RB. *Movement science. Foundations for physical therapy in rehabilitation*. Rockville, Md, Aspen Publishers Inc, 1987.
28. Fitts PM, Possner MI. *Human performance*. Belmont CA: Brooks/Cole, 1967.
29. Ada L, Dean CM, Hall JM, Bampton J, Crompton S. A treadmill and overground walking program improves walking in persons residing in the community after stroke: a placebo-controlled, randomized trial. *Arch Phys Med Rehabil* 2003; 84: 1486-1491.
30. Dean CM, Richards CL, Malouin F. Task-related circuit training improves performance of locomotor tasks in chronic stroke: a randomized, controlled pilot trial. *Arch Phys Med Rehabil* 2000; 81: 409-417.
31. Shepherd RB, Carr JH. Neurological rehabilitation. *Disabil Rehabil* 2006; 28 : 811-812.
32. van Twillert S. Zelfmanagement in Beweging: Regietraining en Circuittraining voor de Revalidatie na een Beenamputatie. [*Self-management Training for Prosthetic Rehabilitation*]. Groningen, the Netherlands: Centrum voor Revalidatie, Universitair Medisch Centrum Groningen, 2012.
33. Sullivan M, Kone A, Senturia KD, Chrisman NJ, Ciske SJ, Krieger JW. Researcher and researched-community perspectives: toward bridging the gap. *Health Educ Behav* 2001; 28: 130-149.
34. Ottmann GF, Laragy C. Developing consumer-directed care for people with a disability: 10 lessons for user participation in health and community care policy and program development. *Aust Health Rev* 2010; 34: 390-394.
35. Lettinga A, Mol A. Clinical specificity and the non-generalities of science: on innovation strategies for neurological physical therapy. *Theor Med Bioeth* 1999; 20: 517-535.
36. Pols J. Knowing patients: turning patients' knowledge into science. *Sci Technol Human Values* 2014; 39: 73-91.
37. Rauscher L, Greenfield BH. Advancements in contemporary physical therapy research: use of mixed method designs. *Phys Ther* 2009; 89: 91-100.

6

Reconsidering evidence-based practice in prosthetic rehabilitation: a shared enterprise

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ABSTRACT

Background: A divide is experienced between producers and users of evidence in prosthetic rehabilitation.

Objective: To discuss the complexity inherent in establishing evidence-based practice in a prosthetic rehabilitation team illustrated by the case of prosthetic prescription for elderly patients with a dysvascular transfemoral amputation.

Study Design: A qualitative research design was used, in which data from multiple sources was triangulated to extract themes for discussion.

Methods: This discussion paper draws on empirical material gathered by individual and focus-group interviews with members of a prosthetic rehabilitation team, information on technological advancements presented on websites of orthopaedic industry, guidelines and literature study.

Results: A prosthetic rehabilitation team needs to deal with lack of evidence, contradictory results, various classification systems, diverging interests of different stakeholders and many modifying factors, and all of this in a continuous technological changing environment. Integrating research designs with different strengths but not sharing the same biases may help researchers to deal with the multimorbidity and multifaceted disability of the target group. Articulating clinical knowledge, patients' needs and values in a systematic way provides depth, detail, nuance and context for evidence-based practice issues in prosthetic rehabilitation.

Conclusions: Reconsidering the relationship between evidence, technology and rehabilitation practice is an imperative shared enterprise for clinicians and researchers. Scientific, clinical and patient-related knowledge are seen as important knowledge practices that should inform and strengthen each other.

CLINICAL RELEVANCE

This discussion paper puts the academic clinical debate on evidence-based practice in prosthetics and orthotics in another light. By demonstrating the complexities surrounding evidence-based practice, it is argued and illustrated how both researchers and clinicians can contribute to optimal patient care in which evidence, technology and rehabilitation practice are integrated.

BACKGROUND

Evidence-based practice (EBP) is growing in the field of Prosthetics & Orthotics (P&O), and its importance is emphasized.¹⁻⁴ Establishing an EBP is considered as highly relevant in a time of increasing pressure on health service budgets for all health-care branches.⁵ Rehabilitation researchers have been quite successful in proving that multidisciplinary rehabilitation assessments and treatments are effective in optimizing the functional recovery after acute injury/disease and during chronic illness.⁶⁻⁸ At the same time, there is mounting awareness of the complexity in establishing a coherent evidence base for multidisciplinary rehabilitation: that is, in determining, translating and integrating external evidence from systematic research on different patients in improved and more efficient assessments and treatments for rehabilitation settings. This definitely yields for clinicians working in prosthetic rehabilitation with patients with a lower-limb amputation.⁹

In line with Sackett et al.'s¹⁰ definition of evidence-based *medicine* (EBM), EBP in prosthetic rehabilitation is characterized as the process of integrating individual clinical expertise and patient values with the best available evidence from systematic research, in order to provide the best clinical care.¹⁻⁴ This definition comes across as attractive. It gives the impression that it is the 'simple' task of (rehabilitation) clinicians to combine original evidence produced in different research settings with their own individual clinical expertise including the individual needs of patients to whom they wish to give the best treatment. Of course, it is not that simple. A number of practical barriers in performing EBP are to be dealt with, such as lack of high-level evidence in P&O, time constraints and workload demands experienced by clinicians and finally limited skills, knowledge and resources required to perform EBP.¹⁻⁴ Researchers interested in P&O point variously to limitations in both research and practice hindering the evidence-based integration process. A culture change is plead for, in which clinicians in P&O are to be educated as lifelong, self-directed learners and are encouraged to pursue relevant clinical research themselves.³ In this discussion paper, it will be argued and illustrated that the evidence-based integration process implied in EBP

is an extremely complex task in general, and in prosthetic rehabilitation in particular, and should therefore be considered as a shared enterprise of both clinicians and researchers.

METHODS

This discussion paper stems from a broader research project aimed at narrowing the experienced divide between research and practice in multidisciplinary rehabilitation. Inspired by theory-driven programme evaluation,^{11,12} participatory action research,^{9,13,14} and social studies of science,^{15,16} questions about the complexity of EBP are addressed from the perspective of rehabilitation clinicians. In this discussion paper, the case of prosthetic prescription for older patients with a dysvascular transfemoral amputation is explored. The argument presented here draws on the following: (1) empirical material gathered by individual interviews and a focus-group interview with members of a prosthetic rehabilitation team, (2) information on technological advancements presented on websites of orthopaedic industry and the clinical practice guideline for rehabilitation of lower-limb amputation and (3) prosthetic rehabilitation literature and literature on the research-practice divide.

For the empirical part of the study, first individual interviews and a focus-group interview were conducted with members of a multidisciplinary prosthetic rehabilitation team in a Dutch rehabilitation centre. The rehabilitation centre is part of a university medical centre. Two physiatrists, five physical therapists, two occupational therapists, and one prosthetist participated in the interviews. All professionals provided informed consent. The interviews were recorded and transcribed verbally. S.v.T. asked individual respondents about the motives behind their actions in prosthetic prescription and prosthetic training and about the impact of technological advancements on their actions. They were also asked about the sources they used to keep up to date with technological advancements. An independent experienced moderator led the focus-group interview on topics that needed to be further explored. The prescription of a knee mechanism for elderly patients with a transfemoral amputation was taken as case in order to make the discussion more concrete. The moderator also gave room for reflections on new topics that arose in the efforts of participants to understand each other. Based on these interviews, a scene was sketched of clinicians that needed to operate in a complex health landscape in order to perform EBP.

Second, the websites of two orthopaedic industries (Otto Bock and Össur) were explored, as these were used by the clinicians to keep up to date with the technological possibilities. The clinical practice guideline for rehabilitation of lower-limb amputation¹⁷ was also added as source of information for implementation of EBP.

Third, the scientific literature on prosthetic rehabilitation and on the research-practice divide collected by our research group within the past 10 years was studied to explore the scientific context. The literature studies were not conducted in a systematic manner, as is required for systematic reviews summarizing and critically appraising published evidence on certain issues. Indeed, our intention was neither to give an overview of the research-practice debate nor to present evidence for prosthetic rehabilitation that is methodologically generalizable. Rather, we wanted to reflect from a scientific point of view on issues and on-going dilemmas the rehabilitation clinicians had to face in attempting to work in an evidence-based manner and explore promising solution directions in the scientific literature.

The themes that emerged from the empirical and scientific material across sources are (1) the methodological complexity in research on elderly patients with an amputation, (2) the impact of technological advancements on evidence-based prescription, (3) diverging classification systems in prosthetic prescription and (4) additional modifying factors in the transfer to individual patients. With this discussion paper, we invite both researchers and clinicians to comment on the solution directions we recommend and participate in the academic debate in a shared effort to establish EBP in P&O.

RESULTS

Methodological complexity in research on elderly patients with an amputation

In EBM, proofs of effectiveness of treatment are preferably assessed in clinical trials and its evidence summarized and critically appraised in systematic reviews. Most systematic reviews judge research findings on a basis of a hierarchy of study designs, with randomized controlled trials (RCTs) at the top, producing the highest level of evidence, and case studies at the bottom, producing the lowest level of evidence. RCTs are placed on the top of the hierarchy, as they are best suited to rule out threats to internal validity. Therefore, RCTs are preferably carried out on homogeneous populations of adult patients who are preferably not older than 65 years and who have only the condition in question.¹⁸ Indeed, most research and clinical practice guidelines are based on a single-disease paradigm, which may not be appropriate for elderly patients with complex and overlapping health problems.¹⁹ Optimizing the care of older persons with multiple medical conditions is therefore a complex task, with clinicians receiving potentially contradictory recommendations regarding how to tailor care for elderly from the medical literature.²⁰ The majority of the patients in the field of P&O for whom clinicians need to make evidence-based decisions are also elderly with two or more morbidities such as diabetes and vascular diseases.^{21,22}

That introduces bias into data, which makes it difficult to get conclusive evidence for this complete target group. Excluding patients based on confounding factors such as multimorbidity results in a more homogeneous group and more conclusive results but at the same time limits the applicability of research findings for the complete group. Therefore, exclusions made by researchers to prevent bias entering the research setting in order to produce methodological sound and generalizable results, do not resolve the complexity of the clinical decision process in prosthetic rehabilitation of older patients with dysvascular amputations.

Although researchers in the field of P&O do recognize the complexity of the research in question, many of them continue to rely above all on the traditional study design hierarchy articulated in the EBM movement. Cumming et al.,²¹ for instance, concluded in their systematic review on older dysvascular amputee patients that more reliable evidence from high-quality and sufficiently powered RCTs on interventions is needed. They could include only one trial in their systematic review, a trial of which the methodological quality was judged as moderate because of lack of power (only 10 patients), a missing description of the randomization, no intention to treat analysis, lack of point estimates and measures of variability presented for the primary outcome measures, and so on.²¹ The researchers explained that they conducted this study because they felt that the results of the previous studies on their research topic might not be directly attributable to the older less active poorly conditioned patients with dysvascular amputations.²³

Thus, researchers are urged to conduct high methodological quality in experimental settings (internal validity), on the one hand, and need to ensure applicability of the research findings for the wider population seen in clinical settings (external validity), on the other hand. A relative neglect of external validity in the EBP health literature is reported, which does have consequences for the relevance, generalizability and applicability of the research findings in varied circumstances in clinical settings.²⁴ In the light of an ageing society, in which clinicians will face more and more older people with multimorbidity and multifaceted disabilities, there is an urgency to incorporate other research designs for this heterogeneous group. We therefore argue that researchers working in the field of P&O should reconsider traditional study design hierarchy, where appropriate, and explore other options like mixed methods research.

Mixed methods research can also provide high internal validity and at the same time offer the opportunity to deal with the heterogeneity of characteristics of patients with an amputation. It involves the combination of two or more research designs having different strengths and not sharing the same biases.²⁵ Often mixed methods research refers to the combined use of both quantitative and qualitative methods, in which the researcher collects and analyses the data concurrently or sequentially, integrates the findings and draws inferences using both methods in a single study or programme.²⁶ In post hoc evaluations for instance, qualitative examination

can identify why differences in intervention outcomes occurred, uncover additional treatment benefits and explore barriers to achieving the best intervention outcomes.²⁷ But the approach of mixed methods research can also encompass combining different qualitative methods such as in-depth interviews, focus-group discussions, documentary analyses or observations.^{9,28} Mixed methods research may thus assist in enhancing internal validity in a heterogeneous research population as well as balancing issues of internal and external validity. To our opinion, researchers in prosthetic rehabilitation could and should therefore profit from this ‘new’ research approach that can provide evidence that is better attuned to the variability of prosthetic rehabilitation and heterogeneity of the target group.

Impact of technological advancements on evidence-based prescription

Emerging technological advancements in prosthetics is another aspect that adds to the complexity in establishing EBP in P&O. Due to these advancements, clinicians face an overwhelming amount of available prosthetic componentry from which they have to choose.²⁹ A problem is that empirical evidence on the surplus value of novel prosthetic componentry in relation to existing technologies comes quite some time after the innovations have been put on the market. Let us take the developing technology in prosthetic knee mechanisms as an example. Knee mechanisms must provide stability and swing at appropriate rates to properly match the ability of a patient with an amputation.³⁰ Several orderings in available knee mechanisms can be distinguished.

In the interviews, clinicians illustrated the impact of developing technology on their clinical decision process as follows; in former days, it was relatively simple: clinicians and their patients could choose between several passive knee mechanisms comprising locked knee mechanisms and free swinging mechanisms. Interviewed clinicians elucidated that when they were in doubt about the most appropriate knee mechanism in former days, they chose a manual locked knee mechanism because of its safety. After prosthetic training, they could then decide whether a free swinging knee mechanism was optional for the longer term. With the invention of, for example, stance and swing phase control techniques, free swinging knee mechanisms got more and more sophisticated. These novel mechanisms became applicable for a wider variety of patients. For the clinicians in the local setting, this led to an actual shift in the prescription of prosthetics. They reported that nowadays they mostly select a free swinging mechanism with stance-control technique, and when that does not work out well, they can still choose a locked knee mechanism. The clinicians rationalized their choice for this sequence by arguing that it fits the learning strategy that patients use to incorporate the mechanism of the prosthesis in their movements. They argued that it is very hard for a patient to unlearn a ‘stable’ movement pattern A (locked mechanism) and learn movement pattern B (free swinging mechanism) that is far more unstable. That is why they now often choose to start with the free swinging mechanism.

For elderly patients with dysvascular amputation, however, issues like muscle weakness, loss of coordination and balance are common additional conditions. Therefore, patient safety is a primary concern for clinicians.³¹ With the incorporation of several electronic control systems into prosthetic knee mechanisms, the range of available knee mechanisms is again broadened.³² In these active controlled knee mechanisms, microprocessors direct the knee's resistance to flexion and extension, thereby influencing a user's ability to ambulate safely and/or effectively.³¹

Most interviewed clinicians, however, clarified that they barely prescribed microprocessor controlled knee mechanisms (MKMs) for the older patients with transfemoral amputations. They felt that most of these prostheses were developed for younger, more active patients. Nonetheless, there were also clinicians who pointed to advantages: that is, MKMs might require less cognitive demand for older patients, who find it in general harder to conduct dual tasks. This might attribute to the safety of their functioning. But even then, prescription of MKMs remains a complex activity. The interviewed clinicians reported that the relative high costs of MKMs lead to resistance by health insurers. When they decided to take advantage of innovative technology in MKMs and prescribe a prosthesis with such a knee mechanism for an elderly patient, health-care financiers were not eager to pay for it.

Clinicians in prosthetic rehabilitation thus not only have to keep up-to-date with the technological advancements and fit its pros and cons in their prescription process, but they also have to take into account the interests of other stakeholders such as the care financiers of their patients. There is thus an urgent need for evidence in P&O: first, to support clinicians in making evidence-informed prosthetic prescriptions for different target groups, and second, for grounding that prescription towards health-care financiers. Lack of evidence to support clinicians in the prescription process is indeed experienced as a huge barrier.^{21,33} In a meeting on the state of the evidence in P&O, 'the 'science' of P&O was even referred to as severely immature.³⁴ The scientific literature on MKMs, for instance, showed mixed results on energy expenditure, gait performance and cognitive demand, while users' satisfaction was globally positive. This is confirmed by a recent survey with prosthetists and orthotists, who also felt that research studies presented too many contradictory results, and what is more, the research findings were considered out of date.¹ Contradictory research findings and various opinions about prescription of MKMs are among other things attributed to a lack of knowledge on the exact target group for MKMs. Are the most technologically advanced prosthetic components only suitable for the young athletic patients or can patients with a lower level of functioning also profit from this technology?^{31,35} The possibilities nowadays seem endless, but at the same time, clinicians in prosthetic rehabilitation are warned for too much optimism: when an individual is unable to ambulate with a nonmicroprocessor knee, there is little chance that he or she is able to ambulate and benefit from the features and

functions of a MKM.³⁶ More conservative components are often prescribed for patients with limited mobility, although several studies provided evidence that can counter this presumption.^{29,31}

Therefore, advancements in technology certainly have an impact on clinical practice, and contradictory evidence on these advancements contributes to the complexity of EBP in P&O. Clinicians, researchers and designers are seen as important actors in this combined field of technology, research and prosthetic rehabilitation. We therefore applaud initiatives that stimulate the multi-actor process in which all stakeholders combine their knowledge. Meetings in which clinicians, prosthetic users, researchers and prosthetic device manufactures³⁷ or where prosthetists, orthotists, user representatives and research engineers³⁴ come together in order to attune their agendas on research projects on prosthetic technology are seen as promising examples.

Diverging classification systems in prosthetic prescription

Despite contradictory results and various opinions influencing clinicians in their decision process, there are evidence-based guidelines available for clinicians. These clinical practice guidelines for rehabilitation of lower-limb amputation dedicate two subparagraphs to the prosthetic prescription phase. Clinicians are recommended to determine functional goals of prosthetic fitting (D1) and prescribe the prosthesis based on the current or potential level of ambulation (D2).¹⁷ To determine the potential level of functioning, the guidelines refer to the use of K-levels. K-levels stem from a coding system of the Health Care Financing Administration (HFCA), comprising a 5-level functional classification system ordering the functional abilities of persons who have undergone lower-limb amputation.³⁸ This system was originally developed to assist a health-care insurance company (Medicare) with the decision which prosthetic components to cover but is now also incorporated in the guidelines to support clinicians in the prescription process. The K-level system can assist clinicians in selecting available componentry that is indicated for the specific K-levels. When a patient is resided in K-level 2, for instance, a prosthesis that meets the functional goals of limited community ambulation is recommended (see Table 1).

Table 1. Description of K-levels

K-level 0	The patient does not have the ability or potential to ambulate or transfer safely with or without assistance, and a prosthesis does not enhance the quality of life or mobility.
K-level 1	The patient has the ability or potential to use a prosthesis for transfers or ambulation on level surfaces at fixed cadence. Typical of the limited and unlimited household ambulator.
K-level 2	The patient has the ability or potential for ambulation with the ability to transverse low-level environmental barriers such as curbs, stairs, or uneven surfaces. Typical of the limited community ambulator.
K-level 3	The patient has the ability or potential for ambulation with variable cadence. Typical of the community ambulator who has the ability to transverse most environmental barriers and may have vocational, therapeutic, or exercise activity that demands prosthetic utilization beyond simple locomotion.
K-level 4	The patient has the ability or potential for prosthetic ambulation that exceeds basic ambulation skills, exhibiting high impact, stress or energy levels. Typical of the prosthetic demands of the child, active adult, or athlete.

The question, however, is how patients will be assigned to a certain K-level. Especially when taken into consideration that patients are being evaluated on their potential, which could affect their future care as with Medicare patients. Therefore, it is important that what constitutes potential is standardized and measurable.³⁹ The clinical guidelines nevertheless do not provide direction for this selection. It is again the clinician or the rehabilitation team that has to determine the skills and features of the patient and combine that with the desired level of participation of the patient. Therefore, this recommended classification system depends heavily on subjective procedures and clinical expertise of the rehabilitation team. The evidence-based guidelines thus implicitly pass the responsibility to clinicians.

With the involvement of another stakeholder, the orthopaedic industry, the use of the classification system as a helpful instrument for clinical decision-making gets even more ambiguous. Certainly since providers, like Össur⁴⁰ and Otto-Bock,⁴¹ present their own 'unique' classification systems on their websites. Otto Bock present a classification system that is named the MOBIS-Otto Bock mobility system with levels that are called 'mobility grades' and Össur presents a classification system with 'impact levels'. The four mobility grades of the MOBIS-Otto Bock mobility system resemble the K-levels 1-4, omitting K-level 0, as this indicates no prosthesis. Both the MOBIS-Otto Bock system and the K-level system base their levels on the possibilities of the patient with an amputation to perform certain transfers, on which surface and with a certain kind of cadence. The impact levels of Össur, however, present ranges of activities and focus on the loading force (minimal, moderate amount, high and extreme). The activities like shopping, gardening and household tasks are, for instance, linked to the low impact level. Although all three classification systems do have common features, they diverge in terminology and content. It

is understandable that different industrial ventures wish to present their products as exclusive and therefore introduce their own 'unique' classification system. Yet for clinicians who need to decide on prosthetic componentry, this leads to more unnecessary complexity. We therefore argue to further work in a joint manner on a more standardized classification system that is attuned to the needs of clinicians and their patients.

Transfer to individual patients: additional modifying factors

The functional abilities as categorized in the classification system recommended by the guidelines are indeed not conclusive for the clinical decision process in the prescription phase. Also physiological factors - including general health, weight, height, level of the amputation and length and shape of the residual limb – are to be considered when prescribing a prosthesis. According to the suppliers of prosthetic componentry, it is therefore not possible to offer an exact prescriptive tool online.⁴⁰ In addition, also psychosocial factors need to be considered in the choice of componentry.

Interviewed clinicians emphasized within this context, the impact of fear of falling, which is present by many older patients with an amputation. According to them, a disabling fear of falling has a negative impact on autonomous movement, which endangers safe functioning. Therefore, in order to succeed with the prosthetic fitting, elderly patients must feel confident enough to deal with the knee mechanism.

The scientific literature, however, provides little insight into the predictive character of the different physiological and psychosocial factors. Therefore, also on these issues scientific knowledge is lacking to inform clinicians in prosthetic rehabilitation. Even of greater importance for a good prescription of prosthetic componentry are the wishes and preferences of patients themselves. Considering all the advancements in technology, it is necessary to examine what patients prefer. Several researchers have actually focused on the patients' perspective on prosthetics including the role of advancements in prosthetics.⁴²⁻⁴⁴ They expressed their concern that patients' preference into the decision process lacks intention. They plead for standardized methods in which to measure patient preferences within prosthetic prescription. In this technology-driven time frame in prosthetic rehabilitation, clinicians should be well aware of the patients' psychosocial issues and patients' emotions and feelings towards technological devices.⁴³

These researchers⁴²⁻⁴⁴ thus impute an important role for clinicians in rehabilitation to balance the functional opportunities offered by technology with a holistic view on the patient. We argue that researchers themselves can also fulfil an important role in this balancing process. Combining several qualitative research techniques provides a fuller and deeper understanding of a certain issue.⁴⁵ With the help of in-depth interviews individual perceptions, beliefs, feelings

and experiences with prosthesis can be identified.²⁸ Focus-group discussions can accordingly be used to gain in-depth understanding of the values of subgroups of patients and about the acceptance and use of certain prostheses, thereby comprising more comprehensive knowledge on the issue. Researchers can provide clinicians in this way with in-depth knowledge about the grounds underlying articulated patients' values and preferences by giving words to the voices of elderly patients and their caregivers in the field of P&O.

Explicating and comparing the tacit knowledge of clinicians working in P&O

There is not a simple recipe for prosthetic prescription that supports clinicians in the implementation process of EBP of patients with a lower-limb amputation in general, and elderly patients with dysvascular amputation in particular. The selection of the right componentry for a prosthesis cannot easily be made by summarizing and critical appraising available evidence in systematic reviews. To the contrary, clinicians do face a lack of evidence and when available contradictory results. On top of that, they have to deal with various classification systems, diverging interests of different stakeholders and many modifying factors, and all of this in a technological changing environment. In their search for an optimal prosthesis for individual patients, clinicians are thus confronted with many uncertainties and unidentified knowledge areas that contribute to the complexity of evidence-based prescription in P&O. The rehabilitation team therefore relies for a great part on their own clinical experience to select the right prosthesis for an individual patient. In the individual and focus-group interviews, clinicians described the prescription phase in this context as '*an art*', '*a sensitivity*', or '*something speculatively*'. Unfortunately, this so-called tacit knowledge is scarcely made explicit in prosthetic rehabilitation, which does not attribute to transparency in the field of P&O. This is a well-known problem and also seen in other fields. It is indeed acknowledged that it is difficult for clinicians in general to put the reasoning behind their decisions and actions into words.^{46,47} Clinical knowledge is understudied and needs more articulation to make it transportable for sharing and thus for improvement.⁴⁸ How to profit from this area of clinical knowledge and expertise?

Participatory action research can be of great help in explicating this implicit knowledge of clinicians and can also be helpful in facilitating improvement. The participation part in participation action research implies that clinicians are seen as partners in the research process, and the action part defines the commitment to change.²⁸ Participatory action research aims at (1) conducting research with people, not on people; (2) improving the situation and (3) learning and reflection between the researcher and researched.²⁸ Researchers trained in participatory action research can assist clinicians to make their implicit practical knowledge explicit with help of documentary analysis, observations of treatments, individual and focus-group interviews and

so on. By incorporating clinicians as partners in a research process, the researcher and clinicians can co-construct knowledge.⁴⁹ In a previous study,⁹ a participatory action research design helped us to collect, unravel and articulate tacit knowledge of clinicians in prosthetic rehabilitation on specific issues, which was accordingly specified by asking clinicians to critically reflect on them in focus-group discussions.⁹ Through this articulation process, we were able to identify the essential issues for improvement of the intervention and its conceptual underpinnings in terms of problem-solving principles and practices.

Participation research, however, demands several skills of the researcher. To be able to articulate knowledge from an insider point of view (tacit knowledge of clinicians), researchers must have the skills to put themselves in the shoes of clinicians. From an outsiders point of view, they accordingly have to be able to put together the articulated knowledge in conceptual frameworks developed to work on programme development.^{9,11,12} For example, they have to be able to specify systematically the treatment content (the features of the interventions, recipients and their environment) and its theoretical underpinnings. With this knowledge, treatment outcome research can be designed that can enhance both the understanding of research findings and their usefulness in rehabilitation practice.^{11,12}

We thus argue that participatory research provides depth, detail, nuance and context to EBP issues. Explicating the implicit knowledge of clinicians can contribute to a better understanding of clinical decision processes and can examine issues that are too complex to be easily disentangled by clinical epidemiological research. Integrating clinicians and patients in the research process involves recognizing the rights of those whom research concerns, enabling people to set their own agendas for research and development and so giving them ownership over the process.¹³

DISCUSSION

In this discussion paper, we have unravelled and explicated the problems that clinicians encounter when they want to implement the results of scientific research into practice of the P&O field. We focused on just one part of prosthetic rehabilitation, namely, the prosthetic prescription phase for older patients with dysvascular transfemoral amputation and in particular on innovative technology of knee mechanisms. We illustrated that clinicians motivated to work on EBP in a lifelong manner not only need to handle a number of practical barriers in performing EBP but also have to be in accord with emerging technological advancements in this field⁵⁰ and are on top of that asked to translate the collective and averaged body of external evidence (when available) to the individual needs of their patients.² This means that a lot is asked from clinical and academic

reasoning of clinicians in their effort to perform EBP. Certainly when taken into consideration that a prosthesis encompasses much more componentry than just a knee mechanism like ankle and foot mechanisms. All these mechanisms interact with each other, which increases the complexity of the prescription of the right componentry.

We argued that it is a shared responsibility of both clinicians and researchers to deal with the complexity in P&O and rethink the relation between evidence, technology and rehabilitation practice. This implies that researchers have to learn to experiment with the many shades of grey designs that lie between black (case studies) and white (RCTs) designs, in order to provide scientific knowledge that will be better attuned to the complexity seen in clinical practice. Take the elderly patient with a dysvascular amputation, their multimorbidity and multifaceted disabilities indeed influence the linear relationship between experimental interventions and outcomes presumed in clinical trials thereby confounding research results. Adding qualitative research on the situated perceptions and experiences of the researched elderly will provide researchers with more detailed knowledge on the confounding factors. These findings will help them to place the quantitative data in perspective. It could be stated that in experimenting with the research designs researchers also have to become lifelong learners, just like the clinicians, as was plead for in the culture change in P&O.³ It would even mean a culture change for funders, publishers and educators to enable, teach and support such research designs.

The role of clinicians in establishing EBP in P&O can also be seen in another light. Clinicians need to deal with several complex issues when they are asked to integrate individual clinical expertise and patient values with the best available evidence. This holds for rehabilitation medicine in general and prosthetic rehabilitation for elderly patients with dysvascular amputation in particular. To put it more encouragingly, it can also be said that clinical decision-making in rehabilitation practice requires craftsmanship, creativity and pragmatic considering and assembling of all multifaceted aspects.¹⁶ Explicating this craftsmanship, creativity and resourcefulness, which clinicians make use of when dealing with the complexity, is of great importance. This is still a blind spot in rehabilitation research that does not do justice to the hard work of rehabilitation clinicians. The articulation of clinical practice as having a quality and logic of its own is a first step in the quest for more situated strategies for the improvement of rehabilitation practice.¹⁶ Although there is the tradition of writing case reports and transferring clinical knowledge through medical education, researchers seldom reflect on clinical experience as a form of knowledge in itself. The practical knowledge of patients is even less studied and reflected on.⁴⁸ It is therefore important to distinguish between evidence-based knowledge produced in experimental settings, clinical knowledge gathered by assessments and treatments of patients and practical knowledge from patients living with a condition or disease.

With this, we touch upon a more fundamental question being: is the term based in 'EBP' in this perspective an accurate term? If we argue that research evidence produced in experimental settings should not override, or take precedence over, clinical experience, clinical embodied skills, patients' needs, values and knowledge, then the relationship between evidence and practice cannot be that of supplying a basis for that very practice.^{9,15,51} It is of course important to critically appraise rehabilitation practices in experimental settings and conduct creative scientific investigations that may help to (im)prove it. But we suggest that all three knowledge practices, scientific knowledge from researchers, clinical knowledge from clinicians and practical knowledge from patients are important and should inform and strengthen each other. We therefore propose to replace the term *based* in EBP for *informed*. In evidence-informed practice (EIP), clinicians are encouraged to be knowledgeable about the findings coming from all types of scientific studies, and researchers are urged to support them in translating it to the local realities of different rehabilitation settings in an integrative manner.^{9,51}

CONCLUSION

Researchers should learn to take into consideration both articulated clinical experiences and judgments, clients' preferences and values, context of intervention and relevant evidence produced in experimental settings and help clinicians to attune it to each other. In our opinion, EIP acknowledges both the crucial role and craftsmanship of the clinician and the researcher in providing the knowledge for the performance of optimal patient care in prosthetic rehabilitation.

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REFERENCES

1. Andrysek J, Christensen J, Dupuis A. Factors influencing evidence-based practice in prosthetics and orthotics. *Prosthet Orthot Int* 2011; 35: 30-38.
2. Geil MD. Assessing the state of clinically applicable research for evidence-based practice in prosthetics and orthotics. *J Rehabil Res Dev* 2009; 46: 305-314.
3. Ramstrand N, Brodtkorb TH. Considerations for developing an evidence-based practice in orthotics and prosthetics. *Prosthet Orthot Int* 2008; 32: 93-102.
4. Christensen J, Andrysek J. Examining the associations among clinician demographics, the factors involved in the implementation of evidence-based practice, and the access of clinicians to sources of information. *Prosthet Orthot Int* 2012; 36: 87-94.
5. Borg K, Sunnerhagen KS. Evidence-based medicine in physical and rehabilitation medicine: is this evidence-based rehabilitation? *J Rehabil Med* 2008; 40: 689-690.
6. Khan F, Turner-Stokes L, Ng L, Kilpatrick T, Amatya B. Multidisciplinary rehabilitation for adults with multiple sclerosis. *Cochrane Database Syst Rev* 2007; 2: CD006036.
7. Stroke Unit Trialists' Collaboration. Organised inpatient (stroke unit) care for stroke. *Cochrane Database Syst Rev* 2007; 4: CD000197.
8. Karjalainen KA, Malmivaara A, Van Tulder MW, et al. Multidisciplinary biopsychosocial rehabilitation for subacute low-back pain among working age adults. *Cochrane Database Syst Review* 2003; 2: CD002193.
9. Van Twillert S, Postema K, Geertzen JHB, Postema K, Lettinga AT. Improving rehabilitation treatment in a local setting: a case study of prosthetic rehabilitation. *Clin Rehabil* 2009; 23: 938-947.
10. Sackett DL, Strauss SE, Richardson WS, et al. *Evidence based medicine: how to practice and teach EBM*. 2nd ed. Edinburgh: Churchill Livingstone; 2000.
11. Siemonsma PC, Schröder CD, Roorda LD, Lettinga AT. Benefits of treatment theory in the design of explanatory trials: cognitive treatment of illness perceptions in chronic low back pain rehabilitation as an illustrative example. *J Rehabil Med* 2010; 42: 111-116.
12. Lettinga AT, van Twillert S, Poels BJJ, Postema K. Distinguishing theories of dysfunction, treatment and care. Reflections on 'Describing rehabilitation interventions'. *Clin Rehabil* 2006; 20: 369-374.
13. Cornwall A, Jewkes R. What is participatory research? *Soc Sci Med* 1995; 41: 1667-1676.
14. White GW, Suchowierska M, Campbell M. Developing and systematically implementing participatory action research. *Arch Phys Med Rehabil* 2004; 85: S3-S12.
15. Lettinga A, Mol A. Clinical specificity and the non-generalities of science. On innovation strategies for neurological physical therapy. *Theor Med Bioeth* 1999; 20: 517-535.
16. Struhkamp R, Mol A, Swierstra T. Dealing with in/dependence: doctoring in physical rehabilitation practice. *Sci Technol Hum Val* 2009; 34: 55-76.
17. Department of Veterans Affairs. Department of Defense. *VA/DoD Clinical practice guideline for rehabilitation of lower limb amputation. version 1.0-2007*. Washington, DC: Department of Veterans Affairs, Department of Defense, 2007.
18. Mol A, Law J. Complexities: an introduction. In: Law J and Mol A (eds). *Complexities; social studies of knowledge practices. (science & cultural theory)*. Durham, NC: Duke University Press, 2002, p. 1-22.
19. Marengoni A, Angleman S, Melis R, et al. Aging with multimorbidity: a systematic review of the literature. *Ageing Res Rev* 2011; 10: 430-439.
20. Fried TR, Tinetti ME, Iannone L. Primary care clinicians' experiences with treatment decision making for older persons with multiple conditions. *Arch Intern Med* 2011; 171: 75-80.
21. Cumming J, Barr S, Howe TE. Prosthetic rehabilitation for older dysvascular people following a unilateral transfemoral amputation. *Cochrane Database Syst Rev* 2006; 4: CD005260.
22. Geertzen JHB, Martina JD, Rietman HS. Lower limb amputation Part 2: rehabilitation - a 10 year literature review. *Prosthet Orthot Int* 2001; 25: 14-20.
23. Meikle B, Boulias C, Pauley T, Devlin M. Does increased prosthetic weight affect gait speed and patient preference in dysvascular transfemoral amputees? *Arch Phys Med Rehabil* 2003; 84: 1657-1661.
24. Green LW, Glasgow RE. Evaluating the relevance, generalization, and applicability of research: issues in external validation and translation methodology. *Eval Health Prof* 2006; 29: 126-153.

25. Johnson RB, Onwuegbuzie AJ. Mixed methods research: a research paradigm whose time has come. *Educ Res* 2004; 33: 14-26.
26. Tashakkori A, Creswell JW. Editorial: the new era of mixed methods. *J Mix Method Res* 2007;1: 3-7.
27. Kroll T, Morris J. Challenges and opportunities in using mixed method designs in rehabilitation research. *Arch Phys Med Rehabil* 2009; 90 (Suppl. 1): S11-S16.
28. Hennink M, Hutter I, Bailey A. *Qualitative research methods*. 1st ed. London: SAGE, 2011.
29. Kahle JT, Highsmith MJ, Hubbard SL. Comparison of nonmicroprocessor knee mechanism versus C-leg on prosthesis evaluation questionnaire, stumbles, falls, walking tests, stair descent, and knee preference. *J Rehabil Res Dev* 2008; 45: 1-14.
30. Romo HD. Prosthetic knees. *Phys Med Rehabil Clin N Am* 2000; 11: 595-607.
31. Hafner BJ, Smith DG. Differences in function and safety between Medicare functional classification level -2 and -3 transfemoral amputees and influence of prosthetic knee joint control. *J Rehabil Res Dev* 2009; 46: 417-434.
32. Bellmann M, Schmalz T, Blumentritt S. Comparative biomechanical analysis of current microprocessor-controlled prosthetic knee joints. *Arch Phys Med Rehabil* 2010; 91: 644-652.
33. Van der Linde H, Hofstad CJ, Geurts ACH, Postema K, Geertzen JH, van Limbeek J. A systematic literature review of the effect of different prosthetic components on human functioning with a lower limb prosthesis. *J Rehabil Res Dev* 2004; 41: 555-570.
34. Northwestern University Feinberg School of Medicine. *Research in P&O; are we addressing clinically relevant problems?* Report on the state-of-the-science meeting in prosthetics and orthotics. 28 February, 2006. Chicago, IL: Northwestern University.
35. Schaffer HM. Advancements in prosthetic technology provide more options to amputees. *Lippincotts Case Manag* 2006; 11: 282-283.
36. Berry, D. Microprocessor prosthetic knees. *Phys Med Rehabil Clin N Am* 2006; 17: 91-113.
37. Klute GK, Kantor C, Darouzet C, et al. Lower-limb amputee needs assessment using multistakeholder focus-group approach. *J Rehabil Res Dev* 2009; 46: 293-304.
38. Medical Function Classification Level (MFCL). *Health care financing administration. HCFA Common procedure coding system HCPCS*. Washington, DC: US Government Printing Office, 2001, ch. 5.3.
39. Schaffalitzky E, Gallagher P, MacLachlan M, Ryall N. Understanding the benefits of prosthetic prescription: exploring the experiences of practitioners and lower limb users. *Disabil Rehabil* 2011; 33: 1314-1323.
40. Website Össur. Available from: <http://www.ossur.com/prosthetic-solutions/products/knees-and-legs>
41. Website Ottobock. Available from : www.ottobock.nl/cps/rde/xchg/ob_nl_nl/hs.xsl/22271.html
42. Messinger SD. Incorporating the prosthetic: traumatic, limb-loss, rehabilitation and refigured military bodies. *Disabil Rehabil* 2009; 31: 2130-2134.
43. Schaffalitzky E, NiMhurchadha S, Gallagher P, Hofkamp S, MacLachlan M, Wegener ST. Identifying the values and preferences of prosthetic users: a case study series using the repertory grid technique. *Prosthet Orthot Int* 2009; 33: 157-166.
44. Devlin M, Sinclair LB, Colman D, Parsons J, Nizio H, Campbell JE. Patient preference and gait efficiency in a geriatric population with transfemoral amputation using a free-swinging versus a locked prosthetic knee joint. *Arch Phys Med Rehabil* 2002; 83: 246-249.
45. Johnson RB, Onwuegbuzie AJ, Turner LA. Toward a definition of mixed methods research. *J Mix Method Res* 2007;1: 112-133.
46. Atkins S, Murphy K. Reflection: a review of the literature. *J Adv Nurs* 1993; 18: 1188-1192.
47. Mol A. *The logic of care: health and the problem of patient choice*. Oxon and New York: Routledge, 2008.
48. Pols J. *Care at distance. On the closeness of technology*. Amsterdam: Amsterdam University Press, 2012.
49. McIntyre A. *Participatory action research (qualitative research methods series)*, vol 52. Thousand Oaks, CA: SAGE, 2008.
50. Bedotto RA. Biomechanical assessment and treatment in lower extremity prosthetics and orthotics: a clinical perspective. *Phys Med Rehabil Clin N Am* 2006; 17: 203-243.
51. Nevo I, Slonim-Nevo V. The myth of evidence-based practice: towards evidence-informed practice. *Brit J Soc Work* 2011; 41: 1176-1197.

7

General discussion

In this innovation and implementation project we explored potential solutions to reduce the research-practice gap, taking the case of prosthetic rehabilitation as the object of study. The aim of this thesis was twofold: (1) to improve a prosthetic rehabilitation programme with scientific knowledge from 'within' a local setting and (2) to explore theoretical notions, methodological requirements and implementation conditions of a more sociological way of *thinking* and *doing* research.

An important motive behind this project was the notion that innovation and implementation research should be conducted *with* and *for* people rather than *on* people. This explains the methodological choice of participatory action research. An important distinction from regular research is that participatory research must result in action. This was in line with our aim to bring about change in the prosthetic rehabilitation team treating patients with lower-limb amputation (LLA). Rather than gathering knowledge to understand phenomena or proving programme's effectiveness, this study was about co-creating knowledge for action.^{1,2} This implied that we had to deal with aspects such as control and power. In other words, the more participatory a research project is, the more there is movement towards handing over control to and developing ownership of those whom it concerns.¹

This approach to co-creating knowledge and putting it into action in genuine partnership with rehabilitation professionals and their patients led to a tailored self-management intervention for prosthetic rehabilitation, which took written form in a manual for professionals. It also led to the shared ownership of this intervention by the members of the local multidisciplinary prosthetic team (Chapter 5). The self-management intervention consists of two parts: (1) a physical training, in which patients actively learn to deal with the essential components in functioning with a prosthesis, and (2) a psychosocial training, in which patients learn to cope with possible post-discharge problems. Both parts of the intervention rely on a problem-solving approach and are now structurally implemented in the daily practice of the local prosthetic setting.

In addition to the concrete products that are of value to rehabilitation professionals, this thesis also addresses, on a more abstract level, theoretical, methodological and implementation issues that are of interest to researchers who wish to improve rehabilitation care. Throughout this thesis there are many examples of how our sociologically informed conception of science influenced the way in which we perceived and conducted the innovation and implementation research. In this general discussion, I will consider the implications of the lessons learned in this case study. How should we consider the role of theory? What does engaged scholarship entail in this context? Which methodologies appear to be useful for what purposes? and last but not least, What does such a way of improving rehabilitation programmes mean for the role and skills of the researcher? How, after this study, can we address these questions and move on?

The complex role of theory in innovation and implementation research

This case study on prosthetic rehabilitation first of all made clear that the role of theory in innovation and implementation research is rather complex. From theory-driven programme evaluators,^{3,4} I learned to value the importance of analysing and specifying the content and assumed working mechanisms of treatment programmes in close collaboration with rehabilitation professionals and their patients.⁵⁻⁷ The specification of treatment theory in this study indicated that the local prosthetic rehabilitation team used a wealth of biomedical and biomechanical theories in their prosthetic training. However, at the same time, they experienced a lack of knowledge on learning theories that might assist them in teaching their patients to become active learners (Chapter 2). Indeed, the first thing that complicates the role of theory in improving rehabilitation care is that biomedical *and* psychosocial principles and practices *co-constitute* treatment theory in rehabilitation programmes.⁶

Programme evaluators also distinguish theories of the nature of the problem (dysfunction theory) from theories about the solution to the problem (treatment theory).^{6,8,9} This analytical distinction helped us to identify the lack of focus on treatment theory in the research literature on prosthetic rehabilitation (Chapter 2) - an omission that definitely deserves more attention. This omission urged us to explore a broader area of 'treatment theories' in the field of motor and social learning. Learning theories on task- and context-specific training and self-management education (SME) appeared to be promising in this respect. They offered solution directions with regard to the carry-over problem and the related feared decline post-discharge. How then should we integrate the theoretical principles and related practices concerning task- and context-specific training and SME into the biomedical and biomechanical body of knowledge on prosthetic rehabilitation?

Different conceptual frameworks developed for describing theory and putting theory into action were used in this project. The theory-driven framework constructed to work on treatment theory has proven to be very useful in showing how theoretical principles play an informative role in treatment programmes by elaborating on the treatment content.^{5,7,10} In this thesis it was useful for exploring the treatment theory of the prosthetic training and in pinpointing the differences and similarities between rehabilitation medicine and self-management education (Chapter 4). This assisted in the integration of both approaches.

Fortunately, there is increasing awareness that the fine-tuning of methodological and theoretical issues leads to a better understanding of the rehabilitation process, and also provides an opportunity to improve knowledge implementation and treatment.^{6,10} The breadth of rehabilitation treatments requires that many different theoretical principles be incorporated into the design and evaluation of rehabilitation programmes.¹⁰ A recent development within

rehabilitation medicine comprises a specification of this theory-driven conceptual framework. There is a renewed emphasis on the distinction between two different theories: treatment theory and enablement theory in rehabilitation,¹⁰ a distinction that appears to be quite similar to the distinction between action and conceptual theory in theory-driven programme evaluation.⁴ Within the context of rehabilitation medicine, treatment theory defines and links the target of the treatment, the ingredients that produce change in the target and the hypothesized mechanism of action.¹⁰ Enablement theory specifies how the change in the target will influence other levels of functioning within individuals.¹⁰ The distinction of these theories is part of the development of a rehabilitation treatment taxonomy that can serve as a guide for theory-driven evaluation research.^{10,11} Our goal, however, was to put the theory into action.

Thus, after specifying treatment theories in prosthetic rehabilitation and integrating useful principles and practices from motor and social learning theories into the prosthetic rehabilitation programme with the help of the conceptual framework of programme theorists, we used the Knowledge-To-Action (KTA) framework to put the 'new' knowledge into action. Thus, there are different biomedical and psychosocial theories that co-constitute rehabilitation programmes, and there are different conceptual frameworks that assist researchers in describing and improving rehabilitation programmes, as well as putting them into action. These frameworks, in their turn, are guided by theories about how evaluation, innovation and implementation research ought to be done. The action cycle of the KTA framework, for example, is largely informed by planned action theories, which assist implementers in controlling key variables that increase (facilitators) or decrease (barriers) the likelihood of the occurrence of the intended change.^{12,13}

To make things even more complex, there are also different theories of science that implicitly inform the way in which evaluation, innovation and implementation should be conducted. Each notion of science, in fact, suggests a different way of innovating rehabilitation practice. A positivist conception of science prevails, for example, in EBM, in that it considers the evidence produced in clinical trials superior to other forms of knowledge.^{12,14} In EBM, researchers must strictly follow the methodological procedures in order to give the facts that they produce the credence of being evidence-based. If EBM holds that rigorous use of methodological procedures may rule out subjectivity and arbitrariness, then researchers may believe that a coherent evidence-based practice will be developed if they are able to master the methodological problems. Implementation research is then considered as a matter of applying evidence-based guidelines in local practices and investigating the compliance of professionals to the guidelines. Programme theorists in their turn, attempt to integrate positivist notions (detached researcher) with naturalistic notions of science (involved researcher), and thereby attempt to balance internal and external validity issues. That is why they advocate the integration of the scientific and stakeholder perspectives.

However, if we take science as a practice in itself, and research designs, measuring instruments and scientific principles and definitions as mutually shaping the facts produced, then we have to be aware of the local specificities of both research and clinical knowledge practices. Such a sociological way of conceiving what sciences are and do, encouraged us to use the theory-driven and KTA frameworks in a more impartial and disinterested way - that is, by co-creating new knowledge arising from the interaction between researchers and other stakeholders.¹²

The role of engaged scholars

Engaged scholarship with professionals of the multidisciplinary team and patients with LLA is an important characteristic of this innovation and implementation project. Programme theorists emphasize the importance of involving stakeholders (such as professionals and their patients) from the very beginning of the evaluation process to ensure that the design of the evaluation trial is tailored to the goals and needs of those who use the treatment in practice.⁴ They argue that this may help to preserve treatment integrity in the conduct of evaluation research; that is, the degree to which the treatment is implemented in evaluation research as intended. If the practitioners do not adhere to the treatment protocol, for example because it does not fit existing routines and habits of the team, researchers will measure something different than intended. Moreover, this will also make implementation issues less harrowing later on.

Within KTA projects it is also strongly advised to start with all of the relevant stakeholders involved and work in genuine partnership on the implementation of research knowledge.¹⁵ Therefore, these KTA scholars argue that engaged scholarship is not only important from the very beginning of the evaluation research, but also later on when the evidence is to be implemented in local settings. KTA experts increasingly emphasize the importance of bidirectional learning within the knowledge translation process, although how the partnership and bidirectional learning process are given content, again varies depending on the conception of science to which researchers adhere. Conventional KTA experts adhering to a positivist conception of science may assume that it is their task to intentionally and logically plan and put the evidence into action. In other words, the conventional KTA expert has a certain interest in the application of evidence in clinical settings. KTA experts therefore facilitate the use of existing knowledge by developing tools such as clinical practice guidelines and checklists based on review, synthesis and repackaging of pre-existing scientific knowledge. Such a way of putting knowledge into action underrepresents the situatedness of knowledge, or in other words, it implies universally true evidence that is independent of the context, for example, the setting or target group. Acknowledging that research knowledge is a practice in its own right, means that the KTA researcher should be open-minded and disinterested, which may imply that they deviate in a purposeful manner from

evidence-based guidelines, as these do not fit the needs and characteristics of the professionals and their target group in the local setting.

In this thesis, the knowledge creation and action cycle entailed a 'more' bidirectional way of putting knowledge into action. The research knowledge of the researchers and the practical contextual knowledge of professionals and their patients mutually informed each other in the knowledge-creation funnel, and new knowledge arose from their interaction.¹² We also could have started by directly searching for evidence in the scientific literature in response to the problem identified by the professionals (a possible decline in outcome after discharge) and then might have attempted to put this into action in a purposeful way. However, we chose to approach the knowledge translation process in a different way; that is, we detailed with the professionals the problem experienced. This led to the professionals feeling that they were being taken seriously in relation to the problems they had to face and they were eager to contribute to the solution with their own practical and contextual knowledge. This was needed, as the research knowledge to be applied stemmed from interventions intended for other target groups and for other settings. Thus, the situatedness of the research knowledge made it necessary to integrate the knowledge of the professionals with the research knowledge during knowledge creation. Accordingly, we not only used their knowledge, but co-created new knowledge with them, in bringing the self-management principles and practices into action in the context of prosthetic rehabilitation. This genuine collaboration throughout the entire KTA project meant that the intervention developed not only fit the setting but was also owned by those in it.

Collaboration with patients provided numerous examples of possible problems that patients face after discharge (Chapter 3). These experiences and the practical knowledge of the patients also served as a knowledge source for specification of the content of the self-management intervention. Feedback from patients on the self-management intervention in the pilot study gave us valuable information on their satisfaction with the interventions used and the conditional aspects. The active interaction between the researcher and the professionals influenced the learning process and self-reflective capacity of both. The involvement of all stakeholders in the cyclic and interactive translation process meant that they could understand and build upon the knowledge practices in which they participated, which served as a catalyst for this innovation. The engaged scholarship led to sincere and driven professionals who incorporated the patients' lived experiences.

The role of methodology

The use of several, often combined research methods, each with its own strengths and weaknesses, was exemplary for the research in this case study. In contrast to quantitative research methodology based on a positivist conception of science commonly used within EBM,¹⁶ we often used qualitative research methodology guided by a sociologically informed interpretive conception of science (Chapters 2 and 5). The methodology was sometimes influenced by a phenomenological approach- giving voice to the often overlooked lived experiences of professionals and patients- and sometimes inspired by an anthropological approach- exploring, articulating and building on knowledge that is available within rehabilitation practice.¹⁷

Furthermore, we used a combination of qualitative and quantitative research methodologies within one study to gain insight into the complexity of the functioning and participation of patients with LLA (Chapter 3). Such a mixed methods design builds on the different strengths of both qualitative and quantitative research methodology and thereby attempts to minimize the weaknesses of these approaches.^{4,18} This mixed method design enabled us to integrate the patient perspective in the follow-up study. In addition to measurements that were conducted *on* the patients, such as the performance tests, we also carried out interviews *with* the patients, to articulate their experiences and problems in dealing with a life with a prosthesis and LLA. The integration of findings gave us insight into the distinctive fluctuations between the different aspects of functioning and participation, compared to stability and improvement in outcomes from previous follow-up studies in prosthetic rehabilitation (Chapter 3).

To pinpoint the added value of SME for physical rehabilitation medicine (PRM) we detailed similarities and differences in treatment goals, treatment ingredients, underlying theories and the implementation environments of both knowledge practices. Overall, this comparative text analysis revealed a relative neglect of social theory in PRM, with the latter primarily focused on motor learning, disabling conditions, functional recovery and treatment goals in clinical settings, rather than on social learning, the unpredictable course of illness, self-efficacy and life goals in community settings. Thus, this detailed analysis taught us that there is also much to learn from social theory, particularly when the aim is to bring rehabilitation closer to patients' own living environments. More focus on life goals and problem-solving skills, using the expertise of peers, teaching patients when to grasp the baton of responsibility and when to hand it over to others, are a few examples of how self-management could be given a considered place in PRM. In the translation of this new knowledge into the field of prosthetic rehabilitation we learned that generic self-management principles and practices, such as teaching patients problem-solving skills, needed to be given amputation-specific content, for example, in terms of prosthetic fitting, physical complications and housing adaptations.

Our sociologically informed conception of science meant that the activities chosen in the distinct phases of the KTA framework deviated from many of the proposed EBM activities that are attached to these labels.¹⁹ Placing the KTA framework alongside a more engaged approach implies the need to (a) explore and articulate the stakeholders' perspectives, (b) integrate their practical and contextual knowledge into the available research knowledge, (c) co-create the intervention to be implemented and (d) integrate the adaptations made by professionals during the pilot implementation, while ensuring that the active ingredients remain the same. Tools that could support these actions derive from principles and practices found in change management theories, such as system-thinking and collaborative sense-making. Tools from the theory-driven evaluation perspective helped to articulate stakeholder perspectives and identifying generic principles and practices.

The multifaceted role of the researcher

The use of several methodologies and different conceptual frameworks, as well as a conception of science that considers evidence-based knowledge which is produced in research settings and practical- and contextual knowledge of stakeholders in local settings, as distinct but equally valued knowledge practices, also demands a multifaceted role of the researcher. Rather than a researcher who focuses on the rigour of a clinical study, banning all disturbing elements that could potentially endanger the validity of the study and therewith the evidence-base, the role of the researcher in an innovation and implementation project should be characterized by flexibility, open-mindedness and curiosity, being detached and connected at the same time, and knowing how to detail and compare relevant knowledge practices with the many methodologies available.

Basically, such a researcher must have conceptual analytic knowledge and skills at his or her disposal to be able to translate and transform theoretical principles and related practices from one implementation environment to another. One reviewer found it difficult to recognize the role of the innovation and implementation expert as a researcher. With respect to Chapter 5, he *'struggled in understanding the selection of the term "researcher" to identify the person who helped integrate the self-management process into the clinical setting.'* He continued, stating that *'the person seemed much more like an "educator", "trainer", "facilitator" or "translator" than a "researcher."* In order to get the manuscript published, and to prevent possible confusion by other readers, we changed the term 'researcher' to 'KTA expert'. The reviewer did a good job in distinguishing these different roles of the innovation researcher, but appeared to be unaware of the multiple research activities that came with 'simply' facilitating and translating research knowledge into a local setting: how the research knowledge was identified and, additionally, specified in generic principles and practices before it was integrated with the articulated

knowledge of the professionals and the patients with LLA in order to address the lacuna that was explored in the local setting.

The remark of the reviewer reflects the rather conventional and one-sided way scholars may consider the role of a researcher in knowledge translation projects. Perhaps it is not that strange that we often faced reviewers who had difficulties in understanding our research approach, which often made it a challenge to publish our articles. For a long time, the prevailing focus has been on EBM in healthcare, which has influenced the targeted scope of researchers and professionals. The education of researchers in rehabilitation medicine should contribute to widening that scope by teaching students science theory, the importance of specifying treatment theory in evaluation research on rehabilitation programmes, the different theoretical notions and related approaches behind qualitative research (such as grounded theory, phenomenology and discourse analysis) and behind knowledge translation and implementation research. The focus should not only be on the education of researchers, but also on the education of professionals in healthcare. In their education it should be made clear how they can actively contribute to innovation projects. They should be aware of their implicit knowledge and the importance of sharing that knowledge, the necessity of actively reflecting on their expertise and not taking the evidence produced for granted. Rather than teaching them how to determine whether their treatments are evidence-based, students should be taught to be knowledgeable about all kinds of research studies which can inform their work. They should be able to critically reflect on their interventions and on their own role in healthcare.

A final reflection

This thesis represents a first exploration of the issue how to improve rehabilitation practice in a systematic and critical manner. The strengths and limitations of each of the studies that contributed to the end result are described in the several chapters. It should be emphasized that we do not claim that the way in which we conducted this improvement project is the best way for every innovation and implementation situation. On the contrary, following in the footsteps of theory-driven programme evaluators, I argue that the methods to be used in improving rehabilitation programmes depend on the problems identified, the goals to be reached, the maturity and complexity of the programme, the environment in which it has to be implemented, the researchers' and stakeholders' values and the political and organizational context of the programme.⁴

The same should be said regarding the development of the self-management intervention. Situated choices were made in relation to the content of this specific self-management intervention. The intervention is therefore not a ready-made final product. Instead we must continuously refine

the intervention, ensuring that it is offered in a customized and more personalized manner. In a follow-up project, 'Self-management in co-creation', we are now exploring how the self-management principles and practices can be translated to the rehabilitation programmes for other groups of patients, such as patients with heart conditions, rheumatic diseases, or neurological conditions. In close collaboration with members of other multidisciplinary rehabilitation teams, disease-specific and context-specific changes are made, while the essential ingredients remain the same. Further collaboration with the health sciences to assist professionals to improve their communication techniques and better activate their patients is a next step in our effort to support the self-management of patients in rehabilitation practice. We are aware of the constant developments and new insights concerning the concept of self-management itself. This means that we must continue to ask what this new knowledge entails for the intervention developed.

To conclude this thesis, there is one final issue that I would like to discuss: the commonly used metaphor of 'bridging science and clinical practice'. I argue that this metaphor is no longer tenable now that we have realized that (1) the difficulties that are experienced in linking science and clinical practice stem from a knowledge production problem rather than a knowledge transfer problem, and (2) clinical practice and science are two different knowledge practices within the same world, rather than two different worlds divided by a gap. Therefore, we must move beyond the old metaphor. There is nothing that I would rather do than finish this thesis with a new metaphor to replace the old, but I have not yet found one that I feel reflects the complexity of the relationship between research and practice as sketched in this thesis. Since it is good to know your own strengths and limitations, I leave that challenge to others. Meanwhile I will continue to work on transforming research and rehabilitation knowledge practices and thereby hopefully contribute to the improvement of healthcare.

REFERENCES

1. Cornwall A, Jewkes R. What is participatory research? *Soc Sci Med* 1995; 41(12): 1667-1676.
2. Scott RA, Shore AR. *Why sociology does not apply: a study of the use of sociology in public planning*. New York, Elsevier, 1979.
3. Lipsey MW. Theory as method: small theories of treatments. In Sechrest L, Perrin E, Bunker J eds. *Conference proceedings: research methodology: strengthening causal interpretations of non-experimental data*. Rockville US, 1990: 33-52.
4. Chen H-T. *Theory driven evaluations*. London: SAGA Publications, 1990.
5. Lettinga AT, Siemonsma PC, van Veen M. Entwinement of theory and practice in physiotherapy: a comparative analysis of two approaches to hemiplegia in physiotherapy. *Physiotherapy* 1999; 85(9): 476- 490.
6. Lettinga AT, van Twillert S, Poels BJJ, Postema K. Distinguishing theories of dysfunction, treatment and care. Reflections on 'Describing rehabilitation interventions'. *Clin Rehabil* 2006; 20: 369-374.
7. Siemonsma PC, Schröder CD, Dekker JHM, Lettinga AT. The benefits of theory for clinical practice: cognitive treatment for chronic low back pain patients as an illustrative example. *Disabil Rehabil* 2008; 30: 1309-1317.
8. Kazdin AE. A model for developing effective treatments: progression and interplay of theory, research, and practice. *J Clin Child Psychol* 1997; 26: 114-129.
9. Kazdin AE. Current (lack of) status of theory in child and adolescent psychotherapy research. *J Clin Child Psychol* 1999; 28: 533-543.
10. Whyte J. Contributions of treatment theory and enablement theory to rehabilitation research and practice. *Arch Phys Med Rehabil* 2014, 95 (1 Suppl 1): S17-S23.
11. Dijkers MP (ed.) Towards a taxonomy of rehabilitation treatment. *Arch Phys Med Rehabil* 2014, 95 (1 Suppl 1): A1-A10, S1-94.
12. Kitto SC, Sargeant J, Reves S, Silver I. Towards a sociology of knowledge translation: the importance of being dis-interested in knowledge translation. *Adv in Health Sci Educ* 2012; 17: 289-299.
13. Graham ID, Logan J, Harrison MB, et al. Lost in knowledge translation: time for a map? *J Contin Educ Health Prof* 2006; 26: 13-24.
14. Lettinga AT, Mol A. Clinical specificity and the non-generalities of science: on innovation strategies in neurological physical therapy. *Theo Med Bioeth* 1999; 20: 517-535.
15. Bowen SJ, Graham ID. From knowledge translation to engaged scholarship: promoting research relevance and utilization. *Arch Phys Med Rehabil* 2013; 94: S3-S8.
16. Hennink M, Hutter I, Bailey A. *Qualitative research methods*. 1st ed. London: SAGE; 2011.
17. Struhkamp R, Mol A, Swierstra T. Dealing with independence: doctoring in physical rehabilitation practice. *Sci Technol Human Values* 2009; 34(1): 55-76.
18. Johnson RB, Onwuegbuzie AJ. Mixed methods research: a research paradigm whose time has come. *Educ Res* 2004; 33: 14-26.
19. <http://ktclearinghouse.ca/knowledgebase/knowledgetoaction>

Summary

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SUMMARY

This innovation project started with a request from a local prosthetic rehabilitation team to update their treatment programme with new scientific insights. This request was primarily based on their concern that skills learned by patients in the clinical setting were not preserved after discharge from the rehabilitation centre. This seemingly simple request resulted into a complex enquiry. The key question here is: “how to link new scientific insights with rehabilitation practice, in this case a prosthetic rehabilitation setting?” More specifically: what scientific insights are in potential relevant for such a setting, how to translate these insights in useful tools for rehabilitation professionals, how to assist professionals in putting them into action, and indeed what kind of research methodology is therefore useful? These were the questions that came to the fore. Many knowledge translation projects have tried to bring research knowledge into action, and faced several difficulties along the way. These difficulties are often presented in the metaphor of ‘the research-practice gap’. The difficulties experienced make that researchers and professionals point towards each other for not being able or willing to overcome this gap.

In this thesis we explored alternative solutions directions in linking science and rehabilitation. This thesis draws on a sociologically informed conception of science that considers both clinical and scientific knowledge, as different knowledge *practices* that are of equal value for improvement of local settings. Other sources of inspiration were change management principles and practices, participatory action research, theory-driven programme evaluation and integrated knowledge-to-action translation research. So this thesis can be read on two levels: (1) on a practical level, addressing the question “How to improve a prosthetic rehabilitation programme with scientific knowledge from ‘within’ a local setting?” and (2) on a research level, addressing the question “What are the implications of a more sociological way of thinking and doing innovation and implementation research?”

After the introduction, in Chapter 2, the first steps in this innovation project are described. Participatory research methodology helped us to specify the problem felt by the prosthetic rehabilitation team: they feared a decline in outcome of patients with lower limb amputation (LLA) after discharge from the rehabilitation centre. Triangulation of data derived from analysis of treatment documents, individual and focus group interviews with professionals and patients, and treatment observations, revealed a critical issue. The carry-over problem had to do with the struggle of professionals to encourage patients to be active learners, which in turn appeared to be related to the biomedically and biomechanically underpinned treatment programme. Learning theories that encourage patients to actively participate in their training were barely integrated in the treatment programme.

A literature study revealed the value of self-management education for patients with chronic diseases and that of task- and context-specific training for patients with neurological conditions. Both approaches appealed on the problem-solving capacities of patients; the first to provide patients with the psychological skills to deal with the consequences of the condition (self-management education) and the second to teach them motor skills (task- and context-specific training). Therefore their theoretical principles were transferred and translated to the prosthetic rehabilitation programme, and related practices specified with amputation-specific information gathered by focus group interviews with professionals and patients. This resulted in two concept modules: a psycho educative training in which patients actively learn to cope with post-discharge problems, and a circuit training, in which patients actively learn to deal with their prosthesis. The participatory collaboration between the professionals and the research team made that all stakeholders were sincere and driven to work on the implementation of the newly developed treatment programme.

To examine if we could objectify the feared decline in outcome of patients with LLA after discharge from prosthetic rehabilitation, we conducted as a second step a concurrent mixed methods study, described in Chapter 3. More specifically, research knowledge on the functional performance, participation and autonomy of 13 patients with LLA, and the barriers and facilitators affecting these outcomes, was collected at discharge of the rehabilitation centre (T0) and 3 (T1) and 6 months (T2) later. Functional performance was measured using the Two-Minute Walk Test and L test, and participation and autonomy using the Impact on Participation and Autonomy questionnaire. Barriers and facilitators were identified in semi-structured interviews. After discharge, 9 of 13 patients declined in functional performance. Main limitations in participation and autonomy were observed in the "family role" and "autonomy outdoors" domains, with scores of fair to poor. Many diverse factors were found to affect functional performance and participation after discharge, acting sometimes as barrier for some individuals and as facilitators for others. Changes in outcomes on functional performance were not always in line with those observed in participation and autonomy. The presence of barriers and facilitators also fluctuated over time and no collective time patterns were found. We concluded that patients should be educated about the distinctive fluctuations after discharge and the barriers and facilitators in the environmental, personal and medical contexts they could encounter post-discharge. Considering the great diversity in individual reactions to perceived barriers we suggested to teach patients a generic approach to dealing with problematic situations, as seen in self-management education.

To be able to integrate self-management into prosthetic rehabilitation we gained more insight into the differences and similarities between physical rehabilitation medicine (PRM) and self-management education (SME). Chapter 4 describes a comparative text analysis to trace the

differences between and similarities in these knowledge practices. Inspired by discourse analysis, texts on both approaches were contrasted as having vocabularies of their own, expressed under certain material conditions. Four issues arose. First, the difference in illness trajectories between a sudden transition from an able to disabled person after a disease with acute onset in PRM and the indefinite and unpredictable course of a chronic disease in SME. Second, the different material and social set-up of clinical practice delivered by a multidisciplinary team in rehabilitation centres and self-management education originally delivered by peers in local community settings. Third, the influence of these different implementation environments on goal-setting, that is the use of treatment goals within rehabilitation practices versus life goals within self-management education. And fourth, the relative neglect of social theory in PRM compared to SME. This analysis provided us with knowledge on how to give SME a considered place in rehabilitation. Rehabilitation practice could for example change the focus from treatment to life-goals during the rehabilitation process, integrate training of problem-solving skills in real life settings, use the expertise of peers, and teach patients when to grasp the baton of responsibility and when to hand it over to others.

Chapter 5 describes an integrated knowledge-to-action (KTA) project in which the knowledge gathered with participatory action research, mixed methods research, and discourse analysis was brought together, in order to specify and implement the self-management intervention in prosthetic rehabilitation. The scope of this chapter is limited to the development and implementation of the motor learning module of the self-management intervention: the circuit training. Our sociologically informed conception of science influenced the activities chosen in the phases of the KTA framework. The knowledge creation process resulted in a detailed description of the principles and practices described in scientific literature on self-management education and task- and context-specific training. Adapting the knowledge to the local context consisted of two phases: tailoring of principles and practices to the target group (ie, patients with LLA) with help of the professionals' knowledge, and a more generic translation of the principles and practices into concrete treatment instructions, for example on how to give content to variation, or incorporate techniques for enhancing self-efficacy and challenge problem-solving of patients with instructions and feedback. Possible barriers to knowledge use were identified on 3 levels: the organizational, professional and target group level. To tackle these barriers several activities were selected, tailored and carried out in close collaboration with professionals, staff and delegates of a national association for patients with an amputation. During a pilot implementation of the intervention, we gained insight on how professionals brought the knowledge into practice and which adaptations were needed. In a focus group with the professionals and manager, the intervention and the KTA process were evaluated. Patients reflected on the training in individual

interviews. In this iterative and interactive process the intervention was continuously refined and evaluated in practice, which led to a training that was optimized for the local context. The genuine partnership between the professionals and researchers led to a shared ownership of the intervention.

Chapter 6 discusses an overall theme that came to the fore during this innovation project, namely the complexity inherent in establishing evidence-based practice (EBP) in a prosthetic rehabilitation team. We illustrated this with help of the case of prosthetic prescription for elderly patients with a transfemoral amputation due to dysvascular disorders. The discussion draws on empirical material from individual and focus-group interviews with members of the prosthetic team, information on technological advancements presented on websites of the orthopaedic industry, guidelines and scientific literature on prosthetic rehabilitation and literature on the research-practice gap. The discussion indicated that a prosthetic rehabilitation team needs to deal with lack of evidence, contradictory results, various classification systems, diverging interests of different stakeholders and many modifying factors, and all of this in a continuous technological changing environment. To reduce the complexity in working in a evidence based manner we suggested that researchers should integrate research designs with different strengths but not sharing the same biases. That may help in conducting relevant research with this diagnose group in which multimorbidity and multifaceted disability are common. Also articulating clinical knowledge, patients' needs and values in a systematic way, helps in providing depth, nuance and context for evidence based practice issues in prosthetic rehabilitation. We emphasized that it is a shared responsibility of professionals and researchers to deal with the complexity of EBP in prosthetic rehabilitation. We therefore suggested to replace *based* in EBP for *informed*. In evidence informed practice (EIP) professionals are encouraged to be knowledgeable about findings coming from all types of scientific studies and researchers are urged to help translate these findings in a integrative manner.

In the general discussion in Chapter 7 we reflect upon the way we conducted our innovation research in a sociologically informed manner, and the lessons we learned along the way. First, it is discussed how the role of theory in innovation and implementation research is a complex one. It is explicated that there are different kinds of theories: biomedical and psychosocial theories that inform the content and implementation context of rehabilitation programmes, theories on how to conduct evaluation, innovation and implementation research in rehabilitation practice, theories that help in describing knowledge and putting knowledge into action, and theories on the nature and status of scientific results. This means that innovation researchers should have conceptual analytical skills to work with these different theories on different levels, and understand the impact of the theories on the work to be done. Subsequently, the importance and

end results of engaged partnership with professionals of the multidisciplinary team and patients with LLA is discussed. The involvement of all stakeholders in a cyclic and interactive translation process meant that they could understand and build upon the knowledge practices in which they participated, which served as a catalyst for the innovation. Thereafter, it is discussed how the use of several, often combined research methods, each with its own strengths and weaknesses, was exemplary for the research in this case study. Often, we used qualitative research methodology, sometimes influenced by a phenomenological approach, or inspired by an participative approach or by discourse analysis. Placing the KTA framework alongside a more engaged procedure implied the need to (a) explore and articulate the stakeholders perspective, (b) integrate their practical and contextual knowledge into the available research knowledge, (c) co-create the intervention to be implemented and (d) integrate the adaptations made by the professionals while ensuring that the active ingredients stay the same.

Finally, we sketch how the assumptions and methodologies used in such an innovation project impact the role of the innovation researcher. Its role is characterized by flexibility, open-mindedness and curiosity, being detached and connected at the same time, and knowing how to detail and compare relevant knowledge practices with the many methodologies available. We emphasize that the methods to be used in improving rehabilitation programmes depend on problems identified, goals to be reached, the maturity and complexity of the programme, the environment in which it has to be implemented, the researchers' and stakeholders values and the political and organizational context of the programme. The self-management intervention under study in this innovation project is tailored specifically to the local setting: situated and time-related choices were made in relation to the content of the self-management programme. Though other rehabilitation centres can profit from the knowledge, products and learning experiences that were generated in this innovation project.

This thesis made me realize that the metaphor of 'bridging the gap between scientific research and clinical practice' is actually no longer tenable. It became clear to me that the difficulties that are experienced in bringing research knowledge into action in rehabilitation practice is rather a knowledge production problem than a knowledge transfer problem. When innovation researchers link different kinds of knowledge (research, practical and contextual knowledge) on an analytical impartial manner, it is no longer knowledge that is transferred from the world of research to the world of rehabilitation. Indeed, these different kinds of knowledge are part of the same (rehabilitation) world, but are given content by their own material and social set-up. So, there are no two different worlds divided by a gap. Thus, let's move beyond this old metaphor and work on linking research and rehabilitation knowledge practices in order to contribute to the improvement of both practices.

SAMENVATTING

Dit innovatieproject startte naar aanleiding van het verzoek van ons eigen amputatie-revalidatieteam om hun behandelprogramma te vernieuwen met recente wetenschappelijke inzichten. Ze deden dit verzoek vooral omdat ze bezorgd waren dat hun patiënten de vaardigheden die ze geleerd hadden in het revalidatiecentrum, na ontslag niet konden behouden in de thuissituatie. Dit ogenschijnlijk simpele verzoek is in feite een complex vraagstuk: hoe integreer je nieuwe wetenschappelijke inzichten in de revalidatiepraktijk, in dit geval de amputatierevalidatie? Meer specifiek: Welke wetenschappelijke inzichten zijn in potentie relevant voor deze setting, hoe vertaal je deze inzichten in bruikbare handvatten voor revalidatieprofessionals, hoe help je deze professionals om de handvatten in de praktijk te brengen, en welke onderzoeksmethoden zijn hiervoor nuttig? Dat waren de vragen die tijdens dit project naar voren kwamen.

Het is lastig om een vertaalslag te maken tussen wetenschap en praktijk. Velen hebben dit geprobeerd en liepen daarbij vaak tegen verscheidene obstakels op. De metafoor van een kloof tussen wetenschap en praktijk wordt binnen deze context veel gebruikt. De ervaren moeilijkheden maakt dat onderzoekers en professionals elkaar de schuld geven niet bereid of kundig te zijn deze kloof te overbruggen.

In dit proefschrift onderzochten we een alternatieve manier om wetenschap en revalidatie met elkaar te verbinden. Dit proefschrift vertrekt daarbij vanuit een sociologische wetenschapsopvatting die beide, klinische en wetenschappelijke kennis, als kennis*praktijken* beschouwt. Ze verschillen van elkaar, maar zijn van gelijke waarde voor het verbeteren van een lokale setting. Andere inspiratiebronnen voor dit project zijn het verandermanagement, participatief actieonderzoek, theoriegestuurde programma-evaluatie en geïntegreerd 'knowledge-to-action'-onderzoek.

Dit proefschrift kan op twee manieren gelezen worden: (1) vanuit de praktische vraag: "Hoe kan je een amputatierevalidatieprogramma verbeteren met wetenschappelijke kennis binnen een lokale setting?" en (2) vanuit de theoretische vraag: "Wat zijn de implicaties voor het opzetten en uitvoeren van innovatie- en implementatie onderzoek met een sociologische insteek?"

Na de introductie, staan in hoofdstuk 2 de eerste stappen van dit innovatieproject. Met behulp van methodieken uit het participatief actieonderzoek lukte het ons het probleem van het revalidatieteam te specificeren: zij vreesden terugval in functioneren na ontslag bij patiënten met een beenamputatie. Door triangulatie van verschillende data - een analyse van de documenten over het behandelprogramma, individuele en focusgroep interviews met professionals en patiënten, en observaties van de behandeling - werd een cruciaal verbeterpunt zichtbaar. De gevreesde terugval in functioneren na ontslag konden we relateren aan de problemen die professionals ervaarden bij het activeren van hun patiënten. Dit bleek weer te maken hebben

met de biomedische en biomechanische theorieën waar het behandelprogramma voornamelijk op stelde. Leertheorieën die patiënten uitdagen om actief te participeren in de revalidatie waren namelijk nauwelijks geïntegreerd in de behandeling.

Een literatuurstudie liet ons vervolgens de meerwaarde zien van zelfmanagementeducatie voor patiënten met een chronische aandoening en die van de taak- en context-specifieke training voor patiënten met een neurologische aandoening. Beide interventies doen een beroep op de probleemoplossende vaardigheden van de patiënt: de eerste om psychologische vaardigheden aan te leren voor het omgaan met een aandoening (de zelfmanagementeducatie) en de tweede om motorische vaardigheden aan te leren (de taak- en context-specifieke training). Daarom werden de theoretische principes van deze interventies vertaald naar de amputatierevalidatie, en werden hun praktische toepassingen gespecificeerd met amputatiespecifieke informatie uit focusgroep interviews met professionals en patiënten. Dit cocreatie proces resulteerde in twee concept modules: een psycho-educatieve training, waarin patiënten actief leren omgaan met mogelijke problemen na ontslag, en een circuittraining, waarin patiënten actief leren handelen met de prothese. Door de participatieve samenwerking tussen de revalidatieprofessionals en het onderzoeksteam waren alle belanghebbenden oprecht gemotiveerd om het nieuw ontwikkelde programma te implementeren.

Om de gevreesde terugval in functioneren na ontslag bij de patiënten met een beenamputatie te objectiveren, voerden we als volgende stap een concurrent mixed methods studie uit, die beschreven staat in hoofdstuk 3. Meer specifiek, we verzamelden kwantitatieve en kwalitatieve data bij 13 patiënten met een beenamputatie bij het ontslag (T0) en 3 (T1) en 6 maanden (T2) later. De kwantitatieve gegevens over functioneren en participatie en autonomie kwamen voort uit resp. de twee minuten wandeltest en de L test, en de Impact op Participatie en Autonomie-vragenlijst. De kwalitatieve gegevens kwamen voort uit semistruktuurle interviews met de geïncludeerde patiënten over factoren die van invloed waren op deze uitkomsten.

Na ontslag, vielen 9 van de 13 patiënten terug in functioneren. We vonden de grootste beperkingen in participatie en autonomie in de domeinen 'familierol' en 'mobiliteit buitenshuis', met scores van redelijk tot laag. Vele verschillende factoren bleken van invloed op het functioneren en participeren na ontslag. Patiënten reageerden daar verschillend op. Eenzelfde factor, zoals hulp van naasten, werd door de één als faciliterend ervaren, en door een ander als belemmerend. Verder bleek het verloop in het functioneren niet altijd gelijk aan het verloop in participatie en autonomie. De beïnvloedende factoren fluctueerden ook over de tijd, waarbij we geen gemeenschappelijk tijdspatroom ontdekten. We concludeerden dat patiënten voorbereid moeten worden op dit wisselende verloop en op de factoren die een negatieve invloed kunnen hebben op hun functioneren en participeren. Gezien de grote diversiteit in reacties op de factoren, kozen we

voor een generieke aanpak, zoals we die kennen uit de zelfmanagementeducatie, om patiënten te leren omgaan met problematische situaties in het algemeen.

Om principes en strategieën van de zelfmanagementeducatie te kunnen integreren in de amputatierevalidatie brachten we verschillen en overeenkomsten tussen revalidatiegeneeskunde en zelfmanagementeducatie in kaart. Hoofdstuk 4 beschrijft de resultaten van de vergelijkende tekstanalyse gericht op het traceren van de verschillen en overeenkomsten in deze twee kennispraktijken. Geïnspireerd door de discourse-analyse contrasteerden we teksten over beide aanpakken, alsof ze een eigen unieke taal hadden die mede vorm kreeg door de specifieke materiële context waarbinnen de taal werd gebezigd. Vier thema's kwamen hieruit naar voren. Ten eerste, het verschil in ziekteverloop: de plotselinge overgang van een gezond persoon naar iemand die beperkingen ervaart na een acute aandoening in de revalidatiegeneeskunde, en de invloed van het vaak onzekere en onvoorspelbare verloop van een chronische aandoening op een persoon in de zelfmanagementeducatie. Ten tweede, het verschil in materiële en sociale setting: de revalidatiegeneeskunde die wordt aangeboden door een multidisciplinair team van professionals in een (poli)klinische behandelomgeving en de zelfmanagementeducatie die oorspronkelijk werd aangeboden door ervaringsdeskundigen in buurtcentra in de eigen leefomgeving. Ten derde, de invloed van deze twee verschillende implementatieomgevingen op het stellen van doelen bij beide aanpakken, resp. behandeldoelen in de revalidatiegeneeskunde versus levensdoelen in de zelfmanagementeducatie. En ten vierde, de onderbelichting van sociale theorie in de revalidatiegeneeskunde in vergelijking met de zelfmanagementeducatie. Deze analyse geeft ons inzicht in hoe zelfmanagement zo transparant mogelijk te integreren in de revalidatiegeneeskunde. De revalidatiegeneeskunde kan bijvoorbeeld gaandeweg het revalidatietraject de focus verschuiven van behandel- naar levensdoelen, probleemoplossende vaardigheden in hun trainingen integreren, de expertise van lotgenoten inzetten in de revalidatie, en patiënten aanleren hoe en wanneer hulpbronnen in te zetten als dat nodig blijkt.

Hoofdstuk 5 beschrijft de knowledge-to-action cyclus: het proces van kenniscreatie en het in praktijk brengen van deze kennis in een interactief en cyclisch proces. De kennis opgedaan met het participatief actieonderzoek, de mixed methods studie en de discourse-analyse brachten we nu bij elkaar om het zelfmanagementprogramma te specificeren en te implementeren. Dit hoofdstuk richt zich specifiek op de doorontwikkeling en implementatie van de motorische module; de circuittraining. Het kenniscreatie proces leverde gedetailleerde beschrijving van de principes en strategieën van zelfmanagementeducatie en taak- en context-specifieke training op. Het aanpassen van de kennis aan de lokale situatie bestond uit twee stappen. In de eerste stap zijn de principes en toepassingen op maat gemaakt voor patiënten met een beenamputatie met hulp van de kennis van de professionals. In de tweede stap vond een meer generieke vertaalslag

plaats van de principes en toepassingen in concrete behandelinstructies, bijvoorbeeld: hoe geef je inhoud aan variatie in de training, of hoe integreer je technieken om de zelfeffectiviteit van de patiënt te vergroten en hoe daag je probleemoplossende vaardigheden van de patiënt uit met behulp van instructies en feedback. Obstakels voor de implementatie van de training dienden zich op 3 verschillende niveaus aan: het organisatorische, professionele en doelgroepniveau. In nauwe samenwerking met professionals, staf en afgevaardigden van de patiëntenvereniging voor mensen met een beenamputatie verkenden we welke obstakels er waren en hoe die te ondervangen. Een proefimplementatie gaf inzicht in hoe professionals de kennis in de praktijk brachten en wat ze daarbij tegenkwamen. In een focusgroep met het behandelteam en de teammanager werd de training en het implementatieproces geëvalueerd. Patiënten reflecteerden op de training in individuele interviews. In dit stapsgewijze interactieve proces verfijnden we de training continu, wat leidde tot een training op maat gemaakt voor onze setting. Door dit cocreatieproces tussen de professionals en het onderzoeksteam is er gedeeld eigenaarschap van de training ontstaan, een training die nu deel uitmaakt van het reguliere amputatiebehandelprogramma.

Hoofdstuk 6 bediscussieert een overkoepelend thema dat naar voren kwam tijdens dit innovatieproject, namelijk de complexiteit van het realiseren van evidence-based handelen in de amputatierevalidatie. Een casus over het voorschrijven van een prothese voor de oudere patiënt met een transfemorale amputatie op basis van een dysvasculaire aandoening dient daarbij als illustratief voorbeeld. De discussie krijgt inhoud met data uit individuele en focusgroep interviews met professionals uit het team, informatie over technologische vooruitgang op sites van de orthopedische industrie, richtlijnen en wetenschappelijke literatuur over amputatierevalidatie en literatuur over de kloof tussen wetenschap en praktijk. De discussie gaat over professionals die in de dagelijkse praktijk kampen met gebrek aan wetenschappelijk bewijs, tegenstrijdige onderzoeksresultaten en verschillende classificatiesystemen, over uiteenlopende belangen van onderzoekers, patiënten en de prothese-industrie, en de vele andere fysieke en psychologische factoren mede van invloed op het voorschrijven, en dit alles in een tijd van continue technologische ontwikkelingen. Om de complexiteit van het evidence-based handelen te reduceren zouden onderzoekers meer moeten inzetten op het combineren en integreren van verschillende onderzoeksmethoden, waarbij ze juist de verschillende sterke kanten van de onderzoeksmethoden bijeen brengen en hun zwaktes helpen ondervangen. Dit biedt de mogelijkheid om relevant onderzoek te doen bij deze doelgroep waar multimorbiditeit en complexe problematiek zich veelvuldig voordoet. Daarbij hoort ook het systematisch in kaart brengen van de kennis van de professionals en de behoeften en waarden van patiënten, om zo diepgaander inzicht te verkrijgen en context te bieden voor de ervaren problemen in het evidence-based werken in de amputatierevalidatie. Het verhelpen van de complexiteit van EBP in de amputatierevalidatie is dus een gedeelde verantwoordelijkheid van zowel onderzoekers als van revalidatieprofessionals.

We eindigen met de suggestie om de term *based* in EBP te vervangen door *informed*. Het evidence-informed practice (EIP) stimuleert professionals om op de hoogte te zijn van resultaten uit allerlei soorten wetenschappelijke studies, en spoort onderzoekers aan om op een integratieve manier te helpen om deze bevindingen voor de praktijk te vertalen.

In de afsluitende discussie in hoofdstuk 7 reflecteren we op de manier waarop dit innovatieproject vorm heeft gekregen en de lessen die we daaruit leren. Allereerst bediscussiëren we de complexe rol van theorie in dit verhaal. Er zijn verschillende soorten theorieën; biomedische en psychosociale theorieën die verweven zijn met de inhoud en implementatieomgeving van revalidatiebehandelingen, theorieën over hoe je het beste onderzoek kan doen naar revalidatiebehandelingen, theorieën die helpen bij het beschrijven en bij het in de praktijk brengen van wetenschappelijke kennis en theorieën die gaan over de aard en status van wetenschappelijke resultaten. Dit betekent dat innovatieonderzoekers over conceptuele analytische vaardigheden moeten beschikken om deze verschillende theorieën te onderscheiden en te begrijpen welke impact ze hebben op hoe er wordt ontwikkeld, vernieuwd en geïmplementeerd in de revalidatie.

Vervolgens bediscussiëren we het belang en de meerwaarde van het cocreatieproces in innovatieonderzoek. In dit geval met het onderzoeksteam, de revalidatieprofessionals en de patiënten met een beenamputatie. Doordat alle belanghebbenden in een cyclisch en interactief proces zijn betrokken bij het innovatie- en implementatieproces kan iedereen van elkaar leren en voortbouwen op elkaars kennis en expertise. Dit werkt als een katalysator voor innovatie. Daarna blikken we terug op de verschillende, veelal gecombineerde onderzoeksmethoden, die we gebruikten, allen met hun eigen sterktes en zwaktes. Meestal waren het kwalitatieve onderzoeksmethoden, die elkaar versterkten, soms geïnspireerd door een fenomenologisch perspectief, dan weer aangevuld met een participatieve aanpak of door discourse-analytische inzichten. Het doorlopen van alle fasen van de 'knowledge-to-action'cyclus vanuit een betrokken samenwerking met de professionals en patiënten maakt het nodig (a) het stakeholdersperspectief te onderzoeken en articuleren, (b) praktische en contextuele kennis vanuit de lokale setting af te stemmen op de beschikbare wetenschappelijke kennis beschreven in de onderzoeksliteratuur, (c) de interventie te co-creëren en (d) aanpassingen van professionals te integreren, daarbij wakend dat de essentiële ingrediënten van de behandeling hetzelfde blijven.

Tenslotte zoomen we in op de impact van de door ons gebruikte opvattingen en onderzoeksmethoden, op de rol van de innovatieonderzoeker. Die rol kenmerkt zich door flexibiliteit, open staan voor verschillende inzichten en nieuwsgierigheid, onafhankelijk en verbonden zijn tegelijkertijd, en inzicht hebbende in welke beschikbare onderzoeksmethodieken waarvoor ingezet kunnen worden. We benadrukken dat methoden voor het verbeteren van

revalidatieprogramma's afhangen van de geïdentificeerde problemen, de te bereiken doelen, de volwaardigheid en complexiteit van het programma, de implementatieomgeving, de waarden van de onderzoekers en van belanghebbenden, en de politieke en organisatorische context van het programma. Het zelfmanagementprogramma dat ontwikkeld is binnen dit innovatieproject is op maat gemaakt voor de lokale setting: de keuzes ten aanzien van de inhoud zijn toegespitst op de geïdentificeerde lokale problemen en tijdspecifieke kennis. Toch kunnen ook andere revalidatiecentra die soortgelijke problemen tegenkomen voortbouwen op de kennis, producten en leerervaringen die in dit lokale innovatieproject zijn gegenereerd.

Dit promotieproject heeft me doen beseffen dat de metafoor van 'het overbruggen van de kloof tussen wetenschap en praktijk' niet langer volstaat. De problemen die zich voordoen bij het toepassen van wetenschappelijke kennis in de revalidatiepraktijk is meer een kennisproductieprobleem dan een kennistransferprobleem. Als innovatieonderzoekers verschillende soorten kennis (wetenschappelijke, praktijk en contextuele kennis) op een analytisch onpartijdige manier op elkaar weten te betrekken, dan betreft het geen kennis meer die verplaatst moet worden van de onderzoeks- naar de revalidatiewereld. Deze verschillende soorten kennis maken deel uit van één en dezelfde (revalidatie-) wereld, alleen krijgen ze op een andere manier inhoud door de materiële en sociale context waar ze deel vanuit maken. Het zijn dus niet twee verschillende werelden die door een kloof gescheiden zijn. Dus laten we deze oude metafoor verlaten en werken aan het verbinden van onderzoeks- en revalidatie-kennispraktijken om daarmee een bijdrage te leveren aan het verbeteren van beide praktijken.

DANKWOORD

Waarom moeilijk doen, als het samen kan. Loesje

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En dan de grootste verandering die plaats vond in mijn eigen leven gedurende dit innovatieproject: de komst van Koos en Casper. Koos, ik kan niet anders zeggen dan dat mijn leven al erg goed en mooi was voordat ik je leerde kennen, maar de wereld is nog mooier geworden met jou erbij. Dank dat je er bent, me steunt, me laat lachen en me lief hebt. Dat is wat werkelijk telt! En lieve Casper, zo klein als je nog bent, bedankt voor al het mooie dat jij geeft!

CURRICULUM VITAE

Sacha van Twillert werd geboren op 13 augustus 1975 te Hengelo (O). In 1993 behaalde zij haar VWO diploma aan het Ichthus College in Enschede. Ze studeerde af aan de opleiding Fysiotherapie aan de Hanzehogeschool in Groningen in 1997. Na haar opleiding fysiotherapie deed ze parttime invalwerkzaamheden in het Centrum voor Revalidatie-UMCG (CvR), waar ze voornamelijk werkte met mensen met een neurologische aandoening. Tegelijkertijd startte ze haar opleiding Bewegingswetenschappen aan de Rijksuniversiteit Groningen. Met haar scriptie "Hoe verder met pijn? Een inhoudsanalyse van een behandelprogramma voor patiënten met chronische rugklachten" rondde ze in 2001 deze opleiding af. Ondertussen kreeg ze in 2000 een vaste aanstelling als fysiotherapeut in het pijnteam van het revalidatiecentrum.

In 2007 stopte zij met haar werk als fysiotherapeut en startte haar werk voor de afdeling OKER van het CvR, gespecialiseerd in innovatie en implementatieonderzoek. Haar visie op hoe wetenschap en praktijk elkaar kunnen versterken komt tot zijn recht in haar dagelijkse werk. Zij ondersteunt multidisciplinaire teams binnen het CvR bij het opzetten en uitvoeren van verschillende innovatie- en implementatieprojecten. Haar speciale focus ligt op het concreet vorm geven van zelfmanagement in de revalidatiepraktijk in cocreatie met revalidatieprofessionals en patiënten. Daarnaast ondersteunt zij medewerkers en promovendi bij kwalitatieve onderzoeksprojecten. Elk jaar verzorgt zij gastcolleges over innovatie- en implementatieonderzoek en de rol van de onderzoeker en de paramedicus daarin voor de opleiding Bewegingswetenschappen aan de Rijksuniversiteit Groningen en de opleiding Fysiotherapie van de Hanzehogeschool in Groningen.

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