ISBN 978-94-901-2210-2

1

Integrating preferences into decision making

Janine A. van Til

1

Integrating preferences into decision making

The treatment of ankle-foot impairment in stroke

Janine A. van Til

UITNODIGING

voor het bijwonen van
de openbare verdediging
van mijn proefschrift

De rol van voorkeuren in medische beslissingen

De behandeling van enkel-voet afwijkingen na een CVA.

Vrijdag 29 mei 2009
om 16:45 uur

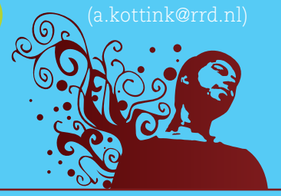
In gebouw de Spiegel
van de Universiteit Twente
Drienerloolaan 5 te Enschede

Na afloop van de promotie is er gelegenheid de promovendus te feliciteren in café De Twee Wezen te Hengelo (www.detweewezen.nl).

Janine A. van Til

Breemarsweg 85
7553 HC Hengelo
j.a.vantil@utwente.nl

Paranimfen
Rianne Huis in 't Veld
(r.huisintveld@rrd.nl)
Anke Kottink-Hutten
(a.kottink@rrd.nl)



ISBN 978-94-901-2210-2

Integrating preferences into decision making

Janine A. van Til

Integrating preferences into decision making

The treatment of ankle-foot impairment in stroke

Janine A. van Til

UITNODIGING

voor het bijwonen van
de openbare verdediging
van mijn proefschrift

De rol van voorkeuren in medische beslissingen

De behandeling van enkel-voet afwijkingen na een CVA.

Vrijdag 29 mei 2009
om 16:45 uur

In gebouw de Spiegel
van de Universiteit Twente
Drienerloolaan 5 te Enschede

Na afloop van de promotie is er gelegenheid de promovendus te feliciteren in café De Twee Wezen te Hengelo (www.detweewezen.nl).

Janine A. van Til

Breemarsweg 85
7553 HC Hengelo
j.a.vantil@utwente.nl

Paranimfen
Rianne Huis in 't Veld
(r.huisintveld@rrd.nl)
Anke Kottink-Hutten
(a.kottink@rrd.nl)

Integrating preferences in decision making

The treatment of ankle-foot impairment in stroke

Janine A. van Til

Address of correspondence:

Janine van Til
University of Twente
MB-HTSR
PO box 217
7500 AE Enschede
The Netherlands
T +31 (53) 4893351
E j.a.vantil@utwente.nl

This thesis is part of the Health Sciences series of the University of Twente

Printed by Gildeprint B.V.
ISBN: 978 94 901 2210 2

Cover design: Martijn Rengelink

INTEGRATING PREFERENCES IN DECISION MAKING

THE TREATMENT OF ANKLE-FOOT IMPAIRMENT IN STROKE

Proefschrift

Ter verkrijging van de graad van doctor
aan de Universiteit Twente,
op gezag van de rector magnificus,
prof. dr. H. Brinksma,
volgens besluit van het College voor Promoties
te verdedigen op vrijdag 29 mei om 16.45.

door

Janine Astrid van Til
geboren op 3 augustus 1976
te Neede

Dit proefschrift is goedgekeurd door de promotoren:

Prof. Dr. M.J. IJzerman
Prof. Dr. A.M. Stiggelbout

Promotiecommissie:

Voorzitter/secretaris:	Prof. Dr. P.J. van Loon
Promotoren:	Prof. Dr. M.J. IJzerman
	Prof. Dr. A.M. Stiggelbout
Ass. Promotor:	Dr. J.G. Dolan
Referenten:	Dr. J.H. Buurke
	Dr. J.F.P. Bridges
Leden:	Prof. Dr. E.R. Seydel
	Prof. Dr. H. Rietman
	Prof. Dr. D. Timmermans
	Prof. Dr. R. Grol

Paranimfen:	Rianne Huis in 't Veld
	Anke Kottink-Hutten

"Every accomplishment starts with the decision to try."
(Unknown author)

This research was supported by The Dutch Organization for Health Research and Development ZonMw (grant number 143.50.026)

ZonMw

The study was carried out at Roessingh Research and Development and supported by the Roessingh Centre for Rehabilitation.

The publication of this thesis was generously supported by:

HTSR
Health Technology and Services Research

Roessingh
Research and
Development

oim
orthopedie

Roessingh
Revalidatie
Techniek

Contents

Chapter 1

General Introduction

Treatment decision making in rehabilitation medicine

According to the model of evidence based medicine, decisions for the management of disease or impairment should be based on (i) the characteristics of the patient, (ii) clinical evidence for the effectiveness of treatment strategies, (iii) the clinical expertise of the physician and (iv) patient aims and wishes (1). Executing the model of evidence based medicine in rehabilitation medicine is difficult. Rehabilitation medicine is characterized by the limited availability of high quality comparative studies into the effectiveness of different treatment strategies. Moreover, existing scientific evidence often does not distinguishes between the treatment strategies (2-4). Decision making is in equipoise. Equipoise is defined as "the lack of a clear strategy of action because the physician can have no clear preference for any of the treatments alternatives based on scientific evidence". A patient is allowed to refuse the treatment alternatives (5).

One good example of an equipoise decision in rehabilitation medicine is the treatment of ankle-foot impairment in stroke. A patient with an ankle-foot impairment is either not able to lift the foot due to weakness of the muscles that elevate the foot (dropfoot or paralytic equinus deformity), or the foot and toe are forcibly extended as a result of increased muscle tone of the calf muscles (spastic equinus deformity). Additionally, an imbalance in muscle activity in medio-lateral direction will cause the foot to rotate inward when the foot is lifted during the swing phase of walking. Ankle-foot impairment can result in problems keeping balance during standing and walking with an increased risk of tripping and falling.

Traditionally, the ankle and foot position are corrected with orthotic aids, e.g. an ankle-foot orthosis (AFO) and/or orthopedic shoes (OS) (6). These treatments, which are aimed at external fixation of the foot in the neutral position, are usually effective in correcting the deviant foot position. The effect of AFO and OS on normalizing muscle tone and improving walking speed, distance and efficiency is limited (7). Alternatives to traditional treatment, such as neuroprostetic devices (NP) (8, 9) and soft tissue surgery (STS) (10) have been introduced more recently in clinical practice. A NP delivers an electrical current to the peroneal nerve to stimulate the muscles that elevate the foot during the swing phase of walking. Both implanted and surface electrodes can be used. In STS, the spastic muscles that pull the foot down and inward in equinovarus deformity are lengthened, cut or transferred. As a result, the muscle forces that act on the ankle-foot complex are balanced and deviant foot position is corrected. The effect

studies of NP and STS are promising (8, 10-15). NP reduces the need for fixed aids. In STS the need for aids is completely omitted and patients are able to walk barefoot. The most important advantage of reducing the need for aids is that push off of the foot is not hindered by external fixation and no daily donning and doffing is required. No clinically relevant differences in effect of AFO, NP and STS on walking speed or energy consumption were identified (8, 10, 14).

In 2003 the international society for prosthetics and orthotics published their latest guidelines for the management of ankle-foot impairment in stroke (16). According to the guidelines, orthotic aids are considered the preferred treatment in ankle-foot impairment (16, 17). With regard to the use of NP, the guidelines state that "where both NP and orthotic management are available and appropriate, the final choice should be made by the patient based on the appearance and use of aids of the respective treatments". With regard to STS, the conference concluded that "while there is a place for surgery in the management of stroke patients, surgery should only be a consideration for deformities which are not responsive to other interventions and/or treatments". Despite the situation of equipoise, these guidelines seem to suggest a hierarchy in treatment alternatives in which invasive and technological treatment are rated less applicable than external aids.

Rationale for the thesis

It can be assumed that in situations of equipoise, the clinical expertise of the physician and the patient aims and wishes for treatment become more decisive in the decision making process than in situations where there is a well-established evidence base. Although the guidelines emphasize the importance of clinical expertise and patient preferences, traditional treatment patterns might be preserved despite new and promising treatment alternatives becoming available.

This is supported because the situation of equipoise is not explicitly stated in the guidelines. The rationale for the inherently subjective preferences and opinions which underlie the guidelines is unclear. The aspects on which the treatments are judged are not made explicit and the extent to which patient preferences can be taken into account in clinical decision making. Also, the trade-offs that patients and clinicians have to make are not stated. This indistinctness hinders the interpretation of the value of the guidelines and the treatment policy in clinical practice. It is stated that more research is necessary to compare the harms and benefits of the treatments and assess specific

patient characteristics that predict functional outcome of the different treatments before final conclusions can be drawn on the best treatment in ankle-foot impairment (17). Given the difficulties in performing high quality comparative trials in rehabilitation medicine it is unlikely that such evidence will become available in the near future (2, 3). Moreover, given the limited potential for improvement in walking function in stroke, it is unlikely that the treatments have clinically different effects on outcome on a group level. The patient preferences for treatment process and physician perception of other treatment benefits and harms will influence decision making. Therefore, alternative methodologies to analyze the potential of treatment and to support decision making are required.

Measuring preferences and supporting decision making

Establishing a preference for treatment in ankle-foot impairment partly depends on the small changes in functioning that are expected as a result of the different treatments. For a larger part, it might be the other characteristics of the treatment that influence physiatrist and patient preference. It was shown that the attractiveness of treatment involves many subjective elements in addition to potential effectiveness, such as the burden of the treatment itself (6, 18). The available treatment alternatives in ankle-foot impairment require different actions on the part of the patient during and after the treatment process and the risks involved in treatment widely differ. The pros and cons of treatment are likely to be different for each patient, and their importance can be perceived differently by each patient. As a result the value of the treatment alternatives in ankle-foot impairment as a whole is dependent on the physician and patient preferences with regard to treatment outcome and process (5). In the decision analysis of ankle-foot impairment in stroke these aspects of treatment must be taken into account to determine the best treatment.

A methodology that allows for the involvement of the multiple aspects of treatment in decision analysis is multi-criteria decision analysis (MCDA) (19, 20). MCDA is defined as “a formal approach to problem solving that attempts to represent imprecise goals in terms of a number of criteria” (21). A criterion or attribute is defined as “a tool allowing comparison of alternatives according to a particular significance axis or point of view”. Characteristic to multi-criteria decision making is the set of criteria on which the alternatives are compared. It is assumed that each criterion can be represented by a surrogate measure of performance, represented by a measurable attribute. The aim of

MCDA is to provide help and guidance to the decision maker in discovering his or her most desired solution to a problem (20). The appeal of quantitative MCDA methods is the sense of objectivity and the focus of discussion on borderline choices (20). MCDA spans a range of techniques. The difference in underlying theory and the framing of the decision task between MCDA techniques influences the theoretical use and practical application of the techniques. Some MCDA methods are more appropriate to support clinical decision analysis than others.

The analytical hierarchical process (AHP) was previously identified as a feasible technique in clinical decision analysis and was previously used in rehabilitation medicine (22-24). The AHP seems especially useful to support group discussion (25). As a decision in rehabilitation medicine is usually made by a team of health professionals, the AHP seems feasible to analyze the decision making process surrounding the treatment of ankle-foot impairment.

Selecting a MCDA method for patient preference elicitation is difficult. In earlier studies several MCDA methods have been successfully used to elicit patient preferences with regard to health and disease management (19, 26-28). One special class of MCDA techniques which is often used is the discrete choice experiment (DCE). Characteristic to the use of a DCE is that treatments are rated holistically, rather than breaking the decision process down to its parts, the decision criteria (20).

An important characteristic of the patients that suffer from ankle-foot impairment after stroke that has to be taken into account in preference elicitation is the cognitive impairment that is associated with stroke. It is likely that cognitive impairment influences the applicability of the techniques (29). The applicability of MCDA to analyze treatment priority setting and decision making in stroke patients is to be investigated.

As a consequence of the multi-dimensional and chronic nature of disease, decision making about treatment is an important and ongoing part of rehabilitation. In a paternalistic approach to health care decision making, the physician is regarded as the authority and actively executes the decision. Consequently, the role of the patient is limited. Previous research has shown a positive experience with post-acute rehabilitation is mostly explained by the sense of ownership of the patient and the recognition of the patient as a person with personal values and preferences (30). Shared decision making is propagated in situations of equipoise (31). Also, the importance of

patient preferences in treatment decision making in ankle-foot impairment is stated in the guidelines in ankle-foot impairment (16).

Shared decision making (SDM) is an approach to decision making that supports the simultaneous participation of physician and patient in all phases of the decision-making process. Information is exchanged between patient and physician and the disease and the treatment alternatives are deliberated and negotiated and patient preferences are taken into account (32, 33). Despite the favorable effects of shared decision making, it was previously shown that shared decision making is not always used (32, 34). The feasibility of a shared approach to decision making in the rehabilitation setting is unknown.

At the same time, high quality information provision to the patient is a prerequisite for a patient to consider their values and preferences for the process and outcome of treatment (35). Traditional educational materials are limited in their potential to help patients understand their personal preferences and values (36). Instead, decision aids (DAs) are promoted as adjuncts to or as preparation for a consultation with the physician (34). A DA is defined as "an intervention designed to help people make specific and deliberative choices among options by providing information on the options and outcomes relevant to a patient's health" (35, 37, 38). A patient DA differs from traditional educational materials because it explicitly describes treatment options, generally includes qualitative and quantitative information about benefits and risks and motivates patients to view the information in the light of their own values and preferences (39). Computer assisted aids have become increasingly popular because they are convenient, accessible and flexible tools and can be easily tailored to the demands of the individual patient. It is known that the use of a DA can result in more realistic expectations of treatment outcome, can improve agreement between personal values and choice of treatment, and can result in an increased desire to actively participate in the decision making process (40). However, the applicability of DAs in the rehabilitation population and their influence on patient preferences for treatment was not previously investigated.

Thesis outline and aims

Given the difficulties in gathering and utilizing evidence for treatment effectiveness in rehabilitation medicine, there is a need for alternative methodologies to support clinical decision making. This thesis is focused on the treatment in ankle-foot impairment in

stroke. This thesis has three general aims. The first aim is to study the patient and physician preferences in treatment of acquired ankle-foot impairment. The second aim is to investigate methodological issues in preference elicitation in stroke patients. The third aim is to study the feasibility of a shared and informed approach to clinical decision making in rehabilitation medicine.

These three aims are investigated in the six chapters that follow the general introduction of this thesis. The outcomes of this thesis should allow for improvements in patient outcomes, clinical decision making and the overall effectiveness of care in the treatment of ankle-foot impairment in stroke. Moreover, the results of this thesis can be used to estimate the potential of novel treatment alternatives in the management of ankle-foot impairment, based on the health professionals and patients perception of the impact of the different aspects of treatment on treatment decision making.

It is the clinical expertise of physiatrists, neurologists and physical therapists that has a high influence on the management of ankle-foot impairment in stroke. The first aim of the study presented in **chapter 2** was to analyze the opinions of a panel of expert health professionals with regard to the treatment of ankle-foot impairment in stroke. A decision analysis was performed using the analytical hierarchical process (AHP). The second aim of the study was to investigate the applicability of AHP in the analysis of decisions in rehabilitation medicine (23, 41, 42).

The use of MCDA techniques is a cognitively demanding process in healthy subjects (29). With regard to the use in stroke patients, MCDA preference elicitation might be complicated by the cognitive impairment which is associated with stroke (26). To our knowledge, MCDA techniques have not previously been used in the fields of geriatric or rehabilitation medicine. Therefore, the aim of the study presented in **chapter 3** was to determine the applicability of MCDA preference elicitation in stroke patients.

In order for the patient to establish values and preferences, high quality information is a prerequisite (35). The decision for treatment and stated preferences might be influenced by prior knowledge (43). The aim of the study in **chapter 4** was to study the influence of an informational brochure on the validity of a discrete choice experiment.

Patient perceived benefit of treatment is important in treatment valuation (6). In the treatment of ankle-foot impairment it is unknown whether the required effort of treatment is an important barrier to treatment acceptance, and whether decreasing the need for aids increases the value of treatment. Regardless, implanted electrodes were introduced in functional electrical stimulation to decrease the patient effort with

treatment (8). The aim of the study presented in **chapter 5** was to study the perceived value of treatment alternatives in ankle-foot impairment in stroke. Patient preferences were elicited using a discrete choice experiment.

Shared decision making is defined as "the collaborative decision-making process in which the doctor and patient share information and values, in order to make an informed choice that is based on the patient's value" (44). The aim of the study presented in **chapter 6** was to explore the current decision making paradigm in rehabilitation medicine, and to identify potential barriers and facilitators for the use of shared decision making and decision aids.

A decision aid is intended to inform a patient about the disease and the relevant treatment options (38, 45). A decision aid aims to assist patients in understanding and evaluating the available treatment options in light of their of personal values and to facilitate shared decision making (37). The aim of the study presented in **chapter 7** was to determine whether a decision aid for ankle-foot impairment is considered a valuable tool in patient information provision to patients and to study the effect of decision aids on patients' knowledge about the treatment alternatives and attitude towards decision making.

Finally, in **chapter 8** the results of the different studies are integrated and the practical and theoretical consequences of the thesis are discussed.

References

1. Haynes RB, Devereaux PJ, Guyatt GH. Physicians' and patients' choices in evidence based practice. BMJ. 2002;324(7350):1350.
2. Frontera WR, Fuhrer MJ, Jette AM, Chan L, Cooper RA, Duncan PW, et al. Rehabilitation medicine summit: building research capacity. Top Stroke Rehabil. 2005;12(4):68-80.
3. Tate DG. The state of rehabilitation research: art or science? Arch Phys Med Rehabil. 2006 Feb;87(2):160-6.
4. Prvu Bettger JA, Stineman MG. Effectiveness of multidisciplinary rehabilitation services in postacute care: state-of-the-science. A review. Arch Phys Med Rehabil. 2007 Nov;88(11):1526-34.
5. Hasman A, Safran C, Takeda H. Quality of health care: informatics foundations. Methods Inf Med. 2003;42(5):509-18.
6. Malas B, Kacen M. Orthotic management in patients with stroke. Top Stroke Rehabil. 2001 Winter;7(4):38-45.
7. Jaivin JS, Bishop JO, Braly WG, Tullos HS. Management of acquired adult dropfoot. Foot Ankle. 1992 Feb;13(2):98-104.
8. Kottink AI, Hermens HJ, Nene AV, Tenniglo MJ, van der Aa HE, Buschman HP, et al. A randomized controlled trial of an implantable 2-channel peroneal nerve stimulator on walking speed and activity in poststroke hemiplegia. Arch Phys Med Rehabil. 2007 Aug;88(8):971-8.
9. Kottink AI, Oostendorp LJ, Buurke JH, Nene AV, Hermens HJ, MJ IJ. The orthotic effect of functional electrical stimulation on the improvement of walking in stroke patients with a dropped foot: a systematic review. Artif Organs. 2004 Jun;28(6):577-86.
10. Piccioni L, Keenan MAE. Surgical correction of varus and equinovarus deformity in the spastic patient. Operative Techniques in Orthopaedics. 1992;2(3):146-50.
11. Burridge JH, Taylor PN, Hagan SA, Wood DE, Swain ID. The effects of common peroneal stimulation on the effort and speed of walking: a randomized controlled trial with chronic hemiplegic patients. Clin Rehabil. 1997 Aug;11(3):201-10.
12. Kottink AI, Hermens HJ, Nene AV, Tenniglo MJ, Groothuis-Oudshoorn CG, MJ IJ. Therapeutic effect of an implantable peroneal nerve stimulator in subjects with chronic stroke and footdrop: a randomized controlled trial. Phys Ther. 2008 Apr;88(4):437-48.
13. Keenan MA, Gorai AP, Smith CW, Garland DE. Intrinsic toe flexion deformity following correction of spastic equinovarus deformity in adults. Foot Ankle. 1987 Jun;7(6):333-7.
14. Edwards P, Hsu J. SPLATT combined with tendo achilles lengthening for spastic equinovarus in adults: results and predictors of surgical outcome. Foot Ankle. 1993 Jul-Aug;14(6):335-8.
15. Lawrence SJ, Botte MJ. Management of the adult, spastic, equinovarus foot deformity. Foot Ankle Int. 1994 Jun;15(6):340-6.
16. Report of a consensus conference on the orthotic management of stroke patients. In: J. CECJM, editor. International Society of Prostetics and Orthotics; 2003; Netherlands; 2003.
17. Hijmans JM, Geertzen JH. Development of clinical guidelines for the prescription of orthoses in patients with neurological disorders in The Netherlands. Prosthet Orthot Int. 2006 Apr;30(1):35-43.
18. Frith L. Priority setting and evidence based purchasing. Health Care Anal. 1999;7(2):139-51.
19. Ryan M, Scott DA, Reeves C, Bate A, van Teijlingen ER, Russell EM, et al. Eliciting public preferences for healthcare: a systematic review of techniques. Health Technol Assess. 2001;5(5):1-186.
20. Belton V, Steward TJ. Multiple Criteria Decision Analysis: An Integrated Approach. Londen: Kluwer Academic Publishers; 2003.
21. Edwards W, Barron FH. SMARTS and SMARTER: Improved Simple Methods for Multiattribute Utility Measurement. Organizational Behavior and Human Decision Processes. 1994;60(3):306-25.
22. Dolan JG. Medical decision making using the analytic hierarchy process: choice of initial antimicrobial therapy for acute pyelonephritis. Med Decis Making. 1989 Jan-Mar;9(1):51-6.
23. Dolan JG. Can decision analysis adequately represent clinical problems? J Clin Epidemiol. 1990;43(3):277-84.

24. Hummel JM, Snoek GJ, van Til JA, van Rossum W, IJzerman MJ. A multicriteria decision analysis of augmentative treatment of upper limbs in persons with tetraplegia. J Rehabil Res Dev. 2005 Sep-Oct;42(5):635-44.
25. Dyer RF, Forman EH. Group decision support with the Analytic Hierarchy Process. Decision Support Systems. 1992;8(2):99-124.
26. Dolan JG. Are patients capable of using the analytic hierarchy process and willing to use it to help make clinical decisions? Med Decis Making. 1995 Jan-Mar;15(1):76-80.
27. Ryan M. Using conjoint analysis to take account of patient preferences and go beyond health outcomes: an application to in vitro fertilisation. Soc Sci Med. 1999 Feb;48(4):535-46.
28. Ryan M, Farrar S. Using conjoint analysis to elicit preferences for health care. BMJ. 2000 Jun 3;320(7248):1530-3.
29. Weber M, Borcherding K. Behavioral influences on weight judgments in multiattribute decision making. European Journal of Operational Research. 1993;67(1):1-12.
30. Wain HR, Kneebone, II, Billings J. Patient experience of neurologic rehabilitation: a qualitative investigation. Arch Phys Med Rehabil. 2008 Jul;89(7):1366-71.
31. Elwyn G, Edwards A, Kinnersley P, Grol R. Shared decision making and the concept of equipoise: the competences of involving patients in healthcare choices. Br J Gen Pract. 2000 Nov;50(460):892-9.
32. Charles C, Gafni A, Whelan T. Shared decision-making in the medical encounter: what does it mean? (or it takes at least two to tango). Soc Sci Med. 1997 Mar;44(5):681-92.
33. Robinson A, Thomson R. Variability in patient preferences for participating in medical decision making: implication for the use of decision support tools. Qual Health Care. 2001 Sep;10 Suppl 1:i34-8.
34. Holmes-Rovner M, Valade D, Orlowski C, Draus C, Nabozny-Valerio B, Keiser S. Implementing shared decision-making in routine practice: barriers and opportunities. Health Expect. 2000 Sep;3(3):182-91.
35. O'Connor AM, Rostom A, Fiset V, Tetroe J, Entwistle V, Llewellyn-Thomas H, et al. Decision aids for patients facing health treatment or screening decisions: systematic review. BMJ. 1999 Sep 18;319(7212):731-4.
36. O'Connor AM, Tugwell P, Wells GA, Elmslie T, Jolly E, Hollingworth G, et al. A decision aid for women considering hormone therapy after menopause: decision support framework and evaluation. Patient Education and Counseling. 1998;33(3):267-79.
37. Bekker HL, Hewison J, Thornton JG. Understanding why decision aids work: linking process with outcome. Patient Educ Couns. 2003 Jul;50(3):323-9.
38. Elwyn G, O'Connor A, Stacey D, Volk R, Edwards A, Coulter A, et al. Developing a quality criteria framework for patient decision aids: online international Delphi consensus process. BMJ. 2006 Aug 26;333(7565):417.
39. Whelan T, Sawka C, Levine M, Gafni A, Reyno L, Willan A, et al. Helping patients make informed choices: a randomized trial of a decision aid for adjuvant chemotherapy in lymph node-negative breast cancer. J Natl Cancer Inst. 2003 Apr 16;95(8):581-7.
40. O'Connor AM, Stacey D, Entwistle V, Llewellyn-Thomas H, Rovner D, Holmes-Rovner M, et al. Decision aids for people facing health treatment or screening decisions. Cochrane Database Syst Rev. 2003(2):CD001431.
41. Dolan JG, Bordley DR. Using the analytic hierarchy process (AHP) to develop and disseminate guidelines. QRB Qual Rev Bull. 1992 Dec;18(12):440-7.
42. Dolan JG, Isselhardt BJ, Jr., Cappuccio JD. The analytic hierarchy process in medical decision making: a tutorial. Med Decis Making. 1989 Jan-Mar;9(1):40-50.
43. Ryan M, McIntosh E, Shackley P. Methodological Issues in the Application of Conjoint Analysis in Health Care. Health Econ. 1998;7(4):373-8.
44. Trevena L, Barratt A. Integrated decision making: definitions for a new discipline. Patient Educ Couns. 2003 Jul;50(3):265-8.
45. Molenaar S, Sprangers MA, Postma-Schuit FC, Rutgers EJ, Noorlander J, Hendriks J, et al. Feasibility and effects of decision aids. Med Decis Making. 2000 Jan-Mar;20(1):112-27.

Chapter 2

The Use of the Analytic Hierarchy Process to Aid Decision Making in Acquired Equinovarus Deformity

Janine A. van Til
Gerbert J. Renzenbrink
James G. Dolan
Maarten J. IJzerman

Archives of Physical Medicine and Rehabilitation 2008; 89(3):457-62.
Reprinted with permission

Abstract

As a consequence of the absence of high quality evidence regarding the management of acquired ankle-foot impairment, decision making is a value sensitive process on the part of the physician. Which factors influence the preference for treatment is unknown. The objective of this study was to increase the transparency in decision making about treatment of acquired ankle-foot impairment in the adult stroke population.

The analytic hierarchy process (AHP) was used to support the decision process. The case of a female stroke patient with ankle-foot impairment who is eligible for multiple treatments was considered as the starting point. Patient details were presented to a panel of ten health professionals from different backgrounds. The possible treatments for this patient were an ankle-foot orthosis, orthopeadic footwear, surface and implanted functional electrical stimulation and soft tissue surgery. The performance of the treatments on outcome, impact, comfort, cosmetics, daily effort, and risks and side effects of treatment was valued. Also, the importance of the decision criteria in treatment decision making was determined.

The results of this study indicate that soft-tissue surgery was (0,413) considered the best treatment in this patient, followed by orthopedic footwear (0,181), ankle-foot orthosis (0,147), surface electrostimulation (0,137), and finally implanted electrostimulation (0,123). Outcome was the most important criterion in decision making (0,509), followed by risk and side effects (0,194), comfort (0,104), daily effort (0,098), cosmetics (0,065), and impact of treatment (0,030).

Soft-tissue surgery was judged best on outcome, daily effort, comfortable shoe wear, and cosmetically acceptable result and was thereby preferred in four of the six criteria considered in this study. Ankle-foot orthosis and orthopedic footwear are most prescribed in clinical practice. According to the experts, the discrepancy between the results of this study and clinical practice might be explained by (1) the unfamiliarity of soft tissue surgery as a valuable treatment alternative in acquired ankle-foot impairment in physiatrists, (2) limited accessibility to or lack of cooperation with an orthopedic surgeon and (3) a patient resistance towards the negative aspects of treatment.

With regard to the methodology that supported the decision analysis, the AHP method was found highly applicable for eliciting opinions and discussion as well as quantifying values and preferences. In this study, this enabled an analytic comparison of treatment alternatives in the absence of scientific evidence.

Introduction

A stroke or a cerebrovascular accident (CVA) is a common disorder that can result in hemi-paralysis. Of the stroke patients, many are confronted with a deviant position of the ankle and foot that hinders standing and walking. The impairment is known as an equinovarus deformity. In 2003, the International Society for Prosthetics and Orthotics developed guidelines for the orthotic management of stroke patients (1, 2). The guidelines provide insight in the available treatments for equinovarus deformity but no direction is given with regard to the preference for treatment if multiple treatments are available.

Although the specifics of the equinovarus deformity influence the range of available treatments, in general, surgical (3), technologic (4), pharmaceutical (5), and orthotic (6) treatments are available to correct the deformity. The treatment is primarily aimed at correcting the deviant foot position. Secondary beneficial effects include reduction or stimulation of muscle force, improvement of walking speed and distance, and reduction of energy consumption (7).

Evidence-based choice of treatment is hindered because the available clinical evidence base consists of only few articles with small sample size or poor methodological quality (2). Despite the absence of high quality evidence favoring one treatment over another, in clinical practice the decision for treatment of equinovarus deformity has to be made on a daily basis. Decision making in acquired neurologic equinovarus deformity can thereby be described as a preference sensitive or equipoise decision, where the decision is influenced by personal preferences and experience of the physiatrist rather than evidence alone (8). The perceived attractiveness of treatment involves subjective elements in addition to potential effectiveness (9). As long as the exact nature and influence of these criteria is unknown, valuable information that might assist treatment decision making in other patients is not available. Especially the opinion of highly experienced and knowledgeable decision makers might hold information on the strengths and weaknesses of treatment alternatives that is not made explicit.

The objective of this study was to elicit and measure subjective preferences in the treatment of acquired ankle-foot impairment. The methodology used for this study was the analytic hierarchy process (AHP). The AHP is an approach to decision making problems of choice and prioritization which are influenced by multiple criteria. The AHP has been previously used to compare the performance of intensive care units (10),

to allocate livers among transplant patients (11), select tests for abdominal pain (12), and to support the decision making process in reconstructive treatment of arm-function in spinal cord injury (13). This decision analysis methodology evaluates a decision by determining the relative importance of criteria and the performance of alternative treatments through a series of trade-offs (14). The analysis can include medical, technical, economic, and social decision criteria. Subjective judgments on aspects of a decision for which no scale of measurement exist are easily accommodated (15). The aim of this study was to test the AHP as a methodology for evaluation of an implicit decision making process and to elicit expert preferences with regard to the management of ankle-foot impairment in stroke.

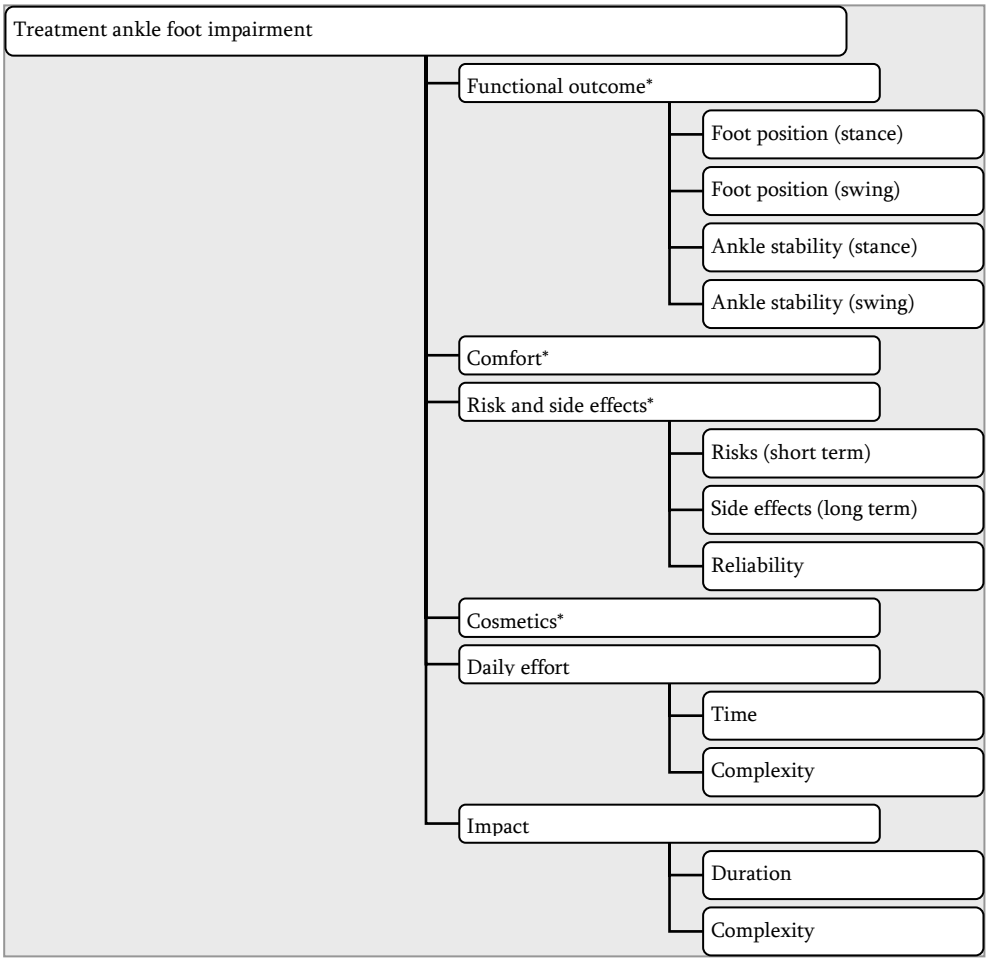
Methods

The decision analysis in the analytical hierarchical process (AHP) is divided into 4 stages, namely, (a) model development, (b) judgment stage, (c) synthesis of results, and (d) sensitivity analysis. For a more detailed discussion on the technique and underlying methodology, we refer the reader to the literature (14, 16, 17).

Model Development

To establish the decision criteria, a Delphi-style paper-and-pencil interview was conducted among a sample of Dutch (n=28; response rate = 68%) physiatrists united in a stroke interest group. The questionnaire was developed to identify a preliminary set of treatment requirements, criteria, and treatment alternatives for acquired equinovarus deformity in the post-acute phase (> 6wk) of stroke. An example of the questionnaire as it was send is presented in appendix 1. Simultaneously, a literature search was conducted using the search terms stroke, equinovarus deformity, ankle-foot impairment, and treatment. A decision tree based on the responses to the initial questionnaire was sent back to the participants along with a proposal for appropriate treatment alternatives for the treatment of ankle-foot impairment in stroke. Two additional rounds of feedback from the group were obtained and the results were processed. After two rounds of feedback, a decision tree was developed based on the group responses (figure 1). Also, five feasible management strategies for the post-acute management of equinovarus deformity were identified based on the frequency of use in clinical practice. These treatments were: soft tissue surgery (STS), a neuroprostetic device using functional electric stimulation of the peroneal nerve (FES), ankle-foot orthosis (AFO), pharmaceutical treatment (PT), and orthopedic shoes (OS).

Figure 1. Decision tree for ankle-foot impairment in stroke



*Notes: The decision criteria marked with * are supported by Blankevoort et al. (18). Impact of treatment comprises the burden of treatment to the patient in the active treatment phase while daily effort comprises the effort on the part of the patient which is required to maintain the effect of treatment (mainly donning and doffing necessary equipment).*

Judgment Stage

The goal of the analysis was to establish the preferred treatment for acquired equinovarus deformity in stroke. A panel of ten professionals in rehabilitation medicine was asked to participate in the judgment phase. The panel consisted of four physiatrists, an orthopedic surgeon, a physical therapist, two senior researchers in the field of stroke, and two certified orthotists. To initiate the discussion, a patient case description (figure 2) and video were presented to the panel on a projection screen.

Figure 2. Patient case description

Mrs. L. is a 61-year-old female who has had a right-side stroke approximately 1 year ago. She is an independent outside walker (FAC 5) but complains about feelings of insecurity during walking on an uneven surface and walking during the night (for instance during toilet visits). Mrs. L. has normal cognitive functioning and no impairment in hand function due to stroke. Additionally, she suffers from high blood pressure.
During physical assessment of walking pattern the following deviations were noticed:
No deviations were seen in the right leg. During stance phase of the right leg, initial contact of the foot is seen on the lateral border and heel of the foot. Increased first rocker. The knee is in flexion at initial contact with delayed extension to terminal stance.
During swing phase there is decreased flexion of the knee, not hindering foot clearance. The heel of the foot is in varus with deviation of calcaneus and supination of forefoot. Hyperextension of the first toe is present during swing and stance phase of walking.
Strength of the hip in flexion and extension is MRC 4. Abduction is 5. Knee flexion is 5 and knee extension 4+. Ankle plantarflexion (in pattern) is 4, dorsiflexion is 4+, inversion is 5 and eversion is 4. Mobility of the hips and knees is normal. Ankle dorsiflexion left is limited with 5° (5/0/20) with a straight leg and normal with bend leg (10/0/20). Normal plantairflexion, decreased mobility of the calcaneus on the left (25/0/0).
No marked spasticity, no sensibility disorder and no peripheral circulation problems were present.

Notes: The patient observation and records were based on extensive manual testing in lying and sitting position and visual observation of the patient during walking by an experienced physiotherapist. Abbreviations: FAC, Functional Ambulation Category; MRC, Medical Research Council muscle strength scale.

The female patient had moderate equinovarus deformity and was selected because she was eligible for all treatment alternatives identified during the Delphi process. The patient's most important expectation of treatment was to walk greater distances without

tripping. The panel members selected the subsequent treatment alternatives: split tibial tendon transfer combined with a transfer of the hallucis longus muscle (STS), an off-the-shelf ankle-foot orthosis (AFO), off-the-shelf semi-orthopedic shoes (OS), an *implanted* and a *surface* neuroprostetic device with functional electrical stimulation of the peroneal nerve (i-FES and s-FES). Pharmaceutical treatment was omitted as a treatment alternative because of the absence of marked spasticity in the patient.

The judgment stage consisted of two phases. First, the performance of the treatment alternatives was judged on the lowest level criteria. Judgments were made by comparing the performance of treatments in a pair-wise fashion using a reciprocal numeric scale ranging from 1 to 9 (an example of the scale can be found in appendix 2). The numbers are associated with verbal statements ranging from equally preferred (1) to extremely more preferred (9).

In the second phase of the judgment stage, the panel members were asked to judge the importance of the sub-criteria in accomplishing the higher level criteria. Also, the panel judged the amount in which these criteria influenced treatment choice in ankle-foot impairment in this patient. Judgments were made using the reciprocal numeric scale described earlier, with verbal statements ranging from equally important (1) to extremely more important (9).

At first individual judgments were made by the panel members. After every member of the panel completed the judgment, disagreement among panel members was made explicit by presenting the numerical judgments and by verbal explanation of the discussion leader. In case of disagreement, the panel members with the most diverging scores were asked to clarify their judgments while other members were encouraged to participate. In most cases, this resulted in a discussion of benefits and harms of the treatment alternatives or the relevance of criteria in decision making. Panel members were allowed to reconsider and alter their judgment if they felt new information was presented. To reduce the time requirements of the analysis, the amount of performance and importance judgments was reduced to the minimal amount required for calculating weights on an individual and group level. A total of 52 performance and 13 importance judgments were made by the ten members of the panel. The duration of the analysis was about 7 hours (including breaks).

Synthesis of Results

In the AHP, the numeric judgments are put in a comparison matrix (A). The reciprocal scores are used to complete the matrix. The principle eigenvector method is used to calculate the individual importance and performance weights from the matrix. For a detailed explanation of the how and why of eigenvector method the reader is referred to the literature (19) but for the scope of the current article it is enough to know that a close approximation of the priority vector of a matrix A can be calculated by dividing each element in the matrix by the sum of its column and then dividing the sum of each row by the sum of the matrix. Group values are calculated using the geometric mean of individual judgments.

A priority score (V) for each treatment (a) is calculated based on the additive value function presented in equation 1.

$$V(a) = \sum_{i=1}^{m} w_i v_i(a) \qquad \textit{(equation 1)}$$

The weight (w) of a criterion is the importance of a criterion in the decision. The value (v) of a criterion is the performance of a decision alternative (a). The weight of each criterion was multiplied with the performance of each treatment on that criterion, after which the outcome was summed for all six criteria (I = 6). This resulted in an overall performance rating (V) for each of the alternative.

Panel judgment consistency was measured by calculating a consistency index, which ranges from 0 (perfect consistency) to 1. Analyses with consistency indices less than or equal to 0,1 were considered acceptable.

Sensitivity Analysis

The impact of the importance of criteria on overall performance rating of the treatment alternatives was determined by randomly varying the importance of the second level criteria between 0 and 100% in 10% increments while keeping the sum of the importance weights at 100% and calculating treatment preference.

Results

Criteria Weights

The relative importance of the criteria in decision making in ankle-foot impairment is presented in table 1. In the opinion of the expert panel, the outcome of treatment was the most important criterion in the decision for treatment in ankle-foot impairment. With an importance weight of 0,509 it influenced half of the decision for treatment. Improving active ankle stability (0,441) and foot position in swing phase of walking (0,398) were judged to be the most important functional outcomes which had to be accomplished and improving the passive ankle stability and foot position in stance were judged less important.

Table 1. Importance weights for decision criteria

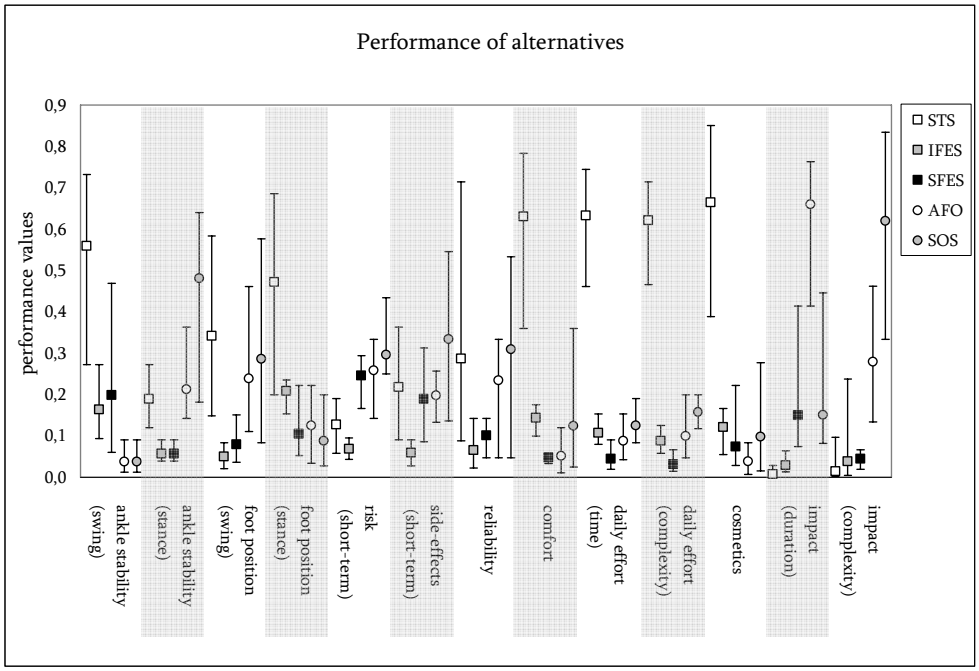
Decision Criteria					
Second Level	Average	SD	Third Level	Average	SD
Functional Outcome	0,509	0,180	Active ankle stability	0,441	0,023
			Passive ankle stability	0,059	0,023
			Foot position in stance	0,102	0,057
			Foot position in swing	0,398	0,057
Risks	0,194	0,115	Short-term risks	0,386	0,099
			Long-term side effects	0,449	0,089
			Reliability of treatment	0,165	0,035
Comfort	0,104	0,086	Consequences on comfortable shoe wear	0,104	0,086
Daily effort	0,098	0,110	Daily time investment	0,770	0,031
			Complexity of daily investment	0,230	0,031
Cosmetics	0,065	0,044	Cosmetic consequences	0,065	0,044
Impact	0,030	0,023	Duration of treatment	0,760	0,055
			Complexity of treatment	0,240	0,055

Notes: SD = standard deviation.

Treatment performance

The integration of the performance judgments of the treatments (figure 3) with the importance of the decision criteria resulted in a value rating of treatments. Soft-tissue surgery was the highest rated treatment, with an average value of 0,413 and a range between 0,313 and 0,614. Semi-orthopedic shoes (0,181; range: 0,081–0,230) were ranked second, followed by the ankle-foot orthosis (0,147; range: 0,098–0,170), surface

Figure 3. The performance of the treatment alternatives



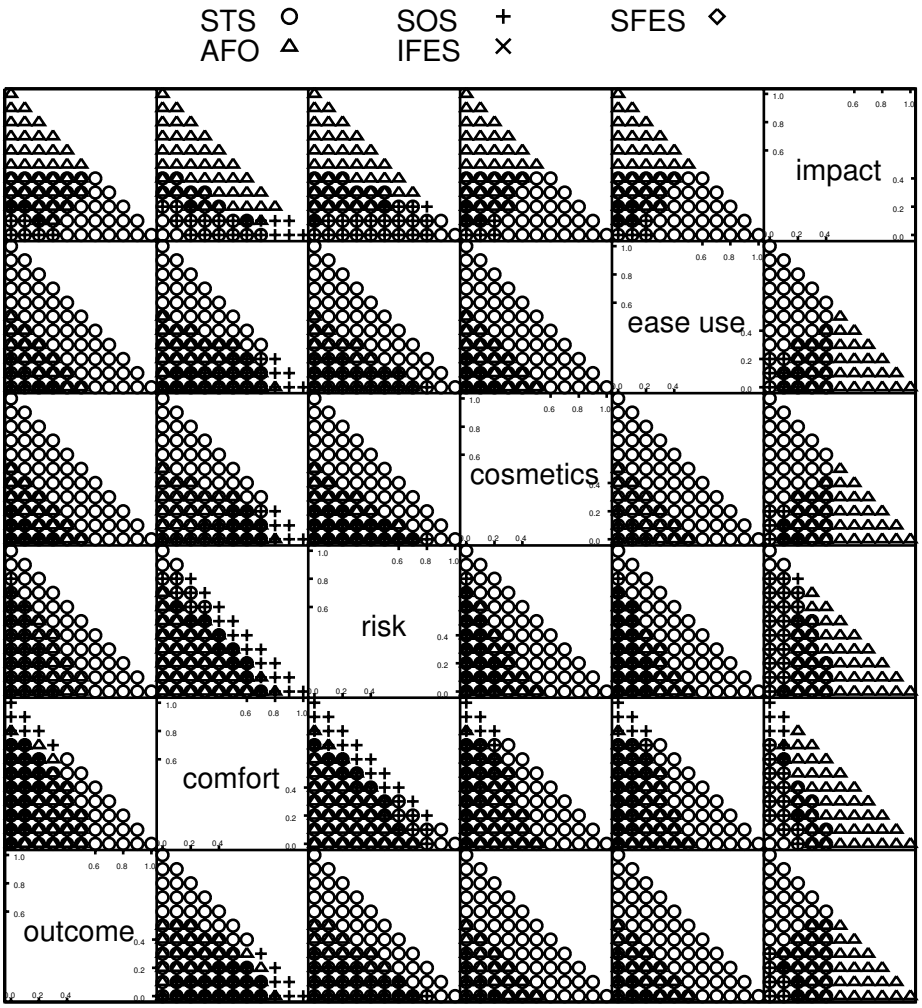
Notes: The average performance with 1 standard deviation for the lowest level decision tree criteria.

functional electrical stimulation (0,137; range: 0,079–0,230), and implanted functional electrical stimulation (0,123; range: 0,099–0,169). Individual performance judgments are presented in appendix 3.

Sensitivity Analysis

The preferred treatment was influenced by the importance of the different criteria (figure 4). If the preferred treatment is calculated for all combinations of treatment importance, the preferred treatment is soft-tissue surgery in 77%, orthopedic shoes in 3%, and AFO in 20% of combinations. No combination of importance weights resulted in either surface or implanted FES devices being the preferred treatment.

Figure 4. Variability in treatment preference



Notes: The squares represent a six dimensional plane of treatment preference based on the relative importance of the six treatment criteria. Outcome = Functional Outcome; Ease Use = Daily effort.

Discussion

According to the AHP decision analysis performed in this study, soft-tissue surgery is the preferred treatment in the treatment of acquired equinovarus deformity in a female stroke patient. The panel judged the performance of soft-tissue surgery superior on functional result, cosmetic consequences, comfortable result, and daily effort required to maintain the result of treatment. Orthopedic shoes and AFO perform averagely on most criteria. Strong features of orthopedic shoes and AFO include the low impact and the low risk that is associated with the treatment. The performance of FES was judged low. The sensitivity analysis revealed that FES performance is dominated by the other treatment alternatives because no combination of criteria weights resulted in FES as preferred treatment. Most noticeably, the panel judged the electrode and heel switch placement of surface stimulation too complex in a patient group that can be both cognitively and physically impaired. Attempts were undertaken to improve the required use of aids in FES by the development of an implantable device. The operative procedure associated with implantation of a nerve stimulator results in a low performance of i-FES on the criteria treatment impact and risks and side effects. Moreover, in both s-FES and i-FES, the timing of the electric stimulus, which is required to induce foot elevation in the swing phase of walking, is considered to be unreliable. The ongoing progress in technologically based aids and effectiveness studies makes updating the performance valuations in the current model with new information as it comes available essential (20).

The preference for soft-tissue surgery expressed in this study is not in agreement with clinical practice. In the Netherlands, OS and AFO are used most frequently in the treatment of equinovarus deformity. Panel discussion revealed that this might be attributed to (a) the low impact of these treatments in patients that are faced with many cognitive and physical disabilities and (b) a great familiarity with and easy access to orthotic treatment in the average rehabilitation setting. According to the panel the preference for soft-tissue surgery in this study is partly explained by the chronic phase of stroke and the high functional status of the patient in the case description. As a direct consequence, treatment impact is judged to be least important and outcome is considered most important.

In stroke, the natural recovery of equinovarus deformity and walking ability often plateaus within weeks and a decision regarding equinovarus management is made at a

time in which the treatment of equinovarus deformity as such does not have the highest priority. As time since injury increases, different trade-offs between the pros and cons of treatment are made. This would argue for the assessment of the status of ankle-foot impairment and patient desired treatment outcome in a later stage of stroke in current clinical practice. A second explanation for the small-scale use of soft-tissue surgery might be the limited experience of physiatrists with the potential of soft tissue surgery in acquired ankle-foot impairment. Consequently stroke patients are only rarely referred to an orthopedic surgeon. As the results of this study indicate there is a high potential for the use of soft-tissue surgery in later stages of recovery, this advocates an active approach in bringing the potential of soft-tissue surgery to the attention of the physiatrist.

With regard to the applicability of the AHP methodology in decision analysis in rehabilitation medicine, in this study the AHP methodology provided the condition for a structured discussion on the harms and benefits of treatment (15, 21). The conscious deliberation of relevant requirements for treatments revealed some of the subjective opinions of panel members. The judgment of performance on a standard set of well-defined criteria enabled a comparison of treatments, which is up to this point impossible based on available scientific evidence. Individual knowledge and experience was made explicit and was shared between panel members, which resulted in a performance judgment of treatment alternatives on other aspects of treatment as well.

The comments of the panel regarding the applicability of the AHP as an alternative tool for treatment comparison were diverse. During the analysis, some of the panel members raised concerns about the validity of the judgments as their experience and knowledge on some of the treatments was limited. In our opinion, the group discussion phase included in the analysis can resolve this issue, as panel members were allowed to alter their judgment if they felt unknown information was presented. In the treatment of acquired ankle-foot impairment, including panel members from different backgrounds is essential as any individual's knowledge and experience of the treatment of equinovarus deformity is incomplete.

The time requirements to complete the model were considered a disadvantage of the decision analysis and the AHP was thought to be bothersome for widespread use as a decision support tool. This reservation might be a result of the large size of the current model. Simpler decision trees are preferable, although care must be taken that

important details are maintained and simpler decision methodologies might be considered. In this study the AHP analysis provided valuable insights in the motivation of panel members. In our opinion, the AHP is an adequate tool in the examination of treatment decision making and guideline development in rehabilitation medicine if preference sensitive decisions are considered and high quality scientific evidence is unavailable.

The high importance that is awarded to performance indicators such as functional outcome and risks of treatment may be a reflection of the professional nature of the panel members. As was shown by Hummel et al, (21) patients value different aspects of treatment when compared to health professionals. Treatment preference could thereby differ for patients. Patient involvement is seen as an important factor in ensuring quality improvement in health care (22, 23) and health professionals are increasingly encouraged to involve their patients in treatment decision making. Communicating decision making process to patients isn't straightforward. The AHP model used in this study could be a way to inform patients and include the personal aims, wishes, and demands of the patient into health care decision making. It was shown previously that patients are capable of using the AHP methodology to express their preferences (24). Some panel members expressed concern on whether the results of the study could be generalized to other patients. The judgment phase was thought to be influenced by the patient case. We shall discuss this issue with regard to two outcomes of the analysis, namely the effect of the patient case on performance judgment of the treatment alternatives and on criteria importance. First, the influence of the case description on the performance judgments of the expert panel is considered negligible. As became apparent from the videotape that was used to document the whole decision analysis, the patient description was rarely referred to by the panel members in the discussion and judgments on performance were made on a more general level. As the influence of characteristics of the impairment on treatment performance is only scarcely documented in literature and is thought to be subtle, it is questionable whether it would become obvious from subjective judgments. For a number of other criteria, the effect of changes in the specifics of the impairment are comparable in all treatments (e.g., more severe deformity would lead to higher treatment impact). As a result, this does not influence the relative performance of treatment alternatives. Therefore, the performance judgments elicited in this study can be generalized to other patients with

equinovarus deformity. Second, as was mentioned in a preceding paragraph, the specifics of the ankle-foot deformity and the time since injury influenced the panel's judgments about the relative importance of the criteria. In this patient, the importance of treatment impact was judged to be low and functional outcome was deemed most important. This trade-off was highly influenced by the specifics of the ankle-foot impairment and the wishes of the patient. The importance of the decision criteria in the rating of treatment alternatives should therefore be determined in each individual case. A next study might focus on the validity of these statements by repeating the analysis in another patient.

Conclusions

When clinical practice is compared with the preference for treatment expressed using the AHP methodology, soft-tissue surgery is an undervalued treatment alternative in the treatment of moderate equinovarus deformity in the swing phase of walking, if a patient is willing and able to undergo a longer and more tedious treatment. The ultimate choice of treatment remains dependent on individual trade-offs of patients and health care professionals, as this study showed that different trade-offs regarding criteria importance could lead to a different preference for treatment.

Although some concerns were raised by the panel, these seem manageable and the use of AHP as a methodology to compare treatment alternatives in rehabilitation medicine is promising. As large randomized controlled trials are not yet available and will remain difficult to execute due to the heterogeneity of patient population and lack of funding in rehabilitation medicine, an alternative for decision aiding is highly applicable.

References

1. Geertzen JH, Hijmans JM, van der Linde H. "Prosthetic prescription in The Netherlands: an interview with clinical experts" by Van der Linde et al. Prosthet Orthot Int. 2005 Apr;29(1):113-4.
2. Report of a consensus conference on the orthotic management of stroke patients. In: J. CECJM, editor. International Society of Prostetics and Orthotics; 2003; Netherlands; 2003.
3. Piccioni L, Keenan MAE. Surgical correction of varus and equinovarus deformity in the spastic patient. Operative Techniques in Orthopaedics. 1992;2(3):146-50.
4. Kottink AI, Oostendorp LJ, Buurke JH, Nene AV, Hermens HJ, MJ IJ. The orthotic effect of functional electrical stimulation on the improvement of walking in stroke patients with a dropped foot: a systematic review. Artif Organs. 2004 Jun;28(6):577-86.
5. Pittock SJ, Moore AP, Hardiman O, Ehler E, Kovac M, Bojakowski J, et al. A Double-Blind Randomised Placebo-Controlled Evaluation of Three Doses of Botulinum Toxin Type A (Dysport ®) in the Treatment of Spastic Equinovarus Deformity after Stroke.
6. Malas B, Kacen M. Orthotic management in patients with stroke. Top Stroke Rehabil. 2001 Winter;7(4):38-45.
7. Jaivin JS, Bishop JO, Braly WG, Tullos HS. Management of acquired adult dropfoot. Foot Ankle. 1992 Feb;13(2):98-104.
8. Trevena L, Barratt A. Integrated decision making: definitions for a new discipline. Patient Educ Couns. 2003 Jul;50(3):265-8.
9. Frith L. Priority setting and evidence based purchasing. Health Care Anal. 1999;7(2):139-51.
10. Hariharan S, Dey PK, Chen DR, Moseley HSL, Kumar AY. Application of analytic hierarchy process for measuring and comparing the global performance of intensive care units. Journal of Critical Care. 2005;20(2):117-24.
11. Ryan Cook D, Staschak S, Green WT. Equitable allocation of livers for orthotopic transplantation: An application of the Analytic Hierarchy process. European Journal of Operational Research. 1990;48(1):49-56.
12. Castro F, Caccamo LP, Carter KJ, Erickson BA, Johnson W, Kessler E, et al. Sequential test selection in the analysis of abdominal pain. Med Decis Making. 1996 Apr-Jun;16(2):178-83.
13. Hummel JM, Snoek GJ, van Til JA, van Rossum W, IJzerman MJ. A multicriteria decision analysis of augmentative treatment of upper limbs in persons with tetraplegia. J Rehabil Res Dev. 2005 Sep-Oct;42(5):635-44.
14. Saaty TL. How to make a decision: The analytic hierarchy process. European Journal of Operational Research. 1990;48(1):9-26.
15. Dyer RF, Forman EH. Group decision support with the Analytic Hierarchy Process. Decision Support Systems. 1992;8(2):99-124.
16. Dolan JG, Isselhardt BJ, Jr., Cappuccio JD. The analytic hierarchy process in medical decision making: a tutorial. Med Decis Making. 1989 Jan-Mar;9(1):40-50.
17. Hatcher M. Voting and priorities in health care decision making, portrayed through a group decision support system, using analytic hierarchy process. J Med Syst. 1994 Oct;18(5):267-88.
18. Blankevoort L, Geertzen JH, Y.F.Heerkens, Hijmans JM, Ursum J. Ontwikkeling van richtlijnen voor de indicatiestelling en het verstrekkingsproces van orthopedische orthesen (ORIVOO). Amsterdam; 2005.
19. Saaty TL. Decision-making with the AHP: Why is the principal eigenvector necessary. European Journal of Operational Research. 2003;145(1):85-91.
20. Dolan JG, Bordley DR. Using the analytic hierarchy process (AHP) to develop and disseminate guidelines. QRB Qual Rev Bull. 1992 Dec;18(12):440-7.
21. Hummel JM, van Rossum W, Verkerke GJ, Rakhorst G. Medical technology assessment: the use of the analytic hierarchy process as a tool for multidisciplinary evaluation of medical devices. Int J Artif Organs. 2000 Nov;23(11):782-7.

22. Kennedy A, Robinson A, Rogers A. Incorporating patients' views and experiences of life with IBS in the development of an evidence based self-help guidebook. Patient Educ Couns. 2003 Jul;50(3):303-10.
23. Robinson A, Thomson R. Variability in patient preferences for participating in medical decision making: implication for the use of decision support tools. Qual Health Care. 2001 Sep;10 Suppl 1:i34-8.
24. Dolan JG, Bordley DR. Involving patients in complex decisions about their care: an approach using the analytic hierarchy process. J Gen Intern Med. 1993 Apr;8(4):204-9.

Appendix 1: Questionnaire for stroke interest group

An open-ended questionnaire with the following questions was sent to the participants.

1. What are the characteristics of post-stroke equinovarus deformity?
2. Which interventions are you familiar with for equinovarus deformity post-stroke?
3. Which of these interventions do you use in daily practice?
4. Which general patient characteristics do you take into account when prescribing treatment for equinovarus deformity post-stroke?
5. Which specifics of the equinovarus deformity do you take into account when prescribing treatment?
6. Which general treatment characteristics do you take into account when prescribing treatment for equinovarus deformity post-stroke?
7. Which specific characteristics or effects of the treatment do you take into account when prescribing treatment for equinovarus deformity post-stroke?

All responses were categorized and returned to the participants. The participants were asked to check the boxes with the treatments, characteristics, or criteria that they found relevant in the decision for treatment. Based on frequency a selection of relevant criteria was made for use in the decision tree. Also, a selection of alternative treatments was made.

Appendix 2: Performance and importance scales

Performance

Which of the next treatments is preferred when the aim is to minimize risks?

9 8 7 6 5 4 3 2 1 2 3 4 5 6 7 8 9

☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐

Soft-tissue surgery or Ankle-foot orthosis

Importance

Which of the next criteria is more important in determining the best treatments for ankle-foot impairments?

9 8 7 6 5 4 3 2 1 2 3 4 5 6 7 8 9

☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐

Outcome of treatment or Risks of treatment

	Verbal Description	
1	Equal	Equal contribution to objective
3	Moderate	Experience or judgment slightly favors one criteria over another
5	Strong	Experience or judgment strongly favors one criteria over another
7	Very strong/demonstrated	Dominance of criteria is demonstrated in practice
9	Extreme importance/dominance	Effect is significantly demonstrated in literature

Appendix 3: Individual performance judgments

Treatment Rating	STS	i-FES	s-FES	AFO	OS
Orthopedic surgeon	0,614	0,114	0,092	0,098	0,081
Orthotist 1	0,313	0,169	0,195	0,164	0,159
Orthotist 2	0,343	0,138	0,139	0,150	0,230
Physiatrist 1	0,337	0,099	0,230	0,170	0,165
Physiatrist 2	0,541	0,116	0,096	0,104	0,142
Physiatrist 3	0,550	0,104	0,079	0,106	0,160
Physiatrist 4	0,430	0,131	0,117	0,159	0,163
Physical therapist	0,475	0,132	0,103	0,104	0,186
Senior researcher 1	0,453	0,129	0,094	0,128	0,196
Senior researcher 2	0,463	0,116	0,149	0,113	0,159

Notes: Abbreviations: soft-tissue surgery (STS); implanted functional electrical stimulation (i-FES); surface functional electrical stimulation (s-FES); ankle-foot orthosis (AFO); semi-orthopaedic shoes (OS).

Chapter 3

Multi-Criteria Value Elicitation Techniques in Patients with a Mild Cognitive Impairment – a Pilot Study

Janine A. van Til
James G. Dolan
Anne M. Stiggelbout
Karin C.G.M. Groothuis
Maarten J. IJzerman

Patient. 2008; 1 (2): 127-135.
Reprinted with permission

Abstract

Multi-criteria value elicitation techniques can be used in health care to study the importance of treatment characteristics on patient preference for disease management. Multi-criteria techniques require trading behavior which can be challenging for cognitively healthy population. It is unknown whether the ability to use these techniques is hampered in, for instance, stroke patients. The objective of the current study was to test the applicability of these preference elicitation methods in cognitively impaired subjects. A convenience sample of sixteen cognitively impaired subjects and twelve healthy controls participated in a pilot study. Five different weight elicitation techniques were used to elicit patient preferences for the management of (hypothetical) disease. The value elicitation techniques were simple multi-attribute rating technique using point allocation and swing weights, Kepner-Tregoe analysis, the analytical hierarchical process and a discrete choice experiment. The subjects determined the relative importance of four decision criteria. The results of this study indicate that the discrete choice experiment was considered the most applicable method for weight elicitation by the control group while no significant differences in applicability of methods was identified by cognitively impaired subjects. Cognitively impaired subjects were capable to use the majority of techniques. Subjects differed in their opinion on the most applicable technique. Most difficulties were encountered with the use of swing weights, in which some subjects employed shortcut strategies. The results of this pilot study suggest that subjects with a mild cognitive impairment are willing and able to use multi-criteria elicitation methods to determine the relative importance of multiple-criteria in a decision context. No preference with regard to any of the methods was identified. In the choice of method, methodological and practical issues as well as the decision context have to be taken into account.

Introduction

A recent health care trend is the increased involvement of patients in decision making, for instance in decision making regarding screening decisions and oncology management (1-4). Historically, clinicians and patients were assumed to share the same goal regarding treatment. In recent years incongruence was identified between patients and clinicians' preferences with regard to disease management. Health professionals across all fields are increasingly encouraged to incorporate patients' preferences in treatment decision making. This so-called "shared-decision making" is seen as an important factor in ensuring quality improvement in healthcare (5-7).

Decision support tools have a high potential to inform about disease and to stimulate patients to consider their preferences with regard to disease and health management. Sometimes these aids include value elicitation tools to assist the patient in developing or clarifying these preferences. Multiple quantitative techniques to value the outcome of life threatening disease have been developed. Well known and tested methods are for instance the standard gamble or the time trade off technique (8). A drawback of the use of these techniques is that they are less applicable in diseases where no prolonging effect of treatment on remaining life-span is expected or in decision situations where treatment outcome does not differentiate between the alternative strategies. The latter decision problems are often value-sensitive, sometimes elective and are influenced by multiple decision criteria (9, 10). Health outcomes but also non-health outcomes and process characteristics are important in decision making (11). If multiple decision criteria are considered, the choice of treatment as decision criteria can be conflicting.

Multi-criteria decision analysis (MCDA) is used to manage multiple criteria in value sensitive decision making (12). MCDA methodology covers a range of techniques that can potentially assist patients in exploring their preferences in decision situations that include multiple courses of action and the multiple criteria. MCDA methods integrate objective measurement with value judgment and aims to organize and synthesize information in a systematic manner. Most MCDA techniques consist of two stages, an information gathering and an information processing stage (12).

The most observable differences between MCDA techniques are found in the information processing stage. In this stage, the value of outcomes is judged and the importance of the decision criteria is determined. Traditionally, multi attribute utility theory (MAUT) is regarded as the methodological standard in MCDA. MAUT is

characterized by a complex assessment procedure that hinders practical clinical application. Alternative weight elicitation techniques, partly based on other theoretical methods, have been developed.

The effect of the format of the rating scales, the explicit focus on performance range of alternatives and the framing of the decision differs between methods. It is suggested that these methods are prone to inconsistency and behavioral issues that may impair their usefulness (13-15) . The use of MCDM techniques is considered to be a cognitively demanding process which might be difficult to achieve in patients who are faced with health care decisions (16). In earlier research no unfaltering elicitation method was identified (14), but these methods have been successfully used to elicit patient preferences with regard to health and disease management (17-20). In geriatric these patients, the use of MCDA techniques might be complicated by the cognitive impairment which is a disease symptom in stroke.

As our general aim was to elicit patient preference in stroke, we needed to test the applicability of MCDA weight elicitation techniques in cognitively impaired patients. We conducted a pilot study which compared five weight elicitation techniques on their feasibility in multi-criteria weight preference elicitation in cognitively impaired subjects. The performance of the cognitively impaired subjects was compared to a healthy control group.

Methods

Study sample

Between January and June of 2006 a convenience sample of sixteen cognitively impaired subjects was recruited by the psychology ward of the Roessingh centre for rehabilitation. At the same time, twelve healthy controls were recruited from the staff. Inclusion criteria for the cognitively impaired subjects were: (1) stroke or other disease with mild to moderate cognitive impairment, and (2) pre-disease understanding of written and spoken Dutch language. Subjects with severe aphasia were excluded. Subjects were contacted by the first author. A short summary of the potential use of individual preferences in health care decision making was provided and the aim of the experiment was explained. If a subject agreed to participate their cognitive ability was tested with the mini-mental state examination (MMSE). Cognitively impaired subjects with a MMSE score lower than 20 were excluded, as well as healthy subjects with a MMSE score lower than 30. All cognitively impaired subjects and controls had the Dutch nationality. Subject characteristics are presented in table 1.

Table 1. Subject characteristics (average and range)

	Cognitively impaired subjects	Healthy subjects
N	16 (11 male, 5 female)	12 (2 male, 10 female)
Age	53 [25-76]	28 [22-43]
MMSE	28.8 [25-30]	30

Decision context

All cognitively impaired subjects were currently enrolled in a post-stroke rehabilitation program. The impairment that was most relevant to a subject was chosen as the decision problem. In most subjects this was a loss in arm or walking function. Two subjects identified memory loss as their most important impairment. Four treatment characteristics were selected as decision criteria, which were duration, user-friendliness, risk, and functional outcome of treatment. The number of decision criteria was restricted to four to limit the burden on the subjects. Two alternative treatment scenarios were compiled using quantitative and qualitative statements, depending on the nature of the criteria. The ranges of treatment duration were quantitatively expressed in weeks (with a minimum of 1 week and a maximum of 6 weeks). The type

of risk was qualitatively described depending on the decision context as either a falling accident during a practice session, shoulder pain as a result of arm function training, or increased confusion after cognitive training due to overload. The likelihood of occurrence was arbitrarily set between a minimum of "10 out of 100" and a maximum of "25 out of 100" subjects. Qualitative statements were used for the criteria user-friendliness (minor or major daily impact) and end-result (cognitively impaired subjects were asked to express the result they strived for and the result they would feel disappointed with). The scenarios were presented to the cognitively impaired subjects.
To explain the general etiology of a stroke and its functional consequences a written brochure was distributed to healthy subjects. Subsequently, two predetermined treatment scenarios were presented.

Data collection

A paper-and-pencil questionnaire was distributed in which the five different weight elicitation methods were arranged randomly. The questionnaire included written instructions on the use of each method and further explanation was given by the research assistant. Then the subjects determined the relative priority of the four decision criteria. The subject performed each weight elicitation method under supervision of the research assistant. Subsequently, the difficulty of the method was judged on a numeric rating scale ranging from 1 (difficult) to 10 (easy). The research assistant conducted a short structured interview, which discussed the 1) clarity of the written manual; 2) difficulty of the weight elicitation task; 3) face validity in the context of the decision problem and 4) feasibility of the method in a practical setting. After qualitative information was obtained, the subjects rated these characteristics of the method on a five-point Likert-scale ranging from very good (or easy) to very poor (or difficult). The procedure was cut short after one hour to avoid fatigue. As a result not all cognitively impaired subjects completed all weight elicitation methods. All healthy subjects completed the questionnaire within the hour.

MCDA weight elicitation techniques

The feasibility of Simple Multi Attribute Rating Technique using traditional weighting by point allocation (SMART) and swing weighting (SWING), Kepner-Tregoe analysis (KT), the Analytic Hierarchy Process (AHP), and discrete choice experiment (DCE) was determined. In SMART weighting, the criteria are first ranked in order of priority. The

least important attribute (criterion) is given a reference weight of 10, or the most important attribute is given a reference weight of 100. The importance of the other attributes is judged relative to the reference criterion. The ratings are normalized to sum to 1. SWING weighting is a further adaptation of SMART. In SWING the subject is presented with the most negative treatment scenario (all criteria at their lowest performance level). Then, the attribute is selected for which a shift to maximal performance would lead to the highest value improvement of the scenario as a whole. This is done for all criteria; next 100 points are allocated among the criteria to reflect the relative priorities.

The first step in KT weighting is the identification of the most important criterion. This criterion is given a reference weight of 10. All other criteria are judged relatively to the first on a numerical rating scale from 10 (equally important) to 1 (not very important). In KT the scores are usually not normalized but for the sake of our comparison we chose to normalize the scores to sum to 1 (21).

In AHP weighting, judgments are made on the relative priority of criteria on a scale ranging from 1 (equally important) to 9 (absolutely more important) using pair wise comparisons. All criteria are mutually compared so each subject is presented with six comparisons of two criteria. The numerical judgments and their reciprocals are put in a matrix and the criteria weights were calculated from the matrix using the principal eigenvector method (22).

In the DCE the subject is presented two possible treatment scenarios that are described by a performance level for all four criteria (the best and worst outcome). The scenarios were generated in an orthogonal main effects plan using SPSS Orthoplan. A fractional design of 16 scenarios was created. One scenario was selected to be compared with all other scenarios. This resulted in fifteen two-scenario choice sets. The desirability of the levels was determined using regression analysis. Criteria weights were calculated by normalizing the difference in the desirability of the two levels of all attributes (23).

Statistics

Descriptive characteristics (median and range) were used to describe the performance of each method on the numerical rating scale and the four Likert-scale questions. Differences between methods were analyzed using a dependent non-parametric test for repeated measures (Friedman) for both the cognitively impaired and the healthy subjects.

Each of the five multi-criteria weight elicitation methods resulted in a criteria weight and criteria ranking of the four criteria. Weight ratios were calculated (the difference in weight between the 1st and 2nd ranked criterion and the 1st and 4th ranked criterion). A mixed model analyses for repeated measurements was used to test the effect of method on criteria weights.

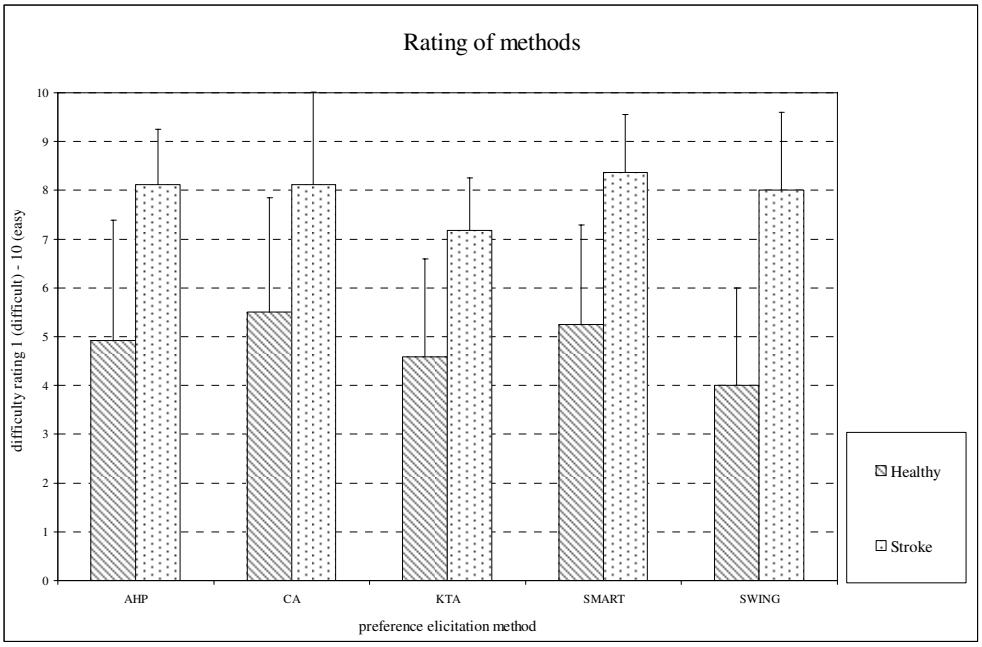
The percentage of rank reversals for each method was calculated (the number of rank reversals between each method and a reference ranking divided by the total number of observations). SMART ranking was taken as a reference standard, because it is the only method that includes ranking of criteria in the weight elicitation procedure. The average percentage of rank reversals was presented for the criterion "result", but the trend seen in frequency of rank reversals with regard to influence of method was comparable for all criteria. A non-parametric test for paired measurements was used (Friedman) to test whether there was a significant effect of elicitation method on the rank order of criteria within subjects. If an overall significant effect of method was found on rank order, methods were compared using a paired non-parametric test (Wilcoxon).

Results

Difficulty of methods

No significant differences were found in the rating of methods in cognitively impaired subjects, although the DCE and SMART were rated most easy. A significant difference was found in difficulty rating of the methods in the healthy subjects, with DCE ranked as most easy (Z=10,00; p=0,04). In general, cognitively impaired subjects gave a lower difficulty rating to all methods compared to healthy subjects (figure 1). They also used a smaller part of the rating scale compared to healthy subjects.

Figure 1. Difficulty rating of the weight elicitation methods (mean and standard deviation)



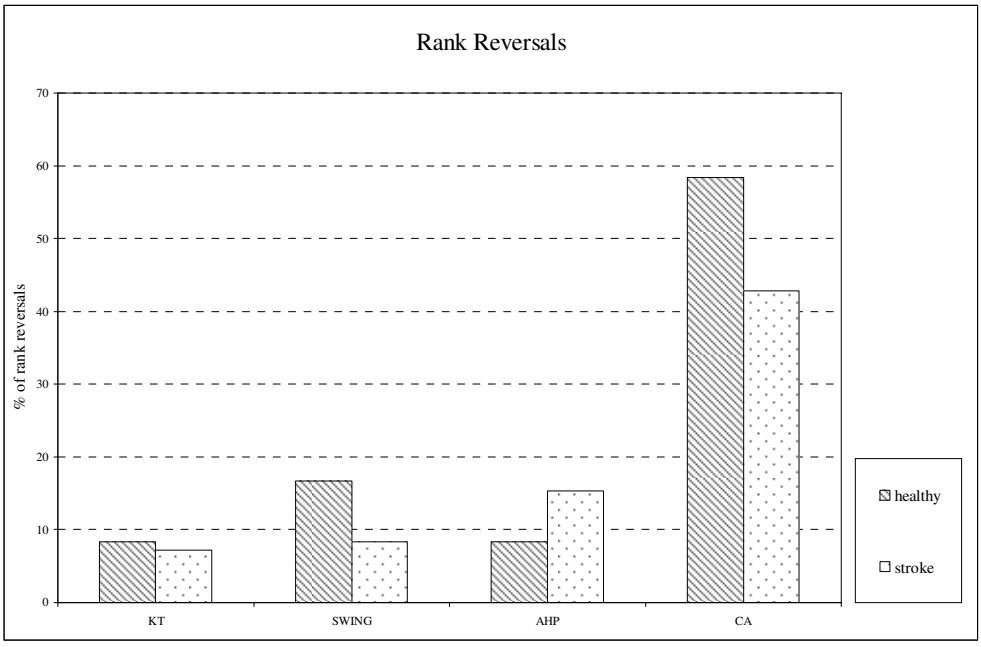
The trend towards more positive and less diverging scores in cognitively impaired subjects was also found in the feasibility ratings. No significant differences were found on any of the items in the cognitively impaired subjects. In the healthy subjects a significant difference was found regarding general understanding of task, with the DCE ranked best (Z=20,16; p=0,00). A significant difference was found regarding the

difficulty of the task (Z=13,23; p=0,00) with AHP being judged as most easy. A significant difference was found in face validity of the tasks with the DCE ranked as the most similar to regular health care decision making (Z=13,46; p=0,01). No significant preference was found in the use of methods in regular practice.

Ranking of criteria

Each method resulted in a ranking of criteria priority. The average ranking of criteria was (1) result, (2) risk, (3) use of aids, and (4) treatment duration. On a group level, a significant difference was found in the ranking of the criteria result (p=0.000) and risk (p=0.002). The number or rank reversals between the ranking that resulted from the DCE, AHP, SWING and KT weights compared to the explicit ranking of criteria during SMART weight elicitation is presented in figure 2. The highest percentage of rank reversals was seen between the DCE and SMART.

Figure 2. Rank reversals between methods



Notes: The percentage of rank reversals in cognitively impaired and healthy subjects for all methods compared to SMART ranking for the criterion result.

Post hoc analysis revealed that only the ranking that resulted from the DCE weights was significantly different from the other methods (KT (Z=3,40; p=0,001), SMART (Z=3,27; p=0,001), SWING (Z=3,10; p=0,002) and AHP (Z=3,31; p=0,002)). As is shown in table 2, the range between minimum and maximum weight and the ratio between 1st and 2nd ranked criteria was largest for SWING, and smallest for the DCE.

Table 2. Criteria weight ratios (mean and standard deviation)

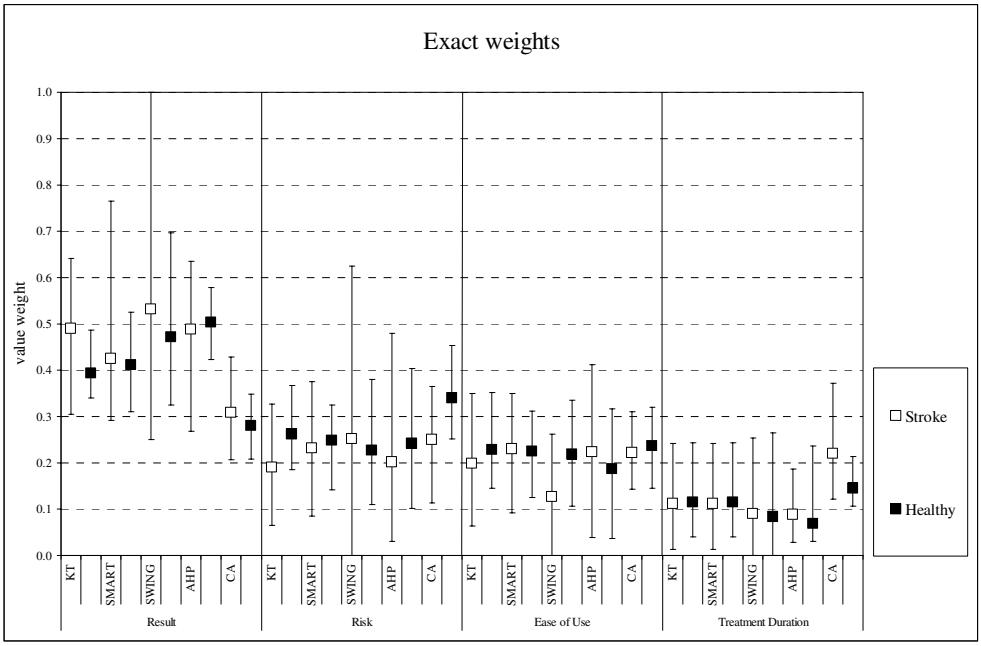
Weight elicitation method	Range 1st/4th	Ratio 1st/2nd
KTA	0,34 (0,16)	1,78 (0,89)
SMART	0,30 (0,18)	1,83 (1,78)
SWING	0,43 (0,30)	2,55 (3,72)
AHP	0,46 (0,11)	1,90 (0,71)
DCE	0,21 (0,09)	1,35 (0,27)

Criteria weights

The average and range of criteria weights are shown in figure 3. There was agreement in criteria ranking, as the criterion "result" received the highest mean weight in all methods, followed by "risk", "use of aids" and "treatment duration".

The DCE shows the smallest weight range. SMART and SWING have large weight ranges. There is a significant effect of the elicitation method on the weight of a criterion for the criteria risk (F=10,74; p=0,00) and result (F=12,73; p=0,00). Post-hoc analysis showed that only the DCE weights differ significantly from the other weights.

Figure 3. Criteria weights



Notes: Exact weights for the five weight elicitation methods and the four criteria in cognitively impaired and healthy subjects (mean and 10 and 90% percentiles).

Discussion

Previous research into the role of cognitive impairment on the use of self-reported questionnaires shows lower reliability and validity in an older and cognitively impaired population (24). Furthermore, cognitively impaired patients are known to avoid the use of end-points of a scale or use only limited categories in rating or verbal scales (25). The aim of this study was to determine if cognitively impaired subjects would be able to make the preference trade-offs necessary for the weighting of criteria. The cognitively impaired subjects were willing and able to participate in the questionnaire. All subjects but one completed the questionnaire.

The results of this study indicate that SWING weighting was judged significantly more difficult than the other techniques. The quantitative analysis of results did not indicate a preference for any method with regard to understanding of the written explanation, perceived trustworthiness or face validity. The qualitative interviews revealed that the explicit inclusion of performance ranges of the criteria caused discomfort in some subjects. Although the explicit inclusion of performance ranges is an important theoretical advantage, it seems that cognitively impaired subjects had trouble incorporating it in the weighting of criteria importance. As a result, they employed a short cut strategy by completely omitting some criteria to complete the weight elicitation exercise.

Although not statistically significant, the DCE weighting procedure seemed to be preferred in the cognitively impaired subjects. In our experience the subjects easily recognized the choice task presented. Furthermore, a DCE asks for ordinal judgments instead of ratio estimates, which means no numerical judgment is necessary while expressing priority. A theoretical drawback of the use of a DCE is that the number of comparisons that is required for priority estimations on an individual level increases dramatically with an increasing number of attributes. The number of comparisons necessary for reliable value estimates can be daunting for the subject, especially if many alternatives or criteria are presented simultaneously. In that case, a practical alternative could be the use of pair-wise comparisons of single criteria, like used in AHP. According to Dyer and Forman (26) pair-wise comparisons are easy to make, discuss, justify and agree on. Although using inexact words and relative judgments are thought to alleviate a discomfort that people feel when forced to put hard numbers on subjective

feelings (26, 27), in this study most subjects seemed at ease with giving relative priorities using both the verbal (AHP) as well as the numerical (KT) scale (27).
With regard to the judgment of the performance of methods some difficulties were encountered. A gold standard for weight or rank order of criteria is lacking and statistically there are no perfect measures available to determine whether two sets of weights are equal. Previous authors used exact weights, normalized weights, weight ratios, weight ranges, and correlation between methods to compare weights between methods and thereby judge performance. The use of different measures for equality of weights complicates the comparison of the results of our study with previous research. In our study, DCE weights exhibited the smallest weight range and ratios. KT and AHP showed slightly higher weight ranges and ratios, while the largest weight range and ratio was seen in SMART and SWING. Comparable differences in weight distribution were found previously (27, 28). It is suggested that differences in criteria weights might not reveal underlying differences in the relative importance of weights, but stem from differences in the way the methods lead the decision makers to choose their responses from a limited set of numbers. If so, differences in the exact weights between methods can be attributed to the elicitation procedure rather than to faults in judgment of the subjects. An explanation for the significantly different weights in DCE might be that the DCE is the only weight elicitation method that estimates rather than calculates weights. Weight estimation is necessary because a fractional set of scenarios is judged.
Limitations of this study include the small sample size and weak sampling procedure, which could have resulted in an absence of statistical significant differences between the methods and the groups. No correction for an order effect of the methods was made. Additionally, preference for a method could be masked by adherence to expectations, because subjective verbal and numerical rating scales were used and the research assistant was present during the assessment. A major drawback of the study was that the decision context included no real decision. This was due to ethical considerations as the results of this study could have influenced the attitude of cognitively impaired subjects towards their current treatment.

Conclusions

The results of this pilot study suggest that subjects with a mild cognitive impairment can use multi-criteria elicitation methods to determine the weight of criteria in a decision context. If cognitively impaired subjects are sufficiently informed about the aim of weighting, they are both willing and able to perform the elicitation procedures necessary for multi-criteria weight elicitation. With regard to a preference for a method, in cognitively impaired subjects the same methodological and practical issues can be identified as in a healthy population and based on the results of this study no preference can be expressed. Any method can be used if the methodology is suited for the decision problem and the decision task is sufficiently explained to the subjects (29). Weight elicitation remains an imperfectly reliable process in cognitively impaired as well as healthy subjects (28). Based on this pilot study we suggest the use of a DCE if weights are calculated on a group level or if a full set of comparisons can be made. If the aim is to calculate individual weights in decisions that involve many criteria, AHP or KT weighting may be good alternatives. Future steps would be to repeat the study in a larger sample of cognitively impaired cognitively impaired subjects in a real decision situation, preferably with more sensitive measures to determine the applicability of methods.

References

1. Bishop AJ, Marteau TM, Armstrong D, Chitty LS, Longworth L, Buxton MJ, et al. Women and health care professionals' preferences for Down's Syndrome screening tests: a conjoint analysis study. Bjog. 2004 Aug;111(8):775-9.
2. Spencer K, Aitken D. Factors affecting women's preference for type of prenatal screening test for chromosomal anomalies. Ultrasound Obstet Gynecol. 2004 Dec;24(7):735-9.
3. Aristides M, Chen J, Schulz M, Williamson E, Clarke S, Grant K. Conjoint analysis of a new Chemotherapy: willingness to pay and preference for the features of raltitrexed versus standard therapy in advanced Colorectal Cancer. Pharmacoeconomics. 2002;20(11):775-84.
4. Fallowfield L, McGurk R, Dixon M. Same gain, less pain: potential patient preferences for adjuvant treatment in premenopausal women with early breast cancer. Eur J Cancer. 2004 Nov;40(16):2403-10.
5. Robinson A, Thomson R. Variability in patient preferences for participating in medical decision making: implication for the use of decision support tools. Qual Health Care. 2001 Sep;10 Suppl 1:i34-8.
6. Frosch DL, Kaplan RM. Shared decision making in clinical medicine: past research and future directions. Am J Prev Med. 1999 Nov;17(4):285-94.
7. Coulter A. Partnerships with patients: the pros and cons of shared clinical decision-making. J Health Serv Res Policy. 1997 Apr;2(2):112-21.
8. Ryan M, Scott DA, Reeves C, Bate A, van Teijlingen ER, Russell EM, et al. Eliciting public preferences for healthcare: a systematic review of techniques. Health Technol Assess. 2001;5(5):1-186.
9. Trevena L, Barratt A. Integrated decision making: definitions for a new discipline. Patient Educ Couns. 2003 Jul;50(3):265-8.
10. Edwards W, Barron FH. SMARTS and SMARTER: Improved Simple Methods for Multiattribute Utility Measurement. Organizational Behavior and Human Decision Processes. 1994;60(3):306-25.
11. Ryan M. Using conjoint analysis to take account of patient preferences and go beyond health outcomes: an application to in vitro fertilisation. Soc Sci Med. 1999 Feb;48(4):535-46.
12. Belton V, Steward TJ. Multiple Criteria Decision Analysis: An Integrated Approach. Londen: Kluwer Academic Publishers; 2003.
13. Weber M. Decision making with incomplete information. European Journal of Operational Research. 1987;28(1):44-57.
14. Weber M, Borcherding K. Behavioral influences on weight judgments in multiattribute decision making. European Journal of Operational Research. 1993;67(1):1-12.
15. Nitzsch Rv, Weber M. The Effect of Attribute Ranges on Weights in Multiattribute Utility Measurements. Management Science. 1993;39:937-43.
16. Dolan JG, Bordley DR. Involving patients in complex decisions about their care: an approach using the analytic hierarchy process. J Gen Intern Med. 1993 Apr;8(4):204-9.
17. Barry MJ. Health decision aids to facilitate shared decision making in office practice. Ann Intern Med. 2002 Jan 15;136(2):127-35.
18. Dolan JG. Medical decision making using the analytic hierarchy process: choice of initial antimicrobial therapy for acute pyelonephritis. Med Decis Making. 1989 Jan-Mar;9(1):51-6.
19. Singh J, Cuttler L, Shin M, Silvers JB, Neuhauser D. Medical decision-making and the patient: understanding preference patterns for growth hormone therapy using conjoint analysis. Med Care. 1998 Aug;36(8 Suppl):AS31-45.
20. Ryan M, McIntosh E, Dean T, Old P. Trade-offs between location and waiting times in the provision of health care: the case of elective surgery on the Isle of Wight. J Public Health Med. 2000 Jun;22(2):202-10.
21. Kepner CH, Tregoe BB. The new rational manager: Princeton Research Press; 1981.
22. Saaty TL. How to make a decision: The analytic hierarchy process. European Journal of Operational Research. 1990;48(1):9-26.

23. Green PE, Srinivasan V. Conjoint analysis in consumer research : issues and outlook. [Stanford, Calif.]: Graduate School of Business, Stanford University; 1978.
24. Seymour DG, Ball AE, Russell EM, Primrose WR, Garratt AM, Crawford JR. Problems in using health survey questionnaires in older patients with physical disabilities. The reliability and validity of the SF-36 and the effect of cognitive impairment. J Eval Clin Pract. 2001 Nov;7(4):411-8.
25. Chibnall JT, Tait RC. Pain assessment in cognitively impaired and unimpaired older adults: a comparison of four scales. Pain. 2001 May;92(1-2):173-86.
26. Dyer RF, Forman EH. Group decision support with the Analytic Hierarchy Process. Decision Support Systems. 1992;8(2):99-124.
27. Shoemaker PJH, Waid CC. An experimental comparison of different approaches to determining weights in additive utility models. Management science. 1982;28:182-96.
28. Pöyhönen M, Hämäläinen RP. On the convergence of multiattribute weighting methods. European Journal of Operational Research. 2001;129(3):569-85.
29. Srivastava J, Connolly T, Beach LR. Do Ranks Suffice? A Comparison of Alternative Weighting Approaches in Value Elicitation. Organizational Behavior and Human Decision Processes. 1995;63(1):112-6.

Chapter 4

The Effect of Information on Preferences stated in a Choice Based Conjoint Analysis.

J.A. van Til
A.M. Stiggelbout
M.J. IJzerman

Patient Educ Couns. 2009 Feb;74(2):264-71.
Reprinted with permission

Abstract

The objective of the current study was to investigate the effect of a priori information on preferences for treatment elicited in a discrete choice experiment.

A convenience sample of 100 subjects was randomly split into two groups. The groups received minimal or extensive information on the treatment of ankle and foot impairment in stroke. Then, they participated in a discrete choice experiment. Possible treatment was described using eight decision criteria with two to four levels each. Part-worth utility coefficients for the criteria levels, criteria importance, and overall treatment preference were estimated. It was tested whether the amount of information that was received influenced the outcome of the discrete choice experiment.

In the extensively informed group fewer reversals in the expected order of part-worth utilities were found. Criteria importance for four of the eight criteria and criteria importance ranking between the minimally and extensively informed subject groups were significantly different. The difference in part-worth utility of the levels had a minor effect on the predicted utility of the available treatments. The lower number of level rank reversals in the extensively informed subjects indicates a better understanding of outcome desirability and thus a better understanding of the decision task. The effect of more extensive information on predicted treatment preference was minimal.

While interpreting the results of a discrete choice experiment, the effect of prior information on the decision problem has to be taken into account. Although information seems to increase the understanding of the decision task, the outcome of the DCE can also be directed by information. Also, more extensive information increases the cognitive burden which is placed on the subjects. Future research should focus on the exact nature and size of the effect of information on the outcome of a DCE and the results of this study need to be clinically validated.

Introduction

In recent years, assessment of health care preferences has been promoted in health care decision making (1-3). On a macro level, policy makers are interested in the values and preferences of the community to explain or predict the uptake of health care programs (4). On a micro level the relevance of patient preferences in decision making is put forward in the models of shared and informed decision making (5, 6). As a result the use and usability of preference elicitation techniques are becoming domains of interest in health care.

A preference elicitation technique that is often used to evaluate the mode and effect of health care is a conjoint analysis (CA) (7). A specific form of CA is a discrete choice experiment (DCE). In a DCE a subject is asked to choose the preferred health state, product or service from a set of two or more scenarios. The hypothetical scenarios are constructed from short statements (levels) on the key characteristics (attributes or criteria) of the health state, product or service. A subject is expected to weigh criteria importance and level attractiveness during the decision task. A set of part worth utilities for the criteria levels is estimated from the observed choices of the subject. A part-worth utility is the value of a criterion level to the subject. More attractive levels have a higher part-worth utility. With the part worth utilities for all levels, the relative importance of decision criteria and the overall preference for treatment can be estimated (8-10).

In earlier studies some methodological issues were raised with regard to the application of discrete choice experiments (11, 12). It is known that the framing of the scenarios can influence outcome (12, 13). No previous studies have focused on the effect of a priori information on the outcome of a DCE. This is important, because although information is seen as a prerequisite for decision making, it is known that the order, type and framing of information can influence the way information is used to make real-life decisions (14-16). Moreover, it was found that observed treatment preference is influenced by the information that is available to a patient (17). It is unknown whether preferences elicited in a hypothetical situation, such as a DCE, are also influenced by the information that is available to a subject prior to partaking in the experiment. In DCEs, much attention is focused on the description of the scenarios by ensuring that relevant information is presented in a comprehensible way in the description of criteria levels (9). It could be hypothesized that the outcome of a DCE study is influenced by

the information which is available to a subject. If so, more attention is required to determine how much and which information is presented prior to a DCE in developing patient experiments.

Therefore, the aim of the current study was to determine if informing subjects with the actual harms and benefits of treatment and the available treatment options in an informational brochure before participating in a DCE influences its outcome, i.e., the part-worth utilities of criteria levels, the importance of decision criteria, and the predicted preference for treatment.

The decision context in the study was the treatment of ankle and foot impairment in stroke. In stroke, a deviant position of the ankle and foot that hinders standing and walking is a common disability. Determining best treatment in ankle and foot impairment is a value based decision, as the evidence of the effect of the treatment alternatives on patient performance is limited (18, 19). Surgical, technological and orthotic treatment alternatives are available, which differ widely in terms of impact of treatment to the patient, in comfort and cosmetics, and in the required use of walking aids or braces during and post-treatment. This makes the decision for treatment in ankle foot impairment extremely suitable for a trading exercise such as a DCE.

Methods

Study design and procedure

The study was reviewed by the Human Subjects Ethics Review board of the Roessingh Centre for Rehabilitation and was exempted from formal approval because it was a onetime experiment without emotional impact to subjects. A convenience sample of 80 bachelor and master students and 20 colleagues in the research department were approached for the study and agreed to participate. All subjects were familiar with health research, as they were involved in a health research project or in a health oriented study program. The subject sample was randomly split into two equal groups using block randomization. Both groups received a short flyer which explained the decision context. Additionally, one group received a more extensive informational brochure. All subjects received one of four versions of a discrete choice experiment (DCE). The informational brochure and the design of the experiment are described in the next paragraph. The subjects were given time to read the information at their own pace before participating in the DCE. Of the whole sample, 41 (21 male and 20 female, mean age 31,0, SD. 11,6) subjects in the minimally informed group and 45 subjects (25 male and 20 female, mean age 29,9, SD. 12,9) in the extensively informed group returned the completed DCE.

Design and content of the informational brochure

The short flyer consisted of 1-page of text which described a stroke as being an interruption of the blood flow to one side of the brain with an effect on the functioning of the muscles on the other side of the body. The decision problem was described as the availability of multiple treatment alternatives for the ankle and foot impairment with different short and long term consequences and with the preferred treatment being strongly dependent on personal preferences. The decisive criteria and the range of levels were described to the subjects using general statements, i.e.: “The duration of a treatment is the time between the first contact with the physiatrist and the moment when the end-result of treatment is final. Treatment duration varies between 1 and 9 months between treatments” or “The result of treatment is the expected benefit for the patient in terms of functioning. A successful treatment can result in improved foot position, increased ankle stability and/or unlimited choice of footwear”.

The extensively informed group received the short flyer along with an extended informational brochure. In five pages of information the specific treatment alternatives were detailed. Each of the five available treatment alternatives(19) was systematically described along the lines of the decision criteria (which are presented in table 1). An example of an extensive description can be found in appendix 1. Positive or negative aspects of each treatment were explicitly stated and a short patient testimonial was added along with some pictures of the treatment. Technical language was not included in the brochure. The comprehensibility of the flyer and the brochure was tested in eight stroke patients with ample experience with ankle and foot impairment. Most patients received at least two of the treatments described in the brochure (in successive order). The pilot testing resulted in some rephrasing of evidence based outcomes such as the presentation of success and risk proportions. Some patients preferred percentages to the proportions which were initially presented. Changes were made accordingly, and the decision was made to present proportions along with percentages, in the brochure as well as in the description of criteria levels.

Discrete choice experiment

The decision criteria were based on a decision tree that had been created in collaboration with an interest group of physiatrists and which was subsequently judged by an expert team in an earlier phase of the study(19). In collaboration with four experts the decision tree was adapted to meet the demands put on decision criteria by the methodology (13). During a meeting each treatment alternative was described on all criteria by the experts (column 1; Table 1). The descriptions were restructured to a successive series of outcome definitions in which duplicate descriptions were combined and some intermediate categories were added. Eight criteria with two to four levels were formulated to cover all treatment alternatives. The phrasing of criteria levels retained as much as possible of the experts original description of the consequences of treatment. The criteria and levels are presented in Table 1. Eight patients with ample experience in the treatment of ankle-foot impairment judged the face validity of a set of example choice tasks derived from the criteria and levels as being adequate.

The random combination of eight criteria with two, three or four levels yielded a potential of (4^{6}*3*2 =) 24576 different treatment scenarios. It is not feasible to obtain a subject's judgment on that many treatment scenarios, so statistical design techniques were used to limit the number of scenarios to a fractional set of 160 scenarios while

maintaining enough variety in the scenarios to estimate main effects. It was verified that no dominant choice-sets (with all levels in one treatment scenario being more attractive) were included. Previous experience taught us that a subject is able to judge 20 two-scenario choice sets (40 scenarios), before becoming tired or bored, so 80 two-scenario choice sets were divided over four different versions of the experiment. These versions of the experiment were distributed equally over the two groups. The experiment was preceded by a short introduction on the growing importance of patient choice in health care and discrete choice experiments were introduced as a possible way to elicit patient preferences for treatment. The importance of trading behavior in determining preference was highlighted with some examples (E.g. "if you are concerned about the impact of treatment on your personal life, you might prefer a treatment that has a slightly worse outcome, but only takes a limited amount of time to complete"). The subjects were asked to select the treatment they would prefer in the case of ankle and foot impairment after stroke from each choice set. For an example of a decision task see appendix 2.

Outcome measures

The choice sets were generated using commercially available software (20) which was also used to estimate the part-worth utility coefficients of the utility function at the group level. A multinominal logit technique was used and a linear main effects additive model was fitted. To estimate part-worth utility coefficients at the individual level hierarchical bayes analysis was performed.

From the part-worth utilities (β) of the levels of the criterion, the importance (W) of a criterion (i) was estimated by calculating the coefficient range (τ_i), which is the difference between the smallest (negative) part-worth utility and the largest part-worth utility within the criterion levels of i, and dividing it by the sum of the coefficient ranges τ_i for the eight criteria (i = 1-8) (equation 1).

(equation 1)

$$W_i = \frac{\tau_i}{\sum_{i=1}^{8} \tau_i}$$

Subjects were classified based on criteria importance (21). If no criterion is more important than 25% a subject is categorized as a balanced chooser. Subjects that choose

a treatment based on one dominant criterion (thus have a distinct preference for that criterion) show an extremely skewed preference distribution. Subjects with a distinct preference for one criterion were subdivided based on the most important criterion. The 25% threshold was arbitrarily chosen because it is twice the importance that is expected compared to a situation when all criteria are equally important. With a total of eight criteria, if a single criterion has an importance of > 25% it is almost always dominant in establishing treatment preference (the best performing treatment on this criterion is the preferred treatment).

The utility (U) of a treatment (AFO (ankle-foot orthotic), OS (orthopeadic footwear), EFES (external functional electrical stimulation), IFES (implanted FES) and STS (soft tissue surgery)) was derived by summing the part-worth utilities which correspond to the level of the criterion (i) that describes the treatment alternative (treatment) for all criteria (i=1-8) (equation 2). The preferred treatment is the treatment with the highest utility.

$$U(treatment) = \sum_{i=1}^{8} \beta_i(treatment) \qquad \textit{(equation 2)}$$

Hypothesis and statistical analysis

The main assumption of this study was that all relevant information on the treatment alternatives is included in the description of the attribute levels in the choice experiments. Therefore, the null hypothesis was that the extensiveness of the brochure would not change subjects' preferences for treatment.

We determined the expected order of criteria levels prior to conducting the experiment. The levels with a natural ordering (criteria 1, 5 and 8) were expected to be ranked accordingly, with shorter duration and lower risk and higher success rates being preferred (a<b<c<d). Although a natural ordering did not exist in the other criteria, we expected non surgical treatment to be preferred to the surgical alternatives (a<b,c) in criterion 2, temporary aids with shorter donning and doffing to be preferred in criterion 3 (a<b<c<d), and skin irritation to be preferred to pressure sores (a<b) in criterion 4. Criteria 6 and 7 were atypical because no a priori expectation on the order of some the levels could be identified. Invisible and imperceptible aids were expected to be

preferred to visible and perceptible aids (a>d) in criterion 6 and the possibility of barefoot walking without aids was expected to be preferred to the other levels (d>a,b,c) in criterion 7. The expected order of criteria levels was compared to the observed order of the part-worth utilities. Agreement can be considered as confirmation of face validity of the level descriptions and is used as a performance evaluation of subjects.

Descriptive analysis of part-worth utility order, criteria order and treatment preference was performed. We expected (1) the sequence of part-worth utilities, (2) the importance ranking of criteria and (3) estimated treatment preference to be similar between the groups, if no effect of the extensive information was present.

A non-parametric Mann-Whitney U test was used to test whether there was a significant difference in the part-worth utilities of the criteria levels and the relative importance of the criteria between the extensively and minimally informed groups.

Table 1. The part worth utilities of the treatment levels

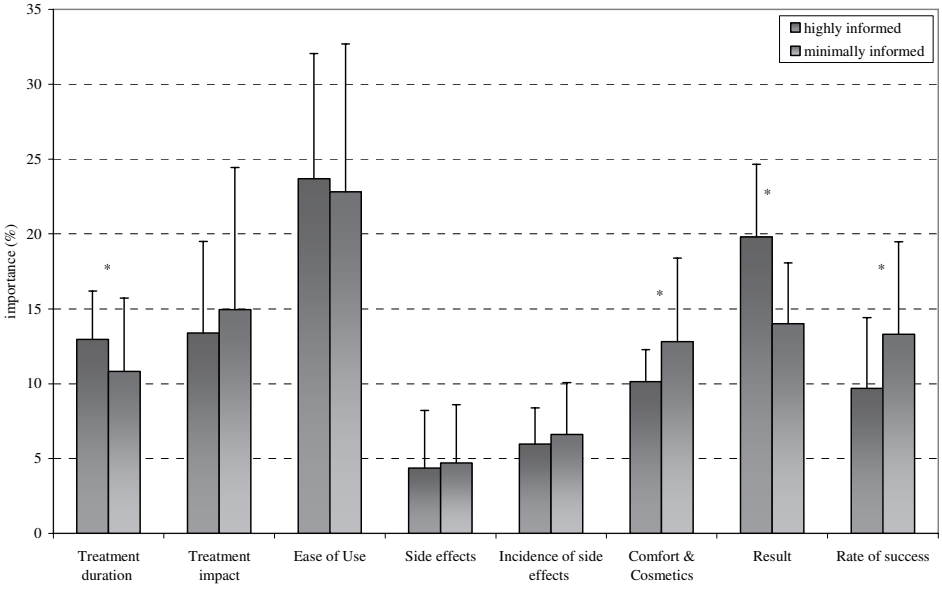
Criteria	Levels	extensively informed	minimally informed	Statistics	
		β (SD)	β (SD)	Z	p
1. Treatment duration	a. 1 month	1,42 (0,97)	3,50 (1,06)	-7,107	0,000
	b. 3 months	1,89 (1,49)	1,73 (1,16)	-0,290	0,772
	c. 6 months	-1,34 (1,30)	-2,84 (1,61)	-4,561	0,000
	d. 9 months	-1,97 (1,56)	-2,39 (1,27)	-1,288	0,198
2. Treatment impact	a. no surgery	2,65 (2,13)	3,98 (2,29)	-2,892	0,004
	b. surgery with implanted technology	-0,12 (2,59)	-1,37 (1,48)	-2,827	0,005
	c. surgery with tendon transfers	-2,53 (3,15)	-2,62 (2,09)	-0,765	0,444
3. Use of aids	a. temporary aid; donning/doffing 3	4,91 (2,62)	6,69 (2,92)	-2,659	0,008
	b. temporary aid; donning/doffing 10	3,28 (1,59)	2,78 (1,93)	-1,025	0,306
	c. permanent aid; donning/doffing 3	-3,46 (1,60)	-3,52 (2,60)	-0,177	0,859
	d. permanent aid; donning/doffing 10	-4,73 (2,67)	-5,94 (3,16)	-2,296	0,022
4. Complication type	a. mild complications	0,84 (0,96)	0,79 (1,44)	-0,571	0,568
	b. severe complications	-0,84 (0,96)	-0,79 (1,44)	-0,571	0,568
5. Complication rate	a. 1/100 (1%)	0,73 (1,17)	0,01 (1,07)	-2,750	0,006
	b. 5/100 (5%)	0,55 (1,21)	1,37 (1,10)	-2,935	0,003
	c. 10/100 (10%)	-1,28 (0,89)	-1,39 (0,91)	-1,301	0,193
6. Comfort & Cosmetics	a. not visible and not perceptible	2,88 (2,21)	3,03 (0,76)	-0,506	0,613
	b. perceptible	-0,06 (1,34)	0,15 (0,76)	-0,960	0,337
	c. visible	-0,74 (1,23)	-2,24 (1,25)	-4,751	0,000
	d. visible and perceptible	-2,08 (1,77)	-0,93 (1,24)	-3,195	0,001
7. Result	a. improved foot position (adapted foot-wear)	-2,42 (1,03)	-5,09 (1,06)	-7,458	0,000
	b. improved foot position (custom made shoes)	-0,74 (1,38)	1,37 (1,88)	-3,454	0,001
	c. improved foot position and ankle stability (adapted foot-wear)	-0,27 (1,37)	-1,68 (2,12)	-5,218	0,000
	d. improved foot position and ankle stability (custom made foot-wear)	3,43 (1,78)	5,39 (2,08)	-4,405	0,000
8. Success Rate	a. 99/100 (99%)	2,35 (1,63)	1,39 (1,93)	-2,261	0,024
	b. 95/100 (95%)	1,32 (2,03)	0,65 (1,72)	-1,595	0,111
	c. 90/100 (90%)	-1,12 (1,85)	0,40 (0,96)	-3,826	0,000
	d. 80/100 (80%)	-2,55 (1,64)	-2,43 (2,19)	-0,272	0,785

Results

Part-worth utilities

Some differences were found in the order of criteria levels between the two groups (table 1). The order of preference of the part-worth utilities in the criteria with a natural order was as expected for criterion eight ("success rate") in both groups. The expected order of preference was violated for criterion 1 in both groups and for criterion 5 in the minimally informed group. The estimated part-worth utility coefficients for the extensively (column 3) and minimally informed subject (column 4) groups are presented in table 1. Z statistics and p values are presented in column 5.
In the criteria with a prior expectation on the order of possible outcome levels (column 2), the level order was as expected for both groups.

Figure 1. The importance of treatment criteria



*Notes: average (with standard deviation) in determining treatment preference for the minimally and extensively informed subject group. *groups significantly different (p<0.05)*

In the criteria without prior expectations about order, the two middle levels were ordered similarly in the groups for the criterion "comfort & cosmetics" (6). An imperceptible aid was preferred above an invisible aid. For the criterion "result" (7) the preference for the two middle levels (b and c) differed between the groups. The benefit of ready-made shoes was valued higher in comparison to improvements in ankle stability in the extensively informed group, and this preference was reversed in the minimally informed group. With regard to differences in preferences between the groups, the most remarkable finding was that the extensively informed group had a higher acceptance of longer treatment duration and of the implantation of foreign materials, whereas the minimally informed group preferred non-surgical treatment and shorter treatment duration.

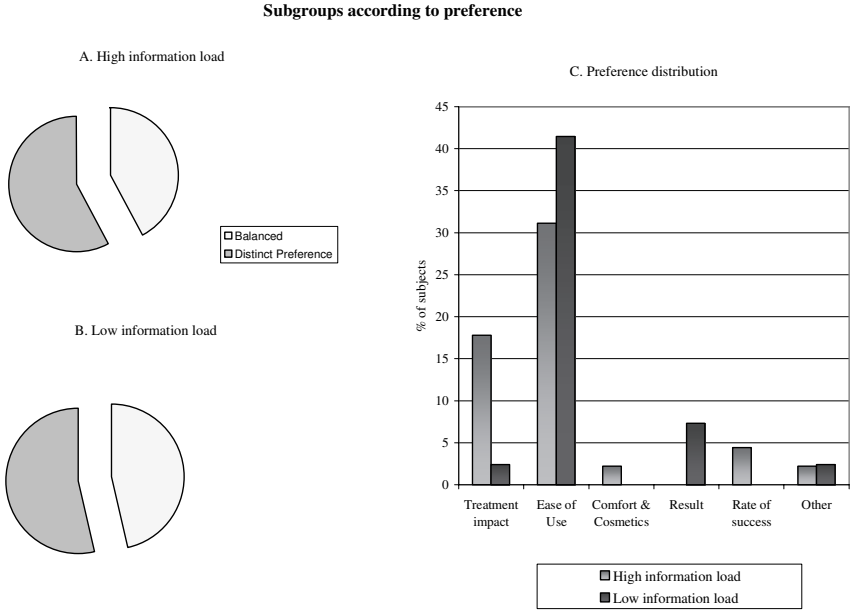
Average criteria importance

"Use of aids" was, on average, the most important criterion in both groups (figure 1). Treatment impact and result were ranked second and third in the minimally informed group, and vice versa in the extensively informed group. This reversal in importance ranking was probably caused by a significant difference in the relative importance of "result" (Z=-5,215; p=0,000) between the groups, because the difference in the average importance of treatment impact was negligible. For the lower ranked criteria, the criteria "success rate" (Z=-2,741; p=0,006) and "comfort & cosmetics" (Z=-2,145; p=0,032) were ranked higher and were deemed significantly more important in the minimally important group, while "treatment duration" (Z=-2,702; p=0,007) was more important in the extensively informed group.

Dominant criteria in treatment preference

From Figure 2a and 2b it can be seen that the proportions of subjects making a balanced choice or having a distinct preference for a criterion were about equal in both groups. The dominant criteria were different between groups, with a larger percentage of extensively informed subjects selecting a scenario based on "treatment impact", compared to "use of aids" in the minimally informed patient group (figure 2c).

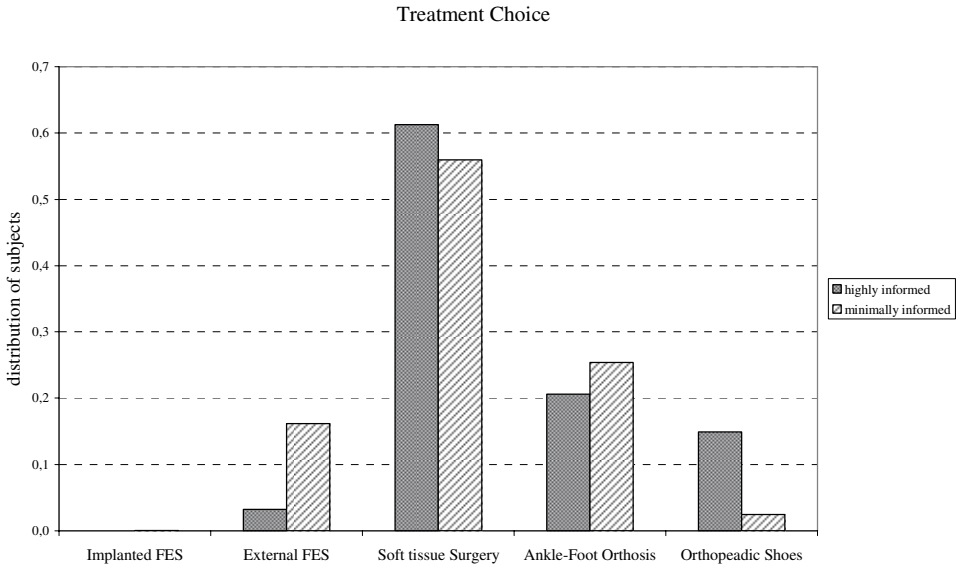
Figure 2. The distribution of subjects with regard to criteria preference.



Notes: A. The effect of minimal information on criteria balance. B. The effect of extensive information on criteria balance. C. Outline of the distribution of dominant criteria in treatment preference in the subject with a distinct preference for one criterion.

The difference between the two groups in criteria importance and part-worth level utilities had only a limited effect on treatment preference (figure 3). A slightly higher proportion of subjects in the extensively informed group preferred orthopedic shoes over external functional electrical stimulation.

Figure 3. The influence of information provision on the preferred treatment of the subject groups



Discussion

In the current study significant differences in preference estimates were found between two groups of subjects. Preference differences were mainly observed in part-worth utilities. It seems that more extensive information resulted in (1) a decrease in level order reversals in the criteria with a natural order; (2) a higher acceptance of negative treatment aspects in favor of a more positive treatment result and (3) a higher preference for ready-made shoes at the cost of ankle stability.

It might be that the decreased amount of rank reversals in the extensively informed group is an indication of a more analytical and higher quality analysis of preference prior to the experiment. It was previously suggested that the first part of a discrete choice experiment (DCE) is used to construct rather than express preferences (22). As a result of more information, it could be speculated that fewer preference "errors" are made during the experiment. This would argue in favor of providing extensive information prior to a DCE. The findings of this study also suggest an effect of information on the value judgments with regard to treatment preference. The higher acceptance of negative aspects of treatment highlights the effect that information might have on subjects' judgment of a positive outcome. For instance, it seems that the extensively informed subjects accept longer treatment duration and surgical intervention in favor of a better result with regard to foot and ankle functioning and choice of footwear. From a health maximization perspective, this could be regarded as a positive effect of more extensive information.

A danger associated with providing extensive information is being directive. The brochure aimed to provide impartial information but the increased desirability for ready-made shoes at the cost of ankle stability might indicate that value based information was included. Although the criterion "result" was presented without recommendation on the most preferred outcome in the extensive brochure, in hindsight it might be that the benefit of ready-made shoes was deduced from the statement "I'm now able to shop for shoes in normal stores" in the patient testimonial. Although being directive is not necessarily detrimental in terms of outcome valuation, it does influence the interpretation of a DCE. More extensive information brings information into the choice task that it is not included in the level descriptions.

Another drawback of providing more extensive information is that it not always result in an increased understanding of the decision task, while at the same time the cognitive

demand on the subject is increased because more information has to be processed (23). From the body of literature on informed consent it is known that older age, lower educational levels and cognitive impairment can negatively influence understanding of written information (16, 24). It is argued that shorter and more simplified formats should be used to improve patients understanding of decision tasks (24), and a DCE is an short and simplified description of the consequences of treatment. Therefore, in future studies the optimum in the amount of information provision and the influence of literacy and disease burden on the effect of informational brochures has to be determined. In this study the extensive informational brochure had only a minor effect on the predicted uptake of treatment alternatives. On a policy level, this seems a positive finding, as it suggest that the outcome of a DCE can be interpreted without making reference to prior knowledge of or experience with the actual situation. However, this finding might be a direct consequence of the design of the experiment. In four out of eight criteria the most positive outcome is associated with surgical treatment, so surgical treatment might be dominant to the other treatment alternatives. We suggest that in future research the most preferred criteria levels are equally distributed over the alternatives.

Some more limitations can be made with regard to the outcome of this study. For one, we have no way of knowing how much of the information in the extensive brochure was new, how well it was read and how much it increased knowledge of subjects, as this was not verified. Second, although the experimental setup of the study was useful for testing our hypothesis, the convenient nature of the sample did influence the generalizability of the results to patient populations and to real-life decision making. The irrelevance of the decision problem to the healthy participants could have negatively influenced the motivation of the subjects to process the information in the brochure and/or express preference for a hypothetical situation. On the other hand, actual patients in the decision making process might have a higher level of hands-on knowledge about the disease and its treatment, which in turn can diminish the effect of an informational brochure in actual patients. Additionally, the preferences expressed in this study might be modified by the age or gender of the participants. These subject characteristics can potentially influence the importance and value of outcomes, for instance with regard to the importance of treatment impact or comfort & cosmetics of outcome. The current sample lacked power to study these potential effects, but future

studies should test the effect of age, gender, disease, literacy and comprehension of information on the valuation of treatment characteristics. Third, because no actual decision for treatment was made predicted preference cannot be compared with observed preference and we have no way of knowing whether the outcome of the experiment is a representation of true preferences. We recommend that these limitations are averted in future studies and that the effect of extensive information on treatment preference is tested in various patient populations during actual treatment decision making. The final limitation with regard to the interpretation of the results of this study is concerned with estimation of part-worth utilities. In conjoint analysis experiments decision criteria should be mutually independent, that is, the outcome on one criterion should not influence the preference for other criteria. In this study some interaction between the levels of the criteria is expected, for instance between complication type and complication rate. From a methodological standpoint, fitting an additive model is considered inaccurate. The use of an additive model arose from the inevitable scenario reduction in the design phase, which prevents the estimation of interaction between criteria. Scenario reduction and the assumption of an additive model are common practice in conjoint analysis research. In literature it is argued that using an additive model works well in practice and that using multilevel analysis would make data analysis more complicated while at the same time it hardly increases the fit of the model (25). Although the choice of model does not account for the differences found between the minimally and extensively informed groups, further study should focus on the effect of model choice on estimated part-worth utilities.

Conclusions

The results of this study indicate that the amount of a priori information influences preferences which were elicited with a DCE. The absence of rank reversals in the extensively informed group suggests that relevant information was acquired from the extensive information. This positive effect of extensive information has to be weighted against the increased demand extensive information puts on the cognitive abilities of the subject. Moreover, the danger of information being directive has to be taken into account. A careful consideration between the benefits and drawbacks of providing extensive information has to be made in each individual study.

References

1. Robinson A, Thomson R. Variability in patient preferences for participating in medical decision making: implication for the use of decision support tools. Qual Health Care. 2001 Sep;10 Suppl 1:i34-8.
2. Frosch DL, Kaplan RM. Shared decision making in clinical medicine: past research and future directions. Am J Prev Med. 1999 Nov;17(4):285-94.
3. Coulter A. Partnerships with patients: the pros and cons of shared clinical decision-making. J Health Serv Res Policy. 1997 Apr;2(2):112-21.
4. Jan S, Mooney G, Ryan M, Bruggemann K, Alexander K. The use of conjoint analysis to elicit community preferences in public health research: a case study of hospital services in South Australia. Aust N Z J Public Health. 2000 Feb;24(1):64-70.
5. Barry MJ. Health decision aids to facilitate shared decision making in office practice. Ann Intern Med. 2002 Jan 15;136(2):127-35.
6. Say RE, Thomson R. The importance of patient preferences in treatment decisions--challenges for doctors. BMJ. 2003 Sep 6;327(7414):542-5.
7. Ryan M, Scott DA, Reeves C, Bate A, van Teijlingen ER, Russell EM, et al. Eliciting public preferences for healthcare: a systematic review of techniques. Health Technol Assess. 2001;5(5):1-186.
8. Ryan M. A role for conjoint analysis in technology assessment in health care? Int J Technol Assess Health Care. 1999 Summer;15(3):443-57.
9. Hall J, Viney R, Haas M, Louviere J. Using stated preference discrete choice modeling to evaluate health care programs. Journal of Business Research. 2004;57(9):1026-32
10. Green PE, Srinivasan V. Conjoint analysis in consumer research : issues and outlook. [Stanford, Calif.]: Graduate School of Business, Stanford University; 1978.
11. Ryan M, McIntosh E, Shackley P. Methodological Issues in the Application of Conjoint Analysis in Health Care. Health Econ. 1998;7(4):373-8.
12. Farrar S, Ryan M. Response-ordering effects: a methodological issue in conjoint analysis. Health Econ. 1999 Feb;8(1):75-9.
13. Ryan M, Hughes J. Using conjoint analysis to assess women's preferences for miscarriage management. Health Econ. 1997 May-Jun;6(3):261-73.
14. Entwistle VA, Sheldon TA, Sowden A, Watt IS. Evidence-informed patient choice. Practical issues of involving patients in decisions about health care technologies. Int J Technol Assess Health Care. 1998 Spring;14(2):212-25.
15. Sillence E, Briggs P, Harris PR, Fishwick L. How do patients evaluate and make use of online health information? Soc Sci Med. 2007 May;64(9):1853-62.
16. Jeste DV, Dunn LB, Folsom DP, Zisook D. Multimedia educational aids for improving consumer knowledge about illness management and treatment decisions: a review of randomized controlled trials. J Psychiatr Res. 2008 Jan;42(1):1-21.
17. Zeliadt SB, Ramsey SD, Penson DF, Hall IJ, Ekwueme DU, Stroud L, et al. Why do men choose one treatment over another?: a review of patient decision making for localized prostate cancer. Cancer. 2006 May 1;106(9):1865-74.
18. Condie A, Campbell J, Martina J. Report of a consensus conference on the orthotic management of stroke patients. Copenhagen: International Society for Prosthetics and Orthotics (ISPO); 2004.
19. van Til JA, Renzenbrink GJ, Dolan JG, IJzerman MJ. The use of the analytic hierarchy process to aid decision making in acquired equinovarus deformity. Arch Phys Med Rehabil. 2008 Mar;89(3):457-62.
20. Sawtooth Software I. Choice-based Conjoint. 530 West Fir Street Sequim, WA 98382-3284 United States of America.
21. Singh J, Cuttler L, Shin M, Silvers JB, Neuhauser D. Medical decision-making and the patient: understanding preference patterns for growth hormone therapy using conjoint analysis. Med Care. 1998 Aug;36(8 Suppl):AS31-45.

22. Payne JW, Bettman JR, Luce MF, Michael HB. Behavioral Decision Research: An Overview. Measurement, Judgment and Decision Making. San Diego: Academic Press; 1998. p. 303-59.
23. Stanley BM, Walters DJ, Maddern GJ. Informed consent: how much information is enough? Aust N Z J Surg. 1998 Nov;68(11):788-91.
24. Dunn LB, Jeste DV. Enhancing informed consent for research and treatment. Neuropsychopharmacology. 2001 Jun;24(6):595-607.
25. Orme B. Getting started with Conjoint Analysis: Strategies for Product Design and Pricing Research. Madison Wis: Research Publishers LLC; 2006.

Appendix 1: The extensive description of Soft Tissue Surgery

An ankle and foot impairment can be treated with soft tissue surgery. In this treatment changes are made in the muscles in your foot. A muscle can either be lengthened or transferred. A muscle with a high muscle tension is lengthened by making small incisions in the muscle fibers. A muscle with a normal tension is transferred to another position on the foot. In doing so, this muscle can compensate for the loss in activity of other muscles. By making these changes in muscle dynamics, the foot is balanced in the neutral position. These changes are permanent.

After the surgery the foot is temporarily placed in a cast for a short period of time. For the duration of treatment, the foot has to be supported by a brace (aid) for 24 hours a day. The aid can result in skin irritation. After treatment, the position of the foot is normalized and ankle stability is improved. Ready made shoes can be worn and it is possible to walk barefoot. The duration of treatment is 6 to 9 months.

The story of Bas Havelaar

Bas Havelaar is 37 years old, father of two sons and had a stroke 2 years ago. After initial treatment, he chose to be treated with soft tissue surgery. This is his story.

"Two years ago i suddenly collapsed during work. I couldn't speak, my mouth dropped and for a short amount of time I couldn't remember the simplest of things, like the names of my kids. Initially, the worst thing was that I could not take care of myself and I could not walk. For the largest part this was resolved by intensive treatment and exercise.

What remained was an annoying"dropping and turning" of my left foot, especially when I was tired. For the first year, I wore high, custom made shoes to prevent this from happening. This was especially bothersome in summer, because the high shoes resulted in skin irritation. During a holiday I even developed pressure sores because my walking ability improved and we were active. Then, I was told of the possibility of soft tissue surgery by my therapist. I was operated on 6 months ago. During the surgery, muscles were transferred to improve the position of my foot. I was told the risks of surgery were acceptable. The surgery went well, although I developed some skin inflammation from the small stitches on my foot and ankle. For the last six months, I have worn a brace during the day and night. Now, I can walk without the brace or the high shoes. I can shop for shoes in regular stores and this summer, I can even go to the pool with my sons, because I can now walk barefoot without aids!

Appendix 2: Example Choice Task

Which treatment do you prefer?

Treatment 1	Treatment 2
You don't need surgery.	You need surgery in which permanent changes are made to the muscles in your foot.
The treatment takes 9 months.	The treatment takes 3 months.
You need to wear a permanent aid after treatment, it will take 3 minutes to donn or doff.	You need to wear a temporary aid during treatment, it will take 10 minutes to donn or doff.
The aid will cause skin irritation and light inflammations in 10 in 100 people.	The aid will cause pressure sores and serious inflammations in 1 in 100 people.
The aid is both visible and perceptible.	The aid is not visible, but it is perceptible.
The result of treatment is an improved foot position with custom-made shoes in 99 out of 100 people.	The result of treatment is an improved foot position and ankle stability with ready-made shoes, and the ability to walk barefoot without aids in 80 out of 100 people.

I prefer

□ treatment 1

□ treatment 2

Chapter 5

Preference for Treatment of Acquired Ankle-Foot Impairment in Patients with Peripheral or Central Neurologic Disorder

J.A. van Til
G.J. Renzenbrink
J. Buurke
C.G.M. Groothuis
A.M. Stiggelbout
M.J. IJzerman

Submitted to Archives of Physical Medicine and Rehabilitation

Abstract

An impairment of the ankle-foot complex is a common physical consequence of stroke. In recent years, surgical treatment and neuroprostetic devices were proposed as viable treatment alternatives in ankle-foot impairment. The most prominent benefit of surgical and technological treatment is the reduced need for aids after treatment. The harms include a longer and more bothersome treatment procedure. Because of the uncertainty of the evidence and lack of consensus on whether the benefits outweigh the harms of treatment decision making for treatment is hindered. The most important aim of this study was to investigate patients' preferences with regard to treatment process and outcome in ankle-foot impairment in patients with central neurological disorder. Patient preferences for treatment were elicited using a discrete choice experiment (DCE). The subjects sample consisted of 73 Patients with a central neurological disease. 69 Patients with peripheral neurological disease were also included to study whether the type of disease influences preferences for treatment in ankle-foot impairment. The results of this study indicated that patients attach high value to the impact of treatment, the required use of aids and the functional outcome. Patients prefer treatment that is non-surgical, reduces the need for aids and enables barefoot walking. The predicted uptake of treatment was equal for surgical treatment, neuroprostetic devices with surface electrodes and traditional ankle-foot orthosis. This indicates that surgery and neuroprostetic devices are accepted by patients and therefore have potential in the treatment of ankle-foot impairment. By offering these treatments to patients in clinical practice the effectiveness of treatment outcome and care pathways in ankle-foot impairment in stroke can be improved. Because of the variability in treatment preferences between patients, treatment decision making should be a careful consideration of the benefits and harms of treatment in each individual patient.

Introduction

Equinovarus deformity and paralytic drop-foot are common physical consequences of stroke. Traditionally, the ankle and foot position is corrected with splinting and adapted footwear, e.g. an ankle-foot orthosis (AFO) or orthopedic footwear (OS) (1-4). These treatments are based on external fixation of the foot in the neutral position. A negative consequence of external fixation of the foot is that it can hinder foot push-off. Also, daily donning and doffing of aids or shoes is required which can be difficult for stroke patients with arm and hand impairment. Donning and doffing of aids can also be a burden when a patient has to visit the bathroom during the night. In recent years surgical treatment and neuroprostetic devices (NP) are increasingly advocated in the management of ankle-foot impairment (5-9). Surgical treatment and neuroprostetic devices can overcome some of the negative aspects of AFO and OS, but also necessitate a longer and more intensive treatment process compared to traditional treatment (10).

Decision making in the treatment of ankle-foot impairment is hindered because of the absence of high quality comparative studies into the effect of and patient eligibility for treatment. In an earlier study it was identified that for some patients, the benefits of surgical treatment might outweigh the harms. At the same time doubts were raised on the willingness of patients to accept invasive treatment (10). Current guidelines in the treatment of ankle-foot impairment emphasize the importance of patient preferences in treatment choice (11). At present, the lack of reimbursement and the organization of the Dutch health care system might hinder the use of NP and surgery and consequently not all eligible patients are offered these treatments (10). The need to overcome these barriers towards implementation of NP and surgery is more important if the desirability of these treatments is high.

A method to estimate patient preferences for the treatment of disease is the use of preference elicitation techniques such as discrete choice experiments (DCEs). Although the DCE methodology was first introduced in market research, these techniques are increasingly used in the health care setting, for instance to estimate the desired management of knee injuries (12-14). In a DCE, patients are asked to indicate their preference for hypothetical treatment scenarios. The hypothetical treatment scenarios are based on random combinations of the true characteristics of the treatment under investigation. The desirability of the outcome and process of treatment, the importance of decision criteria in treatment decision making and the estimated uptake of treatment

can be calculated from the stated preferences of the patient through regression analysis (15-17). This study uses a DCE to estimate patient preferences for treatment in ankle-foot impairment. The first aim of the study was to study the acceptability of surgery and NP compared to traditional treatment in patients with a central neurological disorder (CND). The second aim of the study was to determine the influence of patient characteristics such as age, gender, (the burden of) disease and the severity of ankle-foot impairment on the preference for treatment.

Methods

Subjects and data collection

This study was reviewed by the Human Subjects Ethics Review board of the Roessingh Centre for Rehabilitation and was exempted from formal approval because it consisted of a single questionnaire. To recruit subjects with ankle-foot impairment a sample of 575 clients was drawn from the database of a regional orthopedic service which provided these clients with an AFO or OS between January of 2004 and December of 2006. The subjects were sent a letter which explained the aim and relevance of the study. After a week they were contacted by phone by a research assistant. Subjects were included in the study if they met the inclusion criteria: subjects (1) had non-progressive central or peripheral disease (CND or PND) with ankle-foot impairment, (2) still used their aid and (3) were between 30 and 75 years old. If subjects agreed to participate, a paper and pencil questionnaire was sent by post along with a pre-paid return envelope. A 5 euro gift coupon was sent to the participant after the questionnaire was returned.

Measures

The questionnaire consisted of two parts. In the first part of the questionnaire patient and disease characteristics were collected. In the second part of the questionnaire patient preferences for the treatment of ankle-foot impairment were elicited by means of the discrete choice experiment (DCE).

In the first part, demographic characteristics of the patients, such as age, gender, education and type of disease were collected using a pre-structured answering format. The burden of disease was estimated using a Time Trade Off (TTO) exercise (18). A hypothetical lifespan of 10 years was assumed and the subjects were asked the number of years they were willing to trade to obtain perfect health. The year(s) that a subject was willing to trade against perfect health were divided through the remaining life-span (10) to calculate the burden of disease. To estimate the severity of ankle-foot impairment, the ankle and foot impairment measure (FAAM) was administered. The FAAM measures the ability to perform 21 tasks, for instance standing up or walking stairs on a 5-point scale ranging from 1 (no difficulty) to 5 (impossible to perform) through self-report. An average score was calculated for all subjects.

Attribute selection and DCE design

The development of the DCE started with comparing the available treatments and determining the treatment characteristics (attributes). An extensive description of the DCE methodology can be found here (17, 19, 20). The attributes of the DCE were developed by adapting the decision tree for the treatment of ankle-foot impairment which was developed in an earlier study to meet the requirements of a DCE (10). The attributes were determined by a local team of health professionals with ample clinical experience in the treatment of ankle-foot impairment in stroke. The available treatment alternatives in ankle-foot impairment were also identified in the previous study (10). These treatments were ankle-foot orthosis (AFO), orthopedic shoes (OS), neuroprostetic devices using surface electrodes (s-NP), neuroprostetic devices using implanted electrodes (i-NP) and soft tissue surgery (STS). To determine the attribute levels all treatment alternatives were described on the eight attributes. The descriptions were restructured to a successive series of outcome definitions in which duplicate descriptions were combined and intermediate categories were added in order to balance the design. The phrasing of attribute levels retained as much as possible of the experts original description of the consequences of treatment. This process resulted in eight attributes with two to four levels. The attributes and levels contained the information that was relevant to the patient to decide for treatment. The DCE design was pilot tested in eight patients with ample experience in the treatment of ankle-foot impairment.

The treatment process was described by the attributes treatment duration, which varied between one and nine months, and treatment impact, which was no surgery or minimally invasive surgery with implanted devices or minimally invasive surgery with tendon transfers. The harms of treatment were described using two attributes, risk type (minor or serious) and risk rate, i.e. the probability of the risk occurring (1/100; 5/100; 10/100). The potential benefits of treatment were described using four attributes, of which two were compiled. The attribute use of aids described both duration of use (temporary or permanent) and effort in donning and doffing of aids (3 or 5 minutes). The attribute comfort & cosmetics described whether a treatment had (in)visible and/or (im)perceptible consequences. The attribute result described the main functional result of treatment, which were improved foot and/or ankle stability with either custom made

or orthopedic footwear. The attribute success rate was described as the probability of the treatment succeeding (99/100; 95/100; 90/100; 80/100).

Commercially available software was used to collect the DCE data (21). The eight attributes and 2 to 4 levels were imported into the software to compile the DCE. In total 24576 (4^5*3^2*2) different hypothetical treatment scenarios could be drafted, but it was not considered feasible to obtain a patient judgment on so many treatment scenarios. With the balanced overlap method which is provided in the software the number of treatment scenarios was reduced to eighty two scenario treatment comparisons while the ability to estimate main-effects was maintained. No "no treatment" or "opt out" option was included because the ankle-foot impairment always requires treatment in the patient group which is included in this study. The 80 choice sets were divided over 4 versions of the experiment (20 choice sets each), which were equally distributed over the subjects. It was verified that one dominant choice-set (with one treatment scenario being more attractive than the other on all aspects of treatment) was included in each questionnaire, to test for the ability of the subject to discriminate between a good and a bad scenario. Three subjects that did not prefer the dominant scenario to the dominated one were excluded from the analysis.

The DCE was introduced by explaining the importance of patient preferences in determining the desirability of treatment in ankle-foot impairment and the relevant treatment characteristics (attributes) were explained. To explain the workings of the DCE, the trade-offs in determining best treatment were highlighted with some examples (E.g. "if you are concerned about the impact of treatment on your personal life, you might prefer a treatment that has a slightly worse outcome, but only takes a limited amount of time to complete"). Subjects were asked to state their preference for treatment by ticking the box under their most preferred treatment. For an example of a choice-set see appendix 1.

Statistical Analysis

Simple-t tests were performed to test for significant differences in patient characteristics between subjects that returned and completed the questionnaire and preferred the dominant treatment in the "dominant" choice set to subjects that did not.

The data was exported from the commercially available software to SPSS version 15.0. A group model was calculated using a logit regression analysis model. Age, gender, education and disease and the criteria levels were included as independent variables.

Dummy coding was used for the criteria levels and the worst performance level was used as the reference code. The preference for treatment scenario was considered as the dependent variable. Through logit regression analysis the influence of the levels (beta-coefficients or part-worth utility weights) on the preferred treatment scenario was calculated. Alpha was set at $p<0.05$. A significant positive part-worth utility weight indicated that a level increases desirability of a treatment scenario and a significant negative part-worth utility indicated that a level decreases the desirability of a treatment scenario for ankle-foot impairment.

To estimate individual part-worth utility weights Hierarchical Bayes analysis was performed with the commercial software (21). From the part-worth utilities, the relative importance of treatment characteristics and the preference for treatment were calculated for each subject.

The relative importance (W) of each attribute (i) was calculated by dividing the part-worth coefficient range (τ_i), within each attribute i (the difference between the least and the most desired part-worth utility) by the sum of the coefficient ranges τ_i of the eight attributes (i = 1-8) (equation 1).

$$W_i = \frac{\tau_i}{\sum_{i=1}^{8} \tau_i} \qquad \textit{(equation 1)}$$

The overall value (U) for each treatment alternative (AFO, OS, s-NP, i-NP, STS) was calculated by summing the part-worth utilities which correspond to the performance levels for all attributes (i=1-8) of each treatment alternative (equation 2).

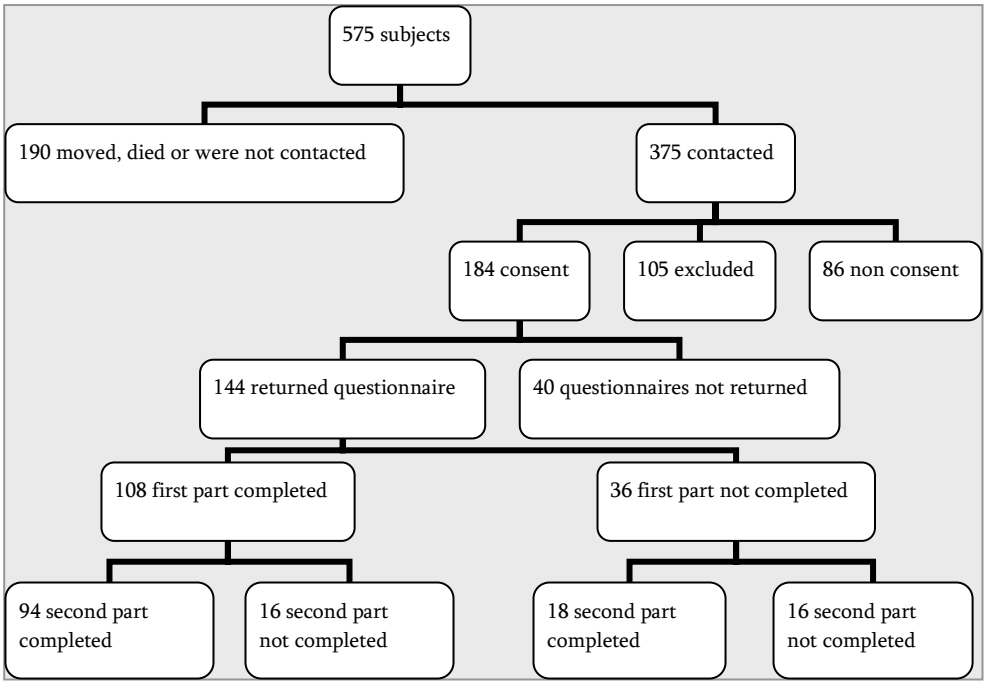
$$U(treatment) = \sum_{i=1}^{8} \beta_i(treatment) \qquad \textit{(equation 2)}$$

The most preferred treatment was the treatment with the highest overall value (U) in each patient. A non-parametric Mann-Whitney U test was performed to test for significant differences in treatment importance and treatment preference between patients with a central and peripheral neurological disorder. Non-parametric Mann Whitney U tests were performed to test for significant differences in patient characteristics and disease characteristics between the patient groups. Bi-variate correlations were calculated to study the effect of age, gender, education or burden of disease on the importance of treatment characteristics and the preference for treatment.

Results

Response rate

Figure 1. Patient inclusion flow chart



Of the total of 565 subjects, 375 (66%) were contacted. Of the 375 subjects, 184 (49%) agreed to participate (figure 1). 105 (28%) Subjects were excluded based on the in and exclusion criteria and 86 (23%) subjects refused participation. Of the 184 subjects, 142 subjects returned the questionnaire (77%). Only 108 Subjects completed the first part of the questionnaire and 112 subjects completed the second part (DCE) of the questionnaire. No effect of disease, gender or education was found on the likelihood to complete the questionnaire, but younger subjects were more likely to complete the first (t=2,435; p=0,016) and second part of the questionnaire (t=2,121; p=0,023).

Background characteristics

The average age of the subjects was 61 years (SD. 10) and equal numbers of males and females were included. 73 Subjects with central neurological disorder (CND) and 69

subjects with peripheral neurological disorder (PND) were included. There were no differences between the two disease groups with regard to age, gender, burden of disease and ankle-foot ability (table 1).

Table 1. Subject characteristics

		Central neurologic disorder (CND)			Peripheral neurologic disorder (PND)		
		N	Mean	SD	N	Mean	SD
Age		73	61,6	10,50	69	60,5	10,83
Gender	male		41			30	
	female		32			39	
Burden of disease (0-1)		54	0,8	0,23	51	0,9	0,19
Ankle-foot ability (1-5)		73	2,7	0,86	69	2,7	0,99

Note: Higher scores indicate lower burden of disease and lower scores indicate less severe ankle-foot impairment.

Influence of treatment characteristics on treatment preference in ankle-foot impairment

The disease (CND or PND), age and gender of the subjects did not significantly influence their preference for treatment on a group level. The expected order of the performance levels within the treatment attributes was mostly as expected, with a higher preference for shorter treatment duration, lower impact of treatment, decreased need for aids, less severe and frequent complications, better functional result and higher success rates. Rank reversals compared to prior expectations were found in two attributes, comfort and cosmetics and the functional result of treatment (table 2). All treatment attributes significantly influenced the preference for treatment, as there was a significant difference in the desirability of the highest and lowest performing treatment (level) in all attributes. The difference in desirability of the intermediate treatment performance levels within the attributes was not significant in most attributes (table 2).

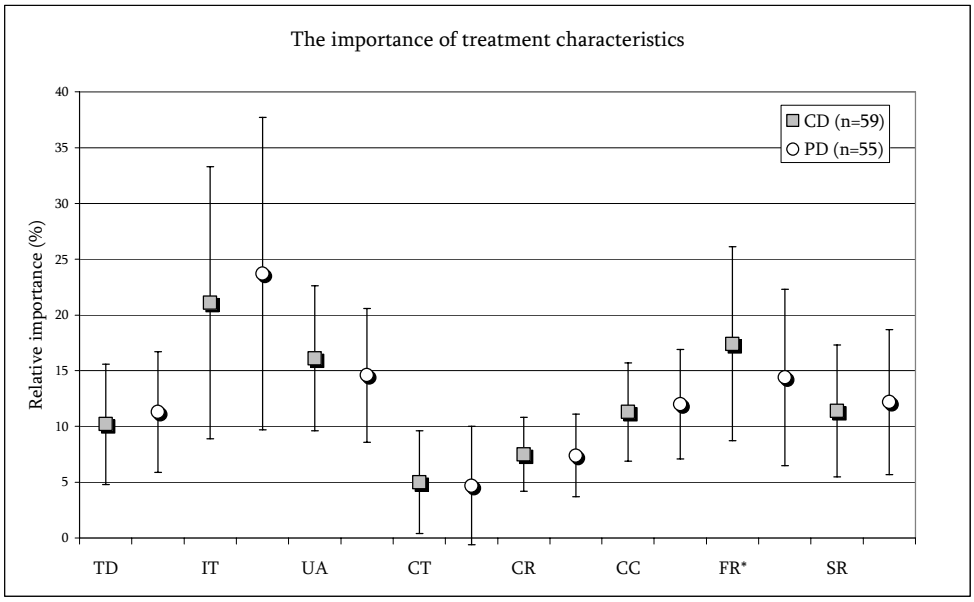
Table 2. B Coefficients of the regression model for treatment preference in ankle-foot impairment (n=109)

Treatment characteristics	levels	B	95% CI		statistics	
					Wald	p
1. Treatment duration	a. 1 month	0,16	0,05	0,28	7,66	0,01
	b. 3 months	0,04	-0,04	0,12	0,51	0,48
	c. 6 months	-0,04	-0,13	0,04	0,71	0,40
	d. 9 months	-0,16				
2. Treatment impact	a. no surgery	0,51	0,42	0,60	115,73	0,00
	b. surgery with implanted technology	-0,02	-0,07	0,04	0,21	0,64
	c. surgery with tendon transfers	-0,49				
3. Use of aids	a. temporary aid; donning/doffing 3	0,33	0,22	0,45	32,08	0,00
	b. temporary aid; donning/doffing 10	0,15	0,03	0,27	6,30	0,01
	c. permanent aid; donning/doffing 3	-0,19	-0,31	-0,07	9,15	0,00
	d. permanent aid; donning/doffing 10	-0,30				
4. Complication type	a. mild complications	0,09	0,04	0,14	12,08	0,00
	b. severe complications	-0,09				
5. Complication rate	a. 1/100 (1%)	0,15	0,06	0,23	11,04	0,00
	b. 5/100 (5%)	0,02	-0,04	0,08	0,16	0,69
	c. 10/100 (10%)	-0,17				
6. Comfort & Cosmetics	a. not visible and not perceptible	0,30	0,19	0,41	28,33	0,00
	b. perceptible	0,09	-0,01	0,19	2,82	0,09
	c. visible	-0,20	-0,31	-0,09	13,55	0,00
	d. visible and perceptible	-0,19				
7. Result	a. improved foot position (adapted foot-wear)	-0,22	-0,33	-0,11	15,48	0,00
	b. improved foot position (custom made shoes)	0,03	-0,05	0,10	0,22	0,64
	c. improved foot position and ankle stability (adapted foot-wear)	-0,03	-0,11	0,05	0,23	0,63
	d. improved foot position and ankle stability (custom made foot-wear)	0,22				
8. Success Rate	a. 99/100 (99%)	0,23	0,12	0,34	17,59	0,00
	b. 95/100 (95%)	0,13	0,03	0,24	5,94	0,01
	c. 90/100 (90%)	-0,10	-0,20	0,01	2,95	0,09
	d. 80/100 (80%)	-0,27				

Notes with table 2 on page 101: The perceived attractiveness of treatment characteristics and attribute levels (importance between parentheses). B = Beta coefficients for the logit regression model (group results).

For instance, with regard to the duration of treatment, there was a significant difference in preference for a treatment that takes 1 month or one that takes 9 months. The desirability of the intermediate levels did not significantly differ from the desirability of a treatment of 9 months. With regard to treatment preference, this suggests that there is no difference in patient preference for a treatment that takes 3, 6 or 9 months. Only the treatment with the shortest duration (AFO) is valued significantly better compared to the other treatments on this attribute.

Figure 2. Importance of characteristics of treatment of ankle-foot impairment



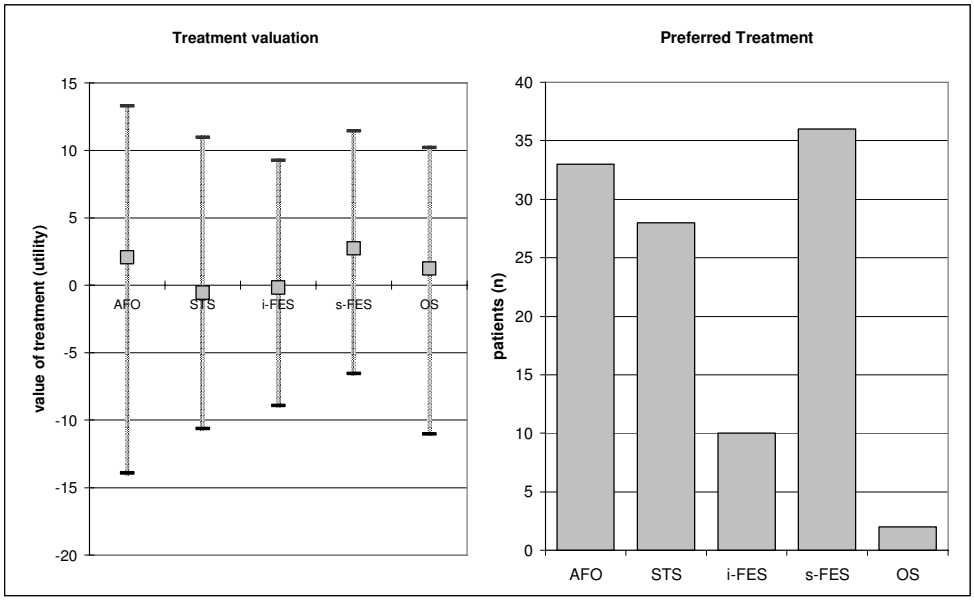
Notes: Preference differences between subjects with peripheral and central neurological disorder. Abbreviations in legend: CND (central neurological disorder) and PND (peripheral neurologic disorder). Abbreviations on x-axis: TD (treatment duration), IT (impact of treatment), UA (use of aids), CT (complication type), CR (complication rate), CC (comfort and cosmetics), FR (functional result) and SR (success rate).

There was a significant decrease in desirability of treatment if the impact of treatment increased because surgery is required, but there was no significant difference in the patient resistance against the different surgical procedures which are required in STS or i-NP (table 2). The intermediate outcome levels in complication rate, comfort & cosmetics, and functional outcome did not influence treatment desirability, which indicates that subjects only do prefer the best performing treatment to the worst with regard to these attributes, but do not distinguish between the treatments that perform slightly better than the worst treatment. For instance, patients do recognize the added value of the ability to walk bare-foot and use custom made shoes, but do not recognize the importance of ankle-support.

Individual differences in criteria importance and treatment preference

There were considerable differences in the influence of the treatment characteristics of the treatment preference between patients and the most desired treatment between patients differed.

Figure 3. Treatment value and preferred treatment



Notes: The mean and standard deviation value (utility) of treatment (left) and the preferred treatment in subjects (right).

There were some small but significant effects of subject and disease characteristics on the importance of treatment characteristics. There was a significant effect of disease (F=3,88; p=0,034) on the importance of the functional result of treatment (figure 2). On average, subjects with a CND attached higher importance (17%) to the functional result of treatment than subjects with a PND (14%). As a result, CND subjects had a lower preference for an AFO (Z=-2,855; p=0,00) and OS (Z=-2,407; p=0,02) compared to PND patients. With regard to the influence of the other patient characteristics, males attached higher importance (8% vs. 7%) to the complication rate compared to females (Z=-0,190; p=0,043). No effects of age or the burden of treatment were found on the importance of treatment characteristics. Based on the regression model treatment preference was predicted. This resulted in an almost equal predicted uptake of AFO, s-NP and STS (figure 3). No effect of age, gender, education or burden of disease was found on the preference for treatment.

Discussion

The aim of this study was to investigate the patient preferences for the management of ankle-foot impairment in patients with central neurological disease (CND). The results of this study indicate that functional result, impact of treatment and required need for aids are the most important determinants of treatment desirability in CND patients, and together they explain more than 50% of the preference for treatment. On average, patients prefer treatment that is non-surgical, omits the permanent need for aids and enables barefoot walking. This preference cannot be satisfied in clinical practice, as all treatment alternatives except for soft tissue surgery require the permanent donning and doffing of aids. Therefore, treatment preference is determined by the willingness of patients to accept the negative characteristics of treatment in favor of the positive ones. Based on the results of this study, an almost equal preference for s-NP, AFO and STS was identified. This indicates that about one third of patients is willing to accept surgery to acquire the ability to walk barefoot or wear custom made shoes without aids in the treatment of their acquired ankle-foot impairment. The preference for either s-NP or AFO depends on small differences in the importance of the duration of treatment and its functional outcome, as these are the characteristics on which these treatments differ. The predicted preference for treatment indicates that according to patients, there is no dominant treatment in ankle-foot impairment. To some extent, the preference for treatment was influenced by the disease and the characteristics of the patient. The difference in the importance of functional result between patients with CND and PND might be explained by the more effortless accommodation to the need to wear shoes and/or aids all the time (i.e. the inability to walk bare-foot), as a result of their localized ankle-foot impairment. The results of this study indicate that some differences in the desired outcome of treatment and the importance of treatment characteristics exist between males and females and lower and higher educated subjects. These differences are minimal and do not influence the predicted preference for treatment alternatives.

With regard to the reliability of the predicted preference for treatment some limitations of the DCE as it was used in this study must be emphasized. The treatment was described according to eight treatment characteristics which were deemed relevant to establishing patient preference for treatment. Some treatment characteristics relevant to actual uptake were omitted, such as access to treatment or treatment costs. It was previously suggested that a knowledge gap exists in the treatment of ankle-foot

impairment (10). The knowledge of and cooperation between physiatrists, neurologist and orthopedic surgeons must be improved to ensure that eligible patients for STS and NP are brought into contact with these treatments, and if they prefer these treatments they can be referred and treated in a facility nearby (22). Costs were not included in this study because in the Netherlands most health care interventions are free at the point of consumption and subjects might object to the private purchase of health care (12). Only NP is not currently reimbursed, and this is considered an important barrier towards patient acceptance (23). Also, the relevant attributes in treatment decision making were determined by health professionals. The results of this study indicate that some attributes were less important to patients. With regard to the agreement between predicted and actual preference of a DCE some comments can be made. In a DCE the decision is framed as a choice between two treatment alternatives. In contrast to most usual clinical decision making in daily practice, explicit trade-offs between the benefits and harms of treatment are expected. Although it is suggested that the framing of the DCE simulated actual decision making between competing alternatives (17), the predicted decision is based on normative principles of maximizing outcome. In actual decision making, it is recognized that people satisfy a certain need, rather than maximizing their outcome (24, 25). For instance, they want a treatment to be shorter than six months, but do not care whether it takes three or six months.

Finally, the DCE was analyzed using an additive logit regression model. An additive model assumes that all characteristics of treatment are independent. This is difficult to achieve in clinical decision making and was certainly the case in this study. To increase the efficiency of the study design, the characteristics risk and result of treatment were split into a quantitative and qualitative criterion. Although it would be possible to fit an independent model to include the dependency between these criteria, previous studies have shown that more complicate models rarely result in an increased fit of the model (26), while it complicates the interpretation of results.

The results of this study are useful in the organization of treatment, technology development and clinical decision making (16). Some of the non-health outcomes and process attributes can be directly influenced to improve the desirability of treatment. Through designing more efficient health care pathways, treatment duration can be shortened. With regard to the development of new treatments and technologies, the results of this study indicate that the diminished necessity of permanent aids is a highly

valued benefit of treatment. In order to improve the appeal of new treatment alternatives the focus of development should be on reducing the effort in donning and doffing additional equipment. With regard to clinical decision making, it seems that patient preferences with regard to treatment process and outcome are not in accordance with the expert health professional priorities in treatment decision making in ankle-foot impairment (10), a finding which was previously identified (27, 28). In the treatment of ankle-foot impairment, health professionals focus on results of treatment, with risk of treatment being the second most important criterion. Ease of use is only the third ranked criterion. The difference between priorities between patients and physicians and the widely diverging preferences in the patient populations indicates that patient wishes and values must be taken into account in the decision process. Naturally, the physical characteristics of the ankle-foot impairment that determine a patient's eligibility for the treatment alternatives should be taken into account before any treatment is offered to a patient.

Conclusion

The results of this study indicate that patients with central neurological disease prefer non-surgical treatment that omits the need for aids and enables bare-foot walking in ankle-foot impairment. No treatment that is currently available meets these preferences. The preference for the treatments that are available is dependent on the willingness of patients to accept surgery and longer treatment duration. The results of this study indicate that about one third of patients are willing to accept surgical treatment in favor of the ability to wear custom made shoes and omit the permanent need for aids in the treatment of their acquired ankle-foot impairment. It is suggested that by offering STS and s-NP to patients, the outcome of care in ankle-foot impairment can be improved. It is important to overcome the barriers towards implementation of STS and s-NP in clinical practice.

References

1. Malas B, Kacen M. Orthotic management in patients with stroke. Top Stroke Rehabil. 2001 Winter;7(4):38-45.
2. Jaivin JS, Bishop JO, Braly WG, Tullos HS. Management of acquired adult dropfoot. Foot Ankle. 1992 Feb;13(2):98-104.
3. Hijmans JM, Geertzen JH. Development of clinical guidelines for the prescription of orthoses in patients with neurological disorders in The Netherlands. Prosthet Orthot Int. 2006 Apr;30(1):35-43.
4. Report of a consensus conference on the orthotic management of stroke patients. In: J. CECJM, editor. International Society of Prostetics and Orthotics; 2003; Netherlands; 2003.
5. Burridge JH, Taylor PN, Hagan SA, Wood DE, Swain ID. The effects of common peroneal stimulation on the effort and speed of walking: a randomized controlled trial with chronic hemiplegic patients. Clin Rehabil. 1997 Aug;11(3):201-10.
6. Piccioni L, Keenan MAE. Surgical correction of varus and equinovarus deformity in the spastic patient. Operative Techniques in Orthopaedics. 1992;2(3):146-50.
7. Keenan MA, Creighton J, Garland DE, Moore T. Surgical correction of spastic equinovarus deformity in the adult head trauma patient. Foot Ankle. 1984 Jul-Aug;5(1):35-41.
8. Kottink AI, Oostendorp LJ, Buurke JH, Nene AV, Hermens HJ, MJ IJ. The orthotic effect of functional electrical stimulation on the improvement of walking in stroke patients with a dropped foot: a systematic review. Artif Organs. 2004 Jun;28(6):577-86.
9. Lawrence SJ, Botte MJ. Management of the adult, spastic, equinovarus foot deformity. Foot Ankle Int. 1994 Jun;15(6):340-6.
10. van Til JA, Renzenbrink GJ, Dolan JG, IJzerman MJ. The use of the analytic hierarchy process to aid decision making in acquired equinovarus deformity. Arch Phys Med Rehabil. 2008 Mar;89(3):457-62.
11. Holmes-Rovner M, Rovner DR. Measuring improved patient choice. J Eval Clin Pract. 2000 Aug;6(3):263-72.
12. Bryan S, Buxton M, Sheldon R, Grant A. Magnetic resonance imaging for the investigation of knee injuries: an investigation of preferences. Health Econ. 1998 Nov;7(7):595-603.
13. Sculpher M, Bryan S, Fry P, de Winter P, Payne H, Emberton M. Patients' preferences for the management of non-metastatic prostate cancer: discrete choice experiment. BMJ. 2004 Feb 14;328(7436):382.
14. Ryan M, Netten A, Skåtun D, Smith P. Using discrete choice experiments to estimate a preference-based measure of outcome--An application to social care for older people. Journal of Health Economics. 2006;25(5):927-44.
15. Ryan M. A role for conjoint analysis in technology assessment in health care? Int J Technol Assess Health Care. 1999 Summer;15(3):443-57.
16. Hall J, Viney R, Haas M, Louviere J. Using stated preference discrete choice modeling to evaluate health care programs. Journal of Business Research. 2004;57(9):1026-32
17. Green PE, Srinivasan V. Conjoint analysis in consumer research : issues and outlook. [Stanford, Calif.]: Graduate School of Business, Stanford University; 1978.
18. Ryan M, Scott DA, Reeves C, Bate A, van Teijlingen ER, Russell EM, et al. Eliciting public preferences for healthcare: a systematic review of techniques. Health Technol Assess. 2001;5(5):1-186.
19. Ryan M, McIntosh E, Shackley P. Methodological Issues in the Application of Conjoint Analysis in Health Care. Health Econ. 1998;7(4):373-8.
20. Ryan M, Farrar S. Using conjoint analysis to elicit preferences for health care. BMJ. 2000 Jun 3;320(7248):1530-3.
21. Sawtooth Software I. Choice-based Conjoint. 530 West Fir Street Sequim, WA 98382-3284 United States of America.

22. Buurke JH, Kleissen RF, Nene A, Bloo JK, Renzenbrink GJ, Zeegers AV, et al. A feasibility study of remote consultation to determine suitability for surgery in stroke rehabilitation. J Telemed Telecare. 2004;10(2):108-12.
23. Fleuren M, Wiefferink K, Paulussen T. Determinants of innovation within health care organizations: literature review and Delphi study. Int J Qual Health Care. 2004 Apr;16(2):107-23.
24. Cohen BJ. Is expected utility theory normative for medical decision making? Med Decis Making. 1996 Jan-Mar;16(1):1-6.
25. Bryan S, Dolan P. Discrete choice experiments in health economics. For better or for worse? Eur J Health Econ. 2004 Oct;5(3):199-202.
26. Ryan M, Hughes J. Using conjoint analysis to assess women's preferences for miscarriage management. Health Econ. 1997 May-Jun;6(3):261-73.
27. Hummel JM, Snoek GJ, van Til JA, van Rossum W, IJzerman MJ. A multicriteria decision analysis of augmentative treatment of upper limbs in persons with tetraplegia. J Rehabil Res Dev. 2005 Sep-Oct;42(5):635-44.
28. Lee A, Gin T, Lau AS, Ng FF. A comparison of patients' and health care professionals' preferences for symptoms during immediate postoperative recovery and the management of postoperative nausea and vomiting. Anesth Analg. 2005 Jan;100(1):87-93.

Appendix 1: Example choice set

Which treatment do you prefer?

Treatment 1	Treatment 2
You don't need surgery.	You need surgery in which permanent changes are made to the muscles in your foot.
The treatment takes 9 months.	The treatment takes 3 months.
You need to wear a permanent aid after treatment, it will take 3 minutes to donn or doff.	You need to wear a temporary aid during treatment, it will take 10 minutes to donn or doff.
The aid will cause skin irritation and light inflammations in 10 in 100 people.	The aid will cause pressure sores and serious inflammations in 1 in 100 people.
The aid is both visible and perceptible.	The aid is not visible, but it is perceptible.
The result of treatment is an improved foot position with custom-made shoes in 99 out of 100 people.	The result of treatment is an improved foot position and ankle stability with ready-made shoes, and the ability to walk barefoot without aids in 80 out of 100 people.

I prefer

□ treatment 1

□ treatment 2

Appendix 3: B coefficients in central (CND) and peripheral (PND) neurological disorder

Treatment characteristics	CND		PND		statistics	
	B	SD.	B	SD.	Z	p
Treatment Duration						
a. 1 month	0,72	1,60	1,15	1,54	-1,14	0,25
b. 3 months	0,42	1,28	0,11	1,10	-1,16	0,24
c. 6 months	-0,50	1,05	-0,35	0,88	-0,74	0,46
d. 9 months	-0,64	1,61	-0,91	1,65	-0,71	0,48
Impact of Treatment						
a. no surgery	2,11	3,27	3,55	2,84	-2,39	0,02
b. surgery with implanted technology	0,09	1,99	-0,57	1,86	-1,82	0,07
c. surgery with tendon transfers	-2,23	2,79	-2,98	2,54	-1,19	0,23
Use of Aids						
a. temporary aid; donning/doffing 3	2,24	1,88	1,58	1,81	-1,81	0,07
b. temporary aid; donning/doffing 10	1,51	1,41	1,04	1,75	-1,31	0,19
c. permanent aid; donning/doffing 3	-1,49	1,39	-0,92	1,30	-2,17	0,03
d. permanent aid; donning/doffing 10	-2,25	1,87	-1,7	2,14	-1,27	0,2
Complication Type						
a. mild complications	0,63	0,88	0,32	0,90	-2,02	0,04
b. severe complications	-0,63	0,88	-0,32	0,90	-2,02	0,04
Complication Rate						
a. 1/100 (1%)	0,66	0,94	0,66	0,84	-0,14	0,89
b. 5/100 (5%)	0,36	1,08	0,15	1,08	-1,09	0,28
c. 10/100 (10%)	-1,03	0,72	-0,81	0,73	-1,56	0,12
Comfort & Cosmetics						
a. not visible and not perceptible	1,23	1,37	1,74	1,13	-1,99	0,05
b. perceptible	0,30	1,34	0,00	1,31	-1,70	0,09
c. visible	-0,78	1,24	-1,07	1,15	-1,19	0,23
d. visible and perceptible	-0,75	1,01	-0,68	1,12	-0,91	0,36
Functional Result						
a. improved foot position (adapted foot-wear)	-1,37	1,61	-1,26	1,30	-0,60	0,55
b. improved foot position (custom made shoes)	0,23	1,95	0,04	1,81	-0,46	0,64
c. improved foot position and ankle stability (adapted foot-wear)	-0,25	1,60	0,21	1,26	-1,24	0,21
d. improved foot position and ankle stability (custom made foot-wear)	1,39	2,74	1,00	2,07	-0,87	0,39
Success Rate						
a. 99/100 (99%)	1,70	1,32	1,45	1,34	-0,97	0,33
b. 95/100 (95%)	0,46	1,23	0,75	1,23	-1,17	0,24
c. 90/100 (90%)	-0,42	1,05	-0,37	1,24	-0,27	0,79
d. 80/100 (80%)	-1,72	1,43	-1,83	1,25	-0,65	0,51

Chapter 6

Feasibility of Web-Based Decision Aids in Neurological Patients

J.A. van Til
C.H.C. Drossaert
G.J. Renzenbrink
G.J. Snoek
E. Dijkstra
A.M. Stiggelbout
M.J. IJzerman

Submitted to Journal of Telemedicine and Telecare

Abstract

Providing patients with information about their disease and treatment options is an important part of providing quality health care. Physicians are not always successful in informing patients. Decision aids (DAs) are promoted as adjuncts to a consultation with a physician to inform patients. The first aim of this study was to investigate the potential for web-based DAs in a rehabilitation population. The second aim was to evaluate the feasibility of two disease-specific DAs. These web-based DAs focused on (1) the treatment of acquired ankle-foot impairment in stroke and (2) the treatment of arm-hand function in cervical spinal cord injury (SCI). The third aim of this study was to measure the effect of the DAs on knowledge, decisional conflict and patient role in decision making. Data collection consisted of a telephone interview and a self-reported paper-pencil questionnaire. 39 Stroke (44%) and 38 SCI (78%) patients returned the questionnaire. The results showed that more than 75% of respondents expressed a need for more information about the treatment of disease-related impairment. The DAs were highly appreciated by both patient groups. Nearly all patients expressed a positive attitude towards the use of the web-based DAs in general practice. A positive effect of the DAs on knowledge was found in the stroke patients. The DAs reduced patients' conflict about treatment. The effect of the DAs on subjects' desired role in decision making was limited. In the treatment of stroke and SCI, DAs could be a valuable addition to the information provision to patients.

Introduction

Providing patients with information about their disease process, treatment options and the expected outcomes of the different alternatives is considered an important part of providing quality health care (1). Legally, it ensures that a patient has good knowledge of treatment process and outcome before agreeing to treatment. Ethically, providing information can enable patients in becoming actively involved in the treatment decision making process (2-4). Although physicians recognize the need to inform patients, they do not always succeed in providing sufficient information in their daily practice (1, 5-7). Lack of time, physicians' erroneous perception of the information need of patients and lack of high quality decision support tools are barriers to information provision to patients (5).

Patient participation in the decision making process is valued in rehabilitation medicine because patient autonomy is an important aim of treatment (6-8). Also, the decisions that have to be made in rehabilitation medicine require patient participation. There is much uncertainty about the characteristics of rehabilitation treatment that determine effectiveness (9, 10). It is likely that other factors than the effectiveness of treatment influence the perceived benefit of treatment to patients (11, 12). For instance, the decision whether to consider surgical treatment in a post-acute stage of rehabilitation is highly dependent on the patients trade-off between the benefits and harms of surgery (13, 14). Although surgical treatment has the potential to improve physical functioning beyond traditional treatment, the 'harms' of surgical treatment include a longer and more invasive treatment procedure.

According to recent models of patient-physician interaction, it is the patient who should determine whether the benefits exceed the harms of treatment. High quality information provision to the patient is a prerequisite for a patient to consider their values and preferences for the process and outcome of treatment (15). Traditional educational materials are limited in their potential to help patients understand their personal preferences and values (16). Instead, decision aids (DAs) are promoted as adjuncts to or as preparation for a consultation with the physician (17). A DA is defined as "an intervention designed to help people make specific and deliberative choices among options by providing information on the options and outcomes relevant to a patient's health" (15, 18, 19). A patient DA differs from traditional educational materials because it explicitly describes treatment options, generally includes qualitative and

quantitative information about benefits and risks and motivates patients to view the information in the light of their own values and preferences (20). DAs can take on several forms, such as a brochure, an audiotape, a leaflet or a video. Computer assisted aids have become increasingly popular because they are convenient, accessible and flexible tools and can be easily tailored to the demands of the individual patient. It is known that the use of a DA can result in more realistic expectations of treatment outcome, improve agreement between personal values and choice of treatment, and result in an increased desire to actively participate in the decision making process (21).
The use of DAs in rehabilitation medicine is limited. The feasibility of web-based computer-assisted aids in this older, chronically ill and sometimes cognitively impaired population is unknown. The first aim of this study was to investigate the need for and general feasibility of web-based DAs in rehabilitation population. The second aim was to evaluate the feasibility of two disease-specific DAs that were developed in the course of this study. The third aim of this study was to measure the effect of the DAs on knowledge, decisional conflict and preferred role in decision making.

Methods

Developmental process of the decision aids

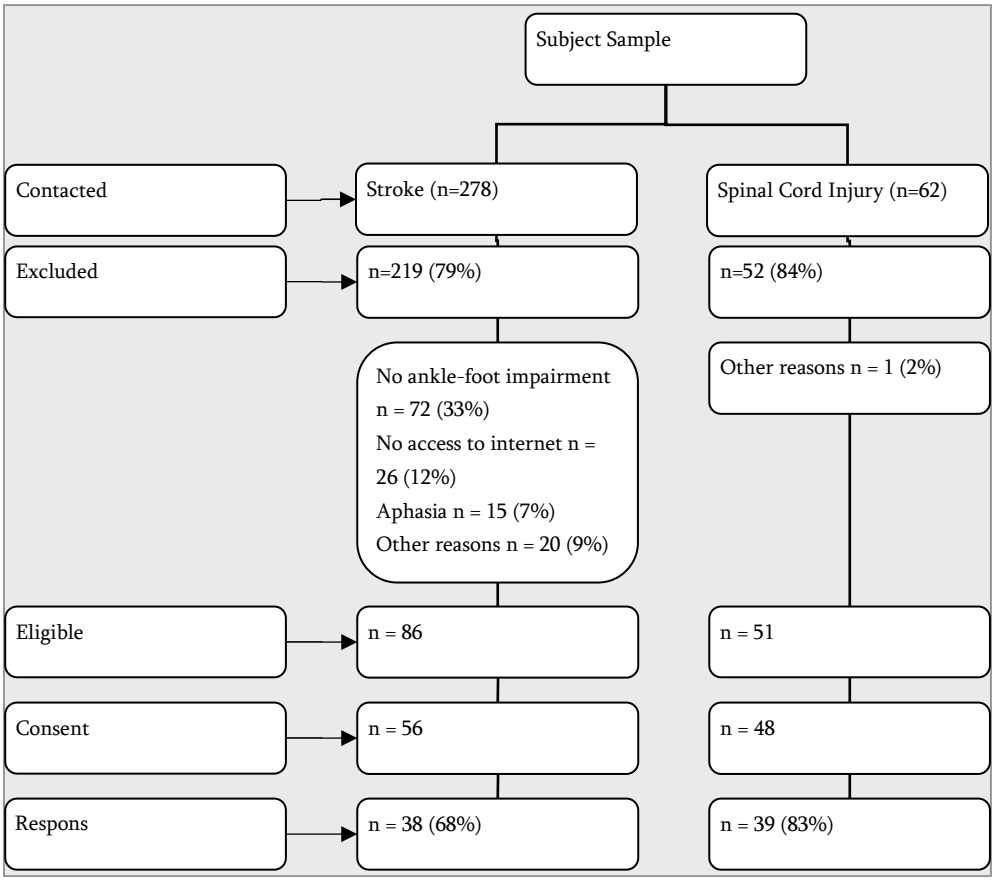
The DAs that were developed in the course of this study were aimed to be self-administered aids which patients could use at home through the use of a computer with internet access. The DAs focused on two relevant issues in rehabilitation medicine, namely (1) the treatment of acquired ankle-foot impairment in stroke and (2) the treatment of arm-hand function in cervical spinal cord injury (SCI). Surgical treatment has been introduced as an alternative to traditional treatments for these conditions. As there is no evident 'best treatment' from a medical perspective, careful deliberation of the patient values and preferences with regard to benefits and harms of treatment are important in determining "optimal treatment" (16).

The DAs were developed by two teams, each consisting of a physiatrist and two physical or occupational therapists with abundant experience in the treatment of stroke and SCI. The teams used existing written informational brochures, scientific literature, and personal and patient experiences to draw up a preliminary version of each DA. Relevant pictures and movies were selected or developed to support the written content. The DAs were developed according to a checklist for decision aids (19). As a result of the absence of well designed comparative trials, probabilistic information on outcome could not be provided and a qualitative description was provided instead. The preliminary versions of the DAs were evaluated by five physiatrists not linked to our institution and by ten patients. Based on the results of this evaluation, improvements were made with regard to the content and lay-out of the DAs.

The final versions of the DAs can be viewed on http://www.lopen-na-cva.nl and http://www.handfunctie-en-dwarslaesie.nl. The homepage of the DAs explains the purpose of the website, its intended audience and site navigation (appendix 1). In subsequent pages the DAs present (1) general information about the disease and the condition requiring a treatment decision, (2) general information about the treatment options, (3) a qualitative description of the health related benefits and harms of each option, (4) the process characteristics of the treatment options, (5) the decision under consideration and the importance of personal values and preferences in determining the optimal treatment, and (6) a value clarification exercise in which subjects weight the importance of decision criteria by performing pair-wise comparisons.

Subject Sample

Figure 1. Flow chart of subject inclusion



Notes: Contact: Number of subjects that were contacted by phone. Excluded: subjects excluded based on the inclusion criteria. Eligible: Subjects eligible for the study. Consent: Subjects that gave verbal informed consent. Respons: Subjects that returned the paper and pencil questionnaire. In contrast to the SCI subjects, the stroke subject sample could not be selected based on the presence of ankle-foot impairment. This explains the larger percentage of excluded subjects in the stroke group based on the exclusion criteria.

The subjects with cervical spinal cord injury (SCI) had been selected from the patient records of seven Dutch rehabilitation centers during two previous studies (11).

The stroke subjects were selected from the patient records of the local rehabilitation center. Stroke patients treated between January 2004 and December 2006 were drawn from the database. Only chronic (> 1 year) patients were selected for this study.
Subjects were informed about the aim of the study in a letter that was sent to their home address. In the week following the letter, three attempts were made to reach a patient by telephone. If contact was established, eligibility for the study was determined. Inclusion criteria were (1) acquired ankle-foot (stroke) or arm-hand (spinal cord injury) impairment, (2) access to a computer with internet connection and (3) physical ability to complete a paper and pencil questionnaire. If a subject was eligible for this study, verbal informed consent was obtained. With patients that agreed to participate, a baseline telephone interview was conducted. If the patients completed the interview, the URL of the relevant DA was provided. After one week, a paper and pencil questionnaire was sent. The response in the post-test was 68% for stroke and 83% for SCI patients (figure 1).

Measures and Instruments

At baseline, a subject's demographic characteristics (age, gender, living situation, and education); and current use of the internet were assessed during the telephonic interview. Information needs were assessed by asking patients whether they had a need for information about the treatment of disease-related impairment and their preferred source of information. To examine the effects of the DAs, the subject's (a) knowledge (b) decisional conflict about treatment and (c) actual and desired role in the decision making process were measured. Knowledge was assessed with six true/false statements about the treatment of the disease-related impairment. A knowledge score was calculated by summing the correct answers. Decisional conflict was measured using the Dutch version of the Decisional Conflict Scale (DCS) (16, 22). In this study, only four of the five subscales of the DCS were administered: uncertainty (3 items), uninformed (3 items), unclear values (3 items), and unsupported (3 items). The subscale ineffective choice (3 items) was omitted because no actual choice for treatment was made in this study. The overall score ranges from 1–5, with higher scores indicating higher decisional conflict.
Subjects' actual role in treatment decision making of disease-related impairment and the subjects' desired role in a hypothetical future decision making process were measured with the Control Preference Scale (23). In this scale, five different vignettes are

described that portray a patient's role in treatment decision-making from very active to very passive.

The post-test paper and pencil questionnaire consisted of two parts. First, the feasibility of the disease specific DAs was determined. The constructs were based on the revised Technology Acceptance Model (TAM) by van der Heijden (2003). The constructs included the perceived usefulness (6 items; Cronbachs' α = 0,56), the perceived user-friendliness (9 items; α= 0,84) and the perceived attractiveness (2 items; α= 0,98) of the disease specific DA, the perceived pleasure derived from using it and the perceived attitude towards the use of the DA in daily practice. Items were scored on a scale ranging from 1 (totally disagree) to 5 (totally agree). The phrasing of the items can be found in appendix 2. Second, (a) knowledge (b) decisional conflict about treatment and (c) desired role in the decision making process were measured using the measures described earlier.

Statistical Analysis

Descriptive statistics were calculated for all variables. The effect of the DA on subjects' knowledge, decisional conflict and desired role in decision making was assessed by comparing baseline and posttest scores using a Wilcoxon Signed Rank tests. The agreement between subjects actual and desired role in decision making was tested using a Wilcoxon Signed Rank test.

Results

Table 1. Demographic characteristics

	Stroke (n=38)		Spinal cord injury (n=39)	
	Average	SD	Average	SD
Age	55,8	(12,0)	41,5	(10,0)
Sex	Frequency	%	Frequency	%
male	23	60,5	29	74,4
female	15	39,5	10	25,6
Living situation				
with partner	31	81,6	15	38,5
alone	7	18,4	18	46,2
other			6	15,4
Education				
low	6	15,8	5	13,8
middle	20	52,6	24	61,5
high	12	31,6	10	25,6
Information need				
yes	30	90,9	30	76,9
no	3	9,1	9	23,1
Desired source of information				
physician	11	35,5	2	5,6
written brochure	6	19,4	12	33,3
CD/DVD	1	3,2	3	8,3
internet	13	41,9	19	52,8
Internet use				
never	1	2,8	1	2,6
occasionally	5	13,9	1	2,6
once a month	2	5,6	0	0
once a week	7	19,4	0	0
a few times a week	3	8,3	12	31,6
every day	18	50,0	24	63,2

Note: percentages are based on valid cases only

Patient characteristics

Patient characteristics are presented in Table 1. The average age of stroke patients was 56 years, most were males and the majority of patients lived with a partner. The SCI subjects were on average almost 15 years younger and the majority was living alone.

Feasibility of a web-based decision aid

The strong majority of stroke and SCI subjects expressed a demand for more information about the treatment of their disease-related impairment. The desired source of information was a web-based information source in about 40% of stroke subjects and in about 50% of SCI subjects. These percentages were in accordance with the baseline experience with the web, with 50% of stroke patients and more than 60% of SCI patients using the web every day (table 1).

Table 2. Feasibility of decision aids in stroke and SCI subjects

	Stroke		Spinal cord injury	
	Average	(SD)	Average	(SD)
Perceived usefulness	3,9	(0,6)	3,6	(0,5)
Perceived user-friendliness	3,8	(0,5)	3,7	(0,6)
Perceived attractiveness	3,7	(0,8)	3,4	(0,9)
Perceived enjoyment	4,0	(0,8)	3,8	(0,8)
Attitude	3,8	(0,9)	3,9	(0,5)

Note: Item properties are presented in appendix 2. Higher scores indicate more positive perception.

The disease specific DAs which were developed in this study were perceived as useful, user-friendly and attractive and the use of the DA was being viewed upon as pleasurable by the majority of subjects in both groups (table 2). There is a positive attitude towards the use of the DAs in clinical practice.

Effect of the decision aids

The DAs had a positive effect on the knowledge about the treatment alternatives in the stroke subjects (Z= -3,195; p= 0,001) (table 3). With average scores around 3 (the scales midpoint) decisional conflict with regard to the treatment of disease-related impairment is moderate in both stroke and SCI patients. A significant reduction of overall decisional conflict was found in the stroke patients (Z=-2,10; p=0,04) and the SCI patients (Z=-3,62; p=0,00). The significant decrease in decisional conflict could be attributed to the effect on the subscales feeling uncertain in both stroke (Z=-2,22;

p=0,03) and SCI (Z=-2,27; p=0,02) subjects and feeling uninformed in stroke (Z=-2,12; p=0,03) and SCI subjects (Z=-4,05; p=0,00).

Table 3. Effect of the decision aids on knowledge and decision conflict

	Stroke		Spinal Cord Injury	
	Baseline	Post	Baseline	Post
	Average (SD)	Average (SD)	Average (SD)	Average (SD)
Knowledge	1,4 (1,3)	2,3 (1,7)**	5,2 (1,0)	5,4 (0,9)
Decisional Conflict Scale	3,0 (0,6)	2,7 (0,6)*	2,8 (0,6)	**2,5 (0,5)
Uncertainty	3,3 (0,9)	2,9 (0,8)*	2,9 (0,7)	*2,6 (1,0)
Uninformed	2,9 (0,8)	2,7 (0,7)*	2,9 (0,9)	**2,3 (0,7)
Unclear values	2,9 (0,6)	2,7 (0,6)	2,8 (0,7)	2,7 (0,6)
Unsupported	2,7 (0,8)	2,9 (0,6)	2,3 (0,7)	2,1 (0,7)

*Notes: lower scores indicate lower decisional conflict and lower knowledge. *p=<0.05. **p=<0,01*

No significant effect of the DA on the desired role in the decision process was found (table 4). A significant difference between actual and preferred role in decision making (Z=-2,018; p=0,043) was found in the stroke subjects, with subjects preferring a more active role than they experienced.

Table 4. Effect of the decision aids on role preference in decision making

	Stroke			Spinal Cord Injury		
		Desired role			Desired role	
Role Preference Scale	Actual role	baseline	posttest	Actual role	baseline	posttest
	N(%)	N (%)	N (%)	N(%)	N (%)	N (%)
very passive	15 (44)	6 (16)	3 (8)	3 (9)		
passive	7 (21)	6 (16)	5 (14)	1 (3)	1 (3)	4 (11)
shared	4 (12)	11 (30)	18 (49)	6 (18)	7 (18)	5 (14)
active	4 (12)	11 (30)	10 (27)	15 (45)	29 (74)	26 (70)
very active	4 (12)	3 (8)	1 (3)	8 (24)	2 (5)	2 (5)

Notes: percentages based on valid cases only.

Discussion

To the best of our knowledge, this is the first study that examined the feasibility of DAs in a rehabilitation population. The first important finding of this study was that more than 75% of the subjects showed a demand for more information about the treatment of disease-related impairment. This confirms the information need that was previously identified in stroke patients (4, 6, 7, 24). Second, the study revealed that the DAs that were developed in this study were appreciated by both stroke and spinal cord injured patients. The subjects also showed a positive attitude towards the use of web-based DAs in daily practice. The feasibility of the DAs was comparable in both patient groups, which are representatives of the heterogenic rehabilitation population.

With regard to the effect, the DA increased knowledge in the stroke subjects. This is in agreement with literature, as increased knowledge is the most consistently confirmed effect of DAs (15, 25). In the SCI patients, knowledge scores were already high at baseline, and could hardly be improved (ceiling effect). The high baseline scores might be attributed to the patient included in the study, of whom the majority had participated in similarly oriented research studies in the past (11, 13). Alternatively, it might indicate that SCI subjects are already well-informed about the surgical possibilities which are available to them.

In agreement with earlier findings, the DAs reduced the decisional conflict in both groups (15, 25, 26), specifically on the subscales feeling uninformed and feeling uncertain. This indicates that the DAs developed in this study mostly targeted the information gaps in patients. Although a value clarification exercise was included in the DA, the aids were less successful in clarifying values, the DAs might be enhanced by addressing values and preferences more extensively (16).

In contract to earlier studies, no significant effect of the DA was found on the subjects' role preference in decision making process (21). In the SCI population the majority of the subjects stated that they preferred and actualized an active role in decision making. Stroke subjects preferred a more passive role both at baseline and after the DA. The more passive attitude of the stroke subjects might be attributed to their older age (27) or to cognitive limitations as a result of stroke. Also, earlier findings suggests that although a majority of patients wants to be informed about disease, this does not imply they want to be equally involved in treatment decision making (4, 28). Noticeably, stroke subjects did prefer a more active role than they had actualized in the past. This indicates that

physiatrists should be receptive towards each individual patient's desire to participate in decision making in clinical practice.

There are some limitations to this study. In the interpretation of the effects of the DAs, it must be taken into account that all subjects had terminated their active rehabilitation process. The DA would ideally be deployed during the decision making process of disease related impairment. In order to draw definite conclusions, the study should be repeated in a subject group that is in the active decision making process. In this study, the DAs were designed as a "one size fits all" application. Although the influence of clinical patient characteristics on treatment usability was discussed; the DAs were not tailored to present only the relevant information to the individual patient. This was not feasibility during this study, but the DAs could be further improved by enabling tailored information provision, which is an advantage of web-based aids.

About a quarter of stroke subjects could not be included in this study because of lack of access to a computer. Given the increasing use of computers and the internet in younger populations, the feasibility of web-based aids might be expected to increase in future generations of stroke and SCI patients. At this time, if a web-based DA would be implemented in clinical practice, alternative information methods must be provided as well. In this study, no alternative to the web-based aid, for instance a paper brochure or a normal physician consultation, was tested. Therefore, the additional value of the web-based aspects is unknown and the results of this study must be seen as exploratory. Further research into this topic should focus on the feasibility and effect of a DA in patients who are in the process of decision making about disease management, and compare a web-based aid with other sources of information, preferably in a randomized design.

Conclusions

This study indicates that stroke and SCI patients have an information need about treatment of disease-related impairment. Web-based DAs can be a valued addition to the current information provision and treatment decision making process in rehabilitation care. With regard to the overall effect of the DAs in the stroke subjects a positive effect of DAs on knowledge was found and reduced decisional conflict about most desirable treatment in both stroke and SCI patients.

References

1. Bernat JL. Informed consent. Muscle Nerve. 2001 May;24(5):614-21.
2. Charles C, Gafni A, Whelan T. Shared decision-making in the medical encounter: what does it mean? (or it takes at least two to tango). Soc Sci Med. 1997 Mar;44(5):681-92.
3. Ford S, Schofield T, Hope T. What are the ingredients for a successful evidence-based patient choice consultation?: A qualitative study. Soc Sci Med. 2003 Feb;56(3):589-602.
4. Robinson A, Thomson R. Variability in patient preferences for participating in medical decision making: implication for the use of decision support tools. Qual Health Care. 2001 Sep;10 Suppl 1:i34-8.
5. Ford S, Schofield T, Hope T. Barriers to the evidence-based patient choice (EBPC) consultation. Patient Educ Couns. 2002 Jun;47(2):179-85.
6. Proot IM, Abu-Saad HH, de Esch-Janssen WP, Crebolder HFJM, ter Meulen RHJ. Patient autonomy during rehabilitation: the experiences of stroke patients in nursing homes. International Journal of Nursing Studies. 2000;37(3):267-76.
7. Proot IM, Crebolder HFJM, Abu-Saad HH, Macor THGM, Ter Meulen RHJ. Stroke patients' needs and experiences regarding autonomy at discharge from nursing home. Patient Education and Counseling. 2000;41(3):275-83.
8. Wain HR, Kneebone, II, Billings J. Patient experience of neurologic rehabilitation: a qualitative investigation. Arch Phys Med Rehabil. 2008 Jul;89(7):1366-71.
9. Frontera WR, Fuhrer MJ, Jette AM, Chan L, Cooper RA, Duncan PW, et al. Rehabilitation medicine summit: building research capacity. Top Stroke Rehabil. 2005 Fall;12(4):68-80.
10. Tate DG. The state of rehabilitation research: art or science? Arch Phys Med Rehabil. 2006 Feb;87(2):160-6.
11. Snoek GJ, van Til JA, Krabbe PF, IJzerman MJ. Decision for reconstructive interventions of the upper limb in individuals with tetraplegia: the effect of treatment characteristics. Spinal Cord. 2008 Mar;46(3):228-33.
12. Frith L. Priority setting and evidence based purchasing. Health Care Anal. 1999;7(2):139-51.
13. Hummel JM, Snoek GJ, van Til JA, van Rossum W, IJzerman MJ. A multicriteria decision analysis of augmentative treatment of upper limbs in persons with tetraplegia. J Rehabil Res Dev. 2005 Sep-Oct;42(5):635-44.
14. van Til JA, Renzenbrink GJ, Dolan JG, IJzerman MJ. The use of the analytic hierarchy process to aid decision making in acquired equinovarus deformity. Arch Phys Med Rehabil. 2008 Mar;89(3):457-62.
15. O'Connor AM, Rostom A, Fiset V, Tetroe J, Entwistle V, Llewellyn-Thomas H, et al. Decision aids for patients facing health treatment or screening decisions: systematic review. BMJ. 1999 Sep 18;319(7212):731-4.
16. O'Connor AM, Tugwell P, Wells GA, Elmslie T, Jolly E, Hollingworth G, et al. A decision aid for women considering hormone therapy after menopause: decision support framework and evaluation. Patient Education and Counseling. 1998;33(3):267-79.
17. Holmes-Rovner M, Valade D, Orlowski C, Draus C, Nabozny-Valerio B, Keiser S. Implementing shared decision-making in routine practice: barriers and opportunities. Health Expect. 2000 Sep;3(3):182-91.
18. Bekker HL, Hewison J, Thornton JG. Understanding why decision aids work: linking process with outcome. Patient Educ Couns. 2003 Jul;50(3):323-9.
19. Elwyn G, O'Connor A, Stacey D, Volk R, Edwards A, Coulter A, et al. Developing a quality criteria framework for patient decision aids: online international Delphi consensus process. BMJ. 2006 Aug 26;333(7565):417.
20. Whelan T, Sawka C, Levine M, Gafni A, Reyno L, Willan A, et al. Helping patients make informed choices: a randomized trial of a decision aid for adjuvant chemotherapy in lymph node-negative breast cancer. J Natl Cancer Inst. 2003 Apr 16;95(8):581-7.

21. O'Connor AM, Stacey D, Entwistle V, Llewellyn-Thomas H, Rovner D, Holmes-Rovner M, et al. Decision aids for people facing health treatment or screening decisions. Cochrane Database Syst Rev. 2003(2):CD001431.
22. Koedoot N, Molenaar S, Oosterveld P, Bakker P, de Graeff A, Nooy M, et al. The decisional conflict scale: further validation in two samples of Dutch oncology patients. Patient Education and Counseling. 2001;45(3):187-93.
23. Degner LF, Sloan JA. Decision making during serious illness: What role do patients really want to play? Journal of Clinical Epidemiology. 1992;45(9):941-50.
24. Wachters-Kaufmann C, Schuling J, The H, Meyboom-de Jong B. Actual and desired information provision after a stroke. Patient Education and Counseling. 2005;56(2):211-7.
25. Molenaar S, Sprangers MA, Postma-Schuit FC, Rutgers EJ, Noorlander J, Hendriks J, et al. Feasibility and effects of decision aids. Med Decis Making. 2000 Jan-Mar;20(1):112-27.
26. Rothert ML, Holmes-Rovner M, Rovner D, Kroll J, Breer L, Talarczyk G, et al. An educational intervention as decision support for menopausal women. Res Nurs Health. 1997 Oct;20(5):377-87.
27. Say RE, Thomson R. The importance of patient preferences in treatment decisions--challenges for doctors. BMJ. 2003 Sep 6;327(7414):542-5.
28. Benbassat J, Pilpel D, Tidhar M. Patients' preferences for participation in clinical decision making: a review of published surveys. Behav Med. 1998 Summer;24(2):81-8.

Appendix 1: decision aid lay-out

Appendix 2: The feasibility questionnaire

Answer scale properties: totally disagree (1) to totally agree (5). [a] *indicates a negatively framed item, to which reversed scoring was applied.*

	1	2	3	4	5
Perceived usefulness					
The information is new					
The information is useful					
The information is complete					
The movies and pictures increase clarity					
The information increases my knowledge					
The information facilitates decision making					
Perceived user-friendliness					
The arrangement of information is clear					
The information is easy to find					
The information is easy to browse					
The amount of information on each page to much [a]					
The information is comprehensible					
The time investment to read the website to much [a]					
The text size is readable					
The movies and pictures are clearly visible					
The information is quickly loaded					
Perceived attractiveness					
The colors of the website are attractive					
The website is well presented					
Perceived enjoyment					
In have enjoyed using this website					
Attitude					
This website could be used in clinical practice					

Chapter 7

Shared Decision Making among Physiatrist and Barriers and Facilitators to Implementation of Shared Decision Making and Decision Aids in Rehabilitation Medicine

J.A. van Til
C.H.C. Drossaert
R.A. Punter
M.J. IJzerman

Submitted to Journal of Rehabilitation Medicine

Abstract

The concept of shared decision-making is increasingly promoted within healthcare settings. Research has shown that the use of shared decision making can result in desirable outcomes such as greater patient satisfaction and greater adherence to treatment plans. The purpose of the present study was to explore the attitude of physiatrist towards shared decision making and the barriers and facilitators towards the use of shared decision making in daily practice. A cross-sectional survey was performed in 408 physiatrists, identified through the Dutch association for physiatrists (VRA). The response rate on the questionnaire was 31%. The results showed that physiatrists expressed the highest levels of comfort with the shared decision making approach as opposed to paternalistic or informed decision making. The majority reported the shared decision approach as their usual approach. The patient receiving conflicting recommendations and the patient having difficulty accepting the disease were perceived as possible barriers for shared decision making. Key facilitators to shared decision making were patient's trust in the physiatrists and the patient being knowledgeable about the disease and treatment option before the consultation. Physiatrists' attitude towards the use of decision aids was moderately positive. Most physiatrists agreed that decision aids may result in better informed patients. Based on the results of this study, shared decision-making seems well at place in the rehabilitation setting. Increasing the use of decision aids may contribute to further implementation of this approach.

Introduction

In recent years, the role of the patient in health care has changed. Patient preferences for disease management are considered increasingly important and influential in decision making (1). This asks for a change in patient-physician interaction. An analytic framework which describes the different styles of patient physician interaction was proposed by Charles et al., (2). The traditional paternalistic model assumes that the physician is the expert and actively executes the decision making. The paternalistic model makes little concession to patient preference for treatment outcome and process (3). Oppositely, in the informed decision-making model, the patient is considered as a consumer. The role of the physician is to provide all relevant information about the disease and treatment to the patient and the 'informed' patient is considered capable of making the treatment decision on his or her own (2). In recent years the shared decision making (SDM) model has been promoted in general, as well as in rehabilitation medicine (4, 5). SDM consists of the simultaneous participation of physician and patient in all phases of the decision-making process. Information is exchanged between patient and physician and the disease and the treatment are deliberated and negotiated. In the ideal situation, agreement is reached about the treatment (2).

The reported benefits of SDM in literature include increased patient satisfaction with decision process (6-8), improved adherence to treatment plans (6, 7, 9) and better psychological adjustment to illness (6). There is also resistance against SDM. Some physicians fear that that revealing the uncertainties inherent in medical care might result in increased anxiety in patients, or that SDM might result in greater demand for unnecessary, costly or harmful procedures (10, 11).

SDM seems to be well at place in rehabilitation medicine for multiple reasons. First, SDM is thought to be especially relevant in situations of equipoise. In equipoise, there are multiple courses of action without a dominating treatment option. The choice of treatment is heavily influenced by the individual preferences of the patient with regard to the outcomes and process of treatment (12). In rehabilitation medicine situations of equipoise are common. Multiple treatment alternatives often exist, the determinants of an effective care pathway are unknown, the risks are low and effect sizes are small (13). Second, the time factor was previously identified as an important barrier to shared decision making. In rehabilitation medicine, especially in an inpatient situation, a physiatrist has repeated and frequent contact with a patient. This enables the physiatrist

to inform a patient about all relevant treatment options while a patient has the time to consider the desirability of the outcomes. Third, in rehabilitation medicine decisions are often made by teams of health professionals of physicians, psychologists and physical and occupational therapists. Patient wishes for treatment are often discussed, and the different perspectives of the health professionals influence decision making. A physiatrist is used to sharing a decision and taking into account patient preferences. To the best of our knowledge, the actual use of shared decision making with patients was not previously studied in rehabilitation medicine. Therefore, the first aim of this study was to identify the use of SDM in physiatrist, and barriers and facilitators towards implementation of shared decision making.

A process of SDM can be supported through the use of decision aids (DA) (14). A decision aid is defined as "an intervention designed to help people make specific and deliberative choices among options by providing information on the options and outcomes relevant to a patient's health (15-17). A patient decision aid differs from traditional educational materials because it explicitly describes treatment options, includes quantitative and qualitative information about benefits and risks, tailors information to the individual patient and motivates patients to view the information in the light of their own values and preferences (18). To our knowledge no previous studies have investigated the feasibility of DAs in rehabilitation medicine. The second aim of this study was to explore the perceived potential of DAs in rehabilitation medicine according to physiatrists (19).

Methods

Participants and Data Collection

A cross-sectional survey of Dutch physiatrist was undertaken in 2008. Physiatrists were identified through the Dutch association for physiatrists (Vereniging van Revalidatieartsen). Only practicing physiatrists were selected. A self-report paper-and-pencil questionnaire was sent out to 408 physiatrists along with a letter inviting them to participate in the study. A prepaid return envelope was enclosed. No incentive for participation was offered. The physiatrists were asked to return the completed questionnaire within three weeks. One reminder was sent after 4 weeks.

Questionnaire design

The questionnaire consisted of three parts. The first part of the questionnaire collected background variables of the physiatrists. The second part of the questionnaire assessed the physiatrists' behavior and attitude towards decision-making. The third part of the questionnaire focused on the physiatrists' attitude towards DAs.

Background variables

The background variables age, years in practice, average amount of patients seen per week and duration of an average consult were collected with an open answer format. Gender, work-setting, the average time spent on direct patient care and primary work-setting were collected using a pre-structured answer format. Physiatrists were instructed to consider their primary work setting for the remainder of the questionnaire.

Attitude and behavior towards shared decision making

The second part of the questionnaire consisted of a questionnaire which was originally developed by Charles et al., (20) to assess the use of shared decision-making among breast cancer specialists and to explore the perceived barriers and facilitators for implementing SDM. The original questionnaire was kindly provided by the authors. All questions were translated into Dutch by three native speakers, after which the wording of each question was discussed until agreement was reached. Questions that were not relevant in the rehabilitation population were omitted based on discussion between three of the authors (JAVT, CHCD, RAP).

At first, four vignettes for patient-physician interaction were presented: (1) the physician dominating the interaction (paternalistic approach), (2) some sharing of information between patient and physician, but the physician was the sole decision maker ('some sharing' approach'), (3) the patient and physician simultaneously participated in each phase of the decision process (shared approach) and (4) the physician providing information to the patient while the patient was the sole decision maker (informed approach). The physiatrists' were asked to indicate whether their usual decision making approach was more like example 1, 2, 3 or 4. Then, they were asked to rate their level of comfort with each approach on a five-point Likert scale (1 = not comfortable – 5 = extremely comfortable). A score of 4 or 5 was considered as a high level of comfort with an approach and the number and percentage of physiatrists with high comfort with each approach was reported.

To study the perceived barriers and facilitators towards shared decision-making in rehabilitation medicine, respondents were asked to indicate the extent to which they perceived each of 19 factors as a barrier to the decision-making process and each of 11 factors as facilitators to the decision making process on a four-point Likert scale (1 = never and 4 = always). In accordance with Charles et al. (20) responses 1 and 2 were coded as 'no, not a facilitator (barrier)' and the categories 3 and 4 as 'yes, a facilitator (barrier)'. Free text fields were used to give physiatrists the opportunity to state own opinions and thoughts with regard to decision making.

Some additional questions focused on the perceived patient attitude towards SDM (4 items). These questions were based on a item list developed by Holmes-Rovner et al., (19), which is further described in the next paragraph.

Attitude towards decision aids

The third part of the questionnaire was based on items with regard to the use of decision aids proposed by Holmes-Rovner et al., (19). First, an example of a decision aid was presented to introduce physiatrists to the format of a decision aid. A series of statements was posed on the extent to which physicians consider DAs useful in the clinical setting. The statements focused on whether a decision aid should be used (2 items), the perceived administrative impact of DAs (3 items) and the perceived effect of DAs on SDM (3 items). Physiatrist agreement with the statements was rated on a five-point Likert scale (1 = strongly agree, 5 = strongly disagree). Free text fields were added

to give physiatrists the opportunity to add their own opinion with regard to the potential of DAs.

Statistical Analysis

The data were analyzed descriptively using means, standard deviations and frequency distributions. Spearman correlations were computed to test whether physiatrist work-settings were correlated.

To test whether the physiatrists attitude towards the decision-making approaches are related to characteristics of the physiatrist (i.e. gender, age and years in practice) or to the work setting (i.e. clinical setting, amount of patients per week, duration of average consult and diagnose group) correlations were calculated. A two-tailed p-value of .05 was considered significant. The SPSS statistical software package version 16.0 was used for the statistical analyses.

Results

Table 1. Physiatrists' demographic and work characteristics

	n (%)		*n* (%)
Gender		**Patient load**	week
Female	56 (44)	≤ 25	45 (38)
Male	70 (56)	26-50	57 (48)
Age (years)		51-75	14 (12)
31-40	47 (37)	>75	3 (2)
41-50	41 (33)	**Duration of average consult**	minutes
>50	38 (30)	≤ 15	19 (17)
Years in practice		16-30	84 (73)
≤ 5	41 (33)	31-45	12 (10)
6-10	25 (20)	**Clinical work setting**	
11-15	17 (14)	Hospital	59 (53)
16-20	18 (14)	Rehabilitation centre	52 (47)
>20	25 (20)	**Specialism**	
Direct patient care	hours/week	Amputation	3
≤ 8	2 (2)	Chronic Pain	25
8-16	22 (18)	Spinal Cord Injury	3
16-24	51 (41)	Neuromuscular Disease	6
>24	50 (40)	Multi-trauma	2
		Traumatic Brain Injury	2
		Cerebral Vascular Accidents	22
		Other	21

Note. Percentages are based on valid cases only. [a] *When more than one box was ticked, data was considered missing.*

Socio-demographic information and response rate

Of the 408 eligible physiatrists, 126 (31%) completed and returned the questionnaire. The majority of respondents were male. About one third was fairly new to rehabilitation medicine and was working as a registered physiatrist for five years or less (table 1). More than 80% of physiatrists spent more than 20 hours a week on direct patient care, and about 50% had between 26 and 50 unique patient contacts a week. Logically, physiatrists that had more unique patient contacts in a week spent more time on direct patient care (r=0,434; p=0,001) and the duration of their average consult was significantly lower (r=-0,264; p=0,005).

Table 2. Physiatrists' self reported usual decision-making approach and level of comfort with decision-making approach

	Usual approach	High comfort level
	N (%)	N (%)
Paternalistic approach	3 (3)	31 (25)
Some sharing	31 (27)	74 (60)
Shared approach	58 (50)	99 (81)
Informed approach	19 (16)	60 (48)
None / other	5 (4)	

Note. Percentages are based on valid cases only.

Attitude and behavior towards shared decision making

Half of the physiatrists indicated that their usual decision making approach resembles the shared decision-making style. Only 3% of physiatrists indicated that they adopted a paternalistic approach (table 2). Also, the majority of physiatrists reported high levels of comfort with the shared decision-making approach and the some sharing approach to decision making.

Table 3. Physiatrists' perception of patient attitude towards shared decision making

Patient attitude towards shared decision making	Mean	SD
Knowing risks and benefits, most patients want to decide how acceptable treatment is to them	3,49	0,91
Patients usually want to be an equal partner with physicians in making important treatment decisions	2,76	0,87
Majority of patients do not wish to be involved in decision-making about their treatment	2,19	0,96
Most patients prefer the doctor to take responsibility for their medical problems	3,30	0,98

Note. (1 = strongly disagree; 5 = strongly agree) Means and standard deviations based on valid cases only.

The majority of the physiatrists (60%) indicated they initiate a discussion on the extent to which the patient wants to participate in the decision-making process with one of their patients on a regular basis. Of the physiatrists, 28% indicated that a patient initiates a discussion about the degree of participation in the decision-making process.

Table 4. Barriers to shared decision-making in rehabilitation medicine

Barriers to shared decision making	Mean (*SD*)	Yes (%)
The patient has received conflicting recommendations from specialists	2.93 (0.84)	88 (71)
The patient has difficulty accepting his/her disease	2,89 (0.78)	83 (68)
The patient has misconceptions about the disease or treatment	2,79 (0.81)	75 (62)
The patient's family overrides the decision-making process	2,55 (0.89)	62 (51)
The patient requests a treatment unknown to be beneficial	2,47 (0.90)	60 (49)
The patient does not understand the information I have given	2.59 (0.80)	57 (46)
The patient is too anxious to listen to what you have to say	2,43 (0.84)	54 (44)
There are cultural differences between the patient and me	2.42 (0,80)	52 (42)
The patient is indecisive	2,40 (0.76)	51 (41)
I have insufficient time to spend with the patient	2.31 (0.89)	51 (41)
The patient does not want to participate in treatment decision-making	2,29 (0,72)	47 (38)
The patient comes expecting treatment rather than consultation	2,34 (0.91)	47 (39)
The patient brings too much information to discuss	2,23 (0.80)	42 (34)
The patient refuses a treatment that may benefit him/her	2,25 (0.89)	41 (34)
I have insufficient information to make a decision about treatment	2.27 (0,85)	41 (33)
The patient has other health problems	2,14 (0.79)	39 (32)
The patient wants to make a decision before receiving information	2,11 (0.85)	36 (30)
The patient wants to participate too much in deciding on her treatment	1,89 (0,73)	23 (19)
I experience difficulty knowing how to frame the treatment options	1.53 (0,71)	11 (9)

Notes: Percentages are based on valid cases only. Scale properties (1 = never; 5 = always)

The majority (80%) of the respondents inform their patients when more treatment options are available. When more treatment options are available most physiatrists (66%) make a recommendation for treatment (data not presented).
Physiatrists' perception of their patients' desire to participate in treatment decision making is moderately positive (table 3).

Table 5. Facilitators to shared decision-making in rehabilitation medicine

Facilitators to shared decision making	Mean (*SD*)	Yes (%)
The patient trusts me	3.78 (0.46)	123 (98)
The patient has emotional support from family or others	3.44 (0.61)	119 (95)
The patient is prepared (knowledgeable about the disease and treatment) prior to the consultation	3.51 (0.64)	117 (94)
The patient has someone with them at the consultation	3.34 (0.66)	114 (93)
The patient wants to participate in making the treatment decision	3.30 (0.70)	114 (91)
The patient is emotionally ready for decision-making	3.27 (0.89)	102 (82)
Providing written information to the patient	3.09 (0.74)	102 (82)
The patient talks to someone else with the same condition	2.91 (0.73)	90 (74)
The patient has contact with a support group	2.70 (0.80)	73 (59)
The patient seeks a second medical opinion	2.46 (0.78)	59 (48)
The patient has friends who work in the health care system	2.29 (0.72)	47 (38)

Notes: Percentages are based on valid cases only.

There is a favorable perception of the effect of knowledge of risks and benefits on the patients desire to participate in decision making, and physiatrist felt that the majority of patients want to participate in treatment decision making. The three most important barriers for SDM were the patient receiving conflicting recommendations from different specialists, difficulty with accepting disease and misconceptions about disease or treatment (table 4). The majority of physiatrists did not consider their own

knowledge and decision framing capacity as barriers for shared decision making. The time barrier is experienced by about half of the physiatrists.
Patients' trust in the physiatrist, emotional support of family or friends and patient preparation before the consult were considered the most important facilitators to SDM (table 5).

Table 6. Physiatrists' attitude towards the use of decision aids in rehabilitation medicine

Attitude towards decision aids	Mean	S.D.
Use of DAs		
Patients should see DA before treatment decision is made	2,98	0,93
DA Patients will be better informed	3,58	0,83
All eligible patients should be referred to a DA	3,52	1,03
A DA may cause some patients to make the wrong choice	3,04	1,01
Shared decision making		
DA will cause patients to be more involved in decision making	3,65	0,90
DA will cause patients to ask more questions than they would otherwise have asked	3,62	0,75
Other		
With a decision aid I will be able to reduce time spent educating patients about treatment	2,72	1,06
A DA will reduce the risk of malpractice	2,59	1,02
A decision aid will eliminate the need for third party utilization such as second opinion	2,43	1,03

Note. (1 = strongly disagree; 5 = strongly agree) Means and standard deviations based on valid cases only.

Attitude towards decision aids

With regard to the use of DAs in practice, physiatrists were moderately positive on the question whether eligible patients should be referred to a decision aid and the ability of a decision aid to inform (table 6). Physiatrists were neutral towards the feasibility of DAs in shared decision making. Physiatrists estimated that DAs could increase patient involvement in decision making. Physiatrists did not feel that DAs would reduce time spend educating patients or improve the quality of health care (reduce malpractice or need for second opinion).

Influence of physiatrists characteristics on decision making behavior

The majority of physiatrists in our sample worked with chronic pain (CP) patients and patients with a cerebral vascular accident (CVA) (table 1). There was a tendency towards more patient involvement in CP patients compared to patients with CVA. About 40% of physiatrists that work with CP patients indicated that the shared approach is their usual approach to decision making, while about 40% of physiatrist working with CVA patients indicated that they only share some information with their patients. Male physiatrists (r=0,215; p=0,017) and physiatrists that treat more patients (r=0,289; p=0,001) during the week are more likely to be comfortable with the informed decision making approach.

Discussion

The most important outcome of this study is that the majority of physiatrists reported the shared decision-making approach as their usual approach in decision-making. These results correspond with findings of Wain et al. (21), who identified that patients in rehabilitation medicine experience a strong sense of involvement in the rehabilitation process.

Barriers for SDM which were identified in this study were conflicting recommendations, problems with accepting the disease and misconceptions with regard to disease and treatment. In the rehabilitation setting, treatment (decision making) is usually a multi-disciplinary approach. This could increase the possibility of conflicting recommendations, as differences in training and therapeutic focus are likely to influence the development of recovery goals for patients (22). The multi-dimensional nature of disease in rehabilitation medicine might complicate understanding and acceptance of disease to patients.

A barrier to the actual use of SDM that was not formally taken into account in this study, but was repeatedly expressed by physiatrists, is the view that no decision making regarding treatment takes place once a patient is admitted to a rehabilitation unit. This indicates physiatrists that might feel that decision making regarding disease management only takes place in acute phases of disease and with regard to referral to home, nursing home or rehabilitation ward. Proot et al. (4) showed that decisions regarding the focus, intensity and specifics of treatment have to be made at several moments during post-acute rehabilitation, and that patients value being involved in this process.

Although the results are difficult to interpret as a result of small numbers of physiatrist in some patient groups, the attitude of physiatrist towards SDM does seem to be influenced by the characteristics of the patient group. Physiatrists who work with CVA executed the paternalistic- and 'some sharing'- models more often than physiatrists working with CP patients. This might be explained by the cognitive impairment of stroke patients, and suggests that when patients are limited in their ability to make a decision, physiatrists are more likely to take responsibility for decision making. Earlier studies indicate that patients are in a state of transition regarding autonomy during the rehabilitation process (4, 5, 21). Initially, patients need support and paternalism to enhance autonomy. Patients gradually develop more skills that can benefit autonomy

and shared decision making. Thus, the ability and desire of patients to participate in shared decision making is not a static concept, but one that develops during rehabilitation. Of course, both the ability and desire for shared decision making differ between patients. Residual post-stroke disabilities, multi morbidity and insecurity are constraining to patient autonomy. Some patients prefer paternalism regarding treatment decisions (8). Some patients will never (re)gain the ability to make shared treatment decisions (4, 5).

It was previously shown there are a number of patients that experience lack of information, deliberation and evaluation about treatment plans during rehabilitation (4, 5). With regard to the potential of DAs to inform patients, physiatrists seem to hold a modestly positive attitude. Also, they feel that a decision-aid will encourage patients to be more involved in decision-making about treatment. DAs could offer a structured methodology to information exchange between patients and physiatrists and thereby benefit deliberation and evaluation. The highly structured nature of information provision in DAs, might also partly overcome the information processing limitations of cognitively impaired patients.

There is a negative perception of the effect of DAs on time investment of physiatrists. Additionally, time constraints were considered a barrier to SDM in about half of the physiatrists. A systematic review by Gravel, Légaré, and Graham (23) identified time constraints as the most important barrier to actual implementation of shared decision making, but it doesn't seem that DAs are viewed upon as a way to overcome this barrier in rehabilitation medicine.

Some limitations of this study should be taken in consideration. First, the response rate was lower compared to the study by Charles et al. (2004), although the total number total number of respondents was higher (20). Given the distribution of physiatrists with regard to age and experience, we feel that we have reached a representative sample of Dutch physiatrists. It must be taken into account that physiatrists with a more positive attitude towards SDM might be more inclined to return the questionnaire. Also, given the increased attention for shared decision making, social desirability might have influenced the results of this study. These factors might have resulted in an overestimation of the use and attitude towards shared decision making. Third, with regard to the potential of DAs, it must be taken into account that the use of real DAs is probably limited in rehabilitation medicine. Therefore, physiatrists experience with

DAs is limited and their ability to estimate the effects of DAs is also. Finally, the fact that this study relied on self-reported measures must be taken into account. For instance, the use of self-reported measures has previously resulted in an overestimation of the actual degree of information provision and SDM compared to analyses of audio- and videotapes (24).

Further research should focus on the characteristics of the rehabilitation setting and patient group and how these influence the potential for shared decision making and DAs. The influence of possible cognitive limitation of the patients could be investigated. Also, more research into the organizational aspects of rehabilitation medicine may provide valuable information on the potential for implementation of shared decision-making and DAs in the rehabilitation setting.

Conclusions

The most important finding of this study is that the shared decision-making approach is the most often reported approach in rehabilitation medicine and physiatrist report high levels of comfort with this approach. These results suggest that physiatrists are at least willing to share decision making with the patient. Whether SDM is actually practiced is influenced by the characteristics of the patient group and the clinical situation, mostly by the cognitive abilities of the patient. The physiatrists' view that no decision making takes place during post acute stroke must be apposed. Future research should focus more on the barriers that are specific to rehabilitation medicine and on how these can be overcome. The potential of DAs should be further investigated in actual clinical decision making.

References

1. Haynes RB, Devereaux PJ, Guyatt GH. Physicians' and patients' choices in evidence based practice. BMJ. 2002 June 8, 2002;324(7350):1350-.
2. Charles C, Gafni A, Whelan T. Shared decision-making in the medical encounter: what does it mean? (or it takes at least two to tango). Soc Sci Med. 1997 Mar;44(5):681-92.
3. Robinson A, Thomson R. Variability in patient preferences for participating in medical decision making: implication for the use of decision support tools. Qual Health Care. 2001 Sep;10 Suppl 1:i34-8.
4. Proot IM, Abu-Saad HH, de Esch-Janssen WP, Crebolder HFJM, ter Meulen RHJ. Patient autonomy during rehabilitation: the experiences of stroke patients in nursing homes. International Journal of Nursing Studies. 2000;37(3):267-76.
5. Proot IM, Crebolder HFJM, Abu-Saad HH, Macor THGM, Ter Meulen RHJ. Stroke patients' needs and experiences regarding autonomy at discharge from nursing home. Patient Education and Counseling. 2000;41(3):275-83.
6. Ford S, Schofield T, Hope T. What are the ingredients for a successful evidence-based patient choice consultation?: A qualitative study. Soc Sci Med. 2003 Feb;56(3):589-602.
7. Edwards A, Elwyn G, Wood F, Atwell C, Prior L, Houston H. Shared decision making and risk communication in practice: a qualitative study of GPs' experiences. Br J Gen Pract. 2005 Jan;55(510):6-13.
8. Edwards A, Elwyn G. Inside the black box of shared decision making: distinguishing between the process of involvement and who makes the decision. Health Expect. 2006 Dec;9(4):307-20.
9. Speedling EJ, Rose DN. Building an effective doctor-patient relationship: from patient satisfaction to patient participation. Soc Sci Med. 1985;21(2):115-20.
10. Coulter A. Partnerships with patients: the pros and cons of shared clinical decision-making. J Health Serv Res Policy. 1997 Apr;2(2):112-21.
11. Elwyn G, Edwards A, Kinnersley P, Grol R. Shared decision making and the concept of equipoise: the competences of involving patients in healthcare choices. Br J Gen Pract. 2000 Nov;50(460):892-9.
12. Trevena L, Barratt A. Integrated decision making: definitions for a new discipline. Patient Educ Couns. 2003 Jul;50(3):265-8.
13. Tate DG. The state of rehabilitation research: art or science? Arch Phys Med Rehabil. 2006 Feb;87(2):160-6.
14. O'Connor AM, Tugwell P, Wells GA, Elmslie T, Jolly E, Hollingworth G, et al. A decision aid for women considering hormone therapy after menopause: decision support framework and evaluation. Patient Education and Counseling. 1998;33(3):267-79.
15. O'Connor AM, Rostom A, Fiset V, Tetroe J, Entwistle V, Llewellyn-Thomas H, et al. Decision aids for patients facing health treatment or screening decisions: systematic review. BMJ. 1999 Sep 18;319(7212):731-4.
16. Bekker HL, Hewison J, Thornton JG. Understanding why decision aids work: linking process with outcome. Patient Educ Couns. 2003 Jul;50(3):323-9.
17. Elwyn G, O'Connor A, Stacey D, Volk R, Edwards A, Coulter A, et al. Developing a quality criteria framework for patient decision aids: online international Delphi consensus process. BMJ. 2006 Aug 26;333(7565):417.
18. Whelan T, Sawka C, Levine M, Gafni A, Reyno L, Willan A, et al. Helping patients make informed choices: a randomized trial of a decision aid for adjuvant chemotherapy in lymph node-negative breast cancer. J Natl Cancer Inst. 2003 Apr 16;95(8):581-7.
19. Holmes-Rovner M, Valade D, Orlowski C, Draus C, Nabozny-Valerio B, Keiser S. Implementing shared decision-making in routine practice: barriers and opportunities. Health Expect. 2000 Sep;3(3):182-91.

20. Charles C, Gafni A, Whelan T. Self-reported use of shared decision-making among breast cancer specialists and perceived barriers and facilitators to implementing this approach. Health Expect. 2004 Dec;7(4):338-48.
21. Wain HR, Kneebone, II, Billings J. Patient experience of neurologic rehabilitation: a qualitative investigation. Arch Phys Med Rehabil. 2008 Jul;89(7):1366-71.
22. Rist PM, Freas DW, Maislin G, Stineman MG. Recovery from disablement: what functional abilities do rehabilitation professionals value the most? Arch Phys Med Rehabil. 2008 Aug;89(8):1600-6.
23. Gravel K, Legare F, Graham ID. Barriers and facilitators to implementing shared decision-making in clinical practice: a systematic review of health professionals' perceptions. Implement Sci. 2006;1:16.
24. Braddock CH, 3rd, Edwards KA, Hasenberg NM, Laidley TL, Levinson W. Informed decision making in outpatient practice: time to get back to basics. Jama. 1999 Dec 22-29;282(24):2313-20.

Chapter 8

Integrating Preferences into Decision Making - The Treatment of Ankle-Foot Impairment in Stroke

General Discussion

General Discussion

This thesis was focused on the use of alternative decision support techniques in situations, where effectiveness of treatment does not distinguish between treatment and the model of evidence based medicine cannot be fully executed. The results of this thesis indicate disagreement between current clinical practice and health professionals and patient preferences in the treatment of ankle-foot impairment. In this thesis, a shared decision making approach between physician and patient is propagated that is supported by decision aids (1). By using this approach in clinical decision making higher agreement between patient preferences for treatment and treatment choice is expected. This could result in improvements in patient outcomes and the overall effectiveness of care in acquired ankle-foot impairment. The use of a normative decision support technique is proposed to assist physicians and patients in exploring their preferences for treatment and to explicitly integrate them into the decision for treatment. The results of this thesis can be generalized to equipoise decision making in rehabilitation medicine. In situations where clinical evidence is hard to obtain or does not distinguish between treatments, decision support techniques as they were used in this study can assist the analysis of the pros and cons of the different treatment strategies and the optimal treatment in the management of disease (2, 3).

Treatment valuation and priority setting by health professionals and patients

In this thesis the treatment of acquired ankle-foot impairment in stroke was analyzed. The current guidelines suggest a staged approach to treatment decision making, where orthotic aids are the first choice of treatment in all patients (4, 5). It can be assumed that this recommendation is pursued in clinical practice, as most patients are treated with ankle-foot orthosis (AFO) and/or ortopeadic shoes (OS). In contrast, the results of this thesis indicated that health professionals felt that in some patients soft tissue surgery (STS) is preferred (chapter 2). It was found that no treatment alternative was judged best on all decision criteria, i.e. there is no superior treatment in acquired ankle-foot impairment in stroke. The preference for treatment depended on the patient eligibility for treatment and health professionals' estimations of patient preferences for the treatment process and outcome.

The health professionals felt that few patients would be willing to accept the longer and invasive treatment procedure of STS in order to attain a slightly more desirable

outcome. The results of this thesis confirmed that about a third of patients had high resistance against invasive treatment. In contrast, also a third of patients attached so much value to the ability to walk barefoot without the need for aids that they were willing to accept invasive surgery. On average, functional result, impact of treatment and required need for aids were the most important determinants of treatment desirability but the variability in the patient preference for treatment process and outcome was large (chapter 5). The patient divergence in the perception of the importance of treatment characteristics in combination with the health professionals' value of treatment process and outcomes indicated that there is no dominant treatment in acquired ankle-foot impairment.

The uptake of STS and neuroprostetic (NP) devices that was predicted on the patient preferences for treatment is comparable to that of traditional AFO. This is not in agreement with clinical practice. The disagreement between predicted and actual uptake of treatment in ankle-foot impairment might result from the disagreement that was shown between patient and health professionals' preferences for treatment and the lack of integration of the patient preferences in treatment decision making. The results of this thesis indicated that offering STS and NP to eligible patients who attach high value to aid-free walking could improve the satisfaction of patients with treatment in ankle-foot impairment.

Preference elicitation methods

In the analysis of treatment choice in ankle-foot impairment, the conscious deliberation of the health professionals' priorities revealed previously unspecified details that influenced treatment applicability. By using this normative decision analysis the influence of (the lack of) evidence to support decision making and the influence of subjective preferences on the decision for treatment were explicitly revealed. The judgment of treatment performance on a set of well-defined criteria enabled a comparison of treatments that had previously been impossible as a consequence of the scarcity of scientific evidence. Thereby, normative decision analysis overcame some of the limitations of current clinical guidelines. In this thesis the analytical hierarchical process (AHP) methodology was used as to analyze the decision for treatment in health professionals. The AHP was previously used in rehabilitation setting with good results (6).

Some pros and cons to using the AHP methodology to analyze decisions in the rehabilitation setting were identified in this thesis. Rehabilitation medicine is characterized by outcomes that occur on a qualitative rather than a quantitative level. Also, there is no agreement on the most applicable outcome measurement scales (2, 3, 7). The AHP is one of the few techniques that allows for a comparison of qualitative outcomes. Also, in the AHP, performance judgments are made relative to the other treatment alternatives. The relative comparisons of the treatment alternatives omit the need for a uniform measurement scale, while still enabling a ranking of treatment alternatives with regard to outcome.

During the decision analysis it became apparent that not all treatment characteristics that influence the decision task were explicitly taken into account in the AHP. It was difficult to capture the subtle perceptions and opinions of health professionals that influence the value of treatment to patients. Some were strongly dependent on individual patient characteristics while others were only relevant in a subset of the treatment alternatives. A pro of the AHP decision analysis was that although these factors were not explicitly described, their influence was discussed between panel members and was implicitly taken into account in priority setting. This confirms the usefulness of the AHP in analyzing all factors that influence a decision and its applicability as a clinical decision tool for those that participate in the decision analysis. This suggests that an AHP analysis might be appropriate when the management of disease or impairment in the rehabilitation medicine setting undergoes considerable changes, for instance when new treatment alternatives enter clinical practice (8). A con of the AHP technique is that these considerations were lost in the explicit decision tree that was constructed and in the numerical caption of the model. Although the detail of recommendations that can be captured in an AHP decision model was increased compared to traditional treatment guideline development methods, this finding reduced the usefulness of the AHP as a tool to pass on subtle knowledge and perception to others (9).

Preference elicitation in patients

In this thesis preference elicitation techniques were used to explore patient preferences for the treatment of ankle-foot impairment (9,13). Preference elicitation is a cognitively demanding process and it was assumed that it might be more difficult to achieve in patients with cognitive impairment such as in stroke. The results of this thesis indicated

that cognitively impaired subjects were capable to use most of the preference elicitation techniques, but subjects differed in the ease with which they completed the decision task and in their opinion on the most applicable technique (chapter 3). Also, the results of this thesis indicate that the outcome of a preference elicitation technique is influenced by the information that is available to a subject prior to decision making (chapter 4). This finding was previously identified in men choosing treatment for prostate cancer (10). From literature it is also known that the order, type and framing of information can influence the way information is used to make real-life decisions (11-13). The results of this thesis indicated that an extensively informed subject group makes fewer reversals in the expected order of part-worth utilities in a DCE decision task. A lower number of level rank reversals indicated a better understanding of the trading between the different characteristics of treatment that is expected to determine the value of treatment. These findings indicate that the knowledge of patients prior to using a preference elicitation technique and the choice of preference elicitation itself influence the outcome of the decision analysis. These factors must be taken into account when the results of preference elicitation techniques are used to support decisions in clinical practice.

Patient preference elicitation is also a complicated process because patients are not used to analytically comparing treatments on their characteristics. The DCE methodology is most in accordance with decision making in (clinical) practice because treatment scenarios are compared as a whole rather than breaking the decision down in its parts (14, 15). Moreover, it had been previously identified that patients are willing to participate in DCEs (16) and this method is also used widely in health care (17). In this thesis it was shown that the ability of stroke patients to complete a DCE was comparable to that of patients with peripheral ankle-foot impairment (chapter 5). One of the major strengths of a DCE is that it is possible to determine the internal validity of the experiment and the consistency of subjects. Validity and consistency testing is not possible in many other stated preference methods (18, 19). Thereby the results of a DCE can be disregarded if a patient behaves inconsistently and does not have well-developed preferences. This is a major benefit in preference elicitation when it is used to aid clinical decision making. A drawback of the DCE methodology is that many comparisons have to be made to obtain reliable individual results, and these time investments rise dramatically with the number of decision criteria. In this thesis, the

DCE methodology was only used to estimate preferences on a group level and make crude estimate of individual preferences to estimate the desirability of the different treatment alternatives. Alternatively preference elicitation techniques could be used to estimate individual preferences for treatment to guide decision making. The feasibility of a DCE questionnaire to reliably determine individual patient preferences in clinical decision making has to be determined. If a DCE is not feasible, adaptive conjoint analysis could be used and other, simpler or more efficient techniques might also be considered (19, 20).

Shared and informed decision making in rehabilitation medicine

The finding that patient and health professionals' preferences for treatment do not always agree is supported in literature (6). The conclusion that there is no dominant treatment in ankle-foot impairment for all patients stresses the need for a personalized approach to treatment decision making. A decision on the most applicable treatment in ankle-foot impairment can only be made if both patient and physiatrists are reasonably certain about which treatment will lead to the outcomes that are required and that are most valued by the patient (21). An approach that is promoted as a way to integrate patient preferences and physiatrists expertise in clinical practice is shared decision making (SDM) (22-24). The results of this thesis indicate that in general, physiatrists had a positive attitude towards the use of SDM. A small majority of physiatrists also reported to practice SDM in clinical practice (chapter 7). The physiatrists indicated that not all patients want to participate in decision making, a finding that is confirmed in literature (25-28).

With regard to the potential of SDM in the stroke population, it was found that the use of SDM was lower in physiatrists working with cognitively impaired patients. The cognitive impairment of patients was also repeatedly mentioned as a barrier towards implementation of SDM. Although it is known that the ability of stroke patients to participate in decision making is impaired, it was previously identified that the desire and ability of stroke patients to participate in decision making progresses with recovery and that the majority of stroke patients will be able to participate in decision making at discharge from the rehabilitation centre (29, 30). The results of this thesis indicated that most chronic stroke patients wanted some influence on decision making in the treatment of ankle-foot impairment, but prefer the physiatrist to make the final choice for treatment (chapter 6). Noticeably, the patients did prefer a more active role in

decision making that they had experienced in the past. The results of this thesis indicated that a physiatrist should not make assumptions about the patients desire to participate, but should initiate a discussion with the patient on their desired influence in decision making about treatment. When patients are not able or willing to participate in decision making, obviously decision making for treatment is left to the physiatrists or to close family (31).

Shared treatment decision making in ankle-foot impairment requires the deliberation of the harms and benefits of treatment between patient and physiatrist. A barrier to SDM that was confirmed in this thesis is the existing knowledge gap between patients and physicians (32-36). According to the literature, patient knowledge can be improved through the use of decision aids (DAs) (13, 33, 34, 36, 37). The results of this thesis indicate a marginally positive attitude towards decision aids in physiatrists. Physiatrist felt that DAs could be used to inform patients and that informed patients were more likely to participate in decision making (chapter 7). The results of this thesis confirmed that knowledge about the treatment of disease was improved in stroke patients after the use of a DA, and that decisional conflict about the most valued treatment was reduced (chapter 6). In the clinical practice of rehabilitation medicine, a DA could offer a structured information source which can be consulted repeatedly at a patients' own time and place in addition to the deliberation with the physiatrist and other health professionals. A DA might even overcome some of the limitations to information processing and decision making that result from cognitive impairments as a result of stroke.

Clinical implications of the thesis

In ankle-foot impairment the eligibility of a patient for the available treatment alternatives partly depends on the characteristics of the impairment. The different treatment alternatives differently affect the stability of the ankle and the position of the foot in the swing and stance phase of walking, and the nature and severity of the impairment determine which treatment alternatives are appropriate. Along with the specifics of the ankle-foot impairment, the hand and arm function of patients has to be taken into account. Impaired hand function hinders correct donning and doffing of aids. In NP, the problems with correct electrode placement might be overcome by implanting the NP device (38-40) or by new NP devices which were introduced in clinical practice since the study presented in chapter 2 was performed (41-43). Whereas

the importance of the other characteristics of treatment can be traded, i.e. is subject to personal preferences, no trading takes place with regard to the required functional outcome of treatment. This being stated, most patients remain eligible for at least two treatment alternatives after the inappropriate treatment alternatives are omitted. At this point, the decision is in equipoise and the optimal treatment depends on patient preferences and physiatrists perception of treatment.

The results of this thesis suggest that at this point, stroke patients should be informed about the value-sensitive nature of treatment choice and the importance of their own goals and wishes with regard to treatment. If patients are offered a decision aid, this gives them the opportunity to explore their short and long term goals for recovery at their own time and pace, and their options in reaching these goals. By referring to the topics discussed in the DA, physiatrists can explicitly raise the influence of preferences for treatment on treatment decision making and also the patients preference for participating in decision making. Further study should focus on how shared decision making could be facilitated, for instance through the use of decision aids. The feasibility and effect of a decision aid in patients who are in the actual process of decision making about the management of ankle-foot impairment should be studied.

The disagreement between the current guidelines and the health professionals and patient preferences for treatment indicate that the effectiveness of the care process in acquired ankle-foot impairment in stroke can be improved. This can be done by increasing the agreement between patient preference for treatment and treatment choice, but some organizational aspects of the treatment offering in acquired ankle-foot impairment must also be taken into account. In clinical practice there are some barriers towards an equal offering of the available treatment alternatives to patients. For instance, at the time of this study, not all health professionals were equally aware of the potential of STS and NP in clinical practice. In recent years the knowledge about STS and NP treatments was further diffused in the Netherlands. Despite the increased knowledge about the possibilities of STS and NP, only a minority of physiatrists have the required experience to determine patient eligibility for STS and NP and the necessary resources to offer treatment. For instance, only few orthopedic surgeons in the Netherlands are familiar and experienced with the operative techniques in STS in acquired ankle-foot impairment. To improve the care pathways the treatment of ankle-foot impairment knowledge, experience and resources have to be improved. A previous

study investigated the potential of e-health applications to disseminate knowledge and experience and the potential of such e-health applications in rehabilitation medicine should be further explored (44). Another barrier towards the offering of treatment alternatives in ankle-foot impairment is the timing of the different treatment alternatives in the recovery after stroke. AFO, OS and NP devices that use surface electrodes are currently utilized in the first stages after stroke. In contrast, there is hesitance towards early intervention with STS and implanted NP devices. It is believed that the dynamics of the ankle-foot impairment are subject to change until months after the stroke has occurred. As it was shown that muscle patterns do not change after the first three weeks after stroke, this belief might be questioned and the potential of STS and implanted NP in more acute phases of stroke might be investigated (45). A final major barrier towards treatment acceptance in clinical practice compared to the predicted uptake in this study is that at present not all treatment alternatives are fully covered by health care insurance companies.

Further topics of study

In this thesis it is suggested that in the treatment of ankle-foot impairment, preference elicitation in combination with SDM could ascertain that given the restrictions of the impairment, a patient receives the treatment that is most in accordance with their personal wishes and aims, if patient preferences are integrated into the decision (46-48). To explore the potential of using preference elicitation methods and SDM to support decision making in clinical practice, further study is required. It can be questioned whether predicting the optimal treatment based on for instance an MCDA technique will result in better decisions. Preference elicitation techniques have been criticized for the hypothetical nature of the questions, and doubts have been expressed on whether individuals behave as normative decision analysis prescribes (49). In MDCA, the decision is highly structured and the factors that influence the decision are judged independently. In clinical practice, it can be assumed that decision making is less structured and does not take into account the characteristics of the treatments independently. Estimating the desirability of treatment in MCDA is a normative process and is based on maximizing the outcome of treatment. In contrast, many people are satisfied with a treatment that performs adequately, rather than choosing the treatment that maximizes the outcome. As a result of normative decision analysis, decisions may be made which would not have been made otherwise (19).

References

1. Elwyn G, Edwards A, Kinnersley P, Grol R. Shared decision making and the concept of equipoise: the competences of involving patients in healthcare choices. Br J Gen Pract. 2000 Nov;50(460):892-9.
2. Frontera WR, Fuhrer MJ, Jette AM, Chan L, Cooper RA, Duncan PW, et al. Rehabilitation medicine summit: building research capacity. Top Stroke Rehabil. 2005 Fall;12(4):68-80.
3. Tate DG. The state of rehabilitation research: art or science? Arch Phys Med Rehabil. 2006 Feb;87(2):160-6.
4. Malas B, Kacen M. Orthotic management in patients with stroke. Top Stroke Rehabil. 2001 Winter;7(4):38-45.
5. Report of a consensus conference on the orthotic management of stroke patients. In: J. CECJM, editor. International Society of Prostetics and Orthotics; 2003; Netherlands; 2003.
6. Hummel JM, Snoek GJ, van Til JA, van Rossum W, IJzerman MJ. A multicriteria decision analysis of augmentative treatment of upper limbs in persons with tetraplegia. J Rehabil Res Dev. 2005 Sep-Oct;42(5):635-44.
7. Prvu Bettger JA, Stineman MG. Effectiveness of multidisciplinary rehabilitation services in postacute care: state-of-the-science. A review. Arch Phys Med Rehabil. 2007 Nov;88(11):1526-34.
8. Hummel JM, van Rossum W, Verkerke GJ, Rakhorst G. Medical technology assessment: the use of the analytic hierarchy process as a tool for multidisciplinary evaluation of medical devices. Int J Artif Organs. 2000 Nov;23(11):782-7.
9. Dolan JG, Bordley DR. Using the analytic hierarchy process (AHP) to develop and disseminate guidelines. QRB Qual Rev Bull. 1992 Dec;18(12):440-7.
10. Zeliadt SB, Ramsey SD, Penson DF, Hall IJ, Ekwueme DU, Stroud L, et al. Why do men choose one treatment over another?: a review of patient decision making for localized prostate cancer. Cancer. 2006 May 1;106(9):1865-74.
11. Entwistle VA, Sheldon TA, Sowden A, Watt IS. Evidence-informed patient choice. Practical issues of involving patients in decisions about health care technologies. Int J Technol Assess Health Care. 1998 Spring;14(2):212-25.
12. Sillence E, Briggs P, Harris PR, Fishwick L. How do patients evaluate and make use of online health information? Soc Sci Med. 2007 May;64(9):1853-62.
13. Jeste DV, Dunn LB, Folsom DP, Zisook D. Multimedia educational aids for improving consumer knowledge about illness management and treatment decisions: a review of randomized controlled trials. J Psychiatr Res. 2008 Jan;42(1):1-21.
14. Shackley P, Ryan M. Involving consumers in health care decision making. Health Care Anal. 1995 Aug;3(3):196-204.
15. Ryan M, McIntosh E, Shackley P. Methodological Issues in the Application of Conjoint Analysis in Health Care. Health Econ. 1998;7(4):373-8.
16. Sculpher M, Bryan S, Fry P, de Winter P, Payne H, Emberton M. Patients' preferences for the management of non-metastatic prostate cancer: discrete choice experiment. BMJ. 2004 Feb 14;328(7436):382.
17. Ryan M, Farrar S. Using conjoint analysis to elicit preferences for health care. BMJ. 2000 Jun 3;320(7248):1530-3.
18. Ryan M. Using conjoint analysis to take account of patient preferences and go beyond health outcomes: an application to in vitro fertilisation. Soc Sci Med. 1999 Feb;48(4):535-46.
19. Verhoef CG, Maas A, Stalpers LJA, Verbeek ALM, Wobbes T, van Daal WAJ. The feasibility of additive conjoint measurement in measuring utilities in breast cancer patients. Health Policy. 1991;17(1):39-50.

20. Fraenkel L, Bodardus S, Wittnik DR. Understanding patient preferences for the treatment of lupus nephritis with adaptive conjoint analysis. Med Care. 2001 Nov;39(11):1203-16.
21. O'Connor AM, Tugwell P, Wells GA, Elmslie T, Jolly E, Hollingworth G, et al. A decision aid for women considering hormone therapy after menopause: decision support framework and evaluation. Patient Education and Counseling. 1998;33(3):267-79.
22. Coulter A. Partnerships with patients: the pros and cons of shared clinical decision-making. J Health Serv Res Policy. 1997 Apr;2(2):112-21.
23. Charles C, Gafni A, Whelan T. Shared decision-making in the medical encounter: what does it mean? (or it takes at least two to tango). Soc Sci Med. 1997 Mar;44(5):681-92.
24. Frosch DL, Kaplan RM. Shared decision making in clinical medicine: past research and future directions. Am J Prev Med. 1999 Nov;17(4):285-94.
25. Holmes-Rovner M, Valade D, Orlowski C, Draus C, Nabozny-Valerio B, Keiser S. Implementing shared decision-making in routine practice: barriers and opportunities. Health Expect. 2000 Sep;3(3):182-91.
26. Robinson A, Thomson R. Variability in patient preferences for participating in medical decision making: implication for the use of decision support tools. Qual Health Care. 2001 Sep;10 Suppl 1:i34-8.
27. Elwyn G, Edwards A, Mowle S, Wensing M, Wilkinson C, Kinnersley P, et al. Measuring the involvement of patients in shared decision-making: a systematic review of instruments. Patient Education and Counseling. 2001;43(1):5-22.
28. Stewart DE, Abbey SE, Shnek ZM, Irvine J, Grace SL. Gender differences in health information needs and decisional preferences in patients recovering from an acute ischemic coronary event. Psychosom Med. 2004 Jan-Feb;66(1):42-8.
29. Proot IM, Abu-Saad HH, de Esch-Janssen WP, Crebolder HFJM, ter Meulen RHJ. Patient autonomy during rehabilitation: the experiences of stroke patients in nursing homes. International Journal of Nursing Studies. 2000;37(3):267-76.
30. Proot IM, Crebolder HFJM, Abu-Saad HH, Macor THGM, Ter Meulen RHJ. Stroke patients' needs and experiences regarding autonomy at discharge from nursing home. Patient Education and Counseling. 2000;41(3):275-83.
31. Gravel K, Legare F, Graham ID. Barriers and facilitators to implementing shared decision-making in clinical practice: a systematic review of health professionals' perceptions. Implement Sci. 2006;1:16.
32. O'Connor AM, Rostom A, Fiset V, Tetroe J, Entwistle V, Llewellyn-Thomas H, et al. Decision aids for patients facing health treatment or screening decisions: systematic review. BMJ. 1999 Sep 18;319(7212):731-4.
33. Molenaar S, Sprangers MA, Postma-Schuit FC, Rutgers EJ, Noorlander J, Hendriks J, et al. Feasibility and effects of decision aids. Med Decis Making. 2000 Jan-Mar;20(1):112-27.
34. Barry MJ. Health decision aids to facilitate shared decision making in office practice. Ann Intern Med. 2002 Jan 15;136(2):127-35.
35. Bekker HL, Hewison J, Thornton JG. Understanding why decision aids work: linking process with outcome. Patient Educ Couns. 2003 Jul;50(3):323-9.
36. O'Connor AM, Stacey D, Entwistle V, Llewellyn-Thomas H, Rovner D, Holmes-Rovner M, et al. Decision aids for people facing health treatment or screening decisions. Cochrane Database Syst Rev. 2003(2):CD001431.
37. Edwards A, Evans R, Elwyn G. Manufactured but not imported: new directions for research in shared decision making support and skills. Patient Education and Counseling. 2003;50(1):33-8.
38. Burridge JH, Taylor PN, Hagan SA, Wood DE, Swain ID. The effects of common peroneal stimulation on the effort and speed of walking: a randomized controlled trial with chronic hemiplegic patients. Clin Rehabil. 1997 Aug;11(3):201-10.
39. Kottink AI, Hermens HJ, Nene AV, Tenniglo MJ, van der Aa HE, Buschman HP, et al. A randomized controlled trial of an implantable 2-channel peroneal nerve stimulator on walking speed and activity in poststroke hemiplegia. Arch Phys Med Rehabil. 2007 Aug;88(8):971-8.

40. Kottink AI, Hermens HJ, Nene AV, Tenniglo MJ, Groothuis-Oudshoorn CG, MJ IJ. Therapeutic effect of an implantable peroneal nerve stimulator in subjects with chronic stroke and footdrop: a randomized controlled trial. Phys Ther. 2008 Apr;88(4):437-48.
41. Hausdorff JM, Ring H. Effects of a new radio frequency-controlled neuroprosthesis on gait symmetry and rhythmicity in patients with chronic hemiparesis. Am J Phys Med Rehabil. 2008 Jan;87(1):4-13.
42. Ring H, Treger I, Gruendlinger L, Hausdorff JM. Neuroprosthesis for footdrop compared with an ankle-foot orthosis: effects on postural control during walking. J Stroke Cerebrovasc Dis. 2009 Jan;18(1):41-7.
43. Laufer Y, Hausdorff JM, Ring H. Effects of a foot drop neuroprosthesis on functional abilities, social participation, and gait velocity. Am J Phys Med Rehabil. 2009 Jan;88(1):14-20.
44. Buurke JH, Kleissen RF, Nene A, Bloo JK, Renzenbrink GJ, Zeegers AV, et al. A feasibility study of remote consultation to determine suitability for surgery in stroke rehabilitation. J Telemed Telecare. 2004;10(2):108-12.
45. Buurke JH, Nene AV, Kwakkel G, Erren-Wolters V, IJzerman MJ, Hermens HJ. Recovery of gait after stroke: what changes? Neurorehabil Neural Repair. 2008 Nov-Dec;22(6):676-83.
46. Ford S, Schofield T, Hope T. What are the ingredients for a successful evidence-based patient choice consultation?: A qualitative study. Soc Sci Med. 2003 Feb;56(3):589-602.
47. Edwards A, Elwyn G, Wood F, Atwell C, Prior L, Houston H. Shared decision making and risk communication in practice: a qualitative study of GPs' experiences. Br J Gen Pract. 2005 Jan;55(510):6-13.
48. Edwards A, Elwyn G. Inside the black box of shared decision making: distinguishing between the process of involvement and who makes the decision. Health Expect. 2006 Dec;9(4):307-20.
49. Cohen BJ. Is expected utility theory normative for medical decision making? Med Decis Making. 1996 Jan-Mar;16(1):1-6.

Summary

Rehabilitation medicine is characterized by the limited availability of high quality comparative studies into the effectiveness of different treatment strategies. Also, scientific studies often do not distinguish between the disease management options, because their effect is comparable. Despite the absence of such evidence, decisions on the management of disease have to be made on a daily basis. An example is the treatment of ankle-foot impairment after stroke. Traditionally, ankle-foot orthosis and orthopeadic footwear are used. Surgical treatment and neuroprostetic devices were more recently introduced into clinical practice. The limited scientific evidence indicates that on a group level, the effect of these treatments on functioning is comparable. In clinical decision making, other characteristics of treatment are thought to be decisive.

Traditional research and decision analysis methodologies do not take into account patient and physician preferences for treatment characteristics such as the process of treatment. Therefore, alternative methodologies to analyze decision making are needed to establish the impact of such characteristics of treatment. An understanding of the characteristics of treatment that determine its attractiveness could give insight into the potential of novel, innovative treatment alternatives. Also, the outcome of such an analysis could aid clinical decision making, for instance by adapting the current guidelines.

In the first part of this thesis the patient and physician preferences for the treatment of ankle-foot impairment in stroke were measured. In the second chapter, it is described how a decision tree was constructed by an interest group of physiatrist. The decision tree consisted of the decision criteria functional outcome of treatment, comfort of shoes, risks and side-effects, cosmetic consequences of treatment, the impact of treatment and the long-term daily effort involved with treatment. The preference for treatment in health professionals was determined using a decision analysis technique known as the analytical hierarchical process. The results of this study indicate that there is no dominant treatment alternative in ankle-foot impairment, as no treatment scores best on all criteria. The choice of treatment depends most on the needed ankle-stability and foot support, the risk involved with treatment and the comfort of shoe wear after treatment. The health professionals stated that the importances of the criteria other than the required functional result are to be determined by the patient. Prior to eliciting patient preferences for the management of ankle-foot impairment, in chapter

three of this thesis the feasibility of decision techniques in stroke patients was determined. It was shown that patients with cognitive impairment were willing and able to use multi-criteria decision analysis techniques to determine their preferences for health care management. Patient preferences for treatment were elicited using a choice experiment in chapter 5. The results of the experiment indicate that patient preferences for the management of ankle-foot impairment vary widely and that no treatment is considered dominant; i.e. is preferred by all patients. The patient valuation of the potential benefits of surgery and neuroprostetic devices suggests that these treatments have potential in the management of ankle-foot impairment of stroke.

The variation in patient preferences for treatment process that was shown indicates that collaboration between patient and physiatrists is necessary to determine the optimal treatment in each patient. In chapter 4, it was also shown that the information that is available prior to expressing a preference for treatment influences the trade-off people make between the characteristics of treatment. Unbiased and full information provision to the patient is therefore very important in the clinical encounter. A decision aid could be a way to give this information to patients. The second part of this thesis investigated the possibility of a shared and informed approach to clinical decision making in rehabilitation practice. The results of the study into the feasibility of a decision aid in stroke patients presented in chapter 6 indicates that a decision aid can increase knowledge about treatment options in stroke patients and reduce the internal conflict about which treatment is most desired. Furthermore, it was shown that stroke patients want to participate more actively in decision making than they have done in the past. It was shown in chapter 7 that physiatrists have a positive attitude towards sharing information and the decision for treatment with their patients. They do feel not all patients want to participate in decision making, and that not all patients are able to do so, for instance as a result of cognitive impairment.

Summarizing, the results of this thesis indicate that the use of the decision analysis techniques to analyze the decision for treatment in ankle-foot impairment can uncover relevant information to clinical decision making. The decision analysis methodologies have benefits that traditional outcome research methodologies have not. With the difficulty of performing high quality outcome studies in rehabilitation medicine, these methodologies might be used to aid guideline development. The importance of treatment characteristics to patients could prioritize the issues physiatrists take into

account in clinical decision making. The priorities in treatment process and outcome that were expressed by patients could be used by health professionals to inform other patients about their treatment options. There is a relationship between the personal importance of different treatment criteria and the preferred treatment in ankle-foot impairment. A process of information sharing and decision sharing between patient and physiatrist is appropriate before a treatment decision is made, if this is the desire of the patient. Decision aids could be used to assist patients in increasing their knowledge about treatment and a shared approach to decision making is propagated in order for patients to vocalize their aims and wishes with regard to treatment process and outcome in the treatment of ankle-foot impairment.

Samenvatting

Er is een algemeen gebrek aan kwalitatief goede studies, die de behandelmogelijkheden in de revalidatiezorg vergelijken. Als gevolg van de diverse behandelpopulatie in de revalidatiegeneeskunde, is het moeilijk gerandomiseerde en gecontroleerde studies uit te voeren. Daarnaast is het lastig voldoende aantallen mensen op te nemen in een studie en zo betrouwbare resultaten te verkrijgen. Ook onderscheiden de verschillende behandelingen zich vaak onvoldoende om op basis van het voorspelde resultaat van de behandeling te bepalen welke behandeling het beste is voor een patiënt. Ondanks dit gebrek aan wetenschappelijk onderbouwde gegevens of de uitkomst van behandeling moeten dagelijks beslissingen worden genomen over op welke manier een patiënt teh behandelen.

Een voorbeeld van een aandoening waarvoor het moeilijk is de juiste behandeling te bepalen is de behandeling van enkel- en voetafwijkingen na een beroerte. Traditioneel wordt een enkel- en voetafwijking na een beroerte vaak behandeld met enkel voet orthesen en/of orthopedische schoenen. Recentelijk werden een operatieve behandeling en de behandeling met neuroprosthesen geïntroduceerd als alternatieve behandelmogelijkheden bij enkel en voetafwijkingen na beroerte. Het aanwezige wetenschappelijk bewijs toont aan dat het effect van alle behandelingen op de functie van de enkel en voet vergelijkbaar is. Op basis van deze gegevens kan dus geen keuze voor behandeling worden gemaakt. Het is aannemelijk dat in de klinische besluitvorming rond de behandeling andere criteria, zoals het proces van behandeling, een rol spelen in de keuze voor de behandeling.

Traditionele onderzoeksmethoden en technieken zijn niet geschikt om de invloed van andere criteria dan het effect van behandeling op de keuze voor behandeling te analyseren. Kennis van het hoe en waarom van behandelkeuzes bij enkel- en voetafwijkingen kan meer inzicht geven in de potentie van nieuwe behandelmethoden in de klinische praktijk. Daarnaast zouden dergelijke gegevens gebruikt kunnen worden om toekomstige beslissingen te ondersteunen, bijvoorbeeld door deze te verwerken in bestaande richtlijnen. Het gebruik van andere onderzoeksmethodieken, die wel geschikt zijn om de invloed van voorkeuren voor het proces van behandeling te meten, lijkt noodzakelijk in de revalidatiegeneeskunde.

In het eerste deel van dit proefschrift werden van een aantal van deze technieken toegepast om de voorkeur van de arts en de patiënt voor de behandeling van enkel en

voet afwijkingen te meten. Er werd een beslisboom samengesteld door een team van revalidatieartsen, met de criteria: het resultaat van de behandeling, het comfort van het dragen van schoeisel, de risico's en bijwerkingen van de behandeling, de cosmetische gevolgen van de behandeling, de lengte van het behandelproces en de langdurige (dagelijkse) inspanning als gevolg van de behandeling. Vervolgens bepaalde een groep ervaren behandelaars hun voorkeur voor de behandeling van een enkel en voet afwijking door het toepassen van een besliskundige analysetechniek, het analytisch hiërarchisch proces, op de beslisboom. De resultaten van deze studie laten zien dat geen enkele behandeling dominant is, dat wil zeggen de beste uitkomst heeft op alle onderdelen van de beslisboom. De keuze voor de behandeling hangt af van de afweging tussen de noodzaak tot stabilisatie van de enkel en verbetering van de voetpositie, de risico's en bijwerkingen van de behandeling en het comfort van het dragen van schoeisel na de behandeling. Volgens de ervaren behandelaars moet het belang van de factoren van de beslisboom, uitgezonderd het noodzakelijke resultaat van de behandeling, door de patiënt bepaald worden.

Er zijn meerdere technieken om de voorkeur voor behandeling bij patiënten te meten. Er kan getwijfeld worden aan de capaciteit van mensen met een beroerte om gebruik te maken van dit soort technieken, omdat een beroerte kan leiden tot cognitieve beperkingen. In dit proefschrift werd echter aangetoond dat mensen na een beroerte in staat zijn om dit soort methodieken te gebruiken, als de methodiek van de techniek goed was uitgelegd. De voorkeur van patiënten met een enkel- en voetafwijking na een beroerte werd bepaald tijdens een experiment waarbij de patiënt moest kiezen tussen verschillende behandelingen. De resultaten van deze studie tonen aan dat het belang van de verschillende criteria die de keuze voor behandeling bepalen varieert tussen patiënten. Belangrijke criteria zijn wel de invasiviteit (het wel of niet opereren) van een behandeling, de noodzaak tot het gebruik van hulpmiddelen en het functionele resultaat (wel of niet de mogelijkheid tot lopen op blote voeten). Geen enkele behandeling is dominant, dat wil zeggen dat deze door alle patiënten gekozen wordt. De positieve beoordeling van de operatieve behandeling en een behandeling met externe neuroprosthesen door een groot deel van de patiënten toont aan dat er zeker potentie is voor deze nieuwe behandelingen in de klinische praktijk, en dat de bestaande richtlijnen deze positieve beoordeling van de behandeling door patiënten zou moeten opnemen.

In dit proefschrift werd een relatie aangetoond tussen de informatie die een patiënt krijgt en het belang van de verschillende kenmerken van de behandelingen. Dit laat zien dat de voorlichting die een patiënt krijgt van invloed kan zijn op de keuzes die hij of zij maakt. Daarnaast toont de grote variatie tussen patiënten wat betreft de voorkeur voor een behandeling aan dat een goede samenwerking tussen patiënt en revalidatiearts noodzakelijk is om de optimale behandeling bij enkel en voet afwijkingen te bepalen. In het tweede deel van dit proefschrift werd daarom onderzocht wat de mogelijkheden zijn om de samenwerking tussen arts en patiënt in de revalidatiegeneeskunde te bevorderen. Het is belangrijk dat de patiënt onbevooroordeelde en volledige informatie ontvangt over zijn of haar behandelmogelijkheden. Een manier om dit te doen is het gebruik van een besliskundig hulpmiddel. Het onderzoek toont aan dat het gebruik van een besliskundig hulpmiddel bij mensen met een enkel en voet afwijking na beroerte de kennis van patiënten over de beschikbare behandeling vergroot en de mate van conflict over de meest gewenste behandeling verkleint. Daarnaast willen mensen na een beroerte actiever deelnemen aan het beslissingsproces dan ze in het verleden konden doen. Ook revalidatieartsen hebben een positieve houding ten opzichte van een beslissingsproces waarbij de behandelingmogelijkheden besproken worden met de patiënt en de verantwoordelijkheid voor de keuze voor de meest geschikte behandeling wordt gedeeld. Revalidatieartsen hebben echter ook het gevoel, dat niet elke patiënt kan en wil deelnemen aan een gezamenlijk besluitvormingsproces, bijvoorbeeld als gevolg van de cognitieve beperkingen die aanwezig kunnen zijn na beroerte.

De resultaten van dit proefschrift tonen aan dat de voorkeur voor behandeling bij enkel en voetafwijkingen bij patiënten in grote mate bepaald wordt door procesfactoren en kwalitatieve uitkomsten van behandeling, zoals de noodzaak tot het gebruik van hulpmiddelen. Het belang van deze factoren verschilt echter per patiënt, en de keuze voor behandeling is daarom ook een individueel proces. De besliskundige technieken die gebruikt zijn in dit proefschrift werden waardevol bevonden om het belang van de verschillende factoren voor zowel patiënten als artsen te bepalen. In afwezigheid van doorslaggevend wetenschappelijk bewijs voor een dominante behandeling, zouden de uitkomsten van dergelijke analyses verwerkt kunnen worden in behandelrichtlijnen, om daarmee de relatie tussen voorkeuren en keuzes voor behandeling te benadrukken.

In de klinische besluitvorming in de dagelijkse praktijk is het van belang patiënten voor te lichten over de relatie tussen persoonlijke voorkeuren en de keuze voor een

behandeling. De resultaten van dit onderzoek geven aan dat het belangrijk is dat informatie wordt uitgewisseld tussen arts en patiënt voor een keuze voor een behandeling gemaakt wordt. Besliskundige hulpmiddelen kunnen worden gebruikt om een gedeelte van de informatievoorziening buiten het directe contact met de arts te laten plaatsvinden en zo de druk op de arts te verminderen, terwijl de patiënt zijn of haar kennis kan vergroten en alvast een voorkeur voor behandeling kan bepalen. Een gezamenlijk besluitvormingsproces wordt hierna aanbevolen om de patiënt de kans te geven zijn of haar eigen wensen ten aanzien van behandeling te uiten, en om deze zo veel mogelijk mee te nemen in de keuze voor de behandeling. Het gebruik van een besliskundige methode, zoals gebruikt in dit proefschrift, zou een expliciete manier kunnen zijn om de patiënt inzicht te geven in en te betrekken bij de keuze voor een behandeling.

Dankwoord

In het traject naar de totstandkoming van dit boekje heb ik vele beslissingen genomen. Bewust en onbewust, intuïtief en analytisch, goed en slecht. Een aantal keer in de afgelopen jaren paste ik zelfs de in dit promotieboekje beschreven technieken toe. De manier waarop een beslissing wordt genomen heeft geen directe relatie met de uitkomst van de beslissing. De beslissing om een carrière als onderzoeker te beginnen nam ik zonder er lang over na te denken. Ik studeerde af, stuurde wat open sollicitaties, werd uitgenodigd voor een gesprek en kon bijna meteen beginnen als onderzoeksassistent. De kans om een jaar te proeven van het onderzoekers bestaan leek me leuk, en daarmee was een beslissing genomen. Een jaar later kon ik ook beginnen aan een promotietraject. Bij deze keuze speelden andere criteria een rol. De impact op de rest van mijn werkende leven was ook groter. Uiteindelijk besloot ik de sprong te wagen. Na veel inlezen en vooronderzoek begon het beslissen toen pas echt. De vraagstelling van deelonderzoeken, de inhoud van vragenlijsten, de focus van de verschillende hoofdstukken. Ik nam het besluit een promotietraject te beginnen dus zonder alle consequenties te overzien. Het proces van het komen tot dit proefschrift is met pieken en dalen verlopen. Ondanks de dalen ben ik blij met mijn beslissing om dit traject in te gaan. Het is een leerzaam traject geweest, zowel op persoonlijk als op werkinhoudelijk vlak. Ik ben nog blijer en zeer trots dit traject te kunnen afsluiten met het boekje dat nu voor u ligt.

In die afgelopen jaren zijn er een aantal mensen geweest die hebben bijgedragen aan de totstandkoming van dit proefschrift. Mensen die me hebben geholpen de beslissingen te nemen, de uitkomsten te verwerken en het proces te relativeren. Een aantal van deze mensen wil ik hier bedanken. Allereerst mijn 1e promotor, Prof. Dr. M.J. IJzerman. Maarten, ik wil je bedanken voor de kans die je me hebt gegeven om dit onderzoek uit te voeren, je begeleiding van een beginnende en koppige onderzoeker en je vertrouwen in mijn kunnen. Ik denk met plezier terug aan de congressen die we samen bezochten, waar je me uitdaagde om op een andere manier naar onderzoek en carrièrekeuzes te kijken. Ik wil je ook bedanken voor de kans die ik nu krijg mijn verdere onderzoeksinteresses te verkennen en als docent aan de slag te gaan op de Universiteit Twente. Dan mijn 2e promotor, Prof. Dr. A.M. Stiggelbout. Anne, ik dank je voor je inhoudelijke begeleiding, je belangrijke bijdrage aan mijn artikelen en voor de prettige

overleggen die we hadden. Na een overleg in Leiden begon ik de terugreis naar het Oosten altijd met nieuw vertrouwen en motivatie om dit project tot een goed einde te brengen. Special thanks to my co-promotor, Dr. J.D. Dolan. Jim, you were very important in the early phases of this project, when I took the trip to Rochester to meet you and to discuss ideas. You were supporting and motivating throughout the process. I very much appreciated your quick responses to my not always timely requests for help. I also really appreciated the way in which you are able to maintain a personal contact, mostly through an impersonal medium like e-mail. Ik wil ook de rest van mijn promotiecommissie bedanken voor de tijd en energie die ze hebben gestoken in het lezen van mijn proefschrift en voor hun bijdrage aan mijn openbare verdediging.

Het onderzoek dat is beschreven in dit proefschrift was niet mogelijk geweest zonder de steun van een aantal belangrijke organisaties en mensen. Veel dank aan ZonMW en het innovatiecentrum revalidatietechnologie voor hun bijdrage aan dit onderzoek. Ook dank aan de artsen en professionals die hebben deelgenomen aan de studie gepresenteerd in hoofdstuk 2, de arts assistenten van het Roessingh die een bijdrage hebben geleverd tijdens het ontwikkelen van de vragenlijsten en alle revalidatieartsen die hebben deelgenomen aan de studie gepresenteerd in hoofdstuk 7. Essentieel voor dit onderzoek waren natuurlijk de patiënten, die hun medewerking hebben verleend aan de onderzoeken die zijn gepresenteerd in hoofdstuk 3, 5 en 6. Dr. Govert Snoek, Ruth, Michiel, Gera en Jocelyn, bedankt voor onze prettige samenwerking tijdens het project van het Innovatiecentrum Revalidatietechnologie. Karin Groothuis, bedankt voor je hulp bij het analyseren van de onderzoeksgegevens. Ook wil ik de bachelor en master studenten bedanken die een bijdrage hebben geleverd aan de totstandkoming van dit proefschrift. Rudolf, Evelien, Brenda en Annemiek, bedankt voor jullie enthousiasme en inzet.

Het project begon voor mij te leven met het samenkomen van het “SPLATT” team op de vrijdagmiddag, waarin de patiënten die mogelijk in aanmerking kwamen voor een operatie werden besproken. Dr. Jaap Buurke, Dr. Anand Nene en Dr. Elgun Zeegers, bedankt voor de kans om mee te kijken hoe een beslissing voor een operatieve behandeling wordt genomen en voor de klinische kennis die ik tussen de regels door opdeed. Een speciaal woord van dank voor Drs. Bertjo Renzenbrink. Bertjo, bedankt

voor je inhoudelijke steun maar vooral ook voor je begrip, steun en aanmoediging tijdens een aantal moeilijke fasen van dit project.

Tot zover de mensen die een belangrijke inhoudelijke bijdrage hebben geleverd aan dit project. De omgeving waarin een promotieonderzoek plaatsvindt, is net zo belangrijk om de motivatie voor een project te houden dan de inhoud. Ik begon mijn loopbaan als onderzoeker op het Roessingh Research & Development. In de bijna vijf jaar dat ik hier werkzaam was is deze organisatie en zijn de mensen die hier werkten erg belangrijk geweest. Ik wil het managementteam van RRD, Prof. Dr. Hans Rietman, Dr. Bart Freriks, Dr. Michiel Jannink, Prof dr. Hermie Hermens en Prof. Dr. Mirjam Vollenbroek dan ook bedanken voor de steun aan en begrip voor deze "verstekeling" aan boord van het RRD schip. De beslissing om het vertrouwde schip te verlaten was een lastige. Waarschijnlijk gaven de natte voeten die ik letterlijk kreeg de doorslag om te kiezen voor een plekje 2 hoog bij de UT, want een uitgebreide beslissingsanalyse ondersteunt door AHP kon in ieder geval niet de doorslag geven. Daarin bleken mijn twee alternatieve keuzes even aantrekkelijk.
Mijn werkende onderzoekersleven begon in de gele houten reddingsboot van RRD. De keet en zijn bewoners maakten de overgang van student naar werknemer makkelijker. Jitske, Gerlienke, Laura, Annerieke, Annemiek, Gerdienke, Michiel en Henk, bedankt voor de gedeelde klaagzangen over "te warm, te koud, te tochtig en te gehorig" en in het bijzonder voor de eindconclusie "af en toe te gezellig". Speciaal dank ook aan niet-keet bewoner Jan Hindrik voor het organiseren van de vele leuke uitjes.
In de loop van de jaren bij RRD zijn er twee mensen geweest met wie ik meer dan gemiddeld heb opgetrokken. Rianne, vanaf het moment dat we kamergenoten werden klikte het enorm goed tussen ons. Ik was vereerd dat ik je, ondanks een slecht getimede zwangerschap, toch kon en mocht steunen in jouw promotietraject en ik ben blij dat je hetzelfde nu voor mij wilt doen. We grapten wel eens dat we elkaar meer "wakker" zagen dan onze partners. Ondanks verschillende werkplekken en carrièrekeuzes die er in de toekomst ongetwijfeld (weer) zullen volgen hoop ik dat we vrienden zullen blijven.
Anke, ik ben jou vooral erg dankbaar voor je nuchtere en relativerende kijk op het (onderzoekers) leven en de prioriteiten die je daarin stelt en vooral ook volgt. Je wist me meerdere malen met de andere kant van mijn keuzes te confronteren, de kanten die ik

zelf wel eens over het hoofd wil zien. Bedankt dat je mijn paranimf wilt zijn op de bijna eerste werkdag na de geboorte van Eva. Jij deed voor hoe een zwangerschap moet, ik doe nu nog een keer voor hoe promoveren moet, in de verwachting dat jij nu snel volgt.
In de 5 jaar bij RRD en het Roessingh waren, kwamen en gingen er veel meer mensen. Elles, Barbara, Karlijn, Inger, Brigitte en alle andere mensen die ik nu niet noem, bedankt voor alles.
Tijdens mijn verblijf op het RRD was ik formeel onderdeel van de vakgroep Biomedical Systems and Signals op de Universiteit Twente. Bij deze groep techneuten voelde ik me af en toe een vreemde eend in de bijt. Maar wel een vreemde eend die welkom was. Ik wil dan ook de hele groep, maar in het bijzonder Prof. Dr. Peter Veltink en Wies Elfers bedanken voor de getoonde belangstelling voor mij en voor het verloop van het project.
Een beslissing om ergens te vertrekken opent ook nieuwe deuren. In dit geval de deuren naar de nieuwe vakgroep Health Technology and Services Research op de Universiteit Twente. Dankzij een voorlopig laatste verhuizing vormen we nu ook fysiek een groep. Bedankt voor jullie steun in de laatste fase van mijn promotie en ik zie er naar uit met jullie de vakgroep verder te ontwikkelen.

Met betrekking tot de inhoud en uitvoering van dit proefschrift op de achtergrond aanwezig, maar daarom niet minder belangrijk in dit dankwoord zijn mijn familie en vrienden. Lieve Jeroen en Mads, jullie zijn de twee belangrijkste mensen in mijn leven en zijn uitstekend in staat gebleken mijn soms malende gedachten over dit onderzoek stop te zetten. Ik weet zeker dat dit niet altijd bewust gebeurde (in ieder geval bij een van jullie), maar deze onderbrekingen waren en zijn erg welkom. Ik houd van jullie!
Papa en mama, jullie zullen soms met verbazing mijn verhalen aangehoord hebben, niet altijd begrijpend waar ik nu precies, of zelfs maar ongeveer aan begonnen was. Misschien dat jullie dit na mijn verdediging een beetje beter snappen. En wellicht is het een geruststelling (en een bron van vermaak) voor jullie dat ik, na eerst grote weerstand te hebben getoond, in ieder geval nog een beetje jullie voorbeeld, het geven van onderwijs, ga volgen. Als laatste mijn dank aan mijn vriendinnetjes die mij afleiding hebben geboden, mijn frustraties hebben aangehoord en mijn overwinningen met me hebben gevierd. Jullie weten wie jullie zijn ;).

Over de auteur

Janine van Til werd geboren op 3 augustus 1976 in Neede. Na het volgen van de middelbare school op het Staring College te Lochem koos ze voor een studie fysiotherapie in Enschede. In het laatste jaar van haar studie kwam zij tot de conclusie dat de praktijk van het behandelen van patiënten interessant was, maar de theorie en het waarom achter de behandelkeuzes nog interessanter. Daarom koos zij voor een studie bewegingswetenschappen aan de Vrije Universiteit te Amsterdam. Deze studie – afstudeerrichting bewegingssystemen en minor gezondheidszorg- rondde zij af in augustus 2001. Tijdens en na deze studie was ze ook werkzaam als fysiotherapeut. In mei 2002 begon zij als wetenschappelijk onderzoeksassistent bij Roessingh Research & Development. In december 2003 is ze gestart met haar promotieonderzoek binnen het ZonMW project revalidatie technische hulpmiddelen. In 2005 en 2006 was ze ook projectleider van het project "beslissingsondersteuning in de revalidatiezorg", dat werd gefinancierd door het Innovatiecentrum Revalidatietechnologie.

Op dit moment is Janine van Til werkzaam als universitair docent aan de Universiteit Twente, bij de bacheloropleiding gezondheidswetenschappen en de masteropleiding Health Sciences, waar ze de vakken Chronische Aandoeningen en Pathologie en Medical Decision Making verzorgt. Ook is ze betrokken bij het door ZonMW gesteunde onderzoeksproject HEADS, HElmet therapy Assessment in Deformed Skulls en is ze bezig met het ontwikkelen van een eigen onderzoeksgebied gericht op de acceptatie van medische technologie en innovatie door patiënten.

List of Publications

Van Til JA, Stiggelbout AM, IJzerman MJ.
The effect of information on preferences stated in a choice-based conjoint analysis. Patient Educ Couns. 2009 Feb;74(2):264-71.

Van Til JA, Renzenbrink GJ, Dolan JG, IJzerman MJ.
The use of the analytic hierarchy process to aid decision making in acquired equinovarus deformity. Arch Phys Med Rehabil. 2008;89(3):457-62.

Van Til JA, Dolan JG, Stiggelbout AM, Groothuis CGM, IJzerman MJ.
The use of multi-criteria decision analysis weight elicitation techniques in patients with mild cognitive impairment – a pilot study. Patient. 2008; 1 (2): 127-135.

Snoek GJ, van Til JA, Krabbe PF, IJzerman MJ.
Decision for reconstructive interventions of the upper limb in individuals with tetraplegia: the effect of treatment characteristics. Spinal Cord. 2008;46(3):228-33.

IJzerman MJ, van Til JA, Snoek GJ.
Comparison of Two Multi-Criteria Decision Techniques for Eliciting Treatment Preferences in People with Neurological Disorders. Patient. 2008; 1 (4);265-272

Van Til JA, Renzenbrink GJ, Groothuis CGM, IJzerman MJ.
A preliminary economic evaluation of percutaneous neuromuscular electrical stimulation in the treatment of hemiplegic shoulder pain. Disabil Rehabil. 2006 30;28(10):645-51.

Hummel JM, Snoek GJ, van Til JA, van Rossum W, IJzerman MJ.
A multicriteria decision analysis of augmentative treatment of upper limbs in persons with tetraplegia. J Rehabil Res Dev. 2005 Sep-Oct;42(5):635-44.

Huis in 't Veld MH, van Til JA, IJzerman MJ, Vollenbroek-Hutten MM.
Preferences of general practitioners regarding an application running on a personal digital assistant in acute stroke care. J Telemed Telecare. 2005;11 Suppl 1:37-9.