

Functional outcome
after a lower limb amputation

RIJKSUNIVERSITEIT GRONINGEN

Functional outcome after a lower limb amputation

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VOORWOORD/PREFACE

Op de afdeling Revalidatie van het Academisch Ziekenhuis Groningen bestaat een jarenlange traditie van wetenschappelijk onderzoek betreffende revalidatie van mensen met een amputatie en de prothesiologie. In het kader van mijn AGIKO-opleiding (Assistent Geneeskundige in opleiding tot Klinisch Onderzoeker) heb ik deze traditie voortgezet in de vorm van dit promotieonderzoek met als centraal thema het functioneren van mensen met een beenamputatie. Dit onderzoek was niet mogelijk zonder de hulp van velen, waarvoor mijn hartelijke dank. Enkele van hen wil ik in het bijzonder noemen.

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Statistiek blijft een moeilijk vak; goede ondersteuning kreeg ik daarbij van Eric van Sonderen. Van hem kreeg ik veel kritische noten en hulp bij alle uitgevoerde analyses en berekeningen, alsmede methodologische kanttekeningen.

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Veel patiënten zijn bereid geweest zich vrijwillig te onderwerpen aan onze metingen, vragenlijsten of interviews. Dankzij hun medewerking is er weer een klein stapje gezet om de zorg voor beenamputatiepatiënten verder te verbeteren.

Zeven jaar lang was ik in opleiding en had ik veel collega arts-assistenten op de afdeling Revalidatie. Dank voor jullie begrip en geduld voor al mijn AGIKO-grillen. Daarnaast vond ik het erg leuk dat er ook enkele AIO's op onze afdeling kwamen werken. Bedankt voor de samenwerking op onderzoeksgebied.

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Nomdo en Romke: 2 mannen in huis. Zonder jou, Nomdo, had ik niet alle moeilijke fasen in het onderzoek goed doorstaan. Rustig bracht je mij weer in de goede richting en werden frustraties gerelativeerd. Romke, misschien lees je dit nog eens: je bracht een heel nieuwe en zeer waardevolle wending in ons bestaan. Het is fantastisch om na een dag broeden op allerlei teksten, bij thuiskomst te worden verwelkomd door jouw volle lach!

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CHAPTER 1

INTRODUCTION AND OUTLINE OF THE THESIS

Introduction

Lower limb amputations have been done since time immemorial. The first surgical description of a leg amputation was by Hippocrates (460–377 BC). Many different surgical techniques have been described through history, for example the guillotine amputation, the double circular incision or two cut technique, and the skin-muscle-flap method. Although prostheses are not mentioned in medical literature from Ancient Times, they were certainly made and used as we learn from non-medical books and pictures.¹ We do not, however, know much about the functional abilities after a leg amputation in those times.

Transplantation of extremities has never yet been successfully carried out and will not be successfully done in the near future, even though it was already depicted as the Miracle of the Black Leg of Cosmas and Damianus at the beginning of the fifteenth century.² Till now, prostheseology gives better functional results than transplantation of the limb. Thus, patients still need to function with their amputated leg with or without a prosthesis. Many aspects in amputation surgery, prostheseology, and the functional possibilities of patients with leg amputations have improved since Hippocrates. However, for the rehabilitation of amputee patients, treatment is still mainly based on clinical experience and only limited on evidence-based medicine.

Knowledge of important aspects for the rehabilitation of patients with a leg amputation is limited. For example, prediction of functional outcome of amputee patients remains a very difficult problem, the relevance of vocational rehabilitation is just becoming evident, the effect of several therapies is uncertain, and the functional benefits of different types of prostheses are not yet proven. Different aspects of the functional outcome of amputee patients are the subject of this thesis. The model in figure 1.1³ forms the basic assumption for the research. This model illustrates the influences of the social environment, physical capacity, and mental capacity on the functional capacity of an individual. The functional capacity consists of ADL (Activities of Daily Living) and HDL (Household activities of Daily Living) abilities as well as work ability. In the rehabilitation of amputee patients, goals are set to upgrade the functional capacity of the subject with the amputation, i.e. independence in self care, and optimal participation in recreational and vocational activities. An amputation causes sustained restrictions in physical capacity but attempts should be made to minimize the influence on the functional capacity of the person. Thus far, most studies have concentrated on the physical influences on functioning after an amputation. Social and mental influences have not very often been included in these studies.

Most amputee patients in developed countries are older than 60 years of age, and 80–90% of lower limb amputations are performed as a result of vascular problems.⁴⁻⁶ The most important functional demands of elderly patients are in the fields of personal care, household activities, and recreational activities. Most lower limb amputations in patients between 18 and 60 years of age, are the result of trauma or cancer. In younger patients, not only are physical mobility and independence in activities of daily living important after the amputation, but return to work or school also plays an important role.

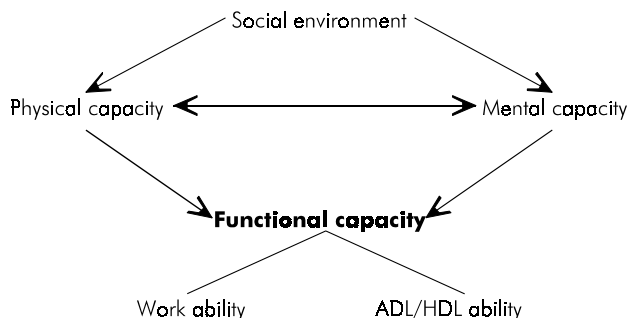


Figure 1.1 The basic model for the research.
(ADL = Activities of Daily Living; HDL = Household Activities of Daily Living)

The main aim of this thesis is to gain a better understanding of the influence of physical, mental, and social characteristics on the functional outcome of patients after a lower limb amputation. The main research questions answered in this thesis are:

1. Which physical, mental, and social characteristics after amputation predict the functional outcome for elderly lower limb amputee patients?
2. What is the relationship between impairments, activities, and participation for elderly amputee patients?
3. What is the employment status of amputee patients in the Netherlands?
4. Which factors are related to successful job reintegration and job satisfaction for working people with a lower limb amputation?

Outline of the thesis

In the first part of the thesis (chapters 2–4) we focus on elderly amputee patients. The most important aim of this part is to assess physical, mental, and social predictors for the functional outcome of amputee patients over 60 years of age. An early prediction of functional outcome is important for providing the patient with adequate information, for making well-founded choices in the rehabilitation path after the initial hospital stay, for assessing the relevance of different therapy aims, and for selecting the right group of patients for future studies. Up till now, the positive predictors for successful rehabilitation described in literature include: good living conditions with lots of support, and a good social and health status before the amputation. Negative predictors mentioned for successful rehabilitation include: comorbidity, advanced age, amputation level, phantom pain, and skin problems.⁷

In chapter 2 we determine the interrater and intrarater reliability and the validity of the Timed "up & go" test for measuring physical mobility in elderly patients

with an amputation of the lower extremity. The "Get-up and go" test was initially developed by Mathias et al⁸ to study the disturbance of balance in elderly people. Podsiadlo and Richardson⁹ modified the test to the Timed "up & go" test to get a more reliable outcome measure and they evaluated whether the test was also feasible for quantifying the physical mobility of the elderly. The reliability and validity of the Timed "up & go" test have not been previously tested for patients with amputations. This test was used for the study described in chapters 3 and 4.

In chapter 3 we present the results of a study of the physical, mental, and social characteristics two and six weeks after amputation, the functional outcome one year after amputation, and the predictors for functional outcome of elderly patients with a unilateral lower limb amputation. The functional outcome was assessed with the Sickness Impact Profile, 68 item version, the Groningen Activity Restriction Scale, the Timed "up & go" test, and a scale for prosthetic use.

In chapter 4 the relationship between physical, mental, and social impairments, and the level of activities and participation of amputee patients one year after their amputation was assessed. The International Classification of Functioning and Disability (ICIDH-2) describes the relationship between structural or functional impairments, activities, and participation, influenced by environmental and personal factors.¹⁰ Understanding how these items are related to chronic diseases increases the understanding of the courses of illness and the differences between patients with the same or with different diseases. Rehabilitation specialists base their treatment of people with chronic diseases on the correlation between impairments, activities, and participation. The main goals are set at regaining independence in daily activities and full participation in daily life. Knowledge of these factors for the different patient groups is important.

In chapters 5 to 8 we concentrate on people between 18 and 60 years of age with a leg amputation. Epidemiologic data for this group of amputee patients in the Netherlands and their quality of life are described in chapter 5. Vocational integration of people with chronic diseases is important and many job rehabilitation programs are being developed. Before starting a job rehabilitation program for a population with a specific disease or handicap, it is important to know the current employment status of these patients and the problems they experience in work or in finding work. The program should be adjusted to the specific problems of the patients. Thus far, the employment status of patients with a lower limb amputation has been very unclear. Only a few articles mention the return to work or school of amputee patients. The most detailed study is that of Millstein et al,¹¹ in which they describe the employment status of employees with an amputation of the upper or lower extremity due to accidents at work, revealing a high return to work but many changes in occupational groups after amputation. Some other studies only mention the number of patients that returned to work without describing any other details.¹²⁻¹⁷ The percentage of return to work varies from 30 to 90% and these studies only included patients with an amputation due to trauma.

In chapter 6 we describe the occupational situation at the time of the amputation and the current employment status of people with a lower limb

amputation in the Netherlands. Current employment status is described with respect to job participation, type of job, adjustments at the workplace, and the person's position in the company. In addition, we compare the health experience of amputee patients to a nonimpaired reference population as well as the health experience of working and nonworking patients with amputations. We study demographically related, amputation-related, and employment-related factors that show a relationship to successful job reintegration of patients after a lower limb amputation in chapter 7. It is important to know which patients are at risk of failure to return to work. Extra attention to return to work during the rehabilitation process is necessary for these people. In general, job participation is important but job satisfaction plays a role as well. Determinants of the vocational satisfaction of working amputee patients and a comparison with the job satisfaction of able-bodied colleagues are described in chapter 8.

In chapter 9 we discuss the clinical implications of our research while giving advice for the management of the rehabilitation of amputee patients. In addition, advice for further research about the different topics is included.

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CHAPTER 2

THE TIMED "UP & GO" TEST: RELIABILITY AND VALIDITY IN PERSONS WITH UNILATERAL LOWER LIMB AMPUTATION

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Abstract

Objective: To determine the interrater and intrarater reliability and the validity of the Timed “up & go” test as a measure for physical mobility in elderly patients with an amputation of the lower extremity.

Design: To test interrater reliability, the test was performed for two observers at different times of the same day in an alternating order. To test intrarater reliability, the patients performed the test for one observer on two consecutive visits with an interval of 2 weeks. To test validity, the results of the Timed “up & go” test were compared with the results on the Sickness Impact Profile, 68-item version (SIP68), and the Groningen Activity Restriction Scale (GARS).

Patients: Thirty-two patients, age 60 yr or older, with unilateral transtibial or transfemoral amputation because of peripheral vascular disease.

Results: The Timed “up & go” test showed good intrarater and interrater reliability ($r = .93$ and $.96$, respectively). A moderate relationship exists between the Timed “up & go” test and the GARS, a good relationship exists with the “physical subscales” of the SIP68, and there is no relationship with the “mental subscales” of the SIP68.

Conclusions: The Timed “up & go” test is a reliable instrument with adequate concurrent validity to measure the physical mobility of elderly patients with an amputation of the lower extremity.

Introduction

Testing physical mobility of patients is important in rehabilitation medicine. Different instruments for measuring physical mobility have been reported in literature. Questionnaires are often used, such as the Sickness Impact Profile (SIP).¹ These questionnaires are time-consuming (especially for elderly patients), and they are difficult to use in patients with cognitive problems.

In laboratory settings different walking tests have been developed to measure physical mobility. These tests require special rooms or complex apparatus to measure all the relevant parameters. There are few simple and quick mobility tests that can be used in rehabilitation medicine in different research and clinical practice situations.

In patients with a lower limb amputation, assessing physical mobility plays an important role. About 2,000 amputations of the lower extremities are registered by the Central Bureau of Statistics in the Netherlands annually; Rommers and colleagues² claimed that this is even an underestimation. More than 80% of the patients are 60 years or older, and 80% to 90% of the amputations are caused by peripheral vascular disease. Most patients have complex comorbidity.² A mobility test may therefore not include difficult and aggravating tasks.

The “Get-up and go” test was initially developed by Mathias and colleagues³ to study the disturbance of balance in elderly people. Podsiadlo and Richardson⁴ modified the test to the Timed “up & go” test to get a more reliable outcome measure, and they evaluated whether the test was also feasible for quantifying the physical mobility of the elderly. In the Timed “up & go” test the subject is observed while rising from an arm chair, walking 3 m, and returning to the chair. The results of the modified test indicated a good interrater and intrarater reliability (both intraclass correlation coefficients .99). The Timed “up & go” test correlated highly with scores on the Berg Balance Scale, walking speed, and Barthel Index. This indicated a good content and concurrent validity. Podsiadlo and Richardson concluded that the Timed “up & go” test is a quick, reliable, and valid instrument for testing the physical mobility of elderly patients. Their study population consisted of patients with different diseases but no patients with a lower limb amputation. The reliability and validity of the Timed “up & go” test have not been tested previously for patients with amputations.

The purpose of this study was to assess the interrater and intrarater reliability of the Timed “up & go” test for measuring physical mobility of elderly patients with an amputation of the lower extremity.

This study also investigated the concurrent validity of the test by comparing the test with measurements of the functional status of elderly leg amputation patients on two questionnaires, the Sickness Impact Profile, 68-item version (SIP68), and the Groningen Activity Restriction Scale (GARS). The hypothesis was that scores on the Timed “up & go” test would have a moderate correlation with scores on the GARS and a correlation only with the physical mobility subscores of the SIP68. No correlation with the mental aspect subscores was expected. We expected only a moderate correlation between the Timed “up & go” test and the GARS because the

Timed “up & go” test measures only physical mobility, whereas the GARS measures total functioning.

Methods

Subjects

Patients with a unilateral transtibial or transfemoral amputation resulting from peripheral vascular disease were included. Their age was 60 years and older, and they had to be able to walk with or without walking aids for more than 6 meters. The observers judged if the patients were able to understand the instructions of the test. All patients used their lower-limb prosthesis during the test. Excluded from the study were patients who had problems with their stump or prosthesis expected to cause changes during the follow-up period of the reliability study.

Patients were recruited from the list of patients of the Orthopaedic Workshop Noord-Nederland. Thirty-two patients, 23 men and 9 women, met the inclusion criteria and gave informed consent to participate. Their mean age was 73.3 yr (range 61 to 86 yr; table 2.1). Twenty-seven patients had transtibial amputations and five had transfemoral amputations. The mean time since operation was 3.7 yr (range 4 months to 17 yr).

Table 2.1 Patient characteristics

Amputation level	Number	Age, mean (range) (yr)	Score on Timed “up & go” test: mean (SD) (s)
Transtibial	27	73.5 (61–86)	23.8 (23.0)
Transfemoral	5	72.4 (68–81)	28.3 (12.2)

Instrumentation

Timed “up & go” test

The Timed “up & go” test is performed in the following way. The patient sits on a standard arm chair (seat height 46 cm as in the original setting, arm height 67 cm) with his or her back against the chair, arms resting on the chair's arms and walking aid at hand. Patients wear their regular footwear and use their customary walking aids. After the patient states that he or she is ready, the test starts. On the word “go” the patient stands, walks to a line on the floor 3 m away (on a standard short-piled carpet with a length of 4 m and a width of 1 m), turns, walks back to the chair, and sits down again. The end of the test is defined when the patient's buttocks first touch the seat surface. Patients choose their own comfortable and safe walking speed. A stopwatch is used to time the performance (in seconds).

SIP68 en GARS

To test the concurrent validity of the Timed “up & go” test, the results were compared with the results on the SIP68^{1,5,6} and the GARS.^{7,9} The SIP68 and the GARS were assessed once in all patients.

The SIP68 measures health-related changes in behavior associated with the accomplishment of daily activities. The questionnaire consists of 68 items, subdivided in 6 categories: Somatic Autonomy, Mobility Control, Psychic Autonomy and Communication, Social Behavior, Emotional Stability, and Mobility Range.

The GARS is a short questionnaire with 18 items that assess disability in activities of daily living (ADL), including mobility, and instrumented activities of daily Living (IADL). It has a four-category response format: 1, able to perform the activity without any difficulty; 2, able to perform the activity with some difficulty; 3, able to perform the activity with much difficulty; 4, unable to perform the activity independently. The score varies from 18 to 72. With a score of 18 the person can perform all the activities without any difficulty; with a score of 72 the person cannot perform any activity without the help of others.

Procedure

The study was approved by the Medical Ethical Committee of the University Hospital Groningen. The patients were tested in their own homes, because the study concerned exclusively older, less mobile patients who had difficulties in traveling to a standard setting. The standard arm chair and carpet were brought along by the observers.

The two observers were a physiotherapist and one of the authors (TS). The observers trained before the study by performing the test in five patients to check the research protocol.

To test the interrater reliability, the test was performed for the two observers at different times of the same day in an alternating order, with 5 to 10 minutes between. The observers did not time the performance of the patients simultaneously during the same test because the objective was to test the reliability of the entire performance (instructions of two different observers included) and not of the timing only. To measure intrarater reliability, patients performed the Timed “up & go” test for one observer (TS) on two consecutive visits with an interval of 2 weeks. The SIP68 and the GARS were assessed on the first visit.

Analysis

To test the interrater and intrarater reliability, the Spearman correlation coefficient was calculated to assess the relationship between the measurements. To test the differences between the groups, the Wilcoxon test and the *t* test were used (depending of the necessity of using parametric or nonparametric tests). The significance level chosen was $\alpha = .05$.

To compare the Timed “up & go” test with the questionnaires, Spearman correlation coefficients were calculated.

Results

The mean time score on the Timed “up & go” test during the first measurement was 24.5 seconds (mean of both observers), with a minimum of 9 s and a maximum of 102 s (standard deviation 21.5 s) (table 2.1).

Intrater reliability

Figure 2.1 shows the scores of the Timed “up & go” test obtained by one observer on two different moments ($t=1$ and $t=2$). One patient could not perform the test a second time because she had stump problems and could not walk. Her data are not used in the study of the intrater reliability; they are used only in the study of the interrater reliability and the validity.

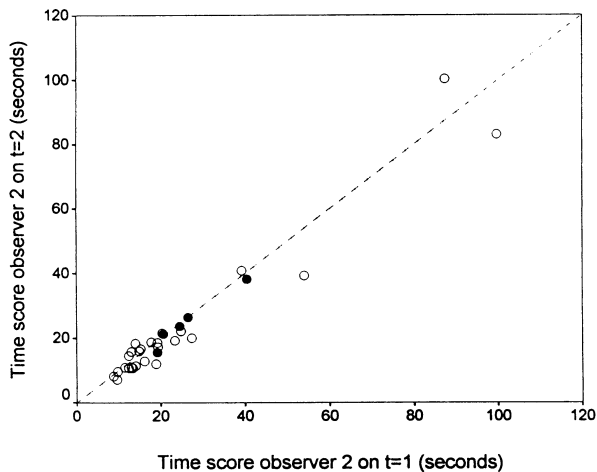


Fig 2.1 Intrater reliability of the Timed “up & go” test. The scores of one observer at two different moments are shown. ●, Transfemoral amputation subjects; ○, transtibial amputation subjects.

The Spearman correlation coefficient was .93 ($P < .001$), showing a good correlation in time scores obtained by the same rater on two consecutive visits (with an interval of 2 weeks). The difference between the mean scores on the two moments was 1.6 s (standard deviation 5.2 s). Only three patients showed a difference between the scores of more than 10 seconds. The difference found between the mean scores when compared with the Wilcoxon test ($P = .047$) was only slightly significant.

Interrater reliability

The scores of both observers are shown in figure 2.2. The Spearman correlation coefficient was .96 ($P < .001$), showing a strong relationship between the scores of the two observers. The difference between the mean scores of the two observers was .5 s (standard deviation 4.7 s). Only two patients showed a difference between the scores

of more than 10 seconds.

We calculated the differences of the scores obtained by both observers in two groups of 16 patients. In one group the first measurement was done by observer 1, in the other group the first measurement was done by observer 2. The mean scores of differences were normally distributed and could be compared with the *t* test. Variation in scores due to sequence of measurements and the practice effects involved were excluded by following this procedure. No difference between the scores of the two observers was found in this analysis ($P=.31$).

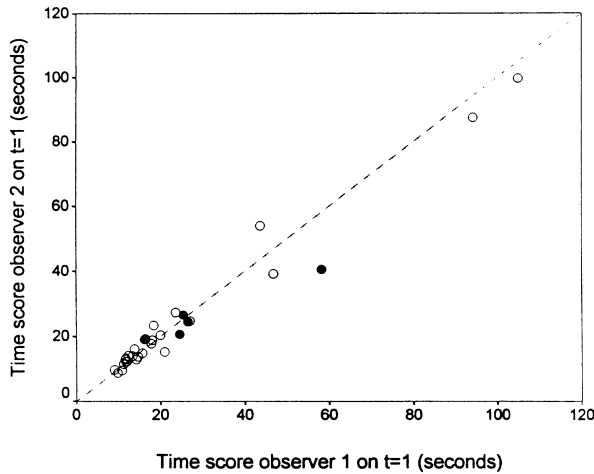


Fig 2.2 Interrater reliability of the Timed “up & go” test. The scores of two different observers at different times of the same day are shown. ●, Transfemoral amputation subjects; ○, transtibial amputation subjects.

Timed “up & go” test and GARS

There was a low, but significant, correlation between the Timed “up & go” test and the scores on the GARS (Spearman correlation coefficient .39, $P=.03$) (fig 2.3).

Timed “up & go” test and SIP68

The Spearman coefficients for the correlations between the Timed “up & go” test and scores on the SIP68 are listed in table 2.2. The relationship between the Timed “up & go” test scores and the scores on the SIP subscales “Mobility Control” and “Mobility Range” was the strongest (.46 and .36 respectively). No relationship with the other subscales could be assessed.

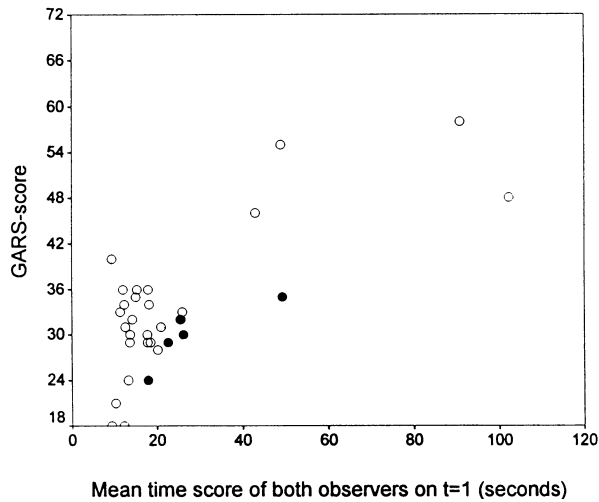


Fig 2.3 Relationship between the Timed “up & go” test and the GARS. ●, Transfemoral amputation subjects; ○, transtibial amputation subjects.

Table 2.2 Correlation between Timed “up & go” test and SIP scores

	Spearman correlation coefficient
Total score	.40*
Subscale scores	
Mobility Control	.46*
Mobility Range	.36*
Somatic Autonomy	.28
Psychic Autonomy and Communication	.31
Social Behavior	.19
Emotional Stability	-.04

* The correlation coefficient significantly differs from 0.

Discussion

Performance of the Timed “up & go” test

In this study the Timed “up & go” test was performed in each patient’s own home, with a standard arm chair brought along by the observers. The seat height was

46 cm and the sitting surface was hard. Any chair that is normally used for working or sitting at a table or desk with an average seat height and a straight seat and back is sufficient for this test. The chair must be solid to prevent it from falling when the patient leans on the chair's arms when standing up. According to the original test, we did not use a chair with variable height. In our study none of the patients had a problem in standing up from or sitting down on the chair.

In general, the test is practical because of its simplicity. It is quick and easy to administer, and it requires no complicated equipment. Professional expertise is not required and the instructions are straightforward. The time score is easy to record.

Intrarater reliability

The P-value when comparing the differences of the scores of the two measurements with the Wilcoxon test is just below .05, and so the difference is significant. A possible learning effect when repeating the test cannot be excluded. Biological variability of the mobility of the patients plays a role as well.

The combination of a very small difference between the mean scores on the two different moments (1.6 s) and the high correlation coefficient (.93) supports the hypothesis that the intrarater reliability is sufficient for measuring the physical mobility using the Timed "up & go" test.

Interrater reliability

The results show a good interrater reliability. This research shows good agreement in the time scores obtained between raters. The two observers had had little training before doing the study. These results indicate that no extended training seems necessary to obtain reliable measurements between different observers.

Scores on the Timed "up & go" test

The mean time score of the Timed "up & go" test in this study (24.5 s) was higher than in a study by Newton¹⁰ (15 s), who tested the Timed "up & go" test with 251 older adults, with no specific disability, recruited from health fairs and senior centers in Philadelphia.

Timed "up & go" test and GARS

Two different aspects play an important role in appreciating the comparison of the Timed "up & go" test with the GARS. First, there is a clustering of the scores of the Timed "up & go" test around the mean. Calculating the Spearman correlation coefficient there is only partly compensated for this clustering. Less clustering should give a stronger relationship between both tests. More variation in scores should show a stronger relation between low or high scores on both tests. Second, the GARS includes questions about functioning of the hand and about general functioning in addition to questions about physical mobility. Both aspects can result in a lower correlation coefficient, but on the other hand confirm the hypothesis that the Timed "up & go" test gives a specific impression of the physical mobility, and not of the total functioning of patients.

Timed “up & go” test and SIP68

The clustering of the scores on the Timed “up & go” test also plays a role in comparing it with the SIP scores. The strongest relationships were found between the Timed “up & go” test and the scores on the subscales “Mobility Control” and “Mobility Range”, as expected, because the questions in these subscales are strongly related to physical mobility. The low correlation coefficient with the subscale Somatic Autonomy can be explained by the fact that almost all patients answered the questions in this part negative. The activities in this subscale were too easy for the group of patients with a lower limb amputation that could perform the mobility test. The bad relationship between the Timed “up & go” test and the subscales Psychic Autonomy and Communication, Social Behavior, and Emotional Stability was as expected. The Timed “up & go” test is not a reflection of mental functioning. The calculated correlations state the good concurrent validity of the test measuring the physical mobility.

Conclusions

The findings of this study confirm the statements mentioned by Podsiadlo and Richardson⁴ about the reliability and the validity of the Timed “up & go” test as a measurement of physical mobility of elderly patients with lower extremity amputation.

In this study the sensitivity for changes during, for example, a rehabilitation process was not investigated. Podsiadlo and Richardson⁴ described some examples that suggested that the time score could be an objective measure of clinical change. This aspect must be confirmed in further research.

It is difficult to determine the right test for studying the concurrent validity because a “gold standard” is lacking. Podsiadlo and Richardson⁴ compared the test with a Barthel Index of ADL as well as with gait speed in a 15 meter walk and found a significant relationship between both tests. We compared the test with two questionnaires about functional capacity because our aim was to show a relationship between the Timed “up & go” test and physical mobility at the level of disability as described by the patients themselves, instead of the level of impairment that plays a major role in, for example, gait analysis. In future research a comparison with other measurements of physical mobility can be useful to investigate other aspects of validity.

In older patients with different diseases, the Timed “up & go” test has shown relationships with several instruments that are indicators of physical mobility (walking speed, Barthel scores, Berg Balance Scale, SIP68, GARS). The construct of the test as an instrument of physical mobility of the elderly, is sufficiently founded by the combination of the results of the current study and of the study of Podsiadlo and Richardson.⁴ This indicates a good construct validity as well.

The Timed “up & go” test as a measure of physical mobility has a good intrarater and interrater reliability. The first hypothesis about the reliability could be accepted. The hypothesis of a moderate relationship between the Timed “up & go”

test and the GARS, a good relationship with the “physical subscales” of the SIP68, and no relationship with the “mental subscales” of the SIP68 was confirmed. These results indicate that the concurrent validity of the test is adequate. There are also indications of a good construct validity of the test. The Timed “up & go” test can be used as a quick and easy objective instrument to measure the physical mobility of patients with an amputation of the lower extremity.

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CHAPTER 3

PHYSICAL, MENTAL, AND SOCIAL PREDICTORS OF FUNCTIONAL OUTCOME IN UNILATERAL LOWER LIMB AMPUTEE PATIENTS

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Abstract

Objective: To study the value of physical, mental, and social characteristics as predictors of functional outcome of elderly amputee patients.

Design: Inception cohort study.

Setting: Main hospitals, rehabilitation centers, nursing homes, patients' own residence settings in the North of the Netherlands.

Patients: 46 patients older than 60 years, unilateral transtibial or transfemoral amputation or knee disarticulation due to vascular disease, living in one of the three northern provinces in the Netherlands.

Interventions: Measurement of physical, mental, and social predictors 2 and 6 weeks post-amputation.

Main Outcome Measures: Sickness Impact Profile (SIP68), Groningen Activity Restriction Scale (GARS), Timed "up & go" test (TUGT), prosthetic use.

Results: 15% died within the first year post-amputation. Seventy-percent of patients lived independently at home one year post-amputation. The functional level of the patients was low, as shown by high scores on the SIP68 (mean 23.6), the GARS (mean 41.2), and the TUGT (mean 23.9). Functionally prosthetic use as measured with the classification of Narang and Pohjolainen was reached by 49%. Of the SIP68-scores, age, comorbidity, one-leg balance, and the 15-Word test predicted 69%. The GARS-score prediction by age, one-leg balance, and the 15-Word test was 64%. Of the TUGT, age and one-leg balance predicted 42%. After correction for age, the only significant predictor for prosthetic use was one-leg balance.

Conclusions: Elderly patients with a leg amputation have a low functional level one year post-amputation. An important part of functional outcome could be predicted two weeks after amputation by age at amputation, one-leg balance on the unaffected limb, and cognitive impairment. Severe comorbidity probably also plays a role. The results may be used in the general policy concerning leg amputee patients.

Introduction

In the Netherlands 3,000 primary amputations of the lower limb are performed annually.¹ Most patients are older than 60 years, and 80–90% of the amputations are performed as a result of vascular problems.¹⁻³ The prediction of functional outcome is an important issue in rehabilitation medicine. The most important functional capabilities of elderly patients are in the field of personal care, household activities, and recreational activities.

Several predictors for functional outcome of amputee patients are mentioned in literature. In general, the functional capabilities of patients with a higher amputation level and a higher age are worse than that of younger patients with a lower amputation level.⁴⁻⁹ It is also generally accepted that the physical condition and the presence of comorbidity predict the functional possibilities after amputation.^{2,4,10-12} Especially cardiopulmonary diseases cause a lack of extra energy necessary for walking with a prosthesis.^{10,13,14} Other diseases affecting the locomotor system diminish the functional perspectives of amputee patients.

Characteristics of the stump are important for the success of prosthetic fitting. Persson and Liedberg¹⁵ and Pohjolainen¹⁶ reported a systematic description of the stump characteristics based on the Clinical Standard of Measurement and Classification of Amputation Stumps, defined at the ISPO (International Society of Prosthetics and Orthotics) congress in Bologna in 1980. Healing problems of the residual limb and restricted mobility in the joint proximal to the amputation cause a delay in prosthetic fitting¹⁰ and reflect a bad stump condition.^{17,18} In literature the negative relationship between stump pain and/or phantom pain and functioning is reported.¹⁶ However, it is not evident that the level of pain immediately after the amputation is predictive of a worse functional outcome.

Geurts¹⁹ described the problems people with an amputation have in maintaining their balance during the performance of dual tasks. Hermodsson²⁰ showed an increase in lateral sway in a two-leg standing test of transtibial amputees, compared to healthy subjects. Standing balance is important in many daily activities and a good standing balance on the unaffected limb can be beneficial for the functional outcome of amputee persons, irrespective of prosthetic fitting.

Information about the predictive value of mental disturbances and cognitive impairments for the functional outcome after a lower limb amputation is scarce. Kashani et al²¹ described many amputee patients with depressive symptoms after an amputation. However, this was not confirmed by the studies of Frank et al²² and Furst and Humphrey.²³ The relationship with functional outcome is unclear. Pinzur et al²⁴ reported a relationship between the results of several psychological tests and the success of prosthetic fitting. Phillips et al²⁵ found that amputee patients' scores were lower for several neuropsychological tests, possibly due to the coexistence of peripheral vascular disease and cerebrovascular disease. In the study of Hanspal and Fisher²⁶ there was a relationship between the mobility of the older amputee patient and the score on the Clifton assessment scale as a measurement for cognitive and psychomotor functions.

In clinical practice, rehabilitation specialists always stress the importance of the

social support of the family and friends in the functioning of the patient. This was also described in the study by Thompson and Haran.²⁷ However, hardly any information about the predictive value for the rehabilitation outcome is available in literature. Helm et al⁵ and Nissen and Newman¹² did not find a relationship between the social situation and the functional results of amputee patients.

Most studies concerning predictors for functional outcome after a lower limb amputation, are retrospective in view. In addition, most studies are carried out only on patients who have been referred for limb fitting. Amputees are not all candidates for a prosthesis; therefore, a course in rehabilitation to learn wheelchair use and transfer activities may also be beneficial. Most of the literature defines functional outcome only in terms of prosthetic use, but general measures of functional outcome with or without a prosthesis are equally important.

The purpose of our research was to study physical, mental, and social characteristics just after amputation, the functional outcome one year after amputation, and the predictors for functional outcome of elderly patients with a unilateral lower limb amputation. It is important, for clinical practise, to predict the functional outcome as soon as possible after the amputation. Our first intention was to predict two weeks after amputation the functional outcome after one year. However, we realised that this early measurement may be greatly influenced by the disease process that lead to the amputation or surgery, and therefore, we also studied predictive factors six weeks after amputation to see if this differed from the early prediction.

Methods

Patients

Patients met the following inclusion criteria: older than 60 years, a unilateral transtibial or transfemoral amputation or a knee disarticulation due to peripheral vascular disease with or without diabetes mellitus, living in one of the three northern provinces in the Netherlands. Patients were excluded if they were not able to understand the test instructions, or if they were severely disabled without any walking ability before the amputation for reasons not related to peripheral vascular insufficiency. Patients were recruited from the main hospitals of the three northern provinces in the Netherlands. Patients were asked to participate by their surgeon or by their rehabilitation specialist and were informed by the researcher (TS) or a research nurse. The patients also signed an informed consent before participating in the study. Ninety-seven patients were recruited by the surgeons and rehabilitation specialists (fig. 3.1). Ten patients were presented too late to participate. Twenty-one could not participate because of severe cognitive impairment or severe physical impairment (dying or very bad condition), and in the case of 2 other patients multiple reasons played a role. Thirteen refused to participate. Three patients died between 2 and 6 weeks after amputation and 2 refused to participate further in the study after the first measurement. A total number of 46 patients participated in the study. Table 3.1 shows the patient characteristics. This table also shows that primary

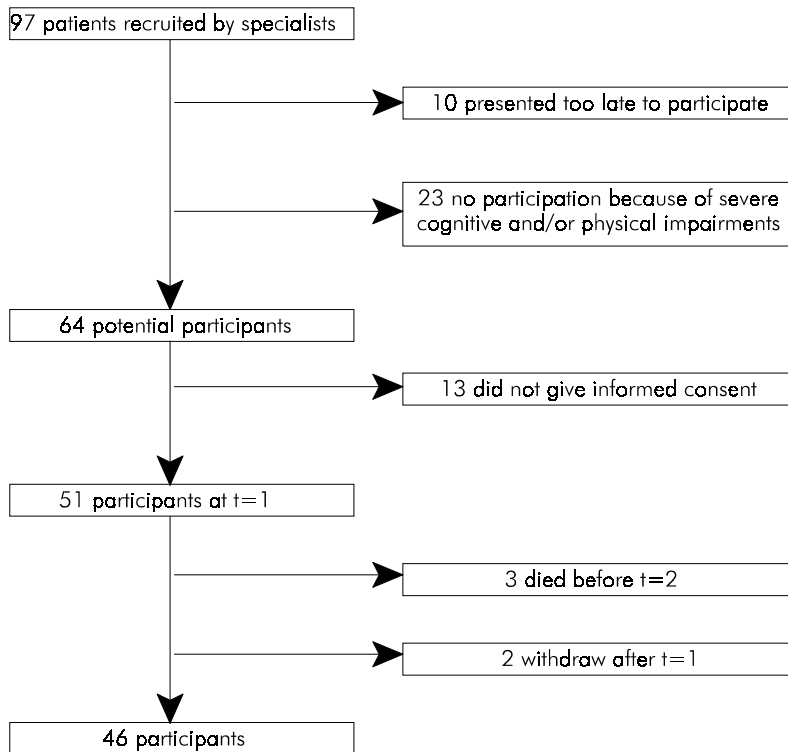


Figure 3.1 Flow diagram of participants

rehabilitation took place in a rehabilitation center in 67%, whereas 26% went to a nursing home to rehabilitate and 7% received another kind of treatment, predominantly physiotherapy at home.

Design

We performed a prospective cohort study with the inclusion of patients from October 1997 till June 2000. Patients were followed from two weeks to one year after the amputation. When a patient had a second amputation of the same leg within two weeks after the first surgery (only 2 patients), the first measurement was done 2 weeks after the second amputation. When the patient underwent a second amputation during the rest of the follow-up period, this was noted as a complication during follow-up. We visited participants 4 times: 2 weeks after amputation, 6 weeks after amputation, 6 months after amputation, and one year after amputation. At 2 and 6 weeks after amputation we measured the physical, mental, and social characteristics. Six months after the amputation we looked at the development of functional capabilities, and one year after amputation we measured the functional

Table 3.1 Patient characteristics (n=46)

men	32 (70%)
age at the time of amputation: mean (SD) (yr)	73.9 (7.9)
amputation level	
transtibial	33 (72%)
knee disarticulation	8 (17%)
transfemoral	5 (11%)
primary location for rehabilitation	
rehabilitation center	31 (67%)
nursing home	12 (26%)
other	3 (7%)

outcome parameters. In this article the results will be presented of measurements 1 and 2 (two and six weeks after the amputation) and 4 (one year after the amputation). At measurement 3 (6 months after amputation), most subjects were still in their rehabilitation process, and their definitive functional outcome could not be assessed. The researchers visited the patients where they were staying at the moment of the visit, i.e. at the hospital, the rehabilitation center, the nursing home, or at their own home. The study was approved by the Medical Ethical Committee of the University Hospital Groningen.

Potential predictors of functional outcome

The instruments used to measure the predictors had to be easily transported, useful at all locations, and minimizing the efforts of the elderly patients. Below, we describe the predictors analyzed and their scoring systems.

Physical predictors:

1. Age.
2. Amputation level: transtibial, knee disarticulation, transfemoral.
3. Healing of the stump: healed versus non-healed.
4. Extension of knee or hip: restricted versus unrestricted. Joint range of movement was measured in the joint proximal to the amputation with a goniometer. Normal knee extension is 0 to -10 degrees. Less knee extension was defined as restricted. Normal hip extension is 0 to -10 degrees. Less hip extension was defined as restricted.
5. Stump pain and/or phantom pain: none/little versus severe.
6. Standing balance on the unaffected limb: not possible, possible with support, possible without support ≤ 10 s, possible without support > 10 s. Detailed measurements, for example, on a balance platform, were not possible 2 weeks after the amputation and in all residence settings. The parameter we therefore used for standing balance was whether patients could stand on their unaffected limb, with or without support by a walking frame. The time they could stand on the unaffected limb was recorded with a stopwatch. During standing patients

were not allowed to hop and they wore their own shoe on the unaffected limb. The researcher was standing next to the patient, the walking frame before the patient, and a chair behind the patient to prevent them from falling.

7. Comorbidity: presence or absence of diabetes mellitus, cardiopulmonary disease, or other diseases/disabilities. Comorbidity was assessed using the combination of a structured self-report questionnaire²⁸ and data from the medical records. In addition, the pulmonary function was measured with a portable spirometer. The Tiffinau index (i.e. the Forced Expiratory Volume/Forced Vital Capacity x 100%) is used as a measurement for obstructional disease.

Mental predictors:

1. Mood disturbances are measured with the Beck Depression Inventory (BDI).^{29,30} The BDI consists of 21 questions with 4 answer categories. The patient should report the feelings and emotions during the last week to assess the degree of depressive symptoms. A higher score indicates more depressive symptoms. The score ranges from 0 to 63.
2. The Cognitive Screening Test (CST)³¹ is a short questionnaire (20 items), based on the Short Portable Mental Status Questionnaire of Pfeiffer. It assesses orientation in time, place, and person, and general knowledge. A lower score indicates more cognitive impairment and the score varies from 0 to 20. An indication of severe cognitive impairment using the Cognitive Screening Test was defined³¹ as a score less than or equal to 15.
3. Memory. The 15-Word Test measures short term word memory and delayed recall after 15–30 minutes.³² The patient hears 15 words in 30 seconds on a tape recorder, and must reproduce as many words as possible. The words are repeated 5 times with reproduction of the subject. The score for the immediate reproduction varies from 0 to 75. In addition, decile scores can be calculated according to age and education level. After 15 to 30 minutes, the subject repeats all the words he still remembers without hearing the words again (delayed recall of 0 to 15 words). The delayed recall score can also be expressed as a decile score, related to the score of immediate reproduction.
4. Information processing and concentration. The Stroop Color-Word Test measures interference in cognitive functioning by color-word denomination.^{33,34} The patient reads 3 cards: one with 10 rows of 10 names of colors (printed in black), one with 10 rows of 10 rectangles of these colors, and one with 10 rows of colored words representing color names that were incongruent with the printed colors. The time score of the last card is taken in the analyses as an indicator of information processing. Decile scores can be calculated, related to the time necessary for the first two cards.

Social predictors:

1. Partner: present versus absent.
2. The Social Support Questionnaire-Interactions, 12 item version (SSL12-I), is a short version of the SSL-I.³⁵ The questionnaire contains 12 questions with 4 answer categories, concerning everyday support, support in case of problems, and the degree of appreciation. The higher the score, the more support someone experiences. The score ranges from 12 to 48.

Functional outcome parameters

1. Sickness Impact Profile, 68 item version (SIP68).³⁶⁻⁴⁰ The SIP68 is a measure of "health-related changes in behavior associated with the carrying out of one's daily activities". The questionnaire consists of 68 items about behavior, subdivided into 6 categories: Somatic Autonomy, Mobility Control, Psychic Autonomy and Communication, Social Behavior, Emotional Stability, and Mobility Range. A total sumscore can be calculated in addition to the subscores on the different subscales.
2. Groningen Activity Restriction Scale (GARS).⁴¹⁻⁴³ The GARS is a short questionnaire with 18 items assessing disability in the area of ADL (Activities of Daily Living including mobility) and also IADL (Instrumented Activities of Daily Living). It has a four-category response format:
 - 1 independent to perform the activity without any difficulty,
 - 2 independent to perform the activity with some difficulty,
 - 3 independent to perform the activity with great difficulty,
 - 4 unable to perform the activity independently.The score varies from 18 to 72. With a score of 18 the person can perform all the activities without any difficulty; with a score of 72 the person cannot perform any activity without the help of others.
3. Timed "up & go" test (TUGT).⁴⁴⁻⁴⁶ The Timed "up & go" test is performed in the following way: the patient is sitting on a standard arm chair (seat height 46 cm, arm height 67 cm) with his back against the chair, arms resting on the chair's arms and his walking aid at hand. The patient wears his regular footwear and uses his customary walking aid. On the word "go" the patient has to get up, walk to a line on the floor 3 meters away (on a standard carpet), turn, walk back to the chair, and sit down again. The patient can choose his own comfortable and safe walking speed. A stopwatch is used to time the performance (in seconds). This test could only be performed by patients with a walking ability one year after the amputation.
4. Prosthetic use. We used the classification as described by Narang et al⁷ and Pohjolainen et al⁸:
 - I. Ambulating with a prosthesis but without other walking aids
 - II. Independent at home, ambulating with a prosthesis but requiring one or two walking sticks or crutches for outdoor activities
 - III. Independent indoors, ambulating with a prosthesis and one stick or crutch, but requiring two crutches outdoors and occasionally a wheelchair.
 - IV. Walking indoors with a prosthesis and two crutches or a walker, but requiring a wheelchair for outdoor activities.
 - V. Walking indoors only short distances, ambulating mostly with a wheelchair.
 - VI. Walking with aids but without a prosthesis
 - VII. Nonambulatory except in a wheelchair, patient possesses a prosthesis
 - VIII. Nonambulatory except in a wheelchair, patient does not possess a prosthesis

Analysis

We calculated with the premise of an explained variance of 30 to 50% and a power of .80, that we needed 100 participants to assess a reliable prediction of functional outcome. Statistics were performed using the Statistical Product and Service Solutions (SPSS).⁸ The association between the predictors and the Sickness Impact Profile, the Groningen Activity Restriction Scale, and the Timed “up & go” test, was shown by using univariate linear regression analyses. The association between the predictors and prosthetic use was shown by using univariate logistic regression analyses. Prosthetic use was therefore dichotomized in “functional use” (score I–IV) and “non-functional use” (score V–VIII). The associations found in the univariate analyses were used for preselection of variables to be included in the multivariate analyses. Prediction models were assessed with forward multivariate regression analysis. Age at amputation was entered as a basic variable in all multivariate analyses. Secondly, other predictors were included in the multivariate regression analysis when their P-value in the univariate analyses in the relationship with the dependent variable was $\leq .05$. The significance level in the multivariate analyses of predictors was chosen as $\alpha = .05$.

The differences in functional outcome scores between the groups with different scores on the one-leg balance test was tested with analysis of variance, with a correction for age at amputation.

Results

Physical, mental and social characteristics two and six weeks after the amputation

Table 3.2 shows the characteristics of the patients two and six weeks after amputation. Physical and mental characteristics apparently improved between the two measurements. According to Bouman et al³⁰ the Beck Depression Inventory scores could be divided into 7 severity categories. Nineteen and 11 percent of the patients had a score above average on the intensity scale for depression at two and six weeks post-amputation, respectively. In our study population 10 amputee patients fulfilled the criteria for severe cognitive impairment two weeks post-amputation and only 4 patients six weeks after amputation according to the scores on the CST. On the immediate recall of the 15-Word Test, most people scored in the lowest 5 deciles (90% and 73%). On the delayed recall, 50% and 59% scored in the lowest five deciles. The decilescores on the Stroop Color-Word Test were very low. Ninety-seven percent and 81% scored in the two lowest deciles, and only 1 patient at t=1 and 2 patients at t=2 scored in the highest decile. The sumscores on the Social Support Questionnaire of 28.3 and 27.9 respectively were slightly higher than that of a healthy reference population of 245 healthy people in the north of the Netherlands (26.4).

Table 3.2 Characteristics two and six weeks after the amputation (n=46)

	2 weeks post-amputation	6 weeks post-amputation
Physical predictors:		
Comorbidity (%)		
diabetes mellitus	54	54
cardiopulmonary	67	67
other	80	85
Pulmonary function (FEV ₁ %VC): mean (SD)	80.4 (14.4)	82.8 (19.4)
Non-healed scar on stump (%)	71	52
Limited extension of proximal joint (%)	50	31
Stump and/or phantom pain (%)	41	28
One-leg balance (%)		
not able to stand on one leg	42	17
able to stand on one leg with support	20	37
able to stand on one leg without support ≤ 10 s	22	17
able to stand on one leg without support > 10 s	16	28
Mental predictors:		
Beck Depression Inventory: mean (SD)	12.7 (10.2)	11.5 (8.4)
Cognitive Screening Test: mean (SD)	16.8 (2.8)	17.6 (2.2)
15-Word Test: mean (SD)		
immediate recall	23.2 (9.9)	29.2 (12.6)
delayed recall	3.8 (2.6)	5.0 (3.4)
Stroop Color-Word Test: mean (median; SD) (s)	236 (188;111)	184 (138;95)
Social predictors:		
Partner present (%)	59	59
Social Support Questionnaire: mean (SD)	28.3 (5.8)	27.9 (5.3)

Survival, comorbidity during follow-up, and loss during follow-up

Seven of the 46 patients included in this study died within the first year after amputation. One patient was too ill to perform the last measurement and one patient could not be traced anymore. Functional outcome data was available for 37 patients. Only one patient died out of the 31 subjects who went to a rehabilitation centre, whereas 6 patients died from the 15 patients who went to a nursing home or received other therapy. During the follow-up period, 1 patient needed a reamputation at a higher level and 3 patients became bilaterally amputated.

Functional outcome one year after the amputation

Living environment

Of the 37 subjects, 28(70%) lived independently at home, 7(19%) lived in a nursing home or home for the elderly, and 2 other subjects stayed in a rehabilitation center.

Sickness Impact Profile, 68 item version

The mean total score of amputee patients on the SIP68 was 23.6 (SD 13.0). This was much higher than the score of 10.5 (SD 9.6) of a reference group of 2387 patients with multiple pathology,⁴⁰ meaning that amputee patients experience more restrictions in their daily functioning.

Groningen Activity Restriction Scale

On the GARS, our patient group showed more restrictions in daily activities than a reference population of healthy subjects in the north of the Netherlands. The mean score of the amputee patients was 41.2 (SD 15.4), whereas for the able-bodied reference group it was 22.1 (SD 7.6).⁴¹ Amputee patients showed more problems in Activities of Daily Living as well as in Instrumental Activities of Daily Living.

Timed “up & go” test

18 subjects were able to perform the Timed “up & go” test. The mean time score was 23.9 seconds (median 21.3 s) with a standard deviation of 13.2 seconds. This score was comparable with the scores of an amputee group in a previous study⁴⁶ in which amputees on average took 25 seconds to perform the test (SD 22 s). In a study by Newton, the mean time on the Timed “up & go” test of 251 healthy elderly people was only 15 seconds.⁴⁷

Prosthetic use

One year after the amputation, 11 out of the 37 patients visited, did not possess a prosthesis (table 3.3). Of the remaining 26 patients, 7 were nonambulatory except in a wheelchair and 1 only used his prosthesis marginally at home. Functional prosthetic use was only reached by 18 patients (49%).

Table 3.3 Prosthetic use one year after a lower limb amputation (n=37)

Ambulating with a prosthesis but without other walking aids	4
Independent at home, ambulating with a prosthesis but requiring one or two walking sticks or crutches for outdoor activities	6
Independent indoors, ambulating with a prosthesis and one stick or crutch, but requiring two crutches outdoors and occasionally a wheelchair	6
Walking indoors with a prosthesis and two crutches or a walker, but requiring a wheelchair for outdoor activities	2
Walking indoors only short distances, ambulating mostly with a wheelchair	1
Walking with aids but without a prosthesis	0
Nonambulatory except in a wheelchair, patient possesses a prosthesis	7
Nonambulatory except in a wheelchair, patient does not possess a prosthesis	11

Prediction of functional outcome 2 weeks post-amputation

Table 3.4 shows the relationship between the potential predictors 2 weeks after amputation and the outcome parameters one year after amputation, tested with univariate linear and logistic regression analyses. Age at amputation was significantly related with the scores of the SIP68 and the GARS. Potential predictors significantly related with the SIP68 and the GARS were: diabetes mellitus, other comorbidity, one-leg balance, BDI, CST, 15-Word test, and the Stroop Color-Word test. Two potential predictors showed a relationship with the TUGT: one-leg balance and the BDI. One-leg balance was the only factor showing a significant relationship with prosthetic use.

Age at amputation and the other significant factors were included in the forward multivariate regression analyses (table 3.5).

Sickness Impact Profile

Age explained 18% of the variance of the scores on the SIP68. The most important other predictors were: presence of other comorbidity (besides cardiopulmonary or diabetes mellitus), one-leg balance, and the 15-Word test. These 3 predictors explained 51% of the variance in the SIP68-scores. The total explained variance was 69%.

Groningen Activity Restriction Scale

Thirty-one percent of the GARS-scores were explained by age at amputation. Another 33% could be explained by one-leg balance and the 15-Word test. The total explained variance of the GARS-score was 64%.

Timed “up & go” test

Age at amputation explained 10% of the scores on the TUGT. An additional 32% was explained by one-leg balance; the total explained variance was 42%.

Table 3.4 Univariate relations between predictors two weeks after amputation (t=1) and functional outcome one year after amputation (t=4)

	SIP68*	GARS*	TUGT*	Prosthetic use†
<u>Basic predictor:</u>				
Age at amputation	.45(.005)	.56(.000)	.31 (.204)	-.02 (.685)
<u>Physical predictors:</u>				
Amputation level				
KD versus TT	-.01 (.943)	-.01 (.949)	-.06 (.818)	-.41 (.679)
TF versus TT	.11 (.518)	.22 (.183)	.30 (.228)	-.69 (.586)
Comorbidity				
diabetes mellitus	.49(.002)	.33(.043)	.42 (.082)	-.77 (.257)
cardiopulmonary	-.01 (.938)	-.02 (.903)	-.26 (.296)	.13 (.842)
other	.59(.000)	.48(.002)	.39 (.112)	-1.18 (.195)
Pulmonary function	.04 (.806)	-.03 (.875)	.25 (.350)	.00 (.923)

	SIP68*	GARS*	TUGT*	Prosthetic use†
Scar healing	.12 (.474)	.20 (.235)	.37 (.127)	.00 (1.00)
Limited joint extension	.27 (.147)	.22 (.249)	.18 (.531)	.00 (1.00)
Stump/phantom pain	-.17 (.303)	-.19 (.256)	.04 (.889)	1.23 (.076)
One-leg balance	-.67(.000)	-.63(.000)	-.59(.011)	1.14(.003)
<u>Mental predictors:</u>				
Beck Depression Inventory	.45(.005)	.38(.022)	.50(.043)	-.00 (.942)
Cognitive Screening Test	-.35(.038)	-.42(.010)	-.22 (.371)	.11 (.386)
15-Word Test				
immediate recall	-.53(.002)	-.54(.001)	-.27 (.301)	.07 (.067)
delayed recall	-.36(.048)	-.39(.030)	-.19 (.500)	.16 (.255)
Stroop Color-Word Test	.40(.022)	.39(.029)	.26 (.311)	-.00 (.551)
<u>Social predictors:</u>				
Partner	-.19 (.273)	-.32 (.055)	-.19 (.448)	.13 (.842)
Social Support Questionnaire	-.05 (.789)	-.02 (.913)	.40 (.097)	.01 (.799)

* bivariate linear regression: β coefficients are given with P-values in brackets.

† bivariate logistic regression: B coefficients are given with P-values in brackets.

Bold numbers represent coefficients with a $P < .05$. SIP68 = Sickness Impact Profile, 68-item version; GARS = Groningen Activity Restriction Scale; TUGT = Timed "up & go" test; KD = knee disarticulation; TT = transtibial; TF = transfemoral.

Table 3.5 Predictors for functional outcome 2 weeks post-amputation, tested with multivariate regression analysis

	SIP68	GARS	TUGT
Age at amputation	.25	.42	.19
R²	.18	.31	.10
Other comorbidity	.43	NS	NS
One-leg balance	-.33	-.40	-.58
15-Word test	-.26	-.32	NS
R²-change	.51	.33	.32
Total R²	.69	.64	.42

β coefficients and the explained variance of the relationship between significant predictors and outcome measures are presented. SIP68 = Sickness Impact Profile, 68-item version; GARS = Groningen Activity Restriction Scale; TUGT = Timed "up & go" test; NS = non-significant.

Prosthetic use

As we already showed in the univariate analyses, the only significant predictor for prosthetic use besides age, was one-leg balance. Of the 18 patients with functional use of their prosthesis one year after the amputation, 3 could not stand on one leg two weeks after the amputation, and 6 could stand without support for more than 10 seconds. Of the 19 patients without a functional prosthesis, 10 could not stand on one leg two weeks after the amputation and 1 could stand without support for more than 10 seconds (table 3.6).

Table 3.6 Functional outcome scores for four categories of one leg-balance

One-leg balance	SIP68 mean (SD) (n=37)	GARS mean (SD) (n=37)	TUGT mean (SD) (n=18)	Functional prosthetic use (n/n _{total})
not possible	31.2 (10.1)	49.9 (12.5)	34.6 (17.2)	3/13
with support	31.9 (9.0)	50.4 (14.5)	27.3 (20.1)	2/8
without support ≤ 10 s	15.9 (9.8)	31.8 (11.3)	24.7 (8.7)	7/9
without support > 10 s	9.9 (7.5)	26.9 (7.2)	12.7 (5.1)	6/7
Total	23.6 (13.0)	41.2 (15.4)	23.9 (13.2)	18/37

Comparison of prediction of functional outcome 2 and 6 weeks post-amputation

Table 3.2 showed differences in the characteristics 2 and 6 weeks post-amputation. Despite these differences in characteristics, the predictors were very much alike at both measurement moments. Small differences existed in predicting the SIP-scores due to the fact that at six weeks, diabetes was somewhat more important than other comorbidity, and the CST became more important than the 15-Word Test. In predicting the GARS, the BDI became more important at six weeks than the 15-Word Test. No other differences existed. In addition, the percentage explained variance was only slightly higher at 6 weeks than at 2 weeks post-amputation. Because of these marginal differences, we only presented the prediction model at 2 weeks post-amputation as the most important for clinical purposes.

One-leg balance and functional outcome

As shown in our previous results, balance on the unaffected leg was the most important predictor for all 4 outcome measurements, after adjustment for age. The differences in functional outcome for the 4 groups of standing balance was shown in table 3.6. It is clear from this data that the most important differences in functional outcome after one year are predicted by a score on the one-leg balance of 0 or 1 (not possible or possible with support) in contrast with a score of 2 or 3 (possible without support). People who were not able to stand without support 2 weeks after

amputation had a score on the SIP68 and the GARS above the mean score one year after amputation. People who were able to stand without support 2 weeks after amputation had a score on the SIP68 and the GARS below the mean score one year after amputation. This difference was less evident in comparing the TUGT-scores, but this is probably caused by the small number of patients in each group; only 2 patients who could perform the TUGT were able to stand on one leg without support ≤ 10 seconds. One year after amputation there was also a marked difference in prosthetic use between people who could not stand without support on the unaffected limb 2 weeks post-amputation (only 5 of 21 with functional prosthetic use) and people who were able to stand on the unaffected limb without support (13 of 16 with functional prosthetic use). The group differences mentioned were significant ($P=.000$), when tested with analysis of variance after correction for age at amputation.

Discussion

The main problem in our research was the number of participating patients. During the study, the number of 100 participants was not attained. To resolve part of the problem, we restricted the number of predictors in the analyses. Factors with very skewed distributions or factors we judged as not reliably measured were not used in the analyses. Despite the restricted number of participants, it is one of the largest sample populations achieved in a prospective study and it gives a great deal of information as a basis for further research about this topic.

Altman describes a framework for assessing the internal validity of articles dealing with prognosis.⁴⁸ Many of these qualities are met in our research, but some problems could not be avoided. His first point concerns the correct sample of patients. We studied prognostic variables for all lower limb amputee patients and not only for those fitted with a prosthesis. However, patients with very severe cognitive or physical problems, not able to perform our tests, were excluded. Our results, therefore, cannot be generalized to amputee patients with very severe cognitive or physical disabilities. In clinical practice, however, there is no discussion about the lack of rehabilitation potential of these patients and their bad functional prognosis. The second criterion is a sufficiently long follow-up period. We feel that one year after an amputation the functional outcome can accurately be assessed. When we visited the patients 6 months after the amputation, most persons were still undergoing therapy or had not returned to their family residence. After a year, most people had finished their therapy programs and were living in their own homes or definitively in a nursing home or a home for the elderly. The third and fourth study features described by Altman concerned the prognostic variables and the outcome measures. The potential prognostic variables were available for most of the subjects. Some stump characteristics could not be measured because of bandages or plaster casts. We used four different instruments to measure functional outcome. The 2 self-report questionnaires (the SIP68 and the GARS) reflect the patients' opinions about their functioning. While visiting the patients, we noticed a good correlation

between the subjects' functional capabilities and their report on the questionnaires. We used generic instruments because we wanted to obtain information about the patients' overall functioning, with or without a prosthesis. The Timed "up & go" test was shown before to be reliable and valid to test functional mobility of amputee patients.⁴⁶ Only 18 patients with the ability to walk and no temporary problems with the stump or prosthesis could perform the test. Many scales for prosthetic use are available.⁴⁹ We selected the classification described by Narang et al⁷ and Pohjolainen et al⁸, because it gives detailed information about the functional use of the prosthesis in our study population. The last criterium about the standardization of treatment subsequent to inclusion in the cohort could not be fulfilled. The treatment was not standardized or randomized. The choice of a certain treatment was made by the rehabilitation specialist at the local hospital. Although this did not influence the prognostic factors two weeks after the amputation, it could have influenced the outcome measurements one year after the amputation. We were not able to study the influence of the therapy between 2 and 6 weeks and one year after amputation.

Functional outcome

Fifteen percent of patients died in the first year after amputation. Mortality within one year ranges from 26% in the USA to 39% in Finland.⁵⁰ Our percentage was somewhat lower, but that may be the result of the exclusion of severely disabled patients as previously mentioned. Fewer patients who went to a rehabilitation center died in the first year after amputation than patients who went to a nursing home after their initial hospital stay. This is probably due to the fact that patients selected for a rehabilitation center were patients with a better physical condition. The percentage of our patients (70%) returning to their homes after amputation, was somewhat lower than in the population of Rommers et al,¹ that was also from the north of the Netherlands. This is caused by their inclusion of patients treated in a rehabilitation center as this creates a selection of better functioning patients. The number of amputee patients returning to home was comparable to the study of Stewart and Jain⁵¹ and somewhat higher than in the study of Larsson et al¹⁷ that only concerned diabetics.

Amputee patients on average have a low level of functioning, as indicated by the SIP68, GARS, and TUGT scores. This was also shown in previous studies.^{2,3,50} The functional prosthetic use was low in our study population (49%). In most other studies patients were only included when they went for prosthesis training, but this was not the case in our research. This may be the cause of the low prosthetic use. It was somewhat higher than in the study by Fletcher et al,⁵² who reported 36% of successfully fitted geriatric vascular amputee patients in an unselected population.

Prediction of functional outcome

The SIP68 and GARS scores showed that age at amputation was especially important for the general functioning. Standing balance on the unaffected limb 2 weeks after amputation was a significant predictor of all functional outcome parameters. The one-leg standing test was easy to apply and may reflect several physical conditions in one simple test. In addition to balance in general, it may reflect

the physical condition of the non-amputated leg, muscle power in the leg and thigh, presence or absence of comorbidity with disturbance of balance or power, and age-related balance problems. In amputee patients the role of the unaffected limb is very important for the functioning of all patients with or without a prosthesis. Table 3.6 shows that in predicting functional prognosis, it is important to test whether a patient can stand on the unaffected limb without support. The functional prognosis is less positive if a patient is not able to stand on the unaffected limb without support. We think that this test can be used soon after amputation for the prediction of functional outcome.

Memory seems to be the most important of the mental predictors for functioning with a leg amputation. The score on the 15-Word Test 2 weeks post-amputation was a significant predictor for the scores on the SIP68 and the GARS. A good memory may be important for relearning many daily tasks after the amputation. Six weeks after amputation, the importance of the CST and the BDI became more obvious (data not presented). The CST and the 15-Word Test both reflect cognitive impairments and will interact. The relevance of the BDI 6 weeks after amputation may partly be explained by the fact that this test was fulfilled by all patients, whereas some patients refused to do the 15-Word Test again because of a dislike of the test. In general, we think that in predicting functional prognosis, it is important to develop a simple test for memory function as well as a test that gives a quick impression of mood disturbances in an individual patient.

Comorbidity was only found as a predictor for the SIP68. Cardiopulmonary disease was surprisingly not a significant predictor in our research. This may partly be explained by an interaction with standing balance which may also reflect someone's cardiopulmonary condition. It is also possible that, by coincidence, the severity of the cardiopulmonary disease was too low to influence functional outcome. A more sophisticated measurement of cardiac condition as was carried out by Cruts¹³ during rowing ergometry, may be necessary to study the influence on functional outcome. However, this kind of measurement is very difficult to apply so soon after amputation.

Amputation level described in literature as an important predictor was not found to be significant in our study. This may be caused by different reasons. The first may be a skewed distribution of the presented variable in our study population of mainly transtibial amputees. The second may be the interaction between this variable with the standing balance. Patients with a higher amputation level may have more difficulties in keeping balance on the unaffected limb because of a greater disturbance of their body scheme.

The mentioned variables explained a high percentage of the functional scores on the SIP68 (69%) and the GARS (64%) and a moderate percentage of the TUGT (42%). The remaining part may be explained by other variables such as the functional abilities before the amputation, personal traits, and motivation of the amputee. This was not measured in our present research because of logistic problems in seeing the patients before the amputation, and because of the restriction in the number of possible measurements in this elderly population.

Conclusions

In general, elderly patients with an amputation of the lower limb have a low level of functioning one year after their amputation. An important part of functional outcome could be predicted two weeks after the amputation by age at amputation, one-leg balance on the unaffected limb, and cognitive impairment. Severe comorbidity probably also plays a role. The results may be used in the general policy concerning leg amputee patients.

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CHAPTER 4

RELATIONSHIP BETWEEN IMPAIRMENTS, ACTIVITIES, AND PARTICIPATION IN LOWER LIMB AMPUTEE PATIENTS

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Submitted.

Abstract

Objective: To assess the relationship between physical and mental impairments, social environmental factors, and the level of activities and participation of amputee patients one year after amputation.

Design: Observational survey.

Setting: Patients were recruited by the main hospitals in the north of the Netherlands; measurements were made in the patients' own living environment.

Patients: Older than 60 years, unilateral transtibial or transfemoral amputation or knee disarticulation due to vascular disease, living in one of the three northern provinces in the Netherlands.

Interventions: Measurement of physical functions, mental functions, social factors, and prosthetic use.

Main Outcome measures: Sickness Impact Profile, Groningen Activity Restriction Scale, Timed "up & go" test.

Results: The results showed a high frequency of limited joint extension, a low frequency of phantom pain, a high level of comorbidity, and many problems with one-leg balance. Scores for cognitive tests were low. Functional prosthetic use was reached by 51%. Patients showed a low level of activities and participation. Mental impairments appear to be even more important for functional outcome than physical impairments and social environmental factors. The strongest relationships were shown between the functional level and diabetes mellitus, 15-Word Test, one-leg balance, Beck Depression Inventory, prosthetic use and amputation level.

Conclusions: The relatively low functional level of elderly amputee patients is mainly related to diabetes mellitus, cognitive impairment, mood disturbances, and standing balance on the unaffected limb.

Introduction

The International Classification of Functioning and Disability (ICIDH-2) describes the relationship between body functions and structures, activities, and participation, influenced by environmental and personal factors.¹ The model of the ICIDH-2 can be better understood when more knowledge is available about the associations of the mentioned factors for specific diseases or handicaps. The understanding of the relationships between these items in chronic diseases also increases the understanding of the course of illness and the differences between patients with the same or different diseases. Rehabilitation specialists base their treatment of persons with chronic diseases on the correlation between impairments, activity limitations, and participation restriction. The main goals set are in regaining independency in daily activities and a full participation in daily life. Knowledge about these factors for the different patient groups is important. One important group of rehabilitation patients are people who have undergone a lower limb amputation.

Most lower limb amputations in the western world are performed on patients over 60 years of age due to vascular disease.² In these patients, regaining independence of personal care, household activities, and participation in recreational activities are the most important goals during the rehabilitation process. The loss of a limb may severely disturb the functional capabilities of an individual. The functional outcome at the level of activities and participation will depend on physical, mental, and social characteristics of the patients. Many relationships between different functional outcome measurements, and between impairments and the level of activities and participation are still unclear.

The existence of positive relationships between a lower amputation age and a distal amputation level, with the functional abilities of amputee patients are generally accepted in literature. There is also agreement about the negative relationship between stump and/or phantom pain and cardiopulmonar comorbidity with the functional level of patients with a leg amputation.³ The correlations between other physical characteristics, and in particular mental and social characteristics, and the functional level remain unclear. Many different outcome measures are used to assess the level of activities as well as the level of participation.⁴ Most outcome measures are disease specific and concentrate on the dependence in activities related to prosthetic use. Measurements of the level of participation are restricted.^{5,6} More generic instruments of functional outcome are scarcely used.⁷⁻¹³

The purpose of the present research was to assess the relationship between physical and mental impairments, social environmental factors, and the level of activities and participation of amputee patients one year after their amputation.

Methods

Design

The impairments, social factors, activities, and participation were measured one year after the leg amputation in the patients' own living environment. One year after

the amputation most of the patients were at a stable level of functioning.

Patients

Patients had to meet the following inclusion criteria: older than 60 years, a unilateral transtibial or transfemoral amputation or a knee disarticulation due to peripheral vascular disease with or without diabetes mellitus, living in one of the three northern provinces in the Netherlands. Patients were excluded if they were not able to understand the test instructions, or if they were severely disabled without any walking ability before the amputation for reasons not related to peripheral vascular insufficiency. Patients were recruited from the main hospitals of the three northern provinces in the Netherlands. Patients were asked to participate at the moment of amputation by their surgeon or by their rehabilitation specialist and informed by the researcher (TS) or a research nurse. Patients signed an informed consent before participating in the study. Ninety-seven patients were recruited by the surgeons and rehabilitation specialists. Thirteen refused to participate, 21 could not participate because of severe cognitive impairment or severe physical impairment (dying or very bad condition), and in 2 other cases multiple reasons played a role. Sixty-one patients agreed to participate in the study immediately after their amputation. Eleven patients died within the first year after amputation and three patients became bilateral amputees. One patient was too ill to perform the tests, two patients withdrew their participation and one patient could not be traced. Finally, 43 patients participated in this study. Table 4.1 shows the patient characteristics.

Table 4.1 Patient characteristics (n=43)

men	29 (67%)
age at the time of amputation: mean (SD) (yr)	72.2 (6.9)
amputation level	
transtibial	30 (70%)
knee disarticulation	6 (14%)
transfemoral	7 (16%)

Physical and mental impairments and social environmental factors

In this section we give an overview of the physical, mental, and social functions we measured in our study one year after the lower limb amputation and their scoring systems.

Physical:

1. Age.
2. Amputation level: transtibial, knee disarticulation, transfemoral.
3. Extension of knee or hip: restricted versus unrestricted. Joint range of movement was measured in the joint proximal to the amputation with a goniometer. Normal knee extension is 0 to -10 degrees. Less knee extension

was defined as restricted. Normal hip extension is 0 to – 10 degrees. Less hip extension was defined as restricted.

4. Stump and/or phantom pain: none/little versus severe.
5. Standing balance on the unaffected limb: not possible, possible with support, possible without support ≤ 10 s, possible without support > 10 s. Detailed measurements, for example, on a balance platform, were not possible 2 weeks after the amputation and in all residence settings. The parameter we therefore used for standing balance was whether patients could stand on their unaffected limb, with or without support by a walking frame. The time they could stand on the unaffected limb was recorded with a stopwatch. During standing patients were not allowed to hop and they wore their own shoe on the unaffected limb. The researcher was standing next to the patient, the walking frame before the patient, and a chair behind the patient to prevent them from falling.
6. Comorbidity: presence or absence of diabetes mellitus, cardiopulmonary disease, or other diseases/disabilities. Comorbidity was assessed by a combination of a structured self-report questionnaire¹⁴ and data from the medical records.

Mental:

1. Mood disturbances were measured using the Beck Depression Inventory (BDI).^{15,16} The BDI consists of 21 questions with 4 answer categories. The patients report their feelings and emotions during the last week. A higher score indicates more depressive symptoms. The score ranges from 0 to 63.
2. The Cognitive Screening Test (CST) is a short questionnaire (20 items), based on the Short Portable Mental Status Questionnaire of Pfeiffer.¹⁷ It assesses orientation in time, place, and person, and general knowledge. A lower score indicates more cognitive impairment and the score varies from 0 to 20. An indication of severe cognitive impairment in the Cognitive Screening Test was defined¹⁷ as a score less than or equal to 15.
3. Memory. The 15-Word Test measures short term word memory and delayed recall after 15–30 minutes.¹⁸ The patient hears 15 words in 30 seconds on a tape recorder, and has to reproduce as many words as possible. The words are repeated 5 times with reproduction of the subject. The score for the immediate reproduction varies from 0 to 75. In addition, decile scores can be calculated according to age and education level. After 15 to 30 minutes, the subject repeats all the words he or she still can remember without hearing the words again (delayed recall of 0 to 15 words). The delayed recall score can also be expressed as a decile score, related to the score of immediate reproduction.
4. Information processing and concentration. The Stroop Color-Word Test measures interference in cognitive functioning by color-word denomination.^{19,20} The patient reads 3 cards: one with 10 rows of 10 names of colors (printed in black), one with 10 rows of 10 rectangles in these colors, and one with 10 rows with colored words representing color names that are incongruent with the printed colors. The time score of the last card is taken in the analyses as an indicator of information processing. Decile scores can be calculated, related to the time necessary for the first two cards.

Social:

1. Partner: present versus absent.
2. The Social Support Questionnaire-Interactions, 12 item version (SSL12-I), is a short version of the SSL-I.²¹ The questionnaire contains 12 questions with 4 answer categories, concerning everyday support, support in the case of problems, and the degree of appreciation. The higher the score, the more support someone experiences. The score ranges from 12 to 48.

Prosthetic use:

In addition to the above-mentioned factors, we studied the relationship between the prosthetic use with the functional outcome. A specific instrument to test the functional use of the prosthesis is the classification as described by Narang²² and Pohjolainen²³:

- I. Ambulating with a prosthesis but without other walking aids
- II. Independent at home, ambulating with a prosthesis but requiring one or two walking sticks or crutches for outdoor activities
- III. Independent indoors, ambulating with a prosthesis and one stick or crutch, but requiring two crutches outdoors and occasionally a wheelchair.
- IV. Walking indoors with a prosthesis and two crutches or a walker, but requiring a wheelchair for outdoor activities.
- V. Walking indoors only short distances, ambulating mostly with a wheelchair.
- VI. Walking with aids but without a prosthesis
- VII. Nonambulatory except in a wheelchair, patient possesses a prosthesis
- VIII. Nonambulatory except in a wheelchair, patient does not possess a prosthesis

Activities and participation

We measured these aspects 12 months after amputation in three different ways:

1. The Sickness Impact Profile, 68 item version (SIP68), measures functional outcome at both the level of activities and the level of participation. The SIP68 is a measure of "health-related changes in behavior associated with the carrying out of ones daily activities".^{21,24-28} The questionnaire consists of 68 items about behavior, subdivided into 6 categories: Somatic Autonomy, Mobility Control, Psychic Autonomy and Communication, Social Behavior, Emotional Stability, Mobility Range. A total score can be calculated as well as the subscores on the different subscales.
2. The Groningen Activity Restriction Scale (GARS), measures functional outcome mainly at the level of activities.²⁹⁻³¹ The GARS is a short questionnaire with 18 items assessing disability in the area of ADL (Activities of Daily Living including mobility) as well as IADL (Instrumented Activities of Daily Living). It has a four category response format:

- 1 independent to perform the activity without any difficulty,
- 2 independent to perform the activity with some difficulty,
- 3 independent to perform the activity with great difficulty,

4 unable to perform the activity independently.

The score varies from 18 to 72. With a score of 18 the person can perform all the activities without any difficulty; with a score of 72 the person can not perform any activity without the help of others.

3. Functional walking ability was measured with the Timed "up & go" test (TUGT).³²⁻³⁴ The Timed "up & go" test is performed in the following way: the patient sits on a standard arm chair (seat height 46 cm, arm height 67 cm) with his or her back against the chair, arms resting on the chair's arms and walking aid at hand. The patient wears his or her regular footwear and uses his or her customary walking aid. On the word "go" the patient has to get up, walk to a line on the floor 3 meters away (on a standard carpet), turn, walk back to the chair, and sit down again. The patient can choose his or her own comfortable and safe walking speed. A stop watch is used to time the performance (in seconds). This test could only be performed by patients one year after the amputation with the ability to walk.

Analysis

Statistics were performed using the Statistical Product and Service Solutions (SPSS).³ The relationships between the impairments and the functional outcome measurements were first shown by univariate linear regression analyses. The associations found in the univariate analyses were used for preselection of variables to be included in the multivariate analyses. Age at amputation was entered as a basic variable in all multivariate analyses. Factors in the univariate analyses with a P-value less than or equal to .05 were also included in a multivariate linear regression analysis to test the functions having the strongest associations with the level of activities and participation. The standardized coefficients β and the percentages of explained variance were calculated. The greater the coefficient β , the greater the contribution is of the independent variable in the explanation of the dependent variable. The R-square is a measurement of the explained variance of the dependent variable (scores on the SIP68, GARS, and TUGT) by the independent variables. One hundred percent times R^2 gives the percentage of explained variance. The significance level was chosen as $\alpha = .05$.

The relationship between the different outcome measures is shown by Spearman correlation coefficients.

Results

Physical and mental impairments and social environmental factors one year after amputation

Table 4.2 shows the impairments and social environmental factors one year after the amputation. There was a high frequency of limited extension of the joint proximal to the amputation level (42%). The frequency of stump pain and/or phantom pain was low. Many patients showed comorbidity. Almost half of the patients were able to stand on the unaffected limb without support (46%).

According to the intensity score of Bouman et al,¹⁶ only three patients scored above the average on the intensity scale for depression. Severe cognitive impairment, as scored on the Cognitive Screening Test, was only present in 4 patients in our population. Seventy-one percent of patients scored in the lowest 5 deciles on the immediate recall of the 15-Word Test. Fifty-one percent scored in the lowest 5 deciles on the delayed recall. All patients but one scored in the lowest 5 deciles of the Stroop Color-Word Test (97%). The level of social support was comparable with that of a healthy reference population (25.5 versus 26.4).

Table 4.2 Physical and mental impairments and social environmental factors one year after amputation (n=43)

Limited extension of proximal joint	42%
Stump pain and/or phantom pain	23%
Standing balance unaffected limb	
not able to stand on one leg	19%
able to stand on one leg with support	35%
able to stand on one leg without support ≤ 10 s	9%
able to stand on one leg without support > 10 s	37%
Comorbidity	
diabetes mellitus	58%
cardiopulmonary	56%
other	86%
Beck Depression Inventory: mean (SD)	8.4 (7.0)
Cognitive Screening Test: mean (SD)	18.0 (2.0)
15-Word Test: mean (SD)	
immediate recall	29.2 (12.6)
delayed recall	5.5 (3.3)
Stroop Color-Word Test: mean (SD) (s)	180 (60)
Partner present	58%
Social Support Questionnaire: mean (SD)	25.5 (4.9)

Prosthetic use one year after amputation

Table 4.3 shows that 12 patients did not possess a prosthesis at all and of the other 31 patients, 7 were non-ambulatory except in a wheelchair and another 2 only used their prostheses marginally at home. Functional use of the prosthesis was only reached by 22 patients (51%).

Table 4.3 Prosthetic use one year after a lower limb amputation (n=43)

Ambulating with a prosthesis but without other walking aids	4
Independent at home, ambulating with a prosthesis but requiring one or two walking sticks or crutches for outdoor activities	6
Independent indoors, ambulating with a prosthesis and one stick or crutch, but requiring two crutches outdoors and occasionally a wheelchair	8
Walking indoors with a prosthesis and two crutches or a walker, but requiring a wheelchair for outdoor activities	4
Walking indoors only short distances, ambulating mostly with a wheelchair	2
Walking with aids but without a prosthesis	0
Nonambulatory except in a wheelchair, patient possesses a prosthesis	7
Nonambulatory except in a wheelchair, patient does not possess a prosthesis	12

Functional outcome one year after amputation

As was already shown in previous research,⁷ amputee patients have a much lower level of activity and participation when compared to patients with other pathology and also when compared to a group of healthy subjects. This was also shown in our present study population on the SIP68 as a high mean score of 23.4 (SD 11.9) compared to 10.5 in a reference group of 2387 patients with multiple pathology,²⁸ and a high mean score of 40.6 (SD 13.9) on the GARS, compared to the mean score of 22.4 of an able-bodied reference group.²⁹ In our study population 23 subjects were able to perform the TUGT. Their mean time of 27.3 seconds (median 22.7 s; SD 16.8 s) on the Timed “up & go” test was much higher than that of 15 seconds in a group of 251 healthy elderly people.³⁵

Relationship between different outcome measurements

The three outcome measures tested different aspects of the functional abilities. The correlation between these methods is shown in table 4.4. Our study showed strong correlations between the different outcome measures. Significant relationships existed between the GARS and the subscales and the total score of the SIP68. The correlation coefficients between the GARS and the subscales Psychic Autonomy and Communication and Emotional Stability were lower than the other correlations. In addition, moderate to high correlation coefficients were presented between most subscales of the SIP68 and the TUGT, except for the subscales Psychic Autonomy and Communication and Emotional Stability. The correlation coefficient between the GARS and the TUGT (.87) was also high.

Table 4.4 Correlation of different measures of functional outcome of amputee patients

		GARS	TUGT
	SA	.82†	.85†
	MC	.66†	.72†
	PAC	.39*	.18
SIP68	SG	.66†	.55†
	ES	.43†	.39
	MR	.63†	.66†
	Tot	.87†	.77†
GARS		---	.87†

SIP68 = Sickness Impact Profile, 68 item version; SA = Somatic Autonomy; MC = Mobility Control; PAC = Psychic Autonomy and Communication; SG = Social Behavior; ES = Emotional Stability; MR = mobility Range; Tot = Total Score; GARS = Groningen Activity Restriction Scale; TUGT = Timed "up & go" test.

* P<.05; † P<.01

Relationship between impairments, environmental factors, and functional outcome

Table 4.5 shows the relationship between the physical and mental impairments, the social factors, and the different measures of functional outcome tested with univariate linear regression analyses. Mental impairments appear to be even more important for functional outcome than physical impairments and social environmental factors. The social support and the presence of a partner did not show any significant relationship with the functioning of the patients one year after amputation.

The multivariate regression analysis (table 4.6) shows that, after correction for age, the SIP68 scores were most strongly influenced by the presence of diabetes mellitus and the 15-Word Test. The most important associations with the GARS scores were shown for the standing balance on the unaffected leg, the use of the prosthesis, and the score on the BDI. Standing balance was also strongly related to the scores of the Timed "up & go" test, in addition to the amputation level. The explained variance of all three outcome measures was between 70 and 80%.

Table 4.5 Relationship between physical and mental impairments, social environmental factors and functional outcome parameters with univariate linear regression analysis

	SIP68	GARS	TUGT
<u>Basic factor:</u>			
Age at amputation	.37(.016)	.49(.001)	.52(.011)
<u>Physical impairments:</u>			
Amputation level			
knee vs transtibial	-.12 (.438)	-.18 (.251)	-.12 (.578)
transfemoral vs transtibial	.21 (.174)	.32(.034)	.64(.001)
Comorbidity			
diabetes mellitus	.54(.000)	.39(.010)	.26 (.238)
cardiopulmonary	.04 (.798)	.02 (.888)	-.23 (.288)
other	.29 (.062)	.24 (.117)	-.12 (.579)
Limited joint extension	.20 (.221)	.09 (.597)	.06 (.804)
Stump/phantom pain	.32(.039)	.30(.050)	-.03 (.893)
One-leg balance	-.58(.000)	-.62(.000)	-.56(.005)
Prosthetic use	-.50(.001)	-.50(.001)	—*
<u>Mental impairments:</u>			
Beck Depression Inventory	.64(.000)	.50(.001)	.39 (.064)
Cognitive Screening Test	-.32(.039)	-.32(.035)	-.18 (.405)
15-Word Test			
immediate recall	-.64(.000)	-.54(.001)	-.56(.016)
delayed recall	-.57(.000)	-.49(.003)	-.40 (.130)
Stroop Color-Word Test	.55(.001)	.59(.000)	.59(.017)
<u>Social environmental factors:</u>			
Partner	-.11 (.468)	-.28 (.071)	-.09 (.677)
Social Support Questionnaire	-.19 (.220)	-.15 (.335)	-.18 (.424)

β coefficients are given with P-values in brackets. Bold numbers represent coefficients with a $P < .05$.

*All patients able to perform the Timed “up & go” test functionally used their prosthesis. SIP68 = Sickness Impact Profile, 68-item version; GARS = Groningen Activity Restriction Scale; TUGT = Timed “up & go” test.

Table 4.6 Association between impairments and social factors and functional outcome with multivariate regression analyses

	SIP68	GARS	TUGT
Age at amputation	.28	.34	.22
R²	.13	.27	.36
Diabetes mellitus	.53	NS	NS
15-Word Test	-.47	NS	NS
One-leg balance	NS	-.39	.57
Beck Depression Inventory	NS	.37	NS
Prosthetic use	NS	-.27	NS
Transfemoral vs transtibial level	NS	NS	.42
R² change	.43	.39	.57
Total R²	.71	.73	.79

β coefficients and the explained variance are presented of the relationship between significant predictors and outcome measures.

SIP68 = Sickness Impact Profile, 68-item version; GARS = Groningen Activity Restriction Scale; TUGT = Timed "up & go" test; NS = non-significant.

Discussion

In this research, we studied the associations between impairments, environmental factors, activities, and participation of patients one year after a lower limb amputation. It is important to learn about these relationships to know which factors have the most important influence on the functioning of these patients, with or without their prosthesis. In the follow-up of amputee patients, workers in rehabilitation medicine may be able to respond more adequately to difficulties mentioned by the subjects and influencing factors.

The number of participating patients (43) in our study was lower than expected. Fewer participants were reported by surgeons and rehabilitation specialists, a number of them refused to participate, and 11 patients died in the first year post-amputation. To resolve part of the problem, we restricted the number of impairments and social factors in the analyses. Factors with very skewed distributions or factors we judged as not reliably measured were not taken into account in the analyses. Despite the restricted number of participants, we still think that it provides a great deal of information as a basis for further research about this topic. It was especially important that we studied an aselect group of elderly amputee patients and not only those who received a prosthesis as is done in most research. The results may therefore be generalized to most elderly vascular amputee patients, except those patients who are

severely ill immediately after the amputation.

One year after amputation, whilst looking at the impairment level, it was notable that 42% showed a limited extension of the joint proximal to the level of amputation. Patients receive instructions from physiotherapists immediately after the amputation in order to prevent contractures. In the course of the first year patients may forget to prevent flexion contractures of the knee and hip. No direct relationship with functional outcome could be shown here but this factor was significantly related to prosthetic use and may have indirectly influenced the functional level. In comparison with other reports,³⁶ the frequency of severe stump pain and phantom pain reported was strikingly low. The reported frequency of severe phantom pain was as low as 9%. We were able to ask patients to specifically pinpoint pain in the part of the leg that was amputated and could explain this further if the patient did not understand what we meant. We recognized that many patients tend to confuse phantom feelings with phantom pain. Phantom feelings are reported by most of the patients. In most other studies a questionnaire was sent to the patients and confusion regarding phantom feelings or phantom pain could not be controlled. The low prevalence of pain may explain the lack of a relationship with the general functioning, as previously mentioned in other research.³⁶

Only 46% of the patients were able to stand on the unaffected leg without support. Hermodsson³⁷ also reported that many amputee patients had problems with standing on one leg. In the rehabilitation of amputee patients, balance training is an important element in the treatment. The different levels of functional outcome are strongly related to standing balance and therefore we conclude that maybe even more attention to balance training could be beneficial to the patients.

Fifty-eight percent of the population had diabetes mellitus. Diabetes mellitus can cause multiple problems influencing the patient's functional abilities. Other comorbidity showed no significant relationship with functional outcome, possibly due to the skewed distribution. Almost all patients had comorbidity, besides diabetes mellitus.

The mean score on the Beck Depression Inventory in our sample of 8.4 was slightly higher than the scores of 6.4 and 5.5 in the studies of Frank et al.³⁸ Although few patients showed severe depressive symptoms, the frequency of milder symptoms was sufficient reason to give psychological support after the amputation to help the patients to manage their loss and to accept the new situation. Although few patients showed severe cognitive impairments in the Cognitive Screening Test, the results from the more sophisticated tests such as the 15-Word Test and the Stroop Color-Word Test showed very low decile scores. These results reflected serious disturbances of memory, information processing, and concentration, possibly due to the combination of peripheral vascular disease with cerebrovascular disease.³⁹ Mood disturbances in addition to a decrease in cognitive functions negatively influenced the new functional equilibrium that patients are expected to regain after their amputation. Learning to walk with a prosthesis and relearning the doing of daily activities with an amputated leg are difficult processes that may require good cognitive skills. Motivation of the patient will play an additional role. This may also be partly reflected in the scores on the cognitive tests in which motivation plays an

important role in the test scores.

Social environmental factors were not found to greatly influence functional outcome. The level of support in our patient group was sufficiently high to prevent problems in this field. The comparison of our findings with that of a healthy population of the same age would be interesting, but this data is not available in literature.

The functional prosthetic use of 51% was low in our study population. In most other studies, patients were only included if they went for prosthesis training, but this was not the case in our research and this may be the cause of the lower prosthetic use. The real prosthetic use may be even lower because patients who were too ill to perform the tests did not participate in the study. Most of these patients will not have received a prosthesis. It was not surprising that the use of a prosthesis was positively related to many functional aspects. Many daily activities are more easily done when walking than sitting in a wheelchair. The scales of the SIP68 with the strongest relationship with prosthetic use (Somatic Autonomy and Mobility Control), contain different items concerning walking activities. The GARS questionnaire, however, concentrates on certain activities, not taking into account how people manage to do them - sitting or standing and walking. The significant correlation between prosthetic use and the GARS shows that the overall functioning is seriously influenced by prosthetic use.

In the multivariate analyses, age explained 13 to 36% of the variance of the outcome scores. The factors with the strongest relationship in the multivariate analyses with the SIP68 were diabetes mellitus and the 15-Word Test. Diabetes mellitus may have many physical consequences for a patient that disturb their general functioning. Memory, and more in general, cognitive functioning, is important in many social activities and this may explain the important influence of this factor in the SIP68. The fact that one-leg balance was not presented as an important related factor to the SIP68 in the multivariate analyses is in contrast with its relationship with the other two outcome measures and may be explained by an interaction effect with diabetes mellitus. One-leg balance was important in explaining the scores on the GARS and the TUGT. In many daily activities as well as in walking ability balance is relevant. This factor is important for people with functional use of a prosthesis, but also for those who mainly function without a prosthesis. People with functional use of the prosthesis were more capable of performing the daily activities as described in the GARS. Mood disturbance also greatly influenced the level of activities of the patients. Amputation level was important for the subject's walking abilities. In general, we saw that the functional walking ability (TUGT) was mostly influenced by physical factors, whereas mental factors became more important for the functional levels of activity and participation. Seventy-one percent to 79% of the level of functional outcome could be explained by the above mentioned factors. The remaining part may be explained by other personal factors, i.e. motivation and personal traits, or other environmental factors, i.e. living environment. Further research could explain the remaining part of the relationship between impairments, activity limitations, and participation restriction for amputee patients.

The low level of functioning of amputee patients was in accordance with former

research.^{7,40,41} Strong correlations existed between the three functional outcome measures even though they differ in some measurement aspects. We checked graphically (not shown) if the strong correlations were caused by outliers, but this was not the case. This supports the fact that all three instruments are different ways of measuring functional outcome. The SIP68 was the only instrument that contains a part concerning psychological or emotional functioning. This part therefore showed a lower correlation coefficient with the scores on the GARS and the TUGT scores. Our present results confirm the relevance of the TUGT as a simple test of the functional abilities of amputee patients, as we have already shown in former research.³⁴ The disadvantage of this test is that it is only applicable to patients with walking ability with a prosthesis. Attention should be paid to the fact that we used the outcome measures in elderly patients. As we mentioned in our research concerning the Timed “up & go” test,³⁴ this test may not be applicable for young patients because they all walk too quickly to differentiate between persons. Both questionnaires can be used in a younger population, but additional questionnaires concerning vocational participation are necessary.

Conclusion

Elderly patients with a unilateral leg amputation have a low level of functional outcome one year after amputation. Diabetes mellitus, cognitive impairment, mood disturbances, and standing balance on the unaffected leg were the most important physical and mental impairments relating to the level of activities and participation. Amputation level is mainly important for the ability to walk. Social environmental factors seem to play a less important role in the explanation of the functional level.

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Supplier

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CHAPTER 5

EPIDEMIOLOGIC CHARACTERISTICS AND QUALITY OF LIFE OF LOWER LIMB AMPUTEE PATIENTS IN ADULTHOOD IN THE NETHERLANDS

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Submitted.

Abstract

Objective: to give a descriptive analysis of patient characteristics and amputation-related problems in adults not older than 60 years of age with a lower limb amputation in the Netherlands and to study the relationship between background and amputation-related factors and quality of life of these patients.

Design: A cross-sectional study, mailed questionnaire.

Setting: Patients were recruited by orthopaedic workshops in the Netherlands.

Patients: 626 subjects, aged 18 to 60 years, with an acquired unilateral major amputation of the lower limb at least 2 years prior to this study.

Interventions: Not applicable.

Main Outcome Measures: Statistical analyses of responses to two questionnaires; one concerning patient characteristics and amputation-related aspects, the other was a general health questionnaire (RAND-36 Item Health Survey [RAND-36]).

Results: The 626 patients had a mean age of 44.4 years and most amputations were done at the transtibial level, caused by trauma. 76% had occasional or frequent skin problems of the stump; 15% suffered from phantom or stump pain. Ninety-two percent of the patients wore their prosthesis for more than 8 hours a day, and most (84%) judged their wearing comfort sufficient. Walking distance was severely restricted and 44% of the patients reported comorbidity. A significant relationship existed between amputation level and presence of skin problems, phantom pain, prosthetic use, and walking distance; the higher levels showed less skin problems, but more phantom pain, a lower prosthetic use, and shorter walking distances. Health perception in many dimensions was significantly lower than in a reference population and was mainly related to wearing comfort of the prosthesis, walking distance, phantom pain, amputation level, and use of the prosthesis.

Conclusions: Most lower limb amputations at adulthood are traumatic transtibial amputations. Most common problems were skin problems and restricted walking distance. The worse health perception of amputee patients when compared to a reference population, may be improved by upgrading the wearing comfort and the use of the prosthesis especially for long walking distances, and adequate treatment of phantom pain.

Introduction

In Western society most amputations are done in subjects of 60 years of age or older and more than 80% are caused by vascular disorders.¹ Patient characteristics and amputation-related problems are mostly described in this group of elderly patients. However, the younger group of amputees up to 60 years old may have specific characteristics that are important for the functioning of subjects who are in a very active period of their life.

In patients up to 60 years old, trauma and cancer seem to play a more important role than vascular disease as a reason for amputation.² Detailed overviews, however, of the reasons for amputations in large groups of younger amputees have not been documented. Many studies about the functioning of amputees less than 60 years old are restricted to trauma patients. The majority of amputations are done at a transtibial level and about one-third are transfemoral amputations.¹⁻³ Kneedisarticulations, hipdisarticulations, and hemipelvectomies form only a small proportion of all amputations. Young amputees use their prosthesis very intensively. In a study by Nielsen et al⁴ carried out on 109 patients with a mean age of 51 years, 67% used their prosthesis more than nine hours a day. In a study by Purry and Hannon⁵ of 25 traumatic amputees, 84% used their prosthesis for more than 13 hours a day. In a larger study by Burger et al⁶ of 223 traumatic amputees, 85% wore their prosthesis more than seven hours a day. Only a few studies describe the level of functioning in terms of walking distance. Walking distance seems to remain restricted in spite of the intensive use of the prostheses. In the study by James⁷ only 25% could walk more than one kilometer and Burger et al⁶ described that only 19% of their patients could walk more than 2 kilometers.

Several studies describe the quality of life of young amputee patients with the MOS 36-item Short form health survey (SF-36; a general health questionnaire). Smith et al⁸ showed lower scores in 20 traumatic amputees than in healthy controls on the subscales physical functioning, role limitations due to physical health, and pain. In a study of Pezzin³ on 78 traumatic amputees (mean age 32 years), subjects scored lower than the reference population on all the physical subscales of the SF-36. In addition, they scored lower on the subscales general health, vitality, and social functioning. No differences existed between amputees and controls on the mental subscales. This result was also found in the study of Legro et al⁹ of 92 amputees with a mean age of 55 years. Overall agreement exists about the negative influence of chronic pain, phantom or stump pain, after an amputation on the quality of life. Unfortunately, the way phantom and stump pain is registered differs very much between the studies because an international standard is not available. The reported prevalence of phantom pain varies from 24 to 85% and depends on the definition and the time elapsed since the amputation.^{3,7,10-14} The prevalence of stump pain varies from 14 to 79%.^{10,14} Other factors mentioned in literature showing a relationship with quality of life are: age, gender, race, amputation level, comorbidity, injury severity score in trauma patients, and inpatient rehabilitation.³ However, most of this data is obtained in selected groups of patients and an overall view of characteristics and functioning of patients with a lower limb amputation aged less than 60 years is

lacking.

The first purpose of the present study was to give a descriptive analysis of patient characteristics and amputation-related problems in adults up to 60 years old with a lower limb amputation in the Netherlands. The second purpose was to study the relationship between several background and amputation-related factors and the quality of life of these amputee patients.

Methods

Subjects

Patients met the following inclusion criteria: an acquired unilateral major amputation of the lower limb, between 18 and 60 years old at the time of the study, and living in the Netherlands. In order to create a stable situation the time since amputation was at least two years. Patients with severe cognitive problems or difficulties with the Dutch language who could not fill in the questionnaire were excluded. The study was approved by the Medical Ethical Committee of the University Hospital Groningen.

We asked 49 orthopaedic workshops (almost all existing workshops) in the Netherlands to participate in the recruitment of patients for the study. Twenty-five orthopaedic workshops had none or very few amputee patients in their files who met the inclusion criteria. Of the other 24 workshops, 13 could not participate for multiple reasons. It is likely that some of these workshops also did not have amputees in their files who met the inclusion criteria. Finally, 11 orthopaedic workshops in the Netherlands with amputee patients between 18 and 60 years sent their patients a letter in which they asked for consent to give their name and address to the department of Rehabilitation of the University Hospital Groningen. Patients were asked to return their signed consent. Approximately 60% of the total number of patients asked to participate by the orthopaedic workshops returned the signed consent. The researchers contacted the patients by phone to check the inclusion and exclusion criteria. After the telephone contact 660 questionnaires were sent out to the patients and 626 patients returned the questionnaire, which is a 95% response.

Questionnaires

The first questionnaire consisted of questions concerning patient characteristics and aspects related to the amputation. We asked, in a self constructed questionnaire, for demographic factors (age, gender), the side, the level, and the reason for amputation, phantom pain, stump pain, skin problems of the stump, use of prosthesis, wearing comfort, walking distance, comorbidity, and the kind of rehabilitation received after the hospital stay (outpatient or inpatient in a rehabilitation center or a nursing home). The questions about the presence and frequency of stump and phantom pain are based on the questionnaire developed by Kooijman et al.¹⁵ This questionnaire was based on two English questionnaires^{16,17} and the questionnaire used by the Dutch Working Group of Users of Lower Limb Prostheses (SLWBG). It explores several aspects including the amount of trouble and suffering experienced

from phantom and stump pain. The frequency of the pain is measured on a seven-point scale from never to always and suffering from the pain was measured on a five-point scale from none to extreme. We scored skin problems on a three-point scale: never, sometimes, often. The use of the prosthesis is expressed as the number of wearing hours of the prosthesis during the day, subdivided into five categories from never, to more than eight hours a day (never, not daily, daily less than 4 hours, daily 4 to 8 hours, more than 8 hours). Wearing comfort was scored as bad, insufficient, sufficient, and good. Walking distance varied from less than 100 meters to more than one kilometer in four categories (less than 100 meters, 100 m to 500 m, 500 m to 1 km, more than 1 km). We asked for comorbidity related to the cause of the amputation (trauma, cancer) and also any other kinds of comorbidity.

The RAND-36 (Dutch version) was used as a general health questionnaire for the measurement of quality of life including psychological, physical, social, and overall well-being. The RAND-36 is a short version of the RAND Health Insurance Study Questionnaire and is similar to the MOS SF-36.¹⁸⁻²⁰ It measures health perception on nine multi-item dimensions: physical functioning, social functioning, physical role restriction, emotional role restriction, mental health, vitality, pain, general health, and health change. A lower score on the RAND-36 is indicative of a worse health experience. The data of a Dutch reference population, aged between 18 and 60 years, without health problems is available.¹⁹

Factors related to quality of life

We studied the following factors and their relationship with quality of life:

- background variables: age at the time of study, age at the time of amputation, gender, comorbidity
- amputation-related variables: kind of rehabilitation after hospital stay, amputation level, reason for amputation, skin problems of the stump, phantom pain, stump pain, use of prosthesis, wearing comfort of prosthesis, walking distance

The choice of these factors was based on the data found in literature as described in the introduction, as well as on clinical experience of the authors. Factors influencing quality of life described in literature are age, gender, amputation level, comorbidity, inpatient rehabilitation, phantom pain, and stump pain. In clinical practice our experience was that skin problems, difficulties with the use and the wearing comfort of the prosthesis, and a short walking distance can negatively influence the quality of life of amputee patients. The influence of the reason for amputation on quality of life is unclear. In this research, we studied the influence of the above mentioned factors on quality of life, and their individual contribution to it.

Analysis

Statistics were performed using the Statistical Product and Service Solutions (SPSS).^a The relationship of amputation-related problems and the level for amputation was tested with the chi-squared test. Differences in the scores of the RAND-36 between amputees and a reference population were calculated using the Student *t*-test. The relationship between background and amputation-related factors

and quality of life (RAND-36) was analyzed with forward multivariate linear regression. First, the relationship between the background variables and the subscores of the RAND-36 was tested. Subsequently the relationship between the amputation-related variables and the subscores of the RAND-36 was tested. The standardized coefficients β and the percentages of explained variance were calculated. The greater the coefficient β , the greater the contribution is of the independent variable in the explanation of the dependent variable. The R-square is a measure of the explained variance of the dependent variable (score on the RAND-36) by the independent variables. One hundred percent times R^2 gives the percentage of explained variance. The significance level was chosen as $\alpha = .05$.

For a clear presentation of the epidemiologic characteristics in the tables and in the analyses, data are dichotomized in the following way:

gender	0	man	1	woman
comorbidity	0	absent	1	present
skin problems	0	never	1	sometimes/often
phantom pain	0	none/little/moderate	1	much/very much
stump pain	0	none/little/moderate	1	much/very much
use of the prosthesis	0	< 8 hours a day	1	≥ 8 hours a day
wearing comfort of the prosthesis	0	bad/insufficient	1	sufficient/good
walking distance	0	< 500 meters	1	≥ 500 meters

Results

Patient characteristics

The study population consisted of 449 (72%) men and 177 (28%) women with a mean age of 44.4 years (standard deviation 10.3 yr). 328 patients had a left-sided and 298 a right-sided amputation. The mean time since amputation was 19.8 years (standard deviation 12.9 yr). Table 5.1 shows the patient characteristics. Within the group of 626 patients with a unilateral amputation, 624 (99.7%) possessed a prosthesis. After the amputation, 285 patients received outpatient treatment in a hospital or rehabilitation center; 225 underwent clinical treatment in a rehabilitation center; 7 had outpatient or clinical treatment in a nursing home; 28 mentioned another type of treatment (mostly physiotherapy at home) and 79 mentioned no treatment at all.

Amputation-related characteristics

Table 5.2 shows the frequencies of amputation-related characteristics for the several levels of amputation. Of all the patients with a unilateral amputation, 76% had occasional or frequent skin problems of the stump. Fifteen percent reported a large amount of phantom pain whereas a large amount of stump pain was also reported by 15%. Only a few patients used their prosthesis for less than 8 hours a day (8%). Sixteen percent judged the wearing comfort of the prosthesis as insufficient or bad. The walking distance was restricted to less than 500 meters in 36%. Some kind

Table 5.1 Patient characteristics (n=626)

	mean	median	range
age at the time of amputation (yr)	24.8	21	0–57
age at the time of study (yr)	44.4	46	18–60
	n	%	
reason for amputation:			
trauma	376	60.1	
cancer	101	16.1	
vascular/diabetes	63	10.0	
other	86	13.8	
level of amputation:			
hip/pelvis	32	5.2	
transfemoral	213	34.0	
knee	73	11.7	
transtibial	291	46.5	
ankle	16	2.6	
missing	1	0.2	

of comorbidity was present in 44% of the patients.

We found a significant relationship - tested with the chi-squared test - between the amputation level and the presence of skin problems, phantom pain, use of the prosthesis, and walking distance. Patients with a hipdisarticulation or hemipelvectomy mentioned the least skin problems (59%). Most skin problems occurred in patients with a transtibial amputation (79%). Twenty-one percent of the transfemoral amputees mentioned much or very much phantom pain, whereas only 10% of the transtibial amputees mentioned this. The use of the prosthesis was shortest in patients with a hipdisarticulation or hemipelvectomy (37% less than 8 hours a day), and longest in transtibial amputees (96% more than 8 hours a day). Patients with a hipdisarticulation or hemipelvectomy were also severely restricted in the distance they could walk. Only 41% of these patients could walk more than 500 meters. In comparison, 80% of patients with an amputation at ankle level could walk more than 500 meters. No significant relationships could be shown between the level of amputation and stump pain, wearing comfort of the prosthesis, and the presence of comorbidity.

Table 5.2 Amputation-related factors in relation to the level of amputation. Percentages are given.

Amputation level	Skin problems		Phantom pain		Stump pain		Use of prosthesis		Wearing Comfort		Walking distance		Comorbidity	
	never	s.t./often	none/little/mod.	much/very much	none/little/mod.	much/very much	<8 h/day	≥8 h/day	bad/insuff.	suff./good	<500 meters	≥500 meters	no	yes
hip/pelvis (n=32)	41	59	81	19	93	7	38	63	22	78	59	41	63	38
femoral (n=213)	25	75	79	21	84	16	10	90	18	82	45	55	56	44
knee (n=73)	26	74	86	14	93	7	7	93	11	89	32	68	59	41
transfemoral (n=291)	21	79	90	10	82	18	4	96	14	86	29	71	55	45
ankle (n=16)	27	73	88	13	88	13	6	94	19	81	20	80	50	50
Total (n=625)	24	76	85	15	85	15	8	92	16	85	36	64	56	44

s.t. = sometimes; mod. = moderate; insuff. = insufficient; suff. = sufficient.

Cancer was the most common reason for amputation (66%) in patients with a hemipelvectomy or hipdisarticulation, whereas in patients with a lower amputation level trauma was the most frequent reason (61%) for the amputation.

Amputation-related factors and quality of life

Table 5.3 shows the RAND-36 scores of the patients compared with the reference group of 18 to 60 years of age. When we compared the amputee patients with the reference population, the amputee patients scored significantly lower on the subscales of physical and social functioning, physical role restriction, vitality, pain, general health and health change.

Table 5.4 shows the results of the multivariate linear regression analysis of the relationship between several background variables and amputation-related factors with the RAND-36 scores. The background variables explained 4% (health change) to 25% (physical functioning) of the RAND-subscores variance. The contribution of the amputation-related factors differed from only 1% for health change to 28% for physical functioning. The characteristics that showed a significant relationship with more than half of the RAND-36 subscores were wearing comfort, walking distance, phantom pain, amputation level, and use of prosthesis. These factors seem to play the most important role in the health perception of people with a lower limb amputation.

Discussion

This study gives an overview of many characteristics of lower limb amputee patients aged 18 to 60 years. Although a great number of amputee patients participated in the study, a selection bias can not be completely ruled out. We recruited patients via the orthopaedic workshops, and we may therefore have missed people who never received a prosthesis. This was reflected in our study population by the fact that almost all patients possessed a prosthesis. Almost 60% of the patients asked to participate by the workshops participated. We have no reason to believe that the respondents were a selected group of people known at the orthopaedic workshop because of their amputation. The results are therefore representative of the amputee population aged 18 to 60 years in the Netherlands who visit orthopaedic workshops.

The associations between amputation level, RAND-36 scores, and several amputation-related characteristics were all measured at the same moment. In this type of research, causal relationships can not be proven. However, it remains important for workers in rehabilitation medicine to learn more about amputation-related problems and their relationship with quality of life. This increases the understanding of amputee patients and of important aspects during rehabilitation.

The most important cause of amputation in this younger population was trauma whereas vascular causes were responsible for the majority of amputations in elderly patients. Almost half of the patients had a transtibial amputation, which is comparable with the distribution of amputation levels in Rommers' study¹ concerning

Table 5.3 Experienced health of amputee patients and a reference population using the RAND-36

	physical functioning	social functioning	physical role restriction	emotional role restriction	mental health	vitality	pain	general health	health change
Amputee patients	54.4 (27.4)†	80.4 (24.6)†	74.6 (36.7)†	86.0 (30.9)	77.1 (16.8)	65.5 (20.0)*	72.9 (25.7)†	71.6 (22.3)*	50.2 (18.9)†
Reference population	86.2 (20.4)	86.6 (20.9)	81.4 (33.8)	84.4 (32.1)	76.8 (18.9)	68.1 (19.4)	82.7 (24.4)	74.2 (21.6)	53.7 (19.2)

The numbers represent the mean scores with the standard deviation in brackets.

* Significant difference in the score of the patients group compared to the reference population; $P < .05$.

† Significant difference in the score of the patients group compared to the reference population; $P < .001$.

all amputations in the three northern provinces in the Netherlands. The majority of people were treated in a rehabilitation center, as outpatient or inpatient. In the Netherlands it is common practice to view all young amputee patients as potential candidates for prosthesis training and this is reflected in our results. The persons who mentioned not having received any treatment at all were mostly patients whose amputation had been carried out a long time ago when rehabilitation facilities were not widespread.

The high proportion of patients reporting skin problems (76%) requires more research into the type and causes of these problems. A relationship with amputation level existed: the higher amputation levels presented less skin problems than the lower ones. This may be partly explained by the fact that patients with higher amputation levels wear their prostheses shorter than patients with lower amputation levels, causing less stress on the skin. In addition, less strain is caused by shearing in higher amputation levels. In trauma patients 81% showed skin problems, whereas in other amputee patients this was 68%. So, part of the problems were directly related to the trauma which had caused the amputation. Skin problems can affect the wearing comfort of the prosthesis and temporary problems may interfere with the functional abilities of the patients, for example in their work. The proportion of subjects suffering from phantom pain and stump pain was surprisingly low in our population. This may be explained by the long mean time elapsed since amputation. Pain may have decreased after a period of time, or people may have learned to cope with it and the suffering from the pain may have become less. Many problems about the origin of phantom pain are still unresolved, but our results suggest that phantom pain may increase when a greater part of the body is lost. Although there was a relationship between phantom pain and amputation level, no relation existed between level and stump pain. The main cause of stump pain is possibly the healing process itself and not the level of the amputation.

The prostheses were intensively used, with most patients wearing them all day, except for the patients with very high amputation levels such as a hipdisarticulation or hemipelvectomy. This was also reported in the studies of Nielsen, Purry and Burger.⁴⁻⁶ Prosthetic prescription is apparently of great value for amputee patients in adulthood. The wearing comfort is sufficient in most patients, although 16% judged it to be insufficient or bad, irrespective of the amputation level. The multiple skin problems reported in our study population could have negatively influenced the judgement concerning wearing comfort. Before the amputation most of the subjects will have been unrestricted in the distance they could walk. After the amputation more than one third of the patients could walk less than 500 meters and in patients with the highest amputation levels this increased to 59%. The restriction in walking ability may have many social consequences for this group of patients and in this study this is reflected in the influence of walking distance on many of the RAND-36 scales.

Multiple pathology is a common problem in elderly amputee patients over 60 years of age. We showed that comorbidity in amputee patients under 60 years of age is also not a negligible problem. Comorbidity was partly related to the amputation. In the trauma patient group, 26% reported other problems caused by the trauma and in cancer patients, 24% mentioned metastases. Comorbidity not directly related to

Table 5.4 Multivariate regression analysis of the relationship between background and amputation-related variables with the different RAND-36 domains

	Physical functioning	Social functioning	Physical role restriction	Emotional role restriction	Mental health	Vitality	Pain	General health	Health change
<u>Background:</u>									
age at the time of study	-.04	-.07	-.08	-.02	.03	.01	-.09	-.10	-.07
age at the time of amputation	-.42	-.17	-.17	-.08	-.11	-.13	-.22	-.16	.01
gender	-.12	-.14	-.12	-.08	-.20	-.19	-.08	-.10	.08
comorbidity	-.17	-.26	-.25	-.19	-.15	-.21	-.20	-.31	-.16
R²	.25	.15	.14	.06	.08	.11	.13	.17	.04
<u>Amputation-related:</u>									
kind of rehabilitation					.10				-.11
amputation level	.12			-.11	-.10	-.13	-.08	-.12	
amputation reason									
cancer			-.11						
vasc./diab.							-.07		.24

	Physical functioning	Social functioning	Physical role restriction	Emotional role restriction	Mental health	Vitality	Pain	General health	Health change
skin problems	-.08					-.11	-.20		
phantom pain		-.12	-.11		-.13	-.16	-.22	-.10	-.10
stump pain		-.11			-.09		-.16		
use of prosthesis		.12	.17	.14		.15		.10	
wearing comfort	.08	.12	.10	.17	.17	.13	.17	.10	
walking distance	.49	.09	.18		.10	.10	.15	.20	
R² change	.28	.10	.12	.06	.09	.12	.25	.16	.01
Total R²	.53	.25	.26	.12	.17	.23	.38	.33	.05

The β coefficients in the upper part are those of the model with background variables only. In the lower part concerning amputation-related factors only significant β coefficients are shown.

the cause of the amputation was present in 35%. Treatment of both the amputation and the comorbidity is essential to optimize the quality of life. This was also shown in previous research in which we showed the relevance of comorbidity for job satisfaction.²¹

The worse health perception of amputee patients compared to a reference population on the RAND-36 was in accordance with other studies.^{3,8,9} The differences on the subscores vitality, general health, and health change were significant, although they were very small. The difference on the subscore physical functioning was highest, reflecting the influence of the amputation on the physical capabilities of an individual. Factors that were mostly related to health perception concerned wearing comfort, walking distance, phantom pain, amputation level, and use of the prosthesis. Some problems existed in comparing these factors with the scores on the RAND-36. For example, walking distance was strongly associated with physical functioning. This may be a consequence of the fact that in the section of the RAND-36 about physical functioning, many questions also concerned walking ability. This may be even more evident in the association between phantom or stump pain in the RAND-36 subscore of pain. This relationship may show the measurement of the same phenomenon in two different ways. However, this was not the case in the other relationships tested, and the results still give important information concerning the role of many amputation-related characteristics related to the health perception of amputee patients. We have already described the relevance of the decreased walking distance of an amputee patient and the effect this can have on the patients' perception on their state of health. The importance of wearing comfort and prosthetic use in the health perception of the patients stresses the benefit of adequate prosthetic fitting for patients. Although not many patients reported severe suffering from phantom pain, our study showed the negative influence of pain on health perception.

The percentage explained variance of health perception was highest for physical functioning (53%) and pain (38%). The contribution of the amputation-related factors in the explanation of these two factors was also the highest (28% and 25%). The role of other dimensions in health perception remains largely unexplained. Other contributing factors may be: restrictions in activities of daily living, having a job,²² being able to do recreational activities, personal traits, and social support.

Conclusion

In adulthood most lower limb amputations are transtibial amputations, caused by trauma. Prostheses are intensively used, despite of the high frequency of skin problems. Walking distance remains severely restricted after the amputation. Comorbidity is present in almost half of the subjects. A higher amputation level was significantly related to less skin problems, more phantom pain, shorter prosthetic use, and shorter walking distance. Health perception of amputee patients is significantly worse than that of a reference population. Important amputation-related factors for health perception are: wearing comfort of the prosthesis, walking distance, phantom pain, amputation level, and prosthesis use.

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CHAPTER 6

EMPLOYMENT STATUS, JOB CHARACTERISTICS, AND WORK-RELATED HEALTH EXPERIENCE OF PEOPLE WITH A LOWER LIMB AMPUTATION IN THE NETHERLANDS

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Abstract

Objectives: To describe the occupational situation of people with lower limb amputations in The Netherlands and to compare the health experience of working and nonworking amputee patients with a nonimpaired reference population.

Design: Cross-sectional study in which patients completed a questionnaire about their job participation, type of job, workplace adjustments to their limb loss, their position in the company, and a general health questionnaire.

Setting: Orthopedic workshops in The Netherlands with a population of lower limb amputees.

Patients: Subjects were recruited from orthopedic workshops in The Netherlands. They ranged in age from 18 to 60 years (mean 44.5 yr) and had a lower limb amputated at least two years (mean 19.6 yr) before this study.

Main Outcome Measures: A self-report questionnaire, with 1 part concerning patient characteristics and amputation-related factors, and the other concerning job characteristics, vocational handicaps, work adjustments, and working conditions; and a general health questionnaire (RAND-36) to measure health status.

Results: Responses were received from 652 of the 682 patients (response rate 95%) who were sent the questionnaire. Sixty-four percent of the respondents were working at the time of the study (comparable with the employment rate of the general Dutch population), 31% had work experience, but were not presently working, and 5% had no work experience. After their amputations, people shifted to less physically demanding work. The mean delay between the amputation and the return to work was 2.3 years. Many people wished their work was better adjusted to the limitations presented by their disability and they mentioned having problems concerning possibilities for promotion. Seventy-eight percent of those who stopped working within 2 years after the amputation said that amputation-related factors played a role in their decision. Thirty-four percent said that they might have worked longer if certain adjustments had been made. The health experience of people who were no longer working was significantly worse than that of the working people with amputation.

Conclusions: Although amputee patients had a relatively good rate of job participation, they reported problems concerning the long delay between amputation and return to work, problems in finding suitable jobs, fewer possibilities for promotion, and problems in obtaining needed workplace modifications. People who had to stop because of the amputation showed a worse health experience than working people.

Introduction

Although the majority of patients with a lower limb amputation in Western Europe are aged 60 years or older, many younger patients have a lower limb amputation.^{1,2} Not only is training of physical mobility and independence in activities of daily living important after an amputation in younger patients, but return to work or school also has an important role. Employment is important to the well-being of people and in enlarging their social environment. Chronically disabled persons have emphasized the importance of work for self-respect, giving meaning to life, and providing a stable income.³⁻⁵ In addition, the chronically disabled view their work more positively than nonimpaired persons, though they report more physical problems caused by their work environment.^{5,6} Verkleij⁷ found a positive relation between long-term unemployment and health problems. In his study patients who returned to work felt that it was a positive influence on their overall health.

Recognition of the importance of vocational rehabilitation is increasing and many job rehabilitation programs are being developed. Schmidt et al⁸ showed that there is a greater chance of return to work when patients with musculoskeletal diseases followed a job rehabilitation program. Before starting such a program for a population with a specific disease or disability, it is important to know the current employment status of the patients and the problems they experience in work or in finding work. The program should be adjusted to these specific problems. Some information has been published about the employment status of patients with neuromuscular diseases,^{5,6} multiple sclerosis,^{9,10} traumatic brain injury,^{11,12} spinal cord injury,^{13,14} and rheumatoid arthritis.^{15,16} These patients showed significantly lower job participation when compared with people without health problems. Until now, the employment status of patients with a lower limb amputation has been very unclear, with only a few articles having addressed their return to work or school. The most detailed study is of Millstein et al,¹⁷ in which the employment status of employees with an amputation of an arm or leg because of accidents at work is described. Ninety-three percent of patients with an arm amputation and 87% of patients with a leg amputation returned to work. However, 75% of the population changed occupational groups after amputation. The amputee patients returned to jobs that were less physically demanding, but required greater intellectual skills. Patients also reported reduced potential for salary increases and fewer opportunities for job promotion. Gerhards et al¹⁸ reported a significantly larger proportion of amputee patients who, compared with controls, had a lower occupational status after amputation. Despite this, they found no difference in vocational satisfaction between amputee patients and nonimpaired control subjects. In other studies, only the number of patients who returned to work are mentioned; other details are not given.¹⁹⁻²⁴ The percentage of amputee persons who return to work vary from 30 to 90% in these studies, which included patients with an amputation resulting from trauma.

Our purpose of this study is to describe the occupational situation at the time of the amputation and the current employment status of people with a leg amputation in the Netherlands. Current employment status is described with respect

to job participation, type of job, adjustments at the working place, and the person's position in the company. This study also compares the health experience of persons with amputations to a nonimpaired reference population, and the health experience of working and nonworking patients with amputations.

Within the framework of vocational rehabilitation, information about the following 4 groups of patients is important: people employed at the time of amputation who are with or without a job at present, people unemployed at the time of amputation who are with or without a job at present. In the last group, only the persons with an employment history were studied in detail.

Methods

Subjects

Patients met the following inclusion criteria: an acquired major amputation of the lower limb; at least two years since amputation; age 18 to 60 years; and living in the Netherlands. The time required since amputation was at least two years to ensure a stable situation in which the employment status could best be judged. Patients with severe cognitive problems or difficulties with the Dutch language who could not complete a questionnaire were excluded. The study was approved by the Medical Ethical Committee of the University Hospital Groningen.

We asked 49 orthopaedic workshops (almost all existing workshops) in the Netherlands to participate recruiting patients for the study. Twenty-five workshops had few or no amputee patients on file who met the inclusion criteria. For multiple reasons, 13 of the other 24 workshops could not participate. It is likely that some also did not have patients on file who met the inclusion criteria. Eleven workshops with qualified amputee patients sent those patients letters asking their permission to give their names and addresses to the Department of Rehabilitation of the University Hospital Groningen. Patients were asked to return a signed consent form. Of the total number of patients asked to participate, approximately 55% returned the signed consent. Researchers phoned the patients to verify the inclusion and exclusion criteria and their employment status. They were sent the questionnaire, if they met the criteria. Of 687 questionnaires mailed, 652 patients returned them (response 95%).

The study population consisted of 465 (71%) men and 187 (29%) women whose mean age was 44.5 years (range 18–60 yr). There were 328 patients with left-sided amputations, 298 with right-sided amputations, and 26 with bilateral amputations (total 678 amputations). Table 6.1 lists the patient characteristics.

Questionnaire

The questionnaire had 2 parts. In the first, the questions concerned patient characteristics and aspects related to the amputation (eg, side, level, reason, pain, use of prosthesis, and comorbidity). The second consisted of a questionnaire developed by the Netherlands Organization for Applied Scientific Research (TNO) Vocational Handicap Research Programme.^{25,26} Three versions of the questionnaire are available:

Table 6.1 Patient characteristics (n=652)

	mean	median	range
Age at amputation (yr)	25.1	22	0–57
Time since the amputation (yr)	19.6	19	2–59
	<i>n</i>	%	
Reason for amputation:			
Trauma	396	58.4	
Cancer	101	14.9	
Vascular	47	6.9	
Diabetes	30	4.4	
Other	100	14.7	
not given	4	0.6	
Level of amputation:			
Transfemoral	316	46.6	
Transfemoral	230	33.9	
Knee	80	11.8	
Hip	21	3.1	
Ankle	16	2.4	
Pelvis	12	1.8	
Not given	3	0.4	

Data include 652 patients with 678 amputations.

for people presently working (type 1); for those with previous work experience but who were not working anymore (type 2); and for those with no work experience (type 3). The differences among the 3 questionnaires are the number of (possible) questions on labor experience.

Job characteristics are explored, vocational handicaps are assessed by comparing job demands and patient/worker (dis)abilities, as well as adjustments at work. People were also asked for their opinion on working conditions and the social atmosphere at work. TNO validated the questionnaire in several other research projects^{25,26} and reported good reliability. To measure health status (psychological, physical, social, and overall well-being), a general health questionnaire was used (RAND-36, Dutch version). The RAND-36 is a short version of the RAND Health Insurance Study Questionnaire, and it is similar to the Medical Outcome Study Short Form Health

Survey.^{27,28} It measures health perception on 9 multi-item dimensions: physical functioning, social functioning, physical role restriction, emotional role restriction, mental health, vitality, pain, general health, and health change. A lower score on the RAND-36 means a worse health experience. The data of a reference population without health problems are available.²⁷ In this study, answers to the questionnaire concerning epidemiologic data about employment status as well as the RAND-36 were used.

Analysis

Statistics were performed using the SPSS statistical software.⁹ In most instances, absolute values and percentages are presented. The proportion of amputee patients presently working at different ages was compared with the total Dutch population by using the chi-square test. Differences in the RAND-36 scores were calculated by using the Student's *t*-test. The significance level was chosen as $\alpha = .05$.

Results

Employment status

Of the 652 respondents, 419 (64%) were working at the time of the study ("patients presently working"). Two hundred (31%) had work experience, but were not working at the time of the study ("patients with previous work experience"). The remaining 33 persons (5%) had never worked ("patients with no work experience"). Table 6.2 shows an overview of the current employment status in comparison with the employment status at the time of amputation.

Table 6.2 Current employment status and employment status at amputation

Current employment status	Employment status at the time of amputation			
	employed	unemployed	unknown	total
presently working	219 (a)	197 (d)	3	419 (h)
previous work experience	112 (b)	87(e)	1	200 (i)
no work experience		33 (f)	0	33 (j)
total	331 (c)	317 (g)	4	652 (k)

The data of 4 patients were incomplete.

We compared the job participation of patients with a lower limb amputation with the employment status of the Dutch population as a whole. Statistics Netherlands collects, interprets, and presents information about Dutch society. Figure 6.1 shows the job participation of amputee patients and the Dutch population

at different ages for men and women in 1998.²⁹ When we compared the distribution of working people in the amputee group with the distribution of working people in the Dutch population by using the chi-square test, we found no significant differences (men, $P \approx .1$; women: $P > .5$). Nevertheless, figure 6.1 shows a lower job participation of amputee patients at the age of 40 years and older; this was significant in men ($.01 < P < .02$), but not significant in women ($.10 < P < .50$).

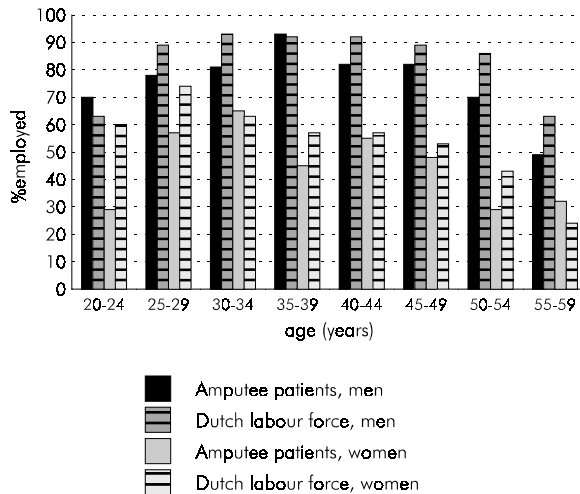


Fig 6.1 The percentage of job participation of amputee patients and the Dutch population at different ages for men and women.

Table 6.3 compares the job participation of people with other chronic diseases in the Netherlands. Most of the studies were performed by TNO.^{6,9} The subjects with an amputation seem to do very well when compared with subjects with neuromuscular disorders and multiple sclerosis.

In the following subsections, the 4 most important groups for vocational rehabilitation described earlier are studied in detail. They concern people employed at the time of amputation with (table 6.2 cell a) or without (table 6.2 cell b) a job at present, and people unemployed at the time of amputation with (table 6.2 cell d) or without a job at present, but with some employment history in the past (table 6.2 cell e). The 33 patients without any work experience were not studied in detail. Forty-six percent of this group were attending school or training at the time of the study.

Population employed at amputation and still working

Of the 331 persons working at the time of amputation, 219 (66%) were working at the time of the study. Thirty-six percent of these patients had a part-time job and 64% had a full-time job. The mean time from amputation to return to work for those patients was 2.3 yr (median 1 yr; range 0–21 yr). The type of work before and after

Table 6.3 The job participation of patients with different diagnoses in the Netherlands

Diagnosis	mean age (yr)	presently working	previous work experience	no work experience
Lower limb amputation (1998–1999)	44.5	64%	31%	5%
Neuromuscular disorders (1995–1996)*	44.0	41%	51%	8%
Multiple sclerosis (1996–1997)*	44.3	25%	69%	6%
Asthmatic bronchitis (1997–1998)*	33.1	70%	19%	11%

* Data from several studies of TNO.^{6,9}

the amputation is given in table 6.4. In this table the bold numbers show the number of patients with the same type of job before and after the amputation. It also shows in all categories the number of patients who went to another type of job after the amputation; it is apparent that after the amputation a shift is made to more administrative or scientific/technical work. Many patients with physically demanding work (agrarian, industrial, transport) changed to a job with fewer physical tasks. When asked if they had ever changed employment status because of the amputation, 33% of the patients answered yes. In addition, 44% said that the amputation was a consideration in choosing their present job. A comparison of these data with the Dutch population as a whole is difficult because Statistics Netherlands used a slightly different classification.²⁹ At the time of amputation, it appears that relatively more persons in the study group had an agrarian, trade, industrial, or transport job than did the general Dutch population. After the amputation, the types of jobs held by amputee persons were comparable with those of the general population.

Several studies have stressed the importance of adjustments in the workplace to enable persons with amputations to continue working. In our study, 95 (43%) patients who worked before and after the amputation mentioned modifications of their jobs as a factor in their continuing to work. Adjustments can be divided into 4 categories: changes in working time, getting aids, changes in workload, and other tasks or extra training. All patients could name adjustments that had been made. Most adjustments mentioned pertained to getting aids (31%) and changing the workload (31%). Despite many of these modifications, 59 (27%) of the people working before and after the amputation still wanted certain adjustments at the workplace. Modifications in workload were mentioned most.

Questions about the persons' position in the company concerned the relationship with colleagues and supervisors and possibilities for promotion. Twenty-seven percent said they were partially dependent on colleagues. Most colleagues (90%) and supervisors (88%) gave sufficient consideration to the person

Table 6.4 Type of job at amputation and the current type of job (n=216)*

Current type of job	Type of job at the time of amputation							total
	agrarian	industrial	transport	administrative	commercial	servicing	scientific/ technical	
agrarian	7	0	0	0	0	0	0	7
industrial	3	48	11	0	1	3	1	67
transport	1	5	17	0	1	0	1	25
administrative	2	10	3	16	4	7	2	44
commercial	2	10	3	1	8	0	1	25
servicing	0	6	0	1	2	9	0	18
scientific/technical	0	7	4	3	1	2	13	30
Total	15	86	38	21	17	21	18	216

Numbers in bold designate the number of patients with the same type of job at the time of amputation and at present.

* The data of 3 patients were incomplete.

with an amputation. Nevertheless, 31% of respondents gave a positive response to the question about the fewer possibilities for promotion. Apparently, patients considered their chances for promotion to be lower than those of their nonimpaired colleagues.

Population employed at amputation, but no longer working

One hundred twelve of the 331 patients (34%) with jobs at the time of amputation had stopped working. This group is especially important in the scope of rehabilitation. The mean time between the amputation and the end of work was 7.7 years (median 1 yr; range 0–40 yr). Of the 112 persons, 55% stopped working within the first two years after the amputation.

Sixty-six percent of the patients said that the challenges posed by their amputation was a factor in the decision to stop. In the group that ended its work within 2 years after amputation, the percentage was 78%. Other reasons for stopping were: marriage, pregnancy, children, removal; another disease or handicap; retirement. Thirty-four percent of the 112 patients thought that they would have worked longer had the right workplace adjustments been made. An adjustment in the workload was the change most preferred (34%). Although 58% of the 112 patients wanted to work again, of these persons, 44% thought they would not succeed in finding a job.

Population unemployed at amputation, but presently working

Of the 317 people with no job at the time of amputation, 197 (62%) had paid employment at the time of the study. Twenty-five percent of these patients had part-time jobs and 75% had full-time jobs. These persons needed to find work despite their amputation. Problems in finding work because of the amputation were experienced by 28% of the 197, and 24% had been unemployed against their wishes for a time - a situation in which the amputation may have been a factor. The amputations were a consideration in the choice of their present jobs by 79 (40%) patients.

One hundred fifty-two of the 197 amputees were still in school at the time of amputation (77%). Our hypothesis is that patients who undergo an amputation while they are still in school or study tend to make a choice for less physically demanding work. Table 6.5 presents the types of jobs these patients held. When we compared these data with data of patients working before and after the amputation (table 6.4), we saw the same pattern in employment status after the amputation, with many patients doing administrative or scientific and technical jobs.

In the group not working before amputation, 24% indicated that modifications had been made in the workplace and 17% wanted (more) modifications. The type of changes mostly concerned working time and adjustments in furniture, tools, or machines.

In this population, 18% of the people were dependent on colleagues. Satisfaction about the consideration of colleagues and supervisors was high (93% said that colleagues and supervisors gave sufficient consideration). Seventeen percent thought their possibilities for promotion to be lower than those of colleagues.

Table 6.5 Type of job after amputation of patients attending school at amputation (n=150)*

Job type	Patients with the type of work after amputation
Agrarian	2 (1.3%)
Trade or industrial	26 (17.3%)
Transport	9 (6.0%)
Administrative	29 (19.3%)
Commercial	13 (8.7%)
Servicing	21 (14.0%)
Other scientific or technical	50 (33.3%)

* data of 2 patients were incomplete.

Population unemployed at amputation, not working at time of study, but with work experience

This group of 87 people consisted of 2 subgroups. The first consisted of 46 people who began and ended their work before the amputation. This subgroup was not analyzed because their employment status seemed uninfluenced by amputation. The second subgroup consisted of 32 people who started and ended their work after the amputation (data were missing on the remaining 9 people). This population found a job despite their amputation, but stopped working before the study. Only 9 of the 32 persons said that the amputation was a factor in stopping their working career. This group was too small to study in detail.

Income source of people with amputation

The source of income was mentioned by 409 of the 416 people working at the time of the study (table 6.2, cell h). Seventy percent (286) of these patients had an income from work only, 94 (23%) had an income from work in combination with social insurance, and social insurance was the only source of income for 29 (7%). The social insurance was a disability insurance payment in nearly all cases.

Of the 199 patients with work experience but who were not working at the time of the study (table 6.2, cell i), 116 (58%) received disability insurance, 12 (6%) received unemployment insurance, and 36 (18%) received a combination of both. The remaining 34 people had no income from social insurances. Some in this group were already retired and others had a partner with a sufficient income.

Health experience of the amputee population related to employment status

The health experiences of the amputee population were measured with the RAND-36. Table 6.6 shows the scores of the patients compared with the reference group of persons aged 18 to 60 years. The amputee patients scored significantly lower

Table 6.6 Experienced health of amputee patients with different employment status as measured by using the RAND-36 questionnaire

	Physical functioning	Social functioning	Physical role restriction	Emotional role restriction	Mental health	Vitality	Pain	General health	Health change
Patients presently working	60.0* (26.0)	86.0 (19.8)	82.7 (31.4)	90.9* (24.5)	79.2† (15.0)	68.4 (18.2)	77.9† (21.7)	75.6 (18.7)	50.5† (16.5)
Patients with previous work experience	38.0* (25.9)	67.3* (28.9)	48.8* (40.2)	70.5* (41.6)	70.8* (20.4)	57.8* (22.5)	60.9* (29.5)	59.3* (27.2)	48.6† (22.0)
Patients with no work experience	54.0* (25.6)	78.1 (28.9)	73.2 (38.5)	82.1 (34.5)	75.2 (17.8)	65.5 (18.7)	74.1 (27.6)	78.5 (19.1)	56.1 (23.4)
All amputee patients	53.4* (27.7)	80.0* (24.8)	73.8* (37.1)	85.4 (31.3)	76.6 (17.2)	65.1† (20.2)	72.6* (25.8)	71.1† (22.7)	50.2* (18.8)
Reference population	86.2 (20.4)	86.6 (20.9)	81.4 (33.8)	84.4 (32.1)	76.8 (18.9)	68.1 (19.4)	82.7 (24.4)	74.2 (21.6)	53.7 (19.2)

Mean scores with standard deviation in brackets.

* Significant difference between score of the patient group and the reference population ($P < .001$).

† Significant difference between score of the patient group and the reference population ($P < .01$).

on the subscales of physical and social functioning, physical role restriction, vitality, pain, general health, and health change. However, the patients who were presently working scored lower than the reference population only on the subscores of physical functioning, pain, and health change. They scored significantly better on some subscales (emotional role restriction and mental health), though the differences were small. However, patients with work experience but who were not presently working scored significantly lower than the reference population on all subscales of the RAND-36. We compared the scores of the patients presently working with the patients who had stopped working and found that the latter group had significantly lower scores on all subscales of the RAND-36, except for health change.

Discussion

In interpreting our results, it is important to remember that the data were obtained through a self-report questionnaire that reflected the situation as experienced by the amputee patients themselves, often long after the amputation. Not all of the orthopedic workshops recruited patients, but the majority of the main workshops selected patients from their databases. Although a large number of patients participated in the study, a selection bias cannot be completely ruled out. The participants could be people with relatively positive experiences in (re)integration, as well as people with negative experiences who wanted to draw more attention to their problems. However, it is the largest sample ever studied and it provides a significant basis for further research into this topic. We excluded 14 people who had severe cognitive problems or who did not speak Dutch well enough to answer the questions. Although it was possible that patients with cognitive problems or Dutch language problems did not return the strip with a signed consent, it nevertheless is a small group compared with the group of participants.

In this study, we describe the occupational situation at the time of the amputation and the current employment status of people with leg amputations in the Netherlands, as well as the health experience of working and non-working amputee patients. In further research, more information will be obtained about the relation between demographically related, amputation-related, and job-related determinants of the job participation of people with leg amputations.

Employment status

In general, our study revealed good job participation of amputee patients. No significant difference could be shown in comparison with the Dutch population as a whole, though there was a decline in job participation when amputee patients were 40 years and older. In the older patients, ageing may negatively influence their physical limitations. The difference in job participation between amputees more than 40 years old and the total Dutch population above this age was significant for men, but not for women. This is explained by the smaller groups of women in each age category; sociodemographic factors may also play a role. In addition, the amputee patients showed higher job participation than people with multiple sclerosis⁹ or

neuromuscular disorders.^{5,6} Patients with traumatic brain injury,^{11,12} spinal cord injury,¹³ and rheumatoid arthritis¹⁶ also showed a lower return to work rate than did amputee patients. However, this last comparison was more difficult because the methods of the studies were not comparable. Millstein et al¹⁷ also reported a lower rate of unemployment of persons with amputations when compared with other disabled groups. An important difference between many of these diseases or disabilities and amputation is that an amputation is not a progressive disease. The symptoms are more circumscribed and adjustments can be effected more easily. Many patients can perform many of their activities almost normally when they wear their prostheses. Most patients were quite young at the time of the amputation and may have had many opportunities to adapt to the consequences of the amputation. We found a slightly higher job participation (64%) than Millstein¹⁷ (56%); this is explained by small differences in defining “employed” and “unemployed,” or by different demographic factors.

Population employed at amputation and still working

Of the patients with jobs at the time of the amputation, 66% returned to work and were still working. This rate is lower than that found by Millstein¹⁷ and Walker et al,²⁴ but higher than in the study by Livingston et al.²¹ The study population in Millstein’s research consisted only of patients with work-related injuries. The responsibility of employers may force them to do their best in organizing the return to work of their employees, giving a high proportion of return. A problem in our study was the long mean time of 19.6 years since the amputation. This could negatively influence the results because, during this long period, many events could have happened that caused the patient to stop working. Although these events could be related to the amputation, it may not be the amputation itself that caused the patient to quit the job.

In our subjects, the time between the amputation and return to work was long (mean 2.3 yr; median 1 yr). Livingston²¹ reported a mean time to return to work of 14 months, and in Hutchins’s study,²⁰ it ranged from 17 to 26 months. All studies indicated a long rehabilitation period, with important economic consequences. When people are not at work for a long period, they may lose contact and involvement with their work. Reasons for this long delay are not clear, but the change in the type of work after the amputation (table 6.4) may be a cause. Retraining may be necessary for many people - a possible explanation for the delay. Many patients indicated that they had changed employment because of the amputation and that their choice of their present job was influenced by the amputation. In the future, efforts should be made to reduce the time between amputation and return to work because of the importance of employment for patients’ well-being, as well as for economic reasons. Patients should start as soon as possible with part-time work on a trial basis and gradually resume a normal working week, as is discussed by Schmidt et al⁸ for patients with musculoskeletal impairments. The Dutch government is attempting to stimulate the return to work of people with a disease or disability by making employers partially responsible financially for their reintegration. However, the effect of this policy is still unclear.

The change to less physically demanding jobs after amputation has also been reported in earlier research.^{17-20,23,24} The amputation has a negative influence on the physical capacity of the patient. The effect of the amputation on the type of job during ageing may be even greater than in the Dutch general population because many patients had physically demanding jobs at the time of amputation.

Despite many adjustments in the workplace, almost 30% of the people wanted still more modifications. The most desired modification was a change in workload. It seems worthwhile to make a detailed inventory of necessary adjustments at the workplace in the rehabilitation program to prevent secondary problems indirectly related to the amputation.

The number of patients who judged their possibilities for promotion lower than their colleagues (31%) was very high. Millstein¹⁷ also mentioned this problem. Amputee persons obviously felt restrained in their development. In this study, the reason for this finding is not clear; it will be studied in further research.

Population employed at amputation, but no longer working

Many patients stopped working within 2 years after the amputation (55%) and 78% of these patients said that the amputation was a factor in their decision. Of the entire population who stopped working after an amputation, 66% said the amputation influenced their ending their work. These results stress the importance of early return to work in the rehabilitation process. Most patients mentioned physical disability as the major reason they could not remain on their jobs. In the group of people who stopped working many years after the amputation, ageing may have contributed additionally to their physical limitations. Re-evaluation of functional capacity when amputee persons become older may be necessary to prevent new problems in the workplace.

The importance of adjustments at work was also stressed by this population; 34% thought that they could have worked longer had certain modifications been made. Again, adjustments in their workload were most desired. It is possible, of course, that people were overestimating the importance of the amputation in their judgement about changes in the work organization. People without health problems also want changes in their work.

Population unemployed at amputation, but working

People without work at the time of amputation needed to find a job, and the amputation greatly influenced their choice of work. Few patients went to a physically demanding job; the majority worked in administrative, scientific, or technical jobs. The job pattern resembled that of the working situation for people who were already working before amputation. Twenty-five percent had problems in finding a job. The number of modifications of the workplace in this group was low compared with the group of patients with a job at the time of the amputation. This is explained by the fact that these patients considered the amputation in making their choice of work more than did patients who already had a job and attempted to return to that job. They may have taken jobs that did not require adjustments. The smaller number of people in this group who indicated fewer possibilities for promotion may also reflect

this selection. In rehabilitation programs, it is important to help these people obtain an adequate education or find a job and to give them information about their possibilities. The same information should be given to their teachers and potential employers.

Population unemployed at amputation, not working at time of study, but with work experience

Although the group of patients who began and ended their work after the amputation was too small to analyze, we believe that the difficulties in finding a job and the reasons for quitting work were the same as for the former groups.

Income source of people with amputation

In the Netherlands, a complex system of social insurance exists. For people with disabilities, the percentage of work disability is calculated on the basis of their present earning capacity. A person who is completely disabled receives disability insurance in an amount up to 70% of the income they earned on their last job. People who are partly or completely disabled always lose a part of their income (10 to 30%). In our study, 30% of all working people received additional income from disability insurance. Most of those who stopped working after the amputation received disability insurance equal to 70% of their last income from working.

Health experience of amputee patients related to employment status

The study's second aim was to compare the health experience of amputee patients with a healthy reference population, as well as the health experience of working amputee patients with non-working patients. All amputee patients had worse scores than the reference population on the physical functioning subscale of the RAND-36, which reflects the physical consequences of amputation. Conversely, there were great differences on the other subscales. Patients who were presently working showed a much better health experience in all domains than did unemployed patients with work experience. This confirms the importance of work for the well-being of people found by other researchers.^{3-5,7} Health experience seemed largely unaffected by the impairments; the consequences for social function seemed more important. Although this is a significant and important finding, from this cross-sectional study, we cannot conclude the bad health experience is the consequence or the cause of being unemployed. For clinical practice, the fact that patients who stopped working had the worst health experience is an important factor that should be remembered during rehabilitation. A prospective study is indicated to learn more about the relation between cause and consequence.

Conclusions

People with lower limb amputations in the Netherlands showed a relatively high job participation in comparison with people with other diseases or handicaps, as well as in comparison with the general population. After the amputation, most amputees

were working at jobs that were not physically demanding. Problems mentioned by the different groups of amputee patients mainly concerned the long delay between amputation and return to work, difficulty in finding a suitable job, fewer possibilities for promotion, and many problems with getting the right workplace adjustments, especially with people who stopped working within two years after the amputation. We confirmed the relevance of work for the feeling of well-being in amputee patients, shown by the differences in health experience on the RAND-36.

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CHAPTER 7

FACTORS RELATED TO SUCCESSFUL JOB REINTEGRATION OF PEOPLE WITH A LOWER LIMB AMPUTATION

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Abstract

Objective: To study demographically, amputation-, and employment-related factors that show a relationship to successful job reintegration of patients after lower limb amputation.

Design: Cross-sectional study.

Setting: University Hospital Groningen.

Patients: Subjects had an acquired unilateral major amputation of the lower limb at least 2 years before, were aged 18 to 60 years (mean 46 yr), and were living in the Netherlands. All 322 patients were working at the time of amputation and were recruited by the orthopaedic workshops.

Intervention: Questionnaires sent to subjects to self-report (1) demographic and amputation information and (2) job characteristics and readjustment postamputation. Questionnaire sent to rehabilitation specialists to assess physical workload.

Main outcome measures: Demographically related (age, gender); amputation-related (comorbidity; reason and level; problems with stump, pain, prosthesis use and problems, mobility, rehabilitation); and employment-related (education, physical workload); information about the success of job reintegration.

Results: Job reintegration was successful in 79% of the amputees and unsuccessful in 21% of the amputees. Age at the time of amputation, wearing comfort of the prosthesis, and education level were significant indicators of successful job reintegration. Subjects with physically demanding jobs who changed type of job before and after the amputation more often successfully returned to work than subjects who tried to stay at the same type of job.

Conclusions: Older patients with a low education level and problems with the wearing comfort of the prosthesis are a population at risk who require special attention during the rehabilitation process in order to return to work. Lowering the physical workload by changing to another type of work enhances the chance of successful reintegration.

Introduction

In patients between 18 and 60 years with an amputation of the lower limb, a major aim in rehabilitation is resumption of work. In general, employment is important to the well-being of people and in enlarging their social environment. Several studies¹⁻⁴ have shown the importance of return to work for chronically disabled people. Disabled people appreciated work even more than healthy people. Therefore, the relevance of vocational rehabilitation for chronically disabled people is stressed nowadays. Schmidt et al⁵ showed that participation in a job rehabilitation program in combination with working on a trial basis increased the chance of return to work of people with musculoskeletal impairments. This finding was confirmed by Sheikh⁶ for subjects with limb injuries and Wehman et al⁷ for subjects with traumatic brain injury.

It is important to find indicators related to successful return to work of people with a disability. Some general factors, such as age, gender, and education level, play a role in the job participation of the population without health problems as well as chronically disabled people. In subjects with a chronic disease, impairments and disabilities related to the specific disease also influence the success of job reintegration.^{2,8-13} Other aspects that were found to be related to successful return to work of disabled people were: health perception, the extent to which the workplace could be adjusted to the limitations presented by their disability, the type of work, and the expectations of the patients with respect to return to work.^{1,14-16}

Until now, knowledge about factors related to the job reintegration of amputee patients has been limited. One of the most detailed studies about this topic is that of Millstein et al.¹⁷ They studied the employment status of people with an amputation of the upper and lower extremities due to accidents at work. They found a high return to work (89%), but many people changed to less physically demanding jobs. In Millstein's study¹⁷ the following factors had a predictive value for the return to work: gender, age, amputation level, and stump or phantom pain of the affected limb. In a more general study, Gerhards et al¹⁸ studied the role of medical, social, and psychological variables in the rehabilitation of adults with a severe physical disability. A good social network, extroverted character, a high education level, and a short time between amputation and being fitted with a prosthesis seemed to play a role in successful vocational rehabilitation of amputees. In a smaller study by Livingston et al,¹⁹ of 42 patients with a traumatic amputation of the leg or arm, the return to work was strongly related to the amputation level.

In a study of 652 amputee patients, we recently showed relatively good job participation of lower limb amputees in the Netherlands in comparison with the general Dutch population.²⁰ However, patients older than 40 years of age showed a decline in job participation. Amputees showed a long delay in returning to work, problems with getting the right modifications of the workplace, and fewer promotion possibilities.

The purpose of the present research was to study demographically, amputation-, and employment-related factors that show a relationship to successful job reintegration of patients after a lower limb amputation. We hypothesized that

subjects who were successfully reintegrated were younger at the time of amputation, had less comorbidity, a lower amputation level, fewer problems with the stump or the prosthesis, a higher mobility level, a higher education level, and a less physically demanding job at the time of amputation than subjects who were not successfully reintegrated.

The present study is part of a larger study that concerns the employment status of amputee patients in the Netherlands. Other data have been presented elsewhere.²⁰

Methods

Subjects

Patients with an acquired unilateral major amputation of the lower limb, aged 18 to 60 years at the time of the study, and living in the Netherlands were included in the study. The time since amputation was at least 2 years to create a stable situation in which employment status could best be judged. All patients were working at the time of amputation. Patients with severe cognitive problems or difficulties with the Dutch language who could not fill in a questionnaire were excluded. The study was approved by the Medical Ethical Committee of the University Hospital Groningen.

We asked 49 orthopedic workshops (almost all existing workshops) in the Netherlands to participate in the recruitment of patients for the study. Twenty-five orthopedic workshops had no or very few amputee patients in their files who met the inclusion criteria. Of the other 24 workshops, 13 could not participate for a variety of reasons. It is likely that some of these workshops also did not have amputees in their files who met the inclusion criteria. Finally, 11 orthopedic workshops with amputee patients between 18 and 60 years old sent their patients a letter in which they asked consent to give their name and address to the Department of Rehabilitation of the University Hospital Groningen. Patients were asked to return a signed consent document. Of the total number of patients asked to participate by the orthopedic workshops, approximately 55% returned the consent document. The researchers telephoned the patients to verify the inclusion and exclusion criteria and to ask for their employment status. After the telephone calls a questionnaire was sent to the patients. The response rate to the questionnaire was 95%.

A total of 322 patients (262 men, 60 women; mean age 46 yr, range 22–60 yr) met the inclusion criteria of whom 170 had a left-sided and 152 a right-sided amputation. All patients possessed a prosthesis. Table 7.1 shows the patient characteristics.

Questionnaires

The self-report questionnaire with regard to amputation and employment status consisted of 2 parts. In the first part, the questions concerned demographically and amputation-related characteristics of patients (eg, age, gender, side, level, reason, pain, use of prosthesis, and comorbidity). The second part consisted of a questionnaire developed by the Netherlands Organization for Applied Scientific

Table 7.1 Patient characteristics (n=322)

	Mean	Median	Range
age at the time of amputation (yr)	30	27	14–57
time since the amputation (yr)	17	16	2–45
	<i>n</i>	%	
reason for amputation:			
trauma	217	67	
cancer	35	11	
vascular	27	8	
diabetes	8	3	
other	35	11	
level of amputation:			
transtibial	151	47	
transfemoral	106	33	
knee	37	12	
hip	12	4	
ankle	8	3	
pelvis	8	3	

Research (TNO) Vocational Handicap Research Program.^{21,22} In the questionnaire, job characteristics are explored, vocational handicaps are assessed by comparing job demands and patient/worker (dis)abilities as well as adjustments at work, and subjects are asked for their opinion on working conditions and the social atmosphere at work. TNO validated the questionnaire in several other research projects and reported good reliability of the test. We used the part concerning the success of job reintegration of those subjects working at the time of amputation.

We characterized the work at the time of amputation as either physically demanding or not physically demanding. We sent a questionnaire to rehabilitation specialists of a national working group for amputation and prosthetics in which they assessed the physical workload of the various job types for amputees on a visual analogue scale (VAS; range 0–10). The mean VAS-score by amputation level was taken as the physical workload of each type of job for amputees.

Definition of successful job reintegration

We defined the amputees as successfully reintegrated with respect to work if they were still working or had stopped working for reasons that were not related to the amputation (other disease or handicap, marriage or children, removal, retirement, dismissal). Amputees were not successfully reintegrated if they had stopped working because of consequences of the amputation.

Factors studied for their relationship to successful job reintegration

Based on literature and clinical experience with patients with a lower limb amputation, the following factors were studied for their relationship to the success of resumption of work after amputation.

Demographically related factors

These factors included age at the time of study, age at the time of amputation, and gender.

Amputation-related factors

These factors included comorbidity, amputation level, reason for amputation, skin problems of the stump, stump and phantom pain, use of prosthesis, wearing comfort of prosthesis, walking distance, mobility level, and type of rehabilitation. We dichotomized the following factors: comorbidity (yes vs no), amputation level (above the knee vs Syme-level amputation up to and including a knee disarticulation), skin problems (never vs sometimes/often), stump and phantom pain (none/little/moderate vs much/very much), use of prosthesis (<8 h/day vs ≥8 h/day), wearing comfort (bad/insufficient vs sufficient/good), and walking distance (<500 m vs ≥500 m). We distinguished 4 etiologic groups for amputation: trauma, cancer, vascular and/or diabetes mellitus, and other reasons.

The mobility level was scored as the number of mobility items (walking, sitting down and standing up from a chair, stooping and rising back up, keeping balance, making accurate movements with feet and legs, squatting and kneeling, walking stairs) for which patients reported restrictions. We discriminated among 3 types of rehabilitation after the amputation: none, outpatient, and clinical treatment.

Employment-related factors

These factors included education level and physical workload at the time of amputation. Education level was divided into lower, intermediate, and higher education. The physical workload was calculated as the mean VAS score by amputation level as viewed by rehabilitation specialists of a national working group for amputation and prosthetics.

Analysis

In the analysis, we distinguished both statistical significance and clinical relevance. Differences in the indicators between the successfully and the unsuccessfully reintegrated groups of patients were tested using univariate logistic regression analysis. The significance level was chosen as alpha equal to .05. Clinical relevance of the differences in the determinants between the groups was defined as a difference of 5 years or more in age and a difference of more than 10% in the other determinants. Of the mobility items, clinical relevance could not be clearly defined;

in this case, we only used statistical significance.

We used forward multivariate logistic regression to test the relevance and interaction of several indicators for successful job reintegration. Factors were tested in the multivariate logistic regression analysis if both the P-value in the univariate regression analysis was $\leq .05$ and the factors showed a clinically relevant difference between both groups.

We looked at how well the multivariate logistic regression model, with the independent variables included, correctly classified amputees who are at risk for failure to return to work successfully, in comparison with a model without any independent variables (prediction made by chance). This was expressed as the sensitivity and positive predictive value of the model. The sensitivity is the proportion of those with failed reintegration who were predicted not to reintegrate successfully. The positive predictive value is the proportion of those predicted not to reintegrate successfully who failed to reintegrate.

Statistics were performed using the Statistical Product and Service Solutions software.^a

Results

Indicators of successful job reintegration

Of the 322 amputees working at the time of amputation, 254 (79%) were successfully reintegrated (ie, still working, stopped working for reasons unrelated to amputation) and 68 (21%) had no successful job reintegration because they had to stop working as a consequence of the amputation (fig 7.1). Table 7.2 shows the comparison of successfully and unsuccessfully reintegrated amputees. Of the demographically related factors, only age at the time of amputation showed a statistically significant as well as a clinically relevant difference between the 2 groups. Age at the time of study was significantly different but showed no clinical relevance.

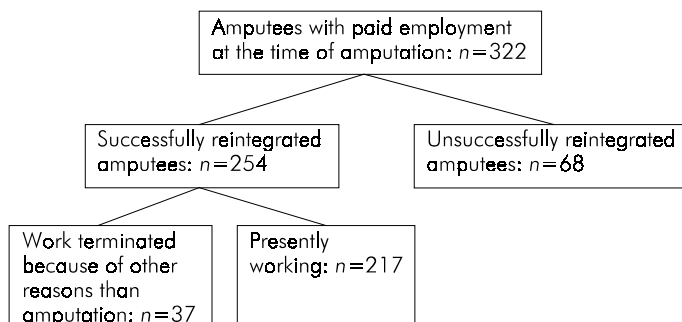


Fig 7.1 The different patient groups and the consequences of the amputation for the job situation

Table 7.2 Comparison of successfully and unsuccessfully reintegrated amputees using univariate logistic regression analyses

Factors	Successfully reintegrated (n=254)	Unsuccessfully reintegrated (n=68)	P
Demographically related factors			
age at the time of study: mean \pm SD*	46.0 \pm 9.0	49.9 \pm 8.7	.002
age at the time of amputation: mean \pm SD*	28.5 \pm 10.3	35.8 \pm 11.9	.000
gender: n(%)			.132
men	211 (83)	51 (75)	
women	43 (17)	17 (25)	
Amputation-related factors			
comorbidity: n(%)*			.039
no	148 (58)	30 (44)	
yes	106 (42)	38 (56)	
amputation level: n(%)			.865
knee-Syme	154 (61)	42 (62)	
pelvis-transfemoral	100 (39)	26 (38)	
reason for amputation: n(%)*			.000
trauma	179 (70)	38 (56)	
cancer	30 (12)	5 (7)	
vascular/diabetes	17 (7)	18 (27)	
other	28 (11)	7 (10)	
skin problems with stump: n(%)			.617
never	62 (25)	15 (22)	
sometimes, often	186 (75)	53 (78)	
phantom pain: n(%)*			.008
none, little, moderate	209 (84)	46 (70)	
much, very much	39 (16)	20 (30)	
stump pain: n(%)*			.011
none, little, moderate	208 (86)	46 (72)	
much, very much	35 (14)	18 (28)	
use of prosthesis: n(%)*			.001
<8 h/day	16 (6)	14 (21)	
\geq 8 h/day	236 (94)	54 (79)	
wearing comfort: n(%)*			.000
bad, insufficient	36 (14)	25 (38)	
sufficient, good	217 (86)	41 (62)	
walking distance: n(%)*			.000
<500 m	88 (35)	44 (67)	
\geq 500 m	160 (65)	22 (33)	

Factors	Successfully reintegrated (n=254)	Unsuccessfully reintegrated (n=68)	P
restrictions in mobility: mean \pm SD(median)*	2.9 \pm 2.2 (2)	4.1 \pm 2.1 (4)	.000
rehabilitation: n(%)			.600
none, other	34 (13)	6 (9)	
outpatient	126 (50)	35 (51)	
clinical	94 (37)	27 (40)	
Employment-related factors			
education level: n(%)*			.007
lower	118 (47)	47 (69)	
intermediate	101 (40)	16 (24)	
higher	34 (13)	5 (7)	
physical workload at the time of amputation: mean \pm SD	6.0 \pm 1.9	6.2 \pm 1.9	.601

* Statistical significance ($P < .05$).

Some questions were not answered by all subjects. By this reason, the numbers in the columns do not always equal $n=254$ or $n=68$.

Amputation-related factors that showed a statistically significant as well as clinically relevant difference between the 2 groups were comorbidity, reason for amputation, phantom pain, stump pain, use of prosthesis, wearing comfort of prosthesis, walking distance, and restrictions in mobility. Education level was the only work-related factor that showed an important difference.

The significant factors mentioned above were included in the forward multivariate logistic regression analysis. In this analysis 3 factors were significant indicators for successful job reintegration: age at the time of amputation, wearing comfort of the prosthesis, and education level. The sensitivity of the model with these 3 variables included is enlarged by the model from 0 to .16. The positive predictive value was enlarged from 0 to .53.

Relationship between change of job type and reintegration

Changing job type after the amputation is not the first aim in vocational rehabilitation. For this reason, it was not included in the multivariate regression analysis, and it is not an indicator of successful reintegration. However, we found a notable relationship of this aspect to job reintegration. We compared the job type of amputees at the moment of amputation with the job type after the amputation. One hundred forty-five amputees had a different kind of job after the amputation than before. Table 7.3 shows the relationship between a change of job and the success of reintegration. Of the subjects who changed their type of job, 131 (90%) were successfully reintegrated, in contrast with 117 (68%) of the subjects who remained at the same job type.

Table 7.3 Relationship between change of job type and success of job reintegration

Reintegration	Job type before-after amputation		
	No difference	Difference	Total
Successful	117	131	248*
Unsuccessful	54	14	68
Total	171	145	316*

* Data of 6 patients were missing.

Subjects with a very high physical workload at the time of amputation (mean VAS score ≥ 8) and no change in job type after the amputation successfully returned to work in 58% of cases. However, subjects with a very high physical workload who changed to another job after the amputation were successfully reintegrated in all cases. The mean decrease in physical workload in this group was 2.4 on the VAS scale. Subjects with a moderately high physical workload at the time of amputation ($6 \leq \text{VAS score} < 8$) returned to work successfully in 68% of cases if they did not change to other work after the amputation and in 82% of cases if they changed to another type of work. The mean decrease in the VAS score in physical workload of this last group was 1.5.

Subgroups of successfully reintegrated amputees

In the group of amputees with successful job reintegration, 2 subgroups could be distinguished (fig 7.1). One subgroup included 217 subjects who were still working at the time of the study. The other subgroup consisted of 37 subjects who stopped working because of reasons unrelated to the amputation. This group consisted of a relatively large percentage of women (41%). The following reasons were mentioned for ending their work: other disease or handicap ($n=10$); marriage, children, or moving ($n=8$); retirement ($n=5$); dismissal ($n=5$); and other ($n=9$). We compared the characteristics of the 2 subgroups with those of the subjects who stopped working because of the amputation. The small subgroup of subjects who stopped working due to some factor other than amputation mostly resembled the subjects who were still working at the time of the study. They only showed similarities with the group that stopped due to the amputation in the presence of comorbidity.

Discussion

We defined successfully reintegrated amputees as subjects who were still working or who had stopped working for reasons that were unrelated to the amputation. Because we used a self-report questionnaire, subjects decided for themselves what they considered to be the main reason for ending their work. It is possible that people with an amputation tend to overestimate the role of the

amputation in the necessity to stop working. Other factors might have played a role as well. In contrast, people who reported that they had stopped because of reasons other than the amputation might have underestimated the role of the amputation. For example, the combination of caring for children and a lower limb amputation may force people to decide to stop working. The influence of these effects could not be measured. Whatever influences may have played a role in the decision to stop working, the feelings and the opinions of the amputee remain important and must be taken into account. When we examined the group of amputees unemployed because of some factor other than amputation, we found that it mostly resembled the subjects who were still working at the time of the study. This confirms our choice to consider this group as successfully reintegrated people.

Some people worked several years after the amputation before they stopped because of the consequences of the amputation. The reintegration immediately after the amputation was possibly successful, but in the course of time the limitations caused by the amputation made it necessary to stop. In our study, we considered these patients as unsuccessfully reintegrated because the careers of these people were apparently negatively influenced by the amputation, perhaps in combination with ageing. In our previous research, we found that patients older than 40 showed a decline in job participation in comparison with the general Dutch population.²⁰

People who were working at the time of the study were scored as “successfully reintegrated”. However, it is possible that we considered some subjects to be successfully reintegrated who will likely end their work in the future because of the consequences of the amputation. This problem could not be avoided in our cross-sectional study. We do not expect it to be a great number of subjects because most patients had their amputation a long time ago (mean 16.8 yr), and the mean time between amputation and ending a job was 4.9 years.

In our study, all patients possessed a prosthesis. Although it is common practice that most amputees between 18 and 60 years will get a prosthesis in the Netherlands, it could also be a consequence of the recruitment procedure by the orthopedic workshops. It is possible that we missed amputees who were not able to get a prosthesis, and as a consequence were not known at the orthopedic workshops. This selection bias may cause a somewhat better reintegration in the study population than in the amputee population as a whole.

To compare differences between successfully and unsuccessfully reintegrated subjects, we did not use only statistical significance. In addition, we defined what we thought to be a clinically relevant difference between the several indicators. Almost no information is available on this topic. For this reason, the definition was mainly based on the clinical experience of the authors. More research is needed to find general definitions of clinically relevant differences between various symptoms related to different outcome measures.

Although in univariate logistic regression analysis many variables showed significant differences among the subjects with and without successful return to work, in multivariate logistic regression analysis the determinants of successful reintegration were age at the time of amputation, wearing comfort of the prosthesis, and education level. Although all amputees were relatively young at the time of amputation, the

difference between getting an amputation at a mean age of 28.5 years (successful) or at the mean age of 35.8 years (unsuccessful) seems very important for the return to work. The influence of age on the return to work was also found by Millstein et al.¹⁷

Of the amputation-related factors, wearing comfort of the prosthesis had the most important influence on successful return to work. Low wearing comfort can have many negative consequences for an amputee. It can cause more visits to an orthopedic workshop, it can negatively influence the walking pattern, and it can cause pain because of malalignment of the prosthesis and the stump. This finding stresses the importance of adequately fitting a prosthesis. It may be important to adjust the type of prosthesis to the requirements at the workplace; in current rehabilitation programs too little attention may be paid to this. In literature, this factor was not mentioned as a predictor of reintegration. This could be caused by the fact that the wearing comfort of the prosthesis was not considered in the analyses. Some effects that are described in other studies might have been caused by low wearing comfort.¹⁷⁻¹⁹ Interactions of amputation level and pain with wearing comfort are probable. In our study an overlap existed between the effects of wearing comfort and pain, but wearing comfort remained as the only significant indicator of successful job reintegration. It is likely that wearing comfort is a better indicator of reintegration than pain because many relevant amputation-related factors play a role in the wearing comfort of a prosthesis.

People with a lower education level were more at risk for failed return to work than people with a higher education level. People with a higher education level have more opportunities to control the scheduling of their work and to keep on working. Gerhards et al¹⁹ and Livingston et al¹⁸ both described the same phenomenon.

In the rehabilitation of amputees, it is important to be able to recognize people who are at risk for unsuccessful return to work. For this group of patients, specialized job rehabilitation programs may offer more possibilities to return to a suitable job. The model with the 3 variables included had an apparently higher sensitivity and predictive value of failure to return than without the variables included. However, an important part of the explanation of failure to return to work remains unclear. This part may be explained by the following reasons: the motivation of the amputee, his/her social situation, other job-related factors that were not measured in our study, and variations in the economic climate in the Netherlands during the last few decades.

A restriction of our study was the absence of questions about the psychosocial factors that might have played a role in the success of job reintegration. The reason for this restriction was twofold. First, it is very difficult to ask retrospectively for these factors at the time of amputation, because the memory is likely to fail after some years. Second, such additional questionnaires would have lowered the compliance in responding of the patients because the number of questionnaires would have been too great. We recommend testing the influence of these factors in future research on this topic. The chance of successful return to work after an amputation will partly depend on national employment patterns at that time. An interaction between the economic situation and the age at the time of amputation was possible. The exact influence of this interaction could not be studied in our research.

The fact that people who had a different type of job before and after the amputation were more often successfully returned to work was a remarkable finding. The possibility to change to another job seems especially important for amputees who had a job with a very high physical workload before their amputation. If these subjects changed to another job type after the amputation, the success percentage of job reintegration was 100%, whereas for subjects who still had the same job type the success rate was 58%. It is probable that this difference in percentage was largely caused by the relevant decrease in physical workload of 2.4 on the VAS scale. For subjects with a moderately high workload at the time of amputation, the influence of changing their job was less clear. Those with the same job type after the amputation successfully returned in 68% of cases, while those who changed jobs after the amputation successfully returned in 82% of cases. This can be partly explained by a decrease in physical workload (VAS score, 1.5), but possibly other factors may play a role as well.

In addition, it may sometimes be more difficult to adapt the “old” workplace to the limitations presented by the amputation than to start in a “new” fully adjusted job. This was also found in research by TNO²³ about the work of chronically disabled people in general. In that study, people who were reintegrated by a new employer had fewer work adjustments than people who returned to their old employer after a period of illness. Some other authors^{17,24,25} have also mentioned the transfer of many amputees to less physically demanding jobs after the amputation. The consequences for a rehabilitation program could be that it is important not only to look to adaptations in the work a patient was doing at the time of the amputation, but also to look for possibilities of changing to another job in an early phase of the rehabilitation process. Further research is needed to find explanations for this phenomenon.

Conclusions

Job reintegration was successful in 79% of the lower limb amputees and unsuccessful in 21% of the amputees. Successful job reintegration of subjects with a lower limb amputation was mainly determined by the age at the time of amputation, the education level, and the wearing comfort of the prosthesis. Older patients with a low education level and problems with the wearing comfort of the prosthesis are a population at risk who require special attention to return to work during the rehabilitation process. For many patients, it is advisable to change to another type of work instead of adapting their former work to enhance their chance of successful reintegration. Lowering the physical workload can contribute to a successful resumption of work.

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CHAPTER 8

JOB SATISFACTION AND HEALTH EXPERIENCE OF PEOPLE WITH A LOWER LIMB AMPUTATION IN COMPARISON WITH HEALTHY COLLEAGUES

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Abstract

Objectives: To describe indicators of job dissatisfaction among amputee employees and to compare job satisfaction and health experience of working amputee employees with that of control subjects.

Design: A cross-sectional study, mailed questionnaire.

Setting: Patients were recruited by the orthopedic workshops of the Netherlands.

Participants: One hundred forty-four patients who had an acquired unilateral major amputation of the lower limb at least 2 years before, were aged 18 to 60 years (mean age 43 yr), and were living and working in the Netherlands. One hundred forty-four control subjects matched for age, gender, and type of job.

Interventions: Not applicable.

Main outcome measures: Statistical analysis of responses to a questionnaire regarding patient characteristics and amputation-related factors, amputee patients' opinions about their work and the social atmosphere at work, and their general health (RAND-36-item Health Survey [RAND-36]).

Results: People with an amputation had greater job satisfaction (70%) than did the able-bodied control group (54%). The wish for (better) modifications in the workplace and the presence of comorbidity were significantly related to job dissatisfaction in people with limb loss. Amputee employees were less often hindered by the failures of others and by fluctuations in temperature. People with limb loss showed a worse physical health experience than controls on the RAND-36.

Conclusions: The vocational satisfaction of people with limb loss may be improved by better workplace modifications, depending on the functional capabilities of the person and the functional demands of the job; improvement may also be achieved by vocational rehabilitation programs, especially for those with an amputation in combination with other comorbidity. Despite experiencing more health problems, the amputee group expressed greater job satisfaction than the able-bodied group, reflecting a great appreciation of job reintegration by people with a lower limb amputation.

Introduction

In previous research,¹ we showed a relatively high job participation - ie, comparable with the general Dutch population - of amputee patients in the Netherlands. However, people with a lower limb amputation who were 40 years or older showed a decline in job participation. In general, job participation is important, but job satisfaction plays a role as well. In research of patients with several chronic diseases, many problems have been described that relate to insurance, reintegration after illness, fewer possibilities for promotion, more hindrances at the workplace, conflicts with colleagues, and threats of dismissal.²⁻⁷ Nevertheless, chronically disabled people emphasized the relevance of job reintegration for their self-respect. Despite the aforementioned problems and more physical restrictions in the workplace, people with a chronic disease or handicap tended to judge their work more favorable than healthy people.^{3,5,7} Job reintegration even positively influenced the health perception of these subjects.^{8,9}

In people between the ages of 18 and 60 years with a unilateral above-knee amputation because of war injury or accidents, Gerhards et al¹⁰ reported that amputee employees rated their job satisfaction higher than their controls despite the amputee employees' lower occupational status. Subjects who reported higher contentment with the current occupational status had enjoyed better social integration after the amputation. They described themselves as being rather extroverted and daring, and they had a higher educational level than subjects who were less content. In other literature on people with an amputation, less attention has been paid to job reintegration, vocational satisfaction, and problems at the workplace.

The first purpose of the present study was to describe demographic and amputation-related indicators of job dissatisfaction among amputee patients. The second purpose was to compare the job satisfaction and health experience of working people with limb loss in comparison with matched control subjects of the same gender, age, and kind of job. The present study is part of a larger study on the employment status of amputee patients in the Netherlands. Other data have been presented elsewhere.¹

Methods

Participants

Participants with a lower limb amputation

Persons who had an acquired unilateral major amputation of the lower limb, between the ages of 18 and 60 years at the time of the study, and were living in the Netherlands were included in the study. To create a stable situation for which the employment status could best be judged, time since amputation was at least 2 years. All patients were working at the time of the study. Patients with severe cognitive problems or difficulties with the Dutch language who could not fill out a questionnaire were excluded. The study was approved by the Medical Ethical

Committee of the University Hospital Groningen.

We asked 49 orthopedic workshops (almost all existing workshops) in the Netherlands to participate in the recruitment of patients for the study. Twenty-five orthopedic workshops had no or very few amputee patients in their files who met the inclusion criteria. These workshops dealt only with orthotics and not with prosthetics. Of the other 24 workshops, 13 could not participate for a variety of reasons. It is likely that some of these workshops also did not have subjects in their files who met the inclusion criteria. Finally, 11 orthopedic workshops in the Netherlands with amputee patients between 18 and 60 years sent their patients a letter in which they asked consent to give the patients' name and address to the Department of Rehabilitation of the University Hospital Groningen. Patients were asked to return a signed consent slip. Of the total number of patients asked to participate by the orthopedic workshops, approximately 55% returned the signed consent slips. Researchers telephoned the patients to check the inclusion and exclusion criteria and to ask about their employment status. After the telephone calls, a questionnaire was sent to the patients. Of the 687 patients who received a questionnaire 652 patients returned it, which is a response rate of 95%. In the present part of the study, we included only 413 respondents who were working at the time of the study. We asked respondents to recommend an able-bodied colleague who also would like to participate in the study. One hundred fifty-one subjects recommended a coworker as control subject. One hundred forty-four coworkers returned the questionnaire. So, in the present study, the data of 144 amputee subjects and 144 control subjects were used.

Control subjects

We asked all patients to search for a colleague within the company who was doing the same kind of job, was of the same gender and was about the same age. Precise instructions were sent along with the questionnaire. Participants with an amputation first informed their colleagues and requested consent to give their name and address to the researchers. Subsequently, a questionnaire was sent to the control subjects.

Questionnaires

The participants with an amputation received 2 questionnaires. The first questionnaire consisted of 2 sections. In the first section, the questions concerned patient characteristics and aspects related to the amputation such as side, level, reason, pain, use and wearing comfort of prosthesis, walking distance, and comorbidity. The second section consisted of a questionnaire developed by the TNO (Netherlands Organization for Applied Scientific Research) Vocational Handicap Research Program.^{7,11-13} In this questionnaire, job characteristics are explored and vocational handicaps are assessed by comparing job demands and amputee employee and coworker (dis)abilities, as well as adjustments at work. Subjects are also asked for their opinion on working conditions and the social atmosphere at work. TNO has validated the questionnaire in several other research projects^{7,11,12} and reported good reliability. In the present study, we used the sections related to the amputee employees' opinions about their work and the social atmosphere at work, and about

patient characteristics and amputation-related factors. The topics referring to job latitude, decision making, and demands are based on the Job Control/Job Demands Model¹⁴ and the Job Characteristics Model.¹⁵ Questions in this section of the questionnaire can be analyzed individually; they investigate 8 aspects of vocational satisfaction: job content, work organization, physical working conditions and safety, management and colleagues, physical and mental exertion, relationship between work and private life, appreciation and job perspective, and general judgement of the job.¹⁶ All questions have the answer categories yes or no, except for the last question about general judgement of the job. This latter question has 4 answer categories: good, reasonable, moderate and bad. This result was dichotomized into 2 categories: good job satisfaction or insufficient job satisfaction, the latter being a combination of the last 3 categories (reasonable, moderate and bad).

The second questionnaire was a general health questionnaire (RAND-36 Item Health Survey [RAND-36], Dutch version) for the measurement of health status (psychological, physical, social, overall well-being). The RAND-36 is a short version of the RAND Health Insurance Study Questionnaire and is similar to the Medical Outcomes Study 36-Item Short-form Health Survey.¹⁷⁻¹⁹ It measures health perception on 9 multi-item dimensions: physical functioning, social functioning, physical role restriction, emotional role restriction, mental health, vitality, pain, general health, and health change. A lower score on the RAND-36 means a worse health experience.

The control subjects received the same questionnaires, but the first questionnaire only consisted of the sections regarding opinions about their work, the social atmosphere at work, and subject characteristics. The RAND-36 was also sent to the control subjects.

Indicators of job dissatisfaction among amputee patients

Amputee participants were divided into 2 categories: those with good general job satisfaction and those with moderate, reasonable, or low job satisfaction (designated insufficient job satisfaction). Based on literature and clinical experience with persons who had a lower limb amputation, we studied the following factors for their relationship to job dissatisfaction of amputee participants.

Demographically related factors

These factors are age at the time of study, age at the time of amputation, gender, and education level. Education level was divided into lower, intermediate, and higher education.

Amputation-related factors

These factors are comorbidity, amputation level, stump and/or phantom pain, wearing comfort of prosthesis, walking distance, mobility level, job category at the time of study, number of restrictions in job tasks, modifications in the workplace, and wish for (more) modifications in the workplace.

We dichotomized the following factors: comorbidity (yes vs no), amputation level (above-knee vs Syme's amputation up to and including a knee disarticulation), stump and/or phantom pain (severe vs mild), wearing comfort (bad/insufficient vs sufficient/good), and walking distance (<500 m vs ≥500 m). The mobility level was

scored as the number of mobility items (walking, sitting down and standing up from a chair, stooping and rising back up, keeping balance, making accurate movements with feet and legs, squatting and kneeling, walking stairs) for which patients reported restrictions. Seven job categories could be distinguished: agrarian, trade or industrial, transport, administrative, commercial, servicing, and other scientific or technical. Restrictions in job tasks were calculated by comparing problems of patients in several activities of daily living with problems in comparable tasks within their job. TNO has defined 4 categories: (1) no difficulty with a certain job task, ie, the job task does not relate to an activity that causes a problem in daily living; (2) normal difficulty with a certain job task, ie, someone has no difficulty with the task in daily living, but experiences difficulty with the task at work (employees without a handicap will have difficulties with the task as well); (3) adjusted job task, ie, someone has to do an activity at work, that, in daily living, creates difficulties but he does not mention problems with the task at work; (4) insufficiently adjusted job task, ie, someone has difficulties with doing a certain activity in daily living and experiences difficulties with the comparable activity at the workplace. This was defined as a restriction in job tasks. The number of restrictions was included in the analysis.

Patients also reported whether modifications had been made in their workplace and whether they would like to make (more) adjustments to adapt their workplace to the limitations of their amputation.

Analysis

Statistics were performed using the Statistical Product and Service Solutions software.^a For the most part, percentages are presented. Differences in the indicators between satisfied and dissatisfied subjects with limb loss were tested by using univariate logistic regression analysis (significance level $\alpha = .05$). We used forward multivariate logistic regression to test the relationship of several indicators with the job dissatisfaction of amputee patients. Factors were tested in this analysis if the P-value of the univariate regression analysis was $\leq .10$.

We looked at how accurately the multivariate logistic regression model which included the independent variables, classified amputee employees at risk for insufficient job satisfaction, compared with a model that had no independent variables (prediction made by chance). This result was expressed as the sensitivity and positive predictive value of the model. The sensitivity is the proportion of those with insufficient job satisfaction who are predicted to have an insufficient job satisfaction. The positive predictive value is the proportion of participants predicted to have an insufficient job satisfaction who indeed reported being insufficiently satisfied with their workplace.

Differences between amputee employees and controls in the section on subjects' opinions about their work and the social atmosphere at work were calculated by using the McNemar test for matched pairs. If statistical significance was reached ($\alpha = .05$), we defined differences in item scores as clinically relevant if they were at least 5%. Differences in the scores of the RAND-36 were calculated by using the paired *t*-test ($\alpha = .05$).

Results

Matching procedure and representativeness

Table 8.1 shows that the matching procedure was executed successfully by the amputee participants. No relevant differences could be shown in gender, age, or type of job between amputee and control subjects. A difference existed between the education level of both groups, but this was not a criterion for matching.

In the present study, we only analyzed the data of the 144 amputee employees who met the inclusion criteria and who could be compared with matched, able-bodied control subjects. We checked the representativeness of this selected group of 144 amputees for the whole group of 413 working amputee patients that returned the questionnaire. No differences could be shown, except for the participants' somewhat higher education level. In all other aspects, the sample with a matched control was representative of the entire sample of amputees who returned the questionnaire.

Indicators of job dissatisfaction among amputee participants

Seventy percent of the subjects with a lower limb amputation judged their work life as good and 30% judged it unsatisfactory. Table 8.2 shows the relationship between job dissatisfaction and demographic and amputation-related factors. Three factors had a statistically significant relation with job dissatisfaction: comorbidity, mobility level, and the wish for more modifications in the workplace. These significant factors were included in the forward multivariate regression analysis. A fourth factor, the number of restrictions in job tasks, was added. Its P-value was less than .10 in the relation with job dissatisfaction. With the multivariate analysis, we found 2 factors that were significant indicators of general job dissatisfaction: the wish for (better) modifications in the workplace and the presence of comorbidity.

The sensitivity of the model - with the 2 variables included - increased from 0 to .18. The positive predictive value increased from 0 to .64.

Job characteristics and job history of amputee participants and control subjects

The number of hours worked weekly was comparable in people with (37.5 h/wk) and without (39.3 h/wk) limb loss. Most subjects had full time employment (in the Netherlands, full time is 36–40 h/wk). No relevant differences existed in the job history of subjects with and without an amputation with respect to how long they had been working at their present job (12.5 yr for amputees, 10.5 yr for controls), the number of employers that subjects had had (mean 3 for both amputee participants and controls), and the percentage who had received supplementary education during their career (71% for both amputee participants and controls). In addition, we asked whether subjects had ever been unemployed against their wishes. Twenty percent of the amputee participants answered this question affirmatively, compared with 15% of the control subjects. In the type of work done by the subjects in the past, only small differences existed between both groups. Forty-two percent of the amputee participants and 39% of the controls had done physically strenuous work; mentally demanding work had been done by 62% of the amputee participants and 58% of the

control subjects.

Table 8.1 Characteristics of control subjects, amputee employees of the defined study group, and all working amputees in the full cohort

	control subjects (n=144)	amputee employees with control subject (n=144)	all working amputee patients (n=413)
age: mean \pm SD (yr)	41.0 \pm 8.3	42.6 \pm 8.4	43.3 \pm 9.5
men (%)	76	78	81
present type of job (%)			
agrarian	2	1	3
trade or industrial	20	21	24
transport	10	8	9
administrative	17	22	20
commercial	10	9	10
servicing	7	9	11
other scientific/technical	33	29	23
education level (%)			
low	15	26	34
intermediate	48	38	41
high	37	37	25
age at time of amputation: mean \pm SD (yr)		21.4 \pm 10.5	22.0 \pm 11.0
reason amputation (%)			
trauma		66	69
cancer		15	15
vascular		4	3
diabetes		0	1
other		15	13
amputation level (%)			
transtibial		49	48
transfemoral		35	34
knee		12	11
hip		3	3
pelvis		1	2
ankle		0	2

Table 8.2 Relation between demographic and amputation-related factors and job dissatisfaction in the amputee employee group

Variables	Job satisfaction good (n=102)	Job satisfaction insufficient (n=42)
age at the time of the study: mean \pm SD (yr)	42.3 \pm 7.9	43.1 \pm 9.5
men (%)	78	76
age at time of amputation: mean \pm SD (yr)	21.9 \pm 10.0	20.1 \pm 11.6
education level (%)		
low	24	31
intermediate	39	33
high	37	36
comorbidity present (%)	28	50*
knee and lower level of amputation (%)	62	57
severe phantom and/or stump pain (%)	16	18
bad/insufficient wearing comfort (%)	6	12
walking distance <500 m (%)	18	24
mobility level: mean \pm SD	2.1 \pm 1.9	3.1 \pm 2.2*
type of job at the moment (%)		
agrarian	1	2
trade/industrial	24	14
transport	6	12
administrative	21	26
commercial	10	7
servicing	8	12
other scientific/technical	31	26
no. of restrictions in job tasks: mean \pm SD	0.9 \pm 2.0	1.7 \pm 2.8
modifications in the workplace (%)	25	35
wish for (more) modifications in the workplace (%)	10	30*

Relations were derived by univariate logistic regression analysis.

* Significant relationship ($P < .05$).

Job satisfaction of amputee participants in comparison with controls

Thirty percent of the subjects with an amputation and 46% of the controls judged their work as unsatisfactory. This difference was statistically significant ($P = .003$). Table 8.3 shows the item scores of the section of the questionnaire that addressed perceptions about working conditions and the social atmosphere at work. Apart from the difference in general vocational satisfaction, significant differences between amputees and controls existed on the items “often hindered by failures of others” and

“much hindrance due to fluctuations in temperature”. Amputee participants scored significantly better on both items than control subjects. The differences were also clinically significant.

On the 31 items, 58% of the amputee participants had 5 complaints or fewer, and 42% had more than 5 complaints. Forty-four percent of the control subjects had 5 complaints or fewer and 66% had more than 5 complaints.

Table 8.3 Percentages of negative judgements on working conditions and social atmosphere at work of amputee participants and controls

	Amputees (n=144)	Controls (n=144)
General job judgement insufficient (%)	30	46*
Job content (%)		
insufficient education for job	8	9
insufficient variability in job	7	6
work is mostly uninteresting	10	13
mostly no pleasure in work	5	7
work too simple	9	13
Physical and mental exertion (%)		
work physically very demanding	19	15
work mentally very demanding	75	69
often working under time pressure	62	66
work often too tiring	14	20
often problems with tempo/busyness	11	13
should go easy on work	31	24
Work organization (%)		
work in general not well organized	23	30
insufficient consultation with others	11	7
often hindered by unexpected situations	28	35
often hindered by failures of others	18	38*
often hindered by absence of others	19	18

	Amputees (n=144)	Controls (n=144)
Management and colleagues (%)		
bad internal atmosphere at work	11	13
often annoyed about others	19	24
insufficient daily supervision	28	38
supervisor has a bad image of your work	22	31
supervisor does not take your opinion into account sufficiently	23	27
Relationship work-private life (%)		
unfavorable influence of work on private life	16	26
Appreciation and job perspective (%)		
insufficient appreciation in the firm	16	22
insufficient payment for this job	31	40
bad job prospects in this job	24	34
Physical working conditions and safety (%)		
much hindrance because of temperature fluctuations	11	21*
much hindrance because of dry air	15	18
much hindrance because of lack of fresh air	19	24
much hindrance because of noise	8	11
much hindrance because of stench	2	4
safety at work insufficient	6	6

* Significant difference $P < .05$ tested with the McNemar test (only data of complete pairs are mentioned).

Health experience of amputee participants and controls

Table 8.4 shows the score results on the RAND-36 for subjects with and without limb loss. Significant differences were shown on the subscales of physical functioning, physical role restrictions, and pain. All other subscales showed comparable scores for amputee participants and controls. On the subscale physical functioning, amputee participants scored worse on all items. The difference on the subscale physical role restrictions was mainly explained by amputee participants having a worse score on the items about restrictions and difficulties in work and recreational activities. On the subscale pain, amputee participants showed mild complaints of pain more often than controls and were mildly restricted by the pain

more often.

Table 8.4 Health experience of amputee patients (n=144) in comparison with healthy control subjects (n=144) as measured using the RAND-36: mean \pm standard deviation

RAND-36	amputee participants	control subjects
Physical functioning	62.6 \pm 25.0	95.0 \pm 16.4*
Social functioning	86.6 \pm 19.7	89.6 \pm 16.1
Physical role restriction	86.0 \pm 28.6	94.3 \pm 17.1*
Emotional role restriction	92.0 \pm 22.4	93.8 \pm 19.4
Mental health	80.1 \pm 15.3	80.2 \pm 13.9
Vitality	69.0 \pm 18.2	69.2 \pm 16.5
Pain	80.4 \pm 20.1	91.3 \pm 14.6*
General Health	76.5 \pm 17.3	76.6 \pm 16.2
Health change	52.3 \pm 17.0	50.4 \pm 13.9

* statistically significant difference $P < .05$ between amputee patients and their control subjects.

Discussion

All data were obtained by self-report questionnaires. They reflect the personal judgements of amputee participants and healthy colleagues regarding their work environment and their health experience. In the present study, we did not ask the employers for their opinions about the work capacity of both groups. From research done by TNO, we know that employers often judge chronically disabled people more negatively than their healthy colleagues.²⁰

The matching procedure was done by the amputee participants themselves. Matching for age, gender and type of job was executed correctly. Other sources of selection bias of control subjects cannot be completely ruled out. In our research, however, this matching procedure was the only opportunity to form a control population with the same type of job diversity as the amputee population. For example, all reference data¹⁶ about the questions concerning subjects' opinion of their work and the social atmosphere at work were available only for specialized groups of working people within one specialized branch of work.

Only a portion of the amputee respondents proposed a healthy colleague to participate in the study (144/413). Because this portion of the amputee participants did not differ from the whole group of working amputee participants who returned the questionnaire, except for education level, bias seems unlikely.

Job satisfaction of amputee participants was good in 70% of cases. A

relationship was shown between job satisfaction and the wish to adjust the workplace (better) to the limitations presented by the amputation and the presence of comorbidity. The model with the 2 variables included had an apparently higher sensitivity and predictive value of insufficient job satisfaction than that without the 2 variables included.

These findings can influence the reintegration policy of people with a lower limb amputation. Rehabilitation specialists have a responsibility to help patients attain a good, functional, job reintegration. In previous research,¹ we showed that many amputee employees (27%) would like their work to be (better) adjusted to the limitations of their amputation. The relationship between insufficient modifications in the workplace and job dissatisfaction again emphasizes the importance of paying attention to adjustments in the workplace in the process of reintegration. Rehabilitation specialists, together with the amputee patient, should make a detailed inventory of the patient's functional capabilities. This should be compared with the functional demands of the job the person is doing or would like to do. The necessary modifications should be made as soon as possible in the reintegration process to prevent delay in returning to work. After some time, the working situation and job satisfaction of the person with limb loss should be evaluated, and the modifications should be adjusted to a possibly changing situation. As an employee with an amputation ages, more physical problems can develop,¹ and more modifications might be needed. As we showed in former research¹ and as is stated by Yelin,²¹ not only material modifications are important. For disabled people, the ability to control the pace and scheduling of work activities is even more important than it is for able-bodied people. We will study this aspect in further research.

Subjects with an amputation in combination with other comorbidity are at risk of having lower job satisfaction. Additional attention should be paid to the working situation of this group of people. Specialized vocational rehabilitation programs might be needed for patients with multiple problems. In these programs individual reintegration routing is important, and disabled people should be supervised from amputation to resumption of work as well as after their return to work. A better cooperation between rehabilitation specialists and company doctors is necessary. In addition, rehabilitation specialists may focus too much on the amputation, and pay too less attention to other diseases and disabilities. Our research shows that treating comorbidity may be important for a successful job reintegration with good job satisfaction.

Despite our results, an important part of the reason for job dissatisfaction remains unclear. This part may be explained by other factors eg, the motivation of the amputee employee, autonomy in the workplace, job control, and relationships with colleagues.²¹ These should be studied in further research.

To compare job satisfaction between subjects with and without limb loss, we used more than statistical significance. We defined what we thought to be a clinically relevant difference between both groups. Because almost no information is available on this topic, the definition was based mainly on the authors' clinical experience. More research is needed to find general definitions of clinically relevant differences for aspects related to different outcome measures.

We found no relevant differences in job characteristics and job history between subjects with and without an amputation. People with an amputation showed greater job satisfaction (70%) than did the able-bodied control group (54%). The better general job satisfaction of subjects with a lower limb amputation existed despite their worse health experience compared with controls, especially on the physical subscales of the RAND-36. Higher job satisfaction despite a worse health experience was also found in previous studies of other chronically disabled people.⁷ Gerhards et al¹⁰ also found higher job contentment in people with an amputation than healthy people despite lower occupational status. A good explanation for this phenomenon is difficult to find, but two factors may be important.

In the first place, a person who has an amputation experiences being at work as valuable, and this perception may positively influence opinions about the working situation. Employees with an amputation might even be less critical toward their working conditions than their healthy colleagues.

In the second place, when we examined whether multiple working conditions could explain the difference in job satisfaction between amputee patients and healthy colleagues, we found very few differences between the groups (see table 8.3). Amputee employees reported fewer hindrances caused by the failures of others and they had fewer hindrances from temperature fluctuations in the workplace. On all other items, no differences were significant, although this was approximated on the items insufficient daily supervision, supervisor has a bad image of your work, and unfavorable influence of work on private life. Apparently, other person- or work-related aspects might play a role to be studied in future. For example, the factors autonomy and ability to control work scheduling were only marginally represented in the questionnaire and may be important in the explanation of job satisfaction. We do not know any other study in which multiple working conditions were studied in relationship with job satisfaction of amputee employees and healthy colleagues.

The number of people who reported complaints differed between the 2 groups. In the amputee group, the number of complaints per subject (58%, 5 or less) was less than the number of complaints per subject in the control group (44%, 5 or less). This means that in the amputee group many people expressed few complaints, whereas in the control group fewer subjects complained, but they had more complaints each. Evidently, a great portion of our amputee subjects has some problems in their job, and more detailed information is necessary to know how these problems can be solved.

Conclusion

Indicators of job dissatisfaction of people with a lower limb amputation are (1) the wish for (better) modifications in the workplace and (2) comorbidity. The rehabilitation specialist and the patient have to work together early in the reintegration process to adjust the functional capabilities of an individual better to the functional demands of the job to obtain optimal job satisfaction. Specialized

vocational rehabilitation programs can benefit those persons who have an amputation in combination with other disabilities.

Despite a worse physical health experience, people with limb loss tend to be more content with their current occupational status than their healthy colleagues. This reflects their appreciation of job reintegration. However, many amputee patients report some problems with their working conditions. These problems may be alleviated if more information becomes available about factors that explain the difference in job satisfaction between people with and without limb loss.

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- a. SPSS, Inc, 233 S Wacker Dr, 11th Fl, Chicago, IL 60606.

CHAPTER 9

GENERAL DISCUSSION AND CONCLUSIONS

General discussion

As mentioned in the introduction, the interaction between many physical, mental, and social characteristics on functional outcome was unclear before the start of this study. In the present research, we have clarified some of the relationships. The functional outcome of elderly amputee patients mainly concerns activities of daily living, whereas for younger patients job participation also plays an important role. The basic model of functional outcome (chapter 1, figure 1.1) should contain more details so that rehabilitation specialists can use it in the treatment of amputee patients. In this general discussion, we will mainly examine the clinical implications of our research while giving advice for the management of the rehabilitation of amputee patients. In addition, advice for further research about the different topics is given.

In the first part of the thesis, we studied the functioning of elderly amputee patients. The Timed “up & go” test (TUGT) turned out to be a useful test for the functional mobility of patients over 60 years of age with a leg amputation and walking ability. Further research needs to be done on the sensitivity of the test for clinical changes. If this is sufficient, the test may also be used for testing the effects of different therapies and changes of the prosthesis on functional mobility. The disadvantage of the test is the restriction of use for only those amputee patients with a walking ability of at least 6 meters. Patients with a leg amputation who function in a wheelchair are not able to perform the test.

In general, the functional level of elderly patients with an amputation caused by vascular disease was low. Patients have restricted mobility and many problems with daily activities and recreational activities. The low functional level of patients exists despite long rehabilitation periods lasting a few months to more than six months. Research is necessary to develop rehabilitation programs that can increase the functional possibilities of patients with a lower limb amputation and efforts should be made to shorten the rehabilitation period, also with respect to the restricted life expectancy of these patients.¹⁻⁷

In the study about the prediction of functional outcome, one remarkable and important finding was the relevance of one-leg balance on the unaffected limb two weeks after amputation. The ability to stand on the unaffected limb was an important predictor for functional prosthetic use as well as for more general measurements of functional outcome, such as the TUGT and the questionnaires used in this study (the SIP68 and the GARS). When we consider one-leg balance (OLB) as a diagnostic test, it is possible to compute the sensitivity, the specificity, the positive predictive value, and the negative predictive value. People not able to stand on the unaffected limb without support are considered as having a positive test result and people able to stand without support a negative test result. A score on the SIP68, the GARS, and the TUGT above the mean is considered a bad functional outcome, whereas a score below the mean is considered as good functional outcome (tables 9.1a and 9.1b). Table 9.1b shows high sensitivity, specificity and predictive values for most functional outcome measures, except for the TUGT. This may be caused by the low number of

Table 9.1a Prediction of functional outcome by one-leg balance

One-leg balance	SIP68		GARS		TUGT		Prosthetic use	
	good score	bad score	good score	bad score	good score	bad score	functional	non-functional
not possible without support	4	17	5	16	2	4	5	16
possible without support	15	1	13	3	8	4	13	3
Total	19	18	18	19	10	8	18	19

Table 9.1b Sensitivity, specificity, and predictive value of one-leg balance (OLB)

	SIP68		GARS		TUGT		Prosthetic use	
	sensitivity	specificity	positive predictive value	negative predictive value	sensitivity	specificity	positive predictive value	negative predictive value
sensitivity OLB	.94		.84		.50		.84	
specificity OLB		.79		.72		.80		.72
positive predictive value OLB		.81		.76		.67		.76
negative predictive value OLB		.94		.81		.67		.81

participants in the study able to perform the TUGT. In amputee patients, one-leg balance on the unaffected limb shortly after the amputation seems an important predictor for functional outcome, and is an easy test to perform in clinical practice. Balance before the amputation may play an additional role in predicting the functioning. To gain an impression of pre-amputation balance, the Activities-Specific Balance Confidence (ABC) Scale may be the instrument of choice. It is a questionnaire developed to detect loss of balancing confidence in elderly people.^{8,9} In future research the additional value of this test should be studied.

Other important predictors for functional outcome were memory and mood disturbances, the latter mainly some time after the amputation. We measured memory function with the 15-Word Test. Although this test did not need sophisticated instruments and is adequate for research purposes, it is not easy to apply in a clinical setting in a hospital where there is too much noise or distraction by other patients or personnel. It may also take too much time. An alternative test to be studied in future to get an impression of memory function that is easy to apply is the Seven Pictures Test.¹⁰ Mood disturbances were measured with the Beck Depression Inventory. Although this test is used in many studies, we found it difficult to apply to patients just after surgery. It is a relatively long questionnaire, very confrontational for patients who have just lost a limb, and not easy to read for patients with vision disturbances. A good alternative for this test may be the Hospital Anxiety and Depression Scale, a questionnaire specifically designed to use in a hospital setting.¹¹⁻¹³ It consists of 14 short questions with simple answer categories that can also be read by the researcher to the patient.

In our study it was not possible to measure the functional abilities of the patients before their amputation. In other studies,^{14,15} premorbid functioning seemed to play a role in predicting functional outcome. We think that the functional history of the patient is important for determining functional outcome and must be taken into account when a functional prediction is made about an individual patient. Serious comorbidity will also influence the opinion about the future function.

In further research, the above-mentioned tests should be prospectively studied to prove the value of prediction for the functional outcome of lower limb amputees. At this moment we recommend performing the following measurements when trying to predict functional outcome soon after a lower amputation by vascular disease in elderly patients:

1. Functional history pre-amputation
2. Activities-Specific Balance Confidence Scale for pre-amputation balance problems
3. One-leg standing balance on the unaffected leg 2 weeks post-amputation
4. Hospital Anxiety and Depression Scale for detection of severe mood disturbances post-amputation
5. Seven Pictures Test for a global impression of memory post-amputation

The model of functional outcome including the above-mentioned factors is reproduced in figure 9.1.

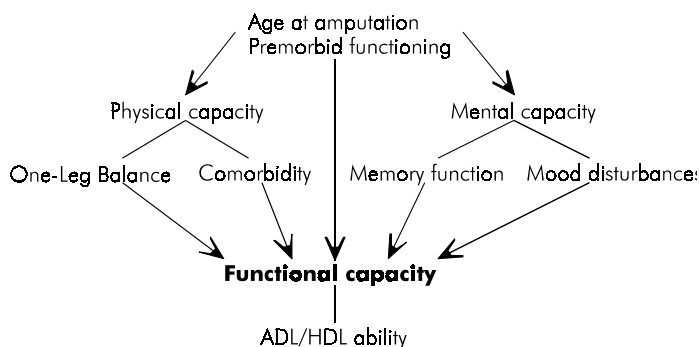


Figure 9.1 Functional outcome of elderly amputee patients and related factors

The International Classification of Functioning and Disability (ICIDH-2) describes the relationship between body functions and structures, activities, and participation, influenced by environmental and personal factors.¹⁶ We studied the relationship between impairments after a unilateral amputation and the level of activities and participation in patients who had functioned with their amputation for one year. The relatively low level of activities and participation of the patients was mainly related to diabetes mellitus, cognitive impairment, mood disturbances, and standing balance on the unaffected limb. This finding was in accordance with our previous results of predictors of functional outcome. It underlines the importance of one-leg balance and cognitive impairment for the functional abilities of leg amputee patients. Apparently, the relationship between certain impairments and functional outcome remains globally the same during the first year after amputation.

In the second part of the thesis, we concentrated on the employment status of young amputee patients. The importance of job participation for people with a lower limb amputation is demonstrated in this thesis. In the first place, we showed a significantly better health perception for working as compared to non-working amputee patients. In the second place, we showed that the job satisfaction of amputee patients was better than that of healthy colleagues. Vocational participation is possible for subjects with a leg amputation, as reflected by the fairly good job participation of these patients in the Netherlands. However, certain aims may be set for the vocational rehabilitation of amputee patients to improve several difficulties with job (re)integration.

Amputee patients over 40 years of age more often withdraw from the labor market than their healthy colleagues. The balance between functional abilities and functional demands in amputee patients seems less stable than in the general Dutch labor force. The combination of the process of ageing and having a leg amputation requires adaptations in the workplace to enable the subject to continue working. Follow-up of patients and repeated adaptation of the job demands may be necessary

to prevent the withdrawal from the labor market of older amputee patients.

Another aim in vocational rehabilitation should be a decrease in the time elapsed from amputation to resumption of work. This is important both for economic reasons and for the individual well-being of the patient. It is possible by early attention to job reintegration in the rehabilitation process. An early inventarization of the functional perspectives of the patients should be compared with the functional demands of the jobs the patients were doing at the time of amputation or had planned to do if the amputation had not been performed. Decisions should be taken about whether extra education or retraining is necessary to continue working. Patients with physically demanding jobs should be informed that their chances of returning to work are increased if they change to another type of job. Once the decision has been taken to return to a certain job, the necessity for job modifications should be evaluated and the right modifications should be made. It should be recommended that patients start as soon as possible with part-time work (some hours a week) on a trial basis and gradually work up to a normal working week to prevent them from losing contact and involvement with the workplace.

An important point of interest is the adaptation of the work to the limitations presented by the amputation. Both material and immaterial adjustments can prevent a workload that is too high. Most amputee patients have limited walking and standing ability, and in patients with higher amputation levels sitting comfort also needs attention. Flexibility in time scheduling may prevent problems in jobs where the subject is hindered in his or her working speed because of the amputation. Additional research is necessary to give more detailed advice about adequate workplace adjustments for people with a lower limb amputation.

Promotion possibilities seem to be decreased for amputee patients. Whether this is a direct consequence of the amputation or whether it is caused by prejudice on the part of employers about the possibilities of people with a leg amputation remains unclear and should be studied in future research. This information is needed to search for the right solutions to this problem.

Amputee patients who attend school or education at the time of amputation should be supported in finding a suitable job. The need for support will depend on the type of vocational training a subject attends. Information should be provided about the problems that may arise in the near or distant future from starting physically demanding jobs. Searching for a suitable job can decrease the need for modifications and difficulties in promotion facilities. Adequate information for employers may improve their understanding and may remove prejudices in job interview procedures.

The success of the reintegration of amputee patients depends on their age at the time of amputation, the educational level of the patient, and the wearing comfort of the prosthesis (figure 9.2). The vocational dissatisfaction of those working depends on the wish for more or better modifications of the workplace and the presence of comorbidity. We recommend specialized vocational rehabilitation programs for those with increased age, a low educational level, comorbidity, and restricted functional abilities with or without a prosthesis. Lowering the physical workload can contribute to a successful resumption of work. Therefore, patients with physically demanding jobs should seriously consider retraining to be able to change to other job types.

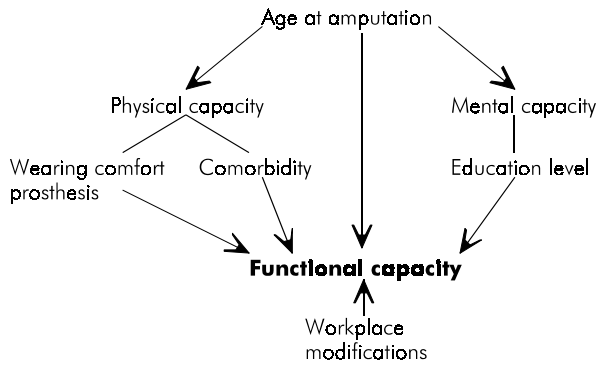


Figure 9.2 Job reintegration and job satisfaction and related aspects

In the choice for individual prostheses, the vocational situation of the subject must be kept in mind. Job demands can be an indication for more sophisticated parts in the prostheses, for example rotators or lotus adaptors. More research is needed into the possible effects of decisions in the prescription of prostheses on the demands in certain jobs. The relevance of adequate adaptation of the work has already been discussed and is emphasized by its relationship with job satisfaction. Future research should clarify other factors that influence the success of reintegration as well as the vocational satisfaction of patients with a leg amputation, for example motivation, job control and autonomy, relationships with colleagues, and psychosocial and personal factors. In this way it should become possible to define in more detail groups at risk of failure to reintegrate. Vocational rehabilitation programs can focus on these patients.

Not all the aspects of vocational (re)integration mentioned are tasks for a rehabilitation specialist. However, one of the main goals set in the rehabilitation of amputee patients is full participation in society and employment is part of this. Company doctors should also play an important role. Cooperation between the rehabilitation specialists, company doctors, patients and employers enhance the success of the (re)integration of people with a leg amputation. The rehabilitation specialist has knowledge of the functional abilities and disabilities of the amputee patient. Case managers from industrial medicine can coordinate the process of reintegration and the follow-up of patients during their working life.

General conclusions

Our prospective research shows that the most important predictors for the functioning of elderly amputee patients are age at amputation, standing balance on the unaffected limb, cognitive impairment (mainly memory), comorbidity, and mood disturbances. The functional level one year after amputation remains low in

comparison with healthy elderly people as well as with elderly patients with other pathology.

One year after amputation, the study of the relationship between impairments, activities, and participation shows that the relatively low level of activities and participation of elderly amputee patients was related to diabetes mellitus, cognitive impairment, mood disturbances, and standing balance on the unaffected limb.

In our cross-sectional study, amputee patients show a relatively good job participation, but amputee patients over 40 years of age more often withdraw from the labor market than their healthy colleagues. Problems were reported due to the long time that elapsed between amputation and resumption of work, the adaptation of the work to the limitations presented by the amputation, and promotion possibilities. The study confirms the relevance of work for the feeling of well-being in amputee patients, revealed by the differences in health experience on the RAND-36 between working and non-working amputee patients.

Successful job reintegration of subjects with a lower limb amputation is mainly determined by the age at the time of amputation, the education level, and the wearing comfort of the prosthesis. Older patients with a low educational level and problems with the wearing comfort of the prosthesis are a risk population who require special attention to return to work during the rehabilitation process. Lowering the physical workload would probably contribute to a successful resumption of work.

Despite a worse physical health experience, people with limb loss tend to be more content with their current occupational status than their healthy colleagues. This reflects the appreciation of amputee patients of job reintegration. However, many amputee patients report some problems with their working conditions. Indicators of job dissatisfaction in people with a lower limb amputation are the presence of comorbidity and the wish for (better) modifications in the workplace. Specialized vocational rehabilitation programs can benefit those subjects who have an amputation in combination with other disabilities.

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SUMMARY

Functional outcome after a lower limb amputation

Most amputee patients in developed countries are older than 60 years of age and 80–90% of the lower limb amputations are performed as a result of vascular problems. The most important functional demands of elderly patients are in the fields of personal care, household activities, and recreational activities. Most lower limb amputations in patients between 18 and 60 years of age are the result of trauma or cancer. In these younger patients, not only are training in physical mobility and independence in activities of daily living important, but return to work or school also plays an important role. The functional level of both patient groups is dependent on the interaction between physical, mental, and social factors.

The most important aim of this thesis is to increase the understanding of the relationship between physical, mental, and social factors and the functional level of subjects with a lower limb amputation. The main research questions are described in chapter 1. We tried to answer the following questions:

1. Which physical, mental, and social characteristics after an amputation predict the functional outcome for elderly lower limb amputee patients?
2. What is the relationship between impairments, activities, and participation for elderly amputee patients?
3. What is the employment status of younger amputee patients in the Netherlands?
4. Which factors are related to successful job reintegration and job satisfaction for working people with a lower limb amputation?

After the general introduction in chapter 1, the thesis consists of two parts. In the first part (chapters 2–4) we describe the functional level of elderly lower limb amputee patients and related factors. In the second part (chapters 5–8) we describe the job participation, job reintegration, and job satisfaction of lower limb amputee patients in adulthood in the Netherlands. Chapter 9 contains the general discussion about the results and recommendations for future research and clinical implications.

In chapter 2 we determine the interrater and intrarater reliability and the validity of the Timed "up & go" test (TUGT) for measuring physical mobility in elderly patients with an amputation of the lower extremity. The reliability and validity of the TUGT test have not been tested previously for patients with amputations. The TUGT test turns out to be a reliable instrument with adequate concurrent validity to measure the physical mobility of elderly patients with a leg amputation and walking ability with a prosthesis.

In chapter 3 we study physical, mental, and social predictors for the functional outcome one year after amputation two and six weeks after amputation. The

prediction of functional outcome is an important issue in rehabilitation medicine and influences choices made in the treatment of amputee patients. In previous research, the influence of mental and social factors was only fleetingly studied, and most studies were retrospective in approach. Our prospective research reveals that the most important predictors for the functioning of elderly amputee patients are the age at amputation, the standing balance on the unaffected limb, cognitive impairment (mainly memory), comorbidity, and mood disturbances.

The International Classification of Functioning and Disability (ICIDH-2) describes body functions and structures, activities, and participation, influenced by environmental and personal factors. Rehabilitation specialists base their treatment of people with chronic diseases on the correlation between impairments, activity limitations, and participation restrictions. In chapter 4 we describe the relationship between these three domains for patients one year after a unilateral lower limb amputation. The low level of activities and participation of the patients is related to diabetes mellitus, cognitive impairment, mood disturbances, and the standing balance on the unaffected limb.

A minority of amputee patients is less than 60 years of age and few epidemiologic data are available for this younger population. Chapter 5 presents an overview of the characteristics and amputation-related problems of amputee patients between 18 and 60 years of age. In addition, we study the level of the quality of life of these amputee patients when compared with a healthy reference population and related factors. In adulthood, most lower limb amputations are transtibial amputations caused by trauma. Prostheses are intensively used, despite a high frequency of skin problems. Walking distance remains severely restricted after the amputation. Comorbidity is present in almost half of the subjects. A higher amputation level is significantly related to fewer skin problems, more phantom pain, shorter prosthetic use, and shorter walking distance. Health perception of amputee patients is significantly worse than that of a reference population. Important amputation-related factors for health perception include the wearing comfort of the prosthesis, walking distance, phantom pain, amputation level, and prosthesis use.

In recent years, recognition of the importance of vocational rehabilitation is increasing and many job rehabilitation programs are being developed. In a cross-sectional study, we sent self-reporting questionnaires concerning job participation to amputee patients in the Netherlands. Chapter 6 reveals that people with lower limb amputations in the Netherlands show a relatively high job participation. However, there is a decline in job participation when amputee patients are 40 years of age or older when compared with the general population. The process of ageing in combination with a leg amputation seem to predispose a withdrawal from the labor market. Other problems mentioned by the different groups of amputee patients mainly concern the long delay between amputation and return to work, problems with getting the right workplace adjustments, and fewer possibilities for promotion in comparison with healthy colleagues.

Job reintegration for subjects working at the time of amputation was successful in 79% of the lower limb amputees. In chapter 7 we describe that successful job

reintegration of subjects with a lower limb amputation is mainly determined by the age at the time of amputation, the education level, and the wearing comfort of the prosthesis. Older patients with a low education level and problems with the wearing comfort of the prosthesis are a risk population who require special attention to return to work during the rehabilitation process. This group of patients may benefit from specialized vocational rehabilitation programs. Lowering the physical workload may contribute to a successful resumption of work.

Chapter 8 shows that despite a worse physical health experience, people with limb loss tend to be more content with their current occupational status than their healthy colleagues. This reflects the appreciation of amputee patients of job reintegration, and they may be less critical with a better sense of perspective with respect to problems at the workplace. Indicators for job dissatisfaction of people with a lower limb amputation are the wish for (better) modifications in the workplace and comorbidity. The importance of workplace adjustments is stressed again in this chapter because adequate modifications may increase the job satisfaction of employers with a leg amputation.

In the general discussion in chapter 9 we describe the consequences of the study results for workers in the field of rehabilitation and for future research. The need to optimize rehabilitation programs because of the low functional level of elderly amputee patients is stressed. We recommend paying attention to the functional level before amputation, the standing balance before amputation and after amputation on the unaffected limb, the severity of mood disturbances, and the memory function, for predicting the functional outcome of elderly amputee patients.

Aims in the vocational rehabilitation of younger amputee patients range from adapting the job demands to problems due to the ageing of amputee patients, shortening the time between amputation and resumption of work, better adaptation of the workplace to the limitations presented by the amputation, and increasing promotion possibilities. Specialized vocational rehabilitation programs may benefit older employers with a low educational level, comorbidity, and restricted functional abilities with or without their prosthesis. Cooperation between the rehabilitation specialists, company doctors, patients and employers enhance the success of the (re)integration of people with a leg amputation.

SAMENVATTING

Het functioneren na een beenamputatie

De meeste mensen die in de Westerse wereld een beenamputatie ondergaan zijn ouder dan 60 jaar en in 80 tot 90% van de amputaties is perifeer vaatlijden hier de oorzaak van. De algemene activiteiten van het dagelijks leven, huishoudelijke activiteiten en het uitvoeren van hobby's vormen de belangrijkste functionele eisen van oudere amputatiepatiënten. Anders is dit bij mensen tussen de 18 en 60 jaar. Beenamputaties bij deze patiëntengroep worden meestal veroorzaakt door een ongeval of kanker. Voor deze groep geldt dat naast het uitvoeren van algemene dagelijkse activiteiten, ook de functionele eisen die nodig zijn in de arbeidssituatie of de opleidingssituatie een grote rol spelen. Het functionele niveau dat beide patiëntengroepen bereiken, is afhankelijk van een samenspel van fysieke, mentale en sociale factoren.

De belangrijkste doelstelling van het in dit proefschrift beschreven onderzoek was het inzicht te vergroten in de relatie tussen de verschillende fysieke, mentale en sociale factoren en het functionele niveau dat mensen bereiken na een beenamputatie. In hoofdstuk 1 worden in een algemene introductie de vraagstellingen nader uitgewerkt. De volgende vraagstellingen worden in het onderzoek beantwoord:

1. Welke fysieke, mentale en sociale factoren na een amputatie voorspellen het functioneren van oudere beenamputatiepatiënten?
2. Wat is de relatie tussen functiestoornissen, activiteiten en participatie van oudere beenamputatiepatiënten?
3. Wat is de arbeidssituatie van amputatiepatiënten in Nederland?
4. Welke factoren zijn gerelateerd aan succesvolle arbeidsreïntegratie en arbeidssatisfactie van werkende mensen met een beenamputatie?

Na de algemene introductie in hoofdstuk 1, bestaat het proefschrift uit twee delen. In het eerste deel (hoofdstuk 2 t/m 4) wordt het functionele niveau beschreven dat oudere beenamputatiepatiënten bereiken en wordt toegelicht welke factoren daarop van invloed zijn. In het tweede deel (hoofdstuk 5 t/m 8) ligt het accent op jongere beenamputatiepatiënten, waarbij wordt ingegaan op de arbeidssituatie, het succes van arbeidsreïntegratie en de arbeidssatisfactie van deze groep patiënten. Hoofdstuk 9 vormt de algemene discussie betreffende de gevonden resultaten en aanbevelingen voor toekomstig onderzoek en de klinische toepasbaarheid.

Hoofdstuk 2 is een beschrijving van de Timed "up & go" test, waarmee de functionele mobiliteit van oudere mensen beoordeeld kan worden. Deze test staat in de literatuur bekend als een maat voor de functionele mobiliteit van mensen met

diverse ziektebeelden, maar werd nog niet eerder toegepast bij mensen met een beenamputatie. De test blijkt een bruikbaar en betrouwbaar instrument om de functionele mobiliteit weer te geven van beenamputatiepatiënten met een prothese.

In hoofdstuk 3 wordt een prospectieve studie beschreven naar predictoren twee en zes weken na een beenamputatie voor het functioneren van oudere mensen een jaar na de beenamputatie. In de revalidatiegeneeskunde is het belangrijk om al in een zo vroeg mogelijk stadium te kunnen inschatten wat de functionele verwachtingen van een patiënt zijn, zodat het revalidatiebeleid hierop kan worden afgestemd. Zowel fysieke als mentale en sociale aspecten zijn van invloed op het functionele niveau dat patiënten uiteindelijk bereiken. In bijna alle eerder verrichte studies werd weinig rekening gehouden met de rol van mentale en sociale factoren bij de predictie van het functioneren. Bovendien was de opzet van de meeste onderzoeken retrospectief. In de prospectieve studie in hoofdstuk 3, komen de volgende predictoren voor het functioneren na een beenamputatie als belangrijkste naar voren: de leeftijd ten tijde van de amputatie, de stabilans op het niet-geamputeerde been, het cognitief functioneren (met name de geheugenfunctie), de comorbiditeit en in mindere mate de aanwezigheid van stemmingsstoornissen.

De International Classification of Functioning and Disability (ICIDH-2) beschrijft lichaamsfuncties en -structuren, activiteiten en participatie, beïnvloed door omgevingsfactoren en persoonsgebonden factoren. De revalidatiegeneeskunde baseert de diagnostiek en behandeling op de interactie tussen de genoemde domeinen en de invloed van een verstoring op één van de niveaus van de ICIDH-2. In hoofdstuk 4 wordt de relatie beschreven tussen functiestoornissen en het activiteiten- en participatieniveau een jaar na een enkelzijdige beenamputatie. Amputatiepatiënten bereiken een relatief laag functioneel niveau dat in hoofdzaak gerelateerd is aan de aanwezigheid van diabetes mellitus, de ernst van cognitieve problemen, de aanwezigheid van stemmingsstoornissen, en de stabilans op het niet-geamputeerde been.

Vanwege het feit dat beenamputatiepatiënten jonger dan 60 jaar een minderheid vormen, zijn er slechts weinig epidemiologische gegevens over deze patiëntengroep bekend. In hoofdstuk 5 wordt een overzicht gegeven van de kenmerken van deze patiëntengroep en de amputatie-gerelateerde problemen die ze ervaren. Daarnaast is de kwaliteit van leven vergeleken met die van een gezonde referentiepopulatie en is bestudeerd welke amputatie-gerelateerde factoren een relatie vertonen met de kwaliteit van leven. De meeste patiënten in de leeftijdscategorie van 18 tot 60 jaar hebben een onderbeenamputatie die veroorzaakt is door een ongeval. Zij gebruiken de prothesen intensief, ondanks veel voorkomende huidproblemen. De loopafstand met prothese blijft echter duidelijk beperkt. Ondanks de (relatief) jonge leeftijd, blijkt toch bijna de helft van de patiënten comorbiditeit te hebben. Patiënten met een hoger amputatieniveau hebben minder huidproblemen, maar meer fantoompijn; zij maken minder intensief gebruik van de prothese en hebben een kortere loopafstand. De gezondheidsbeleving van amputatiepatiënten is slechter dan die van een referentiepopulatie. De belangrijkste amputatie-gerelateerde factoren die een relatie hebben met de gezondheidsbeleving zijn het draagcomfort

van de prothese, de loopafstand, de aanwezigheid van fantoompijn, het amputatieniveau en de mate van prothesegebruik.

De laatste jaren is een toenemende belangstelling waar te nemen voor de arbeidsdeelname van mensen met een beperking of handicap. De aandacht voor (re)integratieprogramma's groeit doordat het belang van deelname aan het arbeidsproces door mensen met een beperking of handicap beter wordt onderkend. Met behulp van een landelijk vragenlijstonderzoek is in de door ons verrichte studie de arbeidssituatie van beenamputatiepatiënten in Nederland in kaart gebracht. Hoofdstuk 6 vormt hiervan een nadere beschrijving. Uit de resultaten blijkt een relatief hoge arbeidsparticipatie van beenamputatiepatiënten in Nederland. Wel blijft de arbeidsparticipatie van patiënten boven de 40 jaar achter bij die van de Nederlandse beroepsbevolking. De combinatie van het hebben van een beenamputatie en het ouder worden verhoogt de kans op het snellere uittreden uit het arbeidsproces in vergelijking met mensen zonder beenamputatie. Daarnaast wijzen de bevindingen in dit deel van het onderzoek uit dat er diverse problemen zijn die deelname aan het arbeidsproces bemoeilijken: de periode tussen de amputatie en de werkhervatting duurt lang, het is moeilijk om de adequate werkaanpassingen te krijgen en de promotiekansen van beenamputatiepatiënten lijken lager dan die van gezonde collega's.

Van de mensen die ten tijde van de amputatie een baan hadden, was 79% op het moment van het onderzoek nog steeds werkzaam. In hoofdstuk 7 zijn de belangrijkste factoren die een relatie hebben met het succes op arbeidsreïntegratie weergegeven. Deze factoren zijn: de leeftijd ten tijde van de amputatie, het opleidingsniveau van de patiënt en het draagcomfort van de prothese. Extra aandacht is nodig voor oudere werknemers met een laag opleidingsniveau en problemen met het draagcomfort van de prothese om hun kansen op de arbeidsmarkt te vergroten. Mogelijk is deze deelpopulatie gebaat bij specifieke arbeidsrevalidatieprogramma's. Verder toont het onderzoek aan dat vermindering van de fysieke belastbaarheid van het werk de kans op een succesvolle reïntegratie kan vergroten.

Werknemers met een beenamputatie ervaren meer fysieke gezondheidsproblemen dan hun gezonde collega's, zoals hoofdstuk 8 laat zien. Desondanks tonen deze werknemers een grotere algemene tevredenheid in het werk dan hun collega's zonder beperking of handicap. Waarschijnlijk wordt dit veroorzaakt door het grote belang dat mensen met een amputatie hechten aan werkhervatting. Mogelijk beschikken zij over een minder kritische houding en meer relativeringsvermogen ten aanzien van problemen in de werksituatie. De belangrijkste indicatoren in dit onderzoek voor ontevredenheid van beenamputatiepatiënten in hun werk zijn de aanwezige wens tot meer of betere aanpassingen in de werksituatie en de aanwezigheid van comorbiditeit.

In de algemene discussie in hoofdstuk 9 wordt met name ingegaan op de consequenties voor de klinische revalidatiegeneeskundige praktijk en voor toekomstig onderzoek naar aanleiding van de bevindingen van dit onderzoek. De noodzaak voor het optimaliseren van revalidatieprogramma's wordt benadrukt in

verband met het lage functionele niveau dat oudere beenamputatiepatiënten bereiken. Aanbevolen wordt om bij het voorspellen van het functionele niveau van oudere amputatiepatiënten aandacht te besteden aan het functionele niveau voor de amputatie, de stabilans voor de amputatie en de stabilans na de amputatie op het niet-geamputeerde been, de ernst van stemmingsstoornissen en de geheugenfunctie.

Doelstellingen in de arbeidsrevalidatie van jongere amputatiepatiënten dienen er op gericht te zijn het werk zodanig aan te passen, dat specifieke problemen waarmee zij in aanraking komen, worden gereduceerd. Te denken valt aan goede begeleiding van relatief oudere werknemers met een amputatie, het verkorten van de tijd tussen amputatie en terugkeer naar de werksituatie, adequate aanpassingen van de werkplek en het verbeteren van de promotiekansen van werknemers met een beenamputatie. Voor oudere werknemers met een laag opleidingsniveau, comorbiditeit en beperkte functionele mogelijkheden met of zonder de prothese kunnen gespecialiseerde arbeidsrevalidatieprogramma's zinvol zijn. Samenwerking tussen revalidatieartsen, bedrijfsartsen, uitvoeringsinstellingen, patiënten en werkgevers vergroot de kans op een succesvolle arbeidsreïntegratie van mensen met een beenamputatie.

NORTHERN CENTRE FOR HEALTHCARE RESEARCH (NCH) AND PREVIOUS DISSERTATIONS

The Northern Centre for Healthcare Research (NCH) was founded in 1986 as a research institute of the University of Groningen (RUG), The Netherlands. Researchers from both the Medical and Social Faculty, with various professional backgrounds, are members of the NCH. These include medical sociologists, medical doctors, psychologists and human movement scientists. Research of the NCH is aimed at optimising quality of life of patients and quality of healthcare, and focuses on (a) determinants of health and illness, (b) consequences of illness, (c) the effects of medical treatment and decision making, and (d) the evaluation of health services and various types of interventions. At the time that this thesis is published, the NCH comprises five research programmes.

Until 1998, the NCH covered two research programmes, i.e. Determinants of Health and Medical Decision Making and Evaluation of Healthcare. The first programme was reformulated in 1996 and was continued as Disorder, Disability and Quality of Life (DDQ). Hence, previous dissertations in this area are listed as part of the present DDQ-programme. The second programme was subdivided in 1998 into two new programmes, i.e. Public Health and Public Health Services Research and Rational Drug Use.

Dissertations published earlier within the second programme are listed retrospectively under these new headings. In 1998, two new programmes, The Outcome and Evaluation of Interventions in Patients with Motor Problems and Process and Effects of Movement Programs, were formulated and officially integrated in the NCH in January 1999. The accomplished dissertations since the start of the programmes in 1998 are included in the list. In 2000 the Department of General Practice joined the NCH and together with the Rational Drug Use group initiated a new research programme, i.e. Implementation of Evidence Based Medicine in the Medical Practice.

More information regarding the institute and its research can be obtained from our internet site: <http://www.med.rug.nl/nch>

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CURRICULUM VITAE

Tanneke Schoppen werd op 10 februari 1969 geboren te Dordrecht. Na de middelbare school studeerde zij Geneeskunde aan de Rijksuniversiteit Groningen. In 1992 werd het doctoraal examen gehaald en in 1994 het artsexamen. Tijdens de Geneeskunde opleiding heeft zij meegewerkt aan onderzoek van dr. A.M. Boonstra naar verschillende kniescharnieren bij patiënten met een bovenbeenprothese. In 1992 verrichtte zij in het kader van haar wetenschappelijke stage onderzoek naar de reproduceerbaarheid en betrouwbaarheid van Straight-Leg Raising bij de vakgroep Revalidatie van het Academisch Ziekenhuis Groningen. Van 1 juli 1994 tot 1 oktober 1995 werkte zij als AGNIO (Assistent Geneeskundige Niet in Opleiding) op de afdeling Neurologie van het Martini Ziekenhuis in Groningen. In oktober 1995 startte zij, onder leiding van prof. W.H. Eisma, als AGIKO (Assistent Geneeskundige In opleiding tot Klinisch Onderzoeker) in het Academisch Ziekenhuis Groningen bij de afdeling Revalidatie. Tijdens deze 7-jarige opleiding combineerde zij de specialisatie tot revalidatiearts met het huidige promotieonderzoek. Sinds 1 november 2001 verricht zij - naast de onderzoeksactiviteiten - gedurende 1½ dag per week patiëntenzorg voor mensen met een beenamputatie in het Centrum voor Revalidatie, locatie Beatrixoord te Haren. Per 1 oktober 2002 zal zij werkzaam zijn als revalidatiearts bij het Centrum voor Revalidatie Groningen.