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Functional outcome after a lower limb amputation

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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 transibial 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 ampute 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 R² 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/modera	te 1	much/very much
stump pain	0	none/little/modera	te 1	much/very much
use of the prosthesis	0	< 8 hours a day	1	\geq 8 hours a day
wearing comfort of the				
prosthesis	0	bad/insufficient	1	sufficient/good
walking distance	0	< 500 meters	1	\geq 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

	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	

Table 5.1 Patient characteristics (n=626)

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.

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Table 5.2

	òkin pro	blems	Phan	tom in	Stu	mp iin	Use prost	: of hesis	Wea Corr	ring Ifort	Wall	king Ince	Como	bidity
<u> </u>	lever	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	ou	yes
I	4]	59	81	19	63	7	38	63	22	78	59	41	63	8 8
	25	75	79	21	84	16	10	06	18	82	45	55	56	4
	26	74	86	14	93	7	7	93	Ξ	89	32	68	59	4
	21	79	06	10	82	18	4	96	14	86	29	17	55	45
	27	73	88	13	88	13	6	94	19	81	20	80	50	50
	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 amputated-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

eneral health nealth change	71.6 50.2 22.3)* (18.9)†	74.2 53.7 (21.6) (19.2)	
pain 9	72.9 (25.7)† ((82.7 (24.4) (
vitality	65.5 (20.0)*	68.1 (19.4)	
mental health	77.1 (16.8)	76.8 (18.9)	
emotional role restriction	86.0 (30.9)	84.4 (32.1)	
physical role restriction	74.6 (36.7)†	81.4 (33.8)	
social functioning	80.4 (24.6)†	86.6 (20.9)	
physical functioning	54.4 (27.4)†	86.2 (20.4)	
	Amputee patients	Reference population	

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

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

	Physical functioning	Social functioning	Physical role restriction	Emotional role restriction	Mental health	Vitality	Pain	General health	Health change
Background:									
age at the time of study	04	07	08	02	.03	10.	09	10	07
age at the time of amputation	42	17	17	08	LL.–	13	22	16	10.
gender	12	14	12	08	20	19	08	10	.08
comorbidity	17	26	25	19	15	21	20	31	16
R ² - 		— 	 .1 	 8 	 .8 	 = 	 3 	 - 	 .5
<u>Amputation-</u> related:									
kind of rehabilitation					.10				۲۱
amputation level	.12			11	10	13	08	12	
amputation reason cancer vasc./diab.			- 11				07	.24	

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
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	71.	.10	
walking distance	.49	00	.18	 	.10	.10	.15	.20	
R²change	.28	.10	.12	90.	60 [.]	.12	.25	.16	-10
Total R ²	.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 $\overline{\beta}$ 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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