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Functional outcome of hip disarticulation and hemipelvectomy: a cross-sectional national descriptive study in the Netherlands

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Objective: To describe characteristics of hip disarticulation and hemipelvectomy amputees, to assess their level of activities, participation and experienced limitations in mobility and to describe the amputation-related problems.

Design: A cross-sectional study.

Setting: Patients were mainly recruited via orthopaedic workshops in the Netherlands.

Subjects: Forty-six patients with an acquired unilateral hip disarticulation or hemipelvectomy at least one year post amputation.

Main outcome measures: Sickness Impact Profile 68 (SIP 68) to assess the level of activity and participation and the questionnaire Rising and Sitting Down, Walking and Climbing Stairs to assess perceived limitations in mobility.

Results: The 46 patients (31 with hip disarticulation and 15 with hemipelvectomy) had a mean age of 55.8 years (SD 12.1). In 78% of cases the reason for amputation was a tumour. Mean SIP 68 was low, 10.5 (SD 6.9). Hip disarticulation amputees had significantly poorer emotional stability than the hemipelvectomy amputees ($P=0.04$). All amputees experienced considerable limitations in their mobility according to the Rising and Sitting Down, Walking and Climbing Stairs scores.

Conclusions: Hip disarticulation and hemipelvectomy amputees have a relatively high level of activity and participation (SIP scores) but at the same time experience limitations in walking, rising and sitting down and climbing stairs.

Introduction

The incidence of lower limb amputations in the Netherlands is about 18–20/100 000/year and the number of lower limb amputations nationwide is about 3000/year.¹ The number of hip disarticulations and hemipelvectomies in the Netherlands was approximately 40 in 2006 (1.3% of the total

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amount of lower limb amputations). A hip disarticulation is an amputation directly through the hip joint and a classical hemipelvectomy is an amputation of one half of the pelvis. The majority of the lower limb amputations in the developed countries are performed on patients over 60 years of age due to vascular disease.¹ In contrast, hip disarticulation and hemipelvectomy are performed in the early decades of life.²⁻⁵

The commonest reason for performing a hip disarticulation or a hemipelvectomy is a tumour. Other reasons are trauma, vascular insufficiency, femoral osteomyelitis and seldomly decubitus, failed hip arthroplasty and congenital abnormality.^{2-3,5}

The functional outcome of patients with a higher amputation level is generally worse compared with patients with a lower amputation level.⁶ Little is known about activities, participation and experienced limitations in mobility of amputees with hip disarticulation and hemipelvectomy. The literature is restricted to case reports,⁷⁻¹⁰ studies describing hip disarticulation prostheses^{2,11} or hip disarticulation prosthetic training,^{3,12-16} and studies reporting energy consumption while walking with a hip disarticulation prosthesis.^{4,17} The largest study concerned 41 hemipelvectomy patients.¹⁴

The aims of this cross-sectional study were to describe the patient characteristics of hip disarticulation and hemipelvectomy amputees in the Netherlands, to assess their level of activities, participation and experienced limitations in mobility, and to describe the amputation-related factors such as skin problems, phantom pain and prosthetic use of these amputees. By knowing the level of activities and participation of hip disarticulation and hemipelvectomy amputees it will be easier to set realistic goals for a rehabilitation team. Furthermore, by knowing the amputation-related factors the rehabilitation team can inform the amputee better about future possible problems.

Methods

Subjects

Subjects had to meet the following inclusion criteria: an acquired unilateral hip disarticulation or hemipelvectomy, at least one year post

amputation, in order to create a stable clinical situation and sufficient knowledge of the Dutch language. Subjects under the age of 16 years were excluded. Because of the small number of hip disarticulation and hemipelvectomy amputees, different methods were applied to include as many participants as possible. In total, 36 orthopaedic workshops in the Netherlands were contacted and asked to participate in the recruitment of patients for this study. Only 12 orthopaedic workshops had patients in their database who met the inclusion criteria. Those patients received from the orthopaedic workshop a letter in which they were asked to participate in this study by initially giving their name and address to the Center for Rehabilitation of the University Medical Center Groningen. In addition, the Dutch patient organization for amputees was asked to assist in the recruitment of possible patients. Finally, we recruited patients through the Dutch hemipelvectomy website (www.beenamputatie.nl).

Questionnaires

In a self-constructed questionnaire information was gathered on demographics, date of amputation, level of amputation, reason for amputation, ability to drive a car or ride a mobility scooter or bike, home adaptations, sport activities, paid employment, pregnancies and amputation-related problems, such as phantom pain, skin problems, prosthesis use, overloading of upper extremity, sitting comfort and seating device. A seating device is mostly a custom-made orthotic device supporting correct seated body alignment.

Furthermore, the subjects were asked to fill out the Sickness Impact Profile, version 68 (SIP 68) and the Rising and Sitting Down, Walking and Climbing Stairs questionnaire.

The SIP 68 is a measure of 'health-related changes in behavior associated with carrying out daily activities'. It is a valid and reliable instrument, which measures functional outcome at both the level of activities and the level of participation.¹⁸ A higher score indicates a lower level of activity and participation. The questionnaire consists of 68 items about behaviour, subdivided into six categories: somatic autonomy, mobility control, psychological autonomy and communication,

social behaviour, emotional stability, and mobility range. The sum score is calculated by adding the scores of the subscales.

The Rising and Sitting Down, Walking and Climbing Stairs questionnaire is validated and assesses the perceived limitations in rising and sitting down, walking and climbing stairs in patients with lower extremity disorders who live at home.^{19–21} Scores range between 0 (not possible) and 100 (no limitations). A higher score indicates a better physical mobility.²²

Statistics were performed using the SPSS version 14.0 (SPSS Inc., Chicago, IL, USA). Data are presented as means and standard deviations. Differences between hip disarticulation and hemipelvectomy were tested for significance ($P < 0.05$) by the chi-square test and t -test for independent samples.

Results

Forty-four subjects returned a signed consent in response to the letter sent by the orthopaedic workshops.

The recruitment assistance of the Dutch patient organization for amputees resulted in one subject. Four subjects from the hemipelvectomy website sent their name and address by e-mail to the authors. A total of 49 questionnaires were sent out to the respondents. One subject did not respond despite repeated contact, one subject could not be traced and one subject was excluded afterwards for not meeting the inclusion criteria. Finally, 46 (94%) subjects returned the questionnaire.

The study population consisted of 21 (46%) men and 25 (54%) women with a mean age of 55.8 years (SD 12.1), and the mean age at the time of amputation was 32.7 years (SD 18.7). The distribution according to the level of amputation was hip disarticulation 31 (67%) and hemipelvectomy 15 (33%). The reason for amputation was a tumour in 36 cases (78%), vascular in 6 (13%), trauma in 2 (4%), and other causes in 2 (4%). The patient characteristics are summarized in Table 1.

About half the study population 25 (54%) were in paid employment. Eight subjects worked full time and 17 part time, 13 of whom worked

Table 1 Characteristics of patients ($n=46$), reason for amputation and outdoor ambulation

	Total group ($n=46$) mean (SD)	HD ($n=31$) mean (SD)	HP ($n=15$) mean (SD)	P -value (t -test/ χ^2)
Age at time of amputation, years	32.7 (18.7)	29.1 (19.9)	40.2 (13.6)	0.57
Age at time of inclusion, years	55.8 (12.1)	55.7 (12.5)	55.9 (11.7)	0.97
Interval, years	23.0 (17.5)	26.6 (18.8)	15.6 (11.9)	0.04
Gender, no. (%)				0.17
Male	21 (46%)	12 (39%)	9 (60%)	
Female	25 (54%)	19 (61%)	6 (40%)	
Reason for amputation ^a , no. (%)				0.74
Tumour	36 (78%)	24 (77%)	12 (80%)	
Vascular	6 (13%)	4 (13%)	2 (13%)	
Trauma	2 (4%)	1 (3%)	1 (7%)	
Other	2 (4%)	2 (7%)	0 (0%)	
Outdoor ambulation				
Able to drive a car	37 (80%)	25 (81%)	12 (80%)	0.95
Able to ride a mobility scooter	19 (41%)	14 (45%)	5 (33%)	0.44
Able to ride an adapted bicycle	22 (49%)	14 (47%)	8 (53%)	0.67
Other topics				
Adapted home	25 (56%)	19 (63%)	6 (40%)	0.13
Sport	18 (39%)	14 (45%)	4 (27%)	0.22
In paid employment	25 (54%)	17 (55%)	8 (53%)	0.92
Pregnancies 7/25 ^b	7 (28%)	7/19	0/6	

HD, hip disarticulation; HP, hemipelvectomy; SD, standard deviation.

^aTotal of percentages is not 100% because of rounding off.

^bFemale.

Table 2 Scores of hip disarticulation and hemipelvectomy amputees on the SIP 68, representing activity and participation

	Total group (<i>n</i> =46) Mean (SD)	HD (<i>n</i> =31) Mean (SD)	HP (<i>n</i> =15) Mean (SD)	<i>P</i> -value (<i>t</i> -test)
SIP total	10.5 (6.9)	10.9 (6.9)	9.8 (6.9)	0.64
Subscales				
SomaticAutonomy	0.6 (1.7)	0.4 (1.0)	1.0 (2.6)	0.39
Mobility control	4.9 (2.7)	5.0 (2.5)	4.8 (2.9)	0.81
Psychological autonomy and communication	0.5 (1.5)	0.6 (1.7)	0.1 (0.5)	0.12
Social behaviour	2.9 (2.5)	3.1 (2.5)	2.6 (2.2)	0.50
Emotional stability	0.4 (0.8)	0.5 (0.9)	0.1 (0.2)	0.01
Mobility range	1.1 (1.5)	1.0 (1.6)	1.2 (1.3)	0.78

HD, hip disarticulation; HP, hemipelvectomy; SD, standard deviation; SIP, Sickness Impact Profile.

Table 3 Mobility of hip disarticulation and hemipelvectomy amputees assessed using the Rising and Sitting Down, Walking and Climbing Stairs questionnaire

	Total group (<i>n</i> =46) Mean (SD)	HD (<i>n</i> =31) Mean (SD)	HP (<i>n</i> =15) Mean (SD)	<i>P</i> -value (<i>t</i> -test)
Walking	55.0 (22.1)	51.8 (20.8)	61.6 (23.8)	0.16
Rising and sitting down	53.6 (13.1)	52.3 (12.7)	56.1 (14.0)	0.35
Climbing stairs	58.1 (28.2)	54.2 (28.3)	66.2 (27.1)	0.17

HD, hip disarticulation; HP, hemipelvectomy; SD, standard deviation.

part-time because of the amputation. Sports that were practised by the amputees were swimming, fitness, sailing, golf, hand biking, wheelchair tennis, volleyball and badminton. Apart from interval (time between amputation and inclusion) ($P < 0.04$) there were no statistically significant differences between hip disarticulation and hemipelvectomy amputees (Table 1).

The SIP score and subscales are summarized in Table 2. On the SIP 68 the amputees reported a mean score of 10.5 (SD 6.9). Hip disarticulation amputees had significantly poorer emotional stability than the hemipelvectomy amputees. No other significant differences were found between hip disarticulation and hemipelvectomy amputees in SIP 68 subscales.

Table 3 shows the results of the Walking, Rising and Sitting Down and Climbing Stairs questionnaire. All amputees experience considerable limitation in their mobility.

No significant differences were found between hip disarticulation and hemipelvectomy amputees with respect to their scores on the Walking, Rising and Sitting Down and Climbing Stairs questionnaire.

Amputation-related factors are summarized in Table 4. Phantom pain was reported by 36 amputees (78%), and skin problems by 4 amputees (9%). Thirty five amputees (76%) used a prosthesis. One hip disarticulation amputee used a prosthesis only for cosmetic reasons. Almost half of all amputees reported overloading of the upper extremities. Of all amputees 32 (71%) could sit comfortably. This percentage was somewhat lower in hemipelvectomy than in hip disarticulation amputees. The percentage of amputees that used a seating device was 40% of all amputees. Significantly more hemipelvectomy amputees used a seating device than hip disarticulation amputees. No other significant differences were found between hip disarticulation and hemipelvectomy amputees.

Discussion

The results of the current study indicate that hip disarticulation and hemipelvectomy amputees reach a relatively high level of activities and

Table 4 Amputation-related factors in hip disarticulation and hemipelvectomy amputees

	Total group (n=46) No. (%)	HD (n=31) No. (%)	HP (n=15) No. (%)	P-value (χ^2 -test)
Phantom pain	36 (78%)	25 (81%)	11 (73%)	0.57
Skin problems	4 (9%)	3 (10%)	1 (7%)	0.73
Prosthetic use	35 (76%)	24 (77%)	11 (73%)	0.57
Cosmetic prosthesis	1 (2%)	1 (3%)	0 (0%)	
Overload upper extremity	20 (43%)	13 (42%)	7 (47%)	0.76
Sit comfortably	32 (71%)	23 (74%)	9 (60%)	0.49
Seating device	19 (42%)	10 (32%)	9 (60%)	0.04

HD, hip disarticulation; HP, hemipelvectomy;

participation measured by SIP 68, but at the same time experience considerable limitations in walking, rising and sitting down and climbing stairs.

Most of the literature defines functional outcome only in terms of prosthetic use, but general measures of functional outcome with or without prosthesis are equally important.⁶ In the current study a generic instrument (SIP 68) was used because we wanted to obtain information about the amputees overall functioning, with or without prosthesis. The SIP reflects the patient's opinions on their functioning. Our finding of low SIP (mean 10.5) is in contrast to the findings of other studies. In unilateral lower limb amputees older than 60 years due to vascular disease,⁶ the mean SIP score was 23.4 (SD 11.9), and for patients with a vascular bilateral amputation the mean SIP was 23.3 (SD 11.6).²³ The low SIP score in the current study may be related to the young age at which the amputation was performed. Moreover, since amputations were performed on average 23 years ago, it is possible that the amputees had reached a stable situation and were psychologically adapted to the amputation.

The Rising and Sitting Down, Walking and Climbing Stairs questionnaires were used to assess perceived limitation in the mobility of amputees. Most amputees reported considerable limitations in walking, sitting and rising from a chair and climbing stairs.

Although a long period had elapsed between amputation and participation in this study (interval >10 years) 36 patients (78%) reported phantom pain. The prevalence of phantom pain in patients with an acquired amputation ranged between 49 and 78%.²⁴ One study about phantom pain and health-related quality of life found no

significant differences between amputees with and without phantom pain. The most important amputation-specific determinants of health-related quality of life were walking distance and stump pain.²⁵

Only 4 (9%) amputees (3 hip disarticulations, 1 hemipelvectomy) noticed skin problems. Previous studies reported that most skin problems occurred in patients with transtibial amputations (79%) and amputations due to a vascular disease.^{6,26} Only 13% of our study population was amputated due to vascular disease. The low prevalence of skin problems in hip disarticulation and hemipelvectomy amputees may also be explained by the fact that amputees with a higher amputation level wear their prostheses for shorter periods of time than patients with a lower amputation level, causing less pressure on the stump skin. Use of a prosthesis is generally shortest in patients with a hip disarticulation or hemipelvectomy; 37% used their prosthesis less than 8 hours a day, whereas 96% of transtibial amputees use their prosthesis more than 8 hours a day.⁶ Finally it is possible that amputees in our study were provided with an adequately fitted prosthesis.

In spite of the high amputation level, about 75% of the patients in our study used a prosthesis. In contrast to many publications about transtibial and transfemoral amputees, there are few publications about long-term outcome of hip disarticulation prosthesis wearers. For hip disarticulation the reported prosthetic use was about 43%.^{11,13} Prosthetic use for transtibial and transfemoral amputees varied between 36 to 89%.^{1,6,27}

The relatively high percentage of prosthetic use in the current study might be explained by the age of amputation and reason for amputation.

Young amputees are mostly motivated towards rehabilitation and prosthetic use. Furthermore, after curative surgery for cancer amputees are often relatively healthy, have a good general condition and a well-functioning contralateral limb, in contrast to vascular amputees.^{3,6,13,26}

Overloading of the upper extremities was reported by 20 (43%) of the amputees. Hip disarticulation amputees spend about 82% and hemipelvectomy spend 125% more energy during walking with a prosthesis than able-bodied subjects.⁴ The energy cost of walking with crutches (without prosthesis) at a comfortable walking speed for hip disarticulation amputees was only 45% more than for able-bodied subjects.⁴ This explains why many patients with hip disarticulation or hemipelvectomy may prefer 'use of crutches' instead of 'use of a prosthesis'. If the amputees in our study preferred to walk with crutches, this could explain the complaints of overloading of the upper extremities.

All women who had been pregnant after the amputation were hip disarticulation amputees. Their mean age at the time of amputation was 29.1 years. In the current study no hemipelvectomy amputees reported a pregnancy, probably because their mean age of amputation was above 40 years. Pregnancy is not contraindicated after a hemipelvectomy when there is no evidence of recurrent or residual tumour.^{28,29}

A limitation of our study is that selection may have influenced our results, because 93% of the study population were recruited via the orthopaedic workshops and we therefore may have missed people who never received prostheses. This selection was reflected in the high number of patient using a prosthesis. We are aware that we may not have included amputees who never were referred for a prosthesis. We also know that we have not contacted every hip disarticulation or hemipelvectomy amputee in the Netherlands because of the practical difficulties of identifying the total amputee population. In addition amputees were not asked whether they used walking aids or their prosthesis during walking, rising and sitting down and climbing stairs. Therefore we are not sure whether overloading of the upper extremity was related to the use of walking aids.

Although the number of hip disarticulation and hemipelvectomy in the Netherlands is about 40 per

year, we could include only 46 amputees in this study. This means that we were unable to include a substantial proportion of subjects. An adequate data registration system is needed to be able to include more amputees with hip disarticulation or hemipelvectomy in future research.

The results of our study indicate that hip disarticulation and hemipelvectomy amputees have a relatively high level of activities and participation but they experience limitations in walking, rising and sitting down and climbing stairs. Our recommendation is that patients with a hip disarticulation or hemipelvectomy should be sent to a rehabilitation team with experience with this kind of amputation and prosthetic training to set realistic goals.

Clinical messages

- Amputees with a hip disarticulation or hemipelvectomy experience limitations in walking, climbing stairs and seating.
- Hip disarticulation or hemipelvectomy amputees have nonetheless a relatively high level of activity and participation.

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