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ORIGINAL REPORT

HEALTH SERVICES UTILIZATION IN ADULT ACQUIRED MAJOR UPPER-LIMB AMPUTEES: A POPULATION-BASED SURVEY

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Objective: **To increase knowledge of health services utilization and related factors in adult acquired major upper-limb amputees.**

Design: **Population-based cross-sectional study conducted in Norway.**

Subjects: **Twohundred and twentyfour adult acquired major upper-limb amputees (57.4% response rate). Mean age was 53.7 years, 83.5% were men and mean post-amputation time was 24.0 years.**

Methods: **Data were collected by postal questionnaires. Amputation-related health services utilization, perceived benefit and unmet needs were reported and associations between these factors and background factors were estimated by multivariate logistic regression analyses.**

Results: **Reported health services utilization was relatively low. The reported benefit of utilized services was generally high. For several non-utilized services, considerable unmet needs for utilization were reported. Several background factors were significantly associated with different aspects of the services examined. A considerable discrepancy between reported pain and utilization of specified pain treatments was noted.**

Conclusion: **The findings of this study suggest that several health services available to acquired major upper-limb amputees should be strengthened. Establishing routines to ensure access to optimal, individualized rehabilitation may prevent disability. We recommend additional, longitudinal studies to further assess the need for mental health care and pain treatment in acquired major upper-limb amputees.**

Key words: amputees; upper limb; health services research; patient satisfaction; rehabilitation.

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INTRODUCTION

Major arm amputation causes a loss of function that affects all aspects of life (1, 2), and obtaining functional competence requires a substantial effort by the patient and the therapist(s) during rehabilitation (3, 4). The importance of optimal rehabilitation is emphasized by upper-limb amputees (ULAs) typically being young, healthy individuals who should expect a normal life-span with many years of productive employment and active contribution to society (5–7).

Patient satisfaction is a health outcome often used to evaluate quality of care (4, 8–10). There have been few studies of ULA health services utilization and patient satisfaction, and there is a considerable lack of population-based knowledge. Earlier studies are limited in generalizability due to limited study samples or due to assessing only certain aspects of healthcare. Such studies have been conducted on amputees with phantom pain (4), in samples of veterans and service members (10, 11) and on the satisfaction with prosthetist services (9). Studying service members who sustained major limb amputations during during military operations ($n = 158$, of which $n = 32$ ULAs), Pasquina et al. (10) found that army centre inpatient treatment, peer visitors, overall medical care and pain management received particularly high satisfaction ratings. Examining the use of health services and the perceived benefit of such use in Scottish amputees with phantom pain ($n = 315$, the number of ULAs not specified), Whyte & Carroll (4) found that few amputees made use of available services for general amputation-related problems and that even fewer services were used for pain. The services used were not perceived as helpful.

The associations between patient sociodemographic characteristics and satisfaction with medical care are not well understood (8, 12). A meta-analysis (12) concluded that greater satisfaction was significantly associated with greater age and lower level of education. No overall relationship was found for ethnicity, gender, income or family size. In amputees, there is a paucity of studies addressing this topic. In previous studies, age, level, side and aetiology of amputation have been shown to have little effect on overall satisfaction ratings (9, 10), whereas men and persons with fewer years of education have been shown to be less likely to be satisfied with amputee healthcare (9).

To the author's knowledge, no population-based study broadly assessing ULAs' perspectives on available health services has been performed previously. The aims of this population-based study were to describe amputation-related health services utilization in adult acquired major ULAs, to describe the perceived benefit of such use, to estimate the extent of unmet needs for utilization and to estimate associations between demographic and amputation-related factors

(background factors) and health services utilization, perceived benefit and reported unmet needs.

METHODS

Design and subjects

As part of a larger study (13), we performed a survey with inclusion from 1 October 2006 until 30 May 2008. Eligible amputees from the known population of adult acquired major ULAs in Norway were invited to participate. This amputee population was identified through a combined search of the databases of the 2 companies in Norway that make upper-limb prostheses and of the medical records of 3 major Norwegian hospitals. The inclusion process is described in detail in a previous paper (13). Inclusion criteria were: acquired upper-limb loss, major amputation, adult (age ≥18 years on 1 October 2006), resident in Norway and fluent in spoken and written Norwegian. Exclusion criteria were: physical or mental inability to provide the required information. Demographic and amputation-specific features of the responders ($n = 224$, 57.4% response) are shown in Table I.

Data collection and variables

Data were collected by postal questionnaires returned by pre-paid post. Each informant received a maximum of two written reminders. The questionnaire was developed by expert clinicians (two physicians, one physiotherapist and one occupational therapist). Prior to data collection, our study was approved by the Norwegian Regional Ethics Committee. Data on demographic features, amputation-related features, pain and utilized health services were collected. Pain was reported as the occurrence of phantom pain, stump pain and musculoskeletal pain during the last 12 months (yes/no) in amputees amputated >12 months before survey. The amputees were asked to indicate which health services they had utilized related to the amputation or related to post-amputation problems from a 19-item list. For utilized services, the amputees were asked to report the perceived benefit on a 5-point Likert scale, where 1 was "completely useless" and 5 was "very useful". This satisfaction outcome measure is likely to reflect the health service's perceived effect on the amputee's symptoms and functional status (8). For non-utilized services, the amputees were asked to report whether they had a wish to utilize such a service (yes/no). Such a wish was interpreted as an indicator of unmet need. Furthermore, the overall satisfaction with all utilized health services was reported on a 5-point Likert scale, where 1 was "very unsatisfied" and 5 was "very satisfied".

Data analysis

Data were analysed using SPSS version 14.0. 95% confidence intervals (CIs) for percentages were calculated with a binomic formula. To assess the representativeness of our sample, we used independent samples *t*-test (for continuous variables) and Fisher's exact test (for frequencies) to compare the questionnaire responders ($n = 224$) and the questionnaire non-responders ($n = 166$). Variables compared were: gender, age at survey, place of residence, ethnicity (based on name), unilateral/bilateral amputation, amputation level and prosthetic supply (registered in prosthetist databases). The significance level was set at $\alpha = 0.05$.

The utilization of each health service (% utilization) and the stated wish to utilize non-utilized services (% wish) were reported. For utilization the number of non-responders was low and non-response was analysed as "no utilization". The perceived benefit of utilized services was re-coded to a dichotomous variable indicating whether the amputee perceived the service as useful (Likert scale 4–5) or not (Likert scale 1–3) and the recoded perceived benefit was reported (% useful). These analyses were conducted separately in unilateral ($n = 214$) and bilateral ($n = 10$) amputees. The occurrence of phantom pain, stump pain and musculoskeletal pain during the last 12 months before survey in amputees amputated > 12 months before survey was reported, and the utilization of specified pain treatments in amputees reporting pain was detailed.

In unilateral amputees, the associations between background factors and: (*i*) health services utilization; (*ii*) the perceived benefit of

Table I. *Demographic and amputation-related features for the questionnaire-responders (*n = *224*[a]*)*

Demographic features		Amputation-related features	
Variable	Value	Variable	Value
Gender, % men	83.5	Unilateral amputation, *n* (%)	214 (95.5)
Age at survey in years, mean (range)	53.7 (20.3–95.3)	Age at amputation in years, mean (range)	29.6 (0.0–80.0)[b]
Native country, % Norway	90.2	Time since the amputation in years, mean (range)	24.0 (0.3–76.3)
Place of residence at survey, region, %		Cause of amputation, %	
Eastern Norway	48.7	Traumatic	84.5
Other[c]	51.3	Other[d]	15.5
Marital status at survey, %		Level of amputation (unilateral only), %[e]	
Married or cohabitant	70.1	Transradial	61.5
Single, widowed or divorced	29.3	Elbow disarticulation or more proximal	38.5
Educational level at survey, %		Occupational status at amputation, %	
No education	2.7	In paid employment	62.1
Primary school/comprehensive school (≤3 years)	64.9	Not in paid employment[f]	11.2
College or university (≥4 years)	32.4	Student/child/youth[g]	26.8
Occupational status at survey, %		Current prosthesis wear, % yes[h]	80.8
In paid employment	37.9		
Not in paid employment[i]	58.5		
Student	3.6		

[a]The number of responders ranges from 220 to 224, [b]0.0 indicates traumatic amputation as a newborn, [c]Western Norway 24.1%, Northern Norway 10.7%, Trøndelag (≈ Mid Norway) 8.9% and Southern Norway 7.6%, [d]Cancer ($n = 15$), infection ($n = 14$), arteriosclerosis/poor circulation ($n = 3$), overdose ($n = 2$), [e]Bilateral amputees: through wrist ($n = 2$), through forearm ($n = 2$), through upper arm ($n = 1$), through wrist + forearm ($n = 2$), through wrist + elbow ($n = 1$), through forearm + shoulder ($n = 1$), through elbow + shoulder ($n = 1$), [f]Disability pension ($n = 9$), retired ($n = 7$), occupational rehabilitation ($n = 2$), work at home ($n = 3$), unemployed ($n = 4$), [g]Student ($n = 27$), child/youth ($n = 33$), [h]Based on the amputee's own definition of being a wearer (yes/no), regardless of the frequency of wear or the type of prosthesis worn, [i]Disability pension ($n = 72$), retired ($n = 45$), occupational rehabilitation ($n = 7$), work at home ($n = 4$), unemployed ($n = 3$).

utilized services; and (*iii*) the reported wish to utilize non-utilized services were estimated using multivariate logistic regression. Such analyses were performed for the 5 most frequently utilized services, the 5 services reported as most useful and the 5 non-utilized services with the highest percentages of reported unmet need, respectively. Background factors analysed were: gender, ethnicity, age at amputation, amputation level, amputation cause, time since the amputation and occupational status at amputation (utilization); gender, ethnicity, age at survey, place of residence at survey, marital status at survey, educational level at survey, occupational status at survey, amputation level, amputation cause, time since the amputation and current prosthesis wear (benefit and need). Furthermore, the pairwise associations between utilization of all 19 health services were analysed. Each association was controlled for the same background factors as for utilization, using multivariate logistic regression. Regression analyses were not performed in bilateral amputees due to the small sample size.

RESULTS

Subjects

A total of 390 eligible amputees were identified. Of these 224 completed questionnaires (57.4% response rate). There were no significant differences between questionnaire responders and non-responders for the variables compared.

Utilization of health services

Tables II and III show that health services utilization was relatively low in major ULAs. The mean number of services utilized was 3.41 in unilateral amputees (95% CI 3.05–3.77, range 0–14) and 3.30 in bilateral amputees (95% CI 1.45–5.15, range 0–8). Among unilateral ULAs, 18.7% (40/214; 95% CI

Table II. *Unilateral amputees: amputation-related utilization of health services, perceived benefit and wish to utilize non-utilized services*

	Utilization ($n=214$)			Perceived benefit of utilized services				Wish to utilize non-utilized services			
	Utilized	Utilized	95% CI	Useful	Not useful	Useful	95% CI	Wish	No wish	Wish	95% CI
Health services	*n*	%	%	*n*	*n*	%[a]	%	*n*	*n*	%[b]	%
Hospital: inpatient (rehabilitation ward)	73	34.1	27.8–40.5	46	23	66.7	55.5–77.8	14	71	16.5	8.6–24.4
Hospital: inpatient (other ward)	14[c]	6.5	3.2–9.9	9[d]	2[e]	81.8	59.0–100.0	8[f]	94	7.8	2.6–13.1
Hospital: outpatient (limb centre)[g]	70	32.7	26.4–39.0	44	18	71.0	59.7–82.3	10	77	11.5	4.8–18.2
Private rehabilitation centre (inpatient)	41	19.2	13.9–24.4	24	12	66.7	51.3–82.1	19	82	18.8	11.2–26.4
Community-level physiotherapy	117	54.7	48.0–61.3	81	23	77.9	69.9–85.9	16	38	29.6	17.5–41.8
Community-level occupational therapy	64	29.9	23.8–36.0	37	17	68.5	56.1–80.9	24	65	27.0	17.7–36.2
Employment services (Norway: NAV, Aetat)	79	36.9	30.5–43.4	39	31	55.7	44.1–67.4	6	69	8.0	1.9–14.1
Occupational health services	31	14.5	9.8–19.2	13	13	50.0	30.8–69.2	16	95	14.4	7.9–20.9
Community social worker	20	9.3	5.4–13.2	8	4	66.7	40.0–93.3	46	75	38.0	29.4–46.7
Psychiatrist/psychologist (in/outpatient)	36[h]	16.8	11.8–21.8	13	17	43.3	25.6–61.1	5[i]	105	4.5	0.7–8.4
Psychiatrist/psychologist (community-level)	11[h]	5.1	2.2–8.1	8	1	88.9	68.4–100.0	6[i]	117	4.9	1.1–8.7
Pain treatment (general practitioner)	43[j]	20.1	14.7–25.5	26	9	74.3	59.8–88.8	11[k]	94	10.5	4.6–16.3
Pain treatment (specialized outpatient clinic)	30[j]	14.0	9.4–18.7	14	13	51.9	33.0–70.7	14[k]	97	12.6	6.4–18.8
Pain treatment (other in/outpatient treatment)	19[j]	8.9	5.1–12.7	9	4	69.2	44.1–94.3	14[k]	106	11.7	5.9–17.4
Home care/home nursing care	25	11.7	7.4–16.0	16	3	84.2	67.8–100.0	17	101	14.4	8.1–20.7
Peer support	20	9.3	5.4–13.2	12	6	66.7	44.9–88.4	17	96	15.0	8.5–21.6
Post-amputation stump surgery (prosthesis)[l]	23	10.7	6.6–14.9	13	5	72.2	51.5–92.9	10	105	8.7	3.5–13.8
Post-amputation stump surgery (grip)[m]	6	2.8	0.6–5.0	3	2	60.0	17.1–100.0	4	119	3.3	0.1–6.4
Other treatment	8[n]	3.7	1.2–6.3	4[o]	3[p]	57.1	20.5–93.8	1[q]	10	9.1	0.0–26.1

[a]Percentages were calculated as "(*n* perceiving treatment useful)/(*n* perceiving treatment useful + *n* not perceiving treatment useful)". Due to non-response regarding perceived benefit, the denominator in the calculation of these percentages does not equal *n* reporting utilization of each treatment, [b]Percentages were calculated as "(*n* reporting a wish to utilize treatment)/(*n* reporting a wish to utilize treatment + *n* reporting no wish to utilize treatment)". Due to non-response regarding wish to utilize non-utilized treatments, the denominator in the calculation of these percentages does not equal *n* reporting non-utilization of each treatment, [c]Fire damage ward ($n=1$), multitrauma ward ($n=1$), drug abuse inpatient treatment ($n=1$), hospitalization due to back pain ($n=1$), specialized inpatient occupational rehabilitation ($n=1$), specialized hand/arm surgery ward ($n=2$), unspecified surgical ward ($n=2$), unspecified ($n=5$), [d]Fire damage ward ($n=1$), multitrauma ward ($n=1$), drug abuse inpatient treatment ($n=1$), specialized hand/arm surgery ward ($n=1$), unspecified surgical ward $n=2$), unspecified ($n=3$), [e]Hospitalization due to back pain ($n=1$), unspecified ($n=1$), [f]Not specified, [g]Limb centres offer specialized, multidisciplinary outpatient rehabilitation to ULAs and are located in each of Norway's health regions, [h]A total n=40 unilateral amputees reported utilization of at least 1 level of psychiatrist/psychologist treatment, [i]A total $n=9$ unilateral amputees reported a wish to utilize at least 1 level of psychologist/psychiatrist treatment, [j]A total n = 67 unilateral amputees reported utilization of at least 1 type of specified pain treatment, [k]A total $n=26$ unilateral amputees reported a wish to utilize at least 1 pain treatment, [l]To ease prosthesis use, [m]To promote grip without prosthesis use, [n]Acupuncture ($n=1$), healing ($n=1$), chiropractor ($n=1$), surgery to remove neuroma ($n=2$), surgery to improve stump circulation ($n=1$), other stump surgery ($n=1$), RISK-treatment for methadone users ($n=1$), [o]Healing ($n=1$), surgery to remove neuroma ($n=1$), surgery to improve stump circulation ($n=1$), RISK-treatment for methadone users ($n=1$), [p]Acupuncture ($n=1$), chiropractor ($n=1$), surgery to remove neuroma ($n=1$), [q]Specified: "Professional pain treatment" (all 3 pain treatments specified were utilized by this amputee).

As prosthetist services are included in hospital inpatient rehabilitation and outpatient treatment at limb centres, these services were not evaluated separately. Some details of prosthetic adjustment and follow-up among adult acquired major ULAs in Norway have, however, been published previously (14).

CI: confidence interval; ULA: upper-limb amputee.

Table III. *Bilateral amputees: amputation-related utilization of health services, perceived benefit and wish to utilize non-utilized services*

	Utilization (n=10)	Perceived benefit of utilized services		Wish to utilize non-utilized services	
Health services	Utilized, *n*	Useful, *n*	Not useful, *n*	Wish, *n*	No wish, *n*
Hospital: inpatient (rehabilitation ward)	5	3	1	1	1
Hospital: inpatient (other ward)	1[a]	1	0	0	3
Hospital: outpatient (limb centre)[b]	1	ND	ND	1	4
Private rehabilitation centre (inpatient)	2	1	0	1	2
Community-level physiotherapy	5	4	0	0	2
Community-level occupational therapy	5	4	0	0	1
Employment services (Norway: NAV, Aetat)	1	1	0	1	2
Occupational health services	2	0	2	1	3
Community social worker	4	2	1	1	1
Psychiatrist/psychologist (in/outpatient)	0	NA	NA	0	5
Psychiatrist/psychologist (community-level)	0	NA	NA	0	5
Pain treatment (general practitioner)	0	NA	NA	0	5
Pain treatment (specialized outpatient clinic)	0	NA	NA	0	5
Pain treatment (other in/outpatient treatment)	0	NA	NA	0	5
Home care/home nursing care	5	4	1	0	2
Peer support	0	NA	NA	2	3
Post-amputation stump surgery (prosthesis)[c]	2	1	0	0	4
Post-amputation stump surgery (grip)[d]	0	NA	NA	0	6
Other treatment	0	NA	NA	ND	0

[a]Specialized inpatient occupational rehabilitation, [b]Limb centres offer specialized, multidisciplinary outpatient rehabilitation to ULAs and are located in each of Norway's health regions, [c]To ease prosthesis use, [d]To promote grip without prosthesis use.
As prosthetist services are included in hospital inpatient rehabilitation and outpatient treatment at limb centres, these services were not evaluated separately. Some details of prosthetic adjustment and follow-up among adult acquired major ULAs in Norway have, however, been published previously (14). Percentages are not given due to the small sample size.
NA: not applicable; ND: no data; ULA: upper-limb amputee.

Table IV. *Pairwise associations between utilization of different health services among unilateral amputees (*n=*210)*

	Service																		
Service	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19
1	–																		
2	1.76	–																	
3	1.63	1.66	–																
4	3.48*	2.60	3.67*	–															
5	1.98*	NA	3.53*	2.71*	–														
6	1.55	NA	2.35*	1.43	3.63*	–													
7	1.55	NA	0.62	1.04	2.40*	3.29*	–												
8	1.71	NA	2.30	1.30	6.88*	1.69	1.20	–											
9	0.96	NA	5.68*	1.64	2.45	4.11*	3.42*	1.59	–										
10	1.42	NA	1.24	3.91*	2.40	2.67*	3.37*	2.49	1.12	–									
11	0.59	NA	2.00	4.27	2.24	9.71*	1.38	1.81	1.80	20.73*	–								
12	1.09	NA	1.16	1.45	4.88*	0.65	1.19	2.87*	1.95	0.47	1.58	–							
13	0.77	NA	2.68*	1.27	5.13*	1.91	1.92	1.63	1.43	3.75*	2.39	5.13*	–						
14	0.49	NA	1.23	1.56	1.71	1.26	1.16	3.37*	5.64*	1.87	2.01	4.30*	NA	–					
15	0.70	NA	1.24	1.11	0.41*	6.71*	1.77	0.93	2.09	2.21	2.29	1.40	NA	NA	–				
16	2.28	NA	1.32	1.36	0.46	0.46	0.54	1.06	3.10	2.09	4.89	0.81	NA	NA	4.38*	–			
17	1.35	NA	0.81	0.51	1.80	1.78	5.62*	1.94	2.67	3.22*	5.76	1.60	NA	NA	1.62	2.33	–		
18	1.93	NA	1.00	0.69	0.60	0.37	1.06	0.87	2.03	NA	NA	3.88	NA	NA	NA	2.23	NA	–	
19	4.87	NA	1.65	0.78	2.07	0.23	0.80	0.79	0.78	0.91	NA	0.60	NA	NA	1.92	2.50	NA	NA	–

*Significant at the 5%-level, i.e. confidence interval not including 1.
Pairwise associations were calculated using logistic regression and are given as adjusted odds ratios (aORs) for utilization of one service given utilization of another service. The aORs were adjusted for gender, ethnicity (native country), age at amputation, amputation level, amputation cause, time since the amputation and occupational status at amputation. Services: 1, hospital inpatient treatment (rehabilitation ward); 2, hospital inpatient treatment (other ward); 3, hospital outpatient treatment (limb centre); 4, private rehabilitation centre (inpatient treatment); 5, community-level physiotherapy; 6, community-level occupational therapy; 7, employment services; 8, occupational health services; 9. community social worker; 10, psychiatrist/psychologist (in/outpatient); 11, psychiatrist/psychologist (community-level); 12, pain treatment (general practitioner); 13, pain treatment (specialized outpatient clinic); 14, pain treatment (other in/outpatient treatment); 15, home care/home nursing care; 16, peer support; 17, post-amputation stump surgery to ease prosthesis use; 18, post-amputation stump surgery to promote grip without prosthesis use; 19, other treatment. Specifications of "other ward" and "other treatment" are given in footnotes to Table II.
NA: not applicable; association not possible to calculate.

Table V. *Pain last 12 months before survey in amputees amputated > 12 months before survey*

	All amputees ($n=214$)			Unilateral amputees ($n=205$)			Bilateral amputees ($n=9$)		
	n	%	95% CI	*n*	%	95% CI	*n*	%	95% CI
Phantom pain	130[a]	60.7	54.2–67.3	127	62.0	55.3–68.6	3	33.3	2.5–64.1
Stump pain	119[b]	55.6	49.0–62.3	114	55.6	48.8–62.4	5	55.6	23.1–88.0
Musculoskeletal pain[c]	167[d]	78.0	72.5–83.6	161	78.5	72.9–84.2	6	66.7	35.9–97.5
At least 1 pain type	192	89.7	85.7–93.8	185	90.2	86.2–94.3	7	77.8	50.6–100.0

[a]$n=5$ reported solely phantom pain ($n=4$ unilateral, $n=1$ bilateral amputees), [b]$n=3$ reported solely stump pain (all unilateral amputees), [c]Pain in at least 1 of: neck/upper back, shoulders, lower back or non-amputated arm below shoulder level, [d]$n=50$ reported solely musculoskeletal pain ($n=49$ unilateral, $n=1$ bilateral amputees).
CI: confidence interval.

13.5–23.9) had utilized at least one level of psychologist/psychiatrist treatment and 31.3% (67/214; 95% CI 25.1–37.5) had used at least one type of specified pain treatment. In contrast, no bilateral amputees reported utilization of these treatments. Several statistically significant pairwise associations between utilization of different health services were noted. For instance, ULAs who had utilized psychologist/psychiatrist treatment in in/outpatient care were much more likely to have utilized a community-level psychologist/psychiatrist than ULAs who had not utilized such treatment in in/outpatient care (adjusted odds ratio (aOR) = 20.73) (Table IV).

Overall satisfaction, perceived benefit and unmet need

Fifty-five percent of subjects (95% CI 48.1–61.9) were satisfied with the health services utilized (overall satisfaction), 23.5% were "very satisfied" and 9.0% were "very dissatisfied". There was no statistically significant difference between unilateral and bilateral amputees. Tables II and III show that the reported benefit of each service was generally high. The most important exceptions include the employment services, the occupational health services, in/outpatient psychologist/psychiatrist treatment and specialized outpatient pain treatment. For several services, especially at the community level, the reported unmet need for utilization was considerable.

Pain and pain treatments

Table V shows that most ULAs reported having experienced at least one type of pain during the last year. Table VI shows that the reported utilization of specified pain treatments in ULAs reporting pain was low. The frequent occurrence of more than one pain type (Table V) did not allow for independent analyses of utilization within each pain type. Excluding treatment non-users, the mean number of pain treatments utilized was 1.4 (95% CI 1.23–1.55). The reported unmet need for utilization of these treatments was low.

Background factors

Significant associations were found between health services utilization and several background factors, e.g. amputation level and aetiology (Table VII). Furthermore, ULAs with ≥4 years education and ULAs residing in Western Norway were more likely than those with fewer years of education and those residing in Eastern Norway to report hospital inpatient treatment in a rehabilitation ward as useful (aOR 5.23, 95% CI 1.25–21.96 and aOR 7.55, 95% CI 1.04–54.83, respectively). Current prosthesis wearers were more likely than non-wearers to rate community-level physiotherapy as useful (aOR 4.48, 95% CI 1.08–18.66) and women and ULAs aged ≥40 years at survey were more likely than men and ULAs aged 18–39 years to rate community-level occupational therapy as useful (aOR 20.26, 95% CI 1.20–342.27 and aOR 24.17, 95% CI 2.67–218.97, respectively). Moreover, through or above elbow (proximal) ULAs were more likely than transradial ULAs to report a wish to utilize hospital inpatient treatment in a rehabilitation ward (aOR 8.45, 95% CI 1.42–50.31) and community-level occupational therapy (aOR 4.23, 95% CI 1.22–14.69). Non-ethnic Norwegian ULAs were more likely than ethnic Norwegian amputees to report a wish to utilize

Table VI. *Utilization of specified pain treatments among unilateral amputees reporting pain (*n=*185*[a]*)*

	Utilization (yes)[b]			Utilized treatment perceived useful (yes)			Wish to utilize non-utilized treatment (yes)		
Pain treatment	*n*	%	95% CI	*n*	%[c]	95% CI	*n*	%[d]	95% CI
General practitioner	41	22.2	16.2–28.1	24	72.7	57.5–87.9	10	10.8	4.5–17.0
Specialized outpatient clinic	28	15.1	10.0–20.3	13	52.0	32.4–71.6	13	13.1	6.5–19.8
Other in/outpatient treatment	17	9.2	5.0–13.4	8	72.7	46.4–99.0	13	12.0	5.9–18.2

[a]Unilateral amputees amputated >12 months before survey and reporting at least 1 type of pain during the last year, [b]$n=57$ reported utilization of at least 1 pain treatment (30.8%, 95% CI = 24.2–37.5), [c]Percentages were calculated as "(*n* perceiving treatment useful)/(*n* perceiving treatment useful + *n* not perceiving treatment useful)". Due to non-response regarding perceived benefit, the denominator in the calculation of these percentages does not equal *n* reporting utilization of each treatment, [d]Percentages were calculated as "(*n* reporting a wish to utilize treatment)/(*n* reporting a wish to utilize treatment + *n* reporting no wish to utilize treatment)". Due to non-response regarding wish to utilize non-utilized treatments, the denominator in the calculation of these percentages does not equal *n* reporting non-utilization of each treatment.
CI: confidence interval.

Table VII. *Significant associations between background factors and utilization of health services among unilateral amputees (*n*=214)*

Service and significant covariates	Utilized %	Logistic regression			
		cOR	95% CI cOR	aOR	95% CI aOR
Hospital inpatient treatment (rehabilitation ward)					
Amputation level					
Through or above elbow	47.6	2.59	1.44–4.64	2.33	1.21–4.48
Transradial	26.0	Ref	Ref	Ref	Ref
Time since the amputation					
≥40 years	25.0	0.40	0.17–0.93	0.36	0.13–1.03
20–39 years	23.4	0.37	0.19–0.70	0.35	0.16–0.76
<20 years	45.5	Ref	Ref	Ref	Ref
Hospital outpatient treatment (limb centre)					
Cause of amputation					
Traumatic	28.8	0.34	0.16–0.72	0.35	0.15–0.85
Other	54.5	Ref	Ref	Ref	Ref
Community-level physiotherapy					
Gender					
Women	75.0	2.93	1.31–6.59	5.34	1.99–14.30
Men	50.6	Ref	Ref	Ref	Ref
Cause of amputation					
Traumatic	57.1	1.80	0.85–3.83	3.13	1.28–7.64
Other	42.4	Ref	Ref	Ref	Ref
Time since the amputation					
≥40 years	30.6	0.27	0.12–0.60	0.17	0.06–0.48
20–39 years	55.8	0.76	0.42–1.40	0.62	0.29–1.32
<20 years	62.4	Ref	Ref	Ref	Ref
Community-level occupational therapy					
Gender					
Women	58.3	4.40	2.08–9.27	5.92	2.32–15.15
Men	24.2	Ref	Ref	Ref	Ref
Amputation level					
Through or above elbow	43.9	2.88	1.57–5.27	2.05	1.01–4.16
Transradial	21.4	Ref	Ref	Ref	Ref
Time since the amputation					
≥40 years	5.6	0.07	0.016–0.31	0.05	0.01–0.27
20–39 years	20.8	0.31	0.16–0.61	0.31	0.13–0.73
<20 years	45.5	Ref	Ref	Ref	Ref
Employment services					
Age at amputation					
≥40 years	19.2	0.34	0.15–0.79	0.10	0.03–0.40
20–39 years	43.8	1.12	0.60–2.10	0.42	0.14–1.26
<20 years	41.1	Ref	Ref	Ref	Ref
Time since the amputation					
≥40 years	19.4	0.34	0.14–0.85	0.20	0.07–0.60
20–39 years	39.0	0.90	0.49–1.64	0.62	0.29–1.33
<20 years	41.6	Ref	Ref	Ref	Ref

cOR: crude odds ratio; CI: confidence interval; aOR: adjusted odds ratio, controlled for gender, ethnicity (native country), age at amputation, amputation level, amputation cause, time since the amputation and occupational status at amputation (included $n=210$); Ref: reference category.

hospital inpatient treatment in a rehabilitation ward (aOR 17.65, 95% CI 1.23–252.69).

DISCUSSION

Our main findings were that utilization of health services in major ULAs was relatively low, that the utilized services mainly were reported as useful and that, for several non-utilized services, considerable unmet needs for utilization were reported. A considerable discrepancy between reported pain and utilization of specified pain treatments was noted. Several background factors were significantly associated with utilization, reported benefit and reported wish to utilize the health services examined.

Low utilization of health services among amputees was also described by Whyte & Carroll (4), and may, in part, be explained by the amputees lacking information about available services and their potential benefit. The rehabilitation of ULAs in Norway is not standardized (13), and thus access to several services may depend on the amputee's initiative. Furthermore, healthcare providers may ration access to services such as physiotherapy and occupational therapy, which often depend on referral from a general practitioner (GP). Other factors may include communication barriers (15, 16), waiting lists that are too long, and regional differences in availability of services (13). However,

Norway has a well-organized public health system offering health services at no/low cost for the amputee, and issues related to treatment expenses are less likely to explain non-use.

Existing literature suggests that phantom limb pain and residual limb pain diminishes with time, that persistent phantom limb pain is most often intermittent, and that musculoskeletal pain may often be slight, and not require specific pain treatment (15, 17–21). This may, in part, explain the low utilization of specified pain treatments. However, in a recent study (22) present musculoskeletal pain was graded as bothersome, suggesting that for this type of pain, other factors may be more likely to explain non-use. For instance, the amputees may have found other methods to cope with their pain (4, 15, 16). Furthermore, as phantom limb pain frequently is discussed in the literature as intractable, some individuals may give up seeking treatment (4).

In accordance with earlier literature (4), our findings suggest that a GP may provide useful pain treatment. A low satisfaction rating for specialized outpatient pain treatment suggests that this service should be evaluated further. To some extent, this rating may indicate unrealistically high expectations of this treatment (8) in amputees with continued and/or intractable pain, emphasizing the importance of conveying adequate information to the amputees and promoting realistic expectations of the available treatments. The high percentage of amputees rating "other pain treatment" as useful calls for further investigation of the contents of, and indications for, this treatment. It might also be useful to assess the prevalence of amputation neuroma and experiences with neuroma-specific treatment among ULAs reporting stump pain.

Our findings suggest that specialized healthcare in rehabilitation wards, limb centres and private rehabilitation centres is useful in ULA rehabilitation, and that these services should be strengthened. Such strengthening may increase utilization and thus prevent disability (5, 17, 23). Furthermore, the community-level health services were in great demand and should probably be offered to a greater extent. Thus, coordination of different levels and types of health services seems important.

Amputation may have severe consequences in terms of employment (4, 6, 13), and receipt of occupational services may improve the amputees' prognosis for return to work (17, 23, 24). However, the low reported benefit of the occupational health services and the employment services observed in our study suggest that these services may not have been optimal. It is likely that better cooperation between the specialized rehabilitation services, the employment services and the occupational health services could reduce work-related disability in major ULAs.

The long-term association between acquired upper-limb loss and mental health is not clear (25–27). It is, however, known that amputees frequently manifest emotional reactions such as grief, anxiety and depression (1, 28), and our findings regarding psychologist/psychiatrist utilization suggest that post-amputation mental distress should be recognized in ULA rehabilitation. A strong association between community-level and in/outpatient psychologist/psychiatrist treatment suggest that these two service levels supplement each other. The observed differences regarding utilization and perceived benefit may be explained by community-level mental health care often being offered later and for a longer time period than in/outpatient evaluations conducted shortly post-amputation. Furthermore, the community-level services may mainly be offered to ULAs identified as in need of further services when still in in/outpatient care. A spontaneous decline of symptoms with increasing post-amputation time (1, 28, 29) may lead to a more favourable view of the continued treatment. Factors such as lack of resources (i.e. lack of a community psychologist/psychiatrist) and the use of other mental health services (e.g. a psychiatric nurse) may also have affected our findings. We suggest additional, longitudinal studies to further assess the need for mental health services in acquired major ULAs.

Peer visitation may facilitate the rehabilitation process by the peer demonstrating practical skills and giving advice regarding accomplishment of everyday activities. Earlier studies have found peer visitation to enable patients better to cope with depression, fear and helplessness. A coordinated multidisciplinary approach balancing professional therapy with peer therapy has been demonstrated as the most effective (10, 30). Our findings of a low utilization rate and a considerable unmet need for this service, especially among bilateral ULAs, suggest that peer support should be strengthened in future ULA rehabilitation.

The results of the present study suggest that surgery to ease prosthesis use (i.e. stump shortening/lengthening or osseointegration (16, 31, 32)) may be useful to major ULAs. As expected, only a few amputees had undergone grip-promoting surgery (33). Low utilization of home care and home nursing care may be explained by ULAs often performing everyday activities one-handedly or with prostheses (3, 17).

Our findings regarding gender and educational level are in accordance with earlier literature addressing associations between background factors and satisfaction with healthcare in amputees (9). However, our study also provides new information. We found that the utilization and the reported unmet need for utilization of rehabilitation wards and community-level occupational therapy was higher in proximal than in transradial ULAs, suggesting a need for extra rehabilitation in these ULAs. Furthermore, our findings suggest that more frequent referral to the employment services should be considered in amputees over 40 years of age at amputation, and that community-level occupational therapy might be especially useful in this age group. Also, more frequent referral to rehabilitation wards should be considered among non-ethnic Norwegian amputees. It seems that cause of amputation may affect health services utilization, possibly due to differences in co-morbidity between traumatic and non-traumatic ULAs. The observed negative association between post-amputation time and utilization of several health services may reflect an increasing availability of services during the past decades. We recommend further studies on the importance of these and other background factors to ULA health services utilization and satisfaction.

It is likely that our findings may apply to other western countries (13), with caution regarding differences in healthcare organization. There are, however, some limitations to this study. A relatively low response rate may have produced selection bias; although our analyses of background factors

indicate that the questionnaire responders may be considered as representative of the sampling frame, we have no knowledge of health services utilization and experiences with rehabilitation among the non-responders. Information bias may have been introduced by missing data; if those satisfied have a larger chance of responding to questions on benefit, our estimates of service usefulness may be too high. Correspondingly, our estimates of unmet needs for utilization may be too high. Recall bias may have affected reported utilization, and the time between amputation and survey may have affected the reported unmet need for healthcare. Our sample size of bilateral amputees was small and our findings regarding these ULAs should be interpreted with caution. Another probable limitation of this study is the use of a non-standardized satisfaction questionnaire.

In conclusion, our findings suggest that several health services available to acquired major ULAs should be strengthened. Establishing routines to ensure access to optimal rehabilitation tailored to meet individual needs may prevent disability. Such routines should include conveying adequate information to the ULAs about the available services. We recommend additional, longitudinal studies to further assess the need for mental health care and pain treatment in acquired major ULAs.

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