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The prevalence and characteristics of phantom limb pain and non-painful phantom phenomena in a nationwide survey of 3374 unilateral limb amputees

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Disclosures

The authors declare that there is no conflict of interest regarding the material discussed in the manuscript.

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Abstract

The experience of phantom limb pain (PLP) is a common consequence of limb amputation, resulting in severe impairments of the affected person. Previous studies have shown that several factors such as age at or site of amputation are associated with the emergence and maintenance of PLP. In this cross-sectional study we assessed the presence of several phantom phenomena including PLP and other amputation-related information in a sample of 3,374 unilateral upper and lower limb amputees. Clinical and demographic variables (age at amputation, level of amputation) explained 10.6% of the variance in PLP and perceptual variables (intensity of phantom limb sensation (PLS), referred sensations, intensity of telescoping, residual limb pain (RLP) intensity) explained 16.9% of the variance. These variables were specific for PLP and not for RLP. These results suggest that distinct variables are associated with PLP (age at amputation, level of amputation, PLS intensity, referred sensations, intensity of telescoping, RLP intensity) and RLP (PLP intensity) and point at partly different mechanisms for the emergence and maintenance of PLP and RLP.

Perspective

Clinical/demographic variables as well as perceptual variables are two major components related to PLP and explain ~11% and ~17% of the variance. These results could potentially help clinicians to understand which factors may contribute to chronic phantom limb pain.

Keywords: amputation, phantom limb pain, residual limb pain, phantom limb sensations, telescope

Introduction

After an amputation, most amputees report phantom limb awareness (PLA), i.e., the continued presence of their removed limb, [e.g. 31] which is stable over time [30]. In addition, they experience specific sensory and kinesthetic sensations (phantom limb sensations, PLS) or even pain in the amputated body part (phantom limb pain, PLP) [e.g. 18]. A peculiar phenomenon experienced by some amputees is a shrinking or expansion of the phantom limb, referred to as "telescoping": the distal part of the limb is relocated to more distal or proximal positions or even moves into the residual limb. These sensations have to be distinguished from non-painful and painful sensations in the residual limb (residual limb sensations, RLS and residual limb pain, RLP). PLP affects quality of life [46], has high rates of chronicity [8] and is difficult to treat [1,2]. Current explanations of PLP highlight the influence of peripheral, spinal and brain changes [18,21] in the development of PLP.

In a longitudinal study, Bosmans et al. [8] reported that being male, a lower versus upper limb amputation and a longer time since amputation are protective factors for PLP intensity. In contrast, in a cross-sectional design, Dijkstra et al. [13] reported that a lower limb or a bilateral amputation, older age at amputation and a short residual limb are risk factors for PLP. In addition, chronic pain before the amputation as well as sub-acute pain post amputation have been shown to predict both the incidence and severity of PLP, RLP and PLS 12 months post-amputation [36]. However, these studies so far mainly focused on clinical and demographic variables; we know little about the potential influence of perceptual and behavioral variables.

Psychological variables such as depression and anxiety before the amputation have also been shown to predict the severity of PLP, RLP and PLS at 12 months post-amputation [36] but the data are not consistent [23,28,49]. In cross sectional studies, depressive symptoms predicted PLP [16] and have a high prevalence [10]. In a prospective study, Richardson et al. [45] found that a passive coping style (especially catastrophizing) prior to amputation was also associated with PLP.

Studies so far have small samples [e.g. 14,34]. The goal of this study was to examine which variables are related to PLP in a large sample of more than 3000 amputees at varying time-points after the amputation and to specifically investigate perceptual and behavioral variables (time of prosthesis usage, PLS intensity, referred sensations, telescoping intensity, telescope length, RLP intensity) beyond demographic and clinical variables (sex, reason for amputation, age at amputation, time since amputation, level of amputation, presence of pain before amputation). We added perceptual and behavioral variables because they were found to contribute to brain changes, which have been related to phantom limb pain [c.f. 4]. To test for PLP specificity, we also examined which variables were related to RLP. For this purpose, we used multiple simultaneous linear regressions of demographic, clinical, perceptual and behavioral variables assessed in a cross-sectional nationwide survey. Most of the studies so far only investigated clinical and demographic variables [13,22,33]. For a better comparison with these studies, we therefore examined perceptual and behavioral variables in a separate regression analysis. In order to identify factors possibly underlying these phantom phenomena, we conducted in a second step a principal component analysis (PCA). We hypothesized that age at amputation and level of amputation are related to PLP [8,13]. In a subsample we investigated the influence of depression on PLP. Additionally, this paper provides reference data for demographic and clinical characteristics differentiated by site and extremity of amputation.

Material and Methods

Study Design and Sample Recruitment

The study is based on a cross-sectional nationwide survey that was conducted as part of the European Research Council Advanced Grant PHANTOMMIND ("Phantom phenomena: A window to the mind and the brain") on persons having undergone a unilateral amputation of one of their upper or lower limbs. In subsamples, part of the data were used for a study on body representation in dreams [6] (data on the site and time of amputation, residual limb length,

prosthesis use, lifetime prevalence of mental disorders, presence of post-amputation pain, and presence of non-painful phantom phenomena were included in logistic regression analyses using recalled body representation in dreams (impaired, intact, no memory) as dependent variable) and in a study on prosthesis ownership [5] (investigating the relationship between prosthesis ownership and PLP, RLP, PLS, sex, age, location and side of the amputation, dominance of the amputated limb, length of the residual limb, time since amputation, frequency of prosthesis use, and prosthesis type) by our group. The amputees were recruited from large data bases in public support institutions in several (11 of 16) states in Germany. To ensure data protection, prepared envelopes containing the patient information, informed consent forms, the questionnaires, and pre-paid return envelopes were sent by the respective office. Between August 2009 and November 2013 a total of 31,887 questionnaires were distributed to the selected amputees. ~3,000 questionnaires were returned as undeliverable and 3,862 questionnaires were completed. Participants with multiple amputations (n = 127) were excluded and data on them were published elsewhere [52]. All questionnaires were checked for completeness and plausibility, and incomplete or implausible questionnaires were completed or corrected via telephone interviews, whenever possible. Ultimately, our sample consisted of 3,374 amputees, corresponding to an inclusion rate of 10.6 %. All included participants gave written informed consent to take part in the study and the Ethics Committee of the Medical Faculty Mannheim of Heidelberg University approved the protocol, which adhered to the Declaration of Helsinki.

Assessment

This survey (see Supplemental Material) included core items of the Phantom Pain and Limb Phenomena Interview [55], an interview on prosthesis use, a modified version of the West Haven-Yale Multidimensional Pain Inventory [19] to separately assess phantom limb and residual limb pain, items based on the Trinity Assessment of Body Plasticity questionnaire [37], and items assessing dream recall frequency [6,47]. The survey used a methodology that focused on pictorial

materials to obtain a better grasp of the exact nature of the phenomena, which can often not be assessed properly in a verbal manner. Therefore, the location of the amputation or the different phenomena could be marked in body schemas. The survey consisted of 53 items including drawings, divided into 5 parts: (A) demographic information, characteristics of the amputation, prosthesis and medication use, general physical and mental health and well-being; (B) measures of PLP; (C) measures of PLS; (D) measures of RLP; and (E) measures of empathy for pain, attitude towards transplantations, sleep, dreams, and ethnicity. There were different versions for arm and leg amputees. The used items were (A) age, sex (male/female), location (side: right/left, site: arm/leg) and level of amputation (%, pictorial material), age at amputation, time since amputation, reason for amputation (accident/ injury/ congenital/ infection/ tumor/ vascular disease/ other reason), presence of pre-amputation pain (yes/no), handedness before amputation (right/left), prosthesis usage per week (0 = never, 1 = less than twice, 2 = every other day, 3 = almost daily, 4 = daily), daily prosthesis usage (0 = never, 1 = 1-2 hours, 2 = several hours, 3 = morning or afternoon continuously, 4 = whole day), prostheses experienced as part of the body (0-10), lifetime prevalence of mental disorder (yes/no), family history of a mental disorder (yes/no); (B) PLP intensity (0-10); (C) PLS intensity (0-10), referred sensations (yes/no), telescoping intensity (0-10), telescope length (pictorial material); (D) RLP intensity (0-10); (E) attitude toward the transplantation of a limb (arm, leg) or an internal organ (kidney) (very comfortable / comfortable / neither / uncomfortable / very uncomfortable). Time of prosthesis usage was calculated as the product of prosthesis usage per week and daily prosthesis usage. Depression was assessed with the Center for Epidemiological Studies Depression Scale (CES-D) [27,44].

Data Analysis

Statistical analyses were conducted using *IBM SPSS Statistics Desktop for Windows, Version* 21 *(IBM, Armonk, NY,* USA). For a better comparison of the clinical and demographic data with other studies in which amputees were subdivided into groups (PLP and non-PLP), we

split our sample in three groups taking into account the variability of PLP intensity and frequency. The non-PLP group (n = 1,321) never experienced PLP and 0 on the PLP NRS. The high PLP group (n = 1,047) reported a PLP frequency of at least 1-2 times per week with a minimum of 3 on the PLP NRS scale (a similar criterion was used previously [12]). All other amputees fell into the low-PLP group (n = 1,006). We compared the means of the three groups for age, age at amputation, time since amputation, duration of pre-amputation pain, level of amputation (%), PLP intensity, PLS intensity, RLP intensity, telescoping intensity, telescope length (%), prosthesis experienced as part of the body with an univariate ANOVA with Bonferroni corrected post-hoc tests, and the categorical variables of sex, side of amputation, type of amputated limb, pain before the amputation, telescoping, and referred sensation with a χ^2 test.

In order to differentiate between clinical/demographic and perceptual/behavioral factors, we examined the relationship of these two sets of variables and PLP intensity in separate multiple simultaneous linear regression analyses in the entire sample. To evaluate the additive value of clinical/demographic and perceptual/behavioral factors we conducted a multiple simultaneous regression analysis of both sets of factors in the next step. We chose multiple simultaneous linear regressions to determine the explained variance of a set of variables. In order to restrict the analyses to variables of potential relevance, we first conducted individual linear regressions to determine the individual influence of each variable on PLP and selected those variables yielding an amount of explained variance (R^2) in the two upper quartiles of the distribution, i.e. more than the median of 2.7 %. We report R^2 and not standardized β. The set with clinical/demographic variables consisted of questions about sex (male/female), reason for amputation (accident/ injury/ congenital/ infection/ tumor/ vascular disease/ other reason), age at amputation, time since amputation, level of amputation (pictorial material), presence of pain before amputation (yes/no); the set of perceptual/behavioral variables consisted questions about time of prosthesis usage (product of prosthesis usage per week (0 = never, 1 = less than twice,

2 = every other day, 3 = almost daily, 4 = daily) and daily prosthesis usage (0 = never, 1 = 1-2 hours, 2 = several hours, 3 = morning or afternoon continuously, 4 = whole day)), PLS intensity (0-10), referred sensations (yes/no), telescoping intensity (0-10), telescope length (%, pictorial material), RLP intensity (0-10).

To evaluate if the results of the regression analysis were specific for PLP intensity, we repeated them with RLP intensity (0-10) as the predicted variable and included PLP intensity (0-10) as an independent variable. In order to identify factors possibly underlying these phantom phenomena, we conducted a principal component analysis (PCA) with the items age at amputation, level of amputation (%, pictorial material), pain before amputation (yes/no), PLP intensity (0-10), PLS intensity (0-10), intensity of telescoping (0-10) and RLP intensity (0-10) with orthogonal rotation (varimax). We verified the sampling adequacy for the analysis with the Kaiser-Meyer-Olkin measure with values above 0.5 as acceptable limit. Further, sufficiently large correlations between items for the PCA were verified using Bartlett's test of sphericity [17].

Results

Sample description

From our sample of 3,374 unilateral limb amputees, 80.5 % (n = 2,715) were male. The mean age ± standard deviation was 64.1 ± 16.0 (range: 18-98) years. The cause of the amputation was reported as related to accident (53.5 %), injury (7.3 %), congenital (2.9 %), tumor (7.5 %), infection (4.7 %), vascular disease (11.4 %), and other reasons (12.7%). The mean age at amputation was 31.2 ± 19.8 (range 0-93) years, which resulted in a mean time since the amputation of 33.2 ± 22.7 years (median = 31.0, range 0-86) at the time of the study. Upper limb amputations were present in 26.9% of the amputees (n = 909) and 73 % (n = 2,462) had a lower limb amputation (n = 3 missing data), with 45.1 % (n = 1,520) being right-sided and 54.9 % (n = 1,852) being left-sided amputees (n = 2 missing data) (see Figure 1). On average, the participants lost more than half of the respective limb (length of the residual limb 42.3 ± 22.5 %).

Insert Figure 1 about here

On average, 79.6 % (n = 2,687) of the amputees were regularly using a prosthesis (46.6 % / 425 upper limb, 91.8 % / 2,264 lower limb). Upper limb amputees most frequently employed cosmetic (24.3 %), myoelectric (15.5 %) or cable-controlled (6.8 %) prostheses. Lower limb amputees most frequently used a modular (37.3 %), or exoskeletal construction (28.8 %). In total, 59.6 % n = (2,010) of the amputees experienced PLP. Of those, 32.6 % (1,101) reported PLP at least once per week (see Figure 2a). The mean PLP intensity over the last four weeks (on a numerical rating scale (NRS), ranging from 0-10) of the total sample was 2.66 ± 3.05 (range 0-10), and of all amputees having PLP 6.01 ± 2.25 (range 1-10), (see Figure 2b). Forty-nine percent (1,653) experienced RLP, 28.6 % (n = 967) had RLP at least once per week. The mean RLP intensity of the total sample was 2.76 ± 3.23 (range 0-10) and of all amputees having RLP 5.64 ± 2.25 (range 0.5-10). In the sample, 22.2% (n = 750) reported telescoping with a mean NRS intensity of 5.17 ± 2.53 (range 0.5-10, total sample 1.07 ± 2.39, range 0-10) and 15.9% (n = 537) reported referred sensations (sensations in the phantom elicited by stimulation of parts of the body, for example, the face). Regarding body plasticity, we also assessed attitudes towards the transplantation of a limb or an internal organ. On average, the sample was a little more comfortable (scale 0 = very comfortable, 1 = comfortable, 2 = neither, 3 = uncomfortable, 4 = very uncomfortable) imaging a transplantation of a kidney (1.3 ± 1.3) compared to an arm (2.0 ± 1.3) or leg (2.1 ± 1.3). Tree-hundred-and-thirteen amputees (9.3%) reported a lifetime prevalence of mental disorder, and 204 (6.1%) amputees had a family history of a mental disorder.

Insert Figures 2a & b about here

Group descriptions

Age at amputation was lowest in the non-PLP group, medium in the low-PLP and highest in the high-PLP group ($F(1,2) = 174.635$, $p < 0.001$, see Table 1a for the mean values, standard deviations, ranges and p-values of post hoc tests). In line with this, time since amputation was highest in the non-PLP group, medium in the low-PLP and lowest in the high-PLP group ($F(1,2) = 120.136$, $p < 0.001$). Presence of pain before amputation was lowest in the non-PLP group, medium in the low-PLP and highest in the high-PLP group ($\chi^2[2] = 61.618$, $p < 0.001$). The level of amputation was more distal in the non-PLP, medium in the low-PLP and more proximal in the high-PLP group ($F(1,2) = 90.475$, $p < 0.001$).

The different phantom phenomena (PLP ($F(1,2) = 3,585.782$, $p < 0.001$), PLS ($F(1,2) = 276.942$, $p < 0.001$), RLP ($F(1,2) = 67.224$, $p < 0.001$), and intensity of telescoping ($F(1,2) = 80.715$, $p < 0.001$) showed a similar pattern with low intensity values in the non-PLP, medium values in the low-PLP and high values in the high-PLP group. The non-PLP group experienced the prosthesis more strongly as part of the body compared to the low-PLP and the high-PLP group ($F(1,2) = 68.672$, $p < 0.001$.). The number of amputees with a telescope ($\chi^2[2] = 113.483$, $p < 0.001$) or referred sensations ($\chi^2[2] = 143.187$, $p < 0.001$) was lowest in the non-PLP, medium in low-PLP and highest in high-PLP. The length of the telescope was not significant different between groups. Reference data for non-PLP, low-PLP and high-PLP in all these variables for right and left arm amputees are provided in Table 1b and for right and left leg amputees in Table 1c. Values for all PLP amputees (pooled low-PLP and high-PLP) can be found in Table S1 of the supplementary material.

Insert Table 1 a&b&c about here

Relationship of clinical, demographic, perceptual and behavioral variables and Phantom Limb Pain

The regression analyses of all separate variables revealed a median of 2.7 % explained variance per variable (see table 2). Thus all variables with a percentage of explained variance higher than 2.7% were included in the subsequent multiple regression analyses. As no behavioral variable was above our criterion we called the perceptual/behavioral variables perceptual variables.

Insert Table 2 about here

Relationship of clinical/demographic variables and Phantom Limb Pain

Multiple simultaneous regression analyses with the set of independent clinical and demographic variables (age at amputation, level of amputation (%)) explained 10.6% of the variance ($R^2 = 0.106$, $p < 0.001$, β age at amputation = 0.037, β level of amputation = -0.036). The β coefficients suggest that the higher the age at amputation and the shorter the residual limb, the more intense the PLP. For the explained variances of each variable see Table 2.

Relationship of perceptual variables and Phantom Limb Pain

Multiple simultaneous regression analyses with the set of independent perceptual variables (PLS intensity, referred sensations, intensity of telescoping, RLP intensity) explained 16.9% of the variance ($R^2 = 0.169$, $p < 0.001$, β PLS intensity = 0.357, β referred sensations = 0.604, β intensity of telescoping = 0.119, β RLP intensity = 0.125). The β coefficients suggest that the higher the PLS, referred sensation, intensity of telescoping and RLP intensity, the more intense the PLP. For the explained variances of each variable see Table 2. By adding depression, the regression explained 21.9% of the variance (analysis of a subsample, regression of perceptual variables without depression in this subsample reveals an explained variance of 20.0%). For more details, please see Table S3 of the supplementary material.

Relationship of combined clinical/demographic and perceptual variables and Phantom Limb Pain

Combined multiple simultaneous regression analyses with the set of independent clinical/demographic and perceptual variables above our criterion (age at amputation, level of amputation (%), PLS intensity, referred sensations, intensity of telescoping, RLP intensity) explained 23.8% of the variance ($R^2 = 0.238$, $p < 0.001$, β age at amputation = 0.033, β level of amputation = -0.030, β PLS intensity = 0.323, β referred sensations = 0.608, β intensity of telescoping = 0.083, β RLP intensity = 0.113).

Relationship with residual limb pain

The explained variance of all clinical/demographic variables for the prediction of RLP was low, between 0 and 1.7% (see Table 3). For the perceptual variables only PLP intensity explained a variance above 2.7 % (PLP intensity: $R^2 = 0.031$, $p < 0.001$).

Insert Table 3 about here

Factors underlying Phantom Phenomenarevealed with principal component analysis

As a prerequisite for applying the PCA, sampling adequacy was confirmed with the Kaiser-Meyer-Olkin measure (KMO = 0.813 across all items; KMO values for individual items > 0.77), and sufficiently large correlations between items with Bartlett's test of sphericity ($\chi^2(21) = 1{,}905.943$, $p < 0.001$). The PCA results suggest two factors underlying phantom phenomena: Two components had eigenvalues larger than Kaiser's criterion of 1 and the scree plot confirmed retaining two components. The two components together explained 45.61 % of the variance (Table 4). Component 1 appears to represent perceptual characteristics of phantom phenomena and component 2 appears to represent clinical/demographic characteristics of the patients. These results suggest that these two factors are important for phantom phenomena.

Insert Table 4 about here

Discussion

The present study reports clinical and demographic characteristics and investigated variables related to PLP intensity in a large sample of upper and lower limb amputees using data from a nationwide questionnaire survey. For the relationship of PLP with clinical/demographic variables, the variables age at amputation and level of amputation (%) explained most of the variance. For the perceptual variables, PLS, RLP, intensity of telescoping and presence of referred sensations explained most of the variance. A PCA revealed two factors that can be considered as (a) perceptual characteristics and (b) clinical/demographic characteristics.

By taking into account only epidemiological studies with more than 500 amputees, the reported prevalence of PLP in the literature varies between 50 and 85 % [16,39,50,51,53]. However, the frequency of PLP was not always reported in these studies. Our PLP prevalence of 59% is in the lower range compared to the findings reported above. Interestingly, intensity and frequency of PLP show a high variance in our sample. An amputee with a PLP intensity of 9 and a frequency of once every 6 months probably differs from an amputee with an intensity of 6 once a week. Thus, we believe that our approach of combining both measures for the grouping of the non-PLP, low-PLP and the high-PLP group achieves a better sub-grouping of amputees compared to a grouping based on PLP intensity or frequency alone.

Previous studies reported associations between PLP intensity and some of the variables explaining variance of PLP in our analyses (e.g. level of amputation (%), age of amputation, pain before amputation, PLS, RLP and depression). For example, for level of amputation, Fraser et al. [22] reported that the limbs of amputees with PLP-evoking trigger points were shorter. We found an association between shorter residual limbs and higher PLP. We did not assess if PLP

could be evoked by the stimulation of trigger points. However, the amputees with trigger points of the study by Fraser et al. [22] had more PLP than those without trigger points, suggesting a relation between more PLP and a shorter residual limb similar to our data.

We found that an amputation at a lower age is associated with less PLP. Previously, one study reported that subjects with congenital absence of an upper limb have no PLP and non-painful phantom limb phenomena and no cortical reorganization compared to traumatic upper-extremity amputees [20]. Another study found lower PLP frequencies in subjects with a congenital absence of a limb compared to those with surgical amputations [54]. In the latter study, the subjects with surgical amputations were split into amputees with the amputation before the age of 6 years and those who were older than 6 years, with lower PLP frequencies in the younger group. Dijkstra et al. [13] also reported that a higher age at amputation was a risk factor for PLP.

Interestingly, we found only a small influence of pain before amputation on PLP. Previously, it was reported that that acute and chronic pain before amputation and sub-acute pain post-amputation significantly predicted up to half of the variance in the incidence and severity of PLP, RLP and PLS 12 months post-amputation [36]. Similarly, acute PLP intensity predicted chronic PLP intensity at 6 and 12 months after the amputation, whereas pain before amputation predicted chronic PLP intensity at 24 months [26]. Other studies reported that PLP and pre-amputation pain were similar in localization and character shortly after the amputation but not in later, persistent PLP [33]. This finding was supported by Nikolajsen et al. [41], who noted that PLP was more frequent 1 week and 3 months after amputation in patients with pre amputation pain, but not 6 month after amputation. This could provide an explanation why this variable was not of high relevance in our data because the time since amputation in our sample was on average more than 33 years ago.

We found a positive association between PLP, PLS and RLP. Similar, Kooijmann et al. [35] observed a significant association between PLP, PLS and RLP. An explanation for these associations might be that RLP could possibly trigger PLP [28]. Marshall et al. [38] reported that

PLP, RLP and back pain accounted for 20% of the variance in pain interference. Kern et al. [34] reported high prevalence rates of RLP and PLS in amputees with PLP while the prevalence rates were low in amputees without PLP. The advantage of our results is that we could directly relate PLP intensity with the variables PLS and RLP. However, a conclusion on causality is still not possible. Painful referred sensations and % telescope length were reported to be positively related with PLP and cortical reorganization [24]. In another study, brain activations related to evoked phantom sensations were found bilaterally in SI and the intraparietal sulci, which significantly correlated with the intensity of evoked phantom sensations [3].

In a subsample analysis we did not find a strong relation of depression and PLP intensity. Previous reports did not report associations of depression and pain but rather a small predictive value (less than 1 % variance) of pain intensity on depression [9]. Horgan and MacLachlan [29] concluded that depression within the first years after the amputation is linked more strongly to the consequences of losing a limb and not to PLP and they reported that two years after the amputation the depression rates in amputees declined to rates similar to those in the general population. However, having PLP one year post amputation was associated with higher anxiety and depression scores in the week prior to the amputation [36].

This study has several limitations. First, the low response rate might have introduced some bias on the interpretation of the results and the generalizability. Second, we contacted all amputees in the database available to us and many of these were many years past amputation. Thus, our results are probably not representative for acute amputees. Additionally, there might be a recall bias for pain before the amputation. Third, we had a preponderance of male and lower limb amputees, which is quite representative for Germany [56] (30.46% upper- and 69.54% lower limb amputees). Fourth, in addition to pain intensity and frequency, duration of pain attacks would as well have been an interesting variable to consider for the grouping of patients, however, this would have increased the pain subgroups. Although we covered a broad range of possible variables related to PLP, we did not consider psychological variables such as coping

style nor peri-amputation variables (e.g. global and/or local anesthesia during amputation), genetic data, structural and functional brain data (e.g. cortical reorganization [15,19]) or quantitative sensory testing. In addition, we did not perform a longitudinal study where we could predict the onset of PLP but had to rely on cross-sectional and thus correlational data.

It has previously been proposed that genetic factors influence susceptibility to neuropathic pain [7], supported by genetic findings in animal data [11,42,48]. Pressure pain thresholds (as a measure of Quantitative Sensory Testing) before the amputation predicted PLP and RLP intensity one week after the amputation [40]. Higher pressure pain thresholds predict lower PLP and RPL intensity. However, after 6 months this prediction could not be replicated. In a study by Jensen et al. [32] it has been shown that cognitions, coping style, and social environmental variables predict 43% of the variance of PLP intensity and could influence depressive symptoms [25]. Catastrophizing predicted PLP six months after the amputation in another study [45]. Further, personality factors such as rigid and compulsive self-reliant personality assessed directly after the amputation were significantly correlated with PLP intensity 1 year after the amputation [43]. But it should be noted that other studies could not substantiate such a relationship [49].

Conclusion

This paper provides reference data for demographic and clinical characteristics differentiated for site and extremity of amputation. Clinical/demographic variables (older age at amputation and shorter residual limb) are related to PLP and explained ~11% variance. Perceptual variables (higher PLS, referred sensation, higher intensity of telescoping and higher RLP) are related to PLP and explained ~17% variance. A principal component analyses revealed two major components: perceptual characteristics and clinical/demographic characteristics.

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Figure Legends

Figure 1: Frequency of the amputation at the different sites of the body.

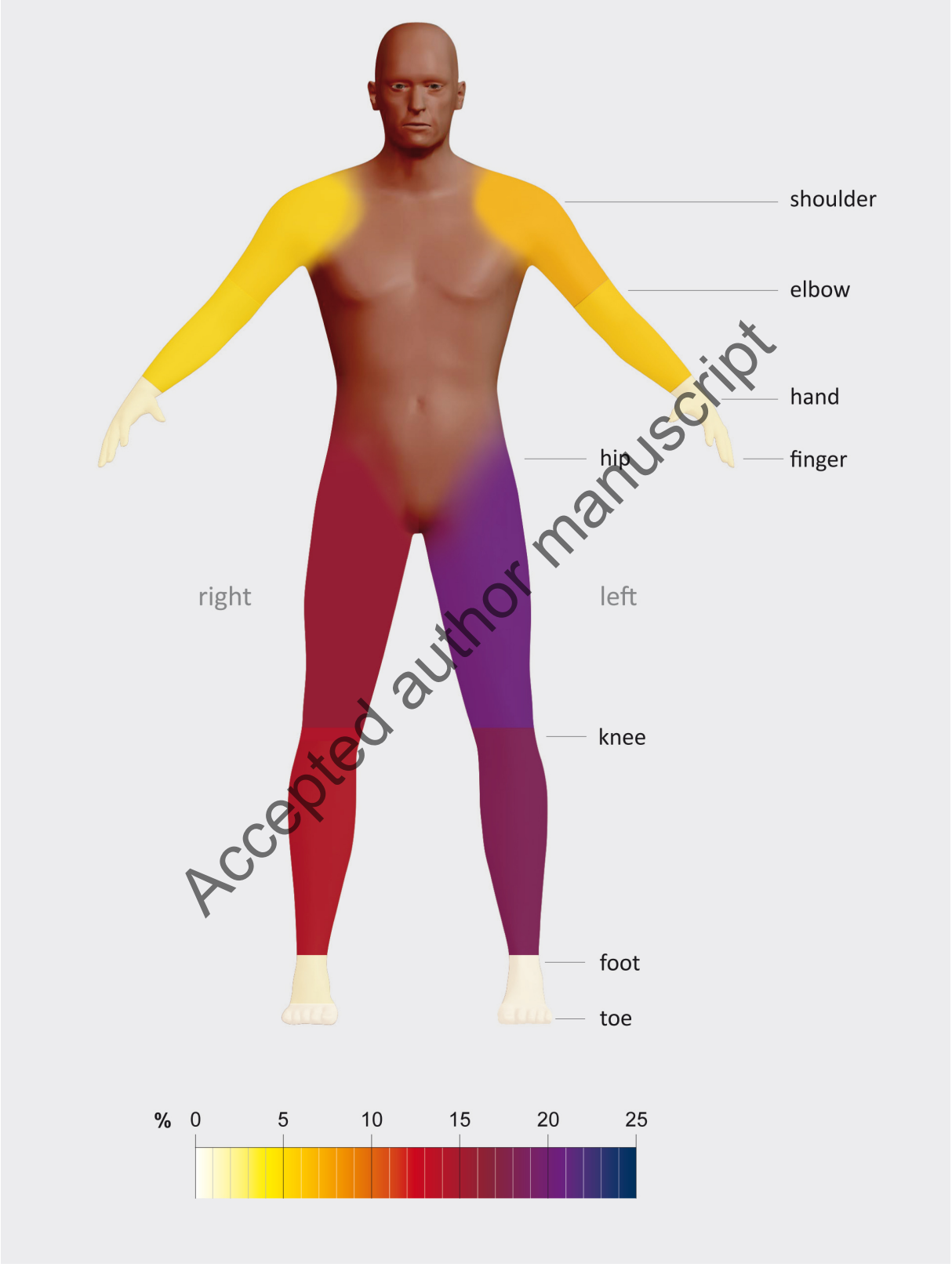


Figure 2: Number of amputees related to a) frequency of phantom limb pain (PLP) and b) intensity of PLP. Small numbers behind the bars are % of amputees.

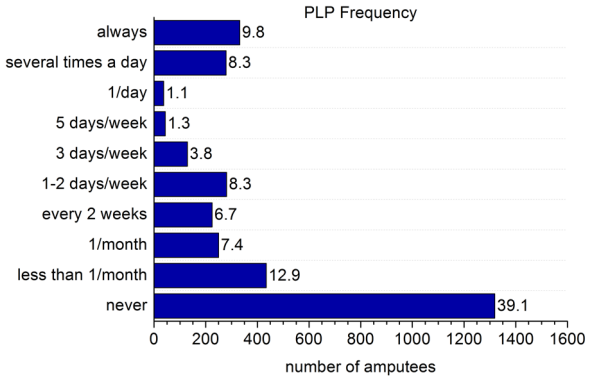


Figure 2a

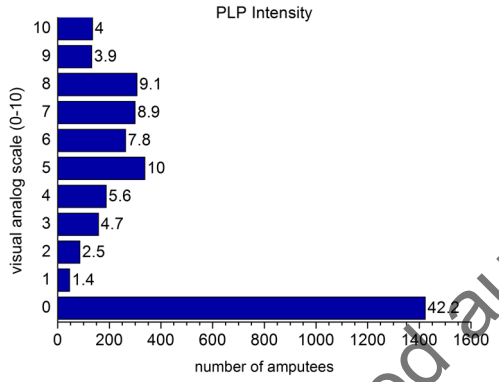


Figure 2b

Table 1a: Total sample: Clinical and demographic characteristics of the non-PLP group (never PLP and 0 on the PLP intensity NRS (0-10)), the high-PLP group (PLP frequency of at least a 1-2 times per week with a minimum of 3 on the PLP NRS scale), and all other patients in the low-PLP group.

	non-plp	**low-plp**	**high-plp**	**F-test/χ^2**	**post hoc tests**		
					non vs. low	**non vs. high**	**low vs. high**
n	1321	1006	1047				
sex (m/f)	1061/260	821/185	833/214	$\chi^2[2] = 1.403$, $p = 0.496$			
age in years	63.34 ± 16.48 (19-97)	64.63 ± 15.73 (19-98)	64.52 ± 15.52 (18-98)	$F(1,2) = 2.402$, $p = 0.091$			
age at amputation (years)	24.40 ±17.42 (0-93)	31.30 ± 18.78 (2-87)	39.12 ± 20.37 (2-88)	$F(1,2) = 174.635$, $p < 0.001$	**	**	**
time since amputation (years)	39.65 ± 22.0 (0-86)	33.35 ± 21.45 (0-74)	25.39 ± 22.41 (0-71)	$F(1,2) = 120.136$, $p < 0.001$	**	**	**
	median 41.0	median 31.0	median 18.0				
side of amputation (L/R)	707/612	554/452	591/456	$\chi^2[2] = 1.922$, $p = 0.383$			
limb (arm/leg)	481/837	172/834	256/791	$\chi^2[2] = 118.505$, $p < 0.001$	**	**	**
pain before amputation (y/n)	306/917	324/664	420/617	$\chi^2[2] = 61.618$, $p < 0.001$	**	**	**

duration pre amputation pain	56.3 ± 247.92	46.49 ± 144.33	70.07 ± 230.88	F(1,2) = 0.999, p = 0.369			
in weeks	(1-3300)	(1-1560)	(0-3276)				
reason for amputation:							
accident	735	521	549				
injury	105	77	64				
congenital	94	5	0				
infection	44	47	69				
tumor	77	115	62				
vascular disease	92	110	181				
other	174	131	122				
level of amputation (%)	48.58 ± 23.33 (0-98)	37.99 ± 20.44 (0-98)	38.37 ± 21.24 (0-97)	F(1,2) = 90.475, p < 0.001	**	**	
PLP intensity	0 ± 0 (0-0)	5.11 ± 3.0 (0-10)	6.29 ± 1.86 (3-10)	F(1,2) = 3585.782, p < 0.001	**	**	**
PLS intensity	1.27 ± 2.38 (0-10)	3.2 ± 3.0 (0-10)	3.9 ± 3.17 (0-10)	F(1,2) = 276.942, p < 0.001	**	**	**
RLP intensity	2.3 ± 3.1 (0-10)	2.39 ± 3.04 (0-10)	3.70 ± 3.37 (0-10)	F(1,2) = 67.224, p < 0.001		**	**
telescope (bigger/smaller/n)	15/163/1139	27/216/758	42/287/717	$\chi^2[2] = 113.483$, p < 0.001	**	**	**

intensity of telescoping	0.52 ± 1.67 (0-10)	1.09 ± 2.35 (0-10)	1.75 ± 2.95 (0-10)	$F(1,2) = 80.715$, $p < 0.001$	**	**	**
telescope length (%)	57.3 ± 23.6 (5-125)	57.0 ± 21.6 (1-120)	59.2 ± 21.4 (15-130)	$F(1,2) = 0.778$, $p = 0.460$			
referred sensation (y/n)	101/1216	167/834	269/773	$\chi^2[2] = 143.187$, $p < 0.001$	**	**	**
prosthesis (y/n)	991/330	848/157	848/198				
arm amputees	217/264	76/96	130/126				
leg amputees	772/65	772/61	718/72				
arm							
cosmetic	123	37	62				
cable-controlled	32	13	17				
myoelectric	71	22	48				
hybrid	1	1	2				
sauerbruch	7	4	1				
leg							
early care	8	14	23				
interim	19	10	34				

exoskeletal construction	238	223	248				
modular construction	315	747	263				
prostheses experienced as part of the body	6.61 ± 2.96 (0-10)	6.12 ± 3.03 (0-10)	4.99 ± 2.95 (0-10)	F(1,2) = 68.672, p < 0.001.	*	**	**

mean ± std (range) or n are depicted, m = male, f = female, y = yes, n = no, ** = p < 0.001, * = p < 0.01

Table 1b: Arm amputees: Clinical and demographic characteristics of the non-PLP group (never PLP and 0 on the PLP intensity NRS (0-10)), the high-PLP group (PLP frequency of at least a 1-2 times per week with a minimum of 3 on the PLP NRS scale), and all other patients in the low-PLP group.

	non-plp		**low-plp**		**high-plp**	
	right arm	**left arm**	**right arm**	**left arm**	**right arm**	**left arm**
n	225	256	75	97	126	130
sex (m/f)	180/45	193/63	69/6	84/13	109/17	16/114
age in years	63.83 ± 15.94 (24-97	62.02 ± 16.82 (19-93	64.77 ± 15.88 (30-92	69.05 ± 16.08 (27-91	62.91 ± 16.90 (24-93	63.55 ± 17.09 (30-90)
age at amputation (years)	18.42 ± 13.19 (0-70)	18.91 ± 14.00 (0-81)	25.19 ± 13.04 (5-72)	22.34 ± 11.72 (2-82)	28.11 ± 14.81 (2-81)	28.26 ± 13.55 (9-72)
time since amputation (years)	47.25 ± 18.08 (2-81)	44.90 ± 19.03 (1-82)	39.59 ± 19.28 (0-69)	46.73 ± 19.89 (4-74)	34.74 ± 22.04 (1-69)	35.28 ± 22.12 (1-69)
	median 49.0	median 46.0	median 37.0	median 53.0	median 33.0	median 32.5
pain before amputation (y/n)	26/169	11/201	10/64	11/84	22/103	21/106
duration pre amputation pain	8.00 ± 12.696	9.71 ± 13.00	9.89 ± 7.25	12.22 ± 16.81	51.90 ± 88.294	76.67 ± 140.23 (1-470
in weeks	(1-50)	(1-36)	(4-28)	(2-54)	(1-360)	
reason for amputation:						
accident	143	157	52	59	92	88

injury	25	31	7	11	14	22
congenital	25	47	0	0	0	0
infection	4	3	0	2	3	7
tumor	6	4	8	5	7	5
vascular disease	2	0	0	3	0	0
other	51	52	17	26	26	35
level of amputation (%)	54.85 ± 26.72 (0-98)	53.56 ± 26.93 (0-98)	40.67 ± 27.48 (0-98)	37.74 ± 27.46 (0-96)	33.58 ± 28.98 (0-95)	35.10 ± 27.30 (0-95)
PLP intensity	0 ± 0 (0-0)	0 ± 0 (0-0)	3.96 ± 2.55 (0-10)	4.20 ± 2.78 (0-10)	6.06 ± 1.91 (3-10)	6.24 ± 1.65 (3-10)
PLS intensity	1.20 ± 2.32 (0-10)	1.27 ± 2.60 (0-10)	3.65 ± 2.89 (0-10)	3.64 ± 3.20 (0-10)	4.26 ± 3.11 (0-10)	4.31 ± 3.32 (0-10)
RLP intensity	1.22 ± 2.33 (0-10)	1.29 ± 2.47 (0-10)	2.47 ± 3.01 (0-10)	2.39 ± 2.77 (0-10)	3.87 ± 3.35 (0-10)	3.09 ± 3.38 (0-10)
telescope (bigger/smaller/n)	1/38/184	4/37/214	3/29/43	3/39/55	5/51/70	5/50/75
intensity of telescoping	0.63 ± 1.78 (0-10)	0.70 ± 2.04 (0-10)	2.07 ± 3.05 (0-10)	2.07 ± 3.14 (0-10)	2.49 ± 3.19 (0-10)	2.66 ± 3.53 (0-10)
telescope length (%)	51.8 ± 23.6 (5-95)	47.7 ± 22.6 (10-120)	51.1 ± 25.5 (10-120)	45.3± 22.8 (1-97)	52.8 ± 20.8 (15-95)	45.1± 18.8 (20-100)
referred sensation (y/n)	13/211	20/236	10/65	21/76	40/85	33/96

prosthesis (y/n)	126/99	107/149	35/40	42/55	65/61	65/65
cosmetic	67	55	13	24	35	27
cable-controlled	13	19	7	6	8	9
myoelectric	41	30	13	9	21	27
hybrid	1	0	0	1	0	2
sauerbruch	4	3	2	2	1	0
prostheses experienced as part of the body	5.37 ± 3.34 (0-10)	5.32 ± 3.30 (0-10)	6.16 ± 3.06 (0-10)	4.01 ± 3.61 (0-10)	4.81 ± 2.98 (0-10)	3.97 ± 3.10 (0-10)

mean ± std (range) or n are depicted, m = male, f = female, y = yes, n = no

Table 1c: Leg amputees: Clinical and demographic characteristics of the non-PLP group (never PLP and 0 on the PLP intensity NRS (0-10)), the high-PLP group (PLP frequency of at least a 1-2 times per week with a minimum of 3 on the PLP NRS scale), and all other patients in the low-PLP group.

	non-plp		**low-plp**		**high-plp**	
	right leg	**left leg**	**right leg**	**left leg**	**right leg**	**left leg**
n	387	449	377	457	330	461
sex (m/f)	315/72	372/77	305/72	363/94	260/70	350/111
age in years	64.09 ± 15.95 (21-96	63.19 ± 17.05 (20-95	64.28 ± 15.46 (19-92	63.96 ± 15.75 (20-98	66.48 ± 14.67 (18-98	63.83 ± 15.17 (20-93)
age at amputation (years)	27.09 ± 18.95 (0-93)	27.54 ± 17.95 (0-84)	33.68 ± 19.87 (2-84)	32.27 ± 19.14 (5-87)	44.91 ± 21.94 (5-88)	41.04 ± 19.85 (8-86)
time since amputation (years)	37.10 ± 22.94 (0-80)	35.75 ± 22.79 (0-86)	30.59 ± 21.29 (0-73)	31.75 ± 21.06 (1-74)	21.56 ± 22.00 (0-71)	22.79 ± 21.39 (0-69)
	median 37.0	median 33.0	median 28.0	median 29.0	median 11.0	median 14.0
pain before amputation (y/n)	116/260	153/285	139/233	164/283	167/161	210/247
duration pre amputation pain	74.77 ± 223.79	54.02 ± 291.76	54.23 ± 148.09	44.25 ± 149.74	55.63 ± 109.847	83.45 ± 310.14
in weeks	(1-1560)	(1-3300)	(1-1300)	(1-1560)	(1-624)	(0-3276)
reason for amputation:						
accident	187	246	190	220	136	233

injury	47	61	50	56	42	52
congenital	9	11	3	2	0	0
infection	34	46	50	37	39	63
tumor	39	35	48	60	23	32
vascular disease	52	49	57	67	101	107
other	92	94	68	99	77	98
level of amputation (%)	44.98 ± 21.48 (0-97)	45.75 ± 19.45 (0-95)	38.21 ± 18.98 (0-98)	37.43 ± 18.45 (0-88)	40.32 ± 18.94 (0-95)	39.20 ± 18.17 (0-97)
PLP intensity	0 ± 0 (0-0)	0 ± 0 (0-0)	5.32 ± 3.09 (0-10)	5.31 ± 2.96 (0-10)	6.32 ± 1.89 (3-10)	6.34 ± 1.89 (3-10)
PLS intensity	1.39 ± 2.39 (0-10)	1.22 ± 2.27 (0-10)	2.91 ± 2.89 (0-10)	3.27 ± 3.05 (0-10)	4.01 ± 3.09 (0-10)	3.60 ± 3.18 (0-10)
RLP intensity	2.91 ± 3.31 (0-10)	2.89 ± 3.28 (0-10)	2.48 ± 3.15 (0-10)	2.30 ± 3.02 (0-10)	3.92 ± 3.29 (0-10)	3.67 ± 3.42 (0-10)
telescope (bigger/smaller/n)	5/40/342	5/48/395	10/62/302	11/86/358	16/76/238	16/110/334
intensity of telescoping	0.47 ± 1.57 (0-10)	0.41 ± 1.45 (0-10)	0.85 ± 2.09 (0-10)	0.92 ± 2.13 (0-10)	1.50 ± 2.79 (0-10)	1.46 ± 2.74 (0-10)
telescope length (%)	62.2 ± 24.4 (18-125)	65.5 ± 20.4 (20-115)	61.2 ± 20.0 (10-105)	60.4± 19.1 (20-115)	65.0 ± 21.4 (23-120)	64.5± 19.1 (20-130)
referred sensation (y/n)	28/358	40/407	56/318	80/375	76/254	120/338

prosthesis (y/n)	267/120	313/136	260/117	329/128	237/93	331/130
early care	2	6	10	4	18	5
interim	10	9	6	4	13	21
exoskeletal construction	116	122	100	123	112	136
modular construction	139	176	144	198	94	169
prostheses experienced as part of the body	6.83 ± 2.96 (0-10)	7.12 ± 2.53 (0-10)	6.07 ± 3.05 (0-10)	6.37 ± 2.88 (0-10)	5.10 ± 2.91 (0-10)	5.10 ± 2.93 (0-10)

mean ± std (range) or n are depicted, m = male, f = female, y = yes, n = no

Table 2: Regression analyses of clinical/demographic and perceptual/behavioral variables for phantom limb pain

clinical/demographic variables	R^2 (p)
Sex	<0.001 (0.211)
reason of amputation	0.006 (<0.001)
age at amputation	**0.050** (<0.001)
time since amputation	0.024 (<0.001)
level of amputation	**0.065** (<0.001)
pain before amputation	0.014 (<0.001)
multiple regression clinical/demographic	**0.106** (<0.001)
perceptual/behavioral variables	
time of prosthesis us	<0.001 (0.795)[a]
PLS intensity	**0.141** (<0.001)
referred sensations	**0.030** (<0.001)
intensity of telescoping	**0.042** (<0.001)
% telescope length	0.016 (<0.001)
RLP intensity	**0.031** (<0.001)
multiple regression perceptual/behavioral	**0.169** (<0.001)
multiple regression clinical/demographic & perceptual/behavioral	**0.238** (<0.001)

Values depicted in bold are above our inclusion criterion of 2.7 %. [a] when time of use of a cosmetic prosthesis was equaled the use of no prosthesis, the results changed to 0.001 (0.050)

Table 3: Regression analyses of clinical/demographic and perceptual/behavioral variables for residual limb pain

clinical/demographic Variables	R^2 (p)
Sex	0.002 (0.016)
reason of amputation	0.000 (0.641)
age at amputation	0.000 (0.265)
time since amputation	0.005 (<0.001)
level of amputation	0.006 (<0.001)
pain before amputation	0.001 (0.036)
perceptual/behavioral variables	
time of prosthesis us	0.001 (0.170) [a]
PLS intensity	0.021 (<0.001)
referred sensations	0.008 (<0.001)
intensity of telescoping	0.005 (<0.001)
% telescope length	0.001 (<0.084)
PLP intensity	**0.031** (<0.001)

Values depicted in bold are above our inclusion criterion of 2.7 %. [a] when time of use of a cosmetic prosthesis was equaled the use of no prosthesis, the results changed to 0.002 (0.013)

Table 4: Principal component analysis

	Rotated Factor Loading	
	F1	F2
PLS	**0.713**	0.027
PLP	**0.682**	0.290
Tele	**0.654**	-0.123
RLP	**0.377**	-0.048
Lev Amp	**-0.445**	0.109
Age Amp	0.029	**0.834**
PbA	0.024	**0.801**
Eigenvalue	1.742	1.451
%variance	24.88	20.72

PLS = phantom limb sensation intensity, PLP = phantom limb pain intensity, Tele = intensity of telescoping, Lev Amp = level of amputation, Age Amp = age at amputation, PbA = pain before amputation.

Supplementary Material

The prevalence and relationship of non-painful phantom phenomena and phantom limb pain in a nationwide survey on 3374 unilateral limb amputees

Martin Diers[1,2], Bertram Krumm[3], Xaver Fuchs[1,4], Robin Bekrater-Bodmann[1], Christopher Milde[1,5], Jörg Trojan[1], Jens Foell[1,6], Susanne Becker[1,7], Gerhard Rümenapf, [,8] Herta Flor[1,9]

Table S1: Clinical and demographic characteristics of the pooled high-PLP and low-PLP group for the total sample and for the arm and leg amputees.

	total sample	**right arm**	**left arm**	**right leg**	**left leg**
n	2053	201	227	707	918
sex (m/f)	1654/399	178/23	198/29	565/142	713/205
age in years	64.58 ± 15.62 (18-98)	63.61 ± 16.52 (24-93)	65.90 ± 16.85 (27-91)	65.31 ± 15.13 (18-98)	63.90 ± 15.45 (20-98)
age at amputation (years)	35.29 ±19.99 (2-88)	27.02 ± 14.21 (2-81)	25.72 ± 13.11 (2-82)	38.94 ± 21.59 (2-88)	36.67 ± 19.98 (5-87)
time since amputation (years)	29.29 ± 22.3 (0-74)	36.55 ± 21.13 (0-69)	40.18 ± 21.9 (1-74)	26.36 ± 22.07 (0-73)	27.25 ± 21.68 (0-74)
	median 26.0	median 34.5	median 39.0	median 20.0	median 23.0
side of amputation (L/R)	1145/908				
limb (arm/leg)	428/1625				
pain before amputation (y/n)	744/1281	32/167	32/190	306/394	374/530
duration pre amputation pain i	59.66 ± 197.62	38.86 ± 75.47	55.19 ± 117.91	54.99 ± 128.51	65.86 ± 251.60
weeks	(0-3276)	(1-360)	(1-470)	(1-1300)	(0-3276)

reason for amputation:					
accident	1070	144	147	326	453
injury	141	13	25	47	56
congenital	5	0	0	3	2
infection	116	2	6	50	58
tumor	177	14	10	65	88
vascular disease	291	0	3	138	150
other	253	28	36	78	111
level of amputation (%)	38.19 ± 20.9 (0-98)	36.24 ± 28.56 (0-98)	36.23 ± 27.34 (0-96)	39.19 ± 18.98 (0-98)	38.32 ± 18.319 (0-97)
PLP intensity	5.71 ± 2.55 (0-10)	5.28 ± 2.39 (0-10)	5.37 ± 2.42 (0-10)	5.79 ± 2.65 (0-10)	5.83 ± 2.53 (0-10)
PLS intensity	3.56 ± 3.11 (0-10)	4.04 ± 3.04 (0-10)	4.03 ± 3.28 (0-10)	3.42 ± 3.04 (0-10)	3.44 ± 3.12 (0-10)
RLP intensity	3.06 ± 3.28 (0-10)	3.35 ± 3.29 (0-10)	2.79 ± 3.15 (0-10)	3.15 ± 3.29 (0-10)	2.99 ± 3.3 (0-10)
telescope (bigger/smaller/n)	63/503/1475	8/80/113	8/89/130	26/138/540	27/196/692
intensity of telescoping	1.42 ± 2.69 (0-10)	2.33 ± 3.14 (0-10)	2.41 ± 3.37 (0-10)	1.15 ± 2.46 (0-10)	1.19 ± 2.47 (0-10)
telescope length (%)	58.3 ± 21.5 (1-130)	52.2 ± 22.5 (10-120)	45.2 ± 20.3 (1-100)	63.3 ± 20.8 (10-120)	65.0 ± 21.4 (23-120)

referred sensation (y/n)	436/1607	50/150	54/172	132/572	200/713
prosthesis (y/n)	1696/355	98/103	108/119	654/51	836/82
arm amputees	428				
leg amputees	1625				
arm					
cosmetic	79	39	40		
cable-controlled	24	14	10		
myoelectric	69	34	35		
hybrid	3	0	3		
sauerbruch	5	3	2		
leg					
early care	35			26	9
interim	39			17	22
exoskeletal construction	449			203	246
modular construction	594			234	360

prostheses experienced as part of the body	5.55 ± 3.04 (0-10)	5.26 ± 3.06 (0-10)	3.99 ± 3.29 (0-10)	5.61 ± 3.02 (0-10)	5.74 ± 2.97 (0-10)

mean ± std (range) or n are depicted, m = male, f = female, y = yes, n = no

Table S2 Differences between location and side of amputation

To verify if the location (arm/leg) and side (right/left) of amputation has an effect on the clinical/demographic and perceptual/behavioral factors we calculated t-tests for the variables which were above our criterion of declared variance (age at amputation, level of amputation, PLP intensity, PLS intensity, RLP intensity, referred sensations and, intensity of telescoping). For variables reporting frequency, a χ^2 test was used.

Side of amputation (right/left) had no significant effect. The location of amputation (arm/leg) was significant different on all variables behalf of PLS intensity and referred sensations (see Table S2).

Table S2: Differences in location of amputation for the variance declaring variables of the regression analyses.

	m±sd arm◊	m±sd leg◊	t-value○	p-value
Age Amp	22.52±14.14	34.15±20.56	-18.207	<0.001
Lev Amp	45.73±28.74	40.97±19.41	4.617	<0.001
PLP	2.51±3.13	3.84±3.46	-10.621	<0.001
PLS	2.55±3.14	2.71±3.02	-1.280	0.201
RLP	2.10±2.96	3.01±3.29	-7.649	<0.001
Ref Sens	137/796◊	400/2051◊	1.279○	0.528
Tele	1.47±2.77	0.92±2.21	5.349	<0.001
	m±sd right◊	m±sd left◊	t-value○	p-value
Age Amp	31.51±20.50	30.88±19.15	0.908	0.364
Lev Amp	42.60±23.06	41.98±21.96	0.795	0.427
PLP	3.39±3.43	3.55±3.42	-1.324	0.186
PLS	2.66±3.0	2.67±3.1	-.0102	0.919
RLP	2.83±3.24	2.70±3.22	1.150	0.250
Ref Sens	223/1291◊	314/1530◊	3.271○	0.071
Tele	1.06±2.35	1.08±2.42	-0.308	0.758

Age Amp = age at amputation, Lev Amp = level of amputation, PLP = phantom limb pain intensity, PLS = phantom limb sensation intensity, RLP = residual limb pain intensity, Ref Sens = referred sensations, Tele = intensity of telescoping, m = mean, sd = standard deviation, arm = amputation at the arm, leg = amputation at the leg, right = amputation on the right side, left = amputation on the left side. ◊For frequency of referred sensation yes/no is depicted. ○For frequency of referred sensation a χ^2 test was used.

Table S3 Influence of Depression

Depression scores (Center for Epidemiological Studies Depression Scale, CES-D) [27,44] were collected in a subsample of n=1,145 amputees. In this subsample we used the scores on depressive symptoms in a regression analysis to predict PLP and also added perceptual/behavioral variables in an additional multiple simultaneous regression analysis.

The mean CES-D value of our sample was 9.37 (SD: 7.71, range: 0-40). Depression explained 4.0% of the variance ($R2 = 0.040$, $p < 0.001$).

Prediction of Phantom Limb Pain by perceptual/behavioral variables including depression

By adding depression in the regression analyses of the independent perceptual variables (PLS intensity, referred sensations, intensity of telescoping, RLP intensity, depression) the regression explained a variance of 21.9% ($R^2 = 0.219$, $p < 0.001$, β PLS intensity = 0.358, β referred sensations = 0.662, β intensity of telescoping = 0.151, β RLP intensity = 0.096, β depression = 0.061). As the sample for this analysis was different from the original regression analyses we repeated the regression with the perceptual variables in this smaller sample without depression (explained variance of 20.1%, $R^2 = 0.201$, $p < 0.001$, β PLS intensity = 0.371, β referred sensations = 0.681, β intensity of telescoping = 0.153, β RLP intensity = 0.121). Depression added more explained variance for RLP compared to PLP (Table S3).

Table S3: Regression analyses of clinical/demographic and perceptual variables for phantom limb pain (PLP) and residual limb pain (RLP).

perceptual/behavioral variables	R^2 (p)
PLP	
Depression	**0.040** (<0.001)
multiple regression perceptual/behavioral (depression sample)	**0.201** (<0.001)
multiple regression perceptual/behavioral with depression	**0.219** (<0.001)
RLP	
Depression	**0.032** (<0.001)
PLP intensity (depression sample)	0.027 (<0.001)
multiple regression PLP intensity with depression	**0.046** (<0.001)

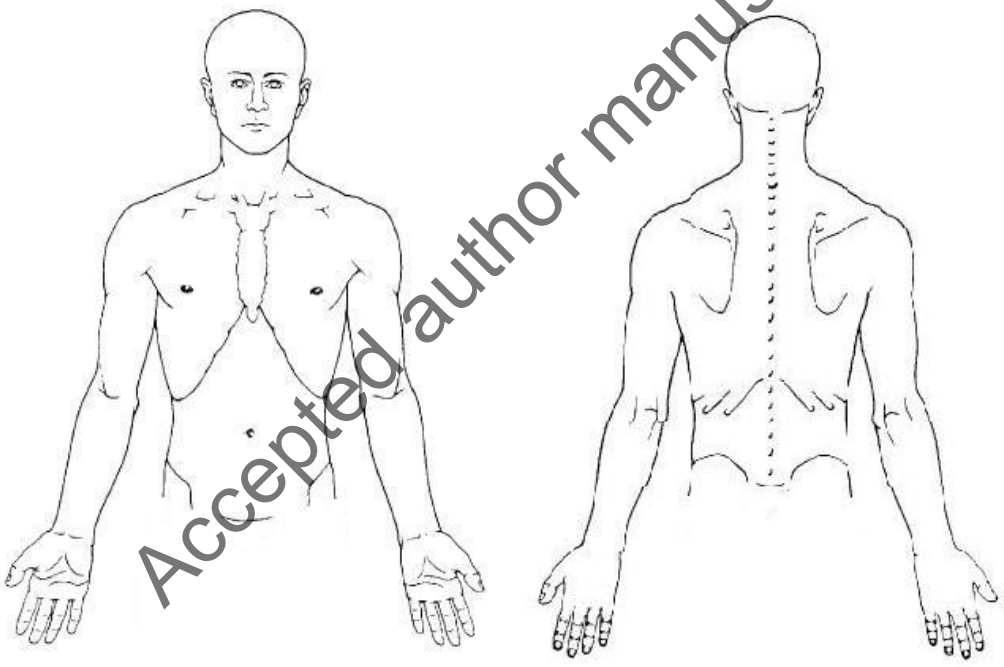
Values depicted in bold are above our inclusion criterion of 2.7 %.

Used Questionnaire:

Thank you for your willingness to support our project to investigate consequences of amputation and phantom pain. Please fill out the following questionnaire truthfully and completely. Before answering the questions about your perceptions, please take a bit of time for contemplation and reflect if you feel the sensations given. You will need about 30 minutes. If you have difficulty in answering one or more questions, you can reach us by telephone at 0621/1703-6344, contact Ms Astrid Wolf. If we cannot answer your call personally, please leave a message on the answering machine and we will call you back asap.

Part A

1. Age: _____ Height (cm): _____ Weight (kg): _____
2. Sex: □ male □ female
3. Do you have a living twin sister / twin brother?
   □ no □ yes, viz.: □ monzygotic □ dizygotic □ unknown
4. Please specify as exactly as possible amputation side and location in blow drawing.



5. Please indicate the date of the amputation?
   Month: _____ Year: _____
6. Please specify the reason for the amputation?
   □ accident □ sequela of injury □ congenital malformation
   □ infection □ tumour □ vascular disease
   □ other reason/s: _____
7. Did you suffer from pain in the affected arm during the weeks prior to the amputation?
   □ no □ yes, for approx. _____ weeks (please specify number of weeks)
8. Which hand did you use for writing before the amputation?
   □ left □ right □ both □ re-educated from the left to the right hand

9. Do you wear a prosthesis?
   - □ no (→ please continue with question 12)
   - □ yes (please specify what type of prosthesis you use):
     - □ cosmetic prosthesis
     - □ cable-controlled
     - □ myoelectric prosthesis
     - □ hybrid prosthesis
     - □ Sauerbruch prsthesis
     - □ other (please describe): _____

10. How often do you wear the prosthesis?

a) times per week	**and**	**b) hours per day**
□ not at all (pls continue with question 12)		□ not at all
□ less than twice a week		□ 1-2 hours a day
□ every 2nd day		□ several hours, but not continuously
□ almost every day		□ the whole morning/afternoon
□ every day		□ from morning to night

11. While wearing the prosthesis, how do you perceive it?

⓪ ① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨ ⑩

The prosthesis feels like a foreign object — The prosthesis feels like affiliated with my body

12. Are you suffering from any chronic disease (e.g. hypertension, herniated vertebral disc, diabetes)?
    - □ no
    - □ yes (please specify disease(s) and year of diagnosis)

_____
_____
_____

13. Do you take medicine regularly?
    - □ no
    - □ yes (please specify name(s) and year of prescription)

_____
_____
_____

14. Has any mental disorder been diagnosed in your lifetime?
    - □ no
    - □ yes (please specify diagnosis and year of diagnosis)

_____
_____
_____

15. Has any mental disorder been diagnosed in your family (first and second degree relatives)?
    - □ no
    - □ yes (please specify degree of relationship and diagnosis)

_____
_____
_____

16. Are there any metal parts remaining in your body following surgery or accident (e.g. nails or bone screws, vascular clips, shrapnel, etc.)?

□ no □ yes

17. Are you wearing a pacemaker, an implanted drug pump or any other implants?

□ no □ yes

Part B

The following part is about the so-called **phantom pain**. Phantom pain refers to painful sensations in the absent part of the body – not in the amputation stump. Stump pain will be referred to in a later part of this questionnaire!

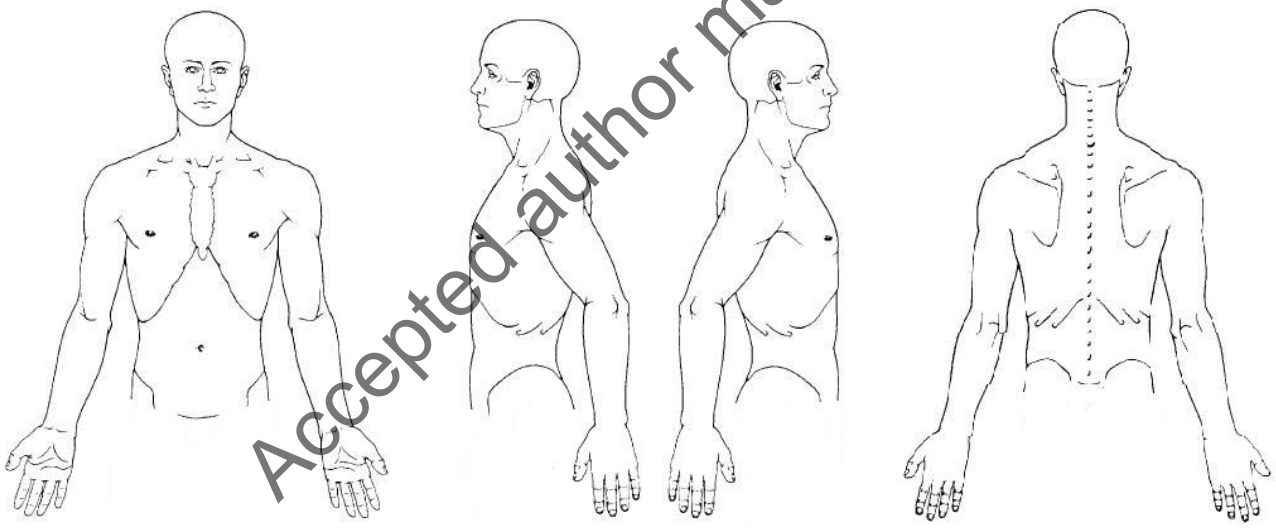
18. Are you suffering from **phantom pain** (during the past three months)?

□ No, I never had phantom pain (→ please continue with Part C)

□ No, but I used to have phantom pain in the past (→please continue with Part C)

□ Yes, I am suffering from phantom pain

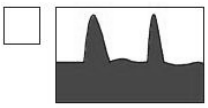
19. If you are suffering from **phantom pain**, where do you feel the pain? Please indicate as exactly as possible the localisation of the phantom pain in below drawing.



20. Which pattern best characterizes your **phantom pain**?

persistent pain with slight variations

persistent pain with strong variations



persistent pain with pain attacks

pain attacks with pain free intervals

21. How often do you suffer from **phantom pain**?

□ less than once a month □ 1 or 2 times a week □ once a day

□ once a month □ at least 3 days a week □ several times a day

□ every 2 weeks □ at least 4 days a week □ constantly

22. How long is the average duration of the **phantom pain**?

□ seconds □ minutes □ hours

□ days □ I am constantly suffering from phantom pain

23. How strong was the **phantom pain** on average during the past 4 weeks?

⓪ ① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨ ⑩

no pain intolerable pain

24. When did the **phantom pain** occur for the first time after the amputation?

□ immediately afterwards □ within the first week

□ within the first month □ within the first year □ later

25. Did the intensity of the **phantom pain** change over time?

□ No

□ Yes, the phantom pain has become more intense

□ Yes, the phantom pain has become less intense

26. Is the **phantom pain** currently treated?

□ no □ yes (please specify kind of treatment): _____

Part C

Part C is considering the so-called **non-painful phantom sensations** after amputation. This refers to non-painful sensations in absent limb (arm, hand, individual fingers), such as prickling, movements, numbness or cramping. These sensations are not related to the amputation stump, which is referred to in a later part of this questionnaire.

27. Did you perceive any **non-painful phantom sensations** lately (during the last 3 months)?

□ No, I never felt non-painful phantom sensations
(→ please continue with question 34)

□ No, but I used to feel non-painful phantom sensations in the past
(→please continue with question 34)

□ Yes, I recently perceived non-painful phantom sensations

28. Please chose the **non-painful phantom sensation(s)** in the absent limb from below list:

□ I perceive length, circumference or posture of the amputated limb

□ I perceive pressure in the amputated limb

□ I feel warmness in the amputated limb

□ I perceive spontaneous, unintentional movements of the amputated limb

□ I can deliberately move the amputated limb

□ I perceive associated movements of the absent limb with the intact limb

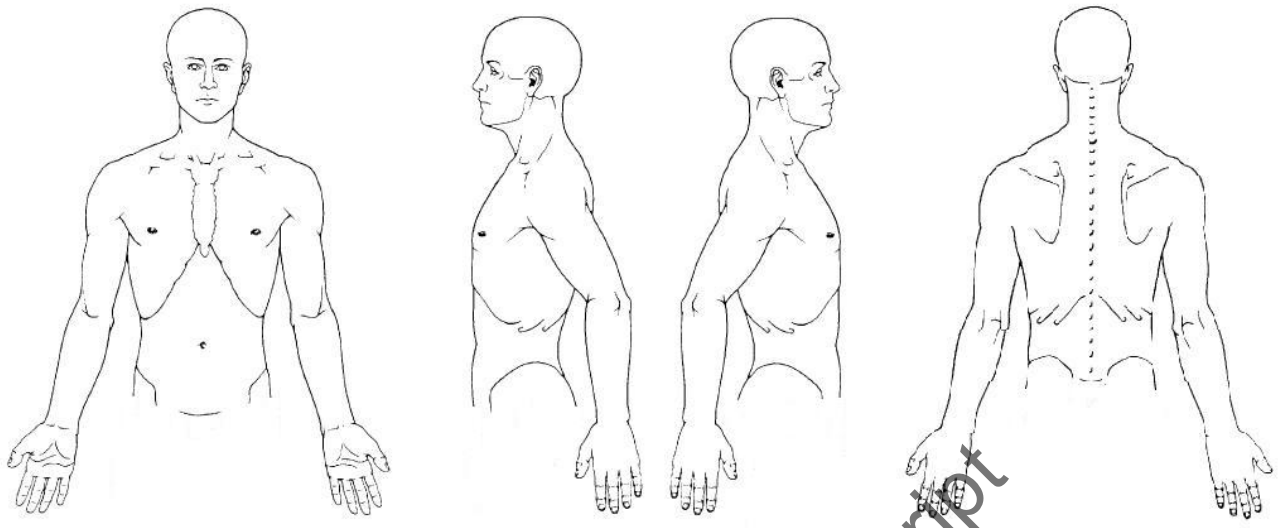
□ I feel prickling, itching or numbness in the absent limb

□ I feel coldness in the absent limb

□ I perceive the absent limb as twisted, inflated or deformed

□ I perceive the following sensation in the absent limb: _____

29. Please mark all locations of **non-painful phantom sensations** in the following drawing as exactly as possible.



30. How frequent do you perceive these **non-painful phantom sensations**?

□ less than once a month □ 1 or 2 times a week □ once a day
□ once a month □ at least 3 days a week □ several times a day
□ every 2 weeks □ at least 4 days a week □ constantly

31. How long is the average duration of the **non-painful phantom sensations**?

□ seconds □ minutes □ hours
□ days □ I am constantly suffering from phantom pain

32. How strong were the **non-painful phantom sensations** on average during the past 4 weeks?

⓪ ① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨ ⑩

no sensations very strong sensations

33. When did you first feel these **non-painful phantom sensations** after the amputation?

□ immediately □ within a week
□ within a month □ within a year □ later

34. Do you perceive any sensation in your **phantom limb** while having contact to specific parts of you body, e.g. shaving, applying body lotion, showering etc., so-called **referred sensations**?

□ no (→ please go on with question 38) □ yes

35. Can you randomly trigger this **referred sensation**, i.e. does the referred sensation always occur upon contact to a specific part of the body, and fades away after the end of the contact?

□ no □ yes □ the referred sensation lasts longer than the contact;
if so please specify the duration in minutes _____

36. Do you perceive the **referred sensation** in the absent limb as painful or as non-painful?

□ no □ yes □ both painful and non-painful

37. If contact to a specific part of the body causes a sensation in you phantom limb, please specify in which part of the phantom you perceive it.

part of the body	referred sensation perceived in	**part of the phantom**
_____	gespürt in ➡	_____
_____	gespürt in ➡	_____
_____	gespürt in ➡	_____

38. Some amputees describe their phantom limb changed its posture or as gradually shortened resp. lengthened over time, i.e. that the hand has approached to the stump resp. distanced from the stump, the so-called **telescoping** effect. Did you perceive this telescoping effect?

□ No (→ please continue with Part D)

□ Yes, in my perception the phantom has shortened, i.e. the phantom hand has approached to the stump

□ Yes, in my perception the phantom has lengthened, i.e. the phantom hand has distanced from the stump

39. How often do you perceive this **telescoping** effect?

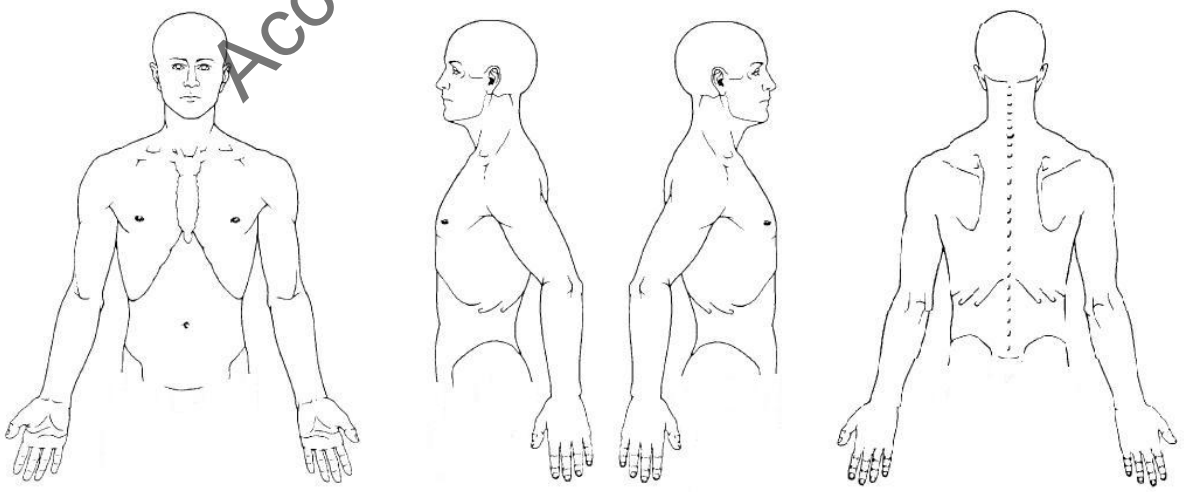
□ less than once a month	□ 1 or 2 times a week	□ once a day
□ once a month	□ at least 3 days a week	□ several times a day
□ every 2 weeks	□ at least 4 days a week	□ constantly

40. Please specify the intensity of the telescope perception over the past 4 weeks.

⓪ ① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨ ⑩

no telescope perception — very strong telescope perception

41. Please sign the dimensions of the **telescope** as exactly as possible in below drawing.



42. Can you deliberately mentally influence the **telescoping** effect?

□ no □ yes

Part D

This part refers to **stump pain**, i.e. pain that you feel in the amputation stump. This does not refer to phantom pain. Stump pain is located in the remaining part of the limb, not in the phantom limb.

43. Did you suffer from **stump pain** during the past 3 months?

□ No, I never suffered from stump pain (→ please continue with Part E)

□ No, but I used to suffer from stump pain in the past (→ please continue with Part E)

□ Yes, I a suffering from stump pain

44. How often are you suffering from **stump pain**?

□ less than once a month □ 1 or 2 times a week □ once a day

□ once a month □ at least 3 days a week □ several times a day

□ every 2 weeks □ at least 4 days a week □ constantly

45. How strong was the **stump pain** in average over the last 4 weeks?

⓪ ① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨ ⑩

no pain extremely painful

46. Is you stump pain being treated?

□ no □ yes (please specify the kind of treatment)

_____

_____

Part E

In order to better assess your amputation and pain status, we need some more information.

47. If you see someone who is suffering from pain or has just painfully hurt himself/herself, can you also feel his/her pain?

□ no (→ please continue with question 49) □ yes

48. If the answer is YES, where do you feel the pain? (multiple answers possible)

□ in the phantom limb

□ on the same location as your vis-à-vis

□ on another location, viz.: _____

49. People are differing from each other regarding their attitude towards transplantation. How comfortable would you feel if you were to receive one of the following human transplants? Please specify for all given possibilities.

a) **Arm** □ very well □ well □ undecided □ uncomfortable □ very uncomfortable

b) **Leg** □ very well □ well □ undecided □ uncomfortable □ very uncomfortable

c) **Kidney** □ very well □ well □ undecided □ uncomfortable □ very uncomfortable

50. Are you currently suffering from insomnia?

□ no □ yes

51. How often can you recall your dreams (during the past 3 months)?

□ not at all (→ please continue with question 53)

□ almost every morning
□ several times a week
□ once a week
□ 2-3 times a month
□ once a month
□ less than once a month

52. Please quantify how much the following statements are true for your dreams.
Your answers should add up to 100 %.

The impairment from amputation appears in my dreams.	_____ % of my dreams
In my dreams my body is unimpaired.	_____ % of my dreams
I cannot remember my body perception in my dreams.	_____ % of my dreams
	= 100 %

53. Please specify origin and nationality of your natural grandparents. This does not apply to adoptive parents or step parents or grandparents.

	Federal State/Country	**Nationality**
Grandfather: *(maternal)*	……	……
Grandmother: *(maternal)*	……	……
Grandfather: *(paternal)*	……...	……
Grandmother: *(paternal)*	……..	…….

Only to be specified if origin of grandparents in unknown:

	Federal State/Country	**Nationality**
Father:	……	…….
Mother:	……	…….