# **ORIGINAL ARTICLE**

# Frequency and determining factors of phantom limb pain in amputee patients assisted by a rehabilitation center in the Midwest region of Brazil

Frequencia e fatores determinantes da dor do membro fantasma em pacientes amputados assistidos por um centro de reabilitação situado no centro-oeste do Brasil

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#### **ABSTRACT**

**Objective:** This descriptive, longitudinal and prospective study has the objectives to evaluate the frequency of phantom limb pain (PLP) in amputees who are assisted at a rehabilitation center as well as to verify the influence of biopsychosocial profile, use of assistive technologies, medications and therapies for PLP. **Method:** Sixteen subjects were interviewed twice with an interval of six months between July / 2016 and August 2017. A semi-structured questionnaire addressing social and clinical profile, Visual Analogue Scale (VAS), SF-36 and McGill Questionnaire were the evaluations used in this study. Data were analyzed descriptively and statistically with the student T-test and Pearson correlation. **Results:** Of the participants, 8 were male (50%), with 55.5 years of age (SD: 15.7). They were mostly from Goiânia (75%) and had transfemoral amputation (68.7%) of traumatic etiology (56.2%). PLP frequency was 68.5% in the first interview and 50% in the second interview. Between the two interviews, there was a decrease in pain intensity reported by individual, decrease in pain index and number of McGill descriptors, as well as increase in the SF-36 domains. No positive correlation was found between the use of prostheses, use of medications or therapies for pain. **Conclusion:** The patients studied presented a high prevalence of phantom limb pain. Further studies on PLP and its determinants are needed to evidence the impact of PLP on the amputee's daily life.

Keywords: Amputation, Pain, Phantom Limb, Quality of Life

## **RESUMO**

Obietivo: Este estudo descritivo, longitudinal e prospectivo busca avaliar a frequência de dor do membro fantasma (DMF) em pacientes amputados que são assistidos por um centro de reabilitação assim como verificar a influência do perfil biopsicossocial, uso de tecnologias assistivas, medicamentos e terapias no caráter da DMF. Método: Foram entrevistados 16 indivíduos em dois momentos com intervalo de seis meses no período de Julho/2016 à Agosto de 2017. Como instrumentos de avaliação foram utilizados: questionário semi-estruturado abordando perfil social e clínico, EVA, SF-36 e Questionário de McGill. Os dados foram analisados descritivamente e com os testes T e Pearson. Resultados: Dos participantes, 8 eram do sexo masculino (50%), com idade média de 55,5 anos (DP:15,7), sendo maior parte procedente de Goiânia (75%) e com amputação transfemural (68,7%) de etiologia traumática (56,2). A frequência de DMF foi de 68,5% na primeira entrevista e 50% na segunda. Entre as duas entrevistas, houve diminuição na intensidade da dor relatada pelos indivíduos assim como no índice da dor e número de descritores do McGill e também acréscimo nos domínios do SF36. Não foi observada correlação positiva entre o uso de próteses, medicamentos ou realização de terapias com o quadro álgico dos amputados. Conclusão: A amostra estudada apresentou alta prevalência de dor do membro fantasma. São necessários mais estudos sobre a DMF e seus determinantes a fim de evidenciar seu impacto na vida do amputado.

Palavras-chave: Amputação, Dor, Membro Fantasma, Qualidade de Vida

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## INTRODUCTION

Despite being one of the oldest human health problems, amputation is still of great importance due to its social, economic and personal burden. Amputation is an irreversible conduct, it is considered only when other therapeutic means are depleted and it aims to ensure the patient's living conditions.<sup>1,2</sup>

There is no precise figures of the worldwide and Brazilian incidence of amputations, it is estimated that the global proportion of new cases ranges from 2.8 to 43.9 cases per 100,000 inhabitants/year, whereas in Brazil it may reach 13.9 per 10,000 inhabitants/year. <sup>2-6</sup>

The clinical and therapeutic approach of amputees with pain is a challenge for the healthcare professionals, once their pain can manifest in different ways, such as somatic pain due to surgery or stump neuroma, and phantom limb pain.<sup>3-7</sup>

Phantom limb pain (PLP) is a type of neuropathic pain, whose incidence varies from 2% to 90%. 4.5.7.8 Its pathophysiology has not yet been elucidated, but it is believed to be a result of a reorganization of the structures mapping represented in the sensitive cerebral cortex and the thalamus. This event seems to initiate after amputation. 4.5.7.9

Given PLP is yet a subject to be explored scientifically, there are few studies that focus on its prevalence, characteristics and the time lapse between amputation and its onset. 4,5,6,10 Also, once PLP can lead to important changes in the amputee's biopsychosocial profile, studies that address its epidemiological characteristics may be essential tools for the development of an adequate rehabilitation process for this population. 3,9-11

#### **OBJECTIVE**

The objective or this study is to evaluate the frequency of phantom limb pain (PLP) in amputees who are assisted by a rehabilitation facility as well as to verify the influence of biopsychosocial profile, the use of assistive technologies, medications and therapies for PLP.

#### **METHODS**

This is a descriptive, longitudinal, and quantitative study, which was conducted with a sample of amputees assisted at the Dr. Henrique Santilo State Rehabilitation Center (CRER) from July 1, 2016 to August 28, 2017. The included participants met the following inclusion criteria:

a) Single or multiple upper or lower limb amputation;

- b) 18 to 75 years of age;
- c) Cognitive ability to attend and answer the questionnaires in the interview;
- d) Provide a signed Informed Consent Form (ICF);
- e) Availability to join in the three visits: invitation, first and second evaluations:

Those who did not meet the inclusion criteria were not included in this study. To preserve the participants' confidentiality, they were identified by a number ranging from 01 to 16 and by their name initials. The following assessment tools were applied:

- a) Amputees profiling CRER: It was a semi-structured interview in which the following data was collected: sex, age, time after trauma, time after amputation, amputation etiology, presence of PLP, stump complications, use of medications, and use of prothesis;
- b) Quality of life questionnaire 36-item
  Short-Form Health Survey (SF-36);
  - c) Visual analogue scale for pain (VAS);
  - d) McGill pain questionnaire.

The participants were addressed three times:

- 1) Invitation: The patient was approached and screened on whether the patient met all inclusion criteria of the study. If so, the participant was invited to participate. After agreeing, the Part A of the assessment, "Amputated Patient Profile CRER", was applied;
- 2) First Assessment: It was conducted in a doctor's office about fifteen days after the invitation. During this time, Parts B, C and D of the CREER Profile was completed and applied (VAS, SF-36, and McGill);
- 3) Second Assessment: it was conducted on average about six months after the first assessment. The patients were assessed regarding adherence to drug therapy, the prosthetization process and the use non-drug therapies. The VAS, SF-36 and McGill Pain Questionnaire were applied a second time.

The data was compiled, organized and paired according to the variables in the Excel 2010 program. Then, means and standard deviations were descriptively analyzed and compared to the existing literature regarding the subject. Statistical analysis was performed with Excel 2010, Student T-test and Pearson correlation were applied. The significance level was set at 5% (p <0.05).

This study was conducted in accordance with the CNS Resolution 466/2012 (Brazilian resolution) and was approved by the Ethics Review Board for Research on Humans "Centro de Excelência em Ensino, Projetos e Pesquisas Leide das Neves Ferreira - LNF/

SES-GO", and received the identification CAAE 56205716.4.0000.5082. The data collected will be incinerated 5 (five) years after the end of the study.

## **RESULTS**

Twenty-two individuals were invited, of which 16 completed the survey. Six were excluded - four at the first evaluation and two at the invitation. Of the sixteen individuals, eight were male. The participants' ages ranged from 18 to 79 years, with a mean of 55.5 years of age (SD 15.7). Regarding gender, the mean were 58.2 (SD 11.4) and 52.7 (SD 19.5) years of age among the male and female participants respectively. This difference was not statistically significant (p > 0.05). Most individuals were from Goiânia (75%). Regarding education, six individuals (37.5%) concluded high school and there was one functional illiterate patient. About 70% (11) of the individuals were retired or received disability social security benefits.

Only two individuals do not have a morbid antecedent. Most of the comorbidities were cardiovascular (62.5%) and endocrine (43.75%). Systemic arterial hypertension and diabetes mellitus were the most prevalent diseases. Two individuals reported to be diabetic, but did not undergo drug treatment and one participant was pregnant during both evaluations. Metformin and losartan were the most prevalent medications, used by 18.7% and 37.5% of the participants respectively. 50% were smokers, all of them denied using of illicit drugs and four (25%) reported they were alcoholics.

Regarding amputation, there was no upper limbs amputation. One patient had amputation in both lower limbs - right toe and left transtibial amputation. Most of them underwent transfemoral amputation (11; 68.7%) of traumatic etiology (9; 56.2%) and with an average age of 44.3 years (SD: 19.8). Six individuals (37.5%) underwent two or more amputations, either due to complications of the first amputation or of another limb.

There was an increase in the number of individuals who used prosthesis between the two interviews. In the first interview, five participants used prosthesis (31.2%), whereas it was found in eight patients during the second interview (50%). Most individuals (9; 56.2%) did not perform therapies in either the first or second interview. Demographic, clinical and amputation data of participants are presented in Table 1.

Of the eight domains of SF 36, vitality was the only one to show a decrease between the interviews. All the others showed slight increases, except for Role Limitations Due to Physical Health and Role Limitations Due to Emotional Problems. The domains had an average increase of 9.9 points (SD 5.5), with the largest increase in the Social Functioning and Role Limitations Due to Emotional Problems.

Regarding the results of the McGill Questionnaire, the average total number of descriptors decreased between interviews, evidencing differences in the sensitive (4.7 to 1.8 points) and miscellanea (1.4 to 0.4 points). There was also a reduction in the average total score of the descriptors (8.5 to 3.2 points). The mean scores of both interviews are summarized in Table 2.

At the first interview, the incidence of Phantom Limb Pain was observed in 68.7% of participants, more frequent in male participants when compared to female participants (6; 54.5% x 5; 45.5%). In the second interview, there was a decrease of 18.7 points in the prevalence (50%), due to the decrease in the number of male individuals with pain, from 8 to 6, and female - from 5 to 2.

Pain intensity evaluated with VAS at the first moment ranged from 1 to 9 with a mean of 6.2 (SD 2.5). In the second interview, a reduction of more than two points was observed (4.4; SD2.1), ranging from 2 to 7, a statistically significant difference (p = 0.00194).

In the first interview we observed that the pain was more intense among female participants, with average VAS of 6.4 (SD 2.7) when compared to the male counterparts (5.7; SD 3.1). In the second interview, this situation was the opposite. The male participants reported greater pain intensity (4.7; SD 2.3), whereas the female participants had lower pain intensity (3.5; SD 2.1).

In both the first and second moments there was no significant differences in pain between the groups of participants with or without prosthesis, but we observed that the average pain is higher among patients with prosthesis and that the intensity decreased between the interviews  $(6.3 \times 61; 5 \times 3.5)$ .

Regarding drug therapy for PLP in the first interview, only two individuals (12.6%)

reported the use of continuous medical drugs, with an increase to four (25%) in the second interview. The medications used to treat PLP were: gabapentin (2; 12.6%) and amitriptyline (3; 18.6%). One patient reported improvement in pain after the introduction of gabapentin 900mg/day at the time of the first interview.

When comparing the scores obtained from SF 36 in the groups with and without pain in both moments of the study, we found that there was a significant difference in the domain "Pain" in the first interview (p=0.0083). The average score of all domains of the questionnaire was higher in individuals without pain. There was an increase in the mean scores of each SF36 domains for both individuals with and without PLP between both interviews. The average scores of the groups at both moments are shown in Figure 1.

Regarding the McGill Questionnaire average score, we observed that there was a reduction (8.5 to 3.18). There was a statistically significant difference between the sum of the evaluative, sensitive and miscellaneous descriptors. There was also a reduction in the number of descriptors, what suggests improvements in the general state of individuals with pain, what was also evidenced with VAS and SF-36. It was possible to establish a weak positive correlation (r = 0.34 and 0.5) between o VAS measurements and McGill scores obtained in both moments. There was a negative correlation between the score obtained in the SF3-6 domains and pain intensity measured by VAS and McGill.

Table 1. Demographic, clinical and amputation characteristics of participants

Characteristics	Distribution (%)	P	
Age (Mean/SD)	55.5 (15.7)		
Female / male	52.7 (19.5) / 58.2 (11.4) 0.508		
Hometown			
Goiânia / Countryside	12 (75%) / 4 (25%)		
Education (years)			
Up to 8 years	6 (37.5%)		
Between 8 and 12 years	9 (56.2%)		
Above 12 years	1 (6.3%)		
Labor status			
Retired / Benefits	14 (68.7%)		
Employed	2 (12.6%)		
Morbidity			
Cardiovascular	10 (62.5%)		
Endocrine	7 (43.7%)		
Smoking	8 (50%)		
Alcoholic	4 (25%)		
Amputation level			
Transfemoral	11 (68.7%)		
Transtibial	5 (31.2%)		
Foot	1 (6.3%)		
Amputation etiology			
Vascular	6 (37.5%) / 65.2 (DP: 8.84)		
Trauma	9 (56.2%) / 44.33 (DP: 19.81)		
Infection	2 (12.6%) / 47.5 (DP: 16.26)		
Number of amputations			
Single / Multiple	10 (62.5%) / 6 (37.5%)		
Prosthesis			
1st interview / 2nd interview	5 (31.2%) / 8 (50%)		
Physical Therapies			
1st interview / 2nd interview	7 (43.7%) / 7 (43.7%)		

SD, standard deviation.

#### DISCUSSION

This study was conducted with amputees assisted by a reference rehabilitation center for multiple disabilities in Goiás, Brazil. We investigated the frequency of phantom limb pain (PLP), as well as socio-demographic and clinical characteristics involved in this process. Other aspects evaluated were the influence of PLP on quality of life and multidimensional pain qualification.

Regarding the demographic profile, the sample studied is similar to that of other studies, except for equity between participants of both sexes. In the studies analyzed, there is a predominance of unemployed men with an average age between the 5th and 6th decades of life. These individuals are retired or under some benefit program. 1,2,6,9,10,11 Padovani et al. 10 states that the limitations and complications resulting from an amputation can lead to impaired functional independence and

Table 2. SF-36, VAS and McGill pain questionnaire

Evaluation	First Interview	Second Interview	P
VAS (10-cm Visual Analogue Scale)	4.3/10	2.2/10	0.075
SF-36			
Physical Functioning	33.1/100	44.4/100	0.0241*
Role limitations due to physical health	15.6/100	32.8/100	0.0519
Pain	61/ 100	64.8/100	0.7109
General Health	64.7/100	67.8/100	0.598
Energy/fatigue	61.9/100	60.6/100	0.851
Social functioning	37.5/100	87.5/100	0.0263*
Role limitations due to emotional problems	33.4/100	48/100	0.1285
Emotional well-being	57.9/100	67.2/100	0.0783
McGill pain questionnaire			
Sensory	4.7	1.8	0.0377*
Evaluative	1.3	0.4	0.0343*
Affective	1	0.5	0.0561
Miscellaneous	1.4	0.4	0.0208*
Total score	8.4	3.1	0.0172*

<sup>\*</sup> Statistically significant

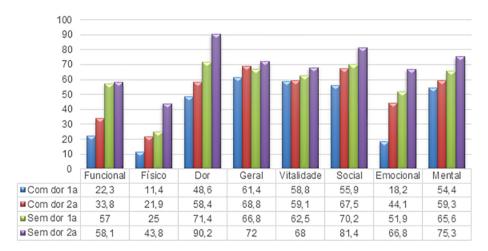


Figure 1. SF-36 scores comparison of both interviews of patients with and without PLP

consequently to a negative relationship with return to work.

The high prevalence of smoking, cardiovascular history besides diabetes may justify that vascular diseases were the second most common morbidity observed in this group (6; 37.5%). Multiple amputations are also usually associated with these causes. 1,2,6,10 Similar to that observed in other studies, the average age at which amputation occurred was higher in vascular than in traumatic and infectious etiologies.<sup>2,6,7,11</sup> The absence of individuals with lower limb amputations also occurred in other studies, a fact that could be explained by the low frequency of upper limb amputations in relation to lower limbs amputations. 1,2,6,7,8,10

Disturbance caused by the loss of a limb or part of it may lead to disorder in the physical and psychological aspects of the amputee, and PLP is a common sequela. 1,4,11 In this study, the frequency of PLP after amputation was 68.5% in the first interview and 50% in the second. This finding is in agreement with the literature which shows that the frequency may range from 2 to 90%. 1,2,6,8,12 This broad proportion may be due to the lack of standardization and criteria in its evaluation. The decrease in the number of individuals who report pain over six months may not be related to initiation of therapy, as reported by Quadros. 13

As PLP can lead to important changes in the amputee's biopsychosocial profile, the

assessment tools VAS, McGill, and SF-36 sought to holistically address both pain-related variables and the impact on the amputees' quality of life.<sup>2, 14,15</sup> These are widely and worldwide used questionnaires which are validated for Brazilian Portuguese language.<sup>16-18</sup> Lima, when performing a review on PLP during gait acquisition, shows that VAS and McGill were used by most of the selected articles.<sup>12</sup>

Although many studies use VAS, McGill and SF-36 as assessment tools, there was no study that correlated their results. <sup>10-14</sup> When comparing the mean scores of the SF-36 domains of our study, we observed they are similar to other studies. <sup>10,12,14,15</sup>

The reduction in pain intensity measured by VAS observed in this study agrees with that found in other studies.  $^{7,11-14}$  No relationship was found between gender and VAS in other studies. Quadros  $^{13}$  states that the incidence of PLP is not affected by gender, age or amputation level. There was a positive correlation (r=0.34 and 0.5) between the VAS measurement and the McGill score at both moments of the study, that is, pain had a smaller impact on life of the individual with amputation.

Since there are no methods that have been proven to prevent the chronicity of the pain process, the treatment of PLP remains a challenge. 3,4,13,14,15 It is believed that the presence of depressive symptoms and the intensity of pre-amputation pain influence this pain. 6,7,11,13,14,15 In our study, subjects were using gabapentin and amitriptyline. The frequency of participants who use medication at both times is lower when compared to other studies. 3,4,13,14,15

Transfemoral amputation has a strong negative impact on the quality of life of the amputated individual, as they lead to important physical limitations.<sup>6</sup> There was a significant difference in QoL of the population with and without PLP studied by van der Schans et al.<sup>14</sup> At the present, there was statistical difference only in the SF-36 Pain domain between both groups of amputees, as it is in agreement with that observed in the population studied by Van der Schans et al.<sup>14</sup> and Grilo<sup>4</sup>, whose literature review shows that there is no significant difference in the quality of life of the individual with or without PLP.

Lima<sup>12</sup> observed that in one of the studies, about 8% of the lower limb amputees sample worsened PLP the use of the prosthesis. In the case series of this study, there was agreement with what was observed by this author, i.e. although there was no significant difference

in pain measured between groups with or without prosthesis between both interviews, we observed that the average pain intensity is higher in patients with prosthesis, opposite to the findings by Machado Vaz et al.<sup>15</sup> who reported that patients with PLP had lesser access to prosthesis. Marques<sup>7</sup> reported that, most of the amputees did not use prosthesis, opposed to what we observed the first interview.

The total or partial removal of a limb leads to body disorder that, in turn, implies physical and psychological changes, what negatively impacts the individual's quality of life and rehabilitation process.<sup>2</sup> In this context, studies to explore this subject in different amputees populations is relevant in order to proportionally improve the therapeutic approach, facilitating the rehabilitation process and functional independence of amputees.

# CONCLUSION

From the evaluated data, we concluded that phantom limb pain was highly prevalent in the study subjects, as it was reported by 68.7% in the first interview and 50% in the second interview. There is negative impact of PLP on the individual's quality of life. There was no difference regarding the intensity and prevalence of PLP in individuals undertaking therapy, with or without medication, or even with prosthesis.

The sample size was a limiting factor of this study, especially for the statistical analysis. The lack of pre-amputation pain assessment as well as the patient's emotional state were other limitations of this study. However, this research agrees with what has already been published, that is PLP negatively affects the quality of life of amputees. This reinforces the importance of epidemiological studies on this subject in order to understanding the extent of its effects and to improve, therefore, the amputee rehabilitation process.

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