# Improving quality of life of neuropathic pain patients by continuous outpatient setting monitoring\*

Melhora da qualidade de vida de pacientes com dor neuropática utilizando de monitorização ambulatorial contínua

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## **SUMMARY**

**BACKGROUND AND OBJECTIVES**: Chronic pain management requires a multifunctional approach implying physical, psychological, social and occupational support. The understanding of pain physiopathology and

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its evaluation have to optimize the treatment. This study aimed at comprehensively evaluating the strongest predictors of quality of life through weekly data recorded in outpatient settings or at home to check practical and daily life activities.

**METHOD**: The following tools were applied: Wisconsin Pain Inventory, Mood Chart, McGill's Pain Questionnaire, Post-sleep Protocol and Generic quality of life questionnaire (Whoqol-bref).

**RESULTS**: Physical activity, occupational performance and sleep patterns have predicted better quality of life. Pain sensitivity, avoiding fear, and dependence on other people are responsible for significant variations in proposed activities. These findings suggest that external support and orientation sources may influence physical and social behavior in addition to internal clues, such as avoiding fear or pain.

**CONCLUSION**: Chronic neuropathic pain should be evaluated taking into account its peculiarities of clinical and behavioral presentation and social aspects, since such elements are critical for a positive evolution.

Keywords: Evaluation, Neuropathy, Pain, Quality of life.

## **RESUMO**

JUSTIFICATIVA E OBJETIVOS: O manuseio da dor de paciente com dor crônica exige uma abordagem multifuncional, que implica física, psicológica, social e ocupacional. O entendimento da fisiopatologia da dor e sua avaliação precisam otimizar o tratamento. O objetivo deste estudo foi avaliar de forma abrangente os mais fortes preditores de qualidade de vida através de registros semanais realizados em regime ambulatorial e

domiciliar verificando atividades de vida prática e diária. **MÉTODO**: Foram aplicados os instrumentos: Inventário de Dor de Wisconsin, Gráfico de Humor, Questionário de Dor McGill, Protocolo Pós-Sono e Questionário genérico de qualidade de vida (Whoqol-bref). **RESULTADOS**: A atividade física, o desempenho ocupacional e o padrão de sono prenunciaram melhor qualidade de vida. A sensibilidade à dor, evitar o medo, e dependência de outra pessoa são responsáveis por quantidade significativa da variação nas atividades propostas. Estes achados sugerem que as fontes externas de reforço

**CONCLUSÃO**: A dor crônica neuropática deve ser avaliada em suas particularidades de apresentação clínica, comportamental e aspectos sociais, já que tais elementos são fundamentais para uma boa evolução.

e orientação podem servir para influenciar o comporta-

mento físico e social além de pistas internas, tais como

Descritores: Avaliação, Dor, Neuropatia, Qualidade de vida.

## INTRODUCTION

evitar o medo ou a dor.

Among painful syndromes, chronic pain primarily characterized by neuropathic pain is the most significant<sup>1</sup>. Conventional handling and treatments are ineffective and may appear weeks, months or years after the injury, and occur when there is total or partial injury of peripheral or central nervous system nervous pathways<sup>2</sup>.

Among neuropathic pains more often associated to diseases there are peripheral diabetic neuropathy (PDN), post-herpetic neuralgia (PHN), trigeminal neuralgia, peripheral neuropathy associated to infection by human immuno-deficiency virus (HIV), phantom limb pain, radiculopathy, compression neuropathies, and neuropathic pain originated in the central nervous system (pain after stroke, post vertebral-medullar injury and multiple sclerosis)<sup>3</sup>.

Chronic pain people, more specifically neuropathic pain, often have dramatic changes in their lifestyle, which are result of the persistent distress caused by pain, with reflexes on the way they perceive their quality of life (QL). In addition to pain-related distress, there are frustrations of failed treatments, of the myriad of exams which explain very little and of unsatisfactory explanations by the health team as to the lack of an accurate diagnosis, or that little can be done to relieve it<sup>4</sup>.

In this context, pain evaluation and handling, performing daily activities as independently as possible, recovery of functionality, behavioral and social aspects are essential for such people. Evaluating them as from this part of their distress is just one of the stages aimed by the multi-

disciplinary team involved with the complex process of reestablishing their biopsychosocial balance and reintegrating them to their daily lives<sup>5</sup>.

So, one should incorporate new health dimensions to the traditional evaluation of clinical, laboratory and radiographic parameters in chronic patients to identify factors which allow the expression of self-evaluation aiming at giving them better self-knowledge and QL for them to be the authors of their own healing.

This study aimed at comprehensively evaluating the strongest QL predictors through weekly records collected in outpatient settings and at home to check practical and daily life activities.

#### **METHOD**

After the FAMERP Research Ethics Committee approval (2384/2010), this descriptive, exploratory, comparative, transversal and quantitative study was carried out in the Outpatient Setting of the Pain Clinic of the Hospital de Base (FUNFARME/FAMERP), in addition to the homes of studied sample.

Participated in this study people of both genders, with cognitive level sufficient to understand the procedures and follow given orientations. People agreed to participate in the study and signed a Free and Informed Consent Term. For people with neuropathic pain, their diagnosis should be according to CID-10. Exclusion criteria were patients with psychiatric disease and lack of clinical follow up in the Pain Clinic.

Patients were distributed in two groups: test group (TG), with neuropathic pain diagnosis (4), post-herpetic neuralgia (3), HIV-related pain (2), pain originated in the CNS (4) and radiculopathy (3); and control group (CG) with 22 individuals submitted to interconsultation in the Pain Clinic and with diagnosis of musculoskeletal system diseases and recommendations to walk.

The group was made up of individuals paired by age and educational level with regard to the test group. Evaluation used a specific protocol with questions about incapacities and functional impairment caused by pain – practical and daily activities (work, concentration, appetite, personal hygiene, sexual activity, ambulation, home activities, interpersonal relationships and leisure); Wisconsin Pain Inventory<sup>6</sup>, with numerical scales from zero to 10 (where zero means no pain and 10 the worst imaginable pain), which evaluated general pain intensity and its repercussions in labor and extra-labor life of individuals; Mood Chart<sup>7</sup> which reflects behavioral sensations during the day (0-4 from sad to happy); McGill Pain Inventory, with 78 descriptors organized in 4 groups

and 20 subgroups (components of sensory-discriminative, affective-motivational and evaluative pain) and which are important indices to evaluate pain, and Post-Sleep Protocol (PSI)9 which evaluates sleep quality and is made up of 30 items divided in 3 categories: pre-sleep (going to bed), during sleep and post-sleep (awakening) (30-390 – higher scores mean better sleep quality). Whogol-bref<sup>10</sup> was used to evaluate OL. This is a psychometric simplified tool created by the World Health Organization (WHO) to evaluate QL as from the original Whoqol-100. It asks how the individual felt about his QL, health and other areas of life in the last weeks. It consists of 26 questions related to four domains: physical, psychological, social relations and environment; there are also two questions for global evaluation. Each domain identifies a particular focus of attention to people's QL. The original document has 23 specific facets with 4 questions each.

All participants of both groups were submitted to four quarterly evaluations after being assisted by an outpatient group made up of an interdisciplinary team holding an intensive educational training program, essential to decrease pain and prevent pain recurrence with educational actions aimed at body biomechanics, kinesiotherapy, ergonomics and addressing psychosocial and occupational aspects.

Excel was used for descriptive analysis. Quantitative data were analyzed by Odds Ratio and ordinals by non-parametric tests. Significance level was 0.05.

## **RESULTS**

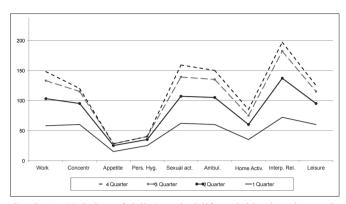
Sixteen TG individuals adhered 100% to the program. There were two follow up losses because patients did not return.

Mean general sample age was  $38.6 \pm 10.5$  years, varying from 28 to 64 years of age, with predominance of females (56%). Mean pain duration was 1 year and 3 months and mean time for clinical diagnosis of neuropathic pain in TG was  $8 \pm 3$  months. Table 1 shows sample characterization of both studied groups (FT and CG).

Table 1 – Characterization of sample of studied groups

Variables	Groups	n	Mean $\pm$ SD (years)	%
Age	Test	16	$34.3 \pm 4.3$	
	Control	20	$42.9 \pm 3.5$	
Gender	Test	16		Female-56%
	Control	20		Female-54%
				Single- 9 %
Marital status	Test	16		Married- 57%
				Divorced-31%
				Widow-3%
				Single- 20%
	Control	20		Married- 46%
				Divorced-31%
				Widow-3%
Pain duration	Test	16	$0.2 \pm 2$	
	Control	20	$0.5 \pm 1.2$	
Education	Test	16	$1.3 \pm 3.5$	
	Control	20	$2 \pm 1.7$	
				Unemployment- 49%
	Test	16		Retirement- 22%
	Control	20		Benefit- 29%
Social losses				
				Unemployment- 13%
				Retirement- 14%
				Benefit- 28%
Diagnosis time	Test	16	$8 \pm 3$ months	
	Control	20	1.8 ± 1	

Table 2 shows general mean of each test, however the content of each test has oriented group activities to focus on major problems and to introduce specific activities to them. QL evaluated by generic Whoqol-bref questionnaire showed QL improvement in four evaluated domains, showing that groups are statistically different, however they are lower for neuropathic pain patients (Table 3). Graph 1 shows practical and daily life activities which were identified during continuous TG outpatient monitoring, showing changes caused by factors impairing QL with consequent improvement after intervention and control.



Graph 1 – Variation of daily/practical life activities impairment in each evaluation moment of the test group

Table 2 – Data obtained with the application of Wisconsin Pain Inventory, Mood Chart, McGill Questionnaire and Post-Sleep Protocol (PSI) in studied groups.

Questionnaires	N	1 <sup>st</sup> Evaluation	2 <sup>nd</sup> Evaluation	3 <sup>rd</sup> Evaluation	4 <sup>th</sup> Evaluation	p value
Wisconsin Inventory	Test – 16 Control – 20	39 (0-100) 52 (0-100)	45 60	52 60	75 75	0.03
Mood Chart	Test - 16 $Control - 20$	2 (0-4) 2 (0-4)	3 2	4 3	4 4	0.0048*
McGill Questionnaire	Test – 16	Sensory-12(0-20) Evaluative- 9 (0-20)	Senso- ry-10(0-20) Evaluative- 8 (0-20)	Senso- ry-8(0-20) Evaluative- 6 (0-20)	Sensory-6(0-20) Evaluative- 5 (0-20)	
	Control – 20	Sensory-13(0-20) Evaluative -11 (0-20)	Senso- ry-12(0-20) Evaluative 9 (0-20)	Senso- ry-10(0-20) Evaluative 8 (0-20)	Sensory-9(0-20) Evaluative -7 (0-20)	0.0035*
PSI	T – 16 C- 20	92 (30-390) 150(30-390)	130 190	150 210	172 230	0.0035*

<sup>\*</sup> Significance level p < 0.05. Kruskal-Wallis Test

Table 3 – Variations and mean values of domains of the generic quality of life questionnaire Whoqol-bref in different evaluation periods, for both studied groups.

Domains	$Mean \pm SD$						
	N	1st Evaluation	2nd Evaluation	3rd Evaluation	4th Evaluation	p value	
Physical	T-16	$49.3 \pm 23.6$	$53.6 \pm 20.6$	$65.0 \pm 19.5$	$72.0 \pm 21.6$	0.05	
	C-20	$55.5 \pm 22.5$	$62.5 \pm 20.5$	$55.5 \pm 22.5$	$85.0 \pm 22.5$		
Psychological	T-16	$35.8 \pm 23.6$	$48.3 \pm 23.6$	$60.0 \pm 19.5$	$70.0 \pm 19.5$	0.062	
	C-20	$55.5 \pm 22.5$	$65.5 \pm 22.5$	$75.5 \pm 21.5$	$85.5 \pm 20.5$		
Social Relations	T-16	$48.3 \pm 23.6$	$55.5 \pm 19.6$	$69.3 \pm 18.6$	$75.0 \pm 20.6$	0.048*	
	C-20	$70.5 \pm 22.5$	$80.0 \pm 15.2$	$85.5 \pm 13.5$	$90.0 \pm 22.5$		
Environment	T-16	$55.0 \pm 22.6$	$65.3 \pm 21.6$	$79.3 \pm 21.6$	$85.0 \pm 13.6$	0.036*	
	C-20	$70.0 \pm 14.5$	$90.0 \pm 11.0$	$90.0 \pm 12.5$	$95.0 \pm 11.0$		

<sup>\*</sup> Significance level p < 0,05. Multiple linear regression analysis.

## DISCUSSION

In general, results suggest that, among chronic neuropathic pain individuals, those with chronic complications have poorer QL as compared to those without such pain. This difference is seen when factors involving the daily lives of these individuals and their biopsychosocial behavior are specifically analyzed.

Some authors tried to relate pain with medullar injury and neuropathic pain to psychological factors and physical incapacity in a longitudinal study lasting five years and have obtained surprising data<sup>11</sup>. Pain was the third most mentioned difficulty, associated to medullar injury, only after motor incapacity and sexual dysfunction which were, respectively, the first and the second mentioned problems. Pain patients also showed more mood changes according to the mood inventory<sup>12</sup> as compared to those painless.

Some studies<sup>13,14</sup> are in line with our study and mention the importance of developing further longitudinal researches to provide us with better understanding of the way how different development stages and factors contribute or affect the prognosis of this pain. They have also reported, to date, the lack of a tool for clinical use, which is simple and able to distinguish neuropathic symptoms and signs from those caused by nociceptive chronic pain<sup>13</sup>. Monitoring leads us to infer to determine causes and existence of a common pattern among these individuals.

Regarding the use of QL parameters to evaluate chronic neuropathic pain individuals, the literature is scarce. Other authors refer in their studies that pain intensity has only decreased after one year of follow up, while QL indices and anxiety have improved after 6 months<sup>15</sup>. They concluded that educational activities and thorough interdisciplinary evaluation lead to better QL, thus confirming our study.

Very often, impressions about the direct relation between pain and low quality of life, brought from the clinic, cannot be confirmed by uncontrolled studies. However, even considering these difficulties, all analyzed results have shown that pain may negatively interfere with the QL of individuals with neuropathic pain, changing their mood and self-perception, as well as the difficulty to deal with problems originated from this state.

In spite of the methodological limitation of a small sample size, we need to better understand people in several domains of their lives and effectively monitor them so that healing is permanent.

## CONCLUSION

The use of several tools has suggested that physical activity, occupational performance and sleep pattern were factors contributing to improve quality of life. Further analyses have shown that pain sensitivity, avoiding fear and dependence on other person are responsible for a significant amount of variation in proposed activities.

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Presented in September 01, 2011. Accepted for publication in November 16, 2011 Conflict of interests: None.