

STING Study: SStudy on Individual perceptiON, knowledGe and characterization of neuropathic pain, in Portugal – Community data

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ABSTRACT

Objective: Portuguese data concerning general population knowledge and prevalence about neuropathic pain (NeP) are sparse and many patients remain frequently undiagnosed as this disease is still under recognized among population. This study aimed to evaluate Portuguese perception about NeP and to characterize their knowledge and information sources. Additionally, the study had the exploratory objective of determining NeP prevalence.

Materials and Methods: Epidemiological, cross-sectional study of a representative sample of the Portuguese population aged 18 years old or more, by direct application of a structured questionnaire. Demographic data and data on knowledge and perception about NeP were collected. It was also collected data about NeP diagnosis. Descriptive analysis and a logistic regression assuming a significance level of 0.05 were performed.

Results: 1072 subjects were included, 47.9% male, mean±SD age 46.4±18.6 years old. 71.3% referred never having heard about NeP. The percentage of individuals who declared to know about NeP characteristics decreased as the specificity of the theme increased: 24.8% referred knowing the disease's symptoms, 23.0% knew how it is treated and 15.6% knew which situations/ pathologies can cause NeP. The three most referred symptoms of the disease were itching (42.6%), numbness (33.6%) and joint pain (31.2%). An older age and a higher educational level were associated with a higher knowledge about this pathology. A 3.2% auto-referred prevalence of NeP was observed.

Conclusions: The data highlight the lack of information about NeP in Portugal. Defining multidimensional strategies to improve people's awareness about NeP might improve early diagnosis and treatment of this very debilitating condition.

Keywords: Pain; Epidemiology; Awareness; Knowledge; Neuropathic pain; Portugal

INTRODUCTION

Neuropathic pain (NeP) is defined by the NeuPSIG (Special Interest Group on Neuropathic Pain) group of The International Association for the Study of Pain (IASP)¹ as "pain arising as a direct consequence of a lesion or disease affecting the somatosensory system". Diabetes, cancer, HIV, nutritional deficits, radiculopathy, trauma, phantom limb pain or postherpetic neuralgia are some of the causes of peripheral NeP; frequent situations associated with central NeP are multiple sclerosis, post-stroke pain and spinal cord injury²⁻⁶.

The most frequent symptoms related to NeP are paresthesias, burning and shooting pain, described by patients as electric shock sensation, throbbing, itching, numbness antcrawling and tingling, and are commonly associated with hypoesthesias, hypo and hyperalgesia and allodynia^{5,6}.

NeP causes a significant burden to both individuals and society as it is associated with impaired quality of life, with emotional and physical disability, reduced productivity and increased healthcare costs⁷⁻¹¹.

The prevalence data about NeP in general population are scarce, with values varying between 1% and 8%^{12,13}. In Portugal, chronic pain affects 36.7% of the population¹⁴ but it is unknown the number of persons that suffer from NeP. Diagnosis is challenging and some

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patients remain undiagnosed for several years¹⁵⁻¹⁸.

There is scarce data concerning what people from general population know about this disease. The knowledge about the disease, its risk factors and symptoms are preventive factors in health, allowing an earlier diagnosis and leading to a better and anticipated treatment and follow-up¹⁹. Thus, it is important to know the level of individual's disease awareness in order to develop public campaigns and actions that can lead to increase the literacy about health and diseases and, consequently, health status.

Considering the growing number of elderly people, the incidence increase of chronic diseases, the considerable burden of NeP and its interference with patient's and caregivers' quality of life, the awareness of population and health caregivers is essential to identify NeP cases earlier, improving and anticipating treatment and follow-up strategies²⁰.

The objective of this study was to evaluate the perception about NeP in the Portuguese population and to characterize their knowledge and information sources. Additionally, the study had the exploratory objective of determining self-reported NeP prevalence in Portugal.

MATERIALS AND METHODS

SAMPLE DEFINITION

The sample was defined considering the primary objective of evaluate the perception about NeP in the Portuguese population and characterize their knowledge and information sources. Considering a universe of 7,938,886 residents in Portugal aged 18 years or older (according to the Census 2001 data), an error of 3% and a significance level of 0.05, and a response distribution of 50/50, a sample of 1072 subjects stratified by gender, age group and Portugal regions (North, Centre, Lisbon and Tagus Valley, Alentejo and Algarve) was included in this study.

STUDY DESIGN AND PROCEDURES

An epidemiological, cross-sectional, nationwide study was developed with the application of a structured questionnaire in a face-to-face interview, using a random route methodology. This consisted in an established predetermined route with successive turns to the right starting from a predefined departure point in each randomized locality - the local church, giving each individual the same probability of being selected

to participate in the study. We have contacted all the even number households, even floors, right side. In the household the person questioned was the one who date birth was next, if 18 years old or more and if his/her sex/age quote was not full. Participants needed to give their oral consent to participate in the study. Demographic information and data concerning NeP knowledge and perception were collected. The questionnaire was structured in matters that respondents could give spontaneous answers. First, people were asked, in yes-no questions, if they knew or ever heard about NeP, the associated physical system, its causes, symptoms, treatment and impact on patient's life. Those who answer that they knew or had heard about this concepts, were asked to enumerate the physical system, the causes, the symptoms, the available treatments and the impact on patient's life respectively (using open questions, giving no answer options). It was also questioned if subject was ever diagnosed with NeP with a brief clinical characterization of the disease. Data collection took place in September 2009. The percentage of refusals was less than 10%.

STATISTICAL ANALYSIS

Socio-demographical data, knowledge and concepts were characterized using descriptive analysis, with relative frequencies for categorical variables and, means and standard deviations values for continuous variables (presented as mean \pm std. deviation). Proportions and prevalence are presented along it 95% confidence intervals (presented as CI 95%) in what concerns knowledge related with NeP. A logistic regression was performed, assuming a significance level of 0.05. SPSS software, version 15.0, was used in statistical analysis.

RESULTS

The study included 1072 subjects, 47.9% male, mean age 46.4 \pm 18.6 years old. Table I presents study population demographic characteristics.

Seventy one percent of subjects (71.3%, CI 95% 68.6-74.0%; n=764) referred never having heard about NeP. For those who affirmed having some knowledge about this disease, the general practitioner (31.3%), friends (30.6%) and the television (25.8%) were the main information sources. Family was referred by 24.7%, 11.7% named school, 11.3% books and 9.3% internet. Other healthcare professionals were also mentioned, pharmacists were referred by 11.7% and

TABLE I. DEMOGRAPHIC CHARACTERISTICS

	Study population N=1072
Age – Mean ± (SD)	46.41±18.56
Marital status – %	
Single	23.2
Married	63.9
Divorced	4.0
Widower	9.0
Educational level - %	
≤4 years	25.7
5-9 years	22.9
10-12 years	31.5
≥12 years	19.8
Professional activity - %	
Student	11.8
Housewife	9.3
Unemployed	6.8
Active	53.9
Retired	18.2

(SD) – Standard deviation

nurses by 6.0%. Other information was gathered from journals and magazines (10.7%) and leaflets (6.2%).

Figure 1 presents the percentage of respondents affirming to know something about NeP and its clinical features (n=1072). Except for the impact on patients' life (63.9% answered they knew how the disease influenced their life), 30% or less affirmed having some knowledge about the physical system involved in this disease or its causes, symptoms and treatment.

From the 30% who affirmed knowing which system

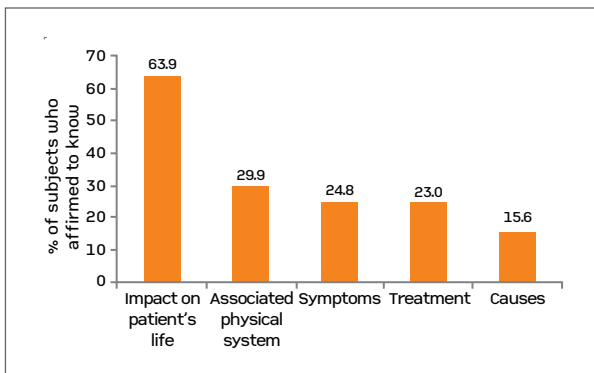


FIGURE 1. Knowledge related with NeP (1072)
NeP: Neuropathic pain; CI – Confidence interval

is associated with NeP (n=321), 87.1% indicated that it was the central nervous system (CNS), 4.4% answered muscular skeletal system, 2.2% the circulatory system and 1.3% the endocrine system.

The situations or diseases indicated as might causing NeP (referred by 15.6% of the respondents that answered to knew them; n=167) were: diabetic peripheral neuropathy (26.9%), CNS NeP syndromes (26.3%), compression neuropathies (19.8%), trigeminal neuralgia (16.2%), NeP related to cancer (16.2%), phantom limb pain (14.4%), postherpetic neuralgia (12.0%), radiculopathy (10.8%) and HIV-associated peripheral neuropathy (6.0%).

From the 24.8% who refer that could identify the characteristic and suggestible symptoms of the disease (n=266), 42.6% referred itching, 33.6% numbness, 26.7% electric-shock and 19.5% burning. Bone and joints pains were the two incorrect more frequently reported symptoms (Figure 2).

“NeP has no treatment” was the answer given by 8.1% of the subjects who affirmed knowing how NeP is treated (23.0%; n=247). Drugs were indicated by 81.4%, 19.0% referred physiotherapy and 11.3% surgery.

Quality of life, tiredness, walking difficulties and lack of energy were the items subjects most referred when asked about the impact of NeP in patients' life (Table II).

The regression model included as independent categorical variables gender (male; female), marital status (single; married; divorced; widower), educational level (≤4 years; 5-9 years; 10-12 years; ≥12 years) and professional activity (student; housewife; unemployed; active; retired). The age entered as a continuous variable. An older age (OR 1.028; CI 95% 1.017-1.040) and a higher educational level (OR 1.27; CI 95% 1.20-1.35) were the variables, identified in the multivariate analysis, which were associated with a higher knowledge about NeP.

In this sample, a known prevalence of NeP of 3.2% (CI 95% 2.25-4.25%) was observed (n=34). Subjects referred that the clinical diagnosis was performed, mainly, by the general practice physician (85.3%); 11.8% affirmed they were diagnosed by the neurologist, 8.8% named the rehabilitation and physical specialist, 5.9% the rheumatologist and 5.9% the orthopedist. After the occurrence of the first symptoms, 46.9% of the subjects identified as having NeP waited more than 6 months to be diagnosed (varying between 15 days and 3 years).

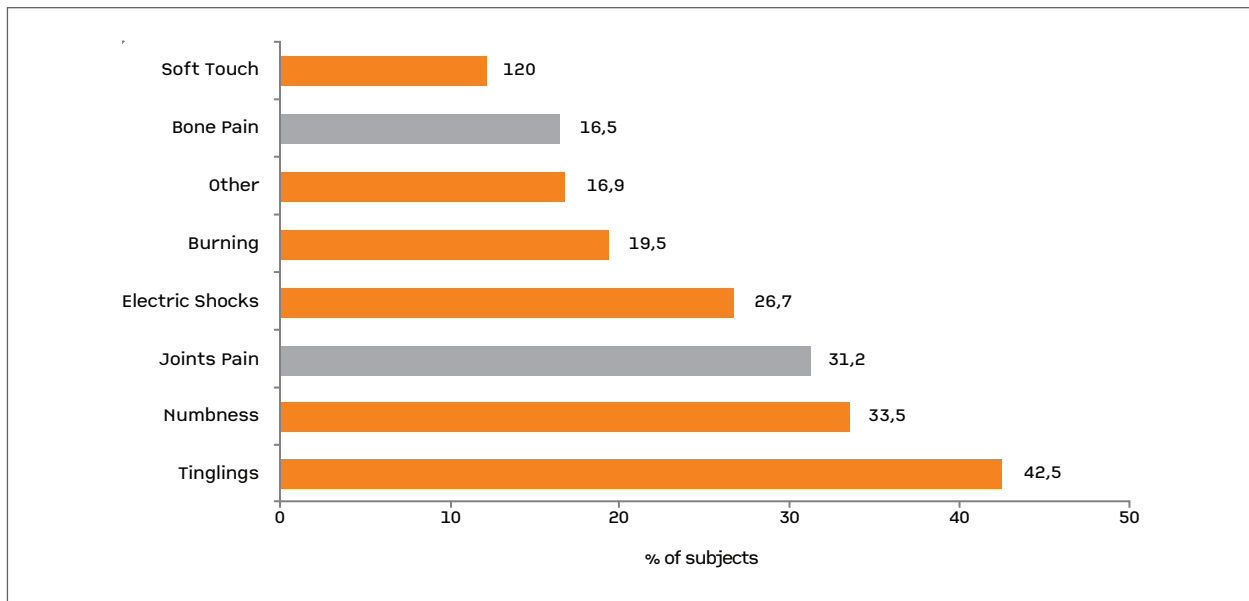


FIGURE 2. NeP referred symptoms (n=2266)

NeP: Neuropathic pain

TABLE II. NEP IMPACT ON PATIENTS' LIFE

	Subjects who affirmed knowing NeP impact N=387
Quality of life	75.7%
Tiredness	39.8%
Walking difficulties	27.9%
Lack of energy	24.3%
Concentration difficulties	22.0%
Sleeping disorders	18.1%
Economic	12.1%
Absenteeism	9.3%

NeP: Neuropathic pain

DISCUSSION

This study, with a representative sample of the Portuguese population, depicts the actual knowledge that the general population has on what is NeP, its characteristics and impact on patients' lives. It points out areas of misperception and lack of information, and can point the way on how to improve the understanding, identification and adequate valorization of this clinical entity within the population.

NeP is under recognized among the Portuguese

population with nearly 70% mentioning that never have heard about this condition. Older age and higher educational level was associated with a higher knowledge about NeP. We believe that age can be a positive mediator of knowledge, as older patients have a higher probability of having had contact with some kind of pain in the past, either self-experienced or in their family or social circle. The higher educational level as a positive mediator of knowledge seems intuitive since people may have access to more information and may be more qualified to understand the available information. Moreover, the percentage of individuals who declared to know about NeP characteristics decreased as the specificity of the questions increased, showing great illiteracy about the theme.

The Institute of Medicine Committee for Health Literacy²¹ defines health literacy as “the degree to which individuals have the capacity to obtain, process, and understand basic information and services needed to make appropriate decisions regarding their health”. It is widely known that the knowledge that a population has about a disease (including risk factors, symptoms, outcome, health service use) has a direct relation with early diagnosis (and thus correct treatment and follow-up) and influences the definition, at several levels in society, of health promotion and prevention measures, causing a positive social, financial and demographic impact^{22,23}. Low knowledge about a disease, as found in

this study, can be related with worse health outcomes and more inadequate use of health care services²⁴. Thus, the results of this study stress the importance and need of defining communication strategies about NeP, allowing a better awareness of the population, which could impact on earlier diagnosis and treatment.

The most referred sources of information were the general practitioner, friends and television, with 11% or less referring other media or leaflets. This study data are, in some extent, in line with data reported by other studies including rheumatoid arthritis (RA) in the Portuguese population, where medical professionals were named as the primary source of information about the disease and treatment; in contrast, in RAISE study, conducted in 8 European countries (France, Germany, Greece, Italy, the Netherlands, Spain, Sweden and the United Kingdom) and Canada, internet and written media were the primary information sources named by RA patients²⁵. Considering that the access to more information, both in terms of quality and quantity, means a higher probability of being familiar with the term “NeP” and correctly identifying its characteristics and comorbidities, these results points out the need to increase educational information about NeP in written platforms, including internet, in order to improve general literacy about the disease.

Nevertheless, physicians and other health professionals take one of the most important and indispensable roles in an early diagnosis. Although NeP still represents a challenge in clinical practice^{15-18,26} an interdisciplinary approach, including clinical examination and laboratory tests, as well as patient verbal descriptions and the application of questionnaires and pain scales conducts to better diagnosis²⁷⁻²⁹. The painDETECT questionnaire is one of the several exiting instruments, developed to determine the presence of neuropathic pain components³⁰. This is an easy to use, self-administered questionnaire that could help physicians to identify probable NeP patients; however there should be more clinical guidelines for the use of these type of instruments, as they are not widely known by the majority of professionals, namely family physicians.

An earlier diagnosis would diminish the burden of this disease, improving patient quality of life and diminishing the emotional and physical impairment associated with NeP^{7-11,20}. On the other hand, a sooner detection of the disease, with an earlier treatment, would also limit the social burden of NeP by decreasing healthcare costs associated with drugs consume, physician visits and use of other health care facilities,

and increasing patient and caregivers productivity, with less missed work days^{7,8,10,11}.

In this study, we found a self-reported NeP prevalence of 3.2%, which is consistent with published data from Spain³¹, with a prevalence of 3.9%; in France¹³ and United Kingdom¹² the prevalence was twice the value presented – 7% and 8% respectively. The discrepancy between values may be due to the small sample involved in the study or to differences between countries and further studies should be undertake to explore this situation. Nevertheless, this is an indicative value of NeP magnitude in Portugal.

Study limitations should be considered. The sample dimension allows the evaluation of the Portuguese perception and knowledge about NeP but it did not permit data analysis in specific subgroups, by age or sex. Future studies should focus on subgroups investigation in order to define more accurate and directed communication strategies. Additionally, and although the determination of NeP prevalence was an exploratory objective, the study sample did not allow to explore data concerning NeP patients. Future studies should further analyze and characterize this population in terms of the clinical follow-up and treatment and, burden associated with the disease. Secondly, with this methodology it is not possible to investigate the direct relation between people health literacy about NeP and health status or health services used. More studies are needed to assess the impact of addressing the identified variables in this study, in order to evaluate if improving population knowledge about NeP would lead to an earlier diagnosis and treatment, decreasing the burden of the disease to patients and to the society.

CONCLUSION

This study gave insights on perception about NeP of the Portuguese population, namely their knowledge about its causes, symptoms, treatment and perceived impact on patients lives. The data highlight the existing illiteracy in several dimensions of the disease and showed the primary information sources about this matter, enabling the definition of multidimensional strategies to improve people's awareness about the disease. Future studies should address the questions raised by this study in target populations and should investigate the relations between NeP knowledge and earlier diagnosis and treatment.

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