Care strategies and therapeutic pathways for chronic pain patients in Abruzzo Region, Italy

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Abstract

Background. Chronic pain is considered to be among the most disabling and costly diseases in North America, Europe and Australia. A large survey was conducted on chronic pain in Europe, called Pain in Europe. Italy ranks third in Europe in terms of prevalence, with 26% of the population suffering from chronic pain at some point. In 2010 Italy passed Law 38/2010, to ensure treatment for pain control in patients with oncological diseases as well as in patients with chronic non-cancer pain through a network of care services. This study aims to provide preliminary information regarding the application of L.38/2010 in the Abruzzo region of Italy.

Methods. A descriptive study was conducted on a non-probabilistic sample of people who attended pain therapy centres of the local health service in 2014. The patients (129) were interviewed by centre staff using a validated questionnaire. Recruitment was carried out by enrolling consecutive cases over a three-month period (February to April).

Results. Almost two-thirds of the patients had visited several physicians before requesting help. The initial visit to the pain therapy centre was made after some months in 37.2% of cases, and in 38% of patients it was made years after the onset of pain. The reasons given for this long wait before seeking specialist medical treatment for chronic pain reveal a wait-and-see attitude on the part of patients, who controlled their pain by taking painkillers. Responsibility for this delay in requesting assistance can however also be attributed 'externally' to the fact that patients were not aware that this kind of centre was available.

Conclusion. The results of the study describe, in a regional context, a situation in which L.38/2010 is hard to apply. The study showed how the care pathway for these patients is still characterised by difficulty in accessing the network of local services. Clearly, more effort needs to be directed towards an effective application of L.38/2010, with increased availability of resources to develop and strengthen the network of services at regional level.

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Introduction

Chronic pain is an ever-growing problem, especially among the elderly population, and involves, in most cases, serious physical disability often associated with psychosocial distress (1). This problem is more widespread in economically developed countries and may be due to overall aging of the population, which is accompanied by an increased incidence of chronic degenerative diseases, almost always characterised by pain symptoms (2). Chronic pain is considered among the most disabling and costly diseases in North America, Europe and Australia; the extent of the problem is likely to be similar in developed countries where epidemiological data are not yet available (3).

There is a large unmet need in Europe for greater understanding of such a widespread and frequently debilitating pathology. This has led to the launch of an extensive survey of chronic pain in Europe, called *Pain in Europe*. Conducted by telephone in 2003, this survey involved 15 European countries and Israel. Recruitment was limited to adult (>18 years) subjects, who had been experiencing pain for at least six months, several times a week. The results of this survey, which involved more than 46,000 people, showed that about one-fifth (19%) of the adult population in Europe suffered chronic pain (4). Italy ranked third in Europe for the prevalence of patients suffering from chronic pain (26%), preceded only by Norway (30%) and Poland (27%). The United Kingdom and Spain had the lowest prevalence of chronic pain (13% and 11%, respectively).

The high incidence of chronic pain in Italy is accompanied by a high percentage (44%) of patients who report pain of severe intensity (Numeric Rating Scale = 7-10) (5). This finding appears to be in contrast with data related to prescription drugs. Although the types of analgesics prescribed differ

somewhat between European countries, nonsteroidal anti-inflammatory drugs were the most frequently prescribed analgesic: 71% in Poland, 68% in Italy, but only 23% in the United Kingdom. In the latter case, weak opioids and acetaminophen are the most widely used. The highest use of opioids was found in the United Kingdom, while in Italy and Spain the treatment of chronic pain with these drugs is close to zero. Not surprisingly, the prevalence of chronic pain increases with age, particularly in women (4, 6, 7).

In Italy, the population over 60 years of age, which was about 6 million in 1950, almost doubled in the 40 years between 1950 and 1990. It is estimated that this group will reach around 16 million in 2020 (29.3% of the total population) (8). This will have predictable consequences on the incidence of chronic degenerative diseases and prevalence of chronic pain in a category of patients at risk for inadequate treatment (9, 10). A clear priority is to generate accurate estimates on the prevalence of chronic pain in the population and the limited number of epidemiological studies hampers the attempts to respond with adequate resources (11).

In 2010, the Italian Government passed Law 38: "Measures to ensure access to palliative care and pain therapy." The purpose of the law is to ensure adequate pain treatment in patients with oncological diseases and patients with chronic pain, using pharmacological and non-pharmacological interventions implemented through a network of services that provide care for these patients.

In order to obtain relevant information about the care provided to patients with chronic pain in accordance with Law 38/2010, the Non-Profit Organisation "Citizen Initiative – Tribunal for Patients' Rights" disclosed the results of an investigation called "We are not born to suffer. Chronic pain and care pathways" (12). This initiative was inspired by the theme of unnecessary

suffering and the right of all citizens not to suffer, as laid out in the European Charter of Patients' Rights, presented in Brussels in November 2002. Article 11 of the Charter states, in fact, that "everyone has the right to avoid as much suffering as possible, at every stage of his or her illness" (13).

The survey was conducted in seven regions of Italy: Campania, Calabria, Latium, Liguria, Lombardy, Veneto and Sicily and involved 418 patients treated at pain therapy centres. The study was intended to highlight critical pain management issues for these patients.

The resolution adopted by the World Medical Association (14) states the need to ensure access to care and adequate treatment to people with chronic pain, and encourages governmental institutions to put in place resources (facilities and staff) that can implement intervention strategies that respond to the needs of this population.

The survey presented here was conducted in 2014 at centres for pain therapy of the Abruzzo Region in Italy. Its aim was to provide preliminary information about the application of Law L.38/2010 in this region. We assessed the accessibility of the network of services using data collected from a sample of users of the centres over their course of treatment, covering the period of time from when therapy was first sought until its completion. Information about patient experiences in relation to the centres, in particular their criticisms, can provide guidance to improve chronic pain management and thereby aid administrators in planning interventions in this area of public health.

Methods

This descriptive study was conducted on a non-probabilistic sample of users who were attending local health centres for pain therapy of the Abruzzo region. The study included patients suffering from chronic pain (as defined by the International Association for the Study of Pain) of a non-oncological nature. Recruitment was carried out by enrolling consecutive cases over a three-month period (February to April). The patients, after being informed about the study's objectives, were asked to provide written consent to the gathering and use of information, and were interviewed by specially trained centre staff using an approved questionnaire. The questionnaire was divided into groups of questions to describe:

- treatment regimen
- relationship between the centres for pain therapy and patient

Data were analysed using descriptive statistics; the frequencies and percentages for the variables considered were calculated. Analysis was performed using IBM SPSS version 19.0 (IBM Corp., Armonk, NY, USA).

Results

A total of 129 questionnaires were completed. Patient characteristics are summarised in Table 1. Of the patients who responded, 66.7% were female (70.5% of them married); education level could be divided into two subgroups: no qualification/primary and secondary school (57.4%) and high school/graduates (42.3%).

The age group 59-78 years accounted for 47.3% of the patients, who had an average age of 65.7 ± 15.9 years (range 26-86 years). Distribution according to employment reflected the prevalence of women and elderly patients: 41.9% were retirees and 31.0% were housewives.

Course of treatment

Before presenting to the centre, 86% of interviewees had consulted their doctor (GP) or a specialist, in particular an orthopaedic

Table 1 - Patients' characteristics

	No.	%
Sex		,
F	86	66.7
M	43	33.3
Marital Status		
Married	91	70.5
Single	11	8.5
Separated/Divorced	22	17.1
Widowed	5	3.9
Age Groups		
18-38	3	2.3
39-58	38	29.5
59-78	61	47.3
≥79	27	20.9
Education level		
No qualification	11	8.5
Primary School	26	20.2
Secondary School	37	28.7
Further education /Graduate	55	42.6
Working Activity		
Student	1	0.8
Housewife	40	31.0
Unemployed	7	5.4
Worker	27	20.9
Retired	54	41.9

surgeon (58.1%) and a neurosurgeon (30.2%). A high proportion (65.1%) visited several doctors (2 to 5) before being addressed to the centre (Table 2). It was in fact the GPs and medical specialists who guided the patients' care pathways, defining pain as a problem to be treated (Table 3) and referring them to the centre for pain therapy. Patients' social networks also played an important role in their decision to approach the centre; 15.5% of respondents were advised by friends to pursue this direction. Furthermore, 32.6% of patients resorted to alternative therapies, especially acupuncture.

Another significant element characterising patients' treatment pathways is the time lapse between the onset of pain and seeking treatment. Information was obtained both

Table 2 - Doctors consulted before attending the Centre for Pain Therapy

Qualification	%
Diabetologist	0.8
Physiatrist	21.7
Internist	3.9
General Practitioner (GP)	86.0
Neurosurgeon	30.2
Neurologist	13.2
Orthopaedic surgeon	58.1
Rheumatologist	16.3
Other	10.1
No. doctors	
None	3.1
1	20.9
2 - 5	65.1
6 - 10	9.3
> 10	1.6

about the amount of time that passed before medical consultation (with GPs and specialists) and the time lapse before the patient presented at the centre for pain therapy. Table 4 shows that a high percentage (27.1%) of patients turned to a

Table 3 - Pain and decision to intervene

	(%)
Who identified pain as a problem to treat.	?
GP	47.3
Medical Specialist	31.8
Specialist from Centre for Pain Management	10.9
Other	13.0
Who sent you to the Centre for Pain There	ару?
GP	38.8
Medical Specialist	31.0
Local Health Unit Operators	1.6
Acquaintances	15.5
Other	13.2
Use of alternative therapies	
Yes	32.6
No	65.9
N.R.	1.4

Table 4 - Time lapse between onset of pain and seeking	5
treatment at the Centre for Pain Management	

	Medical	Centre for Pain	
	consultation	Management	
	(%)	(%)	
Days	27.2	10.1	
Weeks	24.8	14.0	
Months	27.1	37.2	
Years	20.9	38.7	

doctor only months or years (20.9%) after the onset of pain; the sample interviewed distributed fairly evenly between the options provided by the application. A majority of patients consulted a centre for pain therapy only after months or years from the onset of pain: 37.2% after months and 38% after years.

The reasons for this long wait before turning to health facilities for chronic pain treatment (Fig. 1) show a combination of a frequent "wait and see" attitude on the part of the patient, who attempted to control the pain by self-medication (86.8%) and an underestimation of the problem (32.6%). The 'external' factors involved in the delay in requesting assistance were: lack

of knowledge of the centre, (35.7%) and the centre's failure to prescribe services (34.1%). On examining the data in Table 4, one observes some differences between the time lapse for requesting medical consultation with doctors (GPs) and that for seeking treatment at the centre for pain therapy. In the first case, the percentage of respondents who waited days/weeks is quantitatively similar to the percentage who waited months/years. The situation is somewhat different with respect to the centre for pain therapy, where most patient requests for care come months/years after the onset of the "pain problem". Thus, the centre appears to be a structure not yet well-established in the course of patient treatment, and one that is not accredited by doctors in the area.

Relationship of the patient with the centre for pain therapy

The above interpretation is supported by the answers given to the questions about the relationship between the patient and the centre for pain therapy (Table 5). In particular, a large number of patients (67.4%) indicated that they became aware of the centre only at the time of first contact:

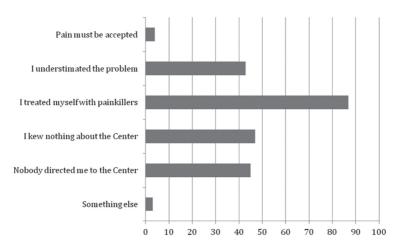


Figure 1 - Reasons for long wait (Months/Years) before contacting the Centre for Pain Management (Multiple answers possible)

in most cases (71.3%), service was provided only after several days.

The list of the required informations to the patients during their examination at the centre highlights all the problems present in patients suffering from pain; the emphasis was mainly on clinical factors (pain intensity 89.9%) and drug treatment (86.8%). The centre less frequently requested information about the impact of pain on daily life, with the exception of sleep disorders (70.5% of patients were asked about these). Other questions regarding the consequences of pain were about its impact on employment (51.9%) and the patient's autonomy in daily activities (60.5%).

Treatments reported are predominantly pharmacological (84.5%), non-opioid drugs (35.7%) being used more frequently than opioid drugs (19.4%), while these drugs are sometimes combined (28%). Only 7% of patients received psychological support. As previously mentioned, the GP plays an important role in the treatment of patients with chronic pain; however, after the patient was transferred to the centre for pain therapy, there was a noteworthy lack of communication between the GP and the centre (25.6%) or, in most cases, the interviewee was not aware of any communication (53.5%).

At the end of treatment, respondents were asked to provide an overall opinion of their pain management, which was in general positive (55.8%), and often very positive (39.5%).

Discussion and Conclusions

Chronic pain represents a major public health problem, although epidemiological studies on its prevalence and distribution among the Italian population are scarce. Attention to the problem is emerging at the regulatory level, with legislation to promote interventions to help this group of patients by establishing regional pain therapy centres (15, 16). The present survey was carried out to assess the role of these centres in the Abruzzo region in caring for patients suffering from chronic pain. While four years have passed since Law 38/2010 came into effect, at least in this region, the law's application and its impact on the region's healthcare structure are yet to be assessed. By using interviews to map out patients' treatment pathways, we wanted to analyse whether the opening of specialist regional centres has impacted on pain management.

Our research confirmed the central role played by the GP in the management of patients with chronic pain, both in identification of the problem and in subsequent therapeutic decisions. However, pain specialists were seldom considered as specific interlocutors for the patient (17). The arrival of the patient at a centre for pain management was preceded by multiple visits to doctors with different specialisations. This not only prolonged the time it took before achieving effective pain management, it also increased private and public health costs (18-20).

Table 4 further illustrates the delay in patients' decisions to request medical help: for about 48% of respondents, a request was made only months or years after the onset of pain. Even longer periods elapsed prior to the patient contacting the centre for pain management. Some of the reasons given for this behaviour (Fig.1), such as underestimating the problem (32.6%) and self-medicating with painkillers (86.8%) may reflect the individual patient's attitude towards his/her pathology. Education and awareness-raising are important tools for encouraging patients to turn to facilities and professionals that specialise in pain treatment (21, 22).

The survey highlights the critical organisational issue of the high percentage of patients who wait months or years before contacting a centre because of an information gap and/or not being aware of its

existence. Poor visibility of the centres and their non optimal activities can compromise effective control of disease progression, with implications for morbidity related to disease chronicity. While the importance of the doctor-patient relationship is clear from scientific evidence among healthcare workers, and is widely appreciated within the scientific community, it struggles to find acknowledgement in the practice of patient care (23-25).

While the patient care pathway to the centre for pain management was difficult, the benefits obtained from it were deemed satisfactory. However, some answers provided by respondents point to features of the facility that deserve consideration by the centre's management. As documented in other studies (4, 26), healthcare strategies indicate a preference for pharmacological responses, in particular non-opioid, with other therapy types, e.g. physiotherapy, taking second place (Table 5). In our study, opioid prescriptions were comparable in percentage terms to non-opioids. Based on current knowledge one cannot say if this is a result of L.38/2010, although it is likely that the simplification introduced by the law for the prescription of opioid drugs may have given their prescription a boost (11, 15).

Despite the widely published sociopsychological implications of chronic pain, psychological support is almost entirely absent; interviews with centre staff and patients clearly show the prevalence of pharmacological therapeutics. The complexity of pain treatment, particularly chronic pain, calls for an interdisciplinary therapeutic and organisational response. The involvement of various professional skills is laid down in international guidelines (14) and in the policies of countries where the problem of chronic pain is a priority within health assistance programmes (16, 20, 27, 28). Likewise, Law 38/2010 provides for a network of local services and the staffing of these clinics with health professionals

Table 5 - Patients and Centre for Pain Therapy

	(%)
Did you know the Centre before now?	
Yes	32.6
No	67.4
Time elapsed between request and treatment	nt
Days	71.3
Weeks	24.0
Months	4.7
At the Centre, they asked for information o	<i>n</i> (*):
Pain intensity	89.9
Consequences on my job	51.9
Consequences on independence in daily activity	60.5
Sleep disturbance	70.5
Painkiller consumption	86.8
Medical prescriptions and advice (*)	
Minor surgeries	24.0
Physical therapies	23.3
Physiotherapy	20.2
Nursing services	1.6
Pharmacological therapy	84.5
opioids	19.4
non-opioids	35.7
both	27.9
I don't know	1.5
Have you ever had psychological support?	
Yes	7.0
No	93.0
Is there a way of communicating with the C	GP?
Yes	20.9
No	25.6
I don't know	53.5
Opinion on pain therapy	
Satisfactory	55.8
Very satisfactory	39.5
Unsatisfactory	0.8
N.R.	3.9

(*) Multiple answers possible

having a range of skills. Optimisation of drug therapy is necessary but not alone sufficient, and multidisciplinary assistance should aim to improve the patient's physical and psychological well-being, while seeking to reduce the use of drugs (16, 29).

The present survey highlights the important role of the GP in defining the patient's therapeutic plan in spite of the long time gap before joining the medical consultation and, as it has been pointed out, before seeking the services of the centre for pain therapy.

The delay in referral represents a critical shortcoming in the region's assistance to patients with chronic pain as it undermines their access to care. Data on communication between the centres and the GPs reveal a "disconnect" between these two basic elements in the network of local services (Table 5). It is important that the GP's role does not end once the patient enters the centre, the GP should rather participate in the management of specialized therapeutic interventions. This will also serve to enhance the sector's professional growth through GP training. Limits to initial training and to the updating of doctors and other healthcare professionals constitute a barrier to improving care (11, 16, 30).

The results of the study describe, within the regional dimension of the survey, a context on the ground in which Law 38/2010 is hard to apply. Abruzzo, as part of a network of services, does not seem to be effective in ensuring access to care and treatment for pain patients. The commitment demonstrated by establishing L. 38/2010 should be followed by increasing the availability of resources to develop and strengthen the regional network of services. Epidemiological information on the prevalence of chronic pain should be the starting point from which policymakers can plan interventions and allocate resources to combat a growing pathology, with significant implications for the patient's quality of life and the fulfillment of the right to treatment.

Strengths and limitations

The major limitations of the study are the non-probabilistic nature of the sample and its limited size, which do not allow us to generalise its results for the entire region. However, it represents a first attempt to assess, four years after its coming into force, how Law 38/2010 has impacted on health of these patients and, more generally, on the development of services for treatments of pain. The strength lies in its highlighting some faults in network services for chronic pain treatment, so that stakeholders can make organisational improvements. A repetition of this survey should be accompanied by an epidemiological study to estimate pathology prevalence and geographical distribution which, through suitable parameters, will provide an evaluation of outcomes of pain management centres.

Ethical approval

Research ethics approval was obtained from the L'Aquila Hospital Ethics Committee (No.51/2013).

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Conflict of interest

No conflicts of interest have been declared.

Riassunto

Strategie terapeutiche e percorsi assistenziali per i pazienti affetti da dolore cronico nella Regione Abruzzo, Italia

Introduzione. Il dolore cronico è considerato tra le patologie più invalidanti e costose in Paesi quali Nord America, Europa e Australia. In Europa è stato realizzato un ampio sondaggio sul dolore cronico denominato *Pain in Europe*. L'Italia si colloca al terzo posto in Europa per prevalenza con il 26 % di pazienti affetti da dolore cronico. Nel 2010 in Italia è stata promulgata la Legge 38. per garantire terapie per il controllo del dolore sia a pazienti con patologie oncologiche che a pazienti con dolore cronico non da cancro, attraverso una rete di servizi. Questo studio ha come obiettivo di fornire informazioni preliminari circa l'applicazione della L.38/2010 nella Regione Abruzzo.

Metodi. Uno studio descrittivo è stato condotto su un campione non probabilistico di utenti che si sono rivolti ai

Centri di terapia del dolore delle Aziende Sanitarie Locali della Regione Abruzzo nel 2014. I pazienti (n. 129), sono stati intervistati da personale del Centro che ha utilizzato un questionario validato. Il reclutamento è avvenuto con arruolamento di casi consecutivi in un periodo di tempo fissato in tre mesi (da febbraio ad aprile).

Risultati. Prima di rivolgersi al Centro oltre il 60% dei pazienti si è rivolto a più medici (da 2 a 5) prima di richiederne le prestazioni. Il ricorso al Centro di terapia del dolore da parte dei pazienti intervistati è avvenuto per il 37,2% dopo alcuni mesi e per il 38% dopo alcuni anni Le motivazioni per questa lunga attesa nel rivolgersi alle strutture sanitarie specializzate per chiedere una terapia adeguata al problema del dolore cronico, evidenziano una situazione attendista da attribuire sia a responsabilità del paziente che controllava la sintomatologia dolorosa assumendo farmaci antidolorifici. Responsabilità, che si potrebbero definire di tipo esterno invece, fanno emergere le risposte che attribuiscono il ritardo nella richiesta di assistenza alla non conoscenza del Centro.

Conclusioni. I risultati dello studio descrivono, per il contesto regionale dove è stata condotta l'indagine, una realtà in cui la Legge 38/2010 stenta ad essere applicata. Lo studio ha rilevato che il percorso di cura per questi pazienti è ancora caratterizzato da difficoltà di accesso alla rete dei servizi. All'impegno manifestato attraverso la promulgazione della L. 38/2010 dovrebbe seguire maggiore disponibilità di risorse per sviluppare e potenziare la rete dei servizi a livello regionale.

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