



Research Article

Speak Up Your Pain: Patient's Chronic Pain Pathway

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Abstract

Introduction: The management of chronic pain is a priority in the western world, the ageing of the population and the development of chronic diseases will increase the demand for care. In order to alleviate their symptoms, patients must navigate the maze of options offered by the healthcare system. The "Speak up your pain" study gives patients the opportunity to describe their relationship with the health system and the different stages of their care.

Method: A descriptive study was carried out. A questionnaire containing 113 questions, designed in partnership with patient associations, was published on the Internet for 3 months with the aim of developing a complete portrait of the chronic pain patient. **Results:** 646 questionnaires were collected. Fifty-seven percent of respondents suffer from at least one rheumatic condition. Fifty-four percent of the patients had to wait more than a year to have their chronic pain diagnosed. Seventy-nine percent of the patients use their GPs to follow up on their chronic pain. Eighty-five percent of patients feel confident with their GP and 86% feel listened to. Eighty-six percent of patients follow a prescribed drug treatment. Only 44.8% of patients said they followed the dosage strictly. As for the social aspect of pain, the annual out of the pocket cost is €250.35. Ninety-five percent of respondents mention pain impacts their family life. One request from patients for better pain management would be to reduce the level of associated fatigue, as well as new therapeutic solutions for pain. **Conclusion:** This study highlights the need to improve chronic pain care pathways. With a high number of patients waiting over a year for diagnosis, trying alternative treatments, and facing impacts on work and social life, a coordinated, comprehensive approach is essential to ensure global care without interruptions.

Keywords: Chronic pain; Patient pathway; Patient empowerment

Introduction

For some time, pain management has been one of the priorities of French health policy [1]. This commitment has resulted in the adoption of three successive national plans (1998-2000, 2002-2005, 2006-2010). The last governmental plan recommended the structuring of care networks and emphasized the progress still to be made in the prevention, evaluation, and management of pain. Unfortunately, since then, initiatives have dried up, even though

the stakes for the French people remain just as high.

In addition to the already considerable human cost of chronic pain, there is also a significant financial cost. Patients who report pain often consult health professionals. The NHWS (French National Health and Welfare Survey) [2] estimated that 72.2 million consultations were for this reason. Their cost to the health insurance system amounted to 1.16 billion euros per year.

The aim of our study is to understand the daily experience of patients suffering from chronic pain in France. It aims to

study the care pathway of pain patients, with its shortcomings, difficulties and changes that patient expects to see to put an end to these dysfunctions. A care pathway is defined by the succession of care actions from which the patient benefits [3]. This approach brings the patient into contact with different health professionals with complementary skills, whose interventions are ongoing. The patient's pathway must be based on the most recent recommendations of good practice. In the case of pain, if we consider the diversity of its etiological and symptomatic manifestations, a multitude of care paths can be followed.

Method

Self-Questionnaire Based on Patient Verbatim

The online questionnaire, distributed between 15 June and 14 September 2020, was developed from verbatims collected during semi-structured interviews with patients from the Association Française de Lutte contre les Affections Rhumatismales (AFLAR), and the Association Francophone Vaincre les Douleurs (AFVD) focusing on their experience of managing painful symptoms in the context of chronic pain. This research was supervised by SFETD learned society, the AFVD association and the scientific committee. Divided into 23 sections and with a total of 113 questions, the questionnaire was reviewed and validated by patient partners from the AFLAR and AFVD associations to ensure clarity of wording and to propose new wording when there were ambiguities. The online questionnaire was distributed to patients suffering from chronic pain. The complete questionnaire is available in the appendix.

Standardized Supporting Questionnaires

Within the questionnaire, two scales were used to represent the patients' pain. The first was unidimensional (Digital Visual Scale from 0 to 10, VAS) and quantified the overall level of pain over the previous month and on the day of the survey. The second scale was multidimensional, allowing the different facets of pain to be explored by using the French version of the Short McGill Pain questionnaire "Saint-Antoine questionnaire" [4], which comprises sixteen dimensions. Each dimension was rated by patients on a scale from zero to four: 0 representing the absence of this type of pain manifestation and 4 reflecting the extreme pain associated with it.

Photo Language

Two questions in the survey mobilizing photo-language techniques were used: "Choose a photo to express how you felt about your pain over the last 6 months", "Choose a photo to express how you feel about your pain(s) today". Participants in the questionnaire

were invited to choose one of the photographs that best represented their pain. These photographs illustrated the sensation of pain: the infinity of the pain, the impression of being crushed, the isolation, the exposure. The photos were a black road leading nowhere, a rocky mass symbolising crushing, a rock wedged in balance between two cliffs, a staircase, sinusoidally laid out garden slabs, a balcony with a budding shrub, a garden with a ladder, a balcony with flowers. These images were selected beforehand by a psychologist and validated by the patients interviewed during the semi-directive interviews.

Statistical Analysis

Socio-demographic information such as gender, age, current occupation or inactivity, and living areas were analyzed as risk factors for the development of chronic pain. Quantitative variables were described by the mean and standard deviation. Qualitative variables were expressed in terms of numbers and percentages. To compare qualitative data between groups, a Chi-2 test was used. To compare quantitative data, a t-test was implemented. This test tests whether the means in each group are significantly different. The significance level chosen was 5%.

Results

Survey Population

Six hundred and forty-six questionnaires were collected. The mean age of the respondents was 52.21 years (standard deviation = 17.23 years) and the median age was 53 years [interquartile range: 42-64]. 90% of the respondents were female and 10% were male. Thirty-nine percent of the responding patients resided in urban areas, 37% in rural areas, and 24% in suburban areas. The most represented regions were Île de France (15.46%), Nouvelle Aquitaine (13.14%) and Grand Est (10.47%).

Pain Intensity

The average pain intensity in the past month, measured on the VAS, was 6.50. However, 59% of the respondents had an average VAS of 7 or more. This pain was lower on the day of the survey 5.84. The intensity of pain measured on the day the questionnaire was administered was significantly lower ($p < 0.001$) than what individuals remembered for the previous month.

Patients completed the Saint Antoine questionnaire to select the expressions that best reflected their sensations and emotions related to pain, and then assigned a score from 0 to 4 to indicate the intensity (Figure 1). The most distressing characteristics of the pain reported were: exhausting (2.78), irritating (2.47) and exasperating (2.27), based on the average scores given. 31% of respondents considered their pain to be extremely exhausting.

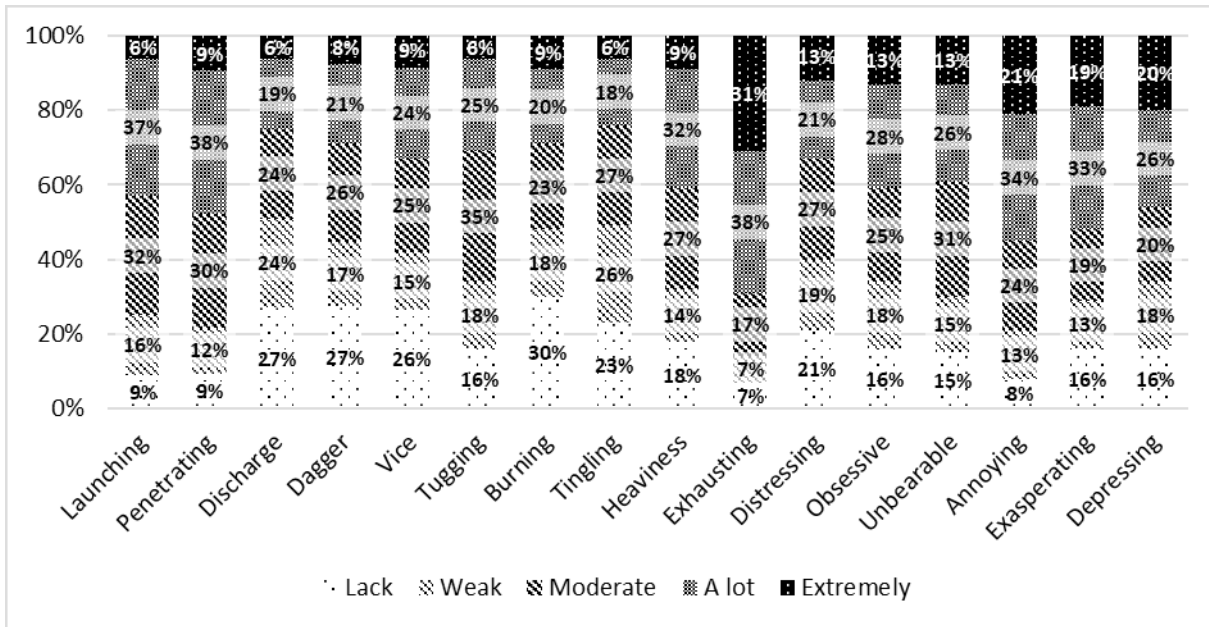


Figure 1: Results of the Saint Antoine Questionnaire.

Patients were asked what their main expectations were for better management of their pain. A large majority of them insisted on the need to reduce the impression of fatigue that they felt after painful episodes. We asked the patient to express himself in his own words. The word most used in the messages received was “pain”, “difficult”, “illness”, “suffer”.

In terms of episodes of pain, 88% of patients consider that their painful episodes are more intense than the chronic pain to which they are used to. 11% of them have never managed to control these attacks, and 57% have sometimes managed to do so. In other words, 68% of patients had painful episodes that they were sometimes or never able to control.

Care Pathway for Patients with Pain

Entry into the care pathway

44% of patients had to wait more than a year before their chronic

pain was diagnosed. 26% of patients had a diagnostic delay of less than six months, and for 20% of them, this delay was between six months and a year. 113 respondents (20%) felt that their pain was normal. The others felt that their pain was abnormal.

The diagnosis of chronic pain was made by a general practitioner in 32% of cases. The specialist who most often diagnoses chronic pain is the rheumatologist. This result must be interpreted in the light of the frequency of rheumatic diseases found in the sample. Indeed, 58% of the patients had at least one rheumatic disease (Table 1). Additionally, 57% of patients reported having other comorbidities not listed in the questionnaire. Among rheumatic disorders, patients suffered mainly of osteoarthritis, back pain and cervicalgia. 26% of patients had a rheumatic disorder other than those listed in the questionnaire. Of these, 48% had Ehlers-Danlos syndrome and 18% had Goujerot Sjorgen syndrome.

Diseases	
Cancer	3.56 % (18)
Cardiovascular disease	7.31 % (37)
Neurological disease	8.89 % (45)
Skin disease	5.53 % (28)
Mental illness	2.96 % (15)
Rheumatic disease	57.51 % (291)
Others diseases	57.31% (290)
Rheumatic disorders	
Osteoarthritis	59.63 % (319)
Osteoporosis	9.53 % (51)
Rheumatoid arthritis	6.54 % (35)
Ankylosing Spondylitis	15.33 % (82)
Psoriatic Arthritis	5.61 % (30)
Back pain	45.42 % (243)
Cervicalgia	42.24 % (226)
MSD: musculoskeletal disorders	21.68 % (116)
Others rheumatic disorders	25.98 % (139)
Several answers were possible, the sum of the percentages does not equal 100%.	

Table 1: Etiology of pain.

Care providers

Of the 646 participants, 625 completed questions about their access to health services. Out of 625 respondents, 615 (98%) said they had a general practitioner and 567 (91%) said they had a preferred pharmacy. Regarding multidisciplinary health centers (MHC), 80 respondents (13%) said they had access to a nearby MHC and used it, 96 respondents (15%) said they had access to an MHC but did not use it.

A total of 501 patients reported consulting at least one Health Care Professional (HCP) for the follow-up to their chronic pain. The number of HCPs consulted varied across patients, with some consulting only one HCP while others consulted up to five. Additionally, when pain intensified, patients reported turning more frequently to one or two HCPs.

Table 2 provides a detailed of the number and types of HCPs. General Practitioners were the most frequently consulted professionals for both pain management and pain episodes, followed by specialists and physiotherapists. The most common combinations involved consultations with a general practitioner alongside either a specialist or a physiotherapist.

Number of HCP consulted	Follow-up of chronic pain (N=501)	Pain increases (N=490)
1	161 (32%)	233 (48%)
2	184 (37%)	196 (40%)
3	126 (25%)	54 (11%)
4	27 (5%)	6 (1%)
5	3 (1%)	1 (0.2%)
Speciality of professionnels consulted	Follow-up of chronic pain	Pain increases
1 HCP consulted	(N=161)	(N=233)
General Practitioner (GP)	102 (63%)	153 (66%)
Specialist	45 (28%)	50 (21%)
Physiotherapist	13 (8%)	19 (8%)
Emergency	-	7 (3%)
Pharmacist	1 (1%)	4 (2%)
2 HCPs consulted	(N=184)	(N=196)
GP + Physiotherapist	85 (46%)	75 (38%)
GP + Specialist	73 (40%)	75 (38%)
Specialist + Physiotherapist	20 (11%)	25 (13%)
GP + Emergency	-	6 (3%)
GP + Pharmacist	6 (3%)	8 (4%)
Others		7 (4%)

Table 2: Number and type of healthcare professionals consulted for follow-up chronic pain and pain intensification.

Out of 529 respondents to the question of their relationship with telemedicine or teleconsultation for the follow-up to their pain, 94 (18%) found it useful and declared that they had benefited from it, 248 (47%) of respondents found it useful but declared that they had not benefited from it. One hundred and eighty-seven respondents (35%) felt that telemedicine or teleconsultation was useless for monitoring their pain.

Self-medication was practiced by 223 patients. Of those who self-medicate, 97 (43%) said they sought information and advice from a single source. The main sources mentioned were personal experience (46%), healthcare professionals (26%), the internet (15%), friends and family (5%), patient associations (3%) and social networks (2%).

Treatment and Compliance

Prescription drugs

86% of the patients with pain declared that they had been prescribed medication by their doctor. However, compliance was very heterogeneous. Only 44.8% of the patients stated that they followed the dosage indicated by the doctor to the letter. 35% of the patients declared to take their treatment only in case of painful crisis. 7% of the patients admitted taking a dose higher than the one recommended by the doctor, in particular in case of important crisis. The most common reason for non-adherence to treatment was fear of side effects (30.5%) and a lack of efficacy (19%). 11% of patients cited polymedication as one of the reasons for non-adherence to treatment.

Non-Drug Prescriptions

We asked patients both if they had tried an alternative therapy and if they were satisfied with it (Figure 2). We note a very heterogeneous perceived effectiveness. Among the conventional therapies, physiotherapy and occupational therapy worked best for patients with pain who had already used them (72% and 73% respectively of favourable opinions). On the other hand, the techniques implemented by nutritionists (43%) and psychiatrists (40%) seem to attract the least attention from patients.

199 patients claimed to have changed their eating habits. 76 patients have started a gluten-free diet, 32 a vegetarian diet and 11 a vegan diet. In relation to drug use: 45 people have changed their use of alcohol, 44 of tobacco, 25 of cannabis, and 20 of other unspecified substances. However, it was not asked whether this use had been modified upwards or downwards.

Patients do not only use medication to relieve their pain. They may use other therapies, both conventional and non-conventional. Patients were asked whether they had tried these types of therapy, whether they had been effective, and if they had not yet used them, whether they were tempted to try them.

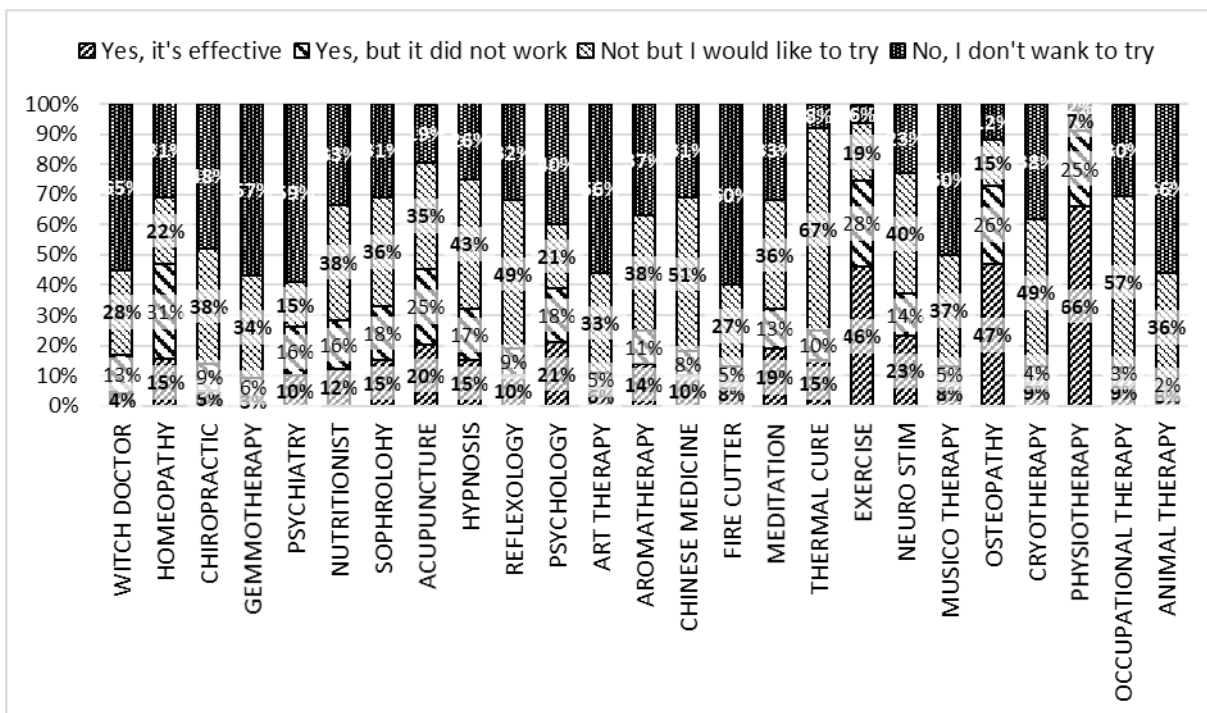


Figure 2: Access, satisfaction and interest in alternative therapies.

Effects of Pain

Impact on family life

Of the people who responded, 95% mentioned the impact of pain on their family life. A majority of them (69%) considered that their pain had a significant or extremely significant impact on their family life. 95% of respondents consider that pain has had an impact on the quality of their sleep. 21% of respondents mention that they have had to adjust their home to cope with pain in better conditions. Often, the expenses related to these adjustments were not included in the financial costs caused by pain that patients were asked to estimate. 48% of respondents have a loved one who helps them cope with pain. For 66% of the people who share their pain experience with their loved ones, these exchanges have had no impact on the intensity of their pain. However, for 10% of respondents, these exchanges made the pain more bearable. 58% of the respondents noted that the people around them had changed their behavior towards them since their pain appeared.

Impact on Professional Life

57% of respondents stated that pain had affected their professional life in various ways, including position reorganization (13%), job changes (14%), extended sick leave following diagnosis (17%), and transitioning to part-time job (14%). Only 32% of respondents stated that pain had no impact on their professional life while 11% indicated they were not working before their diagnosis.

Half of the people noted a change in their colleague's behavior when they learned of their diagnosis.

Financial consequences

Although social security coverage is good in France and in our sample (93.6% complementary health insurance coverage rate), some people refuse or postpone care for financial reasons.

48% of patients have already refused care for financial reasons. Pain care can be expensive, the average amount spent over the year on this item was €250.35, the median was €100. The maximum expense reached in one case fifteen thousand euros 15 000€, operations carried out abroad and not covered by the French social protection.

Discussion

Summary of Results

The typical pain patient in our sample is a French woman between 42 and 64 years of age. This woman has a history of rheumatic disease, and her chronic pain was diagnosed by a rheumatologist. The intensity of her pain over the last month would have reached a level of 6.5 on a scale of zero to ten and she would have had at least one paroxysmal pain episode, this pain was felt to be exhausting, annoying and exasperating. This typical patient would

have spent an average of 250€ per year to fight against the pain. Her family life would have been profoundly disrupted as well as her professional life.

The typical patient consults her general practitioner most often for the follow-up to her pain. When they increase, she turns to him. She also tells him about her pain opportunistically during consultations with him for other reasons. She feels confident and listened to by her doctor. This does not mean that she complies strictly with his treatment recommendations, as the fear of their possible side effects may lead her to be less compliant.

These results make the general practitioner one of the key elements of the health system. The quality of the diagnosis, the confidence shown by the patients, the impression of having a doctor who listens to them are all elements that place the GP at the center of the pathway of painful patients. Within the framework of the individual discussion, the patient is led to describe the symptoms and to mention the greater or lesser relief he or she derives from the treatment prescribed; the doctor, for his or her part, is led to propose a personalized care plan [5,6]. The management of pain is therefore a real therapeutic alliance. Pain ceases to be perceived as a syndrome and becomes a real illness [7] which requires the implementation of a personalized care plan.

Previous Work

Physicians sometimes feel helpless in the management of pain. When 90% of the pain is eliminated in a patient, he or she must nevertheless deal with 100% of the 10% of pain that remains [8]. This is a very uncomfortable situation that leads them to question their usefulness as caregivers [8,9]. The limited effectiveness of certain treatments [8], or certain types of management, which, although a multidisciplinary, do not manage to control all the dimensions of pain, are all causes of failure [10]. The pathophysiology and factors that contribute to the development of pain are not always clear. The pathophysiology and risk factors associated [11] with chronicity, or the reasons for the effectiveness or ineffectiveness of treatments [12] are still partially unknown. Empathy, listening, and the time devoted by the physician to the suffering person, without being a panacea in such a situation, will undeniably be of great help to the patient he or she is accompanying. The reinforcement of this listening through the use of cognitive behavioural therapies could contribute in this context to the improvement of the quality of care [13]. It should not be forgotten that patients' satisfaction with a treatment depends on what they expect from it [14], and that these expectations are often greater than the relief that the drug treatment could provide [15]. However, therapeutic advances do exist [16-19].

Lessons for The French Health Care System

Patients were asked what their main expectations were for better

management of their pain. A large majority of them insisted on the need to reduce the impression of fatigue that they felt after painful episodes. This result should be compared with the results of the Saint Antoine questionnaire, which showed that the item with the highest score was that of exhaustion due to pain. In this context, 72% of patients are waiting for new solutions to their pain.

At the institutional level, the third ministerial pain plan (2006-2010) defined 4 priorities, which concern most healthcare professionals [2,20-22]. The last priority concerns the structuring of the pain care network and the strengthening of pain management in health networks. The establishment of pain care networks makes it possible to improve patient care and the -hospital-community or inter-hospital interface. In recent years, a dozen pain networks with very different profiles depending on their history (hospital-community, inter-hospital, regional, etc.) have been funded in France. All of these networks have been brought together within the French Society for the Study and Treatment of Pain (SFETD) in order to strengthen their actions and pool their skills and projects [2,20-22].

The management of chronic pain in France is also conditional on access to specialized pain treatment structures, but access to these structures is complicated [9,23].

Strengths and Limitations of the Study

The identification of the care pathway is done in a global way on all the respondent patients. The successive description of all these stages makes it possible to define an experience, through the words of the patient. Our desire to describe the patient's feelings by the patient and for the patient is a source of singularities in our study. We asked the patient to express himself in his own words. The word most used in the messages received was "pain". However, we must note the frequent use of difficult, life, illness, suffer.

The use of various scales, questionnaires, and photo language techniques contributes to a comprehensive assessment of pain experiences, impact on life and treatment perspectives. The study aligns with the priorities of the third ministerial pain plan.

Among the questionnaires collected, a certain number were not completed in full. Within the framework of the internet survey, it is impossible to differentiate the causes of the lack of response. Misunderstanding of the question, an unknown answer, questions that were too personal, a questionnaire that was too long, are all explanatory mechanisms of this attrition.

It should be remembered that the patients recruited were mainly recruited by patient associations. That is to say, they will be patients who are already at least partially aware of the possible supports for the management of the disease. There is a sampling bias, our results will not be representative of the average patient.

Conclusion

This study allows us to better understand the pathway of patients with pain: where they are diagnosed, how they behave and what they expect from health professionals. With 54% of the patient having to wait for one year to be diagnosed, many patients trying alternative treatments with more or less success, the impact of pain on social and work relationship, it is important to improve the care pathways for chronic pain patients.

The mapping of these pathways for patients in pain in the French health care system has been drawn up based on the experience of patients who have used it. In this context, one of the major challenges for the many professionals called upon to interact with the person in a "pathway logic" will be to know how to mobilize and assemble the resources available in the area of intervention in order to guarantee a global accompaniment without interruption. But we have seen that this is still far from being the case.

References

1. Société Française d'Etude et de Traitement de la douleur (2017) Livre blanc de la douleur : État des lieux et propositions pour un système de santé éthique, moderne et citoyen. MedLines.
2. Mick G, Perrot S, Poulain P, Serrie A, Eschalié A, et al. (2013) Impact sociétal de la douleur en France : résultats de l'enquête épidémiologique National Health and Wellness Survey auprès de plus de 15 000 personnes adultes. *Douleurs Évaluation - Diagnostic - Traitement* 14: 57-66.
3. Ministère des solidarités et de la santé. Parcours de santé, de soins et de vie 2021.
4. Melzack R (2005) The McGill Pain Questionnaire. *Anesthesiology* 103: 199-202.
5. Chou P-L, Lin C-C (2011) A pain education programme to improve patient satisfaction with cancer pain management: a randomised control trial: Pain education to improve pain management. *J Clin Nurs* 20: 1858-1869.
6. Beal BR, Wallace MS (2016) An Overview of Pharmacologic Management of Chronic Pain. *Med Clin North Am* 100: 65-79.
7. Clauw DJ, Essex MN, Pitman V, Jones KD (2019) Reframing chronic pain as a disease, not a symptom: rationale and implications for pain management. *Postgrad Med* 131: 185-198.
8. Crofford LJ (2015) Chronic Pain: Where the Body Meets the Brain. *Trans Am Clin Climatol Assoc* 126: 167-183.
9. Poucher M, Cherrier C, Poucher A-C, Di Patrizio P (2016) Évolution des pratiques en médecine générale dans la prise en charge des douleurs neuropathiques. *Santé Publique* 28: 505.
10. Vowles KE, Pielech M, Edwards KA, McEntee ML, Bailey RW (2020) A Comparative Meta-Analysis of Unidisciplinary Psychology and Interdisciplinary Treatment Outcomes Following Acceptance and Commitment Therapy for Adults with Chronic Pain. *J Pain* 21: 529-545.
11. Aronoff GM (2016) What Do We Know About the Pathophysiology of Chronic Pain? *Med Clin North Am* 100: 31-42.
12. Häuser W, Tölle TR (2015) Meta-analyses of pain studies: What we have learned. *Best Pract Res Clin Rheumatol* 29: 131-146.

13. Laroche F (2013) Apports des thérapies comportementales et cognitives - Psychoéducation pour les patients douloureux chroniques. *Rev Rhum Monogr* 80: 179-183.
14. Noble PC, Conditt MA, Cook KF, Mathis KB (2006) The John Insall Award: Patient expectations affect satisfaction with total knee arthroplasty. *Clin Orthop* 452: 35-43.
15. Geurts JW, Willems PC, Lockwood C, van Kleef M, Kleijnen J, et al. (2017) Patient expectations for management of chronic non-cancer pain: A systematic review. *Health Expect* 20: 1201-1217.
16. Attal N (2011) Avancées dans le traitement pharmacologique des douleurs neuropathiques. *Rev Neurol (Paris)* 167: 930-937.
17. Attal N, Bouhassira D (2015) Pharmacotherapy of neuropathic pain: which drugs, which treatment algorithms? *Pain* 156: S104-S114.
18. Gilron I, Jensen TS, Dickenson AH (2013) Combination pharmacotherapy for management of chronic pain: from bench to bedside. *Lancet Neurol* 12: 1084-1095.
19. Monti S, Caporali R (2015) Chronic pain: the burden of disease and treatment innovations. *Reumatismo* 67: 35-44.
20. Cazzola M, Atzeni F, Boccassini L, Cassisi G, Sarzi-Puttini P (2014) Physiopathology of pain in rheumatology. *Reumatismo* 66: 4-13.
21. Pozek J-PJ, Beausang D, Baratta JL, Viscusi ER (2016) The Acute to Chronic Pain Transition: Can Chronic Pain Be Prevented? *Med Clin North Am* 100: 17-30.
22. Célant N, Guillaume S, Rochereau T (2017) Institut de recherche et documentation en économie de la santé (France). L'Enquête santé européenne: enquête santé et protection sociale (EHIS-ESPS) 2014.
23. Perrot S, Pickering G, Lantéri-Minet M, Attal N (2021) Real-Life Management Pathways for Chronic Peripheral Neuropathic Pain at Tertiary Pain Clinics in France. *Pain Med* 22: 875-882.