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Interest of registries in neuropathic pain research.

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Abstract

Neuropathic pain is frequent in the general population, with 7 to 10% of adults presenting with chronic neuropathic pain. To date, the gold standard to evaluate treatments is based on randomized controlled trials. Nonetheless, such design is run on a limited sample and for a limited period. Moreover, many treatments will never be compared directly in sufficiently large and representative populations. A way to overcome several of these limitations is to use real-world data. Indeed, the International Association for the Study of Pain (IASP) includes a special interest group focusing on pain registries and promoting the use of such approaches. In this short narrative review, several of the main chronic pain registries are presented. The strengths and weaknesses of this approach are presented. Indication bias is frequent in observational studies because the choice of treatment is generally influenced by the patients' characteristics. However, a propensity score can be computed to adjust for these differences. The use of propensity score is briefly explained. Some data specific to neuropathic pain are discussed.

Keywords

Chronic pain, neuropathic pain, registry, propensity score,

Abbreviations

EGB: échantillon généraliste de bénéficiaires (EGB)

ePPOC: electronic persistent pain outcomes collaboration

IASP: international association for the study of pain

PRO: patients' reported outcomes

PS: propensity score

QPR: Quebec Pain Registry

SNDS : Système National des Données de Santé

SQRP: Swedish Quality Registry for Pain Rehabilitation

RCT: randomized controlled trial

1. Introduction

Neuropathic pain is frequent in the general population, with 7 to 10% of adults presenting with chronic neuropathic pain (neuropathic pain \geq three months) [1]. Despite such a high prevalence, currently recommended treatments are not systematically used [2,3]. Many patients do not respond to them and side effects are frequent. In addition, an important limitation is the absence of predictive factors for clinical success based on patients' characteristics that could be used by clinicians. Several new drugs (e.g., the voltage-gated sodium channel blocker vixotrigine, TGF- α /epiregulin monoclonal antibody named LY3016859, P2X₃ receptor antagonist such as BAY 1817080, oral NMDA receptor modulator such as NYX-2925) are currently under development and will be tested against placebo in randomized controlled trials (RCTs). Although RCTs are the gold standard for evaluating treatment efficacy, the extent to which study findings translate to clinical practice in the real-world is unpredictable. Indeed, an optimal clinical practice could rely on indicators of treatment safety and effectiveness to choose the best molecules to prescribe to the right patient. RCTs however rarely provide data on a drug's effectiveness. Indeed, effectiveness is more specifically used in the context of how well something accomplishes a task (i.e. in daily practice or in the real world) whereas efficacy conveys the extent to which something accomplishes its task under controlled environments (evaluated in RCTs only).

Real-world data provide rich information that could help us understand how effective available drugs are based on different patient profiles. Given the high prevalence of neuropathic pain, it could be studied using population-based datasets. Several medico-

administrative databases are available, but they generally do not contain pain characteristics. For example, many countries have drug reimbursement databases, which collect all claims for prescribed and reimbursed drugs. That is the case in France: drug reimbursement data can be combined with data from national hospital discharge summaries database (*Programme de Médicalisation des Systèmes d'Information*, PMSI). Nonetheless, this approach has an obvious limitation as such databases do not contain pain characteristics. Thus, specific pain registries have been created in many countries to characterize pain phenotypes and monitor treatment responses (table 1).

The goal of this short narrative review is to give a brief overview of available registries, the information collected relevant to neuropathic pain and the gaps that should be addressed.

2. Currently available pain registries

The international association for the study of pain (IASP) includes a special interest group focusing on pain registries. This group provides guidance on best practice in developing pain registries, supports collaborators to join or initiate pain registries and promotes registry-based trials. So far, several registries have been created in various areas of the world, but almost only in developed countries. The special interest group also developed a minimal standard dataset on pain indicators that could be included in existing medical registries (unrelated to pain specifically). Although the following list is not exhaustive, some of the main chronic pain registries will be presented. To our knowledge, there is no registry specifically dedicated to neuropathic pain but most of the registries include various chronic pain types, of which chronic neuropathic pain.

One of the oldest and largest pain registries was created in 1998 by the Swedish Association of Rehabilitation Medicine, the Swedish Quality Registry for Pain Rehabilitation (SQRP). The aim of this registry is to compare patient groups at different rehabilitation clinics and the effect of rehabilitation programs based on patient-reported outcome (PRO) measures concerning function, activity, quality of life and participation in working life and leisure [4]. The registry went online in 2009. The database includes about 54,000 clinic visits (one patient can have more than one clinic visit), with around 4,800 new patients per year. Although of major interest, this registry has not been yet used to study neuropathic pain treatments in the context of pain rehabilitation programs.

Another registry elaborated more than 10 years ago is the Quebec Pain Registry (QPR; 2008-2014) in the province of Quebec, Canada. It is a clinico-administrative and research database

which provides standardized data on a large cohort of chronic pain patients (n = 9,418) who are characterized using a set of common demographic and clinical measures based on uniform and validated measurement tools [5] that are either self-reported or collected through phone conversation with a research nurse. This unique database was conceived in 2007 as a strategic initiative of the Quebec Pain Research Network. Implementation of this registry stopped in 2014 but many articles have been published using it and several studies are still ongoing [6–10]. Among the richness of this dataset is the inclusion of specific pain diagnoses by primary care physicians managing patients within tertiary-care chronic pain clinics.

Many other registries have been implemented more recently. It is the case of the electronic Persistent Pain Outcomes Collaboration (ePPOC), an Australian and New Zealand initiative [11]. ePPOC was established in 2013 and involves the collection of a standard set of information items by specialist pain services. Overall, 13,343 patients attended a pain clinic between July 2013 and February 2016 and were enrolled in the registry [12] and data on over 30,000 patients are currently available. To date, no studies specifically focusing on neuropathic pain have been published using this database.

In the United States, different registries have been put in place. For example, in New York, a Tri-Institutional Chronic Pain Registry has been created in 2012 recording pain patient-reported outcomes (PROs) capturing pain intensity, functional impairment, symptoms (medication side effects and mood), quality of life, and opioid misuse. A study focusing on cancer-related pain management has been published using this database [13]. Another US registry, named PRECISION for Pain Registry for Epidemiological, Clinical, and Interventional Studies and Innovation is also ongoing and a study protocol using a propensity score-matched study of opioid prescribing in patients with low back pain has been published [14]. The Collaborative Health Outcomes Information Registry (CHOIR) is a patient pain collection software, created by the Stanford Pain Management Center in partnership with the National Institutes of Health. The software is made available at no charge to any institution interested in using it and collaborating to improve it. Up to now, 43,330 surveys have been completed with more than 28,000 completed follow-ups. Many studies have been published using this registry [15–17], although none of these were dedicated to neuropathic pain.

In Europe, the Oslo University Hospital Pain Registry [18] was initiated in October 2015. During the first two years of running the registry, a total of 1,712 patient baseline reports were recorded. Clinicians enter data about relevant treatments and interventions, while patients provide self-reported data on aspects related to pain and pain management. The patients

complete an electronic registration immediately before their first consultation at the outpatient pain clinic. Although of great potential, this registry has not yet been used for real-world effectiveness evaluation of pain care.

The Danish Clinical Pain Registry, named PainData, is a clinical pain registry that aims to improve the understanding and treatment of individuals experiencing high-impact chronic pain [19]. This involves the collection of patient-reported outcome data from individuals referred to one of the pain centers that offer specialized interdisciplinary pain treatment in Denmark. As of December 31st, 2020, 12,257 patients have completed the baseline questionnaire and given data consent. Of those, 4,341 completed the questionnaire for at least one follow-up visit. The study published recently showed that one in four patients reported being very much improved or much improved after treatment in a pain center [19].

For acute pain, registries such as the PAIN-OUT [20] have also been created but are out of the scope of the present review, although long-term follow-up has also been conducted to evaluate predictors of pain chronicization [21].

Finally, several other registries will probably be available in the coming years as it is considered as an important point to improve patient care and proper research on real-life data. For France, a registry named e-DOL (<https://www.institut-analgesia.org/portfolio-item/projet-edol/>) has been created recently and inclusions are ongoing. To allow the characterization and a personalized follow-up of chronic pain patients, a smartphone application for patients and a web platform for physicians has been created. More than just an electronic registry, the intrinsic therapeutic effect of this e-health tool will be evaluated in a large impact study involving 5,000 chronic pain patients.

3. Interest of real-life data for neuropathic pain research.

As stated in the introduction, reimbursement databases can be used to explore chronic pain. In France, the SNDS (*Système National des Données de Santé*) can be used for such studies. Pharmacoepidemiological studies using such database [22] have proven to be effective to evaluate the prevalence of neuropathic pain in the general population or in a specific setting. The major strength of such an approach is to allow population-based studies, either using a representative sample (like in the *echantillon généraliste de bénéficiaires* (EGB) that is a permanent representative sample of French health insurance beneficiaries) or even using the database from the entire population. Another important point is to be able to follow individual patient drug consumption for more than 10 years, exhaustively. The major weakness of

pharmacoepidemiological studies is the absence of precise clinical evaluation and the absence of PROs. Concerning clinical diagnosis, extensive data are available from hospitalizations, but for a minority of patients and with unreliable quality. For many patients, diagnosis must be approached using algorithms, including recommended neuropathic pain drugs and excluding as much as possible these drugs when prescribed for other indications such as depression, epilepsy or anxiety.

As presented above, many registries have been specifically created all over the world to overcome some of these problems. The major strength of data recorded in pain clinics is that information is precise concerning diagnosis and pain treatments. The limitation is that the data comes from a selected population of chronic pain patients seen in tertiary care centers, not reflecting the 30% of the general population presenting with chronic pain.

For therapeutic efficacy, the gold standard relies on randomised controlled trials (RCT). Indeed, such design has major strengths: randomization allows to have a perfectly comparable controlled group, follow-up is frequent and regular for all the patients and observance is checked. But the design also has weaknesses. Study duration is generally limited, with three months or less for the vast majority of those RCTs focusing on neuropathic pain [3], which is obviously short. For RCTs, included patients are selected based on strict criteria and the generalizability is often poor. Running RCTs is very expensive and the included sample is limited. Using real-world data allows to overcome some of these issues. Indeed, samples are large and concordant with daily practice. Long-term follow-up can be available. Although it can be hard to launch a registry, once it is created, data can be used quickly and inexpensively. As creating a registry is time consuming and costly, there are obvious challenges related to developing registries in low-to-middle income countries. Joining an existing registry can be easier than creating a new one. With more high-quality registries and collaboration across registries, it would be possible to go further in treatment comparisons and research for predictive factors of response [23–25].

To date, there are very few RCTs comparing neuropathic pain treatment's effectiveness in a real-life setting. One study has made a direct comparison of four neuropathic pain treatments using an innovative design, based on a Bayesian adaptive randomized trial [26]. Combining pain reduction and undesirable adverse effects to a single end point, nortriptyline and duloxetine outperformed pregabalin and mexiletine. Thus, such studies are possible but difficult to conduct. Another way to obtain treatment effectiveness comparison is to analyze prospectively recorded data present in a dedicated database. Of note, indication bias is frequent in observational studies because the choice of treatment is generally influenced by

patients' characteristics [27]. However, a propensity score (PS) can be determined to adjust for these differences [27]. The PS corresponds to the probability of a patient receiving the treatment according to their characteristics. Thus, the weight of patients who are highly likely to receive one treatment based on their observable characteristics is reduced and that of patients who are unlikely to receive it is increased. The different treatment groups are thus rendered comparable because they would have had the same chance of being treated. Considering the characteristics of the participants at baseline, the PS model can include several variables such as age, sex, pain duration, baseline pain intensity, pain interference or co-medications. The validity of the matching can be tested by analyzing the standardized differences ($|d|$), with $|d| > 0.2$ considered to be an imbalance.

Using such an approach, we have been able to compare among the Quebec Pain Registry data four recommended treatments, namely antidepressants (duloxetine, venlafaxine and tricyclic antidepressants), antiepileptics (gabapentine and pregabalin), weak opioids (tramadol), and strong opioids, among patients with neuropathic pain [28]. Inverse probability of treatment weighting confirmed that the proportion of patients who improved was significantly lower among those taking strong opioids compared to those who did not ($p < 0.001$). There was no significant difference in proportions of responders between patients taking or not antidepressants, gabapentinoids or weak opioids. Further analyses could be done to look for predictive factors of response to the different therapeutic classes and help the development of a more personalized medicine.

Developing registries is an avenue for personalized medicine. As connected objects are increasingly available in wealthy countries, it is possible to add as PRO objective data concerning sleep quality, physical activity and heart rate frequency or variability. Such data can be used to explore new questions, especially concerning the impact of chronic pain in daily life and the potential improvement on this aspect after adapted treatment. Indeed, for the patients, gaining functional abilities can be more important than just decreasing pain intensity. But acquiring a huge volume of data will lead to new challenges. Using big data necessitates massive storage capacity, which is expensive and also implies a high level of security. New ways to analyze big data such as data mining and artificial intelligence may lead to great improvements. But it is important for clinicians to keep a significant place to monitor the use of these data. Private firms have already started an important action in the health area (<https://health.google/health-research/>; <https://www.apple.com/fr/healthcare/>) and have allowed great advances. However, it is important to be sure that patient care will still be the priority in the upcoming years.

4. Conclusion

Randomized controlled trials and real-world studies using propensity score matching should be seen as more complementary than opposing. Many registries have already been implemented and there will be many more to come. All these registries offer a chance to improve our knowledge concerning pain treatment in general, and neuropathic pain treatment in particular, if the limits of such real-world data are properly overcome. Going further in the definition of effectiveness probability of each treatment could help to move toward a more personalized medicine.

Conflict of Interest Statement:

Xavier Moisset reports fees from Allergan, Biogen, Grünenthal, Lilly, Merck-Serono, Novartis, Roche, Sanofi-Genzyme, TBWA, and Teva and non-financial support from SOS Oxygène, Boehringer, and Bristol Myers Squibb not related to the submitted work.

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Registry name	Inception date	Location	Target population	Strengths	Weaknesses
Swedish Quality Registry for Pain Rehabilitation (SQRP)	1998	Sweden	Rehabilitation clinics	> 50,000 clinic visits Many publications	Limited to rehabilitation clinics
Quebec Pain Registry (QPR)	2008	Canada	Chronic pain centers	9,418 included patients, well-characterized Many publications	No new inclusion since 2014
PAIN-OUT	2009	International	Post-operative pain (and risk factors for chronification)	Not-for-profit academic project Many publications	
New York Tri-Institutional Chronic Pain Registry	2012	USA	Cancer centers		No publication concerning neuropathic pain. Limited number of parameters recorded
Collaborative Health Outcomes Information Registry (CHOIR)	2012	USA	Both adult and pediatric pain centers	> 28,000 completed follow-ups, well-characterized Open-source project Many publications	No publication concerning neuropathic pain
electronic Persistent Pain Outcomes Collaboration (ePPOC)	2013	Australia and New-Zealand	Both adult and pediatric pain centers	> 30,000 patients, well-characterized Many publications	No data concerning neuropathic pain in the minimum dataset
Oslo University Hospital Pain Registry	2015	Norway	Chronic pain centers	Around 5,000 patients, well-characterized	Single publication, no data concerning neuropathic pain
Danish Clinical Pain Registry (PainData)	2015	Denmark	Chronic pain centers	> 12,000 patients, well-characterized	Single publication, no data concerning neuropathic pain
Pain Registry for Epidemiological, Clinical, and Interventional Studies and Innovation (PRECISION)	2016	USA	Low back pain	Record of patient genotypes for drug metabolism	No studies published yet No data concerning neuropathic pain
e-DOL	2019	France	Chronic pain centers	Well-characterized patients Supported by mobile devices to develop pain management programs through e-health programs	No studies published yet Very limited number of patients currently included

Table 1. Overview of the pain registries presented in this narrative review, arranged by inception date.