Patient journey for those with chronic low back pain in Brazil: a semi-systematic review on the best approach

ABSTRACT: Background. Managing patients with chronic low back pain (CLBP) in many countries, including Brazil, is a major challenge at the primary and specialty care level. Moreover, the information about epidemiology and patient management with CLBP is sparse. The primary objective of this semi-systematic review was to build local evidence about the prevalence and management pattern of CLBP.

Methods. This semi-systematic review used Medline, Embase, and Biosis via Ovid the platform and additional resources (Google, Google Scholar, Incidence and Prevalence Database, World Health Organization, Brazilian Ministry of Health, and anecdotal information from local experts) to identify relevant literature between 2002–2020 to map the patient journey. Original full-text articles from Brazil in English containing data on pre-defined patient journey touchpoints (awareness, screening, diagnosis, treatment, adherence, and control) were screened. Data were synthesized using a simple or weighted mean, as applicable for patient journey components.

Results. Of 297 records including those provided by local experts, eight studies were included for analysis. Awareness of CLBP and CLBP-NeP was 30.4% and 12%, respectively. According to published studies, adherence and symptoms control of patients was estimated with a similar percentage of 38% and 18%, respectively for CLBP and CLBP-NeP. CLBP-NeP prevalence (3.6%) was lower than that of CLBP (20.6%). Except for a comparable percentage of the treated population, for CLBP (39.1%) and CLBP-NeP (38%), the percentage of remaining touchpoints are higher in the case of CLBP than in CLBP-NeP, implying an improved patient journey for CLBP.

Conclusion. The study highlights the usefulness to improve patient outcomes at the national level by measuring these mapping patient journey touchpoints. The outcome of this evidence-based study was fruitful to bridges the know-do gap in CLBP patients. Therefore, it is recommended to ensure continuing medical education, patient awareness, and health system preparedness while embracing the emerging insights on pain management.

Keywords: Brazil; Pain; Health system preparedness; Patient journey mapping; Patient engagement.
It is commonly observed that patients who experience acute back pain have a causal relationship with stimulus categorized temporally as acute, sub-acute or chronic pain. Acute back pain has a causal relationship with stimulus associated with tissue damage or a stimulus responsible for tissue damage, whereas neuropathic pain (NeP) manifests as a direct consequence of a lesion or a disease affecting the somatosensory system. The latter is also known as CLBP with neuropathic component (CLBP-NeP). In 2017, the International Association for the Study of Low Back Pain (IASP) introduced a new terminology ‘Nociplastic Pain’, defined as pain arising from altered nociception despite no clear evidence of actual or threatened tissue damage causing the activation of peripheral nociceptors or evidence for disease or lesion of the somatosensory system causing the pain. In practice, there are no exclusive categories of pain named nociplastic, nociceptive and neuropathic pain observed; rather, these are descriptors of concurrent potential mechanistic drivers of pain. This is supported by evidence from clinical trials showing no utility of differential treatment.

There is a dependency on the physician’s understanding of the underlying pain and the different underlying mechanisms for a similar diagnosis of pain. Chronic pain mechanisms are not well understood by many clinicians due to the complex nature of pain, making primary care practitioners largely rely on expensive diagnostic techniques such as magnetic resonance imaging and surgical treatments eventually proving to be less effective in patients with CLBP. Even in larger centers, most Brazilian healthcare providers are not inclined to extend their services from primary basic care to specialised care and even less to an ideal multidisciplinary holistic approach focused on patients with CLBP. The issue of insufficient training of treatment providers has been highlighted in the previous literature. A poor understanding of the various mechanisms of LBP has been reported through several studies. The complex diagnosis and presence of clinical equipoise of healthcare providers for positive health outcomes in LBP have propelled the stakeholders to consider a multidisciplinary approach to treat patients.
tackle this condition\textsuperscript{24,25}. Importantly, the health systems of several countries are not designed to reduce the burden of LBP\textsuperscript{26}.

It is evident that despite the high socioeconomic impact associated with CLBP, very few studies are published on epidemiologic information from developing countries\textsuperscript{27}. To date, gender-specific data with robust strength of evidence are limited. Furthermore, given the methodological limitations, the generalisability of the findings from published literature remains questionable\textsuperscript{28}.

Given the emergence of personalized medicine, patient journey mapping using published epidemiologic data seems an important step to identifying gaps in the health system\textsuperscript{29}. This includes mainly five interaction points where the patient becomes part of the care delivery ecosystem, namely awareness, screening, diagnosis, treatment, and adherence and palliative care along the care continuum pathway\textsuperscript{30}. While it is evident that mapping patient journeys would provide meaningful insights into the management of pain. The approach for this review was based on an already published study by Upjohn and group, the methodology called ‘Mapping the Patient Journey Towards Actionable Beyond the Pill Solutions for Non-communicable Diseases (MAPS)’\textsuperscript{11}. This study highlights the need for evidence-based research related to patient journey touchpoints. To overcome these barriers, evidence mapping is an emergent approach to bind the gaps in scientific evidence to inform future research priorities\textsuperscript{30}.

As reported recently, the patient journey to quantitatively map and identify data gaps in patient journey touchpoints for chronic low back pain (CLBP) in specific regions is useful and base for this review\textsuperscript{32}. Therefore, the present semi-systematic review is expected to close the gaps in CLBP diagnosis, management, and treatment in different regions.

The key objectives of this semi-systematic review were to assess the CLBP prevalence, exploration of CLBP risk factors, and identification of gaps in the CLBP healthcare system. The authors also aim to devise a strategic model to bridge the know-do gap in LBP care.

### Supplementary Table 1

Search strategy for structured search using Portals: Medline, Embase, Biosis

**Search Terms For Chronic LBP:**
- exp low back pain/OR exp chronic pain/OR exp fibromyalgia/OR exp rheumatoid arthritis/OR exp osteoarthritis/OR exp Arthritis/OR exp headache/OR exp Migraine/OR exp musculoskeletal pain/OR “Chronic pain” or Fibromyalgia or “low-back pain” or rheumatoid or osteoarthritis or “Arthritis pain” or “Arthritis pain” or Migraine or “musculoskeletal pain” AND
- Incidence or Prevalence or Occurrence or burden or Epidemiology* or Screen* or Treat* or Management or Therap* or Aware* or Unaware* or Knowledge or Diagnos* or Undiagnos* or Adheren* or Complian* or nonadheren* or non-adheren* or Control* or Uncontrol* or Untreat* AND
- Brazil*

**Search terms for CLBP-NeP:**
- exp neuropathic pain/OR exp neuralgia/OR exp neuropathy/OR neuropath* adj5 pain OR neurogenic adj5 pain OR neuralgia OR nerve pain OR diabet* adj5 neuropath* OR nerve injury OR peripheral neuropath* OR spinal cord injury or post operative adj5 pain AND
- Incidence or Prevalence or Occurrence or burden or Epidemiolog* or Screen OR Treat or Management or Therap* or Aware* or Unaware* or Knowledge or Diagnos* or Undiagnos* or Adheren* or Complian* or nonadheren* or non-adheren* or Control* or uncontrol* or Untreat* AND
- Brazil*

### METHODS

#### Study design

The semi-systematic review concept is based on the design for conceptualized topics studied by various groups of researchers within diverse disciplines that save the time to avoid a full systematic review process. The approach is typically based on how research within a selected field has tracked over time or how a topic has developed with a broad research area. In this, we follow the systematic review process, but we adjust it in terms of depth of search and screening processes, and data synthesis, due to limited resources. Generally, a thematic or content analysis is used in semi-systematic review and provides guidelines for conducting a meta-narrative review. A potential contribution to map a field of research, including several evidence gap maps and creating an agenda for future research\textsuperscript{29,31}. Typically, the research process should be transparent and develop a research strategy that enables readers to understand the arguments for the judgments made were rational and reasonable. Overall, this research strategy fulfills the criteria of a semi-systematic review and follows the guidelines.

The study was a semi-systematic review of the literature to identify prevalence, awareness, screening, diagnosis, treatment, and adherence data related to patient journey amongst CLBP patients. The present review contained four types of evidence: Structured search, Unstructured search, Studies provided by experts in local languages or based on their knowledge of these studies that were not identified through the literature searches, and Anecdotal data provided by experts based on their personal experience of the current situation in Brazil. Methods of conducting the review and eligibility criteria were documented in advance\textsuperscript{31}. The inclusion criteria for the semi-structured review were sufficiently broad to identify all potentially relevant studies. The detailed search strategy is given in Supplementary Table 1.
Table 1: Data extraction table for “mixed” research question framework

<table>
<thead>
<tr>
<th>Sr No</th>
<th>Title</th>
<th>Year</th>
<th>Type of Article</th>
<th>Population (Patients)</th>
<th>The phenomenon of Interest (Patient Journey Components)</th>
<th>Context (Country)</th>
<th>Condition of Interest (Prevalence of LBP)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Assessment of inflammatory back pain and axial spondylarthritis in Brazil</td>
<td>2016</td>
<td>Observational study with retrospective (phase 1) and one-month prospective (phase 2) data collection</td>
<td>Adult Patients with chronic back pain inflammatory LBP and axial spondylarthritis</td>
<td>No data available</td>
<td>Brazil</td>
<td>CLBP: 35.80%</td>
</tr>
<tr>
<td>2</td>
<td>Prevalence and characteristics of chronic pain in Brazil: a national internet-based survey study</td>
<td>2018</td>
<td>Cross-sectional internet-based survey</td>
<td>Patients with CLBP</td>
<td>CLBP AW: 30.4%; CLBP TR: 40.25%</td>
<td>Brazil</td>
<td>CLBP: 59.85%</td>
</tr>
<tr>
<td>3</td>
<td>Correlates of a Recent History of Disabling Low Back Pain in Community-dwelling Older Persons the Pain in the Elderly (PAINEL) Study</td>
<td>2018</td>
<td>Cross-sectional survey</td>
<td>Older patients with disabling LBP</td>
<td>No data available</td>
<td>Brazil</td>
<td>CLBP: 9.30%</td>
</tr>
<tr>
<td>4</td>
<td>Epidemiology of physician-diagnosed neuropathic pain in Brazil</td>
<td>2019</td>
<td>Prospective observational study</td>
<td>Patients with chronic pain</td>
<td>No data available</td>
<td>Brazil</td>
<td>CLBP-NeP: 36.8%</td>
</tr>
<tr>
<td>5</td>
<td>Prevalence of chronic pain in a metropolitan area of a developing country: a population-based study</td>
<td>2016</td>
<td>Population-based study</td>
<td>Patients with CLBP</td>
<td>CLBP: DG: 28.1%</td>
<td>Brazil</td>
<td>No data available</td>
</tr>
<tr>
<td>6</td>
<td>Prevalence of self-reported spinal pain in Brazil: Results of the national health research</td>
<td>2017</td>
<td>Retrospective data analysis</td>
<td>Patients with CLBP</td>
<td>CLBP-NeP AW: 19%</td>
<td>Brazil</td>
<td>CLBP: 11-25%</td>
</tr>
<tr>
<td>7</td>
<td>Anecdotal data from local experts</td>
<td>2019</td>
<td>N/A</td>
<td>Patients with LBP</td>
<td>No data available</td>
<td>Brazil</td>
<td>No data available</td>
</tr>
<tr>
<td>8</td>
<td>Prevalência de dor lombar crônica na população da cidade de Salvador, Brasil: prevalência, características e associação com capacidade funcional e mobilidade (Estudo SABE)</td>
<td>2008</td>
<td>Cross-sectional Study</td>
<td>General population</td>
<td>No data available</td>
<td>Brazil</td>
<td>CLBP - 14.7%</td>
</tr>
<tr>
<td>9</td>
<td>Dor crônica em idosos residentes em São Paulo, Brasil: prevalência, características e associação com capacidade funcional e mobilidade (Estudo SABE)</td>
<td>2013</td>
<td>Cross-sectional Survey</td>
<td>Community dwelling elderly residents</td>
<td>No data available</td>
<td>Brazil</td>
<td>CLBP - 25.4%</td>
</tr>
</tbody>
</table>

Abbreviations: AD, Adherence; AW, Awareness; CLBP, Chronic low back pain; CLBP-NeP, chronic low back pain with neuropathic component; CT, Control; DG, Diagnosis; LBP, Low back pain; SC, Screening; TR, Treatment.

Search strategy
A structured literature search for chronic low back pain and neuropathic back pain was conducted using Medical Subject Headings (MeSH) terms, their synonyms, and patient journey-related text words (prevalence, awareness, screening, diagnosis, treatment, adherence, and control) in three electronic literature databases, namely Embase, MEDLINE, and BIOSIS via OVID platform. Additionally, unstructured search to identify relevant patient journey information from sources like Google search engine, Pubmed, Google Scholar, Incidence and Prevalence Database (IPD), World Health Organization (WHO), the Brazilian Ministry of Health was also conducted. The idea behind the additional search was to address any gaps in systematic searches (particularly relating to
Specific local data. Search filters in the structured search included language as ‘English’ and time horizon as ‘referred to the period of 2000 to 2020’ to ensure the correctness, relevance, and availability of data from low and middle-income countries. There were no date restrictions applied to the unstructured search. Ancillary data from personal experiences were provided by the subject matter experts on patient journey touchpoints in chronic pain.

**Selection criteria**

Literature searches were performed and retrieved publications were assessed for eligibility by two independent reviewers in a 2-phase screening process based on the predefined criteria. In the first phase of screening, articles were screened as per abstract and titles by reviewer 1. In the second phase, full texts of articles were evaluated for eligibility by reviewer 1 and reviewer 2. Any disagreement between the reviewers was resolved.

Considering patient-healthcare providers interaction, data based on five touchpoints (awareness of disease and knowledge of associated risk factors; (2) screening and risk assessment; (3) diagnosis and treatment decision; (4) treatment experience and access to care; and (5) adherence to treatment for long-term management and 6) Control of Disease Symptoms and Signs were extracted from the final list of publications that were considered relevant for this review. A mixed framework was adopted to capture the epidemiologic and qualitative information on CLBP diagnosis and care, the status of the Brazilian health system, and the level of patient engagement in shared decision making in case of CLBP. This is because unlike mental conditions such as depression, where outcome data and assessment of the effectiveness of an intervention would be an area of research interest, CLBP-related literature commonly includes prevalence and patient journey aspects such as treatment and control.

Thus, a mixed framework was adopted to capture epidemiologic and qualitative information on LBP diagnosis and care, the status of the Brazilian health system, and the level of patient engagement in shared decision making and improvement of decision outcomes in case of LBP.

Studies included as per the screening criteria: systematic reviews and/or meta-analyses, randomized controlled trials, observational studies and narrative reviews (both in abstract and full-text format) with the pertinent study information with the CoCoPop + PICo framework [studies conducted in adult (≥ 18 years) patients (Population), representing Brazilian nationality (Context) and providing information about prevalence and incidence of LBP (Condition) plus Population, phenomenon of Interest and Context] were included for the review. Case studies, letters to editors and editorials, and/or articles with a mention of specific patient groups (patients with comorbidities, pregnant women, and children) were excluded.

An additional targeted search was performed to identify literature focusing on the key issues in LBP diagnosis and treatment/management (phenomenon of Interest) and the status of the Brazilian health system (Context) to address patients with LBP (Population).

**Data extraction**

Data from the identified studies were extracted using a predefined extraction grid, which included touchpoints of the patient journey (prevalence, awareness, screening, diagnosis, treatment, adherence, control) and information on study type as well as sample size. This was piloted by a reviewer and validated by local experts to ensure consistency with real-world insights as well as an expert opinion. The extraction grid focused on epidemiology and patient journey touchpoints (Awareness, Screening, Diagnosis, Treatment, Adherence, and Control) in patients with CLBP and CLBP-NeP.

**Data analysis and evidence synthesis**

For quantitative data, simple or weighted means for patient journey touchpoints were calculated as applicable. The synthesized data for each touchpoint was tabulated and qualitative information on a patient journey was provided as a narrative summary. Considering the policy context, only descriptive statistics were planned for the pooled data. Thus, no advanced statistical tests were used for prediction purposes. The synthesized data was holistically reviewed verified and refined by local experts to ensure consistency with real-world insights and expert opinion. The synthesized evidence was then mapped to the patient’s journey.

**Ethical consent**

This review is based on reported studies and is restricted to the analysis of secondary data, hence approval from the Ethics Committee is not required.

**RESULTS**

**Study selection**

**CLBP**

Of 323 publications retrieved from structured search and three retrieved from unstructured search, a total of five publications were shortlisted. Three additional publications were provided by local experts during the data validation phase along with anecdotal data. Of a total of eight publications screened for eligibility, six were included for the main analysis. Details about included CLBP literature are presented in Table 1.

**CLBP-NeP**

Of 115 publications from structured search and five from unstructured search, a total of two publications were shortlisted. One additional publication was provided by local experts during the data validation phase along with anecdotal data. Considering one duplicate, the remaining
two publications were included for the main analysis. Data about included CLBP-NeP literature are given in Table 1. The consolidated Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) Flowchart for both CLBP & CLBP-NeP is given in Figure 1.

**Findings from the analysis of pooled data**

Of 9 selected publications on both CLBP and CLBP-NeP, four\textsuperscript{34–37} and one\textsuperscript{38} reported CLBP and CLBP-NeP prevalence in Brazil, respectively. Whereas two publications\textsuperscript{39,40} mentioned data regarding awareness, diagnosis, and treatment of patients with CLBP and one article\textsuperscript{41} with percentage awareness about CLBP-NeP. Anecdotal data on screening, treatment, adherence, and control was provided for both CLBP and CLBP-NeP with the information about remaining data points made available only for CLBP-NeP.

Pooled analysis using published literature and anecdotal evidence for patient journey data on all touchpoints for both the conditions is presented in Figure 2. The kappa score of both the reviewer is zero for this study.

![Figure 1: PRISMA flow diagram](image)

**Figure 2: Summary estimates of the included studies**

Notes: \textsuperscript{a}Peer Reviewed Publication; \textsuperscript{b}Scientific Literature + Expert Opinion; \textsuperscript{c}Expert Opinion Only

\textsuperscript{*}Studies including population subgroups, single-centre studies or samples size <500. \textsuperscript{ǂ}Simple average.
DISCUSSION

Mapping of patient journey has been considered an important strategy to optimize the clinical care outcomes by separating the management of a specific condition or treatment into a series of consecutive events or steps. The present review aimed at mapping the patient journey touchpoints, namely patient awareness, screening, diagnosis, treatment, adherence, and control, about epidemiologic data. We adopted a semi-systematic approach in the literature search, which included anecdotal data from local experts along with retrieved records to gain insights on CLBP management at a local level.

Analysis of the evidence synthesis findings was performed to identify both practice and research gaps. Practice gaps were categorized in terms of the responsibility of the stakeholders: (1) Patient, (2) Clinician, and (3) Governance system.

The literature suggests that patients with CLBP had limited awareness regarding the type of pain. This could be partially attributed to low health literacy, limited screening and diagnostic modalities, and limited or inadequate patient-health care professionals (HCP) dialogue. One of the major concerns that patients had was the flare-ups. Patients’ poor ability to report the pain, partially attributed to low educational levels, may have resulted in the underutilization of the healthcare services.

Clinicians, especially general practitioners (GPs), were often found to approach CLBP patients with misconceptions such as ‘it is all in the patient’s mind’ or ‘the problem is only in the spine’. There is negligible consensus on incorporating patient-reported outcome measures (PROs) for clinical decision-making. Second, there is fragmented availability of clinical practice guidelines at a local or international level on how to utilize PROs for determining the care pathway in CLBP. It was also noticed that there was a poor clinical handover during referral from one health access point to another.

A recent cross-sectional survey reported that point prevalence of 31.8%, approximately one-third of the study population reported CLPB in Brazil in Brazilian military firefighters. While high in other developed countries such as Canada (75%), the United States (67%), Sweden (49%), China (39.2%), and Japan (32%)41,42,43. It is well-known that management of CLBP could be improved by insights from cross-functional data addressing physical, psychological, and sociocultural aspects of pain. Moreover, it has a significant impact on the holistic well-being of the patients, healthcare providers, society, and government. There is a dearth of national studies in Brazil that assess social determinants and risk factors for CLBP. It was a common observation that women and older patients were more likely to suffer from CLBP. However, it is also to be noted that the risk factors associated with CLBP had been influenced by a high level of geographical diversity. Thus, cautious interpretation is warranted. Thus, it is apparent that given the imbalance between local data and data from developed countries on CLBP, Brazil’s national CLBP burden is probably underestimated, implying the need of the hour to generate robust epidemiologic evidence.

Unclear concepts in pain diagnosis have led the clinicians to adopt several practices that are not established. For example, a majority of the clinicians prescribe Magnetic Resonance Imaging (MRI) investigation regardless of its clinical need. This leads to an increased financial burden to the patients due to additional investigations, referrals, and surgeries with questionable effectiveness. In addition, the scope of services rendered by the primary care physicians (GPs) was found to be very limited, focusing on basic care without any specialized role.

The Hospital Information System contains all records of inpatient care, which are processed and sent to the Ministry of Health and included in a national database. The outpatient information system includes all outpatient care by public and private providers contracted by the Brazilian Public Healthcare System (SUS). The expenses are based on reimbursement values determined by the Brazilian Ministry of Health, i.e., the payments are made to healthcare providers who deliver care in the public health system setting. Seemingly, payment models are a strong barrier to access to effective interventions delivering high value to patients. There are private insurance schemes available, which cover chronic conditions like non-communicable diseases and chronic respiratory diseases. Most of the patients with private insurance cover are found to be referred to pain specialists and not treated locally.

There is a lack of information about various capacity-building programs prevalent in the Brazilian health system (SUS). Although lack of training has been identified as a primary reason for lack of confidence in clinical judgments and assessment of CLBP by the clinicians, there are no active models on capacity building on procedural and psychological aspects of the clinicians.

There were no in-patient services for chronic pain or no studies focusing on management information statistics (MIS) data. Importantly, there was no data available about which services are most commonly accessed by patients with CLBP. There was a significant paucity of interdisciplinary research mindsets aiming at cross-functional evidence generation for policy adjustments.

Strategies to establish value-based, patient-centric care

Integrated care delivery model

It is well-established that CLBP is a multifactorial non-communicable disease, which demands a high quality of care. The effectiveness of clinical practice guidelines’ implementation depends on a complex and integrated role play by every stakeholder in the health system including patients with CLBP. The integrated care delivery model
aims to involve not only pain specialists and GPs but also behavioral therapists, occupational health consultants, pharmacists, physiotherapists, and researchers. 

Implications for research
The review findings indicate that there is a need for high-quality large-scale epidemiologic studies to assess the CLBP burden in Brazil and its surrounding areas. To the authors’ best knowledge, there is no study in the Brazilian population that assessed PROs in CLBP. Also, studies focused on patients’ preferences and utilisation of real-world evidence to get deeper insights into the patient journey in CLBP are highly warranted. Furthermore, it is highly recommended to acquaint the primary care providers in Brazil with evidence-based practice guidelines available from local and global sources. In cases where such guidelines are not available, KOLs should be encouraged to develop clinical protocols and practice guidelines based on their experience in a primary healthcare setting.

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REFERENCES

CONCLUSION
To the best of our understanding, this is the first-ever patient journey-related study in the Brazil region. Despite the limitation due to the paucity of data, it was possible to show the vital need for re-considering current health resource allocation. Various evidence-based prevalence study highlights the usefulness to improve patient outcomes at the national level to common patient journey touchpoints. The outcome of this evidence mapping patient journey is implicated to fill the gap with CLBP patients. In conclusion, a patient-centric, value-based care delivery approach with a shear focus on integrated care continuum, robust capacity-building programmes, and improved policy framework in Brazil would be a great step to improve all the 5 touchpoints related to the patient journey for those with CLBP.


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