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**Preliminary report**

# **The invisible pain: Gaps in Brazil's public health system data on menstrual and pelvic pain**

## Authors

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# Executive Summary

Menstrual and pelvic pain affect millions of women and girls throughout their reproductive lives. However, these conditions are often neglected health information systems, especially in primary health care in Brazil. This is one of the main conclusions of an exploratory study supported by Alana Institute and conducted by Vital Strategies in partnership with the FrameNet Brasil Laboratory of the Federal University of Juiz de Fora (UFJF).

The study analyzed data from more than 469,000 Brazilian girls and women between 10 and 49 years of age attended in primary care in Recife, a city in the Northeast of Brazil, over almost a decade (2016-2025). The study analyzed data from e-SUS (primary care), SIH/SUS (hospital admissions system) and Sinan (violence notification system). Based on the records identified in the databases, the participants were classified into two groups for analysis purposes: women with a history of pain and women with no history of pain.

The work, presented at the 70th UN Commission on the Status of Women (CSW70), in New York, in March 2026, sheds light on four dimensions that are still little discussed in Brazilian public health:

- The invisibility of menstrual health data;
- The weaknesses of structured data from medical records and traditional forms of data analysis in identifying menstrual health issues, pointing to the need for innovative approaches;
- The transformative potential of new methodologies based on text processing with artificial intelligence;
- When pain and violence co-exist, the data point to the need for an integrated, cross-sectoral approach to women's health care.

# 1. Menstrual pain is almost invisible in official data

In the more than 469,000 records analyzed, only 0.5% of women (1,906) were identified with a history of menstrual or pelvic pain through ICD-10 referral codes — the official International Classification of Diseases. However, other information was identified in the electronic medical records in addition to those parameterized through codes.

This is reflected in the entries documented by health professionals in the open-text fields of patient records. Through an innovative methodology used in the study, which combines semantic analysis and artificial intelligence, it was possible to “read” the contents of these fields and turn this information into standardized data, comparable with those of the other data sources used.

By incorporating information found in doctors' notes into the analysis, it was possible to identify more than 41,000 cases of menstrual or pelvic pain. This data is compatible with the experience of doctors specializing in chronic pain in women and shows that the clinical language recorded by health professionals contains much more information than coding systems can capture.

But there is a second problem: even when pain is recorded, the data is structurally fragile. Although it is mentioned in text, whether as “menstrual pain”, “pelvic pain” or “pain during sexual intercourse/relation”, clinical notes rarely included information on duration, frequency or intensity of symptoms. Among the occurrences of high association with pelvic pain, less than 5% mentioned these key clinical attributes. This means that even where the pain appears, it reaches the medical record without qualification - without duration, without pattern, without history.

In addition, women with a recorded history of pain visited health services an average of 24 times in the studied period, which is almost five times more than women in the group without pain, who had an average of 5 visits. This high frequency of use of the health system indicates that these women seek care on a recurring basis, but without their complaints being properly recorded and monitored.

## 2. Conditions relevant for the diagnosis of endometriosis and adenomyosis are underrepresented in the data

Two semantic analysis methods were used in the study. The first makes a survey of key terms that appear in the medical records and indicates how greater is the frequency of mentions of a given condition in the group with pain compared to the group without a history of pain. This metric, called keyness, points to a revealing pattern: conditions directly linked to the diagnosis of endometriosis and adenomyosis appear in medical records with relatively low frequency considering the number of women with pelvic pain and suspected endometriosis and adenomyosis in the data.

Hemosalpinx - accumulation of blood in the uterine tubes, direct manifestation of tubal endometriosis - appears in only 4 records. Infertility, which is associated with up to 50% of cases, according to the clinical literature, appears in 155 records, an expressively low number for a sample of this size, especially when considering that the average prevalence of infertility in the female population varies between 10 and 12%. Vaginismus, which is expected to coexist with chronic dyspareunia, appears in only 25 cases. Still, the keyness analysis applied in open-text fields shows that the presence of this condition is 131% higher in the group with pain than in the group without it.

There are also notable absences: dyschezia (pain when defecating, classic symptom of intestinal endometriosis); endometriomas, as a distinct clinical entity; and irritable bowel syndrome, strongly associated with endometriosis, are not systematically named in the data.

The way the terms endometriosis and adenomyosis appear in electronic medical records also sheds light on what happens during consultations. Of the total texts in a medical record, 41% are in the field called "Subjective", that is, in the field where health professionals record patients' complaints and reports. The analysis revealed that 40.6% of all mentions of endometriosis and adenomyosis appear precisely in this field, that is, in the context of recording what is mentioned by the patient.

At the same time, the "Objective" field, which contains the doctor's notes on the focus of care based on the patient's report, concentrates 17% of the total semantic data in the medical records, while only 7.28% of mentions of endometriosis and adenomyosis appear in this field. That is, the professional's focus during care ends up on aspects of the patient's report other than endometriosis or adenomyosis.

Only 7.08% of the mentions of these two conditions appear in the “Plan” field, which defines the agreed conduct between health professional and patient. This field represents 22% of all e-SUS textual data.

Finally, the “Referral” field contains 21% of mentions of endometriosis and adenomyosis, while containing only 5.5% of the total data.

	Subjective Field (patient’s report)	Objective Field (Clinical focus defined by the health professional based on the patient’s report)	Plan Field (course of treatment defined by health professional from Objective Field)	Reason for Referral Field (indication of the need for a patient to receive care from another professional)
% of occurrence of the terms “endometriosis” and “adenomyosis”	<b>40,60%</b>	<b>7,30%</b>	<b>7,10%</b>	<b>21,90%</b>
Expected % of text completion rate of this field	<b>41,60%</b>	<b>17,20%</b>	<b>22%</b>	<b>5,50%</b>
Relation between occurrence of terms and expectation	<b>Practically equal</b>	<b>2,3x less</b>	<b>3x less</b>	<b>4x more</b>

From this data, we see that, during a consultation, the patient reports a series of complaints, including those related to the diagnosis of endometriosis or adenomyosis, to the health professional. However, when defining the focus of conduct (reported in the “Objective” and “Plan” fields), in some cases that professional leaves the health conditions related to endometriosis and adenomyosis, and their consequences, in the background. The doctor then carries out the referral to a specialist. They refer these women to another specialist, but do not offer a therapeutic plan that can, in fact, improve the symptoms or condition.

The keyness analysis regarding the drugs most prescribed for the group with pain highlights the lack of focus on the treatment of chronic pain: the average frequency for drugs for constipation and gas is 150% higher in the group with pain, while drugs for acute pain have an increased frequency between 60% and 185%, depending on the drug. There is no mention of prescribing contraceptives or hormonal drugs. In summary, the patient with endometriosis and adenomyosis is dependent on a future referral to treat the problem.

This scenario reflects limitations in the organization of the health care network, in which primary care, although playing a central role in care delivery, often lacks the conditions or support needed to provide effective interventions, resulting in dependence on referrals and long waits for diagnosis and treatment at other levels of care.

The data also reveal a phenomenon of pain taking over medical consultations: In the medical records of women with a history of pelvic pain, conditions such as diverticulitis, pancreatitis, abdominal distension, colitis and kidney stones appear between 140% and 252% more often than in the medical records of women without pain. Possibly, these are some of the diagnostic hypotheses that appear in the medical records.

At the same time, general aspects of health tend to disappear from these records: mentions of diabetes are 18% lower, and of hypertension, 23% lower compared to the group without pain. The hypothesis raised by the researchers is that pain begins to dominate the space of the medical consultation, shifting the clinical gaze to acute and circumscribed symptoms, with diverse diagnostic hypotheses that end up privileging clinical views and more conventional measures, such as treatment for gastrointestinal issues.

This finding suggests that conditions relevant to women's health are being recorded in a dispersed and unsystematic manner, hindering both diagnosis and care planning.

### 3. Co-occurrence of pain and violence against women and girls in medical record

A particularly revealing finding concerns the quality of the records when cross-referencing pain with the history of interpersonal violence. Among women in the group who have reported pain, those who also have records associated with violence have proportionally fewer mentions of conditions such as menstrual cramps and hypertension in the medical records, even when having pain as frequently or more often than the others.

When not only formal notifications but also the textual information in the medical records are incorporated, women with a history of pain have a 43% higher chance of having some record associated with interpersonal violence compared to women without pain. This risk appears in all age groups studied, being more expressive among adolescents aged 10 to 14 years and among women aged 45 to 49 years.

Women with a history of pain who also had records associated with interpersonal violence visited primary care services on average 35 times during the studied period, 50% more than women with pain but without records of violence. The data indicates these women are visiting public health services often and need integrated and intersectoral approaches, starting from primary healthcare units.

## Conclusion

The proposed methodology generates results that suggest that the ICD registry does not always coincide with the clinical history described in free text, which can lead to the omission of clinically relevant information. In addition, there is a very limited characterization of pain, with little detailed description of symptoms and absence or low frequency of records of structured empirical therapeutic plans, which makes it difficult to propose adequate investigative and therapeutic strategies. The study also suggests possible gaps in the diagnostic record, including the omission of ICDs potentially relevant to the clinical picture.

The methodology applied in the study creates an opportunity for a more qualified intervention of health services with the population suffering from conditions related to pelvic pain, which can be developed on three fronts:

1. The methodology allows the health system to understand the true magnitude of the population affected by these conditions, contributing to the organization of care and to timely referrals across different levels of care, thereby reducing the interval between the first complaints and the correct diagnosis of the condition. The Brazilian Federation of Gynecology and Obstetrics Associations (FEBRASGO) advises that, when a woman exhibits chronic pelvic pain, a complete medical evaluation is necessary and that musculoskeletal aspects, pelvic floor problems, myofascial disease, urinary alterations, constipation and irritable bowel syndrome need to be considered for an adequate differential diagnosis. That is, the protocol includes exactly those conditions that appear underreported in the data.
2. As the semantic search methodology in the open-text fields of medical records is based on a linguistic model interpretable by humans, it is possible to construct very specific patterns to be found in medical records, allowing, for example, a query on associations between pelvic pain and violence over time.
3. The findings indicate an opportunity for sensitizing and capacitating primary care professionals to care for women and girls with chronic pain, so that they receive adequate care as early as possible.
4. It also paves the way for the future construction of a real-time alert system, embedded in the electronic medical record system, as has already been implemented in Recife for cases of violence against women.

# Recommendations for improving care for women with chronic pelvic pain

(Based on FEBRASGO guidelines)

## Diagnosis

- Include detailed anamnesis with systematic recording of pain duration, frequency and intensity.
- The health care network must ensure rapid and facilitated access to diagnostic tests, with transvaginal ultrasound as the initial examination and magnetic resonance imaging and videolaparoscopy indicated for more complex cases.
- Extend differential diagnosis beyond gynecological causes, including irritable bowel syndrome, interstitial cystitis, pelvic floor changes, and musculoskeletal causes.

## Multidisciplinary approach

- Overcome the organ-centered approach in favor of integrated care with pelvic physical therapy, mental health and other specialties as needed.
- Actively investigate associated psychological factors, including depression, sleep disorders, and a history of sexual or interpersonal violence.
- In cases of menstrual pain or when there is suspicion or mention of endometriosis and/or adenomyosis, hormonal treatment should be considered, in accordance with clinical protocols and with support from the health care network, even empirically and in the absence of confirmation by imaging tests. This approach is widely recommended by important international guidelines and is included in the FEBRASGO recommendations.

## Quality of clinical record

- Document in the medical records the clinical attributes of the pain (intensity, pattern, frequency, functional impact) and not only the final diagnosis.
- Record associated comorbidities, such as infertility, dyspareunia, vaginismus and urinary urgency, which are relevant for the differential diagnosis of endometriosis and adenomyosis.

## Reception and education

- Ensure that the pain reported by the patient is recognized as legitimate by the health professional, preventing consultations from being captured exclusively by nonspecific diagnostic hypotheses.
- Invest in educating the population about what constitutes normal pain versus pain that requires investigation, reducing the time to diagnosis.

# Recommendations for referral and care of women, children and adolescents victims of violence

Brazilian Ministry of Health (MS), World Health Organization (WHO), Brazilian Statute of the Child and Adolescent (ECA) and INSPIRE/WHO

## Identification and reception

- Adopt active listening and non-judgmental attitude, recognizing that reporting violence respects each person's time and that there is no "ideal victim". (MS)
- Perform active violence screening even when the main complaint is somatic: chronic pain, migraines, and gastritis may be expressions of spontaneously unreported violence. (MS)
- Ensure privacy and confidentiality during care, informing that the compulsory notification is not the same as a police report and does not imply referral to the police. (MS)

## Notification and recordkeeping

- Perform compulsory notification in the Notifiable Diseases and Conditions Information System (Sinan) within 24 hours in all suspected or confirmed cases of interpersonal violence. (MS, Directive 1271/2014)
- In cases involving children and adolescents, it is mandatory to report to the Council of Guardianship (Brazilian equivalent of Child Protective Services) any cases of suspicion or confirmation of mistreatment, physical punishment, sexual abuse or cruel and degrading treatment. (ECA, Art. 13)
- Document clinical findings, description of injuries and referrals made accurately in the medical record, without drafting an expert report, a function exclusive to forensic medicine. (MS)

## Immediate referrals

- Ensure, during health care: reception, recording of clinical history, gynecological examination when indicated, emergency contraception, prophylaxis for HIV, STIs and Hepatitis B, and scheduling of multidisciplinary follow-up. (MS, Technical Standard)
- Refer to and coordinate with the social protection network: Social Assistance Reference Center (CRAS), Specialized Social Assistance Reference Center (CREAS), Specialized Women's Care Center (CEAM), Casa da Mulher Brasileira and, when there is a risk to life, refer to shelters. (MS)

- For children and adolescents, engage the Council of Guardianship so they may apply the protection measures provided for in Article 101 of the ECA, including psychological treatment and inclusion in family support programs. (ECA)
- When there is an interest from the victim in denouncing or requesting protective measures, guide and direct them to a Women's Police Station. (MS, Maria da Penha Law)

## Intersectoral approach - INSPIRE

The INSPIRE package organizes seven complementary and mutually reinforcing strategies to prevent and respond to violence against children, with the participation of the health sector in coordination with other sectors:

- **I – Implementation and enforcement of laws:** Ensure that protection legislation (ECA, Maria da Penha Law) is effectively applied in the care flows.
- **N – Norms and values:** Act on beliefs that normalize domestic violence and female pain, including within health teams, through continuing education.
- **S – Safe environments:** Identify and reduce risk contexts in the territories served by primary care, in conjunction with social assistance and public security.
- **P – Parent and caregiver support:** Offer positive parenting programs and support to families in vulnerable situations, reducing the risk of intrafamily violence.
- **I – Income and economic strengthening:** Consider economic vulnerability as a structural risk factor and coordinate with income transfer and job generation programs.
- **R – Response and support services:** Ensure integrated response services that connect health, social care, justice and education, with no sector operating in isolation.

