



Exploring women's chronic disease experiences: A mixed-methods analysis of endometriosis narratives

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ARTICLE INFO

Keywords:

Endometriosis
Chronic pain
Mixed-methods
Word embeddings
Natural language processing

ABSTRACT

Endometriosis is a chronic gynecological illness faced by an estimated one-tenth of women worldwide. Despite being a common condition, studies of the disease in Latin American settings are still scarce. This paper presents a study of 30 autobiographical interviews with Chilean patients who are L1 Spanish speakers. Our study aims to fill the gap in understanding the endometriosis experience of Latin American women, unveiling how to assist the patients better and improve their quality of life. It is one of the first studies to describe the experience of Chilean women in navigating the disease and the impacts on their routines. We used a mixed-methods approach to achieve our goal, employing a combination of NLP and content analysis. First, we generated word embeddings for three main keywords, "pain," "endometriosis," and "menstruation." Furthermore, we processed the data to locate occurrences of "pain" in the corpus. We coded the occurrences into nine semantic domains of the endometriosis pain experience: intensity, normalization, treatment, frequency, menstruation, feeling, pain location, symptom, and impact. Our results shed light on the details of the journey with endometriosis and may lead to improvements in patient-doctor communication and policymaking to benefit patients.

Endometriosis is a chronic disease characterized by the growth of endometrial-like tissue outside of the uterus (Hudson, 2022). Pelvic pain is one of the main symptoms, and it can worsen or change its characteristics with time (Giudice, 2010). The definitive diagnosis is under visualization at surgery (laparoscopy) (Seear, 2009). Before the surgery, doctors may prescribe nonsteroidal anti-inflammatory drugs (NSAIDs) to relieve dysmenorrhea (pain during the menstrual cycle); combined oral contraceptives may also be administered for treatment (Giudice, 2010). Although it is a gynecological condition, a recent study describes endometriosis as a chronic systemic disease affecting the pelvis area and widely spreading to several body organs and tissues (Taylor et al., 2021). Besides the physical symptoms, endometriosis leads to mental health conditions such as anxiety and depression (Lagana et al., 2015). Since patients suffer from chronic pain during their menstrual cycles, having to remain in bed on the worst days, their professional and personal lives are at risk – the cyclic psychological suffering might worsen the pain (Quintero et al., 2017).

In economic terms, endometriosis may cost US\$ 22 million per year in the US (Simoes et al., 2012), and in terms of incidence of the disease leads to a slow diagnosis based on trial and error (Whelan, 2007).

Hudson (2022) argues that the will of ignorance, a biased view that does not favor research about women's conditions, might cause a lack of focus in deepening the studies of endometriosis.

Effective communication between patients and doctors is a critical aspect of the diagnosis of endometriosis. Rolla (2019) states that anamnesis is crucial and can help the early detection of the disease. However, doctors have shown tendencies to normalize pain (Ballard et al., 2006), postponing the diagnosis and prolonging the uncertainty of the patients. Despite being a widespread condition, endometriosis takes four to eleven years to be diagnosed (Greene et al., 2009). Bullo (2020) reported that the estimated time to diagnose the condition in the UK is 7.5 years. In Chile, the time is even longer, between 10 and 12 years (Proyecto de Ley Endometriosis, 2021).

In the context of prolonged delay and to get a better description of the impact of Chilean social factors, our objective is to identify and assess the discourse patterns of patients' descriptions of their experience with endometriosis. We present one of the first endometriosis studies focusing on the community of L1 Chilean Spanish speakers. Chile is part of the Global South, while most studies focus on the Global North: Europe and the United States (Matías-González et al., 2022).

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Understanding how diverse societies perceive the disease and how other issues like unequal income distribution aggravate patients' struggles is essential. Furthermore, our study is relevant for health researchers, practitioners, and policymakers who need to understand the Chilean endometriosis context. An Endometriosis Law has been under consideration by the Chilean Chamber of Deputies since 2021. If incorporated into the Constitution, the law will guarantee access to better treatment and paid leaves, among other patients' rights.¹

As part of a larger project to improve communication regarding chronic diseases in Chile, this study analyzes a corpus of 30 autobiographical interviews with endometriosis patients in their reproductive age. The analysis conducted in this study uses information retrieval techniques as described in Schütze et al. (2015), Manning and Schütze (1999), and Bird et al. (2009). Also, we applied Word2Vec to extract word embeddings, taking them as a framework to detect word meanings, as described by Mikolov et al. (2013). Our mixed methods approach also involves coding and analysis of sentences where "pain" is used in the interview to develop an overview of the Chilean women's experience with endometriosis. By using these methods, this article aims to answer the following questions:

1. What meanings do endometriosis patients make of the words "pain," "endometriosis," and "menstruation"?
2. How do Chilean women experience endometriosis pain?

The paper is divided as follows: following the introduction, the second section explores endometriosis from a linguistics perspective and a brief contextualization of the Chilean case. The third section describes the data collection process and the corpus analysis methods. The fourth section discusses findings about the meanings of "pain," "endometriosis," and "menstruation" and the analysis of the semantic domains of pain. Finally, we present our conclusions, limitations, and highlights for further research. By analyzing the patients' discourses, we expect to contribute to a better understanding of their perceptions and, in turn, to improve health communication practices.

1. Literature review

The first two decades of the century have witnessed a growing interest in health communication focusing on the patient, moving away from the traditional centrality of doctor-patient communication (Antón & Goering, 2015). Most studies from a linguistic perspective have focused on doctor-patient interaction (see, e.g., Wodak, 1997; Demjen et al., 2016; Potts & Semino, 2017; Barnes et al., 2020, among several others) and the impact of communication practices on patients' adherence to medication treatments (Bukstein, 2016). Those studies have proved that good communication practices positively affect patients' adherence and compliance and, therefore, their quality of life. Several studies have been conducted on genres that highlight the importance of researching other types of interaction in health contexts. Of relevance are those focusing on the interaction in mental health institutional settings (see, e.g., Bonnin, 2014, 2017, 2018), who have shed light on how diverse social actors construct and negotiate roles in communication in health settings. In addition, other scholars, like Pardo and Buscaglia (2008) and Marchese and Celerier (2017), have adopted a critical discourse approach to institutional texts to determine certain forms of institutional violence, among other results.

Endometriosis is a gynecological condition that has been studied for decades. Because of the similarity of its symptoms with the pain from menstruation, health practitioners frequently ignore it, postponing diagnosis and delaying treatment (Rea et al., 2020). This situation becomes even more harmful to the patient's condition and quality of life

when social factors exert a substantial impact on women's self-esteem. Also, cultural stereotypes indicate that females have "dramatic" reactions and, at the same time, are supposed to endure pain, which combine to underestimate or disregard gynecological symptoms related to the disease, as has been clearly shown in the literature (see, e.g., Facchin et al., 2015; Laganà et al., 2017).

Studies focusing on endometriosis from the patients' discourses have emerged since 2018. One example is Bullo (2018), who studied the disempowerment that women with endometriosis are subjected to, concluding that it is caused both by their health care and social environments. Other studies focused on the meaning-making of the disease, particularly in metaphors. In Bullo (2020), the author argued that women resort to metaphors to express their pain due to the lack of lexical tools; "stabbing" was one of the metaphors to describe the pain. Bullo and Hearn (2021) understood which types of metaphors are prevalent and their meanings in the communication of patients to doctors. Overall, the researchers concluded that the pain was characterized as a "distressing agent," a negative controller of their experiences. Also, they noted that metaphors for temperature, pressure, physical damage, and external attackers were predominant. Moreover, Bullo and Weckesser (2021) addressed what patients and doctors consider vital in communicating endometriosis pain; they pointed out that the current tools, like NRS (pain scale), are insufficient to describe endometriosis pain accurately.

Recently, a batch of new studies on endometriosis has emerged, also focusing on patient-authored content in English on social media platforms. Those studies focus on understanding the uses of the platforms by patients as communities to exchange experiences and find emotional support and information (Towne et al., 2021; Holowka, 2022; Lindgren & Richardson, 2023).

Concerning the focus on Latin America, in previous works, and from a mixed-methods discourse perspective, we researched endometriosis patients communicating in the context of Facebook comments (Pascual, 2021; Pascual & Díaz Alegría, 2021). We aimed to determine the purposes of their interaction on social media and the types of meanings that they negotiate in their discourse. Pascual (2021) addressed the three purposes that Facebook serves Chilean endometriosis patients: a place for emotional support, information exchange, and storytelling. Pascual and Díaz Alegría (2021) focused on the types of affect that women with endometriosis foster on Facebook, concluding that the un/happiness (sadness) and dis/satisfaction (pleasure and discontent) were the prevailing ones. Pascual (2020) interviewed Argentinian endometriosis patients, who recognized the negative effects of isolation, lack of credibility, and information that are attached to the women's pain normalization. Furthermore, Bullo et al. (2022) compared the construction of endometriosis pain in British English and Argentinian Spanish, finding that women in both languages address pain as an overpowering actor; however, they argued that Spanish speakers tended to express pain in a closer relation to mental imagery.

This study aims to partially fill the gap in understanding patients and their experiences from a mixed-methods perspective. The interviews bring a different type of text to be analyzed, oral narratives, to complement other works focusing on social media (e.g., Pascual, 2020). Also, by focusing on a Latin American location in a non-English-speaking country, we can account for similar ways endometriosis is linguistically constructed in different languages. Furthermore, it brings a new perspective on the diagnosis and treatment of endometriosis patients immersed in Latin American society, expanding studies from an intersectional perspective. Until 1818, Chile was a Spanish colony, with several native peoples in the population's composition. Over the last decades, and because of migratory movements in Latin America and the Caribbean, its mixed demographic composition has been enriched by the arrival of migrants from other countries, mainly from Venezuela and Haiti, and today, immigrants in Chile constitute one-tenth of the country's population (de la Maza Cabrera, 2020). The number of inhabitants from different ethnic backgrounds represents 13%; of these, about 10%

¹ See the whole Law project at <https://ojs.uc.cl/index.php/bjur/article/view/45849/>

are of Mapuche origin.

In this social context, the health system has experienced significant changes. By the 1960 s, the country had a universal health service, which was then profoundly transformed into a neoliberal reform in the 1970 s, and the next two decades witnessed a series of legislative reforms that led to strong claims regarding the evolution of health outcomes and equity in Chile (Doña-Reveco, 2022). Such varied composition and the corresponding co-existence of various forms of medicine, diverse ways to deal with diseases, and culturally related gender issues make the Chilean case particularly valuable to study. The perspective adopted in this research allows for the incorporation of relevant, situated samples of language use, which construct meanings that are shaped socially and, consequently, highly relevant to the communication practices in which they are produced. By assuming this approach to the analysis of linguistic practices, we adhere to the notion that language is a social phenomenon shaped by socio-historical factors and, in turn, a fundamental tool for creating and consolidating social values.

2. Data and methods

2.1. Corpus design and composition

We gathered and analyzed patient oral narratives, defined in the literature as autobiographical recounts (Martin & Rose, 2008). The data were collected through semi-open interviews due to their enormous potential to yield linguistic information that may shed light on various social phenomena (Chamberlayne, Bornat, & Wengraf, 2000; Elliott, 2005). We implemented flexible interviews, which have proved to function as practical tools for constructing highly personal information. They are similar to life stories collected in the form of semi-structured interviews, which allow for a reduction of the elements of stressful observation usually imposed by other less flexible tools (Seidman, 2013). Also, they were conducted by two Chilean linguists, who were selected to minimize biases that could surface in the results of our analyses.

The research design incorporated the implementation of 30 interviews. The informants were all women of reproductive age whom a licensed practitioner had diagnosed. They volunteered to participate in this study in response to a post distributed on social media. The women who participated in the study ranged in age from 23 to 47 years. They were all Chilean and L1 speakers of Spanish.

The interviews took place in April and May 2021, in times of strict sanitary restrictions resulting from the Covid-19 pandemic. Because of this, all interviews took place online, using Zoom, Meet, or WhatsApp video calls. Although the virtual environment might promote a sense of distancing, it also allowed participants to feel more comfortable since they were in their homes; this was the usual practice for the time being. A set of guidelines that had been validated in previous studies (e.g., Bullo, 2018; Bullo & Hearn, 2021) and approved by the university Ethics Committee² was used to conduct the sessions. The areas of experience covered in the guideline included personal information (age, duration of the condition, family background, information before and after the diagnosis) and details regarding their experiences with the chronic condition with which they had been diagnosed (see the complete questionnaire in the Appendix). The interviews ranged from 30 to 45 min, averaging 39.6 min. The total recording time was 19.53 h. The interviews were transcribed into text documents, resulting in a corpus of 180,159 words. We removed all traces of personal identity to protect the participants' integrity and anonymity. All participants signed the ethics consent form for participation.

² The project and tools used for conducting the interviews were approved by Pontificia Universidad Católica de Chile Ethics Committee Protocol #190325007

2.2. Mixed-methods analysis

This study was conducted with the incorporation of data analytics into linguistic data, as highlighted by Tay and Pan (2022). We considered the mixed-methods approach in the sense that the first step of the analysis was generating word embeddings to extract critical information from raw data, and the second step consisted of coding and content analysis of the data.

First, we removed the interviewers' questions from the texts, leaving only the patients' answers. This measure ensured that we would primarily focus on the patients' words. We conducted a series of pre-processing tasks to remove terms or topics that were out of the study's scope, and other oral marks that could bias the results. For this purpose, we created a personalized list of stop words for the process of cleaning. Besides that, numbers and punctuation were also eliminated.

In Table 1, we inform the general statistics of the corpus after the preprocessing phase.

We trained a model of word embeddings from the data, due to its capability of capturing semantic information from terms. Word embeddings are based on the distributional hypothesis by Harris (1954), who claimed that words with similar meanings tend to occur in similar contexts. We applied the Word2Vec package, based on the algorithm by Mikolov et al. (2013), to extract the word vectors. Before generating the word embeddings, we processed the tokens into lemmas. Lemmas are the roots of words that show that they have a relationship although they are different on their surface (Jurafsky & Martin, 2008). This process allows us to group words with similar semantic content, like "pain" and "pains." However, we may lose some differences from the meanings attributed to singular or plural forms. We decided to take this approach since our study focuses more on detecting main themes from a corpus than on studying precise morphosemantic relationships.

Three keywords were chosen to extract the word embeddings from our trained model: "pain," "endometriosis," and "menstruation." Understanding the meaning of each of these words would allow us to reach our research objectives. Because of the study design, we expected that those words were common in all testimonials, which would comprehensively yield data from the corpus. Concerning "menstruation," besides "menstruación" ("menstruation"), we used the term "regla," an informal Spanish synonym. After generating the closest terms to the keywords, we captured a few examples of the emerging themes from the interviews to confirm if the context in which they were produced was related to the experience with the disease.

For our coding process, we centered on the perceptions of pain. Based on the literature review, we knew that understanding how the patients expressed pain would be a vital contribution to our work. For this purpose, we extracted the sentences of each interview and filtered only data where "pain" or its variants (plural and verbal forms) were present. Both authors had analyzed the recordings of the interviews and already had notes on the highlights of each speaker. By reading the extracts and revisiting the notes, both authors performed the coding. We ended up with nine semantic domains of the endometriosis experience: intensity, normalization, treatment, frequency, menstruation, feeling, pain location, symptom, and impact.

Table 1
General Statistics of the Corpus after Preprocessing and Tokenization.

Item	Count
Number of interviews	30
Number of tokens	20,520
Vocabulary items	2139
Mean of tokens	5146
Minimum of tokens	1530
Maximum of tokens	10,521

3. Results and discussion

3.1. The meanings of pain

The word embeddings model generated the ten most similar terms to "pain." The noun "dolor" (pain) presented terms referring to the location of the pain in the body. Besides the abdominal location, the back and the bones were reported in the interviews. The character of the pain was also detected as constant, intense, and abundant. Medication to control the pain is reflected in "analgesic." The pain is also characterized as an "inconvenience." [Table 2](#).

One striking feature is "niña" (girl). We found that there is a context in which women refer to close friends as "niñas," people that would be around when they are in pain. However, the most relevant context for our analysis is regarding the recollection of the beginning of the symptoms. Some described the feeling that something was off from a very young age, as in example (1).

(1) "o sea desde desde que era niña yo creo | a mí me llego la regla a los trece | de ahí en adelante:: el periodo era: horrible" (thus since since I was a girl, I believe | to me, my period arrived when I was thirteen | from that moment on:: the period was: horrible) (M09)

The description of noticing the pain in adolescence relates to another underlying issue: being absent from school classes. In segment (2), we located an occurrence of "chica," a synonym for "niña," where the interviewee told us how she began to enjoy the painful period because she was absent from school.

(2) "siempre siempre desde que me llegó onda me llegó la menstruación eh:: a los 10 años super chica y bueno en la en el colegio pasada como piola entre comillas porque claro ese día faltaba" (always, always since I had my first period eh:: at the age of 10 very young and well that day was like, kind of nice because I didn't have to go to school) (M04)

Other women reported that they tried to go to school even though they were not feeling well. The narrative in (3) describes what a woman, as a teenager, went through to "disguise" her abundant period, rolling multiple pads to avoid leaks.

(3) "yo tenía que ir al colegio todo eso unas toallitas de mano | la enrollaba | y eso me lo ponía y así todo yo sentada en el banco pasaba con todo || y dejaba la silla manchada y era todo un show" (I had to go to school with the pads | I rolled them | and I wore them all and even so when I was sitting on the bench I left the seat all stained and it was all a show) (M02)

The word embedding for "doler" (to ache) presented similarities to other verbs like "to regulate," "to last," "to rest," and "to forget." The latter has the least obvious meaning, and it is in the context of the patients trying to forget that they have pain to live a normal life. The location of the pain is translated into the words "back" and "stomach." "Menstruation" is also an associated term for "to ache."

In the analysis of "pain" we found that "normal" is a related term. This finding resonates with other works, which claimed that the normalization of women's pain makes them be seen as exaggerated ([Pascual, 2020](#)). In our interviews, it was common for women to talk about how

Table 2
Word2Vec Most Similar Terms to "Pain".

Keyword	Most similar terms from Word2Vec model
dolor (pain)	constante (constant), contracción (contraction), espalda (back), abdomen (abdomen), intenso (intense), hueso (bone), analgésico (analgesic), abundante (abundant), niña (girl), molestia (inconvenience)
doler (to ache)	reglar (to regulate), durar (last), normal (normal), espalda (back), gana (will), dolor (pain), descansar (to rest), regla (menstruation), olvidar (to forget), guata (stomach)

narratives about their pain being normal permeated their pilgrimage with doctors. In example (4), the doctor claimed that her pain was normal, not even considering the possibility of endometriosis.

(4) "Entonces ese ginecólogo me dijo que estaba bien | no me habló de endometriosis ni de nada | me dijo que el dolor era normal" (Then that gynecologist told me that it was all right | s/he didn't talk to me about endometriosis or anything | s/he told me that the pain was normal) (M25)

We observed that this behavior often occurs when patients are still unaware of their condition and pain is misdiagnosed as an intense cramp. In other cases, as in examples (5) and (6), the interviewees report their dissatisfaction with how women's pain is normalized by society in general. The patients mention the frequent social misconception that establishes that women should endure pain and how they feel it is not appropriate.

(5) "porque nos siguen normalizando y creyendo que las mujeres tenemos que tolerar un nivel de dolor peor que de un parto" (because we are still normalized and believed that as women we have to tolerate a high level of pain than of giving birth) (M02)

(6) "no es normal que no normalicemos los dolores porque en el fondo la sociedad ya los tiene súper normalizados" (it's not normal that we don't normalize pain because deep inside society has already normalized them) (M10)

The normalization of pain in Chilean endometriosis patients is a finding that can relate to the optics of the study of [Grace and MacBride-Stewart \(2007\)](#), about chronic pelvic pain in women. The authors refer to biological normalization, which consists of justifying women's pain due to anatomic differences, and psychological pathologizing, the association of women with hypochondria, an exaggerated reaction to symptoms. Both cases are present in our article, especially the second. Women stated that not only doctors but people from their social circle tried to convince them that the pain was an exaggeration.

3.2. The meanings of endometriosis

Concerning the similar terms of "endometriosis," we found that many are related to the diagnosis process. The main actor in this process is the "especialista" (specialist). Endometriosis is similar to "to investigate," "to suspect," "to become aware," and "to do", in a sense of doing medical exams. "Common" refers to endometriosis being a common disease, and "deep" is a disease characterization. [Table 3](#).

We highlighted the term "information" because it reveals the complaints that patients have scarce information about endometriosis and their perceptions of how the condition should be more known. One of the main complaints is in (7) on how information is dispersed and, therefore, difficult to access.

(7) "porque hay poca información po |o sea si bien hay información está como muy dispersa" (because there is little information you know | I mean even though there is information it is all scattered) (M06)

The patients also explicitated that they use social media to get informed (8) even when they did not have accounts on the platforms.

Table 3
Word2Vec Most Similar Terms to "endometriosis".

Keyword	Most similar terms from Word2Vec model
endometriosis	especialista (specialist), investigar (to investigate), profundo (deep), sospechar (to suspect), enterar (to become aware), resonancia (resonance), común (common), hacer (to do), grado (degree), información (information)

(8) “de hecho yo no tengo Instagram pero me metí así como uno | para dar información más que nada porque igual hay uno se informa” (in fact I don’t have Instagram but I got involved like | to offer information mostly because you get informed there) (M04)

One further reflection on information is in (9). The importance of the school is emphasized since it is a place where teenagers feel the impact of menstrual pain. Also, there is a claim for the availability of information in a broader sense – involving disease awareness in society.

(9) “entonces yo creo que hay una larga línea que tiene que ver con información | eh: para todos | para todos: desde los profes en el colegio: en todos los ámbitos de entender” (then I think there’s a long line that has to do with information | eh: for everyone | for everyone | from school teachers: in all fields of knowledge) (M10)

Not having good quality information about endometriosis is one of the reasons why it is so difficult to diagnose. Hudson (2022) argued that the information about the disease is scarce because of the will of ignorance, a society that is not looking forward to studying themes considered too challenging. Endometriosis is a common disease with a significant economic impact. It would be expected that it would receive more funding and studies, but that is still different from reality.

3.3. The meanings of menstruation

The Word2Vec analysis comprised the generation of word embeddings for the words related to “menstruation,” according to the report of Table 4. Similar to “pain,” we observed attempts to quantify menstruation. Nonetheless, differently from “pain,” there is an aspect that “menstruation” is easier to describe, as we see in the word “abundant.” Pain is directly related to menstruation, in the adjectives “painful,” “huge,” and “severe.” Duration of bleeding is related to “to last.”

In (9), the example refers to the “debilitating/disabling” aspect of the disease. Although some women do not experience pain, those who must stay in bed for many days report that they see the condition as debilitating/disabling.

(9) para mí lo más complejo es que es algo invalidante ” (for me, the more complex is that it is something debilitating) (M22)

The verb “to cut” was highlighted concerning “menstruación” since it is a different way of characterizing pain. One patient used this verb to describe how the menstrual pain felt inside.

(10) “es un dolor que tú sentís como que te están cortando por dentro” (it is a pain that you feel like they are cutting you inside) (M06)

The relationship with the verb “to cut” agrees with Semino, (2010) that pain is characterized metaphorically as a discomforting experience, construed in the form of the result of the pressure exercised by a sharp object. It is also a similar metaphor that women used in Bullo (2020), which was “stabbing,” in the study focusing on the English language.

Table 4
Word2Vec Most Similar Terms to “menstruation”.

Keyword	Most similar terms from Word2Vec model
menstruación (menstruation)	abundante (abundant), hueso (bone), hemorragia (hemorrhage), doloroso (painful), cortar (to cut) , anticonceptivo (contraceptive), tremendo (huge), durar (to last), severo (severe), sangrar (to bleed).
regla (menstruation)	abundante (abundant), empezar (to begin), desmayar (to faint), mes (month), doloroso (painful), oportunidad (opportunity), sabi (lemma of “to know”), invalidante (debilitating/disabling) , durar (to last), típico (typical).

3.4. The experience of endometriosis pain

Endometriosis pain has particularities in how patients and doctors perceive it. Our processed data for this part of the study had only the sentences where “pain/pains” occurred. By performing the coding of the data, we found nine semantic domains on how patients talk about pain. These are detailed in Table 5.

First, pain intensity is the most cited, accounting for 41% of the occurrences. Patients describe the severity of pain with adverbs like “mucho” (much) or adjectives like “intensa” (intense) or through metaphors and comparisons. Again, metaphors that refer to sharp objects are present (“punzando” which means “stinging”). The normalization of pain comes in second with 14%, when the patients talk about negligence in their diagnosis or even lack of support from their social environment. Details about treatment (e.g., the drugs they take and the frequency of pain) are in fourth, with 10%.

The pain associated with the menstrual cycle is present in 7% of the cases, being common in the segment of the narrative where women refer to when they first experienced symptoms. The category of when a patient associates a feeling with experiencing pain is tied to menstruation. Usually, the feelings are negative when the patient is not aware of the disease, turning into relief when they get the diagnostics and a feeling of strength when the disease is finally under control. The pain location is in 5% of the descriptions, with many reporting backaches, stomachaches, and even bone pain. Other symptoms of endometriosis comprised 5%, like fainting or developing acne. The last category, impact, refers to the

Table 5
Semantic Domains of Experience and Proportion in the Corpus with Examples.

Semantic Domains	Description	Example	Proportion
Intensity	On how intense the pain is	“y eran dolores así como como que te estuvieran punzando” (and they were pains like they were stinging you)	41%
Normalization	When doctors, family or the society in general normalized the patients’ condition	“me dijo que el dolor era normal” (s/he said the pain was normal)	14%
Treatment	When the patient cites surgeries or doctors’ appointments	“tomaba muchos medicamentos para el dolor” (I took many drugs for pain)	10%
Frequency	On how often the patient experience pain	“estuve varios meses como manejando el dolor” (I was for several months handling the pain)	10%
Menstruation	When pain is associated with the menstrual cycle explanation	“los dolores menstruales que son como lo más clásico” (the menstrual pain that are the most classical)	7%
Feeling	When the patient associates a feeling towards the pain	“porque te sentí mal porque es tan íntimo el dolor que sentí ” (because you feel so bad because it is so intimate the pain you feel)	7%
Pain Location	Description of where in the body the pain is felt	“como que de alguna forma ese dolor empezó a ser más dolor lumbar” (like somehow this pain started to be more lumbar pain)	5%
Symptom	Description of other symptoms of endometriosis	“me desmayé de puro dolor” (I fainted of pure pain)	3%
Impact	how endometriosis limits their movements or daily activities	“no puedo levantarme estoy con dolor de ovarios” (I can’t get up, I have ovaries’ pain)	3%

limitations that the pain imposes on women's lives, for example, a series of physical constraints (not being able to get up from bed, exercise, go to school, or work).

The excerpts exemplify how the subject of pain leads to other themes and gains other tones, not always related to the physical pain itself. The journey of a patient with chronic pain involves not only the symptoms but also the constraints it imposes. Other impacts that concern their life quality and social experience are intrinsic and develop pre- and post-diagnosis.

4. Conclusions

Data from interviews is usually the raw material of qualitative analysis (Creswell, 2009). However, with the help of mixed methods, we identified some patterns that may have been overlooked from the exclusive use of manual qualitative inquiry in the description of endometriosis by patients. The implementation of a more innovative methodology proved to be useful to our objective, the description and interpretation of the data provided by these Chilean women, allowing us to detect certain discourse strategies that may have been otherwise ignored. These include, for example, referential strategies that refer to certain actors who are usually disregarded in studies on health communication, such as the school. It seems that in the Chilean context, the role played by educational contexts may be of high relevance, particularly in the pre-diagnosis stages.

The usage of these linguistic tools has also proved useful for the triangulation of our data with that from previous research. For instance, in line with Bullo, (2018) findings, the way that endometriosis patients describe pain is associated with metaphors like "stabbing" and "knives." Along these lines, the informants in our study also reported the "cutting" pain. Unfortunately, the incapacitating effects of the condition appear not to be related to contextual aspects, as they have been proved to exert a serious impact on the women's life quality regardless of their origins and residence site.

When we explored terms related to endometriosis, we found that endometriosis has several meanings for these patients. They reveal the need for more information about endometriosis, reporting that the current information is scarce and scattered. A demand for having more disease awareness in society is also a highlight of the terms studied in this work. Also, they refer to the process of investigating the disease (trial-and-error), until they find a specialist. The complicated journey of diagnosing the condition is an issue that we can extract from this analysis.

We also highlight that the need for information for high school teachers is alarming since the early detection of the condition may determine a much better life quality for the patient and even the possibility of motherhood. This finding is particularly revealing for policymakers, teenage and early-adulthood health practitioners, and educators in general, who need to become aware of the prevalence and severity of the condition, and of the need and relevance of early detection.

Another result that should not be underestimated refers to the patterns of pain normalization detected in our corpus. It constitutes another serious matter that requires consideration by various social actors. In the case of chronic illness patients, the normalization of their suffering brings about serious consequences. It leads doctors to send patients home, but on the other hand, it also forces patients to endure pain. Following this discursive line of argument, the patient seems to be expected to embrace the symptoms and get along with them without complaining. This is not only insensitive but also abusive on the part of any society.

Being a condition characterized by high incidence but frequently ignored, endometriosis requires specific action in the form of laws to protect those who suffer it, as in the case of other chronic conditions such as cancer, HIV, diabetes, or many others, even with lower incidence. Systematic and recurrent awareness campaigns are called to offer

information to many sectors, including high school educators and doctors. This is key to an early diagnosis; initiatives like guidelines for physicians to recognize the discourse construction of pain in their interactions with patients may be beneficial in the diagnosis.

One limitation of our study was not having interviews with Chilean doctors, to understand their perspective on the disease in the country. Also, we did not have access to any patients' records, which would allow us to perform some cross-data analysis. Furthermore, we interviewed each patient only once. Another round of interviews would be interesting to confirm our first takeaways, and to have the interviewees more familiar with the process of being recorded.

Though much has been done to assist women in modern society in several arenas, the results of our study have shown that when it comes to women's pain, gender bias is still an obstacle to obtaining appropriate treatment. Further studies may help refine the identification of some linguistic features that could contribute to a more subtle indication of the forms in which pain is linguistically encoded, thus raising awareness and a deeper sense of humanity towards those who suffer.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Data Availability

The authors do not have permission to share data.

Acknowledgements

This research was funded by FONDECYT Grant 1240097 Discurso y Salud: Las patologías crónicas y el dolor asociado a partir de las voces de pacientes y profesionales de salud. We would also like to thank the participants who took part in our study and the comments we received from the editor and anonymous reviewers.

APPENDIX

Questionnaire

1. Personal Demographic Information.

Could you tell me something about yourself? [age, occupation, family composition, level of formal education].

[Interviewer's information as a way of interpersonal approach].

2. Information about the Disease.

"This interview is being conducted because you volunteered as someone suffering from endometriosis."

Have you been diagnosed with endometriosis? When and how did this happen?

3. Pre-diagnosis Stage.

3.1. How much time passed between the moment you realized something was wrong and the actual diagnosis?

3.2. When did you realize that what you were experiencing wasn't normal? What made you realize that what was happening wasn't normal? How long did you experience menstruation-related issues before seeking help?

3.3. Did you find information about what was happening to you? In school, with friends, colleagues. Did you search for information on the internet?

3.4. Were you ever embarrassed or did you find it difficult to talk about your menstruation?

4. Diagnosis.

4.1. What was the process like until you were finally diagnosed? How was the journey to the diagnosis? How did you feel during this process?

4.2. Do you remember the moment you were diagnosed? What

exactly were you told about what was happening to you? How was the illness described? Were you informed about the potential consequences? [Did you seek a second opinion?].

4.3. What information were you given about the treatment?

5. Post-diagnosis Stage.

5.1. How did you react to the diagnosis?

5.2. What treatment were you advised? How did you react to the treatment? Did you undergo it? Why or why not?

5.3. Were you given sufficient information about the treatment?

6. Living with Endometriosis.

6.0. [If you experience pain, could you describe it?].

6.1. What does endometriosis represent in your life? How do you see yourself in relation to the illness? How do you feel as a person with endometriosis?

6.2. Do you feel in any way that illness controls your life? How?

6.3. What have been, overall, the effects of the illness on your life?

6.3.1. What is the impact on your work?

6.3.2. What is the impact on your social life?

6.3.3. What is the impact on your family life/with your partner?

6.3.4. Have there been changes in how you see yourself?

6.3.5. Have you had to face economic impacts because of the illness?

6.4. What's the worst thing that has happened to you as an effect of endometriosis?

6.5. [Infertility] [If it hasn't emerged and is a concern for the interviewee] We know that 50% of infertility cases result from endometriosis. Is this a problem for you? How did you face it/will you face it?

6.6. [Hysterectomy] Is this an option you would consider? Why or why not?

6.7. What do you think people perceive about you as someone with endometriosis? Do you have any particular experiences where you felt stereotyped, rejected? How?

7. Support Networks.

7.1. Do you sometimes feel alone?

7.2. What is your main support?

7.3. In what aspect of your life do you feel unsupported? [work, information, healthcare system, family].

7.4. Do you feel supported by the healthcare system?

7.5. Are you in any support group, on a Facebook group, participating in an internet forum? Do you engage in activities related to the illness? Do you feel it helps? Do you think it's worthwhile?

7.6. What advice would you give to a woman suffering from endometriosis or suspects she has it?

8. Overall Evaluation.

8.1. What would you have liked to be different? What should have been different in your journey with endometriosis?

8.2. Have you experienced anything positive related to endometriosis?

Research data

Due to the sensitive nature of the questions addressed in this study, interviewees were assured data would remain confidential and would not be shared.

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