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The *existential itinerary* of the person with lupus, as a tool to humanize clinical diagnosis**

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Vania, Mexican, nursing graduate and person with lupus, kidney transplant, in her participation in the Mexico City International Marathon. Photo: Laura Athie

Background

One of the biggest challenges facing **systemic lupus erythematosus (SLE)** in Latin America is **diagnosis**. Thus, information, access to timely and adequate medical services, and timely doctor-patient communication is vital. For this reason, this research aimed to analyze the **identity reconfiguration of the person with lupus** based on the characteristics and discursive **patterns of language through the doctor-patient dialogic relationship**, as well as the discourse generated in health spaces, and social and institutional relationship.

The uncertainty of lupus, as a disease, goes beyond the medical discourse and the discourse of the sick person. In the case of this disease, there is no single diagnostic test that allows confirming or ruling out the diagnosis, so it often lasts four years and even longer. This disease is so unpredictable that it not only disrupts the emotionality of the "patient" but also of the doctor who is forced to give the diagnosis, since the symptoms tend to be different in each person, without the necessary conditions for it to be accurate. For this reason, **the diagnosis is named as a "calvary"** by those who give testimony for this investigation. Thus, from the definition that patients give of their medical journey before and after being diagnosed, the concept is defined: **"Existential itinerary of the person with lupus".**

The main objective is to determine, from the critical analysis of autobiographical discourse and autoethnography, the possible discursive profiles of people with lupus, so that their autobiographical views provide lines to potentiate clinical diagnosis and doctor-patient communication.

Methods

The design of this research is quasi-experimental of a longitudinal type, which implies **having followed up groups of people with lupus and people diagnosed, from 2015 to 2022**. The approach was given through two information gathering techniques: autoethnography and **22 in-depth interviews** (children and adolescents, families, doctors, associations), with an instrument of semi-structured questions. **The sample was observed, during 7 continuous years.** Finally, the analysis includes medical documents and a **digital survey answered by 330 people from Mexico, Latin America and the Caribbean, the United States, and European countries.**

Table 1. General sociodemographic characteristics of people with lupus who answered the online survey

Women	Men	Education level	Geographic location
98.1%	1.9%	Doctorate/PhD: .30% Complete mastery: 7.27% Truncated mastery: .30% Mastery on course: .30% Complete postgraduate: .90% Postgraduate truncated: .30% Complete specialty: .30% Complete bachelor's degree: 42.42% Degree in progress: 3.33% Truncated degree: 6.36% Complete technical career: 12.72% Technical career cut short: .30% Complete business career: 2.42% Complete baccalaureate: 13.33% Truncated baccalaureate: 1.81% Current high school: 2.42% Completed secondary: 14.24% High school in progress: .30% Truncated secondary: .90% Complete primary: 1.51% GBS in progress: .30% Ongoing studies (not specified): .60%	**Respondents by country:** Argentinian (21) Bolivian (3) Chili (11) Colombian (11) Costa Rican (3) Cuba (2) Ecuador (3) Spain (15) Guatemalan (3) Lime (5) Mexico (241) Peru (3) Uruguayan (2) USA (3) Venezuela (4)

Mexico and other countries

* Socioeconomic level was not asked. Source: self-made.

Of the people who responded to the online survey, 2.72% (9) stated that they had a diagnosis of 5 to 10 years, 36.06% (119), having been diagnosed for more than 10 years, 21.81% (72), more than a year with diagnosis and 38, 11.51% being newly diagnosed.

Six discursive moments (plots) in which the identity of the sick self is fragmented

a. **Fear:** the arrival of the disease
b. **The search:** self-diagnosis
c. **Uncertainty:** the diagnosis
d. **Fear:** the possibility of dying
e. **Degradation:** the consequences of a self that degenerates
f. **The agency:** A chance to become different but better

Results

The analysis made it possible to **delimit the relationship between emotion and discourse throughout the disease**, before and after diagnosis, from both positions: the one that diagnoses and the one that receives the news of the disease. Based on these samples, observations and interviews, a discursive corpus was concentrated that allowed the derivation of **"Itineraries",** that is, transits of the self in accordance with the existential Itinerary of the sick person and analysis categories using the Grounded Theory methodology.

In contrast to the aforementioned typologies, based on the findings of this research, the following Itineraries emerge with visible traits in their narratives and actions, and which, because they are part of the lupus community, have a particular vocabulary, that is, they belong to a sociolect and handle an idiolect linked to the disease. **The itineraries are organized as follows:**

Before the diagnosis: a) "The invincible", a self of the woman who complies; b) "The redeemed", the self of the woman who punishes herself. **After the diagnosis:** c) "The patient", a self that has learned to accept herself, d) "The anti-heroin", a tired self, e) "The uncertain", an indecisive self, f) "The immutable", a self that remains. And finally, **an archetype:** "La Guerrera/The woman Warrior", the self that breaks barriers.

These Itineraries define, in each person, an **existential Itinerary,** that is, **a journey observed through the analysis of autobiographical discourse, in which the sick person searches** —throughout his visits or medical stays, analysis, emotional disagreements, rejections, moments of discrimination, operations, violent, unequal treatment or mistreatment by members of the medical service, damage to their organs, impossibility of becoming pregnant or fetal deaths and failed diagnoses...— the certainty of knowing exactly what disease they are suffering from, as well as the right to receive an accurate diagnosis and treatment.

Conclusions

No one is free from identity fragmentation but they are free from exercising awareness towards the other. Communication between doctors, health personnel and sick people can be enriched by what is found here. **The medical position requires recognizing the knowledge of those who live and suffer from the disease.** The diegesis of those who call themselves lupus provides not only methodological analysis tools, useful for locating moments of agency, but also possibilities of working around the profiles of those who suffer, which will allow building bridges so that diagnoses and treatments are assumed and supplied from more human perspectives.

Presenters:

* **Laura Athie**, main autor. PhD student of the ICSyH of the BUAP and co-director of LEM: Center for the Production of Readings, Writings and Memories. Master in Educational Policy from IIPE UNESCO in Paris. Specialist in Education from IIPE Buenos Aires and FLACSO Mexico. Communicologist from the UABC. Diploma in Narrative Therapy from ILEF. Since 2006 he has been documenting, disseminating and researching the testimonies of people with lupus, he has been an activist for the disease since 2000. This poster is part of his doctoral research: ***Counternarratives to discursive violence: The case of people with lupus***, completed in March 2023 .

* **Maria Cristina Manzano-Munguia**. co-author. Research professor of the Postgraduate Course in Language Sciences at the ISCyH BUAP, member of the SNI Level 1. She directs Laura Athié's thesis: *Counternarratives to discursive violence.* Ph.D. in Anthropology, Western University, Ontario, Canada; M.A. Anthropology, University of Guelph, ON, CA. and Graduate in Anthropology, UDLA. He has received multiple awards and published articles and books on Chinese in Puebla, Transnationalism, Mexico, USA and Canada Border, Aboriginal Population, First Nations, Indigenous diaspora, inclusion and exclusion, precarious work.

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