Gendered Career of Lupus in El Salvador: The male cases

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Abstract

Despite increasing prevalence, lupus in the Salvadoran context continues to be rendered invisible—occurring in the show of other more prominent autoimmune diseases such as cancer and HIV/AIDS. In El Salvador, there are two patient advocacy foundations dedicated to lupus, and it is not uncommon to hear members complain that lupus is considered "the cancer of the poor” and a “woman’s disease.” Drawing on and substantially revising Goffman’s concept of "moral career,” I argue that the gendered trajectory of the lupus patient in El Salvador, characterized primarily by diagnostic and prognostic ambiguity, is particularly useful for understanding the labor involved in the individual management of lupus, which in turn has the potential to guide the bureaucratic and biomedical diagnosis and provision of care in both institutional settings and domestic environments or la casa, understood not only as physical space, but also as a place where networks of care operate and challenge biomedical imperatives. I examine the feminized trajectory of the disease as something that impacts the experience of the male lupus patient, who in the case of El Salvador is associated with a high mortality rate that comes from a late diagnosis. Attending to lupus in terms of structures and norms that impact the experience of patients with lupus in their daily life, I examine practices of self-medication, self-diagnosis and self-care that foment disruptive and tense relationships between those diagnosed with lupus and those who provide medical care.

Keywords: lupus, self-medication, gender, social sciences.

Resumen

A pesar de su creciente prevalencia, el lupus en el contexto salvadoreño continúa siendo una entidad invisible, eclipsada por la presencia de otras enfermedades autoinmunes como el cáncer y el VIH/SIDA. En El Salvador, existen dos fundaciones de pacientes con lupus, y no es raro escuchar a sus miembros quejarse de que el lupus se considera "el cáncer de los pobres" o una "enfermedad de mujeres". En base al concepto de Goffman sobre "carrera moral", y, a través de una revisión sustancial a la literatura, se argumenta de qué manera la trayectoria de género del paciente con lupus en El Salvador es caracterizada principalmente por la ambigüedad diagnóstica y pronóstica; esto fue particularmente útil para comprender el trabajo de autogestión del lupus, que a su vez tiene el potencial de guiar al paciente en contextos burocráticos-biomédicos y la prestación de atención tanto en entornos institucionales como en el ámbito doméstico, o “la casa”, entendida no solo como espacio físico, sino también como un lugar donde operan redes de cuidado que desafían los imperativos biomédicos. En este espacio se examina la trayectoria feminizada de la enfermedad como algo que impacta la experiencia del paciente masculino con lupus, quien en el caso de El Salvador está asociado a una alta tasa de mortalidad derivada de un diagnóstico tardío. Al abordar el lupus en términos de estructuras y normas que impactan la experiencia de los pacientes en su vida diaria, se exploran las prácticas de automedicación, autodiagnóstico y autocuidado, las cuales fomentan relaciones disruptivas y tensas entre las personas diagnosticadas y los proveedores de atención médica.

Palabras clave: lupus, automedicación, genero, ciencias sociales

Background (from biomedicine)

From the biomedical perspective, systemic lupus erythematosus (SLE) is an autoimmune, chronic, and systemic disease characterized by affecting organs (Bernal-Macías *et al.*, 2023). Currently, the etiology of SLE is considered very complex, with a multifactorial origin described, including genetic predisposition, hormonal changes, and environmental exposures ranging from smoking to ultraviolet radiation (Colombian Association of Rheumatology, 2023).

Clinical manifestations occur in episodes of relapse or lupus activity and also remission episodes. Commonly, these episodes involve the compromise of various organs, for example, the kidneys (Bernal-Macías *et al.*, 2023). The evaluation of lupus activity is in three major dimensions: quality of life, overall assessment, and assessment by specific organs. Like other autoimmune diseases, lupus is a multifactorial disease with a complex etiology, and its diagnosis and prognosis can be very ambiguous. The comprehension of lupus demands knowing its biological and physiological bases, but also the subjective experience, in order to comprehend the impact that lupus has on the social lives of those who suffer from it.

In Latin America, the estimated average rate is one rheumatologist per 106,838 habitants. With the highest rate in Uruguay (one rheumatologist per 27,426 inhabitants) and the lowest in Nicaragua (one rheumatologist per 640,648 inhabitants) (Colombian Association of Rheumatology, 2023). For El Salvador, considering data from 2021 census by the World Bank Group and the number of 19 rheumatology specialists, the estimated rate is one rheumatologist per 332,324 inhabitants (World Bank Group, 2021; Martelli, 2023, slide 18).

Lupus in the Salvadoran context

My work started in 2015 when I got a call to be part of a team of professionals for a caregiver seminar. From that moment I felt the need of research on lupus disease, since I saw discrimination, mistreatment by the professional team and a derogatory attitude from professionals to patients and their caregivers, as well as abandonment and a huge gap in knowledge from the social sciences, I realized that most of the studies conducted refer to the patient’s experience in a rheumatic context, while the lupus patient is a *polipaciente* and usually is polymedicated (polypharmacy), a very different and complex experience which ranges from the interaction between different medications, their pharmacodynamics and pharmacokinetics, to the economic and personal impact that this has on a Salvadoran. As I studied the documentation on lupus epidemiology, a peculiar observation emerged: the elevated mortality in groups of vulnerable patients. These individuals were not necessarily older or very sick; the contributing factors were mainly sociocultural. Among them, delayed diagnosis played a significant role, particularly within one of the less explored populations: male lupus. This is a part of my PhD dissertation.

Studies in El Salvador observed unfavorable prognoses, with a particular emphasis on men, who accounted for 63% of the mortality index. This data is termed "a prognosis of controversial nature". The primary causes of death in men associated with lupus in El Salvador are the inherent activity of the disease and renal failure and cardiovascular issues (García & Sermeño, 2008). In my country Lupus has been labeled as a women's disease. This has led to various phenomena, such as delayed diagnosis and poor adherence to treatment among men, who may even go unnoticed by the healthcare system as lupus patients.

Currently, despite the absence of studies or statistical data given the government's confidentiality politic to share and provide access to information since 2020, most of the statistics came from a private university, they said that there has been a sustained increase in lupus cases from 2020 to 2022. In 2022, the age groups most affected were those between 20 and 59 years old, with older adults experiencing more severe manifestations affecting a more significant number of organs (Ingrid Martelli, personal communication, May 17, 2023).

Minorities among minorities

Through my work conducted by participant observation and a series of ethnographic interviews, I examined the feminized trajectory of the disease as something that impacts the experience of the male lupus patient, who in the case of El Salvador is associated with a high mortality rate that usually comes from a late diagnosis. Attending to lupus in terms of structures and norms that impact the experience of patients with lupus in their daily lives, I examined practices of self-medication, self-diagnosis, and self-care that foment disruptive and tense relationships between those diagnosed with lupus and those who provide medical care.

It was usual to find in the men's discourse the high consumption of anti-inflammatories and pain pills especially ibuprofen and dexketoprofen, this is done through the constant practice of self-prescription and self-medication, and to maintain active and with longer duration the spectrum of the maximum drug concentration; therefore they tend to increase the dose with some frequency. It is curious that the literature mentions that one of the causes of death in male lupus is associated with renal disease, and both drugs mentioned are associated with damage and failure in the kidneys. This type of practice increases when it comes to maintaining a status or performance at work that denotes strength. And there is also the fact that not all people with lupus have skin manifestations where the disease can be easily identified. Eritema Malar, despite being one of the main characteristics that are socially linked to the disease, is not present in all cases. In my experience, in fact, after nine years of studying lupus from social sciences, I have never seen a case where is presented.

Regarding the understanding of lupus from the perspective of those who suffer from it, it is essential to mention Ann Miles' book titled "Living with Lupus: Women and Chronic Illness in Ecuador." This work synthesizes the symptoms and afflictions of Systemic Lupus Erythematosus (SLE) in Ecuadorian women and delves into the challenges and constraints associated with the lupus condition. The book elucidates some repercussions regarding the relationship between lupus and gender. It explores how gender expectations, gender-based discrimination, and the roles assigned to women or men impact their lives (Miles, 2013; Charmaz, 2018).

Concerning studies on lupus and gender, there is a common disparity in findings regarding male lupus, which represents a minority among diagnosed cases. Nevertheless, a few researchers have focused on better understanding this condition in men. Sequeira Santos *et al.* (2018) did a review of the literature on male lupus, highlighting gender differences in clinical presentation, diagnosis, and treatment. The study underscores the impact of hormonal and corticosteroid treatments on the male population, particularly in the bodily changes that some men may assume or perceive as feminine.

During my work, it was very common to find men expressing fear of any type of treatment involving the word hormones or steroids. Phrases like I'm going to look like a woman or you know what that does to you, there is no cure (referring to the possibility of feminizing their body and also their sexual preference). In their own words, it was preferable to make eggs or to have eggs compared to being under treatment, and also, to always maintain the hope of having a disease other than lupus, even after several years of being diagnosed.

This seems controversial but is reinforced by the fact that in El Salvador there are cases of people who have been diagnosed and treated for more than 15 years and then realize that they never had lupus.

Nusbaum *et al.* (2020), reviewed the literature on male lupus, specifically systemic lupus erythematosus. The authors noted that male lupus is characterized by lower prevalence, delayed diagnosis, and a higher likelihood of mortality compared to female lupus. An exciting aspect highlighted in the text is how mortality in men with lupus is not necessarily due to more significant complications in organ deterioration but instead to delayed diagnosis compared to women (Nusbaum *et al.*, 2020). Another investigation into male lupus was conducted by Izmirly *et al.* (2021), who, through scientific studies and the analysis of 3,468 cases of men with lupus, determined that the average age of diagnosis for male lupus is 39 years (10 years older than in women). Similar to the studies mentioned earlier, mortality from lupus is higher in men than in women. While the article begins by focusing on gender differences in the disease, one of its significant contributions is the reflection on late diagnosis, often influenced by gender constructs where men do not seek medical attention until their condition gets worse (Izmirly *et al.*, 2021).

In this regard, the discourse that men maintain about the differences is consistent with the aforementioned literature. They mention that indeed, the consequences of living with lupus disease are even worse in men, but not because of the intrinsic characteristics of the disease but because of what is expected of them by society. Salvadoran culture demands that men show physical strength superior to women and emotional fortitude, an unwavering composure in any situation that not only allows him to navigate in life (as a man) but also to create an atmosphere of protection and strength for the people around him. Therefore, the disease and the treatment of lupus not only has the capacity to generate biological alterations, but also a fortitude idea.

Between poor people's cancer and woman's disease

Despite the increasing prevalence, lupus in the Salvadoran context continues to be invisible — to explain it, people tend to use the metaphor of other more prominent autoimmune diseases such as cancer and HIV/AIDS. In some papers in Latin America they call it *un cancer pero más pequeño* (cancer, but a smaller one)—. In El Salvador, there are two patient NGO´s dedicated to lupus, and it is common to hear members complain that lupus is considered the cancer of the poor and a woman's disease. Drawing on Goffman's (2001), concept of moral career, I argue that the gendered trajectory of the lupus patient in El Salvador is characterized primarily by diagnostic and prognostic ambiguity.

I also focused my study on understanding the role of a person who is sick or who suffers from an illness, but also on understanding the disease from a cultural and social expression. When it comes to lupus, in that role, a series of meanings emerge from different social actors such as patients, caregivers, and health teams. These meanings are usually about the body, illness, and health restoration, as well as care received in different contexts (Fábregas, 1976; Martínez, 2008; Kleinman, 1988; Singer, 1995, 2019).

Despite a series of criticisms, the ideas of Talcott Parsons in 1951 still provide a notion of how the sick person has a role that faces a series of social norms that are created and maintained by a political, economic, cultural, and social system, and some of those norms affect and impact the experience of patients with lupus in their daily life (Parsons, 1999). In this regard, Parsons (1999), mentions that "the sick role is a socially defined role, and those who occupy it are expected to act in certain specific ways" (p. 244).

Regarding the concept of moral career, Goffman's ideas became helpful in approaching the trajectory of the patient with lupus in El Salvador, which as I said before it is usually characterized by diagnostic and prognostic ambiguity. This is a trajectory traveled by those who consider themselves patients in a medical and health service. In some cases, especially in the public health system, a person might take up to 11 months to get a doctor’s appointment, and a medical test, and the results up to 6 or 10 months. It is curious how the printed result becomes a category of achievement, a category that is often undervalued by the clinical professional leading the patient to have a negative idea of the medical staff and in many cases to express less motivation to continue with the medical treatment or the diagnostic process (Di Giacomo, 2013; Fábregas, 1976; Goffman, 2001; Mattingly, 1988; Kleinman, 1988).

The daily life of the man with lupus is altered by a need to demonstrate that his strength and fortitude remain intact. At this point it should be taken into account that the majority of cases are not necessarily middle-class men with stable jobs, medical insurance or decent transportation. On the contrary, the cases mentioned and referred to which I am referring are men who have street sales, who often survive by selling sweets and barely have any type of education beyond the first years of school. Their constructions about work revolve around dignity --- and seeing their work threatened by an illness with an ambiguous diagnosis and reserved but disabling prognosis is a total threat to their way of life. It is common for them to employ a religious discourse (based on faith) where the possibility of a cure through a miracle is generated.

Apart from institutionalized spaces such as health care centers —mainly hospitals and doctor's offices— another space was considered, the home or *la casa*. La casa is seen as a healthcare space understood "not only as physical space, but also as a place where human and significant networks are linked, and where there are other levels of care, such as family and friends that influence the forms of care and also caring" (Molina Aguilar, 2022, p. 110). Regarding lupus disease about the role of the individual in terms of the home and the participation that the community has, la casa is considered a space of resistance, a space where sometimes medical knowledge is rejected regarding lupus disease, in fact, it decentralizes that knowledge and creates other ways of managing the disease. Sometimes creating a disruptive and tense relationships between those diagnosed with lupus and the medical professionals.

Finally, *la casa* is where important decisions are made and where more studies are necessary (Molina Aguilar, 2021). The doctor's or pharmacist's discourse is decentralized at home, the diagnosis is assimilated and potentially dismissed or reaffirmed at home, and in the same place (home), it was common to find a large number of medications that come from the public and private health care system of El Salvador. This phenomenon is seen as important due to the lack of regulation in pharmacovigilance, the lack of presence of health pedagogy and the lack of interest in educating the population about the management of medications at home since most national frameworks cling to punitive discourse, precisely by ignoring everyday reality and the spaces where people carry out their activity.

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