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Agency of people with lupus from an editorial platform: Lúpica Magazine

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Background

In the face of late diagnosis, misinformation and the social invisibility of lupus, the *Lupica* magazine approach encourages the active participation of people with lupus in generating questions linked to their interests and in creating educational content designed for the community. This case analysis shows how women and men with lupus generate robust content, learning experiences, and visibility of the disease. This leads to conscious, proactive and dialogic agency.

Objectives

Develop an editorial device to encourage people with lupus to take agency in the following areas:

- Collection and dissemination of reliable information.
- Formalization of the dialogue of clinical and experiential knowledge.
- Documentation of social processes and recording of the contemporary realities of the disease.
- Generating stories that go beyond the testimonial phase and position themselves as expressions of learning.
- To structure a plural, civic and human memory of lupus in Mexico with an international perspective.

Methods

The magazine edited by Cetlu — digital, downloadable, and free — seeks to document the realities of lupus and build a collective memory from a social perspective. To achieve this, it is developed through a training process for patients para they engage with doctors, specialists, and families desde una perspectiva analítica, reflexiva y con sentido documental. This case analysis shows how women and men with lupus convened to conduct interviews, articles and reflective-experiential accounts with the accompaniment of an editorial team generate solid content, learning experiences and visibility of the disease. This also lead to a conscious, proactive and dialogic agency.

To this end, people with lupus and their companions are invited to conduct interviews, to be interviewed, to relate their life experiences and to give an account of the many ways in which the disease is lived. Thus, it is they who, accompanied by an editorial team specialized in knowledge management, make visible the multiple spheres of the disease: medical challenges, development of public policies, contextual frameworks, social incidences, exemplary practices and symbolic experiences. This allows the identification of the configuration and reconfiguration of the imaginary around the disease. In this way, lupus is approached as a social issue in which the labor, affective, educational, political and amorous intersect.

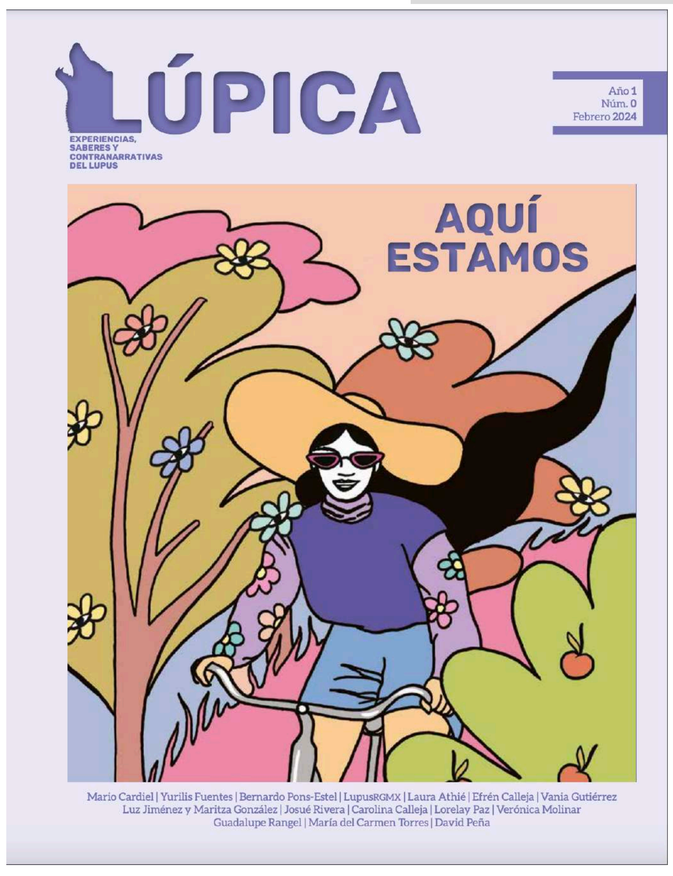
Results

Lupica magazine is an editorial device that triggers empathetic and revealing dialogues between researchers, physicians, people with lupus and companions to provide information, knowledge, experiences, perspectives and horizontal confluences for the benefit of all communities immersed in the lupus universe. This is possible thanks to the conscious taking of agency by women and men with lupus who decide to take action to generate knowledge, reflection and visibility of the disease.

Conclusion

The processes of accompaniment for the taking of agency of people with lupus makes possible the development of discursive devices that amplify the dissemination of the disease from research, challenges, proposals and challenges of the multiple epistemic and experiential territories that interact in the universe of lupus. *Lupica* is proof of this.

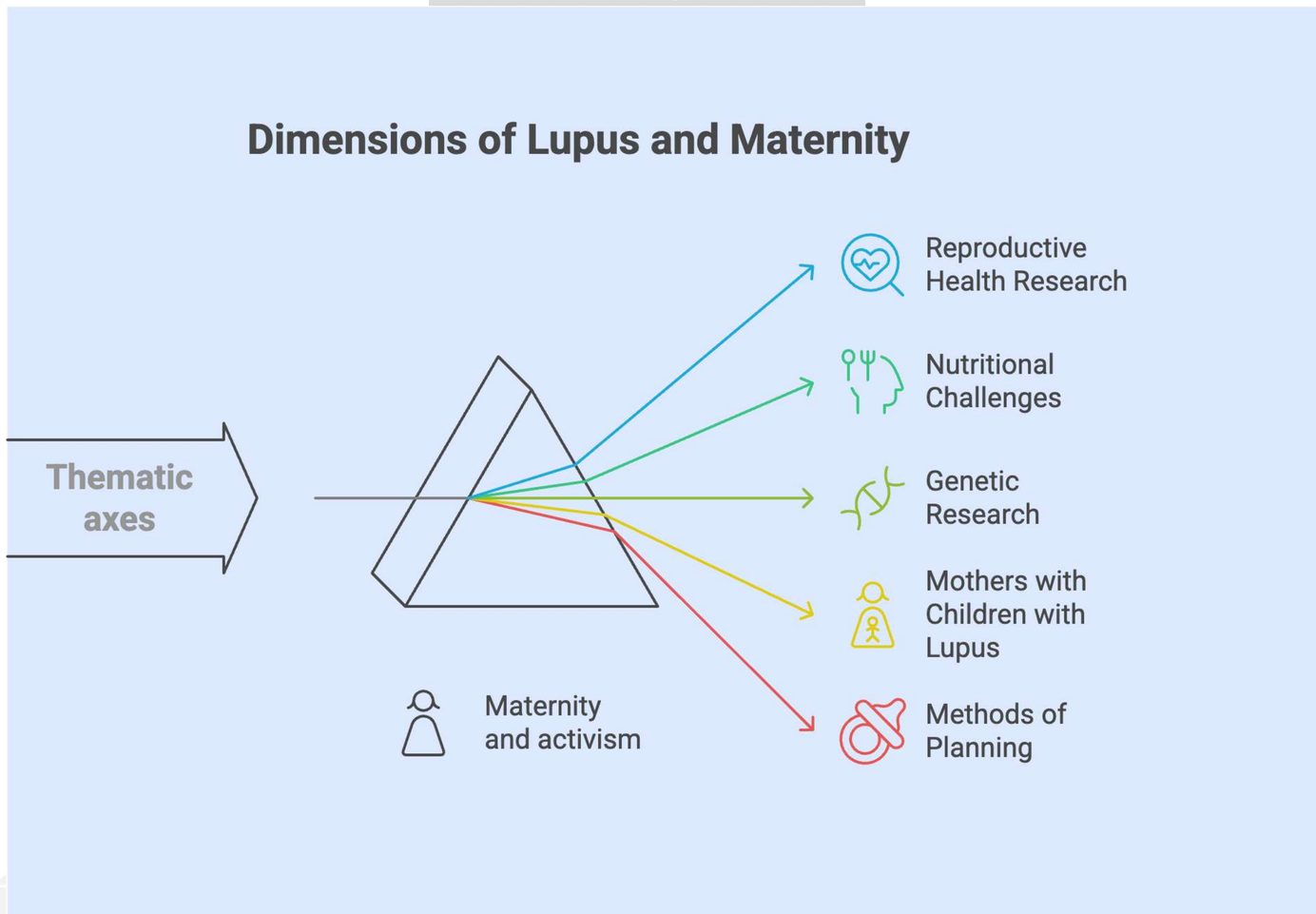
Downloadable PDF



On-line version

	Country	Active users
	Total	5,945 100% of total
1	Mexico	4,261
2	United States	664
3	Chile	227
4	Colombia	93
5	Argentina	83
6	Peru	81
7	Spain	73
8	China	44
9	Germany	42
10	Sweden	33

Edition in process



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