



We Strive and We are Brave: A book to Measure the Identity and Narrative Epicenters of People with Lupus

Dr. Efrén Calleja Macedo, Dra. Laura Athié

Athié-Calleja Transdisciplinary Studies Center for the Rights of People with Lupus A. C. [Cetlu]

EULAR Presentation 2122

Source:

Bamberg, Michael, ed. (1997). Positioning between structure and performance. Journal of Narrative and Life History, 7(1-4), 335-342.

Introduction

Whoever receives the diagnosis of lupus becomes a patient with a chronic, degenerative, incurable disease of autoimmune origin. In addition, it begins the immersion in a sea of speeches that will forever shake the sense of existence.

Objective

Through autobiographical writing, and the review of the self, identify the way people assume their illness and they journey before and after the diagnosis of SLE.

Methods

- Autobiographical narrative writing.
- Work with drawing and self-image.
- Critical discourse analysis.
- Organization in seven chapters that show the stages and protagonists of the disease:

1. Trace Back the Diagnosis (Direct Routes / Disoriented Routes)
2. Living Between Remission and Bursting (Tense Calm / Everyday Shocks)
3. Reconstitute yourself from all the daring (Vitalistic Processes / Thorny Courses)
4. The Wolf in Men
5. Companions of Crossing
6. Decalogue for the Rights of People with Lupus
7. Patient Associations and Facebook Groups in Latin America and USA

Results

Based on the pedagogical power of the testimonial, this book **contextualizes, dimensions and makes visible the life journeys with lupus** in order to establish a social diagnosis, call for community shelter and build bridges between science and the experiential knowledge of the sick person.

This testimonial tissue establishes a narrative chorus that provides emotional radiographics and insurgent writings; it establishes the need for public policies and the reduction of social violence; it demands discursive democracy and the renewal of the vocabulary to refer to people with illnesses; it broadens the fields of academic study and **widens the possibilities of better encounters between those who have medical knowledge and those who possess experiential knowledge.**

Testimonials are the heart of a narrative organism that illuminates multiple domains and **establishes itself as a social diagnosis that can support a comprehensive understanding of identity changes in people with lupus and strengthen quality of life and adherence to treatment.**

Conclusions

- This book allows us to identify, categorize and analyze:
- when and how people with SLE are transformed throughout their lives.
 - what are the stages that, from their own autobiographical testimonies, have helped them to move forward.
 - the community perspective and the power of support groups in the most critical stages of the disease.
 - symbolic episodes that exemplify the changes in the identity of people with lupus and the way they identify themselves at each stage.

