Discoursive Memory and Perception of Lupus in Children, Adolescents, and Young People: Identities and Treatment Adherence

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INTRODUCTION

Lupus is a complex, multisystem autoimmune disease that significantly disrupts the lives of children and adolescents. There is limited data on the relationship between the physical and emotional impact on young patients and its effects on family dynamics, including the imposition of new roles and responsibilities that foster stigma and secrecy around symptoms, posing challenges for healthcare providers. This study explores how children and young people face, remember, and perceive lupus from childhood to adolescence, and how these factors shape their identity, influence their future outlook, and impact treatment adherence

AIM

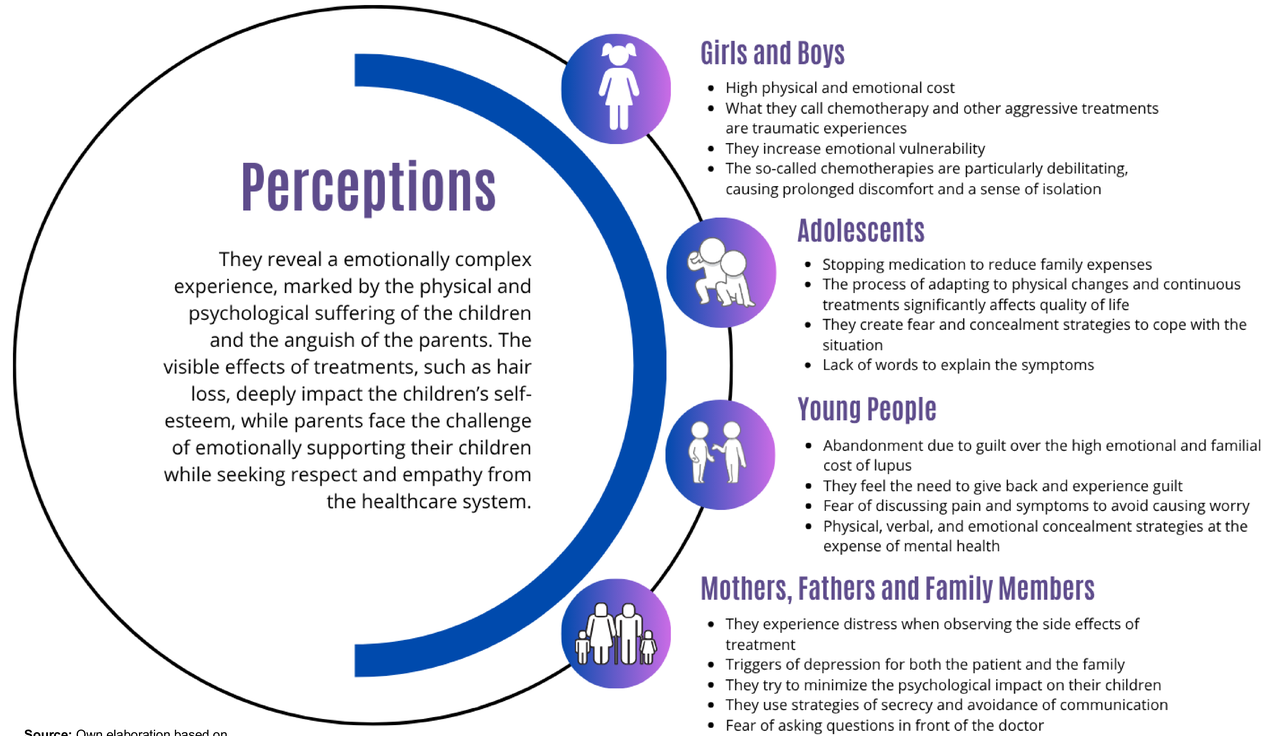
To explore the perceptions of children, adolescents, and young people with lupus regarding treatment adherence, identity, unrevealed perceptions in social and healthcare contexts, and the impact of the disease and treatments on their interpersonal dynamics.

METHOD

Mixed-methods study (quantitative/qualitative) conducted through in-depth interviews, digital surveys, and ethnographic follow-up from 2015 to 2024. From a corpus of 352 testimonies collected in Mexico and other countries, based on an eight-year continuous observation, 12 cases of Mexican families with children aged 11 to 20 living with lupus were selected. These cases were used to develop focus groups and self-representation exercises. The analysis includes cases of heritability (e.g., two children with lupus or a mother and child with SLE). The testimonies were analyzed from a narrative perspective, emphasizing discursive strategies for concealing symptoms and perceptions. A corpus of texts and drawings created by children and young people was recovered, illustrating the impact of SLE on their daily lives.

Figure 1. Perceptions of Medications and Treatments in Children, Adolescents, and Families with Lupus

In many cases, neither lupus nor its symptoms are openly discussed, resulting in a form of communication based on social and medical omission. The sick child is idealized as a figure of strength. Lupus strengthens family bonds but simultaneously imposes a heavy emotional burden. Young people experience identity fragmentation, leading to feelings of guilt over the resources allocated to their treatment. Silence about pain and avoidance of discussing lupus within the family are common strategies to prevent emotional trauma **(see Figure 1).**



Source: Own elaboration based on Athié (2023) and Denzin (2014)

RESULTS

The results show that children and adolescents with lupus tend to assume a role of "responsibility" regarding SLE, minimizing the emotional impact it causes them. Their narratives focus on physical damage, while families often conceal the severity of the situation or silence their own fears **(see Table 1)**. Parents view the disease as a burden that affects the entire family, leading to feelings of guilt.

Table 1. Secrecy Strategies in Families with Children Living with Lupus

Discursive Strategy	Description
Not Naming or Silence	They are rooted in the fear or uncertainty stemming from the sense of not meeting the expectations required to cope with the disease.
Scarcity of Words	There is a scarcity of words to name the condition of the disease and explain its symptoms.
Normalized Violence	Between parents and children, this is evident in the usurpation of turns: the mother answers for the child or interrupts to impose what "should" be said. The child is prevented from explaining their symptoms and perceptions.
Structural and Discursive Violence	It is exercised by healthcare institutions, hindering the fluidity of explanations about the disease.
Avoiding Naming the Disease to Protect Emotions	Both the child and the parent are protected, as the latter tries not to show weakness by avoiding tears or visible fear. What is happening is not named. Concealment arises from shame.
Secrets About the Disease	They become evident through verbalized and non-verbalized signs, revealing the relationship between emotion, memory, and epiphanies in identity changes.
Defensive Discursive Behavior	Parents divert attention from what is left unspoken. They avoid explaining out of guilt.

Source: Own elaboration based on Athié (2023) and Denzin (2014)

CONCLUSIONS

The findings reveal forms of secrecy, self-identifications, and future perspectives linked to treatments. The study emphasizes the importance of understanding SLE as a phenomenon that deeply impacts identities. Family secrets and reluctance to speak openly about the disease are common, which hinders treatment adherence. This report underscores the importance of health intervention strategies that take into account the emotional and familial dimensions in managing lupus during childhood, adolescence, and youth.

REFERENCES

BAMBERG, M. (Ed.) (1997). *Positioning between structure and performance*. Journal of Narrative and Life History, 7(1-4), 335-342.

CARDIEL, M., *et. al.* (2018). *Therapeutic Guidelines for Latin American Lupus Patients: Methodology*. Journal of Clinical Rheumatology, 24(1), 41–44.

DENZIN, N. (2014). *Interpretive Autoetnography*. (Vol. 17). Second Edition. Sage University Paper. University of California.

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