



## Editorial

# Editorial comment: The patient's view about the article: Lupus "A mildercancer" - the perception about systemic lupus erythematosus by adolescents close to transition<sup>☆</sup>



## Comentario editorial «Desde la mirada del paciente» acerca del artículo: Lupus «Un cáncer pero más chiquito» Percepciones del lupus eritematoso sistémico en adolescentes próximos a la transición

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The survival of patients with systemic lupus erythematosus (SLE) has been improving over the last few decades and this reality requires us to address the transition from pediatric to adult care.<sup>1</sup>

Patients must be prepared for this transition process. A way to assess the level of readiness, from the quantitative analysis perspective, is through the administration of questionnaires such as the *Transition Readiness Assessment Questionnaire* (TRAQ) which was recently adapted and validated in Spanish (Argentinian version),<sup>2</sup> assessing 5 areas or domains: Managing Medication, Appointment Keeping, Tracking Health Issues, Talking with Providers, and Managing Daily Activities.

However, although the results of the questionnaires give us some guidance regarding the level of readiness, they are not enough to understand the life experience and the knowledge patients actually have about their disease; therefore, it is absolutely necessary to have the patient's view.

In this regard, the quality of life surveys try to capture the global impact of the disease on the life of patients. In particular, adolescents with jSLE have shown low scores in the domains of physical health, self-esteem, and academic performance.<sup>3</sup>

Nonetheless, in order to have a complete picture of the situation, the patient's perspective is missing; to close that gap we have qualitative studies to bring us closer to that reality.

Learning about their experiences and special needs will help in delivering the appropriate care to meet their requirements to achieve a better quality of life and a more harmonious transition.<sup>4</sup>

Already in 2015, Howland and Fisher<sup>5</sup> published an article describing the results of interviews to teenagers with juvenile idiopathic arthritis, using an interpretative phenomenological analysis. In this study, the most important factors for patients were: the impact of the disease on their daily life, the emotional factors, social life and seeking autonomy.

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The article by Hernández et al.,<sup>6</sup> which is published in this issue of the Colombian Journal of Rheumatology, highlights the importance of considering the perception of patients with respect to their disease - in this case lupus - when preparing to plan for the transition.

The authors of this study were able to identify 3 fundamental categories that summarized concepts, knowledge, and concern of the adolescents interviewed, with the regards to the slogan "living with lupus". The first category "trying to explain the origin" assembles the interpretations about the causes of the disease, the impact of the diagnosis, and makes analogies to other diseases. The second category: "What you miss" with regards to body image, limitations, and relationships with peers. Lastly, the third category: "Positive aspects" refers to acquiring self-care habits and stronger responsibility with regards to health.

Qualitative studies from the Anglo-Saxon literature have also dwelled on the effect of lupus on the life of patients. Tunnicliffe et al.,<sup>7</sup> through the analysis of semi-structured interviews and focus groups with Australian teenagers, identified 5 key items of which the concern about their labor, academic and family future was one of the most frequently mentioned.

It is essential to have publications of studies conducted in Latin America, which consider the viewpoint of patients and their families, within their own cultural framework, in order to be able to plan a transition that is consistent with their particular needs.

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