



Abstract

Reference Models for Children and Young People with Epidermolysis Bullosa: First Case Report on the Protective Factors and Challenges for Psycho-Social Maturation and Resilience [†]

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Abstract: Epidermolysis Bullosa (EB) is a chronic disease with multiple clinical presentations, depending on the subtype. It is characterized by the structural fragility of skin and tissues which results in lesions. Its low prevalence contributes to the lack of knowledge of the disease by the general population and the health sector. The disorder's heterogeneity adds challenges in describing psycho-social affectations. Therefore, our current international project searches for reference models for children and young people with EB, as well as the elaboration of a guidebook with different life stories for them to learn about skills and strategies proven to help to achieve personal/professional success despite the EB condition. In the present work, a qualitative and phenomenological interview with Karen Puga, an expert adult patient with dystrophic EB from Mexico, explored several social dimensions/ages affected in EB and their impact on self-esteem. The semi-structured interview depicted several life events and experiences related to her psycho-social maturation that the patient identified as the most negative or positive. The most severe obstacles were experienced during childhood in the scholarly scenario. However, some of those classmates later became friendly adults, providing evidence of the temporality of some adverse life events and the relevance of maturation and resilience processes, both of herself and her counterparts. Her parents' professional profiles (nurses) and the essential role of her sister were described as foundational for her well-being and self-esteem. Multidimensional understanding of affective relationships, sexuality, and positive engagement in professional activities illustrated the development of positive dimensions of her adulthood despite the complexity of psycho-social factors in EB.

Keywords: reference models; Epidermolysis Bullosa (EB); rare diseases; expert patient; dystrophic epidermolysis bullosa (DEB); storytelling; successful cases; classmates; family; sisterhood; affect; sexuality



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Institutional Review Board Statement: The study was carried out following the deontological standards recognized by the Declaration of Helsinki (52nd General Assembly Edinburgh, Scotland, October 2000), the Standards of Good Clinical Practice, and complying with current legislation and current Spanish legal regulations that regulate research, and clinical practice in humans (Royal Decree 1720/2007 that develops the organic law 15/99 and Law 14/2007 of Biomedical Research). The research had the approval and review of the Associació Envellir bé—Healthy Aging.org, Barcelona, Spain, 20 November 2020.

Informed Consent Statement: The objective of the research was explained to the participant, who gave her informed consent to the protocol and the interview.

Data Availability Statement: The information generated in this study has been considered strictly confidential between the participating parties. The data will be protected from uses not allowed by people outside the research, and the confidentiality of the same will be respected in accordance with Organic Law 15/1999, of 13 December, on the Protection of Personal Data and Law 41/2002, of 14 November, basic law regulating patient autonomy and rights and obligations regarding information and clinical documentation.

Conflicts of Interest: The authors declare no conflict of interest.