

# 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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### INTRODUCTION

- ❖ Epidermolysis bullosa (EB) is a chronic disease with multiple clinical presentations depending on the more than 30 subtypes, characterized by skin and tissues structural fragility resulting in lesions [1].
- ❖ The low prevalence contributes to the lack of knowledge of the disease by the general population and the health sector. The disorder's heterogeneity [2] adds challenges to describing psycho-social affectations [3,4].
- ❖ An inverse correlation between disease severity and quality of life in patients and their families has been described [5].
- ❖ Psycho-social aspects in people with more severe subtypes of EB and body dysmorphism refer to loss of self-esteem and coping skills, low self-control, intense fear, anxiety, depression, and social isolation [3-6].
- ❖ On the other hand, acute, chronic and procedural pain, common comorbidities in EB [7-9] and anxiety can negatively affect cognition and interfere with academic and professional achievements (see Sciforum-063422).
- ❖ The need of reference models for children and young people with EB is specially important with regards to identifying protective factors and challenges for their psycho-social maturation and resilience, the aim of the present work.

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### AIMS

Here, we present the first case report on protective factors and challenges for psycho-social maturation and resilience, and as the second (see Sciforum-063422) of a current international project that searches for reference models for children and young people with EB and the creation of a guidebook with different life stories of strategies and skills proven to help achieve academic/professional success despite EB's condition..

### METHODS

**Participants:** Inclusion criteria was to be a patient with EB according to the consensus reclassification of EB [2], the will to participate, to be an adult or minor with informed consent from parents to be interviewed and to use the written and image material for scientific purposes and divulgation. Exclusion criteria was to be unable to be contacted or interviewed or to sign informed consent for the above issues.

**Data recording:** After informed consent, the participant was interviewed by two clinical researchers in Medical Psychology and Psychiatry from the Universitat Autònoma de Barcelona.

**Data analysis:** The transcript of the semistructured qualitative and phenomenological interview was assessed using qualitative content analysis.

### RESULTS

After considering several candidates according to the inclusion/exclusion criteria, one adult (woman) with Recessive dystrophic epidermolysis bullosa (RDEB), the most severe form of EB [8] from DEBRA Mexico Monterrey, Mexico was contacted. This second participant to be involved in the project was Karen Puga Rivera. Several idiosyncratic characteristics made her eligible as the first case report for protective factors and challenges for psycho-social maturation and resilience. As in the previous case report (see Sciforum-063422) she can be considered an expert patient, as in terms of health education in chronic diseases, an expert patient can be defined as the one that is motivated, knows, searches and accepts help to care him/herself and is confident to be able to do it [10]. She also presents RDEB involving the most complex clinical and psycho-social scenario. She played the role of expert patient as a member of Debra Mexico Monterrey with peers and schoolers. In the present work, several social dimensions/ages affected in EB and their impact on self-esteem were explored. The semistructured 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 scholar 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 stones of well-being and self-esteem. Multidimensional understanding of affective relationships and 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.



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