

Childhood and subjective timings: growing up with hemophilia

Silvia Grases
Psychological Service



Fundació Catalana de l'Hemofília - Associació Catalana de l'Hemofília
Via Laietana, 57, 1^o 1^a 08003 Barcelona www.hemofilia.cat sgrases@hemofilia.cat



The diagnosis of a coagulopathy gives rise to a series of phenomena that a hemophiliac child may experience with his body. In other words, hemorrhaging, pain, functional limitations and even the treatment for hemophilia in the sense that all of this involves manipulating the child's body.

The child experiences this phenomena in his body from a very young age, without being able to speak about it. The diagnosis of hemophilia for the child always comes, therefore, after his own experience. This is a priority and forces the child to embark on a psychic or subjective journey relating to everything that happens to him. Therefore, questions arise from this phenomena in his body: What is this? Why is it happening to me?

The experience related to the body, the diagnosis of hemophilia and the adults' explanations share a subjective journey of building a life with hemophilia. This way is specific for each child, because it's not about completing standard phases, but rather "subjective or logical timings." Each child will use elements from his own experience to create explanations about hemophilia and also to find his own way of dealing with it.

Knowing that hemophilia for a child is, above all, an experience, understanding the ways in which children deal with this experience, the questions they ask themselves and how they manage to form their own explanations can all help parents and professionals to understand better the child's hemophilia experience and accompany them along this journey from childhood to adolescence.

In col-laboration with:

