

Input of a multidisciplinary management approach in announcing the diagnosis for young children with serious constitutional hemorrhagic disease and their families

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INTRODUCTION

Hemorrhagic diseases have numerous consequences for patients and their families including: well-being (Evans et al, 2000), quality of life (Cassis et al, 2012) and adherence to treatment (Weiss et al, 1991; Llewellyn et al, 2003). A specific therapeutic support initiative, based on a multidisciplinary partnership between different health caregivers, patients, their families and members of the French Hemophilia Society has been assessed at the Hemophilia Treatment Center (HTC) in Marseille (France). Starting at the announcement of diagnosis, patients and their families have access to pediatricians and psychologists as often as required, as well as to a specific therapeutic education program and psychomotor workshops.

HYPOTHESES AND EXPECTED RESULTS

Hypotheses:

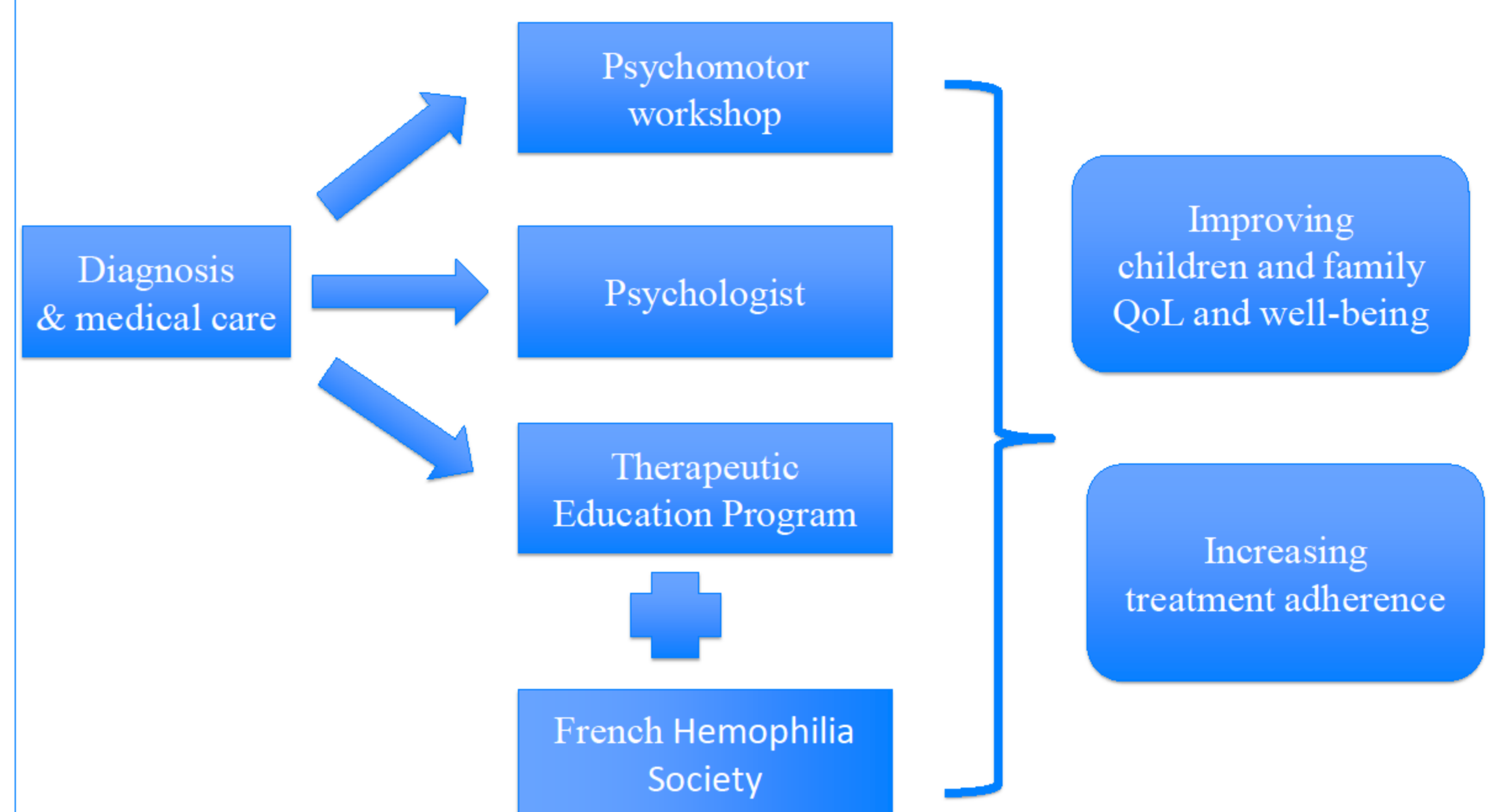
Active participation in the therapeutic setting from the announcement of diagnosis would improve well being, the likelihood of adherence to treatment and quality of life (QoL).

We expect to establish a link between the participation in the partnership with the HTC and well being, adherence to treatment and quality of life.

Involvement in a multidisciplinary therapeutic support could:

- lead patients to feel secure
- give better understanding of their disease
- demonstrate the necessity of targeted treatment(s)

Multidisciplinary therapeutic setting



PATIENTS & METHODS

Participants: 30 children fulfilling the inclusion criteria age from 3 to 12 years old, suffering of hemophilia, severe forms of factor VII or factor XIII deficiency, von Willebrand disease type 3 or Glanzmann Thrombasthenia, and who have been diagnosed at the HTC in Marseille.

Measures:

- Child Behavior Checklists (CBCL; Achenbach, 1991): inventory assessing emotional and behavioral problems of children and adolescents. Parents form (children from 1.5 to 18 years) and self report form (from 11 to 18 years). Figure 1.
- The Body Mapping Test-Revised (Fauconnier et al., 2009): the patient is instructed to draw a little man, then to do jigsaws; one of a man's face, the other of his body. To complete the task the patient has to redraw the little man. Figure 2.
- Questionnaires: Qualin (Manificat et al, 2000), Kidscreen 27 parents and children version (Ravens-Sieberer et al, 2007), and SF36 (Leplege et al., 1995)
- Adherence is measured by collecting data from the records of the HTC.
- Semi-structured interview: subjective perception of the parents about their child's disease and its consequences from the announcement of it.

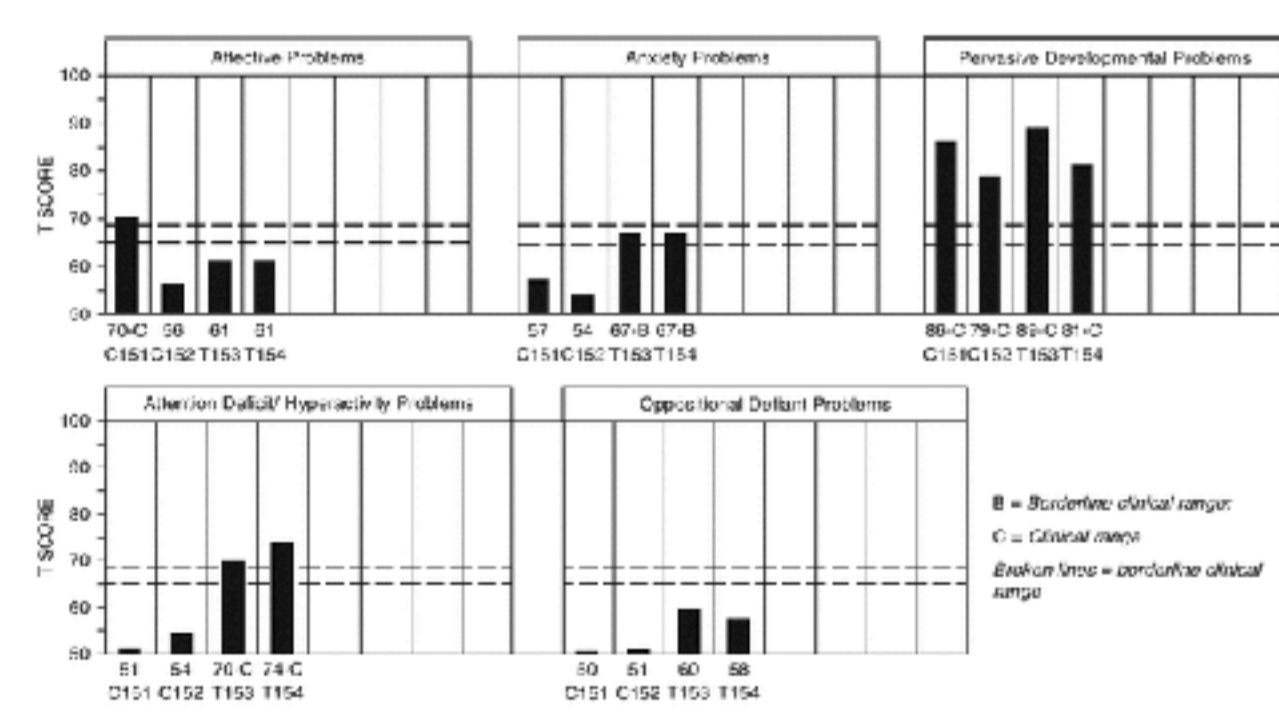


Figure 1. CBCL parents form: Internalisation and Externalisation scores.

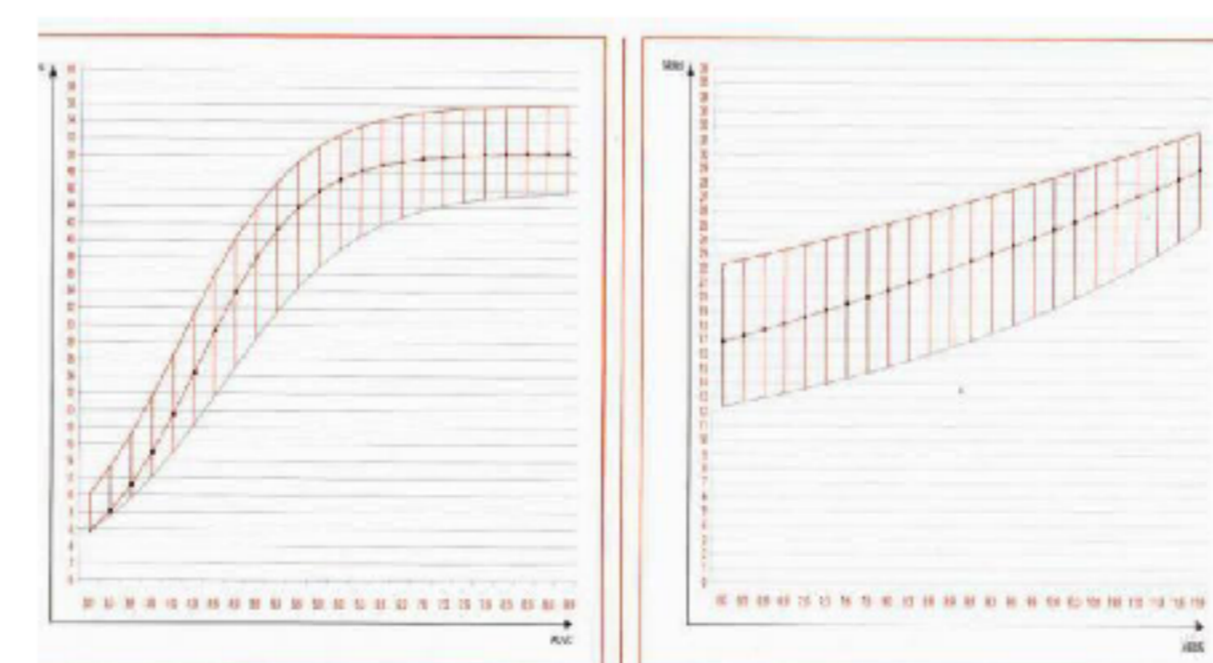


Figure 2. The Body Mapping Test-Revised: Developmental Age

CONCLUSIONS

If this kind of therapeutic support is shown to be relevant it will significantly impact in a positive manner on the well-being of patients and their families and could be extended to other French HTCs.

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