

DISCOVERING HEMOPHILIA

INTRODUCTION

Therapeutic education is intended to help patients acquiring and maintaining the skills they need to optimally manage living with their disease and thus improving their quality of life.

In hemophilia, it is important that young children can describe and above all alert their parents at the time of the first signs during a hemorrhagic stroke. However, when children are very young, it may be difficult for them to talk about their disease, their feelings, perhaps because of the lack of words and knowledge but also because of the fear of what is happening to them.

Acquiring and maintaining the so-called safety skills seems therefore a priority. However, their modes of acquisition must take into account the stage of cognitive or psychomotor development of 3-4-year old children and their degree of independence. The learning process must be progressive, increased over the years so that acquisitions are strong and long-lasting.

At the CRTH of Dijon, therapeutic education sessions on the « discovering the disease » have been implemented for young children from the age of 3 years. The aim is to enable them developing at an early age their knowledge on the disease, and help them better understanding, coping and managing living with the disease, and therefore being actors of their management.

OBJECTIVES

The primary objective is to enable 3- or 4-year old patients with hemophilia to know their body (joints, muscles...) and to better understand what happens during a hemorrhagic episode.

Indeed, it is essential that they note that something unusual, « abnormal » is happening in their body: the pain, a difficulty to mobilize a joint or limb and thus that they warn their parents at the onset of the signs to limit the number of injections.

This learning process will also enable them to gain confidence regarding their disease since their word and feelings will be considered by the adults.

Attending group sessions also enables patients to talk on their experience. It is a free speech unrestrained by the parent presence.

Children become aware that they are not the only one having this condition unlike at school in particular.

These sessions could also help improving the discussion with the parents, siblings but also with caregivers at home through the tools used.

RESULTS

Number of sessions carried out:

3 group sessions:

- 1- Bones and joints
- 2- Muscles
- 3- Hand hygiene

These sessions enabled young patients with hemophilia to express themselves freely on their experience of hemophilia outside the consultation and in absence of their parents. The discussion was facilitated by the use of various personalized tools adapted to their age.

These sessions also enabled setting up a different patient-caregiver relationship because they were carried out outside the medical context. Young patients, easily impressionable, saw caregivers differently which helped them to talk freely.

The topics covered during the sessions seemed to be assimilated by the 3 young patients. Indeed, these children reported more easily the occurrence of pain, impeded mobility related to the onset of hemarthrosis or hematoma. They explained their parents « how to properly wash their hands ». The link seemed to be made between what was explained and their personal history.

Group sessions helped improving the experience and providing knowledge, and had a stimulating effect on the group participants.

Children participated actively. They were happy to attend the next sessions and to meet again. They were involved in the activities proposed, they asked many questions and they made the link with their own experience of hemarthrosis or hematoma while sharing this experience with other children.

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METHODS

Age range studied: 3 to 4 years old

Patients with severe hemophilia A and B treated with prophylaxis once or twice per week (n = 3)

The session:

was carried out in group

was led by a maximum of 1 or 2 persons

lasted no more than 1h30 due to the difficulty to keep the attention of young children for longer durations.

For each session, the tool used had to:

be related to the topic selected

be playful

be manual: coloring, cutting, assembling, gluing...

be personalized to be able to identify themselves to the media

be readily brought home

facilitate the discussion with the family (parents or siblings) or caregivers after the session.

An articulated puppet was made for the topic on bones and joints in order to understand what is a joint, its role and what happens during a hemorrhagic stroke.

Children had to color, cut and assemble their puppet themselves. Then a joint was blocked using a piece of cardboard representing the hemarthrosis. Finally they all had to relate the various hemorrhagic events they had experienced. It helped assessing the degree of understanding of all children and seeing if they properly made the link between the puppet and their body.

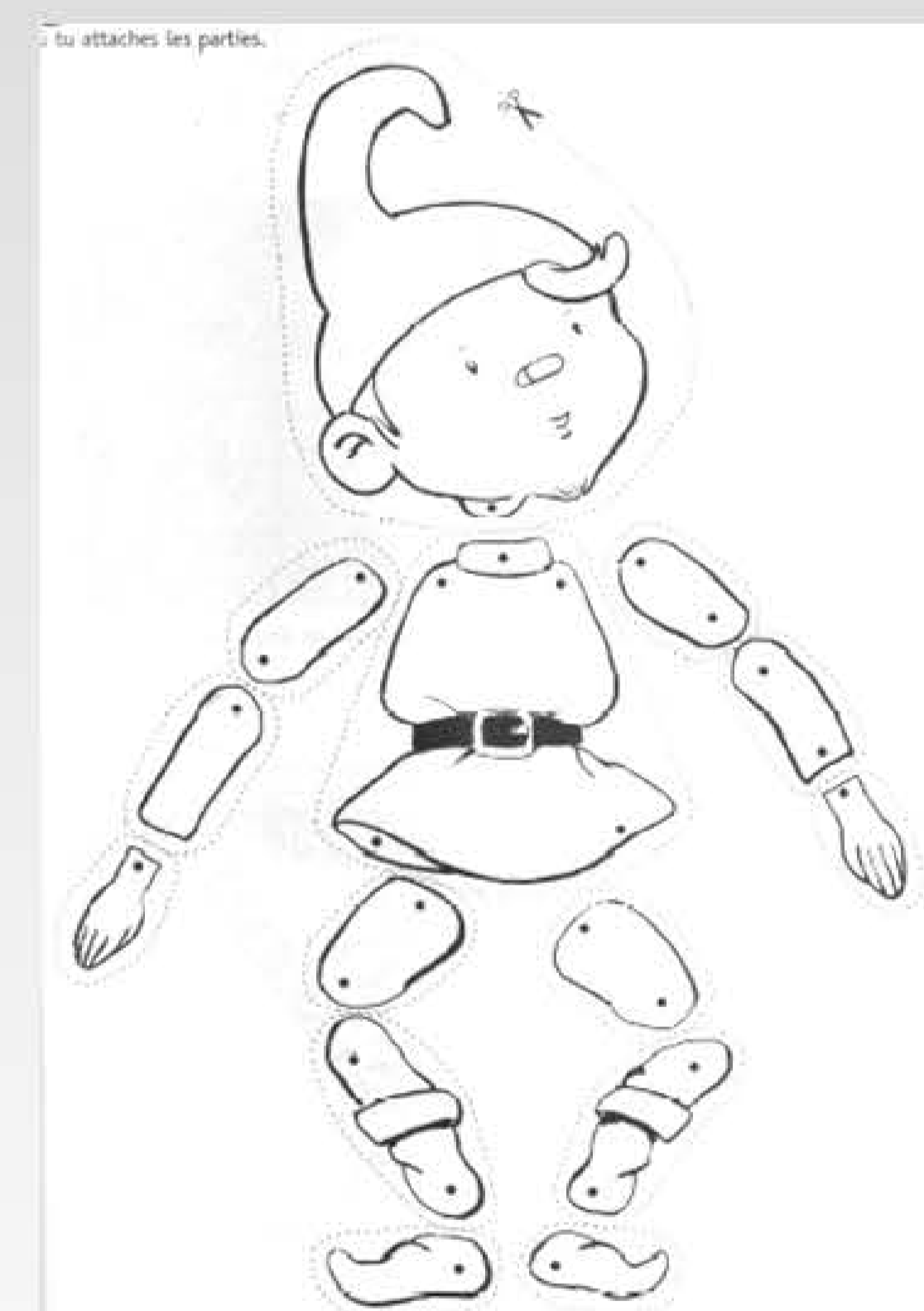
The silhouette of a young boy with his skeleton was chosen for the topic on muscles.

Children glued the muscles, heart, lungs and abdomen on the silhouette to get a representation of the body inside.

To explain muscle hematoma, a saline bag was used into which a red warm fluid was introduced. Children touched and described what they felt then they made the link with their own experience.

Hand hygiene: an activity booklet about the topic on hygiene was developed and given to each child. They had to complete the booklet throughout the discovery session: the various bacteria (their size, appearance, the good and bad bacteria), why and when to wash their hands. Then, an animation on hand washing with mild soap was proposed.

Finally, using a puppet, BAC the Bacteria, the key points discussed during the session were summarized.



CONCLUSIONS

Young children who attend the sessions are happy to come to talk about the disease, discuss with friends like them. The implementation of therapeutic education sessions enables the integration of these young patients in an evolutionary process, allowing a progressive approach of the disease. The child autonomy depends not only on their knowledge but also on the behavior of their parents and adults who accompany them as well as the degree of independence given to them in the everyday life. It is important to help children feeling less guilty with respect to the things they cannot control. Over the years, their knowledge will be further developed, improved to lead to independence at the time of the adolescence with respect to their disease and treatment.

