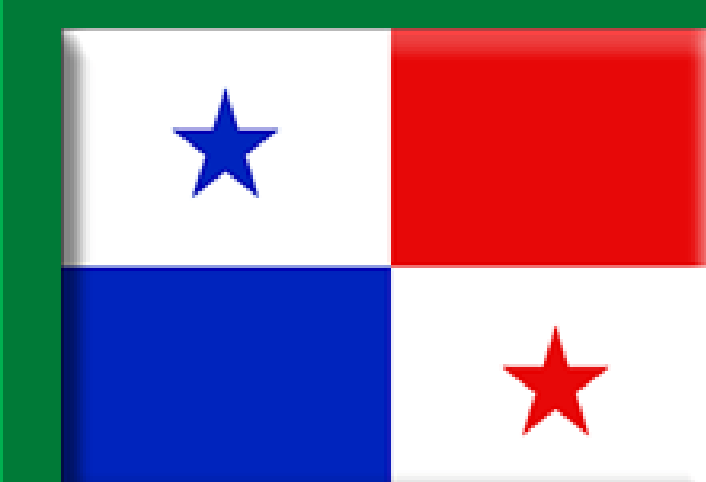


NEW EDUCATIONAL STRATEGY: " EDUCATIONAL MANUAL OF HAEMOPHILIA AND VON WILLEBRAND FOR PARENTS AND PATIENTS " IN PANAMA.



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INTRODUCTION

The personal experiences accumulated for more than 10 years in the daily lives of the parents and children with Haemophilia and Von Willebrand's disease in the Congenital Coagulopathy Clinic of Panama's Children's Hospital (Hospital Del Niño) has made it possible to offer a practical educational tool for the parents to use as a reference on the diseases and all of their basic aspects.

It was an interesting experience because the educational needs of the parents were identified, and it was also very useful as a new educational tool in the aforementioned clinic.

It is the first manual created for the parent's needs and requirements. It is aimed towards the parent's learning, which helps to improve overall understanding, to support continued learning, and to achieve that the children adjust to the diagnosis optimally: physically, emotionally and socially.

PROVED

76 % of the parents demonstrate very little knowledge on their child's disease.

Only 20 % say to know very much on their child's disease.

100 % of the polled parents demonstrated the need for an educational manual.

27 % of the parents wanted information on what activities and the daily lives of their children would be like with the diagnosis, followed by 22 % of parents that were interested in knowing more about the hemorrhages and 18 % which were interested in the medicines that their children need.

OBJECTIVE

To offer a practical tool on the basic aspects of haemophilia and Von Willebrand to parents of the Congenital Coagulopathy Clinic.

METHODOLOGY

Results were obtained through talking to parents whose children ages 0 to 13 received the diagnosis of Haemophilia or Von Willebrand's disease. Subsequently, this led to realization of the parent's knowledge of the disease at the Congenital Coagulopathy Clinic at Panama's Children's Hospital.

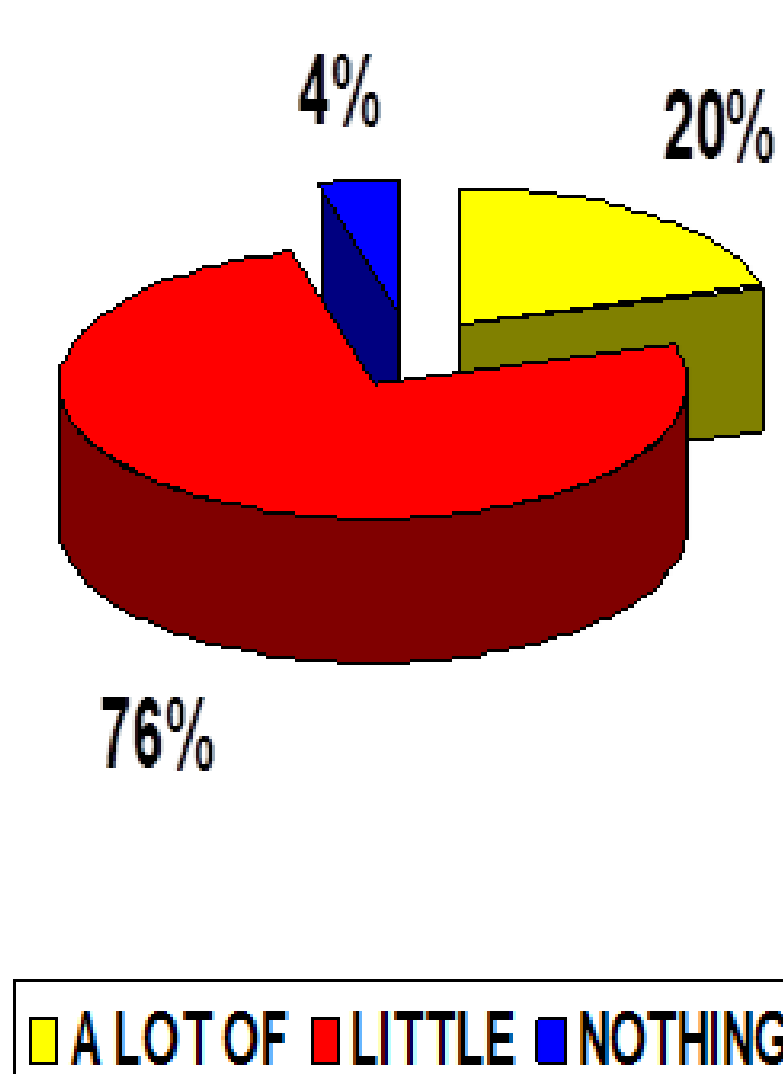
The study is descriptive, exploratory, explanatory.

With a population of 150 parents, 93 parents of children between 0 to 13 years with Haemophilia and Von Willebrand's Disease were interviewed. These families all go to the Congenital Coagulopathy Clinic at Panama's Children's Hospital.

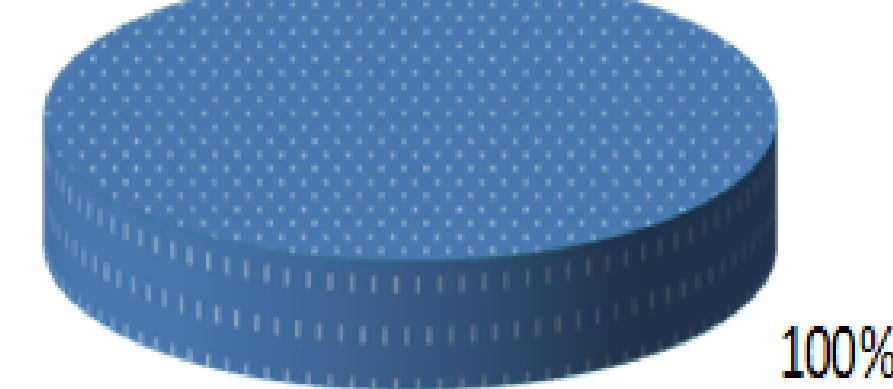
For the compilation of information, a structured interview was used: by means of a questionnaire aimed at obtaining information from the population of study.

IMPORTANT INFORMATION

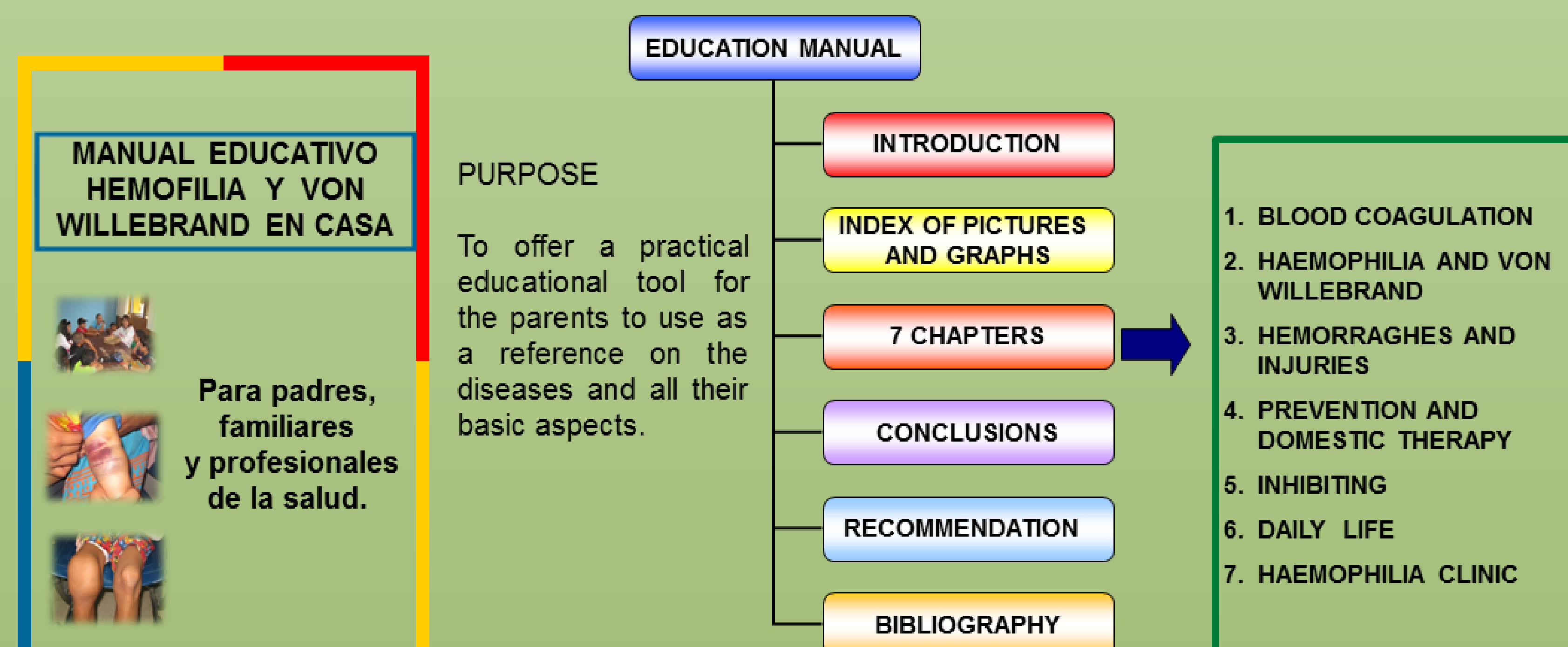
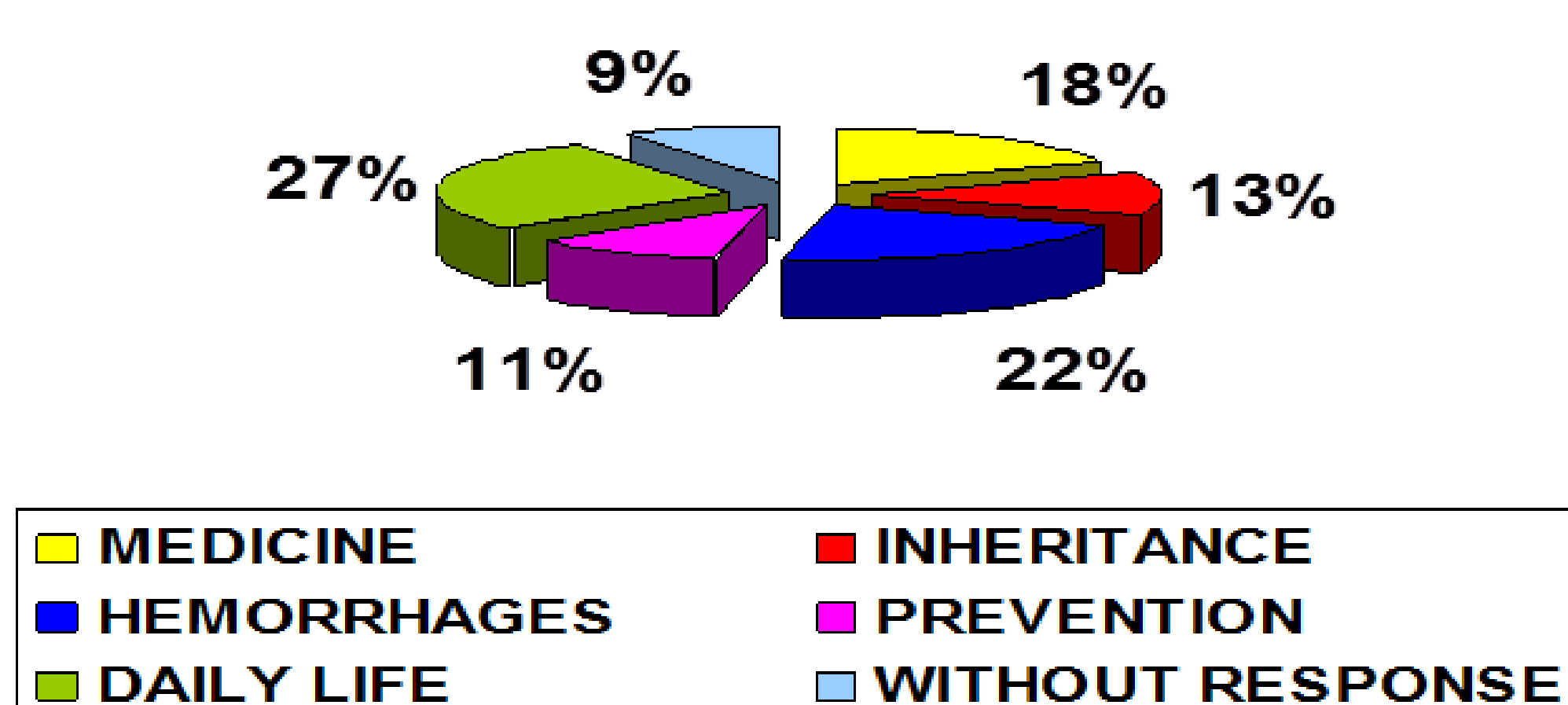
THE PARENT'S KNOWLEDGE ON THEIR CHILD'S DISEASE. 2009



OPINION OF THE PARENTS ABOUT THE NEED TO HAVE AN EDUCATIONAL MANUAL ON THEIR CHILDREN'S DISEASE. 2009.



INFORMATION THAT PARENTS WOULD WANT IN AN EDUCATIONAL MANUAL ON THEIR CHILD'S DISEASE. 2009



CONCLUSIONS

Knowledge of the parents and of their children serves as vital importance for the development and adjustment to the child's family environment, school, and social environment.

The "Educational Manual" contributes to the formation of the own capacity of reasoning and necessary skills that are a part of the competitions to face his critical situations across his life.

The production of the "Educational Manual" will help to improve overall understanding, to support continued learning, and to achieve that the children adjust to the diagnosis optimally: physically, emotionally and socially.

