How to teach children a lifetime treatment in only 10 days?

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Introduction:

Heart surgery can, in some cases, lead to a lifetime anticoagulation treatment. In our pediatric cardiac unit, Vitamine K Antagonists (VKAs) are prescribed following cardiac valve replacement and total cavopulmonary connection.

Oral anticoagulant drugs require a steady supervision. International Normalized Ratio (INR) balance is harder to obtain in pediatric population, leading to frequent dose adjustments throughout life. Therefore, a self-monitoring device is available and reimbursed for children since 2009 in France. To be sure children and their family will be able to handle this system at home, we have to teach them how to use the machine and how to live and grow up with this treatment.

Methods:

In 2008, a nurse and a cardiologist from our unit followed a specific training which allowed the medical and paramedical team to use this new device and set up an education program.

Our challenge is to educate patients and families during the few days of the hospitalization and to adapt our message to the patient age and comprehension level.

This educational program begins after discharge from ICU. The treatment, its link with the surgery and its surveillance are explained. Two days later, we show the device to the family. The nurse performs the first fingerstick test, then the parents, under nurse supervision, during the next session. The last session focuses on daily life (food, school, sports…). These interviews are evaluated and summarized in a booklet we made for the families. The parents were asked to call us or their cardiologist every time the INR was not in the range.

In 2014, a nurse followed a specific course in educational therapy which led to the implementation of a dedicated patient file for VKA education.

Results:

Since 2009, among 187 children (2-18 years) treated by VKAs after surgery in our institution, 160 were eligible for the device. For most patients interviewed, the surveillance was well understood, steady and rigorous.

Conclusion:

Our objective is to make the children and their family responsible, autonomous and confident with their treatment. This education is based on mutual trust to make life easier and safe for children under VKAs.