

Pediatric and Congenital Cardiology Department, University Hospital, Montpellier, France (1)
Pediatric Cardiology Department, Necker for Sick Children, Paris, France (2)
Epidemiology Department, University Hospital, Montpellier, France (3)

Introduction
Children under vitamin K antagonist (VKA) should benefit from self-monitoring of their International Normalized Ratio (INR). In France, since the 2008 Public Health Law, children and/or their family who wish to participate to INR self-monitoring must integrate a formalized authorized education program to anticoagulation therapy led by a pediatric cardiologist. Our national reference center for congenital heart diseases, while building this program, aimed to regularly evaluate the quality of life (QoL) of children.

Methods
All children and parents participating to our INR self-monitoring education program were invited to complete a QoL questionnaire during each group session. Generic pediatric QoL questionnaires were used (QUALIN for infants < 2 years old, PedsQL for children aged 2 to 18). Both parents independently participated. PedsQL Child self-report QoL questionnaires were used for children above 5 years, under trained nurse supervising. This study received the approval of the Ethics Committee. Relations between QoL and patients’ characteristics were studied.

Results
111 children (54 girls) participated to our INR self-monitoring program between 2010 and 2012. Indications for VKA were classical within pediatric population: valve replacement (n=47), total cavopulmonary connexion (n=33), dilated cardiomyopathy (n=13), Kawasaki disease (n=8), others (n=10). No family refused to be enrolled in this study. 476 QoL questionnaires (27 QUALIN, 449 PedsQL) were completed by 265 different persons (80 children, 107 mothers, 78 fathers), depending on the number of group sessions for each family (1 to 3). There were no significant relationships between QoL and patient's sex, type of AVK (warfarin or fluindione), number of group sessions, chronic illness duration or moment of diagnosis (prenatal or postnatal). Qol scores were significantly lower among children with congenital heart disease. Fathers and mothers’ QoL scoring are rather well correlated but are significantly lower than their child’s self-assessment.

Conclusion
Routine QoL assessment well applies to education programs with strong joining of families and children. Our center leads 5 official education programs (pulmonary hypertension, anticoagulation, transition to adulthood, pacemaker-Defibrillator and chronic cardiac failure) and aims in further studies to compare QoL of children participating to such programs to those who don’t.