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# On the use of intra-rectal valium in patients with Dravet Syndrome : family's experience

Nathalie Coqué<sup>1,2,3,#</sup>, Nicole Chemaly<sup>4</sup>, Rima Nabbout<sup>4</sup>

## Abstract

Intra-rectal Diazepam (DZ) is the first rescue medication for acute prolonged convulsive seizures in children in many countries. In this study, we aimed at assessing the experience of the families of patients presenting Dravet Syndrome (DS) with respect to the use of intra-rectal DZ.

## Situation of the problem

Intra-rectal DZ is prepared from a glass vial and pumped with a syringe that is then inserted into the rectum with or without a rectal tube. The administrator must administer the prescribed dose according to the weight of the child. We assessed different aspects of this treatment from the family's point of view.

## Methods

We sent an auto-administered on-line questionnaire to 53 families of patients with DS. Questions addressed different aspects of intra-rectal DZ use:

- usual administrators, and time required to prepare the medicine (parents or other care givers)
- facility, and risk of errors in the preparation and the administration.

Parents were questioned about their feelings concerning the efficacy and utility in emergency settings, facility of intra-rectal DZ administration, and possible refuse of care givers to use this method of DZ administration.

## Result

50 families answered the questionnaire. DZ was usually administered by mothers in 96% of cases, by fathers in 38% and less frequently by other care givers (14%). Almost all parents (78%) agreed on its efficacy. However, they found the use difficult by non-parents care givers, and that preparation and administration are subject to errors when carried out of the parents presence. Many educational and non-medical institutions refused to use DZ administered intra-rectally.

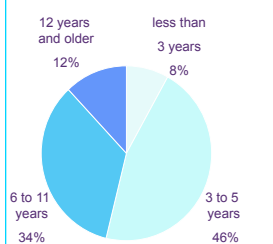


Figure 1 : Age of children included in this study

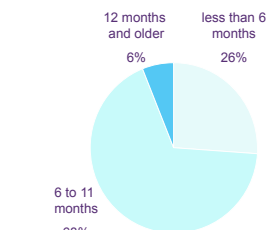


Figure 2 : Age of first intra-rectal DZ prescription

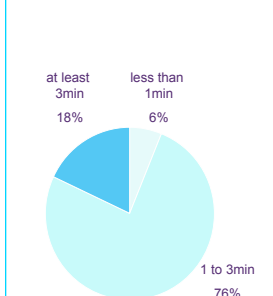


Figure 3 : Estimation of time of drug preparation by parents

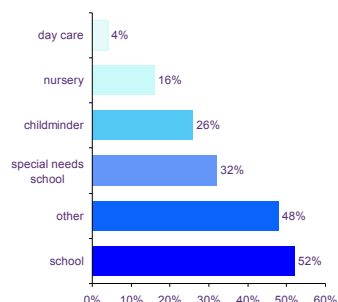


Figure 4 : Non parental administration of intra-rectal DZ

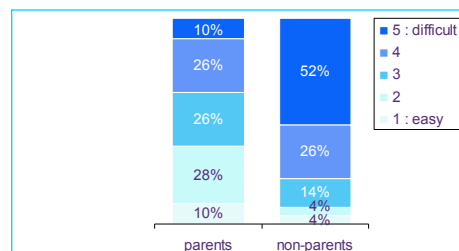


Figure 5 : Estimation of the ease of DZ usage by parents and non-parents

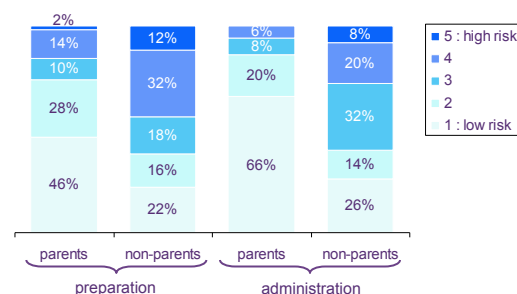


Figure 6 : Estimation of the risk of error in the preparation and administration of intra-rectal DZ by parents and non-parents

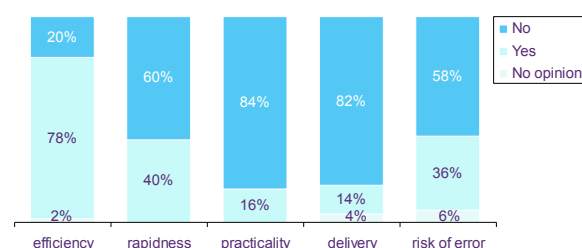


Figure 7 : Feeling of parents concerning the usefulness and the efficacy of intra-rectal DZ in emergency settings

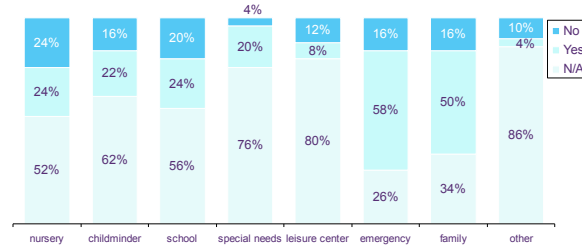


Figure 8 : Percentage of incident in which care givers refuse to use intra-rectal DZ

## Conclusion

Parents confirm the efficacy of intra-rectal DZ. However, they mention the humiliation of children and adults who are obliged to disrobe in order to receive treatment, and also the method of administration which is often considered as a medical practice by the care givers and refused by them. As such, they emphasize the need for a medication that is easier to prepare and to administer.