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# Comparative assessment of family's experience of patients with Dravet Syndrome on the use of rectal diazepam and buccal midazolam

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## Purpose

Rectal Diazepam (DZ) is the first rescue medication for acute prolonged convulsive seizures in children in many countries. Since February 2012, buccal Midazolam (MZ) was available in France with a nominative temporary use authorization. In this study, we aimed at assessing the experience of the families of patients with Dravet Syndrome (DS) with rectal DZ and buccal MZ use through a structured questionnaire. This questionnaire was administered first for DZ then adapted for MZ with a comparison between the 2 medications. Dravet syndrome is a model of choice for such study for the frequency and the intensity of acute seizures.

## Methods

We sent an auto-administered on-line questionnaire to families of patients with DS in France, in December 2011 for DZ and in December 2012 for MZ. Questions addressed different aspects of these medications use: usual administrators, time required, facility, and risk of errors in the preparation and the administration by parents or other care givers. Parents were also questioned about their feelings concerning the efficacy and utility in emergency settings, facility of DZ and MZ administration.

## Results

Respectively, 50 and 48 families answered the DZ and MZ questionnaire. The majority agreed on the facility of MZ administration by parents (83%) and non-parent care givers (75%) versus 38% and 8% for DZ (Fig1). Buccal MZ is easier (pre-filled syringes) and quicker to prepare (less than 1 min) than rectal DZ (Fig2). The preparation and administration are not subject to errors as with rectal DZ, especially when given out of the parent's presence (Fig3). Non-parent care givers accept much more readily to administrate buccal MZ (Fig4). We also notice an increase of MZ administration by fathers and other care-givers (47% and 20% vs 38% and 14% with DZ) (Fig7).

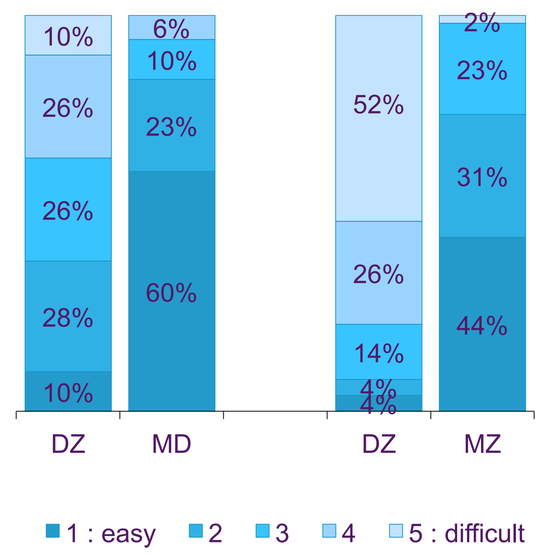


Figure 1 : Estimation of the facility of DZ and MZ usage by parents and non-parents

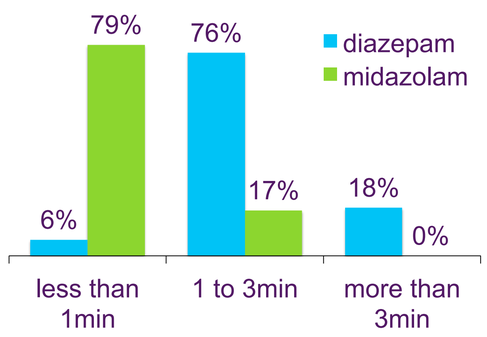


Figure 2 : Estimation of time of drugs preparation by parents

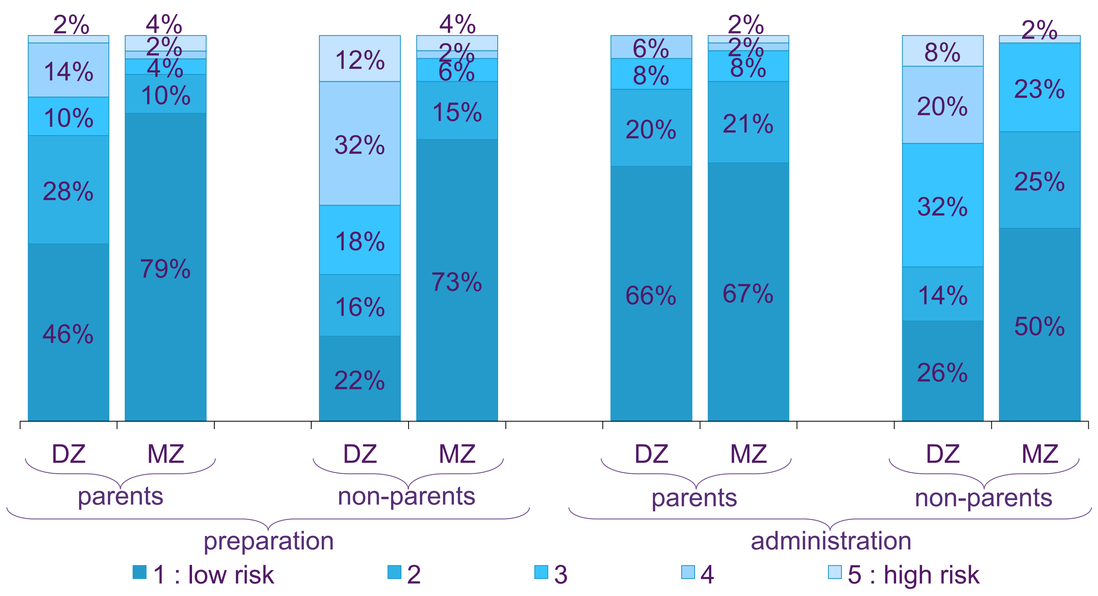


Figure 3 : Estimation of the risk of error in the preparation and the administration of rectal DZ and buccal MZ by parents and non-parents

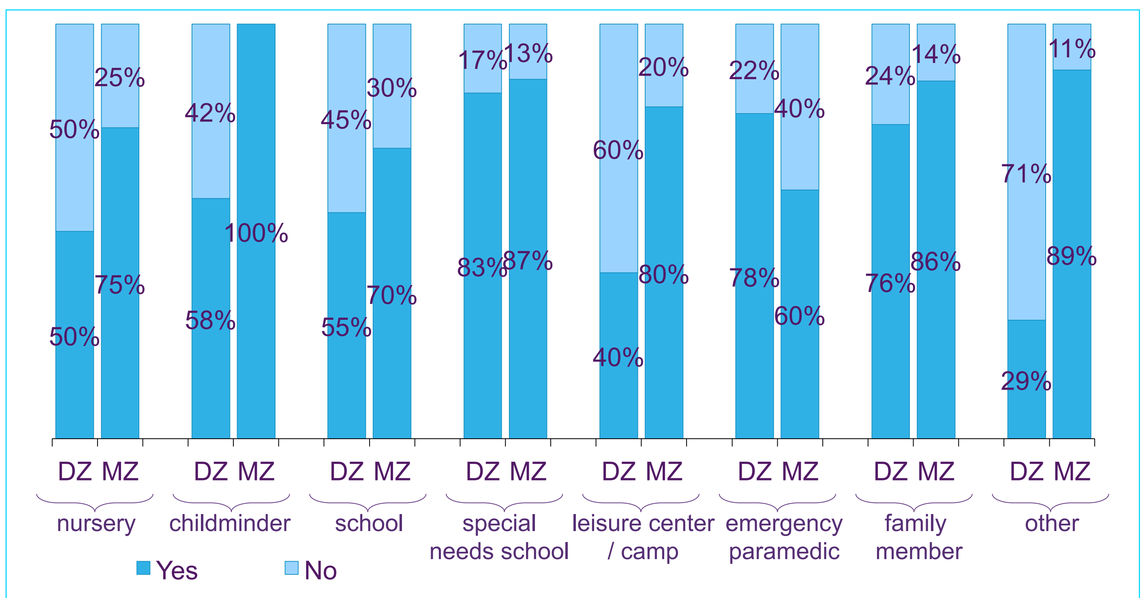


Figure 4 : Percentage of situations in which care givers refuse to use rectal DZ or buccal MZ

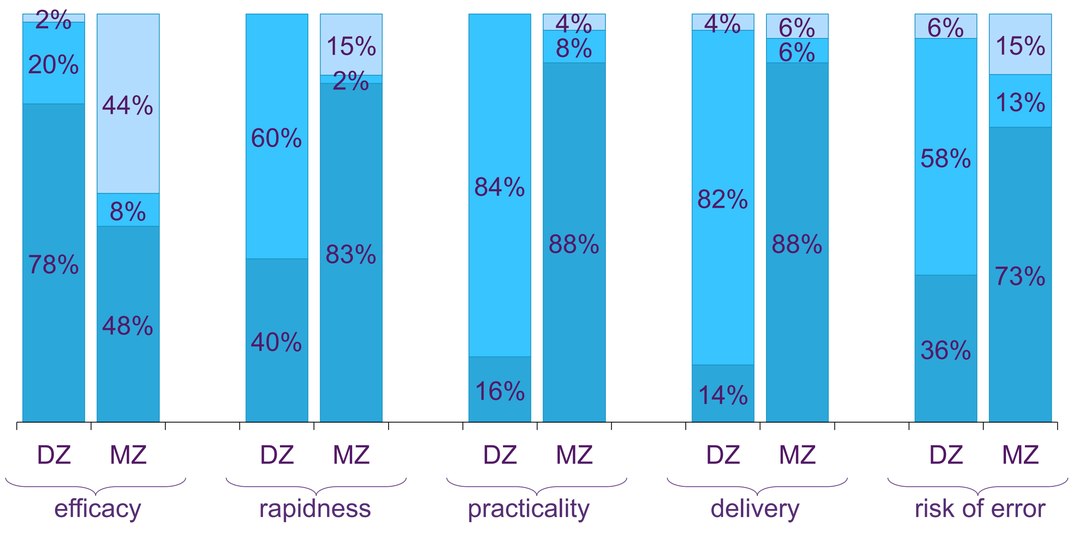


Figure 5: Feeling of parents concerning the usefulness and the efficacy of rectal DZ and buccal MZ in emergency setting

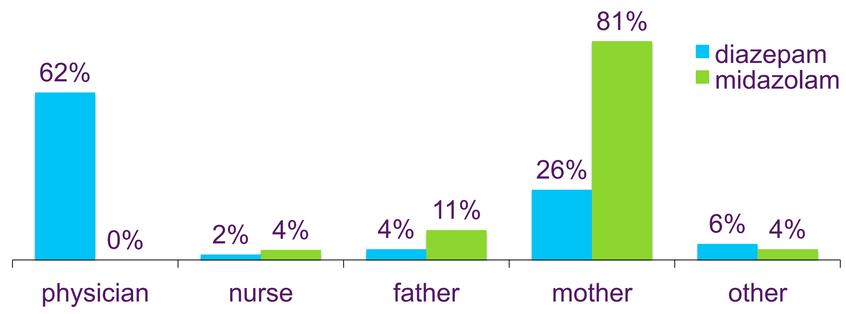


Figure 6 : First administration of rectal DZ and oral MZ

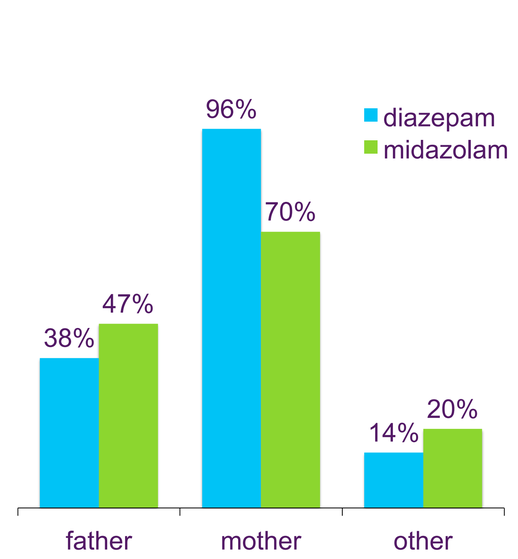


Figure 7 : The most frequent administrator

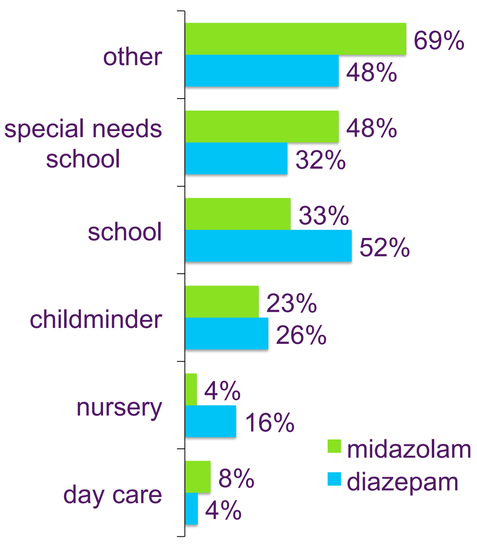


Figure 8 : Non parental administration of rectal DZ and buccal MZ

## Conclusion

Parents emphasize the facility of preparation and administration of buccal MZ compared to rectal DZ with a lower error risk. The care givers accept its administration and estimate it easier than the rectal DZ. As such, oral MZ appears to fulfill the demand of parents for a rescue medication for acute prolonged convulsive seizures in children.