

Acceptance of the Use of Diazepam Rectal Gel in School and Day Care Settings

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This study was conducted to identify how often parents of children with epilepsy encounter barriers to the use of diazepam rectal gel in day care or school settings and how these barriers affect the child and family. Sixty-four parents completed an 18-item questionnaire documenting their experience with asking their child's school to administer diazepam rectal gel. No data regarding its actual use in the school was obtained. Forty-three parents (68%) had asked their school to administer diazepam rectal gel; 35 (81%) reported school

agreement, and 8 (19%) reported refusal. In 5 of these refusals, the cited reason was legal concerns, and in 5 cases the refusal had some adverse effect on their family's life. Most children prescribed diazepam rectal gel do not encounter resistance to its use in school and day care settings. Barriers to its use are usually due to legal concerns and significantly affect the family's quality of life.

Keywords: rectal diazepam; schools; barriers

Diazepam is often used for the acute treatment of seizures. Diazepam rectal gel was developed to allow parents and caregivers to treat acute repetitive seizures at home and outside of the hospital. Although not approved by the United States Food and Drug Administration for the treatment of prolonged seizures, diazepam rectal gel is often prescribed off-label for this use.¹⁻³ Diazepam rectal gel is safe and effective for use outside of the hospital and provides a feeling of control for parents of children with epilepsy.¹⁻⁶

When rectal diazepam is not used, the standard treatment for the child with acute repetitive seizures or a prolonged seizure is the administration of an intravenous antiepileptic medication such as diazepam or lorazepam by trained medical personnel and a trip to the emergency department. Unfortunately, in our experience, this sometimes results in delayed treatment, physiologic changes due to prolonged or repetitive seizures, and emotional and financial burdens associated with the seizure and its treatment.

Parents and caregivers have been administering diazepam rectal gel safely in the home since 1997,⁷ and some parents ask other caregivers in schools or day care settings to administer rectal diazepam if needed. The availability of diazepam

rectal gel in school and day care settings may make it easier for children to participate in school and social activities while parents work or engage in other activities important to the family's quality of life. Some parents, however, report that schools and day care providers refuse to administer diazepam rectal gel, which may have a significant adverse effect on the child's well-being and the child's and family's quality of life. The purpose of this study was to identify the frequency with which parents experience barriers to the use of diazepam rectal gel in day care and school settings, what the barriers are, and the effect of such problems on the child and family.

Methods

A prospective study using a convenience sample was conducted in the Columbus Children's Comprehensive Epilepsy Clinic from December 2003 through May 2004. Parents of the 218 children seen in the clinic for epilepsy were screened to participate in the study at a child's routine clinic visit. Parents eligible to participate in the study were those who had a child aged younger than 18 years with epilepsy who had been prescribed diazepam rectal gel for treatment of prolonged or acute repetitive seizures before the current clinic visit. Only 1 parent per patient participated in the study.

Each participant completed an 18-item questionnaire that included forced-choice and open-ended questions about their experience with asking their child's school to administer diazepam rectal gel. We developed the questionnaire from our clinical experience, and content validity was established by pretesting with 10 parents and content

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Table 1. Parents' Reasons for Not Asking School to Give Diazepam Rectal Gel (N = 21)

Reason	No. (%)
Child does not go to school	7 (35)
Child's seizures occur infrequently or primarily during sleep	7 (35)
Parents did not want school to give	5 (25)
Parents were afraid someone might hurt the child	2 (10)
Parent did not know they could ask the school to give	2 (10)
Parent did not think school staff could learn how or when to give	2 (10)

review by other pediatric neurologists and nurses. The study was approved by Columbus Children's Hospital Institutional Review Board.

Results

Of the 218 children screened, 86 of their caregivers met inclusion criteria and 64 agreed to participate. The average age of the child was 7.9 years (22 months-17 years): 1 (2%) was younger than 2 years old, 12 (27%) were 2 to 5 years old, 25 (58%) were 6 to 11 years old, and 5 (12%) were older than 12 years. Of the 64 children, 31 were boys (48%) and 33 were girls (51%). Twenty (31%) were in a special education classroom, indicating some degree of cognitive, behavioral, or physical impairment. The 64 caregivers who completed the questionnaire consisted of 56 mothers, 5 fathers, 1 foster mother, and 2 legal guardians.

During the last year, 36 of the 64 children (56%) had received diazepam rectal gel at home, school, or elsewhere in the community: 15 (28%) received diazepam rectal gel 1 to 3 times, and 18 (41%) received it more than 3 times. In addition, 12 children (18.8%) had been transported from school to an emergency department at least once in the last year for a seizure.

Of the 64 parents surveyed, 43 (68%) asked the school to administer diazepam rectal gel, whereas 21 parents (32%) had never asked the school to do so. Reasons cited by parents for not asking the school to administer diazepam rectal gel are summarized in Table 1. Parents of children who had received diazepam rectal gel more than 3 times in the last year were significantly more likely to ask the school than were parents of children who had received the medication 3 times or less in the past year (Table 2). Age, gender, and past history of emergency transport from school for seizures did not significantly affect whether parents asked the school to administer diazepam rectal gel.

Of the 43 parents, 35 (81%) reported the school agreed to administer diazepam rectal gel, and 8 (19%) reported school refusal. Reasons for refusal of schools to give

Table 2. Effect of Previous Use of Diazepam Rectal Gel Use on Parents' Decision to Ask the School

Frequency of Diazepam Gel Use in the Past Year	Parents Asking School (n = 43), No. (%)	Parents Not Asking School (n = 21), No. (%)	P Value
Never	19 (44)	9 (42)	NS
1-3 times	6 (14)	9 (42)	NS
>3 times	18 (41)	3 (14)	0.02 ^a

a. $\chi^2 = 8.3$

Table 3. Reasons Cited by Schools for Refusal to Give Diazepam Rectal Gel (N = 8)

Reason	No. (%)
Not legally allowed	5 (62)
Concerned about privacy for child	2 (25)
Concerned they would not know when to give	2 (25)
Parents did not know the reason	2 (25)
Concerned they could not learn how to give	1 (12.5)
Concerned the child would stop breathing	0
Concerned about sexual abuse allegations	0
Concerned they would hurt the child	0

diazepam rectal gel are summarized in Table 3. By χ^2 square analysis, age, gender, past use of diazepam rectal gel, and past history of emergency transport from school to hospital for seizures did not significantly differ between those who reported school agreement and refusal.

Of the 8 parents who reported school refusal, 5 indicated that the refusal had some adverse effect on their child and family: all 5 parents worried their child would be hurt by a seizure, 3 kept their child at home some days or full time and were not able to work or go to school themselves, and 1 went to school with their child. Only 3 of the 8 parents who had reported school refusal had not affected their child or family. Information about these types of concerns was not collected from the parents who reported school agreement. Parents could have these same concerns regardless of whether the school agreed to administer diazepam rectal gel.

The type of school the child attended had a significant effect on the school's willingness to administer diazepam rectal gel (Table 4). Schools administered by the Department of Mental Retardation and Developmental Disabilities were significantly more likely to agree to administer diazepam rectal gel than were private schools (Fisher exact test, $P = .015$). Although not reaching statistical significance, public schools tended to be more willing to administer diazepam rectal gel than were private schools; however, both were less likely to agree than were the Department of Mental Retardation and Developmental Disabilities schools.

Table 4. School Setting and Agreement to Give Diazepam Rectal Gel

School Setting	Parents Who Asked (N = 43), No.	School Agreed (Overall = 81%), No. (%)	School Refused (Overall = 19%), No. (%)
MRDD schools	15	15 (100)	0
Public schools	22	17 (77)	5 (13) ^a
Private schools	6	3	3 ^{b,c}

NOTE: MRDD = Department of Mental Retardation and Developmental Disabilities.

a. MRDD school versus public school: Fisher exact test $P = .067$.

b. MRDD school versus private school: Fisher exact test $P = .015$.

c. Public school versus private school: Fisher exact test $P = .31$.

Table 5. Special Education Services for Child and School's Agreement

Special Education Service	Agreed, No. (%)	Refused, No. (%)
1:1 aide or nurse	9 (90)	1 (10)
Occupation/physical/speech therapy	23 (85)	4 (15)
Special education classroom	17 (85)	3 (15)
Regular classroom	5 (83)	1 (17)
Aide in classroom	13 (81)	3 (19)
Individualized education plan	27 (79)	7 (21)

The type of special education services the children received is listed in Table 5. Although not significant ($P = .42$), schools tended to agree to give diazepam rectal gel if the student had a 1:1 aide or nurse: 9 of 10 schools (90%) agreed to give diazepam rectal gel when the child had a 1:1 aid or nurse compared with only 26 of 33 schools (79%) agreeing if the child did not have such assistance.

Schools that agreed to administer diazepam rectal gel sometimes still expressed concerns about its administration. Parental concerns and school concerns as reported by parents are summarized in Table 6. Overall, parents cited more concerns than did the schools, especially regarding when and how administration should occur.

In schools agreeing to diazepam rectal gel administration, the school nurse was most frequently the person designated to administer the medication (70.6%). However, other personnel, such as the teacher, school aide, 1:1 nurse for child, principal, aide on a bus, and even a bus driver, were trained and designated in the emergency plan to administer rectal diazepam. Information about how school personnel were trained to administer the medication was not obtained; some parents commented that they or the nurse provided training. Parents were generally happy with the plan developed by the school: 24 parents (70.6%) were very happy, 6 (17.6%) were somewhat happy, 3 (8.8%) were somewhat unhappy, and 1 (2.9%) was very unhappy.

Table 6. Concerns Reported Regarding Administration of Diazepam Rectal Gel

Concern	Reported by Parent (N = 40), ^a No. (%)	Reported by School (N = 35), No. (%)
No concerns	17 (42.5)	24 (68.6)
Will not know when or how to give	21 (52.5)	5 (14.2)
Not legally allowed	5 (12.5)	3 (8.6)
Child will stop breathing	5 (12.5)	2 (5.7)
Child will be embarrassed	4 (10)	2 (5.7)
Child will be hurt	2 (5)	0
Child will be sexually abused	1 (2.5)	0

a. Three parents did not answer this question.

Discussion

Most parents in this study did not encounter barriers to the administration of diazepam rectal gel in their child's school or day care setting. Barriers were most often related to legal concerns, and refusal usually resulted in some adverse effect on the child and family. The greatest parental concern was that the child would be hurt by a seizure. Parents were generally happy with the school's plan to administer rectal diazepam; plans usually relied on the nurse but also included a number of other individuals in the school. Only the type of school setting (private schools versus Department of Mental Retardation and Developmental Disabilities schools) had a significant effect on school agreement.

Legal Concerns

Although legal concerns were identified as a concern by both parents and schools, there is no legal reason in most of the United States why school personnel cannot administer a rectal medication such as diazepam rectal gel in an emergency situation.⁸ For example, Ohio Department of Education rules mandate that each school system's board of education adopts a policy authorizing its employees to administer prescription drugs to students enrolled in their schools.⁹ Unfortunately, many schools do not have a full-time licensed nurse and must rely on unlicensed personnel to administer medication. In addition, the Ohio Nurse Practice Act allows for the delegation of medication administration, including rectal medication, to unlicensed school personnel especially in an emergency situation.¹⁰

The Individuals with Disabilities Education Act and Section 504 of the Rehabilitation Act require schools that receive federal funding to provide special education and related services to children with disabilities such as epilepsy. Schools must make reasonable accommodations to allow for the safe inclusion of students with disabilities in school programs.^{8,11} Having trained personnel available to administer

diazepam rectal gel is a reasonable accommodation for students with epilepsy. The Epilepsy Foundation has developed a position statement on the use of diazepam rectal gel in schools, child care centers, and camps. They urge providers of child care and educational services to work with the child, family, and health care providers to learn how to safely administer diazepam rectal gel, citing this as a reasonable accommodation required by federal law.¹²

Quality-of-Life Issues

Several studies have documented an improvement in quality-of-life measures secondary to diazepam rectal gel. Parents report reduced disruption of daily activities and family life, reduced time lost from work and school, and feelings of empowerment by the improved control and management of the patient's epilepsy.³⁻⁵ In our study, parents reported that when the school agreed, they usually were happy with the emergency plan. When schools refused, however, parents often reported some adverse effect on the child and family's quality of life. Parents worried about their child's well-being and, in some instances, had to make significant accommodations in their child's education or their family's life by keeping their child at home or going to school with the child. However, some parents may have these same concerns or make the same accommodations even when the school agrees to administer diazepam rectal gel.

Type of School Setting

All Department of Mental Retardation and Developmental Disabilities schools and most public schools in our study agreed to administer diazepam rectal gel. The Department of Mental Retardation and Developmental Disabilities regulations specifically provide for training of staff on the administration of diazepam rectal gel.¹³ Although public schools are mandated to develop a policy for the administration of medications, policies vary with the local school district's interpretation of state and federal laws. We suspect that private schools, which often receive no federal funding and are under no legal requirement to provide special services for children with disabilities, are less likely to make accommodations to administer diazepam rectal gel. It is also possible that parents in other regions encounter more difficulties than those in Ohio.

Conclusion

In general, the administration of diazepam rectal gel to treat acute, symptomatic seizures is available to our patients in their school and day care settings. The Department of Mental Retardation and Developmental Disabilities schools were the most accommodating environment. A school that refuses to administer diazepam rectal gel most often cites legal concerns as the reason for refusal, and the child and

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