

DIASTAT: A NECESSARY RELATED SERVICE

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ABSTRACT

The purpose of this study was to survey special and regular educators as to their knowledge and attitudes about a newly developed drug for seizure control, Diastat. Recently the administration of this drug by school personnel has been mandated as a related service under IDEA. A total of two hundred schools were surveyed in four different areas of the United States. The results showed that a majority of both special and regular educators were unaware of the use of this drug and many were reluctant to administer it. Implications and suggestions for future research are put forth.

Epilepsy or seizure disorder occurs when an individual has an abnormal discharge of electrical impulses in a given circuit of the brain. The atypical spread of electrical discharges to various locations in the brain determines the specific aspects of the seizure (Weinstein, 2002). Approximately 1 in 10 children will have a seizure at some point in their lives, although many of these seizures are produced by a high fever. Epilepsy, however, is diagnosed only when an individual has a history of reoccurring seizures. Investigators

estimate that 3% of individuals are prone to seizures and that 1% of the population has epilepsy (Goldman, 2006). Epilepsy is more common in children with developmental disabilities, such as cerebral palsy (Epilepsy Institute, n.d.). In fact, Heller, Alberto, Forney, and Schwartzman (1996) report that seizure disorders occur approximately 20 times more frequently in children with disabilities than in those without.

Today, seizures can be brought under control by medication in 70% of individuals diagnosed with epilepsy (National Society for Epilepsy, 2007). This fact, however, leaves 30% of individuals who are not completely seizure free. Recently, a new medication, Diastat, was approved by the FDA to stop a seizure after it begins; effects are typically seen within three minutes. James W. Wheless, Professor and Chief of Pediatric Neurology at the University of Tennessee Health Sciences Center puts the importance of Diastat in perspective, "In the United States, the amount of time that typically elapses between the onset of a seizure and the patient receiving treatment at a hospital can exceed one hour. That's too long for this type of emergency. [Diastat] Acu Dial is a safe, effective treatment, which is a significant patient advantage" ("Children's lives", 2008, ¶ 4). Many students with a seizure disorder, especially those attending school a significant distance from a hospital, may benefit from Diastat. Two randomized double-blind studies found Diastat to be highly effective for the treatment of episodes of increased seizure activity, typically while the patient was also receiving a regimen of anti-epileptic drugs (Physicians' Desk Reference, 2008).

Diastat, a non-sterile medication, is administered through a prefilled, unit dose delivery system. It is a fast acting rectal gel that is generally administered at the onset of a seizure through a suppository-like procedure. The system requires no refrigeration or special handling, so it can be stored in the home, office, or taken along when traveling. The active ingredient in this medication is typically 5 mg/ml of diazepam. The purpose of this medication is to assist with the control of seizures.

Availability of this medication alone is not the only or even the primary issue. The larger issue is related to who will be required to administer or supervise the administration of this medication. If teachers and school personnel are designated to administer this or other health procedures, it would effectively mean a change in their role. The traditional role of a teacher is to instruct and manage a classroom; this new role, to a degree, combines teaching with the duties of health care professionals. This issue was put forth by Bigby (2004), "Educators and administrators completing their preparation programs and certification and embarking on their first jobs only a few years ago would not have considered health services to be the responsibility of the public schools. This is not the case today" (p. 233).

Traditional related services such as those identified in Part A of IDEA include transportation, speech pathology, audiology services, psychological services, and physical and occupational therapy (IDEA, 20, U.S.C. §140(a) (17)). It appears that the watermark for the expansion of these traditional related services occurred in 1984 with the *Irving vs. Tatro* case (Rothstein, 2000). This case dealt specifically with the issue of clean, intermittent catheterization (CIC). Chief Justice Berger noted in his opinion that related services such as CIC which enabled a child with a disability to remain at school during the day, were just as important as transportation and school access. Affirmation of this position occurred in 1999 with the *Cedar Rapids Community School District vs. Garrett F.* case. This case confirmed the use of the “bright line” between prohibited medical services and required health care related services. The bright line clarified medical services as those performed by a licensed physician, and health related services as those that could be performed by a school nurse, health aide, or trained layperson (Osborne, & Russo, 2003). Examples of these school health services include suctioning, management of a tracheotomy, special feedings, positioning, and administering medicine (Downing, 2004).

It is clear that administering medications is a school responsibility, but other issues are unclear including liability, the personnel responsible for administering the medications, and inconsistency between state and local guidelines for health professionals (Cartwright et al., 2007). This lack of clarity may lead to a disinclination to provide more invasive procedures. Specifically, reluctance by school personnel to administer Diastat has resulted in the following difficulties: a tendency by administrators to recommend home bound services due to the medication needs of the student and exclusion from day care, field trips, camps, sports, and after school activities. In addition, many schools have a propensity to call 911 rather than administer Diastat, even if the child’s neurologist has recommended otherwise. However, recently, court decisions and opinions by hearing officers ruled that the administration of Diastat is a related service covered under IDEA (“Diastat administration,” n.d.).

Since the administration of Diastat is a related service, the question remains: Who is required to provide the service? IDEA mandates that each state provide related services, but state legislators are responsible for the regulations that specify licensure, certification, and other requirements (Downing, 2004; Thomas & Hawke, 1999). Theoretically, these regulations should provide answers to questions about health services such as the administration of Diastat. In reality though, each school district must ultimately determine the expertise needed to administer Diastat and be responsible for making that determination, considering the unique make-up of its district.

ADMINISTRATION OF DIASTAT

The procedures for administering Diastat are fairly uncomplicated; it has been compared to using a rectal thermometer. A number of school systems are currently addressing the training needs of teachers. As an example, one Florida school district offers 30-45 minute training sessions and to date has trained 700 teachers and staff (Fitzpatrick, 2007).

To administer Diastat the provider:

1. Places the student on his/her side and lowers clothing to mid-thigh,
2. Locates the Diastat syringe, removes the cap, and lubricates the tip,
3. Bends the upper leg forward and separates buttocks to expose the rectum,
4. Gently inserts syringe into the rectum and slowly depresses plunger until it stops,
5. Slowly counts to three before removing the syringe from the rectum and then holds buttocks together to insure retention,
6. Observes student and contacts authorities if the seizure does not subside.

PURPOSE OF THE STUDY

The purpose of this study was to investigate the knowledge and perceptions of both regular and special education teachers regarding the use of Diastat for seizure control. In addition, school practices and policies concerning Diastat were surveyed.

INSTRUMENTATION

A literature review along with pharmacological information from the Physicians' Desk Reference (2008) and the manufacturer were used to develop a list of potential questions about the use of Diastat. These questions were submitted to a panel of experts (experienced special educators, regular educators, and school administrators) which resulted in a modification of the instrument. From this a 9-item questionnaire was generated. A pilot study was then conducted with 10 regular and special educators which indicated no further changes were needed in the instrument. A copy of this questionnaire is attached as Appendix A.

METHOD

Four states in different geographic areas of the United States (Northeast-New York, Southeast-Mississippi, Northwest-Washington, Southwest-Arizona) were selected. In each of the four states, 25 elementary schools and 25 secondary schools were randomly selected, using a list of schools from the respective state departments of education. This resulted in a total of 100 elementary schools and 100 secondary schools surveyed.

The principal at each of the 200 schools was mailed a cover letter briefly describing the study. The cover letter included a request to disseminate a packet to one regular education and one special education teacher of the principal's choosing. The packet that each teacher received included a separate cover letter, the survey questionnaire, and a self-addressed, stamped return envelope. A code number was affixed to each survey. The letters with the packets then were mailed out to the 200 schools. After a period of four weeks, the code numbers were used to identify nonresponding schools which received a follow-up reminder.

RESULTS

The first mailing produced 77 questionnaires with 83 additional questionnaires returned after the follow-up reminder. This was total of 160 respondents, representing a 40% response rate. Of the respondents, 53% were special educators while 47% were regular educators.

Descriptive statistics are provided for the survey results. Also, *t*-tests and chi square analyses were performed to determine statistical significance where appropriate. The .05 confidence level was used. The results are summarized in Table 1 and discussed below.

Not surprisingly, the majority of educators were unfamiliar with Diastat. This was especially apparent with regular educators as none of them reported any knowledge of this medication. Over 2/3 of educators did not know whether their district had identified specific school personnel to administer Diastat if needed. The vast majority of educators was unaware of Diastat and has not been trained to administer it.

When teachers were asked what setting would be preferable for the administration of Diastat, the nurse's office was chosen by a significant majority of both special and regular educators. A *t*-test reported this setting to be significant below the .05 level ($p=.003$). More than 3/4 of both groups of teachers reported that they did not believe that the administration of Diastat fell

Table 1

Survey Results for Special and Regular Educators (n=160)

	Q1	Q2	Q3	Q4	Q5	Q6	Q7A	Q7B	Q7C
Special Education	Yes-22%	Yes-13%	Yes-4%	Classroom-8%	Yes-17%	Yes-23%	Yes-49%	Yes-43%	Yes-28%
	No-78%	No-19%	No-96%	Restroom-11%	No-83%	No-77%	No-51%	No-57%	No-72%
		Don't Know-68%		Nurse's Office-77%					
				Teacher's Lounge-4%					
Regular Education	Yes-0%	Yes-10%	Yes-5%	Classroom-8%	Yes-14%	Yes-13%	Yes-47%	Yes-36%	Yes-32%
	No-100%	No-16%	No-95%	Restroom-7%	No-86%	No-87%	No-53%	No-64%	No-68%
		Don't Know-74%		Nurse's Office-85%					
				Teacher's Lounge-0%					

within their duties and, further felt that the procedure should not be added to their classroom responsibilities. Although half of the surveyed teachers were willing to administer Diastat to a student of the same gender, they were much less willing to administer it to a student of the opposite gender, especially in older age students.

Since a stratified random survey was conducted in four regions of the country, the investigators were also able to compare the responses of the different geographical areas. A remarkable similarity was seen between the responses across the different regions. Only one of the questions showed a significant difference, based on region of the county. Respondents from the northeast answered the question, "Would you be willing to administer it [Diastat] to a student of the same gender?" differently than did their three counterparts. The respondents from the northeast were more reluctant to administer this medication. A chi-square showed significance at the .05 level ($p=.043$).

DISCUSSION

The purpose of this study was to investigate the knowledge and perceptions of both regular and special education teachers regarding the use of Diastat for seizure control. The study revealed a number of interesting facts. Although some school districts are fully engaged in training their staff to administer Diastat (e.g. an in-service training in St. Lucie County, Florida and a one hour online training program offered by Rio Rancho Public Schools in New Mexico), the vast majority of educators remain unfamiliar with Diastat. In a statewide initiative the governor of Kentucky signed into law a bill that requires all public, private, and parochial schools to train personnel to administer Diastat. There, however, appears to be a large disparity between a limited number of districts heavily invested in training and many other systems either ignoring or unaware of the issue. The issue of training raises a number of unanswered questions. Should teachers be trained in all potential health related issues or only those present in the district? Can online training or a single in-service workshop adequately prepare teachers and staff to safely administer Diastat? Should training be repeated on an annual basis as a refresher course and for new employees? After thoroughly reviewing the literature the investigators found a dearth of information on Diastat as a related service under IDEA. This was not unexpected as there is little available research on medical interventions by teachers.

A disturbing fact is that a significant majority of teachers, both special and regular educators, had no knowledge of whether someone in their school had been designated to administer Diastat. In an emergency situation, this lack of information could prove harmful. Unsurprisingly, both special and regular educators felt that the nurse's office was the most appropriate place to administer Diastat. This setting may be workable for smaller students as they could be carried, but would be extremely difficult with older, heavier students.

The vast majority of teachers did not view the administration of Diastat as a currently accepted practice for classroom teachers and further did not feel that it should be included as an added responsibility for a teacher. This illustrates a tension between the traditional role of the teacher and a role in which health related services become yet another responsibility of the teacher. Diastat has been shown to be an effective medication for the treatment of epilepsy. Since 3% of students are prone to seizures, this is not an insignificant issue. Some school districts have been proactive in addressing the training needs of school personnel. A significant number of states and districts have not considered the issue of Diastat and have no clear policy. This lack of awareness and development of a policy is problematic for parents, teachers and

students. Just as *Irving vs. Tatro* addressed catheterization and *Cedar Rapids Community School District vs. Garrett F.* concerned ventilator management, new cases make it clear that the administration of Diastat is considered a related service. These new cases include: *Christian vs. Clark County School District*; *Silsbee Independent School District*, and *Student vs. San Francisco Unified School District* (Epilepsy Foundation, n.d.). Two issues that remain are the administration of Diastat to students of the opposite gender, especially at the secondary level, and the reality that educators do not see the administration of Diastat as the role of a teacher. In spite of the complexities and sensitivities involved, training willing male and female faculty members at each school would be a sound first step.

The larger issue, however, is the changing role of the special education teacher. The traditional role of a special education teacher was focused on specialized instruction through a differentiated curriculum. The initial related services mandated under IDEA, ancillary services such as specialized transportation and physical and occupational therapy, were provided by professionals other than the special education teacher. However, the profession has incrementally moved to the point that the classroom teacher is directly responsible for the overall management of medically invasive services such as catheterization, suctioning, and ventilator management. This raises the specter of continuing change and the certainty that this will not be the last issue faced by the profession.

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Appendix A

Dear Teacher,

By law public schools are required to provide selective health services. Diastat is a relatively new treatment for seizures that is showing positive results. It is a fast-acting rectal gel which is generally administered at the onset of a seizure through a suppository-like procedure. It can be administered by most individuals after only minimal training. Recently, a number of school systems have begun designating and training staff members to administer Diastat.

Since this is a new procedure, we have a few brief questions concerning Diastat:

1. Are you familiar with Diastat?

- Yes
- No

2. Does your school/school district have someone designated to administer Diastat?

- Yes
- No
- Don't know

3. Have you been trained to administer Diastat?

- Yes
- No

4. If a child needed Diastat what setting would be used?

- Classroom
- Restroom
- Nurse's office
- Teacher's lounge

5. In your opinion, does this procedure fall under the broad role of a teacher's duties?

- Yes
- No

6. In your opinion, should this procedure fall under the broad role of a teacher's duties?

- Yes
- No

7. If you were designated to administer Diastat:

a. Would you be willing to administer it to a student of the same gender?

- Yes
- No

b. Would you be willing to administer it to an elementary age student of the opposite gender?

- Yes
- No

c. Would you be willing to administer it to a secondary age student of the opposite gender?

- Yes
- No