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School Nurses' Participation in Accommodations for Children with Epilepsy: A Quality Improvement Project

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**School Nurses' Participation in Accommodations for Children with Epilepsy: A Quality
Improvement Project**

by

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Paper submitted in partial fulfillment of the
requirements for the degree of

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7/27/2022

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SCHOOL NURSES AND CHILDREN WITH EPILEPSY

Dedication

This project is dedicated to my husband, Steve, and our children, Nicole, Sarah, Natalie, and Katherine.

Without their support, I could not have embarked on or continued this journey.

Acknowledgments

A special thank you to my husband, Steven, for your encouragement. You had far more faith in me than I had in myself. Thank you for not just one, but two new computers.

Nicole, Sarah, Natalie, and Katherine - When I started my DNP, I walked into the first day of class with a pad of paper and a pen; I had much to learn. You showed me how to use Blackboard, and Collaborate, you taught me how to load assignments, post responses, and find lost data; you became my editors, my research assistants, and my instructors on graphs, Excel, and Word. Without you, I wouldn't be here.

A special thank you to Dr. Galloway and Dr. Aleshire for your patience, guidance, and support.

Finally, to all my patients and families: You have been my real teachers regarding children with epilepsy, Thank you.

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Abstract

Epilepsy is the most frequent, chronic, neurological condition in childhood, impacting 0.5 to 1% of the population. Documented learning problems associated with childhood epilepsy include memory problems, attention deficits, reading difficulties, and processing speed abnormalities. Epilepsy also impacts psychological health with poor self-esteem, a high incidence of bullying, and poor school performance. The Every Student Succeeds Act identifies the school nurse as a leader in chronic disease management; advocating for students to receive the resources and support they need to achieve academic success. The large Midwestern school system, studied in this capstone project, has 804 known students with epilepsy. The intervention of this project was an educational program for school nurses about epilepsy and its impact on both learning and self-esteem. The long-term goal would be to identify students not achieving their optimal level of academic success, due to their epilepsy, and implement appropriate interventions. Dr. Wodrich's Epilepsy Knowledge Test was used to assess gain in overall epilepsy knowledge after a teaching intervention with school nurses. Demographic data was gathered to assess for associations between demographic data and epilepsy knowledge. Descriptive statistics and a paired t-test were used for data analysis. Results showed an overall increase in knowledge between the pretest (M= 17.8, SD 2.6) to post-test (M = 20.4, SD 3.1), $t(5.8)$, $p < 0.001$. Limitations of the study included small variable numbers, making statistical inferences difficult, and population access problems related to Covid-19 protocols.

Keywords: epilepsy, learning disabilities, child, school nurse, student

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School Nurse's Participation in Accommodations for Children with Epilepsy, a Quality Improvement Project.

Introduction

Problem Statement

There are no standard educational accommodations, for the common learning difficulties noted in children with epilepsy, within a large, southern, urban school system.

Definition

A seizure occurs when there is an abnormal firing of the neurons leading to a rapid change in brain function while epilepsy is a condition of recurrent seizures (Shorvon et al., 2019). The Centers for Disease Control (CDC), 2020, notes epilepsy state prevalence, for the project location, at 49,500 (95% CI 42,000-57,000) with 6,800 0-17 years (95% CI 4,900-8,700). The studied school system has an epilepsy prevalence of 0.08%, or 804 students, of which 158 function under a medical individual educational plan (IEP). These plans only address the treatment of medical emergencies occurring with epilepsy, not the educational difficulties and interventions needed for this population (Wilson et al., 2013), as explained by the Director of Health Services.

Stakeholders in this problem include students with epilepsy who may have difficulty learning, and their families (Begley & Durgin, 2015). The problem spills into the community as parents may have missed work during exacerbations of seizures and late nights assisting with homework. At school, the nurse managing the child's chronic illness and the teacher educating that child all have a stake in their success (Wilson et al., 2013).

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Significance of the Local Problem

The school system selected for this capstone project is the 29th largest school district in the United States. Their website notes its compilation of 167 schools, of which 134 are traditional, 20 are magnet, and 15 are academies; there are 96,000 students and 6,738 teachers. One hundred twenty-five languages are spoken, and 66.7% of students are eligible for free or reduced-price meals.

The capstone project's chosen school system has approximately 160 nurses who are responsible for a wide range of tasks centered on the health and well-being of all the district students. Crucial to this project, nurses conduct school staff training sessions about medication administration and other required student health needs. School nurses routinely address only the medical needs of epileptic children, not the learning difficulties related to their condition. Only children with educational difficulties, deemed to need assistance based on formal cognitive testing, routinely receive assistance with their learning per the Director of Health Services. Considering 40-60% of children with epilepsy have impairment in one or more areas of learning (Hesdorffer et al., 2013), it is likely that the learning needs of children with epilepsy are not being met.

The National Association of School Nurses (NASN) Framework for 21st Century School Nursing Practice (Maughan, et al., 2015) defines case management as a process in which children who are not achieving their optimal level of health or academic success, due to chronic illness, are identified by the school nurse. Nurses may well be the child's most consistent health provider, giving them the ability to advocate for and protect the rights of those with chronic health conditions (McCabe, 2021). Assessment and Curriculum Development's (ASCD) Whole Child, Whole School, Whole Community notes how students' educational status impacts not just

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the student and school system, but the community as a whole, who are all stakeholders in promoting the academic success of the community members. Johnson (2017) notes that "children's health and education intertwine to determine their future; the health and educational paths of a community of children combine to lay the foundation for powerful forces that benefit or hinder a nation of communities."

Barriers to the capstone project's implementation will include the school nurses' workload, already burdened by national shortages, and worsened additionally by COVID-19 (McIntosh et al., 2022). School nurses assure that all children have access to appropriate educational opportunities regardless of their state of health. They have a foundational role in providing direct services to students with health problems, and additionally, health promotion in the communities in which they live and serve (Johnson, 2017).

Educational assistance requires funding. According to Blad (2021), there are governmental monies set aside for children in a special education classroom, or for specific programs that teach medically fragile children at home. However, when there are simply accommodations needed such as increased time for testing, or both written and verbal instructions, there is no government funding provided for the extra hours these adjustments entail. When Congress passed the predecessor of the Individuals with Disabilities Education Act (IDEA) in 1975, it was to help cover the additional costs of educating students with disabilities (Lipkin & Okamoto, 2015). Unfortunately, the level of funding promised never materialized (Blad, 2021).

Literature Review of the Problem

Children with epilepsy have well-documented learning difficulties (Reilly et al., 2014). Epilepsy-related cognitive issues include memory (Boscariol et al., 2015; Engle & Smith, 2010; Lopes et al., 2014), attention issues (Abramowitz & Hollingsworth, 2018; Lordo et al., 2017), and reading (Lah et al., 2017), and mathematical difficulties (Swanson & Beebe-Frankenberger, 2004). Chronic seizures in the mesial-temporal region scar the brain's short-term memory region. Working memory problems impact various areas of language among children with epilepsy. Nouwens et al. (2016) assessed working memory and reading comprehension, Singer & Bashir (2018) studied verbal working memory, and Swanson et al. (2015) looked at working memory issues in children with mathematical word-problem difficulties. When working memory capacity is small, it cannot hold the information necessary to understand a string of words, whether in reading or performing mathematical word problems. Small memory capacity explains some common deficits of epileptic children in reading and mathematics.

Ekinci et al. (2016) and Engle et al. (2010) compared the attention issues in epileptics and non-epileptics. Epileptic children have lower concentration scores, attention, and short-term (working) memory than their peers. People with epilepsy show more attention deficit without hyperactivity than their counterparts, and cognitive rehabilitation did not improve this problem. In other words, this will be a problem that will follow children with epilepsy throughout their school career (Englebets et al., 2002).

Clinical studies have noted children with epilepsy have a significant risk for attention problems, with a suggested prevalence of 30% to 40%. Inattention is more common than impulsivity and hyperactivity (Dunn & Kronenberger, 2005). Information processing is slower in many students, making schoolwork a daily struggle, even with their best efforts (Reilly et al.,

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2014). Frustration leads to behavior difficulties, withdrawal, and less inclination to continue trying (Center for Disease Control, 2021) (CDC). Even when a patient is not having seizures, underlying abnormal cortical activity can lead to missed directions, slowed seat work, and difficulties with multistep problem-solving (Dunn & Kronenberger, 2005).

Children with epilepsy suffer from decreased self-esteem and stigmatization. They feel out of control, not knowing when a seizure will occur (Jacoby & Austin, 2007). Research has shown that poor self-esteem is linked to poor school performance (Reilly et al., 2014). Epileptic students have twice the chance of bullying than non-epileptic students (Hamiwka et al., 2009).

Hesdorffer et al. (2013) noted in The Institute of Medicine, that many learning difficulties remain unidentified. Though there is a known relationship between epilepsy and educational underachievement, the needs have not been adequately addressed (Reilly et al., 2014). Questions regarding interventions for children with epilepsy have not been answered (Hesdorffer et al., 2013). There is a dearth of literature regarding experimental designs for classroom-based interventions for children with epilepsy.

Intervention

This capstone project was based on the Epilepsy Knowledge Test, designed by Dr. Wodrich (Wodrich et al., 2011) (Appendix A) for a study performed on teachers. His study included pre-testing, an educational intervention based on the test, and post-testing. The intervention for this project was adjusted for and given to, school nurses with permission by Dr. Wodrich. Nurses have historically impacted education, decreased absenteeism, and supported students' health to enable learning (Yoder, 2020). They positively improve the educational outcomes of students through addressing social determinants of health, health needs, and performance of advocacy (Maughan et al., 2015). In a study on the impact of school nurses,

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students attending schools with full-time nurses, had significantly higher graduation rates, lower absenteeism, and higher ACT scores (Darnell et al., 2019). This study suggests that school nurses both impact health and improve academic outcomes. While there are no evidence-based interventions regarding training school nurses as advocates for children with epilepsy, studies show that school nurses are well-positioned to support both the health and academic success of students with chronic conditions (Best et al., 2018). Interventions for specific learning deficits, including language, memory, and attention problems, have been well documented in the literature since the 1970s (CDC, 2020; Grigorenko et al., 2020; Shaw, 2008). However, there is a lack of studies regarding interventions for children with epilepsy.

Summary/Justification

Students with epilepsy have academic challenges in reading (Lah et al., 2017), mathematics (Swanson & Beebe-Frankenberger, 2004), memory (Boscariol et al., 2015; Engle & Smith, 2010; Lopes et al., 2014), and attention deficits (Ekinici et al., 2016; Engle et al., 2010). School nurses should have a pivotal role in assessing the medical health of epileptic children and the impact this chronic condition may have on their academic success (Maughan, 2003; Yoder, 2019). Therefore, school nurses were chosen for knowledge improvement regarding students with epilepsy.

Purpose and Specific Aims

The purpose of this quality improvement project was to educate school nurses about basic epilepsy knowledge, learning difficulties associated with the diagnosis, and its psychological impact on self-esteem. The specific aims of this project were two-fold. First, to improve school nurses' knowledge about children with epilepsy's educational learning difficulties and its impact

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on school success and self-esteem, assessing posttest scores for knowledge improvement.

Secondly, to assess the impact of demographic data on epilepsy knowledge.

Conceptual Framework/Model

Plan/Do/Study/Act or PDSA is one of two models chosen for this project. The model has four stages that bring about a new process, or improvement of a process, already in place. PDSA allows for a quick response after planning, a brief study of the impact, and rapid action to further improve outcomes (See refe) (Barron et al., 2017). This process quickly assesses what is occurring and rapidly makes adjustments if a process is not working. It allows one to monitor a plan's intended and unintended outcomes before significant amounts of staff time, energy, and cost are involved in a project (LoBiondo-Wood et al., 2019).

PDSA helped structure this project from its inception. Initially focused on teachers, COVID ordered changes in the proposed school system that led to an educational program for school nurses. An in-person meeting was shifted to a virtual platform during the pandemic, changing hand-to-hand consent forms to email consents. These consents required a multi-step approach of: flyer emailing consent forms through the Director of Health Services, and the participants signing, scanning, and emailing the form back to the research assistant. Additionally, the initial plan was to have nurses present data regarding epileptic learning difficulties to teachers during individual educational plan (IEP) meetings where children's medical and educational needs are placed into a formal framework to follow for interventions. This type of nursing-led intervention was not supported by the school district and therefore not used.

The Whole Child Initiative Model (Assessment and Curriculum Development, 2014) is the second model on which the project was based. It notes that "a whole child approach to learning, teaching, and community engagement.....is merely a way to boost achievement or

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academics; the whole child approach views the collaboration between learning and health as fundamental.” With this in mind, aligning nursing, within the school system, to improve the outcomes of epileptic students would be in accordance with this theory (Appendix C).

Methods

Context/Design

Bailey, et al (2006) noted quality improvement to be the consequence of a healthcare provider serving their patient’s interests. This quality improvement project was to advance the educational outcomes for epileptic children who have learning difficulties. The pre-and post-testing activities were to assess improvement as well as gaps in learning knowledge.

Setting

The intervention was virtually provided with a power-point slide presentation to school nurses over their lunch hour. They had access to the presentation through an email invitation to the virtual meeting which allowed participation at home or while at their school site. The initial plan for in-person was changed to a virtual platform by Covid mandates. Those who could attend joined synchronously, while a recording provided access to the presentation on their own time, however only those at the synchronous presentation would be part of the actual project.

Sample

The population was a convenience sample open to all 160 school nurses within the system where the project occurred. Following the intervention, nurses took the follow-up post-testing. Recruitment occurred through a flyer invitation from myself, sent to all nurses via the Director of Health. Exclusion criteria included full-time employees out on medical leave and new employees hired during project implementation.

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Procedure

All email contact for the project went through the Director of Health Services who would forward information to the nursing staff. The week before the intervention, a flyer to the nurses informed them of the presentation's subject, the consent form (Appendix D), the type of demographic data requested, and the pretest. In addition, there was information about two \$75 drawings. The first would be randomly drawn among those who completed the pre-test, and the second would be randomly drawn among those who completed the post-test. Also included were the consent document instructions to print, sign, scan, and then email the consent form to a research assistant who de-identified the data for statistical computation. The demographic questionnaire, the pretest, as well as the posttest, all required the last four digits of each participant's phone number and was verified by the research assistant. This number was used as a "pin-number" to match pre-and post-test data, consents, and demographic data forms and was unique for each participant. Reminder emails were to be sent daily, Monday through Friday for both the pre-test and post-test by the Director of Health Services

Initial emailing occurred by use of an informational flyer, the Friday before the pretest release the following Monday, to the Director of Health Services who forwarded it to all nurses within the school system. Emails were not sent on the actual day of release, or the next 2 days following, due to the Director being out of office. Instructional emails were sent out 2-days, then 1-day, prior to the presentation. The pre-test was to be completed by midnight, the day before the presentation, for participation eligibility. All pin numbers from testing were placed in a computerized program that randomly selected one pin number. The pin number was then matched by the research assistant to the email associated with the pin number on the consent form and electronically sent a \$75 gift card. The researcher was not involved in this process.

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Prior to the researcher receiving the completed data of demographics and test scores by excel spreadsheet, the assistant removed pin numbers and email from all data. The researcher never had access to any participant's email. All information was stored on the assistant's computer that required fingerprint authentication. The post-test was open for one week following the intervention. Only pre- and post-tests that had matching pin numbers along with matching demographic data and consent forms were used for data analysis. The same steps for the pre-test drawing were performed for the post-test drawing for the second \$75 gift card. The winner was again informed by email by the research assistant in the same manner as described above.

The intervention was performed during a recorded virtual meeting initiated by the Director of Health Services. The presentation had been emailed the day prior for final review by the Director. The virtual presentation session took 30 minutes with a question-and-answer session afterward lasting an additional 10 minutes. Following the intervention, nurses were requested to refer epileptic children, with school difficulties, back through the school system for assistance, or guide families to discuss these issues with their neurology provider. A letter template was made for the regional pediatric neurology group, regarding epilepsy learning difficulties and interventions. This letter could be given to families, for the schools, upon discussion of such problems.

The total cost for the intervention was \$150. There were no monetary nursing costs as the intervention occurred during a routine, weekly Friday educational meeting, and the school provided the virtual platform without charge. Google Doc forms were free for pretest, posttest, and demographic data.

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Measures

Data collected regarding demographic information included age, ethnicity, years as a nurse, years as a school nurse, and level of nursing education, measured on a Likert scale to evaluate the impact of variables on baseline knowledge.

The Teacher's Epilepsy Knowledge Scale (Wodrich et al., 2011). was used as the pre-and post-test to measure knowledge. This tool was developed by Dr. David Wodrich for teachers, based on information directly from the Epilepsy Foundation's website (Haynes-Smith, 2019). Two epileptologists and a psychologist-researcher reviewed the instruments' topics and subtopics. Further review of topics and subtopics were by two pediatric epileptologists, two Ph.D. nurse-researchers, and a pediatric neuropsychologist-researcher. Other researchers have not used the knowledge test; thus, no reliability data is available. The knowledge subscale coefficient alpha was 0.32. Permission was received from Dr. Wodrich to use and adapt this scale for use on school nurses to measure knowledge change.

Data Analysis

IBM SPSS Statistics for Windows, version 28 (IBM Corp), and Minitab 20 Statistical Software (2010) was used for data analysis. Data that did not have a matching PIN number for demographic variables, pre-test and post-test documents were not included in the final analysis. Descriptive statistics were performed on four demographic variables with $n = 21$. Missing values for all variables led to inconsistent sample sizes. Additionally, there was a wide variance of participant totals within each variable category, and thus further inferential statistics were not performed. Data were tallied and compared simply by percentage totals. A paired t-test was performed on the pre-and post-test total results. Test questions were then divided into three generalized categories to ascertain areas of knowledge weakness among the school nurse cohort.

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Facilitating the process was the ease of the pre-and post-test questionnaires in an electronic format. However, although the Demographic form link was above the pretest link, fewer participants filled out the demographic data than the pretest. Barriers to the process included the consent form, as well as direct contact with the participants via email. The consent form required one to print out the form, fill it out, scan the form, and then send it back electronically. Multiple participants did not have access to a printer, or the ability to scan the finished consent to email back to the assistant. Home printer and scanning access may have negatively skewed consenting ability, thereby impacting total participation numbers.

Ethical Considerations/Permissions

The project received IRB approval from the University of Louisville Review Board as a non-research project on March 14, 2022. The Director of Health Services of the project's school site granted permission on October 28, 2021 (see Appendix E).

Results

Pre-intervention testing was performed the week before the intervention with an invitation to 160 school nurses. Consent forms and demographic information sheets were given to participants at this same time. Demographic data requested included age, ethnicity, years as a nurse, years as a school nurse, and level of education. Thirty-nine participants completed the pretest, of which 15 did not complete the consent to be part of the project. A generic request was sent to the Director of Health Services, then forwarded to school nurses regarding consent forms. The link requested those who had not filled out consents to do so, two further consents were received. The Zoom meeting included 39 school nurses for the interventional educational meeting. The week after the intervention, a total of 30 participants completed the post-test, of which 5 did not complete the consent form. Of the 25 who had the pre-test, post-test, and

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consents, 4 had not filled out demographic data. In total, 21 respondents had completed demographic data, consent, pretest, and post-test and had pin numbers placed on documents so data could be compared.

Demographic data reflects the nurses who completed the consent form, demographic data sheets and completed both the pre-and post-tests. School nurses' results regarding age noted 33.3% 25-35 years and 45-54 years, 19% 35-44 years, and 14.3% ages 55 and older. Years as a nurse were noted as 0-5 years and greater than 20 years at 28.6%, 11-15 years at 23.8%, 6-10 years at 14.3%, and 16-20 years at 4.8%. Years as a school nurse noted 85.7% at 0-5 years, all others from 6 to greater than 20 years were all 4.8%. A Bachelor's degree in nursing resulted at 57.1%, a Licensed practical nurse at 28.6%, and an Associate's degree in nursing at 14.3%.

Demographic data noted that 100% of the nurses answering the surveys were white. Most fell between 25-54 years of age (88.8%). Regarding years as a nurse, there were 5 each (27.8%) 0-5 years, 11-15 years, and 20 years and older. At the same time, 77.8% had only been a school nurse for 0-5 years. Licensed Practical Nurses and Bachelor's Degree Nurses were both at 41.2% with the remaining 17.7% having an Associate's Degree.

Table 1.
Demographics of school nurses (n=21)

Variable / Level	Count (%)
Age (n=18)	
25-34	6 (33.3%)
35-44	4 (22.2%)
44-54	6 (33.3%)
55 and over	2 (11.1%)
Ethnicity (n=13)	
White	13 (100%)
Years as a nurse (n=18)	
0-5 years	5 (27.8%)
6-10 years	2 (11.1%)
11-15 years	5 (27.8%)
16-20 years	1 (5.6%)
20 years and over	5 (27.8%)

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Years as a school nurse (n=18)	
0-5 years	14 (77.8%)
6-10 years	1 (5.6%)
11-15 years	2 (11.1%)
20 years and over	1 (5.6%)
Level of Education (n=17)	
Associates Degree in Nursing	3 (17.7%)
Bachelor's Degree in Nursing	7 (41.2%)
Licensed Practical Nurse	7 (41.2%)

Table 2.**Pre/Post-Test Total Score Comparison**

Variable	Mean/SD	Diff	T-stat	P-value	95% CI
Pretest Score	17.8 ± 2.6	2.6 ± 2.0	5.8	<0.001	1.6 to 3.5
Posttest Score	20.4 ± 3.1				

The purpose of this project and the first specific aim looked at a gain of knowledge for school nurses in the areas of general knowledge, impact on learning as well as self-esteem. The table below shows the results of these findings.

Table 3**Pre- Post-test results: knowledge, learning difficulties and self-esteem**

Variable	Mean/SD	Diff	t	P-Value	95% CI
Knowledge of epilepsy (pre) Questions: 3, 6, 10, 14, 15, 16, 17, 18, 20, 23, 24	9.5±1.2	0.5 ± 1.1	1.94	0.066	-0.0 to 1.0
Knowledge of epilepsy (post)	10.0 ± 1.2				
Impact on learning (Pre) Questions: 2, 7, 8, 9, 11, 12, 19, 22, 25	4.6 ± 1.5	1.3 ± 1.7	3.51	0.002	0.5 to 2.1
Impact on learning (Post)	5.9 ± 1.4				
Impact on self-esteem (psychiatric impact) (Pre) Questions: 1, 4, 5, 13, 21	3.7 ± 1.3	0.8 ± 0.9	3.93	0.001	0.4 to 1.2

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Impact on self-esteem (psychiatric impact) (Post)	4.5 ± 1.0				
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Paired t-tests were performed to assess the pre- and post-test results regarding groupings of test questions related to the purpose and specific aims of this project. Regarding generalized epilepsy knowledge, pre-test (M = 9.5, SD 1.2) to post-test (M = 10.0, SD = 1.2), $t(20) = 1.94$, $p = .066$. The mean increase in knowledge scores was 0.5 with a 95% confidence interval of -0.0 to 1.0. Epilepsy's impact on learning pretest (M = 4.6, SD = 1.5) to post-test (M = 5.9, SD = 1.4), $t(20) = 3.51$, $p = .002$. The mean increase in impact on learning scores was 1.3 with a 95% confidence interval. Epilepsy's impact on self-esteem pre-test (M = 3.7, SD 1.3) to post-test (M = 4.5, SD 1.0), $t(20) = 3.93$, $p = .001$.

Further review regarding specific questions (3, 6, 10, 14, 15, 16, 17, 18, 20, 23, 24) regarding general epilepsy knowledge improvement from pretest to post noted the following: there was a 14.3% increase in knowledge regarding missed medications as a trigger, 23.8% knowledge increase regarding the anatomical description of a partial seizure. Anti-epileptic meds and sedation increased from 90.5 to 95.2%, the nature of generalized seizure stayed the same at 90.5%, while the nature of status epilepticus stayed the same at 80.1%. Both nature of absence seizures and anti-epileptic medication side effects showed 100% in pre-and post-testing, while photosensitivity as a trigger decreased from 100% knowledge on the pretest to 81% knowledge on the post-test. The therapeutic effects of AEDs increased by 9.5%. Emergent responses showed 4.8% for brief seizures but 9.5% for prolonged seizures.

Specific results regarding increased knowledge about epilepsy's impact on learning were over nine questions (2, 7, 8, 9, 11, 12, 19, 22, 25). Eligibility for special education services decreased in knowledge from 76.2% to 66.7%. Acceptable accommodations in the classroom

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remained the same at 100%. Physical education accommodation knowledge increased by 19.1% while eligibility for 504 accommodations increased from 0% to 33.3%. The risk of memory problems increased from 38.1%. Age of seizure initiation as an impact on academic skills increased from 42.9% to 47.6%. The risk of problems learning in a classroom increased by 13.9%, the impact of epilepsy on academic achievement increased from 57.1% to 61.9%, and the risk for attention problems increased from 28.6%.

Finally, knowledge regarding the impact on self-esteem, which looks at the psychiatric impact of epilepsy, had five further questions (1, 4, 5, 13, 21). Knowledge of the emotional impact of a classroom seizure was 100% for both tests. The risk of social isolation increased from 61.9% to 76.2%, steps to bring calm to a classroom after a seizure increased from 90.5% to 95.2%, an epileptic student's risk of depressive thinking increased to 28.6% while the risk of seizure-related embarrassment increased from 61.9% to 90.5%.

Table 4**Test Outcomes by each question**

	Pre = 21	Post = 21
1. Emotional Impact of classroom seizure on class/patient	100%	100%
2. Eligibility for "other health impairment" special ed services	76.2%	66.7%
3. Missed medication as a seizure trigger	66.7%	81%
4. Risk of social isolation	61.9%	76.2%
5. How to calm classmates who have witnessed a seizure	90.5%	95.2%
6. Nature of a partial seizure	61.9%	85.7%
7. Acceptable accommodations in classroom	100%	100%
8. Acceptable accommodations at physical education	57.1%	76.2%
9. Potential eligibility to 504 accommodation plan	0%	33.3%
10. AED and sedation	90.5%	95.2%
11. Risk of memory problems	57.1%	95.2%
12. Age of seizure impact and overall academic skills?	42.9%	47.6%
13. Risk of depressive thinking	57.1%	85.7%
14. Nature of a generalized seizure	90.5%	90.5%
15. Nature of status epilepticus	80.1%	80.1%
16. Nature of absence (petit mal) seizures	100%	100%
17. Photosensitivity as seizure trigger	100%	81%

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18. AED side effects	100%	100%
19. Risk of classroom learning problems	19.1%	33.3%
20. Therapeutic effects of AEDs	90.5%	100%
21. Risk of seizure-related embarrassment	61.9%	90.5%
22. Academic achievement and epilepsy	57.1%	61.9%
23. Emergent response during brief seizure	85.7%	90.5%
24. Emergent Response during prolonged seizure	85.7%	95.2%
25. Risk of attention problems	47.6%	76.2%

Discussion

Fastenau (et al., 2008) notes research has consistently shown academic underachievement unrelated to IQ among students with epilepsy. Underachievement is performance in school significantly discrepant from expectations based on their IQ. Low achievement is independent of IQ and is simply underperformance compared to the mean of other students in that particular academic area. This distinction becomes important as eligibility for support services may be based on one and not the other. Fastenau (et al., 2008) further noted that 41%-62% of students with epilepsy had a learning impairment in at least one subject area.

The purpose of this quality improvement project was to teach school nurses regarding epilepsy, associated learning difficulties for children, and the psychological impact of this diagnosis. The original study performed research on primary and secondary school teachers. This study was aimed at school nurses. The pre-and post-testing results made this self-evident. Regarding basic epilepsy knowledge, the nurses did not show a significant increase in scores, which would be expected given their educational background. However, knowledge regarding learning difficulties and psychological issues showed a significant gain.

Limitations

This QI project had several limitations. The original twenty-five-question knowledge test was divided into 10 specific subscales. However, the literature did not delineate this division. In an email discussion with Dr. Wodrich, he stated the division of twenty-five questions among the

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ten subscales had not been kept. He recommended I divide the questions into logical subscales. The questions were then divided into three main categories of information to include: general knowledge of epilepsy, learning difficulties associated with epilepsy, and the psychological or self-esteem impact of epilepsy. These three categories were taken from his original ten subscales. Two questions were changed to reflect current knowledge. In addition, two further questions, regarding what to do during brief versus prolonged seizures required changing the time of intervention from five minutes to three minutes, thus meeting current medical standards. These changes were reviewed with Dr. Wodrich who agreed that the test being 12 years old would lead to some questions not showing current interventions and standards and gave permission for the changes. These changes will impact the overall reliability of the test.

The approximate number of nurses within the school system at the time of the intervention was approximately 160. The project occurred during the COVID pandemic when nursing resources were minimal. The recorded session had 39 nurses. There were 39 responses to the pretest and 30 responses to the posttest. Obtaining consent was complicated by the need to print the consent, sign it, scan it, and email it back to the research assistant. Multiple nurses discussed their lack of ability to do so, and with multiple attempts to obtain consent through the assistant, only 21 were signed. Difficulty with consent may have skewed responses to nurses who had the financial ability to have printers in their homes.

Demographic data was not complete. Of nurses finishing all required steps, 100% were white. While there is no ethnic demographic data documented on the school's website specifically for nursing staff, those on the zoom intervention represented a much more diverse group. Of the total number of 21, 18 responded to age, 13 responded to ethnicity, 18 responded

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to years as a nurse, and 17 responded to the level of education. Division within these variables may have shown only 1 to 2 responses impacting ability to reach statistical significance.

The original plan, following the interventional session with school nurses, was the education of families. The nurses would send letters to families along with the seizure action plans. If problems were uncovered, referrals could be made to counselors or the child's neurology provider. As sending such letters were not allowed within the school system, it did not occur. Instead, nurses were encouraged to verbally refer children having difficulties back to the school system or their neurologists for assistance. A templated 504 letter was created for the regional neurology office for use with their epilepsy patients. This impact may affect desired long-term outcomes.

Conclusion

Epilepsy has a well-documented impact on a child's educational outcomes, regardless of IQ (Reilly et al., 2014). The learning difficulties are often permanent, following the children into adulthood (Engleberts et al., 2002). This QI project was to help nurses increase knowledge regarding these problems. General epilepsy knowledge did not show a statistical increase. However, there was a statistical knowledge increase regarding learning difficulties and the psychological impact of the disease. The end goal is not simply boosting a child's academic achievement, it is the whole child approach in which there is a collaboration between learning and health, between the child's academic environment in cohesion with their medical needs (Assessment and Curriculum Development, 2014)

The long-term sustainability of this project would involve all school systems, within the project area, where patients of the local neurology practice are served. Involving teachers in this learning experience would open doors for greater collaboration, across the school, to meet the needs

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and reach the potential of each child (Assessment and Curriculum Development, 2014). From this point, further impact could occur on the national level through teaching at various conferences.

Further study would include a larger swath of school nurses in various school systems, and possibly, the addition of teachers, as was Dr. Wodrich's original study. At the current time, a letter for parents, regarding the learning deficits and accommodations for epilepsy, has been made into a templated smart phrase. The letter can be printed for children during visits to their regional pediatric neurology group that serves the project area (Appendix E).

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Appendix A

Knowledge Items Test

The following questions concern information about seizures and epilepsy that some teachers might need to know. We would like to find out what you now know, so please answer the questions independently, without accessing any data sources (e.g., the internet). Please try to answer each question, selecting the “do not know” option when you lack the information called for in a particular question.

1. *After an obvious classroom seizure, teachers should be especially vigilant for which of the following?*
 - a. Emotional upset of classmates
 - b. Emotional upset of the student who had a seizure
 - c. Emotional upset of both classmates and the student who had a seizure
 - d. Unexpressed resentment of classmates
 - e. Do not know
2. *For which special education category is “epilepsy” listed as one of the defining elements?*
 - a. Specific learning disability
 - b. Other health impaired
 - c. Developmental Delay
 - d. Emotional disability
 - e. Do not know
3. *What is the most common trigger of epileptic seizures?*
 - a. Caffeine
 - b. Missed medication
 - c. Overheating
 - d. Anxiety
 - e. Do not know
4. *Which of the following statements about social isolation and epilepsy is true?*
 - a. Social isolation is common in girls with epilepsy but very rare in boys with epilepsy
 - b. Social isolation is common in elementary school but very rare in middle and high school for students with epilepsy
 - c. Social isolation in students with epilepsy can be eliminated if classmates receive appropriate information
 - d. Social isolation remains a risk throughout school for most students with epilepsy
 - e. Do not know
5. *When students witness a classmate’s seizure for the first time, which of the following is a good way to promote calm?*
 - a. Tell classmates that the student will be transferred to another class so they will never witness another seizure
 - b. Tell classmates that seizures occur rarely and thus they are unlikely to see another one

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- c. Tell classmates that the student's parents will be contacted for guidance about what should be done
 - d. Tell classmates (or remind them) that epilepsy is not contagious
 - e. Do not know
6. *What is meant by a partial seizure?*
 - a. A seizure that occurs during one time (part) of the day only
 - b. A seizure that originates in a specific area of one cerebral hemisphere
 - c. A seizure that causes only partially impaired functioning
 - d. A seizure that can only be partially treated by medication
 - e. Do not know
7. *For students with frequent classroom seizures, which of the following is a well-accepted accommodation?*
 - a. Extra time for assignments and exam
 - b. Eliminate formal testing
 - c. Permit tests to be completed with a classmate's assistance
 - d. Use essay tests only
 - e. Do not know
8. *Which of the following is generally the best accommodation for students with epilepsy to reduce injuries in sports?*
 - a. Play contact sports, such as tackle football, as long as wearing helmets, mouth guards, and/or padding
 - b. Excuse them from contact sports and provide another physically-active alternative
 - c. Take a health class or another elective instead of physical education class
 - d. Physical education would be with those in special education classes
 - e. Do not know
9. *Students with epilepsy are eligible for Section 504 accommodation plans under which circumstances?*
 - a. Under all circumstances (such students are universally eligible)
 - b. Under no circumstances (their services must come through special education)
 - c. Only if there is evidence of impairment lasting more than one year
 - d. Only if their epilepsy substantially limits one or more major life activity
 - e. Do not know
10. *When a student with epilepsy appears to be fatigued in class, which of the following is the most reasonable explanation*
 - a. Epilepsy has impact on the sleep-wake cycle
 - b. Students with epilepsy are often exhausted from excessive homework demands
 - c. The student had missed a dose of medication
 - d. Excessive carbohydrate consumptions may be present, inducing fatigue
 - e. Do not know
11. *For students with partial complex seizures, which of the following is a critical task?*
 - a. Limited ability to consolidate what has been learned for later recall
 - b. Limited creative thinking
 - c. Limited artistic ability
 - d. Limited social ability to ask for help from teachers or other students
 - e. Do not know

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12. Which of the following has *least* impact on overall academic skills?
 - a. Seizure frequency
 - b. Age of seizure onset
 - c. Type of seizure
 - d. Having children with epilepsy in special education classes
13. Regarding epilepsy and depression, which of the following is true?
 - a. Depression is common due to the seizures themselves
 - b. Depression is common only if there is a family history of depression
 - c. Depression is common but its causes are unknown
 - d. Depression is no more common among those with epilepsy
 - e. Do not know
14. What type of seizure affects both side of the brain?
 - a. Generalized
 - b. Simple Partial
 - c. Non-epileptic
 - d. Complex Partial
 - e. Do not know
15. What is meant by the term “status epilepticus”?
 - a. A diagnosis for patients who have frequent seizures
 - b. A term used when a patient has a long period of sleeping after a seizure
 - c. A non-emergent prolonged seizure
 - d. A medical emergency in which a seizure does not stop or in which one seizure happens right after another
 - e. Do not know
16. Which of the following is true regarding absence seizures (previously known as petit mal) and school?
 - a. Absence seizures are rare and almost never occur at school
 - b. Absence seizures can be stopped if the student wishes to terminate them
 - c. Absence seizures are brief staring spells that may be mistaken for simple inattentiveness
 - d. Absence seizures do not impact overall academic abilities
 - e. Do not know
17. Which of the following could trigger a seizure in a person who is photosensitive?
 - a. Performing math problems on a tablet
 - b. Watching a power-point slide show in a darkened room
 - c. Watching an educational movie in classroom about the gold rush
 - d. Being around rapidly flashing lights or patterns
 - e. Do not know
18. Which of the following are common side effects of anti-epileptic drugs?
 - a. Changes in emotion, memory, or behavior
 - b. Irritability
 - c. Drowsiness
 - d. All of the above
 - e. Do not know
19. . Which of the following is true regarding types of epilepsy and learning at school?
 - a. All students with epilepsy are equally at risk

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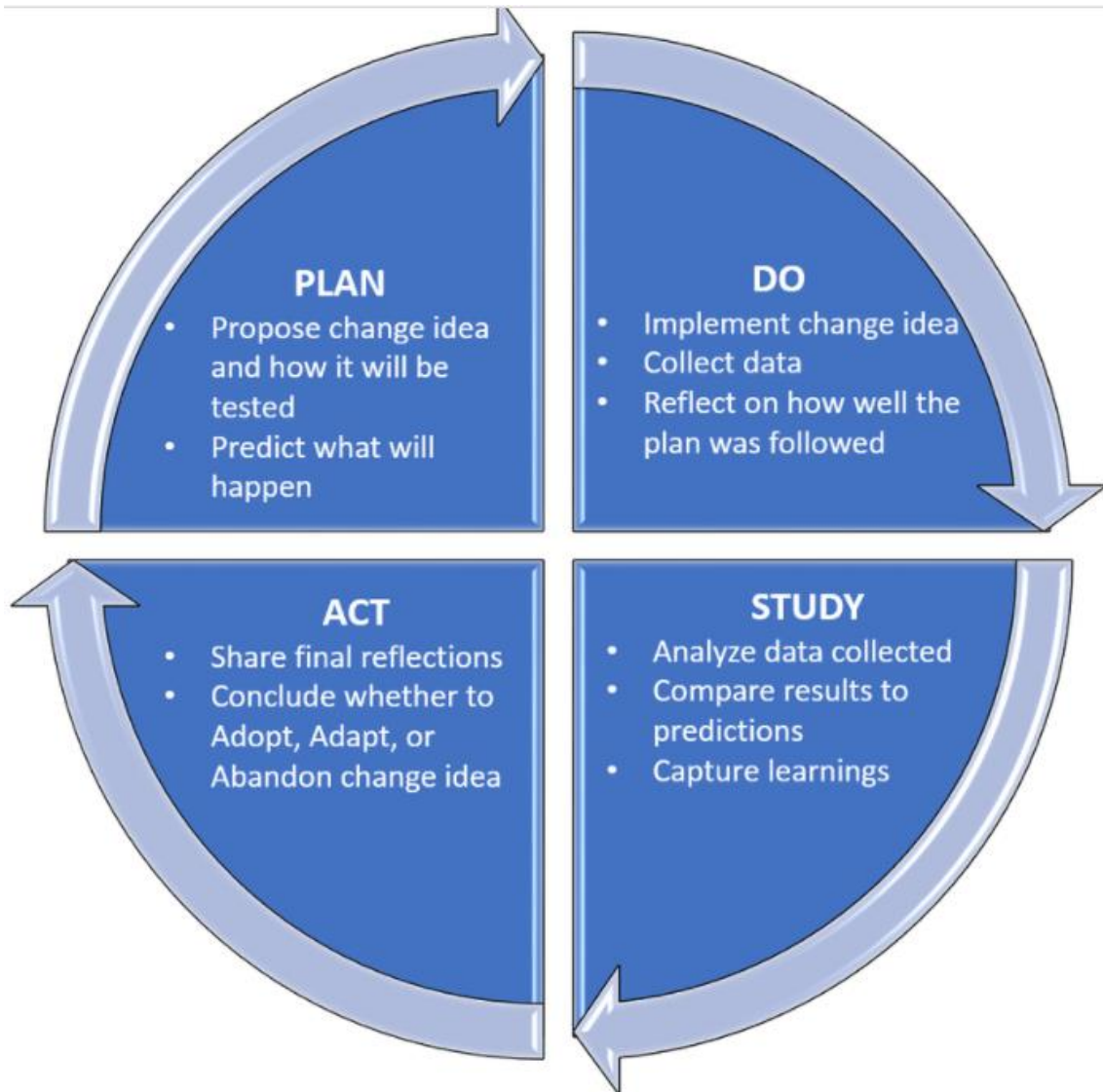
- b. Students with symptomatic epilepsy (i.e., epilepsy associated with an underlying brain anomaly) are at high risk
 - c. Students with idiopathic epilepsy (i.e., epilepsy not associated with an underlying brain anomaly)
 - d. Almost no students with epilepsy have learning problems of any type
 - e. Do not know
20. Which is true regarding anti-epileptic drugs?
- a. Their use eliminates seizures completely
 - b. Their use eliminates seizures, except during times when students are under stress
 - c. Their use reduces the risk of seizure occurrences but may not completely eliminate seizures
 - d. Their use improves attention and reduces the risk of seizure occurrence
 - e. Do not know
21. What is generally true regarding social adjustment among student who have frequent generalized tonic-clonic (grand mal) seizures at school?
- a. Social problems and embarrassment are unlikely
 - b. Social problems and embarrassment are likely but are often mild
 - c. Social problems and embarrassment are likely and are often severe
 - d. No general statement can be made on this topic
 - e. Do not know
22. In regards to academic achievement in children with epilepsy, which of the following are true?
- a. Learning disabilities tend to be subject-specific
 - b. IQ is more affected than actual achievement
 - c. Academic achievement is more affected than IQ
 - d. Math difficulties are greatest in children with epilepsy
 - e. Do not know
23. When a student's seizure lasts less than 3 minutes, what is the best action?
- a. Call 911
 - b. Administer CPR
 - c. Remove any potentially harmful objects away from the student's immediate area
 - d. Try to hold down the student
 - e. Do not know
24. When a student's seizure lasts longer than 3 minutes, what is the best action?
- a. Call 911
 - b. Phone parents
 - c. Administer CPR
 - d. Try to hold down the student
 - e. Do not know
25. Which of the following is true regarding attention and epilepsy?
- a. Many students with epilepsy have poor classroom attention
 - b. Anti-epileptic medication usually improves classroom attention
 - c. Students with epilepsy have no greater risk of classroom attention problems than students in general
 - d. After a seizure is over, very few students with epilepsy have difficulty refocusing attention

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e. Do not know

From: TECKS (Teachers Epilepsy Knowledge Scale). Adapted for nurses with permission.

Wodrich, D. L., Jarrar, R., Buchhalter, J., Levy, R., & Gay, C. (2011). Knowledge about epilepsy and confidence in instructing students with epilepsy: Teachers' responses to a new scale. *Epilepsy & Behavior, 20*(2), 360–365. <https://doi.org/10.1016/j.yebeh.2010.12.002>

Appendix B**PDSA Conceptual Knowledge****Figure 1. PDSA Cycle**

Note: From Barron, K. E., Hulleman, C., & Hartka, T. (2017). *Using improvement science to design and scale up social psychological interventions in schools: The case of the growth mindset app*. Research Gate.

Appendix C

Whole School, Whole Community, Whole Child Model

Figure 1. Whole School, Whole Community, Whole Child Model



Note: From Assessment and Curriculum Development (ASCD). (2014).

<https://files.ascd.org/staticfiles/ascd/pdf/siteASCD/publications/wholechild/wsc-a-collaborative-approach.pdf>

Appendix D
INFORMED CONSENT FORM

Title of Project: School Nurse's Participation in Accommodations for Children with Epilepsy, a Quality Improvement Project.

Principal Investigator: Lynette Galloway

Other Investigators: Paula Johnson

INTRODUCTION

We invite you to take part in a research study and quality improvement project regarding School Nurses' Participation in Accommodations for Children with Epilepsy at Jefferson County Public Schools. This project seeks to educate school nurses regarding epilepsy and the learning deficits seen in these children. With this knowledge, the nurses can then alert parents/guardians of accommodations available for these students if they are interested.

Taking part in this study is entirely voluntary. If you decide to participate, you must sign this form to show that you want to take part. All school nurses, approximately 150, within JCPS, are invited to take part in this study.

PURPOSE OF THE RESEARCH

You are being offered the opportunity to take part in this research study because studies have clearly documented the learning disabilities of children with epilepsy. School nurses have long been on the forefront of advocating holistic care of children with numerous medical conditions with the national school system. Studies have shown nurses contribute not only to health outcomes but also to improved academic outcomes.

VOLUNTARY PARTICIPATION

Taking part in this research study is voluntary. If you choose to participate in this research, your participation would include a pre-test to assess epilepsy knowledge, a teaching intervention by a neurology nurse practitioner, and a post-test to assess knowledge gained. When parents turn into the School Health Plan seizure-action plan, this will trigger the school nurse intervention. Nurses will then send a message to the parents/guardians of these children. This will be performed via email, letter, or phone call. This message will be to inform the parents/guardians regarding the availability of accommodations for children with epilepsy who are experiencing educational struggles and difficulties. If there is interest/need from the parent/guardian, the nurse will submit the child's name to start the process of obtaining needed accommodations. The nurses are to self-report the students submitted for accommodation intervention.

SCHOOL NURSES AND CHILDREN WITH EPILEPSY

PROCEDURES

Protocol for this study:

- Perform a knowledge pre-test regarding epilepsy's impact on affected students in regards to seizures and their types, medications, impact on learning, impact on psychological state. There will be \$75 Amazon gift card drawing for school nurses who participate.
- The initial pre-test will include demographic data asking the following questions:
 - Age (ranges of 10 years starting at age 25-34, ending 55-64)
 - Ethnicity
 - Years as a nurse (ranges of 10 years starting at age 25-34, ending 55-64)
 - Years as a school nurse (ranges of 10 years starting at age 25-34, ending 55-64)
- There will be the removal of identifying data.
- This will be followed by an interventional education intervention by video-conferencing, covering the information which is asked on both the pre-test and repeat post-test.
- A week after intervention, there will be a repeat post-test to assess increase in knowledge. There will be \$75 Amazon gift card drawing for school nurses who participate.
- Upon completion of the post-test, the quality improvement component will begin to improve the learning of epileptic students.
- When parents turn into the School Health Plan seizure-action plan, this will trigger the school nurse intervention.
- Nurses will then send a message to the parents/guardians of these children. This will be performed via email, letter, or phone call. This message will be to inform the parents/guardians regarding the availability of accommodations for children with epilepsy who are experiencing educational struggles and difficulties. If there is interest/need from the parent/guardian, the nurse will submit the child's name to start the process of obtaining needed accommodations.
- The nurses are to self-report the students submitted for accommodation intervention.

TIME DURATON OF THE PROCEDURES AND STUDY

If you agree to take part in this study, the pre-test should take 15-minutes in the week prior to the teaching intervention. The next week, the teaching intervention should take approximately 30 minutes. The next week will be the repeat post-test, taking approximately another 15 minutes. Following the intervention, the seizure action plan should trigger release of a templated letter, taking approximately 3 minutes. If neither is possible, then a phone-call with the same templated information as the letter. Further interest by the parent/guardian will lead to the release of a one-page informational sheet, with possible learning accommodations, by email or postal mail. Release of this pre-templated form should take no more than 3 minutes. A referral will follow this release for accommodations following the typical process within the JCPS system.

RISKS OR DISCOMFORTS

There are no known risks associated with the research.

POTENTIAL BENEFITS

The participant can benefit from increased knowledge of epilepsy, and the chance of a \$75 Amazon gift card from random drawing of participants after both the pre- and post-test. The students with epilepsy will benefit from increased access to accommodations and improvement of their learning experience within the JCPS school system. The results of this

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research may be used to guide the offering of accommodations to students with epilepsy in the school systems within Kentucky and nationally.

CONFIDENTIALITY AND SECURITY

1. Privacy and Confidentiality Measures

Identifying data will be removed from data collection and test scores. This will be stored and analyzed on a computer the researcher owns with access by fingerprint.

In the event of any publication or presentation resulting from the research, no personally identifiable information will be shared as all will be de-identified before even being reviewed by the researcher.

CONTACT INFORMATION FOR QUESTIONS OR CONCERNS

You have the right to ask any questions you may have about this research. If you have questions, complaints, or concerns contact Paula Johnson, co-investigator, at 502-303-1108.

SIGNATURE AND CONSENT/PERMISSION TO BE IN THE RESEARCH

Before making the decision regarding participation in this study, you should:

- Reviewed the information in this form
- Had the opportunity to ask any questions you may have.
- Know you have the right to withdraw from this study at any time

Your signature below means that you have received this information, have asked the questions you currently have about the research, and have received answers to those questions. You will receive a copy of the signed and dated form to keep for future reference.

Participant: By signing this consent form, you indicate that you are voluntarily choosing to take part in this research.

Signature of Participant Date Time Printed Name

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Appendix E

Permission Documents

Permission received by Dr. Eva Stone, DNP, APRN, Manager of District Health, [REDACTED] for DNP Project: School Nurse's Participation in Accommodations for Children with Epilepsy, a Quality Improvement Project.

To: Johnson,Paula
CAUTION: This email originated from outside of our organization. Do not click links, open attachments, or respond unless you recognize the sender's email address and know the contents are safe.
 It went well! We will be fine moving forward with a project that targets school nurses.
 Dr. Eva Stone, DNP, APRN
 Manager District Health

Permission received by Dr. David L. Wodrich, Phd, Professor Emeritus, Department of Disability and Psychoeducational Studies, University of Arizona for use of his Teacher's Epilepsy Knowledge Scale, adapted for nurses.

Wodrich, David L - (dwodrich) <dwodrich@arizona.edu>
 Tue 4/6/2021 10:36 PM
 To: Johnson,Paula
CAUTION: This email originated from outside of our organization. Do not click links, open attachments, or respond unless you recognize the sender's email address and know the contents are safe.
 Hi Paula:
 Sorry for the delay. We had a death in the family. It's fine to use TEKCS. Let me dig out the original items for you and send along soon.
 David
 David L. Wodrich, PhD

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Appendix F

School Epilepsy Letter

Date: @TD@

Patient: @NAME@

DOB @DOB@

Dear ***

This letter is to inform you that @NAME@ has a diagnosis of epilepsy. Children with epilepsy have a wide array of learning difficulties associated with the diagnosis, even with normative IQs.

Children with epilepsy may have difficulties in the following areas:

- Memory (both short and long term), problems with recall of information
- Attention and Concentration problems
- Organizational skills
- Speed: difficulty with timed testing
- Focusing, staying on task, short-term memory problems
- Reading difficulties
- Math difficulties (especially forgetting steps in a problem, word problems)
- Visual or verbal learning

Because of these difficulties, these students may have poor self-esteem, depression, and anxiety in regards to school.

Due to these difficulties, accommodations which may be needed include:

- Frequent repetition of material
- Redirection
- Cueing
- Memory learning strategies/mnemonics
- Extra time for assignments and exams
- Non-timed assessments to measure performance
- Break tasks down into simple steps
- Provide several brief tests instead of one long one
- Use a recognition format for exams rather than a recall format
- Provide extended time for verbal responses
- Limit oral examinations and/or presentations
- Slow the pace of verbal directions
- Provide written directions
- Pair a student with a classmate to help clarify directions
- Use examples and visual guidance

Thank you for your assistance as we work to achieve the best educational outcome for our patients and your students.

@MECRED@