“IT’S HARD!”: ADOLESCENTS’ SCHOOL EXPERIENCE AND SELF-MANAGEMENT OF PSYCHOGENIC NONEPILEPTIC SEIZURES

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DEDICATION

This body of work is dedicated to the adolescents who have been so brave to share their school experiences with me, their families who trusted me, the school nurses who have cheered for me, and my own family who has so selflessly shared my time, attention, and energy to advance the science of nursing.
ACKNOWLEDGEMENT

The inspiration for this research project began many years ago as I witnessed the struggle of students with a diagnosis then called pseudoseizures. Although the name of the diagnosis has changed over the years, the struggles have remained the same. I am forever grateful for the students and families who first introduced me to the world of psychogenic nonepileptic seizures (PNES) and the heart wrenching effects it had on their lives. Thank you for allowing me to join you in those moments and for opening my eyes to a human response in desperate need of nursing’s attention and compassion.

To the students who were brave enough to talk with a stranger about your school experience, thank you for helping me understand what you need, what you want, and what others might not be realizing is important to you. I promise to take your message to those in health care and education to make the school experience better for students with PNES. Continue to advocate for yourself and take the steps you need to take to reach your PNES and life goals.

To my mentor team, Drs. Miller, Buelow, von Gaudecker, and Decker, you have each poured your heart into your love of teaching, researching, and serving those in need. Thank you for seeing something in me I often did not see in myself as I worked through this program of study. Thank you for your encouraging words and support each step of the way.

To my fellow school nurses, thank you for being my cheerleading squad and for being a part of my “why” for pursuing a PhD. I want to make sure you are equipped, supported, and recognized for your amazing contributions to school and public health.
You are amazing leaders and advocates for your students and schools. I am humbled by your creativity and perseverance.

To my parents, thank you for being my biggest cheerleader from my first tumbling meet to my final walk across a college stage. You have believed in me and instilled in me a belief that I CAN do anything I set my mind to, as long as I am willing to put in the hard work. No matter how many voices are cheering for me—your voices are the ones I am listening for in any race.

To my amazing husband and supportive children, thank you for the many sacrifices you made over the last three years. Noah, Micah, and Grace—your sacrifices have pained me, but it brings me pure joy to know that you are all growing into strong, self-sufficient, loving, supportive people. I hope, if nothing else, you have learned that you can do hard things, make difficult choices, and fight for what you want. Chris—life is a balancing act, and you balance me so well. There is no one on earth with whom I would rather go through this madness.

I must also provide hearty thanks to the Robert Wood Johnson Foundation for recognizing my leadership potential as a Breakthrough Leader in Nursing and my scholarship potential as a Future of Nursing Scholar. Thank you for seeing school nursing as a huge contributor to the future of nursing. I am forever grateful for you hearing the voice of this school nurse and thousands of others as you financially support the health of people where they live, work, learn, worship, and play.
Andrea Lynn Tanner

“IT’S HARD!”: ADOLESCENTS’ SCHOOL EXPERIENCE AND SELF-MANAGEMENT OF PSYCHOGENIC NONEPILEPTIC SEIZURES

Adolescents with a type of conversion disorder called psychogenic nonepileptic seizures (PNES) experience many school, relationship, and health care struggles as they attempt to manage their mental health condition with PNES events that strikingly resemble epileptic seizures. Considered one of the top three neuropsychiatric problems, health care providers and school personnel remain ill-informed regarding how to care for adolescents with PNES. Because of the unique multidisciplinary approach needed to address adolescent PNES, school nurses are uniquely positioned to bridge health care and education systems. A review of literature examined the concept of school nurse self-management support for PNES, existing school nurse-led mental health interventions, and the relationships between concepts for a conceptual framework guiding adolescent PNES research. This review of literature reveals an absence of adolescents’ perspective and school emphasis in PNES research.

This study was designed to investigate adolescents’ experience attending school and self-managing PNES. This was accomplished through a qualitative content analysis of data generated from semi-structured interviews and magnitude coding of select quantifiable data. Data were obtained from 10 adolescents, 12 to 19 years of age, with current or recent in-person school attendance. The results indicate adolescents from the sample had school experiences that involved stress, bullying, accusations of faking seizures, and feelings of isolation or exclusion. Their mostly effective proactive self-management activities included seeking protection, persevering in life despite PNES
struggles, and progress monitoring through seizure tracking. Reactive activities of mixed effectiveness included coping responses to seizure warnings. School nurses, school personnel, family members, and peers served as both facilitators and barriers for PNES self-management. Adolescents also contributed information for three emerging themes—family-management, school-management, and illness representation. These findings reveal the difficulties of attending school and self-managing PNES and inform future PNES interventions to improve academic, mental health, and quality of life outcomes.

Wendy Miller, PhD, RN, CNS, CCRN, FAAN, Chair
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<td>ADA</td>
<td>Americans with Disabilities Act</td>
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<tr>
<td>CBT</td>
<td>Cognitive behavioral therapy</td>
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<td>EEG</td>
<td>Electroencephalogram</td>
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<tr>
<td>FAPE</td>
<td>Free appropriate public education</td>
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<tr>
<td>IDEA</td>
<td>Individuals with Disabilities Education Act</td>
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<tr>
<td>IEP</td>
<td>Individualized Education Program</td>
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<td>NASN</td>
<td>National Association of School Nurses</td>
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<td>QOL</td>
<td>Quality of life</td>
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<td>PNES</td>
<td>Psychogenic nonepileptic seizures</td>
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<td>SMS</td>
<td>Self-management support</td>
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CHAPTER I
INTRODUCTION AND NATURE OF THE STUDY

Background and Description of the Problem

In 2011, an international consensus clinical practice statement listed psychogenic nonepileptic seizures (PNES) among the top three neuropsychiatric problems health care providers face (Kanemoto et al., 2017). Unlike epileptic seizures, PNES events, which look very similar to epileptic seizures, are not the result of abnormal brainwave activity, but constitute a mental health condition related to stress and poor coping (Allendorfer et al., 2019; Sawchuk & Buchhalter, 2019). Reported prevalence rates for PNES vary between 2 and 33/100,000 (Benbadis & Hauser, 2000). Each hospitalization for PNES costs, on average, $4724—just slightly less than the cost for epilepsy-related hospitalizations (Luthy et al., 2018). Additional costs accrue when patients and families have difficulty accepting this diagnosis, leading 37% to seek a second opinion (Tolchin et al., 2018). However, when PNES strikes children and adolescents, the financial toll pales in comparison to the toll on their school experience.

The school experience has been identified as a source of predisposing, precipitating, and perpetuating factors for PNES, with adolescents reporting school-related difficulties, learning disabilities, social concerns with friends, bullying, poor relationships with teachers, and poor school attendance as triggers for PNES-inducing stress (Alhafez & Masri, 2019; Asadi-Pooya, Myers, et al., 2019; Doss et al., 2017; Dunne et al., 2019; Uzun et al., 2019; Valente & Alessi, 2014; Y. Yi. et al., 2014). Interestingly, more children and adolescents are diagnosed with PNES in the spring and fall than in the summer, further supporting the connection between school stress exposure
and PNES (Luthy et al., 2018). To best meet the mental health care needs of students with PNES, the students’ school experience and school environment stressors must be better understood and addressed using an approach that involves an understanding of both adolescent health and education needs.

A number of theories and frameworks help bridge health care and education perspectives for multidisciplinary care of adolescents with PNES. The Framework for 21st Century School Nursing Practice (National Association of School Nurses, 2016) and Bronfenbrenner’s Bioecological Model of Human Development (Bronfenbrenner & Morris, 2006) identify strong connections between the influences of a student’s health care experiences and school experiences. Additionally, the Self- and Family Management Framework emphasizes the collaborative management efforts of adolescents and their families to reach disease management and school goals (Grey et al., 2015). Through its focus on illness representation as a means of achieving self-management, Leventhal’s Common Sense Model of Self-regulation (Leventhal et al., 2016) provides concepts that could impact future health care-family-adolescent care coordination efforts.

Coordinating care for students with PNES is challenging for both the health care system and the education system. Health care providers identified providing PNES response guidance as an ethical dilemma because recommending no emergency action be taken for PNES events at school may lead to school personnel not taking appropriate emergency action for epileptic seizures. Conversely, non-nurse school employees have great difficulty witnessing PNES events and not following epileptic seizure first aid protocols, including calling 911 (Cole et al., 2014). Unfortunately, calling 911 for nonepileptic seizures can have dire consequences, such as inappropriate use of
antiepileptic medications, respiratory suppression, and intubation (Benbadis, 1999; Buonsenso et al., 2019). To avoid potentially life-threatening outcomes, experts recommend school personnel, health care providers, and parents work together to override school seizure policies that are not pertinent to students with PNES, possibly through accommodations set forth in an Individualized Education Plan (IEP) per the Individuals with Disabilities Education Act (IDEA) or a Section 504 plan per the Rehabilitation Act of 1973 (Cole et al., 2014).

IDEA, 504, and the Americans with Disabilities Act (ADA) outline the rights of students with disabilities (McCarthy et al., 2019). IDEA requires schools to provide students with disabilities (based on specific disability categories) a free appropriate public education (FAPE), which may include special education and related services as determined by an IEP team. Section 504 and ADA prohibit disability-based discrimination in schools and have a broader definition of disability. Some students with PNES may meet the definition of having a disability under IDEA while others may meet eligibility requirements under the broader definition of 504/ADA. When meeting the definition of disability under either federal law, students with PNES are entitled to a FAPE in a setting that prohibits disability-based discrimination. After meeting eligibility criteria under IDEA or Section 504, a team determines a plan including appropriate services and accommodations to meet the qualifying student’s needs and allow participation in the education program (McCarthy et al., 2019).

School nurses are uniquely positioned to facilitate both health and education plans with health care providers, school personnel, families, and students. Additionally, school nurses can empower students and families to work closely with health care and education
partners through supporting self- and family-management. Self- and family-management are processes in which students and their families use strategies to cope with PNES, including communicating with health care providers and school team members (Miller et al., 2015; Tanner & Miller, 2019). The outcomes of such processes can impact adolescents’ and families’ perceptions of PNES and methods of coping with PNES. For the health and future academic and life success of adolescents with PNES, targeted interventions are needed, but cannot be developed without understanding the experience of school-, self-, and family-management of PNES. This chapter will examine the purpose of this study, including the specific aims, research questions, and the significance of contributions resulting from this research.

**Study Purpose**

There is a preponderance of documented school struggles for students with PNES. Because of these school struggles stemming from a mental health concern, experts have recommended health care providers and school officials align in caring for adolescents with PNES (Cole et al., 2014). Therefore, the purpose of this study was to investigate the experience of students attending school with PNES, students’ expressions of concepts applicable to the development of a conceptual framework for future adolescent PNES research, and opportunities for health care and school alignment in supporting self- and family-management when caring for adolescents with PNES.

**Specific Aims and Research Questions**

Upon reviewing existing literature and theories pertaining to illness representation, self- and family-management, and school environment and interactions, a gap regarding the understanding of the school experience for students with PNES
emerged. Chapter 2 will address these literature review findings in detail. To address the knowledge gap, the following research questions guided this research:

1. What is the experience of attending school as an adolescent with PNES?
2. What do adolescents do to self-manage their condition?
3. What are barriers and facilitators to adolescent PNES self-management?

In addition to answering the research questions, theoretical constructs that emerged from inductive analysis of the qualitative data were examined. Finally, an analysis of how the law relates to the research findings is provided, which may inform future school nurse interventions for adolescents with PNES.

**Significance of Contributions**

Mounting evidence reveals the academic struggles of adolescents with PNES. School-related stressors precipitate and perpetuate PNES and serve as triggers for PNES events. PNES frequently occur in adolescents at a time when school attendance and performance are critical for reaching future education and career goals. PNES in adolescents are associated with poor school attendance, resulting in poorer academic performance than healthy siblings or peers (Akdemir et al., 2013; Dunne et al., 2019). School stressors can trigger PNES events before or during school, resulting in missed full or partial school days. Poor school attendance can decrease the likelihood for high school graduation, which can dramatically decrease future employability and life expectancy (Woolf & Schoomaker, 2019).

In this study, the experience of attending school with PNES as well as perceived relationships between school, stress, coping, PNES event occurrence, self-management strategies, and the effect of current self-management strategies for adolescents were
examined. By understanding these experiences and relationships, researchers can develop a conceptual framework, test relationships, develop interventions, and improve academic, mental health, and QOL outcomes for adolescents with PNES. Improving such outcomes in adolescence can increase the likelihood of improved mental health, employability, and length of life in adulthood (Woolf & Schoomaker, 2019).

**Summary**

The crippling effects of PNES during adolescence impact the school experience in ways that could negatively affect adolescents’ adult lives as well. PNES self- and family-management could potentially mitigate or reverse the deleterious effects of PNES on the school experience. This study was built upon existing knowledge of pediatric PNES and explored the experience of adolescents attending school and self-managing PNES. The results of this study may inform future self-, family-, and school-management interventions for the improvement of academic, mental health, and QOL outcomes for adolescents with PNES.
CHAPTER II
REVIEW OF LITERATURE

Introduction

Literature addressing PNES is growing. The majority of PNES literature addresses PNES in adulthood; however, pediatric PNES literature provides evidence that this mental health condition with debilitating physical effects greatly impacts the school experience for adolescents. There is also evidence to support addressing the mental health aspects of PNES through school-based interventions. School-based interventions addressing self- and family-management, based upon theoretical perspectives related to illness perceptions and coping, may be appropriately driven by the uniquely positioned and equipped specialty of school nursing. This chapter explores existing literature related to the school-related impact of PNES in adolescents, school-based interventions applicable to adolescent PNES, self- and family-management as an intervention for adolescents with PNES, the role of school nurses in providing self-management support, and theoretical perspectives informing adolescent PNES research.

What is the School-Related Impact of Psychogenic Nonepileptic Seizures in Adolescents?

Based upon the documented school struggles for students with PNES and recommendations for health care provider and school alignment in caring for children and adolescents with PNES, a review of studies pertaining to pediatric PNES, school concerns, and potential school-based interventions was conducted. The purpose of this report is to present research findings that supported the development of a new conceptual framework that guided this qualitative study.
Methods

This limited integrative review identified issues relevant to caring for kindergarten through 12th grade students with PNES. A search of CINAHL, ERIC, Medline, PsychInfo, and Embase databases was utilized in November 2019 to identify articles including the following search terms: ("psychogenic nonepileptic seizures" OR "dissociative seizures" OR "dissociative attacks" OR "nonepileptic attack disorder" OR "non-epileptic attack disorder") AND ("pediatric" OR "adolescent" OR "school" OR "academic" OR "learning"). The results were limited to publications between 2009 and 2019.

Only quantitative studies were included in the review. While several studies regarding PNES have included qualitative methods or systematic reviews of existing literature, framework development and PNES research advancement should build upon testable and previously tested concepts related to PNES care. Articles identified during the literature search were excluded if, upon closer review of their abstract or full text, the article fell under the following categories: case studies, reviews, non-research articles, articles regarding achieving a PNES diagnosis, articles involving only adults unless no similar study had been published regarding adolescents and findings could inform framework (used with caution), or conference proceedings.

Literature Review Findings

Using the above search strategies, 955 articles were identified for further review. Upon reviewing titles and/or abstracts, 36 articles were selected for a full review of the text. Twenty articles met inclusion and exclusion criteria. Twelve of the included studies involved children/adolescents as participants (Akdemir et al., 2013; Asadi-Pooya, Myers,
et al., 2019; Bursch et al., 2018; Doss et al., 2017; Kozlowska et al., 2017; Luthy et al., 2018; Plioplys et al., 2014; Sawchuk & Buchhalter, 2015b; Say et al., 2015; Uzun et al., 2019; Valente et al., 2017; Yadav et al., 2015) while eight studies involved adult participants (Baslet et al., 2019; Clegg et al., 2019; Novakova et al., 2019; Pick et al., 2018; Rawlings et al., 2017b; Roberts et al., 2019; Rosales et al., 2019; Tolchin et al., 2018). Studies with adult participants were included if no comparable concepts had been tested with a pediatric population and the concepts could inform future research for pediatric populations. Characteristics of included studies can be found in Table 1.
Table 1

**Characteristics of Included Studies**

<table>
<thead>
<tr>
<th>Primary Author Pub. Year</th>
<th>Theory Used</th>
<th>Country</th>
<th>N</th>
<th>Sex</th>
<th>Age*</th>
<th>Race</th>
<th>Research Design</th>
<th>Variables Measured</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Akdemir 2013</td>
<td>None stated</td>
<td>Turkey</td>
<td>34</td>
<td>79.4</td>
<td>12-17</td>
<td>NR</td>
<td>Cross-sectional non-experimental comparative (with healthy adolescents) descriptive</td>
<td>Health-related quality of life (HRQOL), seizure frequency, comorbid psychiatric disorder</td>
<td>Physical and psychosocial HRQOL (emotional and school functioning) were lower for those with PNES. Seizure frequency and duration did not correlate with HRQOL.</td>
</tr>
<tr>
<td>Asadipooya 2019</td>
<td>None stated</td>
<td>Iran, Brazil, USA, Canada, Venezuela</td>
<td>229</td>
<td>64.6</td>
<td>4-16</td>
<td>NR</td>
<td>Retrospective descriptive</td>
<td>Demographics, country, predisposing factors</td>
<td>There were similar risk-factors for PNES among represented nations. Academic/school difficulties were leading predisposing factors for PNES.</td>
</tr>
<tr>
<td>Baslet 2019</td>
<td>None stated</td>
<td></td>
<td>49</td>
<td>85.7</td>
<td>Mean</td>
<td>46.2</td>
<td>Prospective longitudinal experimental</td>
<td>PNES frequency, intensity, duration, and QOL</td>
<td>PNES intensity, frequency, and QOL improved post-mindfulness intervention</td>
</tr>
<tr>
<td>Study</td>
<td>Design</td>
<td>Sample Size</td>
<td>Mean Age</td>
<td>Gender Distribution</td>
<td>Setting</td>
<td>Methods</td>
<td>Findings</td>
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<tr>
<td>Bursch 2018</td>
<td>Miller’s Monitoring–Blunting Theory of Coping</td>
<td>USA</td>
<td>First PNES follow up appointment</td>
<td>Cross-sectional non-experimental comparative (with siblings)</td>
<td>Child coping styles, parental bonding styles, urgent medical care use</td>
<td>Those with PNES had much higher urgent medical care use than siblings. Higher urgent medical care associated with rejecting and overprotective fathers and youth coping via monitoring. Lower use associated with caring and overprotective mothers and youth coping via solitary venting.</td>
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<tr>
<td>Clegg 2019</td>
<td>Integrative Cognitive Model (mentioned, not used)</td>
<td>Ireland</td>
<td>Neurology outpatient clinic</td>
<td>Cross-sectional non-experimental comparative (with epilepsy and healthy controls) descriptive</td>
<td>Self-compassion, adjustment (coping efficacy, QOL, anxiety, depression)</td>
<td>Self-compassion was associated with adjustment in those with epilepsy and PNES.</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Doss</td>
<td>None stated</td>
<td>USA</td>
<td>55</td>
<td>70.9</td>
<td>8-18</td>
<td>60.0W</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Year</td>
<td>Country</td>
<td>Study Type</td>
<td>Demographics</td>
<td>Research Findings</td>
<td></td>
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<tr>
<td>2017</td>
<td>USA</td>
<td>Tertiary epilepsy centers</td>
<td>Cross-sectional non-experimental comparative (with sibling) descriptive</td>
<td>Psychopathology, intelligence/achievement test scores, language fundamentals, history of bullying. History of bullying, impaired formulation of sentences, and diagnosis of anxiety were associated with increased likelihood of learning problems for those with PNES.</td>
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</tr>
<tr>
<td>Kozlowska 2017</td>
<td>None stated</td>
<td>60</td>
<td>70.0</td>
<td>8-17</td>
<td>NR</td>
<td>Cross-sectional non-experimental comparative (with healthy controls) descriptive</td>
<td>Motor system respiratory readiness, respiratory regulation of CO2 (Baseline CO2 rates and arterial CO2). Those with PNES had higher baseline respiratory/heart rates, five times greater likelihood of hypoxia s/s during hyperventilation challenge. Half experiencing PNES event experienced hyperventilation immediately before event.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Luthy 2018</td>
<td>None stated</td>
<td>399</td>
<td>72.4</td>
<td>8-20</td>
<td>67.1W 26.7B</td>
<td>Retrospective descriptive comparative (with epilepsy controls)</td>
<td>Demographics, health care use. Those with PNES were more likely female, older, African American, have other psychiatric disorders and pain, more likely admitted in fall or spring. Average hospital stay for PNES was $4724 (vs. $5326 for epilepsy).</td>
<td></td>
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</tr>
<tr>
<td>Study</td>
<td>Year</td>
<td>Region</td>
<td>Sample Size</td>
<td>Mean Age</td>
<td>SD</td>
<td>Type of Study</td>
<td>Measures</td>
<td>Findings</td>
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</tr>
<tr>
<td>Novakova 2019</td>
<td>2019</td>
<td>UK</td>
<td>12</td>
<td>70.4</td>
<td>41.8</td>
<td>NR</td>
<td>Outpatient neurology clinics</td>
<td>Prospective randomized control trial pilot</td>
<td>Stress, anxiety, depression, QOL, seizure severity and frequency</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Mean</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Self-help management intervention perceived acceptable and helpful. Significant reduction in stress post-intervention noted. PNES group too small to perform subgroup comparisons.</td>
</tr>
<tr>
<td>Pick 2018</td>
<td>2018</td>
<td>UK</td>
<td>39</td>
<td>79.5</td>
<td>37.9</td>
<td>79.5W</td>
<td>Neuropsychiatry services</td>
<td>Cross-sectional non-randomized healthy control trial</td>
<td>Emotional valence, arousal, skin conductance responses</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Mean</td>
<td></td>
<td>20.5NW</td>
<td></td>
<td></td>
<td>Skin conductance response amplitude was greater for those with DS considered autonomic responders, which could serve as a seizure trigger amenable to interventions for identifying/regulating physical arousal and emotions.</td>
</tr>
<tr>
<td>Plioplys 2014</td>
<td>2014</td>
<td>USA</td>
<td>55</td>
<td>71.0</td>
<td>8-18</td>
<td>60.0W</td>
<td>Tertiary pediatric epilepsy monitoring units</td>
<td>Cross-sectional non-experimental comparative (with sibling) descriptive</td>
<td>Cognitive/academic achievement, school absences, coping, stress, adversities, parental bonding</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Mean</td>
<td></td>
<td>40.0NW</td>
<td></td>
<td></td>
<td>Those with PNES reported higher number of adversities, including bullying, than siblings, increased use of solitary emotional coping, and poorer school attendance.</td>
</tr>
<tr>
<td>Study</td>
<td>Design</td>
<td>Sample Size</td>
<td>Sample Mean</td>
<td>Sample SD</td>
<td>Setting</td>
<td>Methodology</td>
<td>Results</td>
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<tr>
<td>Rawlings</td>
<td>Cross-sectional non-experimental comparative (with epilepsy) descriptive</td>
<td>45</td>
<td>91.1</td>
<td>38.0</td>
<td>NR</td>
<td>UK</td>
<td>Outpatient neurology clinics</td>
<td>Illness perceptions, psychological distress, seizure frequency and severity, HRQOL. Those with PNES had lower HRQOL and perceived their condition as more threatening. HRQOL was negatively correlated with more severe illness perceptions. Seizure frequency was not associated with HRQOL for those with PNES.</td>
<td></td>
</tr>
<tr>
<td>Roberts</td>
<td>Cross-sectional non-experimental comparative (trauma control) descriptive</td>
<td>11</td>
<td>81.8</td>
<td>45.0</td>
<td>NR</td>
<td>USA</td>
<td>Online/mailed questionnaire, laboratory</td>
<td>Relived emotion task pre/during/post-task cardiovascular interbeat intervals and respiratory sinus arrhythmia (RSA). Three with PNES struggled to complete tasks related to shame and anger, had PNES during the task. Those with PNES and history of past trauma had RSA changes indicating difficulty with emotional engagement. Avoidance was used more with those with PNES.</td>
<td></td>
</tr>
</tbody>
</table>
| Rosales    | Cross-sectional non-experimental descriptive                           | 143         | 83.0        | 39.0      | 73W     | USA         | Extended Process Model of Emotion Dysregulation                         | Emotion perception, copying style, psychopathology severity. Those with PNES who had history of child abuse, active PTSD, depression, and reported stress had lower clarity of emotions and
ability to adjust to emotional states. Cognitive-emotion processing deficits were more pronounced in patients with more severe depression and reported stress.

<table>
<thead>
<tr>
<th>Study</th>
<th>Country</th>
<th>Setting</th>
<th>Sample Size</th>
<th>Outcome Measures</th>
<th>Methodology</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sawchuk</td>
<td>USA</td>
<td>Single hospital</td>
<td>15</td>
<td>-</td>
<td>Retrospective descriptive</td>
<td>EMR treatment and outcome (full/partial remission), significant life stressors (peer insecurity, learning difficulty, bullying, family conflict)</td>
</tr>
<tr>
<td></td>
<td>Canada</td>
<td>Neurology psychology services</td>
<td>29 76.0 Peds 79W</td>
<td></td>
<td></td>
<td>Appropriate treatment of dx education and psychological CBT were associated with higher rates of full remission.</td>
</tr>
<tr>
<td>Say</td>
<td>Turkey</td>
<td>None stated</td>
<td>62 71.0</td>
<td>-</td>
<td>Cross-sectional non-experimental descriptive</td>
<td>Gender, presentation of PNES, precipitating factors</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Department of child and adolescent psychiatry</td>
<td>11-18  NR</td>
<td></td>
<td></td>
<td>Academic underachievement was the most prevalent precipitating stressor for boys, more so in boys than girls.</td>
</tr>
<tr>
<td>Tolchin</td>
<td>USA</td>
<td>None stated</td>
<td>123 85.0</td>
<td>-</td>
<td>Prospective non-experimental</td>
<td>Adherence with psychiatric</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Mean 38.0</td>
<td>77W 12B 9H</td>
<td></td>
<td></td>
<td>Lower illness perception score (lower level of</td>
</tr>
<tr>
<td>Study</td>
<td>Location</td>
<td>Sample Size</td>
<td>Mean Age</td>
<td>Sample Type</td>
<td>Methodology</td>
<td>Results</td>
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<tr>
<td>Uzun 2019</td>
<td>Turkey</td>
<td>42</td>
<td>12-18</td>
<td>NR</td>
<td>Cross-sectional non-experimental comparative (healthy controls) descriptive</td>
<td>Those with PNES had more emotional and traumatic sexual experiences and PTSD symptoms, higher perceived communication and lower trust in attachment with parents, increased alexithymia symptoms, and lowered self-esteem.</td>
</tr>
<tr>
<td>Valente 2017</td>
<td>Brazil</td>
<td>53</td>
<td>7-18</td>
<td>NR</td>
<td>Cross-sectional non-experimental descriptive</td>
<td>Average time between seizure onset and referral was 17.76 months, with earlier age of onset correlating with later diagnosis, 49.1 reported school difficulties but did not impact time to diagnosis.</td>
</tr>
<tr>
<td>Yadav</td>
<td>None stated</td>
<td>90</td>
<td>5-18</td>
<td>NR</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Year</td>
<td>Location</td>
<td>Setting</td>
<td>Study Design</td>
<td>Outcomes</td>
<td>Findings</td>
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</tr>
<tr>
<td>2015</td>
<td>USA</td>
<td>Level 4 epilepsy center</td>
<td>Retrospective descriptive</td>
<td>PNES remission, frequency, stressors</td>
<td>One-third achieved early, sustained remission, which was associated with early identification.</td>
<td></td>
</tr>
</tbody>
</table>

*Age reported as range for studies involving children and adolescents and as mean for studies involving adults.*
Use of Theory

Of the 20 included articles in this review, authors of only five studies mentioned a theory that guided or informed their research. The five mentioned theories highlighted key constructs for consideration in future PNES research. Miller’s Monitoring-Blunting Theory of Coping (Bursch et al., 2018) highlights the role that response to stress may have on PNES outcomes, depending on one’s tendency to monitor a threat and choose to problem solve, blunt the threat and make choices to avoid or minimize the threat, or vent and opt for yelling or crying in response to a threat. Novakova and colleagues (2019) based their self-help self-management intervention on the Integrative Model of Stress, guiding participants to identify stressors, appraise the stressors and coping skills, and utilize a variety of coping strategies (addressing negative thoughts, employing relaxation/breathing techniques, and changing negative responsive behaviors). Within this study, the Theory of Implementation Intentions also informed the intervention through the use of an implementation intention plan. Other researchers investigated relationships between parent and peer attachment and ability to talk about emotions, based upon the Attachment Theory (Uzun et al., 2019). Finally, two studies included self-regulation concepts from the Common Sense Model of Self-Regulation (Rawlings et al., 2017b) and the Extended Process Model of Emotion Dysregulation (Rosales et al., 2019). Researchers examined the relationship between illness representation (mental representation formed in response to a health threat that can activate coping strategies) and QOL as well as between deficits in cognitive-emotion processing and PNES severity or illness perception.
Sample and Setting

Authors of the included studies investigated convenience samples typically recruited from neurology or psychiatric departments or from epilepsy monitoring units. Participants ranged in age from 4-20 years for studies targeting children and/or adolescents. For studies with adult participants, mean ages for adults ranged from 37.9 to 46.2. Participants were more often female (60.4%-91.1%), although the gender gap was less pronounced in pediatric studies. Fewer than half of the studies were conducted in the United States. Additionally, fewer than half of the studies reported race/ethnicity; however, for those that did provide data on race/ethnicity, those with PNES were predominantly Caucasian/white.

Research Design

Of the included studies, only three incorporated a prospective design, all of which involved adult participants (Baslet et al., 2019; Novakova et al., 2019; Tolchin et al., 2018). Four of the studies were retrospective, using electronic medical records to identify patients with PNES and gather descriptive data for comparison (Asadi-Pooya, Myers, et al., 2019; Luthy et al., 2018; Sawchuk & Buchhalter, 2015b; Yadav et al., 2015). The remaining 13 studies were cross-sectional, occasionally comparing those with PNES to those with epilepsy (Clegg et al., 2019; Rawlings et al., 2017b), to healthy siblings without PNES (Bursch et al., 2018; Doss et al., 2017; Plioplys et al., 2014), or to a healthy comparison group with no evidence of any psychiatric conditions (Pick et al., 2018; Uzun et al., 2019). Only two of the included studies involved any form of randomization—one a prospective study (Novakova et al., 2019) and the other a cross-sectional study (Asadi-Pooya, Myers, et al., 2019).
Variables Assessed

A wide array of variables was examined within the included studies. PNES characteristics including frequency (Akdemir et al., 2013; Baslet et al., 2019; Novakova et al., 2019; Rawlings et al., 2017b; Valente et al., 2017; Yadav et al., 2015), predisposing factors (Asadi-Pooya, Myers, et al., 2019; Say et al., 2015), intensity/severity (Baslet et al., 2019; Novakova et al., 2019; Rawlings et al., 2017b), duration (Akdemir et al., 2013; Baslet et al., 2019), comorbid mental health conditions (Akdemir et al., 2013; Baslet et al., 2019; Clegg et al., 2019; Doss et al., 2017; Novakova et al., 2019), health care utilization (Bursch et al., 2018; Luthy et al., 2018), time between onset and diagnosis (Valente et al., 2017), and remission rates (Sawchuk & Buchhalter, 2015b; Yadav et al., 2015) were examined. Academic and school environment issues were also examined, including intelligence/achievement test scores (Doss et al., 2017; Plioplys et al., 2014), learning difficulty (Sawchuk & Buchhalter, 2015b; Say et al., 2015; Valente et al., 2017), language fundamentals (Doss et al., 2017), school absences (Plioplys et al., 2014), relationship with teachers (Say et al., 2015; Valente et al., 2017), peer insecurity (Sawchuk & Buchhalter, 2015b), peer attachment (Uzun et al., 2019), and history of bullying (Doss et al., 2017; Sawchuk & Buchhalter, 2015b; Say et al., 2015; Valente et al., 2017).

Family characteristics were frequently examined, including parental bond/attachment (Plioplys et al., 2014; Uzun et al., 2019) and family conflict (Sawchuk & Buchhalter, 2015b; Say et al., 2015). Additionally, self-management components potentially amenable to intervention were routinely investigated. Self-management factors included coping style (Bursch et al., 2018; Plioplys et al., 2014; Rosales et al.,
2019), coping efficacy (Clegg et al., 2019), self-compassion (Clegg et al., 2019), respiratory regulation (Kozlowska et al., 2018a; Roberts et al., 2019), illness perception (Rawlings et al., 2017b; Tolchin et al., 2018), emotion perception (Rosales et al., 2019), and adherence to psychiatric treatment (Tolchin et al., 2018). For studies that involved interventions, measured outcomes included PNES intensity (Baslet et al., 2019), frequency (Baslet et al., 2019), QOL (Baslet et al., 2019), stress reduction (Novakova et al., 2019), and adherence to long-term psychiatric treatment (Tolchin et al., 2018).

**PNES Research Results**

Many research findings related to health care utilization and mental health outcomes. Results of the included studies highlighted higher urgent health care utilization for those with PNES compared to controls (Bursch et al., 2018), although mothers perceived as caring and overprotective (Bursch et al., 2018) and those with PNES using solitary venting coping had lower health care utilization (Bursch et al., 2018). Seemingly contradictory, another study demonstrated more children and adolescents with PNES than their healthy peers used solitary venting emotional coping (Plioplys et al., 2014). Results also indicated lower QOL for those with PNES compared to controls (Akdemir et al., 2013; Rawlings et al., 2017b) and lower QOL for those perceiving their condition as severe (Rawlings et al., 2017b), but improvements in QOL and PNES frequency after a mindfulness intervention (Baslet et al., 2019). Self-compassion was associated with greater adjustment (Clegg et al., 2019) while self-help stress management resulted in stress reduction (Novakova et al., 2019). Participants receiving diagnosis education and cognitive behavioral therapy had higher rates of full remission from PNES (Sawchuk & Buchhalter, 2015b); however, those with lower levels of concern (evidenced by lower
illness perception scores) were less likely to adhere to mental health treatment such as cognitive behavioral therapy (Tolchin et al., 2018).

Academic/school difficulties ranked as leading predisposing factors in PNES diagnosis (Asadi-Pooya, AlBaradie, et al., 2019; Say et al., 2015). Children and adolescents with PNES were more likely admitted to the hospital in the fall or spring coinciding with the school year (Luthy et al., 2018) and had poorer school attendance (Plioplys et al., 2014). Children and adolescents with PNES were more likely to have experienced bullying than their healthy peers (Plioplys et al., 2014), while a history of experiencing bullying also increased the likelihood of learning problems for children and adolescents with PNES (Doss et al., 2017).

Biomarkers brought a more objective lens to the PNES research as well as an indication of identifiable physical cues that may inform students’ illness representation. Those with PNES were found to have higher baseline respiratory and heart rates (Kozlowska et al., 2017). Also, those with PNES were five times more likely to experience signs of hypoxia during a hyperventilation challenge, with half experiencing hyperventilation immediately prior to a PNES event (Kozlowska et al., 2017). Skin conductance response amplitude was greater for those with PNES considered to be autonomic responders, with autonomic response being a trigger for PNES events (Pick et al., 2018). Those with PNES had a greater likelihood of respiratory sinus arrhythmia during relived emotion tasks, indicating difficulty with emotional engagement and emotion regulation (Roberts et al., 2019).
Discussion of Literature Review Findings

Authors of existing research provide a glimpse into what is currently known about pediatric PNES from a health care system perspective. However, none of the authors of identified articles examined pediatric PNES from a student, family, or school perspective. Appropriately, several researchers focused on school environment and school-related variables as correlates to having a diagnosis of PNES. However, thus far, researchers have considered school variables as predisposing, precipitating, and perpetuating factors. Researchers have seldom looked at the consequences of PNES on school-related and long-term outcomes or what might mediate or moderate outcomes for children and adolescents with PNES. Researchers investigating potential interventions targeting mediators (self-management strategies such as mindfulness, self-compassion, or identifying/responding to biological cues) have studied adults; the same interventions might not have similar effects on pediatric participants.

The authors cited in this literature review who reported theoretical underpinnings offered insight into important constructs for future research. Coping with stress and regulating one’s physical and emotional responses to stress and threatening illness representations are critical to the self-management of PNES. These concepts can be applied to the school experience as researchers consider how students can be taught to cope with school-related stressors and respond to illness representations by activating self-management strategies.

The prevalence of school environment issues in extant PNES literature highlights the importance of developing a conceptual framework that includes exploring the school environment from students’ perspectives. Pediatric PNES research must move beyond
correlational studies within neurological and psychological health care environments to better understand associations between school-related variables and outcomes for students with PNES. As researchers expand research from the health care perspective into the education system and student perspectives, they can expand the impact of their research to include not only mental health outcomes (such as decreased PNES events), but also academic and QOL outcomes. School nurses, with an evidence-based guiding framework, can play a critical role in the translation of PNES research to the academic practice settings.

**What School-Based Interventions Exist that Could Address Psychogenic Nonepileptic Seizures in Adolescents?**

The following section is an excerpt from a published manuscript with the following citation and is used with the permission of the co-authors and in accordance with SAGE guidelines:

https://doi.org/10.1177/1059840519854796

Just as PNES impacts not only the health but also the education of adolescents, interventions must move beyond health care-based to school-based to meet the multidisciplinary needs of adolescents. Within the school setting, the school nurse may be the first to realize the extent of both psychological and psychosomatic complaints of students with PNES, as evidenced by frequent visits to the health office. Children and adolescents with PNES experience significant problems with relationships, school
attendance, and academic performance (Morgan & Buchhalter, 2015), which are issues school nurses may detect and address. Roughly 75% of schools in the United States employ a school nurse at least part-time to coordinate care for physical and mental health concerns (Willgerodt et al., 2018). Yet, despite the school-centric nature of students’ concerns and the presence of nurses in most schools to address their concerns, authors of pediatric PNES literature do not recognize school nurses as important contributors to the care of students with PNES (Caplan et al., 2017; Doss et al., 2017; Reilly et al., 2013; Sawchuk & Buchhalter, 2015b). The American Epilepsy Society (2018) does acknowledge the role of the school nurse as first responder for PNES events and trainer of school personnel on how to respond to events; however, the only guidance for responding to PNES events at school includes encouraging bystanders to not interact with the student and to continue normal activities (American Epilepsy Society, 2018; Caplan et al., 2017). Despite documented mental health interventions—including reassurance, clear communication regarding the diagnosis, parent education, and cognitive behavioral therapy (CBT)—being associated with reduction of PNES events (Caplan et al., 2017; Rawat et al., 2015; Sawchuk & Buchhalter, 2015b; Yadav et al., 2015), the role of the school nurse beyond PNES event first responder is unclear.

A preliminary search of the literature revealed no school nurse intervention studies that address appropriate school nurse interventions for PNES; therefore, research is necessary to design and test school nurse interventions that may improve the QOL, academic, and mental health outcomes for students with PNES. Before school-based PNES interventions can be imagined and researched, it is important to examine school-based interventions for related conditions. Because PNES is a mental health condition
and is often influenced by underlying anxiety and/or depression, one approach for planning PNES-specific interventions is to examine the state of the science of school nurse interventions for mental health concerns in general. Therefore, this integrative review answers the questions: “What school nurse interventions have been tested that address mental health concerns of students? What are the QOL, academic, and mental health outcomes of these interventions?”

Methods

This integrative review was completed using the methods outlined by Whittemore and Knafl (2005). This particular method is appropriate for the topic of PNES, school-based mental health, and school nurse interventions, because these concepts lack rigorous research and require reviewing both experimental and non-experimental literature to gain understanding. In accordance with Whittemore and Knafl’s (2005) method, this integrative review included searching the literature, evaluating data, analyzing data, and presenting results.

Search Strategy

The literature search included utilizing CINAHL, MEDLINE, PsycINFO, and ERIC via EBSCO (see Figure 1). This combination of databases ensured the identification of nursing, school nursing, educational, and psychological literature. The search included the following search terms: "mental health" OR "anxiety" OR "depression" OR "stress" OR "conversion disorder" OR "somatic" AND "school nurse" OR "school health nurse" OR "school nursing" OR "school nurse intervention". To confirm a thorough search of school nursing literature, the author hand searched The
*Journal of School Nursing* as well as reference lists of review articles regarding school nurse interventions.

**Figure 1**

*PRISMA Flowchart Reporting the Literature Selection Process*

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**Search Criteria**

Articles were included in the integrative review if they addressed an actual or potential school nurse intervention for mental health concerns, focused on pediatric/child or adolescent age groups (capturing the ages of students in kindergarten through 12th grade), and were written in English. Articles published in the last 20 years were included.
Exclusion criteria included document types that fell under the categories of books, dissertations, reviews, editorial/opinion works, case studies, incomplete trial protocols, or informational pieces as well as works about substance abuse, identification/referral to other care providers, or school-based health centers where the nurse has prescriptive authority.

**Literature Review Findings**

When limiting the search to English language and pediatric/child age, the search yielded 663 articles. After removing duplicates via EBSCO’s “remove duplicates” command, 461 articles remained. A backward search of references from pertinent review articles revealed one additional article. A review of titles and abstracts for inclusion criteria (school nurse mental health interventions or potential interventions) whittled the remaining articles to 57 full-text documents. After applying the previously mentioned exclusion criteria, 15 full-text articles published between 1998 and 2017 met criteria for inclusion in the integrative review (see Figure 1).

**Evaluation of Data**

The Critical Appraisal Skills Programme (2018) checklist provided data evaluation criteria. Further discussion of empirical and theoretical traditions noted in the evaluation as well as their implications is included in a subsequent section. Details regarding each study’s risk for bias were documented in Table 2. Due to the investigative nature of this review, meaningful information was gleaned from the studies’ interventions and qualitative reports’ themes. No articles were excluded due to quality of design or reporting.
<table>
<thead>
<tr>
<th>First Author, Year</th>
<th>Theory</th>
<th>Country Design Sample</th>
<th>Intervention Summary</th>
<th>Risk of Bias</th>
<th>Implications</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bannink, 2014</td>
<td>Not reported</td>
<td>Netherlands</td>
<td>E-health4U tailored web-based mental health wellbeing messages with and without school nurse consultation using motivational interviewing for adolescents at risk for mental health concerns (according to web-based program)</td>
<td>Risk lowered due to large sample size and RCT design, although use of self-report and attrition rate of non-Dutch lower educated adolescents could make results less generalizable</td>
<td>Future study should examine school nurse consultation alone without web-based program. School nurse portion of intervention made greatest impact; however, web-based program can inform school nurse of student needs.</td>
</tr>
<tr>
<td>Clausson, 2008</td>
<td>Illness Beliefs Model, Calgary Family Assessment and Intervention Models</td>
<td>Sweden</td>
<td>Therapeutic conversations with families (through family sessions) in alleviating recurring health complaints among adolescent girls in a school setting. Two school nurses used a semi-structured guide written by the authors. Also, developing ecomaps and genograms with the family and sending therapeutic letter from school nurse to family were used as interventions.</td>
<td>Overgeneralization of positive results with no statistical reporting in write-up</td>
<td>School nurse family sessions using ecomaps and genograms and closing affirming letter may improve student and family perceptions of impact of managing mental health and somatic symptoms.</td>
</tr>
<tr>
<td>Fox, 2005</td>
<td>Cognitive behavioral</td>
<td>US</td>
<td>School based cognitive-behavioral program provided by</td>
<td>Small sample size, no comparison group,</td>
<td>Utilizing schools can be an effective way to mitigate</td>
</tr>
<tr>
<td>First Author, Year</td>
<td>Theory</td>
<td>Country</td>
<td>Design Sample</td>
<td>Intervention Summary</td>
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<tr>
<td><strong>International Journal of Psychiatric Nursing Research</strong></td>
<td>Not reported</td>
<td>US</td>
<td>pre-test, post-test</td>
<td>Bilingual/bicultural teachers, school nurses, and nurse researchers</td>
<td>Including all SEA children instead of only those with depressive symptoms may have masked greater effect. It is possible that similar scores would have been found in non-SEA students living in similar sociodemographic situation.</td>
</tr>
<tr>
<td><strong>Houck, 2002</strong></td>
<td>Cognitive-behavioral</td>
<td>US</td>
<td>pre-test, post-test</td>
<td>Sessions co-led by school nurse and a mental health counselor with cognitive-behavioral and psychoeducational focus. School nurse selected program to meet his/her preferences.</td>
<td>Poor description of data collection. Need to plan for latency in effect. School nurses choose the program they wished to use, so no consistency in intervention for comparison. No comparison group.</td>
</tr>
<tr>
<td><strong>Hoying, 2016</strong></td>
<td>Cognitive-behavioral</td>
<td>US</td>
<td>Manualized CBSB program based on CBT principles utilizing 12 empirically based concepts</td>
<td>One-group study design, no control group, no measurement of long-term effects of the intervention.</td>
<td>Correlation findings support school nurses using the CBSB techniques found in</td>
</tr>
<tr>
<td>First Author, Year</td>
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<tr>
<td>Journal of School Nursing</td>
<td>skill building/CBT</td>
<td>one group pre- and posttest experimental design, feasibility pilot study</td>
<td>31 6th grade convenience sample age 11-13 years</td>
<td>Mental health-promoting dialogue with the school nurse</td>
<td>Term effects. Confounding factors such as change in season could impact results.</td>
</tr>
<tr>
<td>Johansson, 2006</td>
<td>Not reported</td>
<td>Sweden</td>
<td>Descriptive design using inductive qualitative content analysis</td>
<td>26 15-year-olds placed into 5 focus groups</td>
<td>Thorough description of analysis provided decreased risk of bias. Authors may be overemphasizing the role of “good dialogue” in mental health without supporting the statement with empirical data. Using focus groups may limit openness in discussing sensitive topics.</td>
</tr>
<tr>
<td>Kim, 2015</td>
<td>Not reported</td>
<td>US</td>
<td>School nurses trained to deliver psychoeducation about the problem and services, assessment of barriers</td>
<td>Actual follow through for adolescents seeking mental health services</td>
<td>Further testing needed. Need for longer training time. Program seems to be</td>
</tr>
<tr>
<td>First Author, Year</td>
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<tr>
<td><strong>Advances in School Mental Health Promotion</strong></td>
<td></td>
<td>pilot feasibility study, pre-test post-test</td>
<td>to services, problem solving those barriers, setting positive expectations for services, eliciting change talk to address problem, planning for referral, and following up with the student</td>
<td>not measured, but youth readiness for services was.</td>
<td>feasible and accepted by school nurses.</td>
</tr>
<tr>
<td>Lamb, 1998</td>
<td>Developmental tasks of adolescence, didactic and cognitive-behavioral group models, and coping</td>
<td>US Two-phase experimental study</td>
<td>Cognitive-behavioral model with a standard protocol, didactic content on common teen stresses, self-image, coping, family relationships, and communication, experiential learning through identifying their problems and engaging in concrete problem solving tasks, group discussion, role-play, problem solving, worksheets, handouts, films, audio tapes, and group projects, and homework.</td>
<td>Timing of pretest in winter and posttest in late spring could confound depressive symptom results. Females were more responsive to intervention than males; future study should use male interventionists, especially for male groups to see if gender affects outcomes. Further testing should be done to determine effectiveness in non-rural settings.</td>
<td>Intervention was feasible for school nurses and could be very beneficial for rural adolescents who may not have access to mental health services.</td>
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</table>

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<thead>
<tr>
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<tbody>
<tr>
<td>Muggeo, 2017</td>
<td>Not reported</td>
<td>US</td>
<td>Pre-/post-test feasibility study</td>
<td>9 school nurses, 11 students age 5-11 years with elevated symptoms of anxiety</td>
<td>Nurse-administered intervention (CALM—Child Anxiety Learning Modules) based on cognitive behavioral strategies to reduce anxiety symptoms and improve academic functioning.</td>
<td>No randomization or control group, fairly homogenous group. Need for fidelity measures. One could argue that those students with study results indicating anxiety diagnosis should have been referred rather than receiving potentially sub-optimal care from a school nurse.</td>
<td>School nurses found it difficult to find uninterrupted time to deliver intervention to students.</td>
</tr>
<tr>
<td>Olowo-kere, 2014</td>
<td>Not reported</td>
<td>Nigeria</td>
<td>quasi-experimental design (pretest–posttest nonequivalent group design)</td>
<td>15 nurses, 14 teachers from</td>
<td>Nurses were trained, then nurses trained teachers using same modules, teachers and school nurses worked together to identify vulnerable students using an instrument. Student experiment 1 group received resilience training only, group 2 participated in support groups where life skills were taught, and group 3 received both. Control group school nurses, teachers, and students received no</td>
<td>Authors report low statistical power. Relatively low sample size. Recruitment process-students with low scores in only some content areas participated. Future studies should consider which content areas were found to be vulnerable for each</td>
<td>School nurses' training of teachers can influence interventions teachers provide for students.</td>
</tr>
<tr>
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<tr>
<td>Ramirez, 2013</td>
<td>Not reported</td>
<td>US</td>
<td>pilot quasi-experimental</td>
<td>20 middle/high school children from 6 different schools</td>
<td>Listen (reflective listening and non-invasive questioning), protect (use K6 screener to identify response to trauma and refer those at risk for maladaptive responses), connect (to resources and advanced care as needed)</td>
<td>LPC is intended to be offered soon after trauma, but this intervention did not occur until 10 months later, which may skew effectiveness. Small sample size and recruitment by self- or school nurse referral result in limited generalizability. This study was unable to control for effectiveness for different types of trauma. Number of</td>
<td>LPC is a feasible intervention for school nurses and well received by students who experienced trauma. School nurses can use this intervention soon after a traumatic event, including natural disaster, school shooting, loss of loved one, etc.</td>
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</table>

2 schools, 109 children determined vulnerable for psychosocial issues (50 from the randomized school and 59 from control school) intervention. Authors did not mention who delivered resilience program, but teachers facilitated support group. student and should better track psychosocial outcome measures.
<table>
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<th>Implications</th>
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</thead>
<tbody>
<tr>
<td>Spratt, 2010</td>
<td>Not reported</td>
<td>UK</td>
<td>Qualitative</td>
<td>25 school nurse managers</td>
<td>Theme of school nurses building relationships with students and taking a holistic approach were linked to mental health care. However, lack of resources (time/personnel), lack of training/confidence, and tension between offering proactive and reactive care were barriers.</td>
<td>No interviews with school nurses or students to balance the views expressed by school nurse managers. Focus on Scottish schools and their school health model may not be generalizable to US schools and school nursing models.</td>
<td>School nurses offer support in ways that students find accessible and helpful. They can form relationships that support resilience.</td>
</tr>
<tr>
<td>Stallard, 2008</td>
<td>Cognitive behavior theory</td>
<td>UK</td>
<td>1 year follow up pre-test post-test</td>
<td>106 students age 9-10 years</td>
<td>Sessions of universal CBT in schools</td>
<td>Lack of comparison group, inability to know how many students would have become high risk if they had NOT participated, and attrition rate (was similar with other studies of this intervention). Some improvements in anxiety</td>
<td>While time consuming, a universal CBT program is an option. Those with PNES will likely need more targeted interventions, but this suggests that school nurses are capable of delivering CBT and students are receptive and responsive.</td>
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<tr>
<td>First Author, Year</td>
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<tr>
<td>Vessey, 2011</td>
<td>Not reported</td>
<td>US</td>
<td>Two-phased, mixed method design.</td>
<td>11 schools for phase 1, 8 school for phase 2, 65 students age 8-14 years</td>
<td>School nurse-led support groups in strengthening student resilience using 12 webisodes, support group discussion and activities</td>
<td>School nurse's role was not the only factor in improved findings-role of friendship important, concern for those with disability being singled out to attend support group meetings. RCT would be more rigorous and generalizable. Effects over time should be evaluated. No attempts were made to measure effect of parents and school employees being trained on bullying messages as well.</td>
<td>School nurses can provide this care themselves or in conjunction with interdisciplinary group. Visiting school nurse is less stigmatized than principal or counselor.</td>
</tr>
<tr>
<td>First Author, Year</td>
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<tr>
<td>Wall, 2005</td>
<td>Developmental theory, mindfulness</td>
<td>US</td>
<td>Tai Chi and mindfulness training</td>
<td>Lack of details about number of students participating, demographics of participants. No comparison group.</td>
<td>Lacked enough data to draw any conclusions other than program appears to be feasible in school.</td>
<td></td>
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</table>

Note. RCT=randomized control trial; SEA=Southeast Asia; CBSB=cognitive behavioral skill building; CBT=cognitive behavioral therapy; COPE=Coping Openly and Personally with Epilepsy; LPC=Listen Protect Connect; PNES=psychogenic nonepileptic seizures
Data Extraction and Analysis

Each article meeting inclusion and exclusion criteria was reviewed. Data related to the country in which each study was conducted, theoretical/framework underpinnings, study design, sample size and characteristics, intervention, measures, outcomes, risk of bias, and school nurse implications were extracted and summarized in Table 2 (characteristics of articles included in this review) and Table 3 (intervention and outcome details of quantitative studies). For quantitative studies, the details of school nurse interventions were further categorized into length of time required for intervention (number of sessions, frequency, and length of sessions), setting where intervention occurred, audience type (all students in a class, students targeted as “at risk” by a screening tool or process, or students already diagnosed with a condition), and type of school nurse interaction (one-on-one, small group, class, or family). To better understand what outcomes may be beneficial to measure in future school nurse intervention studies, intervention outcomes were categorized as QOL, academic, and mental health outcomes (see Table 3). These outcome categories reflect priorities of the National Association of School Nurses (NASN) and its Framework for 21st Century School Nursing Practice (2016) by focusing on students and their QOL while also considering the academic impact of mental health concerns. The two qualitative studies were examined for themes related to school nurse interventions and outcomes and that offered a deeper understanding of the role school nurses play in student mental health care.
### Table 3

*Intervention Characteristics and Categorized Outcomes*

<table>
<thead>
<tr>
<th>First Author, Year</th>
<th>Summary of Intervention</th>
<th>Length of Overall Intervention Program/Sessions</th>
<th>Setting</th>
<th>Type of Audience (all, at risk, diagnosed)</th>
<th>Type of meeting (individual, group, class, family)</th>
<th>QOL</th>
<th>Academic</th>
<th>Mental Health (MH)</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bannink, 2014</td>
<td>EHealth4U web-based questionnaire and tailored message with and without school nurse consult.</td>
<td>One-time 45 min. class period to complete online questionnaires, read targeted messages, read additional links, and request school nurse consultation if desired.</td>
<td>Classroom; consultation in school nurse’s office</td>
<td>Targeted messages: all School nurse consultation: at-risk students</td>
<td>Individual</td>
<td><strong>QOL:</strong> CHQ-CF-GH4</td>
<td><strong>Academic:</strong> ---</td>
<td><strong>MH:</strong> SDQ, YSR</td>
<td><strong>QOL:</strong> improved B=2.79, 95% CI 0.72-4.87; d=0.09 <strong>MH:</strong> improved SDQ: B=−1.79, 95% CI −3.35 to −0.22; d=0.33; YSR: B=−9.11, 95% CI −17.52 to −0.71; d=0.34</td>
</tr>
<tr>
<td>First Author, Year</td>
<td>Intervention Characteristics</td>
<td>Length of Overall Intervention Program/Sessions</td>
<td>Setting</td>
<td>Type of Audience (all, at risk, diagnosed)</td>
<td>Type of meeting (individual, group, class, family)</td>
<td>Outcome By Category</td>
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</table>
| Clausson, 2008    | Therapeutic conversations with families | 3 sessions per family, approximately 2-3 weeks apart; sessions lasted 1-1.5 hrs each | Families’ homes | Families of targeted students with habitual subjective health complaints | Family | QOL: -----------  
Academic: ---  
MH: SDQ  
MH: improved; no summary statistics provided |
| Fox, 2005         | School-based cognitive behavioral mental health intervention and homework to decrease depression in child refugees from Southeast Asia | After school for 8 weeks, 1 hr per weekly session | In-school afterhours | All (whose parents gave permission to attend after-school intervention) | Groups divided by age | QOL: -----------  
Academic: ---  
MH: CDI  
MH: improved t-value of 4.89 (.000, 2-tailed significance) |
| Houck, 2002       | School-based support groups with skill-building or cognitive | Weekly 45-minute sessions for 14 weeks | Within school but out of class | Female students at risk for depression and suicide risk | Small support group | QOL: -----------  
Academic:  
HSQ (drop out)  
Academic: improved to no risk t=1.53, p≤.10 |
<table>
<thead>
<tr>
<th>First Author, Year</th>
<th>Summary of Intervention</th>
<th>Length of Overall Intervention Program/Sessions</th>
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<th>Type of Audience (all, at risk, diagnosed)</th>
<th>Type of meeting (individual, group, class, family)</th>
<th>QOL</th>
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<th>Mental Health (MH)</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hoying, 2016</td>
<td>behavioral focus</td>
<td>Weekly 50-minute sessions (30 min. didactic, 20 min. physical activity) for 15 weeks</td>
<td>Classroom with referral to school nurse’s office and letter sent home</td>
<td>All students</td>
<td>Class</td>
<td>QOL: ---------</td>
<td>Academic: Self-report academic gains</td>
<td>MH: BYI-II</td>
<td>MH: improved perceived stress t=1.54; family distress t=1.73, p≤.10; Academic: improved anxiety, medium effect t=3.230, p=.003, Cohen’s d=0.42, p&lt;.10; for at-risk students improved</td>
</tr>
<tr>
<td>First Author, Year</td>
<td>Summary of Intervention</td>
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<td>QOL</td>
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<tr>
<td>Kim, 2015</td>
<td>Pilot study for school nurses using engagement practices to improve students’ readiness for mental health services</td>
<td>For low caseload school nurses, 21-30 minutes. For higher caseload, 5-10 minutes.</td>
<td>School health office</td>
<td>At risk (those visiting health office with s/s possibly related to mental health concern)</td>
<td>Individual</td>
<td>QOL: --------</td>
<td>MH: improved hope about (t=-0.48, df=21, p=.64) and perceived need for mental health services (t=-1.40, df=21, p=.175)</td>
<td></td>
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<tr>
<td>Lamb, 1998</td>
<td>Nurse-led (PhD mental health nurse) coping skills group/</td>
<td>8 weeks (first half of each session didactic, second half experiential)</td>
<td>Did not specify where intervention took place.</td>
<td>At risk according to screening tool</td>
<td>Group (10-12 members grouped according to grade level,</td>
<td>QOL: --------</td>
<td>MH: more improved depressive symptoms than control</td>
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<td>First Author, Year</td>
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<tr>
<td>Muggeo, 2017</td>
<td>homework for rural high school students</td>
<td>8 weeks, sessions 15-30 each</td>
<td>Reserved room separate from health office when possible</td>
<td>At risk</td>
<td>Individual</td>
<td>QOL: ----------</td>
<td>Academic: BASC-2, WJ-III, TOCA-C, school attendance</td>
<td>MH: SCARED, ADIS-IV P/C, CGI-S, CGI-I, CSI-24, CGAS,</td>
<td>p=0.074, more supportive coping use</td>
</tr>
<tr>
<td></td>
<td>A brief school nurse-led cognitive behavior-based intervention to decrease student anxiety</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td>MH: JCS, RADS, LEC</td>
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**QOL:**

- Improved anxiety $t(9) = 3.36, p =$

**Academic:** significantly lower teacher-reported concentration problems

- $t(10) = 2.33, p = .02, 95\% CI [.01, .73], Cohen’s $d = .35$; 2 week absences reduced from 16 to 4
<table>
<thead>
<tr>
<th>First Author, Year</th>
<th>Summary of Intervention</th>
<th>Length of Overall Intervention Program/Sessions</th>
<th>Setting</th>
<th>Type of Audience (all, at risk, diagnosed)</th>
<th>Type of meeting (individual, group, class, family)</th>
<th>QOL</th>
<th>Findings</th>
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<td>.004, 95% CI [3.24, 16.56], Cohen’s d = 0.81; improved somatic symptoms t(9) = 2.21, p = .027, 95% CI [-1.18, 15.98], Cohen’s d = .85; significantly higher functioning t(10) =-3.45, p = .003, 95% CI [-12.11, -2.61], Cohen’s d = .35</td>
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<td>Type of Audience (all, at risk, diagnosed)</td>
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<td>QOL</td>
<td>Academic</td>
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</table>
| Olowokere, 2014   | Resilience training support group meetings. Unclear if teacher, school nurse, or other researcher performed the intervention. 6 weeks, 2 hrs per session for students in resilience-only or support group-only intervention groups. 6 weeks, 4 hrs per week for resilience training and support group intervention group. | School but unsure of location within school | At risk as identified by trained teachers and school nurses | Group | QOL: --------  
Academic: ---  
MH: The Resilience Centre Resilience Scale, Spence’s children anxiety scale, CES-D for children, Rosenberg self-esteem scale, Social Connectedness scale | MH: improved resilience M= 19.15, t=4.37, p=.000; significant improvement in depression M¼=4.94, t=2.26, p=.03; self-esteem M=3.27, t=2.26, p=.03, and social connectedness M=2.86, t=3.16, p=.002 |
| Ramirez, 2013     | Listen Protect Connect (LPC), a school-based | One session, avg 25 min (range 10-40 min) | School nurse office | At risk, based upon health office visits r/t | Individual | QOL: --------  
Academic: ---  
MH: improved depression | |
<table>
<thead>
<tr>
<th>First Author, Year</th>
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<th>Length of Overall Intervention Program/Sessions</th>
<th>Setting</th>
<th>Type of Audience (all, at risk, diagnosed)</th>
<th>Type of meeting (individual, group, class, family)</th>
<th>QOL</th>
<th>Academic</th>
<th>Mental Health (MH)</th>
<th>Findings</th>
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</thead>
<tbody>
<tr>
<td>Stallard, 2008</td>
<td>A universal cognitive behavior therapy emotional health program</td>
<td>10 weekly one-hour sessions</td>
<td>Class</td>
<td>All</td>
<td>Whole classes with small group activities</td>
<td>QOL: ---------</td>
<td>Academic: significant improvement of self-esteem F(3,323) = 6.55, P = .0001</td>
<td>MH: Spence children’s anxiety scale, generalized</td>
<td>scores, PTSD symptoms, social support, school connection p &lt; 0.01</td>
</tr>
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<td></td>
<td>program of Psychological First Aid delivered by non-mental health professional</td>
<td></td>
<td></td>
<td>non-specific physical symptoms, student report of trauma/distress, or unexcused absences</td>
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<tr>
<td>First Author, Year</td>
<td>Summary of Intervention</td>
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<td>Type of Audience (all, at risk, diagnosed)</td>
<td>Type of meeting (individual, group, class, family)</td>
<td>QOL</td>
<td>Findings</td>
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<tr>
<td>Vessey, 2011</td>
<td>School nurse-led support group for students with disabilities to provide resiliency skills. Used Take a Stand, Lend a Hand, Stop Bullying Now</td>
<td>Approximately every 2 weeks for 24 weeks (12 sessions 30 min per session)</td>
<td>School, but unsure of location within school or if during or outside of school hours</td>
<td>At risk (due to having a disability)</td>
<td>Group</td>
<td>QOL: ---------</td>
<td>MH: improved sense of calm/peace, sleep, patience (no self-report)</td>
<td></td>
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<tr>
<td>Wall, 2005</td>
<td>Tai chi and mindfulness-based stress reduction educational program</td>
<td>5 weekly one-hour sessions</td>
<td>School (unsure of location in school and if during or</td>
<td>All (who received permission)</td>
<td>Group</td>
<td>QOL: ---------</td>
<td>MH: CATS, PSC, PHCSCS</td>
<td>improvements in and anxiety F(3,323) = 8.58, P = .0001</td>
<td></td>
</tr>
</tbody>
</table>

Note: MH: Mental Health
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<thead>
<tr>
<th>First Author, Year</th>
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<th>Mental Health (MH)</th>
<th>Findings</th>
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<td></td>
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<td>outside school hours)</td>
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<td>calmness, relaxation, improved sleep, less reactivity, self-awareness</td>
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*Note. SDQ= Strengths and Difficulties Questionnaire; YSR= Youth Self Report; CHQ-CF-GH4=Child Health Questionnaire-Child Form; HSQ=High School Questionnaire; BYI-II=Beck Youth Inventory Second Edition; JCS=Jalowiec Coping Scale; RADS=Reynolds Adolescent Depression Scale; LEC=Life Events Checklist; SCARED=Screen for Child Anxiety-Related Emotional Disorders, Child and Parent Versions; ADIS-IV P/C=Anxiety Disorders Interview Schedule for DSM-IV, Parent and Child Versions; CGI-S=Clinical Global Impression—Severity Scale; CGI-I=Clinical Global Impression Improvement Scale; CSI-24=Children’s Somatization Inventory; CGAS=The Children’s Global Assessment Scale; TOCA-C=Teacher Observation of Classroom Adaptation-Checklist; BASC-2=Behavior Assessment System for Children; WJ-III=Woodcock–Johnson Tests—Achievement and Cognitive Batteries; CDI=Children's Depression Inventory; CES-D= Center for Epidemiologic Studies*
Depression Scale; MSPSS= Multidimensional Scale of Perceived Support; CATS= Child-Adolescent Teasing Scale; PSC= Pediatric Symptom Checklist; PHCSCS= Piers-Harris Children’s Self-concept Scale
Study Characteristics

The data extraction results (see Table 2) reveal important details about mental health interventions in schools. Of the 15 included studies, 9 were conducted in the United States (Fox et al., 2005; Houck & Stember, 2002; Hoying & Melnyk, 2016; Kim et al., 2015; Lamb et al., 1998; Muggeo et al., 2017; Ramirez et al., 2013; Vessey & O’neill, 2011; Wall, 2005) while the remaining studies were conducted in the United Kingdom (Spratt et al., 2010; Stallard et al., 2008), Sweden (Clausson & Berg, 2008; Johansson & Ehnfors, 2006), Netherlands (Bannink et al., 2014), and Nigeria (Olowokere & Okanlawon, 2014). The Journal of School Nursing published 5 of the 15 articles (Clausson & Berg, 2008; Houck & Stember, 2002; Hoying & Melnyk, 2016; Olowokere & Okanlawon, 2014; Vessey & O’neill, 2011). Demonstrating the multidisciplinary nature of mental health, the remaining articles were published in journals covering topics such as internet research, psychiatric nursing, psychology/mental health, pediatric health care, and pastoral care in education.

Of the 15 studies, 6 included details about theories or frameworks that guided the study, the majority of which mentioned cognitive behavioral theory or similar mental health therapy as their basis (Clausson & Berg, 2008; Fox et al., 2005; Hoying & Melnyk, 2016; Lamb et al., 1998; Stallard et al., 2008; Wall, 2005). As is acceptable in an integrative review, the included studies varied in design type: randomized control trials (Bannink et al., 2014; Lamb et al., 1998), quasi-experimental (Fox et al., 2005; Houck & Stember, 2002; Hoying & Melnyk, 2016; Kim et al., 2015; Muggeo et al., 2017; Olowokere & Okanlawon, 2014; Ramirez et al., 2013; Stallard et al., 2008), mixed
methods (Clausson & Berg, 2008; Vessey & O’neill, 2011), feasibility (Wall, 2005), and qualitative (Johansson & Ehnfors, 2006; Spratt et al., 2010).

Types of Interventions Tested

This review includes a synthesis of findings based on a variety of school-based intervention studies. A report of qualitative studies follows in a subsequent section. In response to the first research question—“What school nurse interventions have been tested that address mental health concerns of students?”—the following results were obtained: web-based targeted messaging program (Bannink et al., 2014), therapeutic conversation with family (Clausson & Berg, 2008), support group meetings (Houck & Stember, 2002; Vessey & O’neill, 2011), mental health courses embedded in general school curriculum (Hoying & Melnyk, 2016), mental health engagement conversations during health office visits (Kim et al., 2015; Ramirez et al., 2013), coping skills training (Lamb et al., 1998), CBT sessions (Fox et al., 2005; Houck & Stember, 2002; Muggeo et al., 2017; Stallard et al., 2008), resilience training (Olowokere & Okanlawon, 2014; Vessey & O’neill, 2011), and tai chi and mindfulness training (Wall, 2005). Although the interventions were similar in their attempt to offer psychoeducation and skills for coping with mental health concerns, they varied in their target audience type and size.

Targeted vs. Universal. The 13 intervention studies included in the review involved one of two approaches: targeted toward an identified population or universal for all students. Authors of 9 of the 13 articles that examined interventions and their effectiveness described a targeted intervention approach, utilizing either assessment tools or input from school personnel to determine students at risk for or exhibiting mental health concerns (Bannink et al., 2014; Clausson & Berg, 2008; Houck & Stember, 2002;
Kim et al., 2015; Lamb et al., 1998; Muggeo et al., 2017; Olowokere & Okanlawon, 2014; Ramirez et al., 2013; Vessey & O’neill, 2011). The other four intervention studies involved providing the intervention universally to all students, taking the stance that the skills taught during the interventions were helpful for all students, regardless of their risk for or current presentation of mental health concerns (Fox et al., 2005; Hoying & Melnyk, 2016; Stallard et al., 2008; Wall, 2005). Three of the four universal programs were identified by authors as cognitive behavioral interventions or as having cognitive behavioral theoretical underpinnings (Fox et al., 2005; Hoying & Melnyk, 2016; Stallard et al., 2008).

**Group vs. Individual.** In addition to being categorized by intended audience, interventions were also categorized based on whether they were group or individual interventions. Of the thirteen intervention articles, four involved the school nurse intervening on an individual level. Three of the four individual-oriented interventions were structured as one-time therapeutic conversations (Bannink et al., 2014; Kim et al., 2015; Ramirez et al., 2013). The other was structured as repetitive interactions as a part of a CBT program (Muggeo et al., 2017).

The nine group interventions varied in group size. Intervention groups ranged from family units (Clausson & Berg, 2008) to small groups (Fox et al., 2005; Houck & Stember, 2002; Lamb et al., 1998; Olowokere & Okanlawon, 2014; Stallard et al., 2008; Vessey & O’neill, 2011; Wall, 2005) or entire school classes (Hoying & Melnyk, 2016; Stallard et al., 2008). When larger groups were divided into smaller groups, the groups were divided based upon age (Fox et al., 2005; Lamb et al., 1998).

**One-time Interaction vs. Multiple Sessions.** Interventions also varied in their
use of one-time interaction or multiple sessions with students. Interventions consisting of a one-time conversation with the school nurse were noted in three articles (Bannink et al., 2014; Kim et al., 2015; Ramirez et al., 2013). The remaining ten articles consisted of interventions that involved multiple sessions, ranging in length from 3 sessions (Clausson & Berg, 2008) to 15 sessions (Hoying & Melnyk, 2016). Each session ranged in length from 30 minutes to 2 hours, although 1-hour sessions were most commonly noted.

**Types of Outcomes Evaluated**

The studies in this literature review included an array of outcome measurements, which provided answers for the second research question: “What are the QOL, health, and academic outcomes of these interventions?” Of the 35 different outcome measures described in the intervention articles, only two measures were used in multiple studies—the Strengths and Difficulties Questionnaire (SDQ; Bannink et al., 2014; Clausson & Berg, 2008) and Spence Children’s Anxiety Scale (Olowokere & Okanlawon, 2014; Stallard et al., 2008). Because of the extreme variability in outcome measures, between-study outcome comparisons could not be made.

**Quality of Life Outcomes.** Two research teams described student QOL as a motivation for their research (Bannink et al., 2014; Vessey & O’neill, 2011), but only one research team reported the use of a QOL measure (Bannink et al., 2014). Bannink and colleagues (2014) chose the Child Health Questionnaire-Child Form (CHQ-CF-GH4) to measure student well-being (theoretically defined as mental health status and health-related QOL) in their one-time web-based, universal intervention. They found that student QOL scores improved slightly for students in general and moderately for students who were identified as high risk for mental health concerns (Bannink et al., 2014). While
no other authors reported purposefully measuring QOL, other measures may have served as proxies for QOL.

**Academic Outcomes.** When interventions take place in the school setting, researchers must be able to demonstrate academic benefits in order to gain school administration support. Of the 13 intervention articles, 4 included a measure related to students’ academic confidence or abilities (Houck & Stember, 2002; Hoying & Melnyk, 2016; Muggeo et al., 2017; Stallard et al., 2008). In a school-based weekly support group intervention for females at risk for depression and suicide, findings from a pre-/post-test comparison using High School Questionnaire (Houck & Stember, 2002) demonstrated a decrease in school drop-out risk. In a class-wide weekly physical activity and mental health intervention, researchers measured students’ use of new skills from the program to improve academic performance, with 8.7% reporting using skills in this way (Hoying & Melnyk, 2016).

When considering the effects of a small eight-week intervention study for students at risk for anxiety, the Behavior Assessment System for Children anxiety subscale measure was completed by teachers to measure problematic and adaptive school behaviors while the reading, writing, and math subtests of the Woodcock–Johnson Tests—Achievement and Cognitive Batteries were completed by students to measure memory and academic fluency (Muggeo et al., 2017). No statistically significant findings were noted for either measure. However, Muggeo and colleagues found school attendance improved between pre- and post-test measures of number of days missed in the last 2 weeks. Furthermore, teacher perception of concentration problems improved
significantly from pre- to post-test as measured by the Teacher Observation of Classroom Adaptation-Checklist (Muggeo et al., 2017).

Academic Self-Esteem was measured as a part of the Culture Free Self-Esteem Questionnaire Form B used within a universal weekly CBT school mental health intervention (Stallard et al., 2008). Although Academic Self-Esteem scores increased each time the instrument was administered, the findings did not reach statistical significance.

**Mental Health Outcomes.** The majority of study outcomes examined the mental health-specific outcomes with little discussion as to their impact on QOL or academic success. A list of instruments used can be found in Table 3. The selected instruments measured a variety of mental health constructs reported as general mental health status (Bannink et al., 2014); psychological distress (Houck & Stember, 2002); family strain (Houck & Stember, 2002); depressive symptoms (Fox et al., 2005; Hoying & Melnyk, 2016; Lamb et al., 1998; Olowokere & Okanlawon, 2014; Ramirez et al., 2013); elevated anxiety symptoms (Hoying & Melnyk, 2016; Muggeo et al., 2017; Olowokere & Okanlawon, 2014; Stallard et al., 2008), disruptive behavior (Hoying & Melnyk, 2016; Muggeo et al., 2017), anger (Hoying & Melnyk, 2016); self-concept (Hoying & Melnyk, 2016; Vessey & O’Neill, 2011); student readiness for mental health services (Kim et al., 2015); life events and coping styles during recent stressful life events (Lamb et al., 1998); somatic complaints (Muggeo et al., 2017); global functioning (Muggeo et al., 2017); self-esteem (Olowokere & Okanlawon, 2014; Stallard et al., 2008); social connectedness (Olowokere & Okanlawon, 2014); school connectedness (Ramirez et al., 2013); pediatric post-traumatic stress disorder (PTSD) symptoms (Ramirez et al., 2013); perceived social
support from family, friends, and significant people (Ramirez et al., 2013); resilience (Olowokere & Okanlawon, 2014; Vessey & O’neill, 2011); and psychological functioning (Vessey & O’neill, 2011).

Although many constructs were only examined in single studies, certain constructs stood out as common mental health indicators across several studies, including depressive symptoms (Fox et al., 2005; Hoying & Melnyk, 2016; Lamb et al., 1998; Olowokere & Okanlawon, 2014; Ramirez et al., 2013) and elevated anxiety symptoms (Hoying & Melnyk, 2016; Muggeo et al., 2017; Olowokere & Okanlawon, 2014; Stallard et al., 2008). Details about specific mental health outcomes are located in Table 3.

All studies demonstrated some level of mental health symptom improvement, regardless of type of audience (targeted vs. universal), type of meeting (group/class vs. individual), or length of intervention (one-time interaction vs. multiple sessions). For studies with universally delivered interventions, greater improvements were noted for students at risk of mental health concerns than students not at risk (Fox et al., 2005; Hoying & Melnyk, 2016; Stallard et al., 2008; Wall, 2005). Only one of the individual-focused interventions involved multiple sessions, but post-intervention findings demonstrated mental health score improvements, similar to the group multi-session counterparts (Muggeo et al., 2017). One study (Bannink et al., 2014) involved a group web-based universal intervention prior to a targeted individual one-time intervention with a school nurse; those students who received the targeted school nurse intervention had improvements in more QOL and mental health measures than students who only participated in the web-based portion of the intervention. Again, those found at risk for mental health concerns experienced a slightly greater effect than the students not at risk.
The other one-on-one, one-time interventions (Kim et al., 2015; Ramirez et al., 2013) targeted at-risk students only and noted improved mental health outcomes as well.

**Qualitative Study Findings**

The inclusion of two qualitative studies offered a more detailed glimpse into what makes school nurse interventions unique compared to other disciplines’ interventions. In their qualitative study of school nurse managers, both Spratt and colleagues (2010) and Johansson and Ehnfors (2006) identified several key themes for school nurses’ involvement with student mental health, including a distinctive opportunity to build trusting relationships through availability and students’ ease of access to school nurses. Johansson and Ehnfors (2006) described using an introductory questionnaire that students completed before interacting with the school nurse to aid in therapeutic communication and relationship building. The questionnaire, designed to determine students’ existing health and relationship problems, helped guide a more productive conversation between students and the school nurse. The authors of both qualitative studies provided insight into antecedents of therapeutic conversation including confidentiality, feeling safe to discuss mental health concerns (Spratt et al., 2010), trustworthiness, attentiveness, respectfulness, authenticity, and continuity of seeing the same nurse over several visits or over several years (Johansson & Ehnfors, 2006).

**Discussion of Literature Review Findings**

**Theoretical Traditions**

With fewer than half of the reviewed studies including reports of theoretical underpinnings, there is much room for researchers to advance school nursing knowledge based on the foundation of theory. Beck’s (1976) cognitive therapy model-based CBT
intervention was the most tested intervention in school nursing mental health intervention studies and has also been the primary intervention tested in PNES psychological research (Cope et al., 2017; Sawchuk & Buchhalter, 2015b; Takasaki et al., 2016). CBT is a theory-based, scientifically supported psychological treatment for depression, anxiety disorders, severe mental illness, and PNES (American Psychological Association, 2018; Smith, 2014). The therapy is established on the principle that mental health concerns are based, to a certain extent, on faulty or unhelpful thinking and learned patterns of unhelpful behaviors (American Psychological Association, 2018). CBT is valued for its attention to skills that can benefit all students, not just those with identified mental health concerns (Hoying & Melnyk, 2016). Because CBT can provide skills beneficial to all students, it is a promising strategy for addressing some of the mental health care needs of students with PNES and many other identified or undiagnosed mental health concerns. Conversely, universal school-based interventions do not replace the individualized and specialized care of a mental health care professional.

School nurses may find CBT-based interventions attractive because of their flexibility and short duration. Interestingly, of the four studies that reported interventions delivered at the individual level, three were one-time interventions rather than extended multi-session interventions (Bannink et al., 2014; Kim et al., 2015; Ramirez et al., 2013). This observation is pertinent to the common concern of school nurses regarding the time consuming nature of mental health care and the lack of time and resources to provide such care (Johansson & Ehnfors, 2006). Researchers demonstrated that even one brief conversation can make a difference (albeit statistically small) in the life of a student with a mental health concern, as can longer, more structured interventions.
**Empirical Traditions**

Researchers conducting school-based intervention studies encounter a variety of challenges. Researchers most often used a quasi-experimental research design, using pre-/post-test measures without comparison or control groups because of their desire to provide a beneficial opportunity to as many students as possible. Attrition and inability to control for the effect of seasonal changes on affect and mood scores were challenges for research conducted over several months within the same school year. The qualitative studies lacked rigor by failing to provide clear statements of methodology, design, and analysis appropriate for the studies’ aims. Because there is little risk of harm in implementing the tested mental health interventions, less rigorous quasi-experimental and qualitative studies can inform future PNES research and interventions with caution. On the other hand, increased use of randomized control trials could provide greater support for seeking additional funding, creating research opportunities that build upon existing research, and making generalizations for school nursing practice.

Although novel and evidence-based interventions were tested, the vast array of measured outcomes precluded any comparison of outcome findings between studies. Only one research team included QOL as an explicit outcome. Also lacking in studies were academic outcome measures. If researchers want to seek not only permission but also collaboration with schools and education teams, a greater focus must be placed on outcome measures that interest schools, especially school attendance (Attendance Works, 2018), school performance, and learning difficulties among students with PNES and other mental health concerns (Doss et al., 2017).
From Mental Health Interventions to PNES Interventions

Although researchers have advanced knowledge of school-based mental health intervention effectiveness, there are no empirical data to support feasibility and acceptability of current recommendations for responding to PNES events. The American Epilepsy Society (2018), Epilepsy Foundation (2018), and Caplan and colleagues (2017) provided recommendations regarding how school personnel should respond when a student experiences a PNES event. Suggested steps include 1) avoiding emergency medical care unless an injury occurs or seizure activity is unlike previous events, 2) continuing with class without drawing attention to or talking to the student during the event, and 3) encouraging the student to return to class or normal activities as soon as possible after the event. Little is known about schools’ knowledge or use of the above PNES guidance or the experience of school personnel, classmates, and students with PNES when the recommendations are followed.

Summary of Findings

This integrative review offers an analysis of 13 intervention studies, as well as 2 qualitative studies, in which authors investigated a variety of school-based mental health interventions. Most interventions were initiated and/or conducted by school nurses and went beyond simply identifying and referring students to mental health care services. The general mental health interventions could be implemented for students with PNES individually or with other students with and without mental health concerns to investigate their effectiveness on QOL, academic, and mental health outcomes.

Although research exists that tests interventions for the underlying mental health needs of students with PNES, school nurses need evidence-based guidance for PNES-
specific interventions, including how to handle the seizure events as they happen. Guidance found in epilepsy organization reports and textbooks provide untested recommendations for handling PNES events in school. The NASN released evidence-based clinical guidelines for the care of students with seizures and epilepsy (Lepkowski & Maughan, 2018); however, the project-lead confirmed that the guidelines are only intended for those with abnormal electrical brain activity, not for those experiencing PNES (A. Lepkowski, personal communication, October 17, 2018). This review highlights tested school nurse interventions and the QOL, health, and academic measures used to evaluate their effectiveness.

**What is the Role of School Nurses in Self-Management Support for Adolescents with Psychogenic Nonepileptic Seizures?**

Literature suggests that school nurses are uniquely positioned to provide school-based mental health interventions; however, little is known about what PNES-specific interventions may be appropriate to develop and test. Research is necessary to determine the role school nurses can play in improving the QOL, health, and academic outcomes for students with PNES. NASN (2016) identifies chronic disease management, student-centered care, and student self-empowerment as key care coordination tasks of school nurses. Self-management support (SMS) is a nursing intervention that encompasses these key care coordination tasks. Before SMS interventions can be considered for further research, the term “self-management support” must be more clearly defined. A concept analysis of SMS in the context of school nursing is needed to clarify how school nurses may employ SMS to improve outcomes for adolescents with PNES. With a clearer understanding of SMS as a school nurse intervention, research questions investigating the
connection between SMS and outcomes for adolescents with PNES can be formed and tested.

**Concept Analysis Method**

In this concept analysis, the focus was reviewing existing definitions of SMS and ascertain a working definition of SMS in the context of school nursing. The concept of SMS has not been discussed in the school nursing literature. Because the hybrid method includes SMS information not only from literature, but also from the school nurses who perform SMS, the hybrid method of concept analysis was used. The hybrid method allowed current definitions of SMS to guide a semi-structured interview with school nurses for insight into SMS in the context of school nursing. The hybrid model employs three distinct phases of inquiry—a theoretical phase for determining a working definition of the concept based on literature, a fieldwork phase in which qualitative data are collected and analyzed from those experiencing the concept, and a final analytic phase for reexamining the current definition and refining the definition in light of fieldwork findings (Rodgers & Knafl, 2000).

Results of this hybrid concept analysis have the potential to clarify the work school nurses do to support students as they gain self-management skills and attitudes. The findings of this analysis will be used to inform SMS efforts for students with PNES. Defining SMS in the context of school nursing is the initial step in investigating the effect school nurse SMS interventions have on the QOL for students with PNES.

**Literature Search and Data Sources**

The initial phase of the hybrid analysis included gathering relevant literature sources that addressed SMS. The search terms “self-management support AND
psychogenic non-epileptic seizures”, “self-management support AND child”, and “self-management support AND mental health” were used within CINAHL Complete, Cochrane Database of Systematic Reviews, MEDLINE, and PsycInfo databases. No results were found that addressed both SMS and PNES. A combined 277 results were found that addressed SMS as it relates to children, chronic disease, or mental health. These results were narrowed down to 21 articles based upon a review of titles and abstracts for relevance to either SMS in the pediatric population, chronic disease care, or mental health care. No limitations were placed upon year of publication.

Results

Theoretical Phase

Rodgers and Knafl (2000) explain the theoretical phase as a time to “begin searching the literature, comparing and contrasting existing definitions with one’s tentative definition, and moving toward the selection and creation of a working definition with which to begin the fieldwork” (p. 131). The initial theoretical phase includes examining meanings and methods of measuring the concept to guide the working definition development process. The hybrid method of concept analysis does not require a delineation of antecedents or consequences of a concept, as these characteristics are more useful after the “essential aspect of a concept has been identified” (Rodgers & Knafl, 2000). However, because the concept of SMS has already been examined outside of school nursing to a limited extent, addressing antecedents and consequences within the theoretical and subsequent phases could be beneficial in developing a more useful definition for school nursing practice. Therefore, in addition to theoretical underpinnings, this theoretical phase will include discussions of explicit and implicit meanings found in
literature, measurements currently used, antecedents for SMS to occur, consequences that result from SMS, and a working definition of SMS.

**Philosophical and Theoretical Influences.** Of the 21 selected articles, only 12 had an identified philosophical or theoretical influence. Models or theories acknowledged in the selected works include: social cognitive theory (Krieger et al., 2009), transtheoretical stages of change model (Krieger et al., 2009), Bandura’s (cognitive) social learning theory (Marjolijn et al., 2016), cognitive behavioral theory (Marjolijn et al., 2016), behavior change theory (Shomaker & DeVeau-Rosen, 2016; Van Bragt et al., 2015), motivational interviewing (Shomaker & DeVeau-Rosen, 2016), self-determination theory (Ammerlaan et al., 2017; Sinoo et al., 2018), chronic care model (Been-Dahmen et al., 2015; Ludman et al., 2016), shared decision making (Van Bragt et al., 2015), self-efficacy theory (Ammerlaan et al., 2017), pediatric self-management model (Lozano & Houtrow, 2018), International Classification of Functioning, Disability and Health (Lozano & Houtrow, 2018), model of integrated knowledge translation (Hensel et al., 2016), Corbin and Strauss’s notion of illness ‘work’ (Brooks et al., 2016), and recovery model (Ludman et al., 2016).

**Meanings.** Articles pertaining to SMS in chronic care and mental health care of adults and children were reviewed to uncover a broad range of SMS definitions. Only 5 out of 21 articles included an explicit definition of SMS as a part of the introduction, background, results, or conclusion (Cahill et al., 2016; Henry & Schor, 2015; Lozano & Houtrow, 2018; McCusker et al., 2017; van Hooft et al., 2017). In van Hooft et al.’s (2017) review of SMS, a detailed definition of self-management was provided, but the topic of interest, SMS, was defined only loosely as to "coach patients in their self-
management”—a task that "requires a multidisciplinary approach" (p. 1256). A definition of SMS cited routinely (Cahill et al., 2016; van Hooft et al., 2017) comes from Haas and colleagues (2012) in their national standards for diabetes SMS: “activities that assist the person … in implementing and sustaining the behaviors needed to manage his or her condition on an ongoing basis beyond or outside of formal self-management training” (p. 620). The authors continue by detailing that support could fall under the categories of “behavioral, educational, psychosocial, or clinical” (p. 620). Lozano and colleagues’ (2018) definition lists providers of SMS as “health systems and community agencies”. Henry and Schor (2015) dive deeper into the details of providing SMS, stating, “Self-management support is a complex but powerful process that will require the creative use of collaborative health care teams, technology, asynchronous communication, and community resources not typically relied upon” (p. 792). In their pediatric report, Henry and Schor (2015) list key activities of SMS, including “education, supportive interventions, encouragement and assistance to enhance families’ skills and confidence in health promotion and the management of their children’s health problems” (p. 789).

As previously mentioned, a noticeable downfall of existing SMS literature is the lack of SMS definition guiding each review or study, evidenced by more than 75% of articles selected for review lacking a clear definition. Despite the lack of definition within many works, much can be gained from analyzing the implicit attributes under investigation. These attributes of SMS will be categorized according to Haas and colleagues’ (2003) support categories of “behavioral, educational, psychosocial, or clinical” (p. 620).
Behavioral. As complex as self-management is (Miller et al., 2015), finding ways to support one’s self-management is equally as complex. Myriad interventions have been identified in SMS literature that address behavioral support. Goal setting (Krieger et al., 2009; Shomaker & DeVeau-Rosen, 2016), especially shared (Van Bragt et al., 2015) and patient-focused (Henry & Schor, 2015) goal setting stood out as a priority SMS attribute. Progress monitoring (Krieger et al., 2009) via follow-up phone calls (Shomaker & DeVeau-Rosen, 2016) or “check-ins” on effectiveness of a written plan (Hommel et al., 2015; Van Bragt et al., 2015) are reported methods of tracking goal achievement. Also a part of SMS is holding a discussion of the responsibility of each person to reach goals, rewarding patients when goals are met, and re-implementing a plan if a goal is not met (Hommel et al., 2015).

Written action plans (Van Bragt et al., 2015) and technologically recorded and conveyed action plans (Cahill et al., 2016; Henry & Schor, 2015) can serve as guides for positive change, as can health care professionals serving as coaches (Henry & Schor, 2015; van Hooft et al., 2017) for behavior change (D. Morrison et al., 2014), problem solving and relaxation training (Marjolijn et al., 2016), self-management skills (Sattoe et al., 2015; Sinoo et al., 2018), and coping strategies (Milton et al., 2017). Coaches can also promote the monitoring of warning signs of mental health crisis and identification and utilization of help resources (Milton et al., 2017).

Worth mentioning are two additional attributes of SMS that can be addressed by someone serving as a coach—self-efficacy and cognitive behavioral therapy. Self-efficacy includes learning to set goals, have direction in life, and say “no” to non-essential tasks without feeling guilty (Ammerlaan et al., 2017). Self-efficacy has been
identified as a precursor and synonym for self-management (Miller et al., 2015), and a skillset appropriate for supporting in SMS. A skillset valuable for those serving as coaches in SMS is the ability to administer cognitive behavioral therapy, which involves identifying dysfunctional thinking, examining validity and usefulness of thoughts, and testing accuracy of predictions (Hensel et al., 2016; Sharpe et al., 2017).

Coaching does not solely affect the patient—parents and nurses are also affected by this behavioral SMS. For parents, SMS coaching encourages a shift from parent-management to self-management of a child (Cahill et al., 2016). For nurses, serving as a SMS coach leaves nurses with occasional ethical dilemmas, such as taking on management tasks (contradictory to “self” focus of SMS goals) when the patient prefers to remain passive (as a patient-centered goal; Dwarswaard & van de Bovenkamp, 2015). Similarly, allowing choices that do not align with the treatment regimen or becoming involved in patients' private lives (Dwarswaard & van de Bovenkamp, 2015) can be uncomfortable for some nurses and can negatively impact their view of SMS.

Educational. Patient-centered (Shomaker & DeVeau-Rosen, 2016) and individually-paced (Ammerlaan et al., 2017) education is a key attribute of SMS. Education, information support, and the assessment or imparting of knowledge was cited in 8 of the 21 works as a key “ingredient” for SMS (Been-Dahmen et al., 2015; Henry & Schor, 2015; Hommel et al., 2015; Krieger et al., 2009; Marjolijn et al., 2016; D. Morrison et al., 2014; Sattoe et al., 2015; Sinoo et al., 2018). Varying education methods were employed in SMS programs, such as supplying resources (Krieger et al., 2009), providing patient/family with written materials (Henry & Schor, 2015), providing advice (Henry & Schor, 2015; D. Morrison et al., 2014), offering psychoeducation (Sharpe et al.,
2017), and promoting mental health awareness through age-appropriate booklets for all students in a school (Sharpe et al., 2017).

*Psychosocial.* Psychosocial attributes take into account psychological aspects of SMS as well as social roles and interactions. To address the psychological factors of having a chronic or mental health condition, SMS has included emotion/identity management (Henry & Schor, 2015; Marjolijn et al., 2016; Sattoe et al., 2015) as well as cognitive restructuring (Marjolijn et al., 2016).

Authors of SMS literature placed much more emphasis on SMS that addressed social factors, including the role of peers, parents, family, health care providers, or a combination of these entities. Role management including place in society was a part of SMS in three works (Henry & Schor, 2015; Marjolijn et al., 2016; Sattoe et al., 2015). Peer support, often in a group setting, was a part of several SMS programs (Henry & Schor, 2015; Hensel et al., 2016; Marjolijn et al., 2016), while some authors reported involving peer community health workers or specialists (Ammerlaan et al., 2017; Ludman et al., 2016; Milton et al., 2017). Furthermore, Ammerlaan and colleagues (2017) reported that patients with rheumatic diseases preferred an SMS structure that drew upon expert patients as the trainers. Parent involvement (Cahill et al., 2016; Sattoe et al., 2015), including health care provider email communication with parent (Henry & Schor, 2015) and family-involvement in the creation of a plan to meet health goals (Hommel et al., 2015) were found to be effective SMS interventions. In a SMS structure and content study, how to work with the health care provider was identified by patients as a desired SMS topic (Ammerlaan et al., 2017). Additionally, in Henry and Schor’s (2015) pediatric-focused manuscript, the authors specify SMS should include communication
support to improve communication between child, parent, and health care provider. Similarly, Lozano and Houtrow (2018) describe pediatric self-management as “shared management” and suggest SMS should support communication and collaboration between the patient, family, and care providers (Lozano & Houtrow, 2018).

Much like social relationships and communication are ubiquitous in chronic and mental health care, so too is integrating the illness or condition into daily life (Been-Dahmen et al., 2015). SMS should include day-to-day family functioning support (Henry & Schor, 2015) and address the patient’s stage of life, which may include intimate relationships and having children (Ammerlaan et al., 2017). For patients who attend school or hold a job, SMS should address how to tell others at school or work about the condition and how to handle work and attendance concerns with the condition (Ammerlaan et al., 2017). Lastly, SMS should involve day-to-day life planning that considers not only relationships with other humans, but also with pets, which have been found to have therapeutic benefit and are noted by many with mental health concerns as a main source of support (Brooks et al., 2016).

Clinical. While the clinical and medical management aspects of SMS are less desirable topics for patients to dwell upon than improving day-to-day living with a condition, the medical treatment of health conditions cannot and should not be overlooked in SMS (Henry & Schor, 2015; Marjolijn et al., 2016; Sattoe et al., 2015). SMS efforts have been noted to cover adhering to medical regimen (Been-Dahmen et al., 2015), monitoring symptoms (Been-Dahmen et al., 2015), how to handle fluctuations in disease and treatment (Ammerlaan et al., 2017), and targeting barriers to medication adherence (Hommel et al., 2015). Other important clinical themes of SMS take account
of the stage of disease process (Ammerlaan et al., 2017) and family adherence goal setting (Hommel et al., 2015).

**Measurements.** When authors fail to provide a definition of a concept, they may reveal an implicit definition through the use of an instrument that measures the concept’s key attributes (Rodgers & Knafl, 2000). McCusker and colleagues (2017) happened to provide both a definition and measurement tools. The authors developed and validated patient-report measures of SMS from health care professionals for mood and emotional problems. The measures that were examined align with the aforementioned realms: behavioral (“staying healthy”, “improving health”, how to “do treatments”, and “discussion of personal goals and how to reach them”), educational (“helpfulness of information received on adhering to treatment”, “explanations about impact of the health condition”), psychosocial (“coping with minor complications”), and clinical (why to “do treatments”, “required monitoring”, and “visits with other health professionals”) (McCusker et al., 2017, p. 2313).

**Antecedents.** Antecedents are events or situations that must occur before the stated concept can occur (Walker & Avant, 2011). Scrutinizing antecedents can help provide social context for a concept (Walker & Avant, 2011). In the investigation of SMS, a number of antecedents were noted. For all selected works, an assumed antecedent was the existence of a condition that needed “managed” by someone. Additional obvious but critical antecedents include patients attending a clinic/setting where the opportunity for SMS is offered (Been-Dahmen et al., 2015), returning to a clinic for routine care that may coincide with SMS (Van Bragt et al., 2015), receiving technology tools and appropriate training on how to use them (Hommel et al., 2015), and reading at a level that
matches written materials (Milton et al., 2017; Sharpe et al., 2017). Also, there should be some need for knowledge, behavior change, coping, motivation, or self-efficacy (van Hooft et al., 2017) or a need for transition from parent control of care to child control of care (Marjolijn et al., 2016). In the instance of pediatric SMS, being the caregiver of someone with a chronic or mental health condition is an antecedent (Cahill et al., 2016; D. Morrison et al., 2014).

In addition to these somewhat obvious and often assumed antecedents, several other antecedents are also aimed toward the readiness of the patient to receive SMS. Krieger and colleagues (2009) and Milton and colleagues (2017) identified having a connection with the coach/trainer/provider as a key to SMS success. In more high-tech SMS, this friendship or connection may be with a robot and/or avatar (Sinoo et al., 2018). Additionally, successful SMS should start with a patient having a self-efficacy perception of at least a moderate level (moderate belief that goals can be met) (Shomaker & DeVeau-Rosen, 2016), intrinsic capacity, performance ability (Lozano & Houtrow, 2018), and internal motivation to do the work of such therapy as CBT (Hensel et al., 2016). Being committed to a sometimes lengthy program may also be a prerequisite for SMS (Milton et al., 2017), although partial exposure could still constitute SMS and lead to desired outcomes.

Patients and caregivers are not the only ones with pre-qualifications for SMS; providers also must maintain certain knowledge, skills, and attitudes to make SMS successful. To begin, health care providers need to be able to recognize a health concern that would benefit from SMS (Ludman et al., 2016; McCusker et al., 2017). This includes health care providers understanding a child’s dependency on parents and the
developmental stage of the child, which may impact readiness for his or her active role in SMS (Lozano & Houtrow, 2018). Furthermore, providers of SMS need to be competent and confident in their ability to provide SMS (McCusker et al., 2017), especially understanding patients' preferences for SMS content and structure (Ammerlaan et al., 2017). Allowing SMS to be patient-centered requires the provider to be able to relinquish some control as well as balance ethical dilemmas that arise when patient autonomy could result in poorer health outcomes (Dwarswaard & van de Bovenkamp, 2015).

**Consequences.** Henry and Schor (2015) eloquently summarized the overarching consequences, or outcomes (Walker & Avant, 2011), of SMS: “Activate and engage patients to support the acquisition of the knowledge, skills, and confidence requisite to their involvement in managing their health and care” (p. 790). More specifically, SMS consequences included decrease in symptom-free days (Krieger et al., 2009), improved care giver and patient QOL (Krieger et al., 2009; Morrison et al., 2014; Sattoe et al., 2015; Van Bragt et al., 2015), appropriate use of medication and treatment adherence (Krieger et al., 2009; Marjolijn et al., 2016; D. Morrison et al., 2014), disease and treatment knowledge (Marjolijn et al., 2016; Sattoe et al., 2015), decrease in depressive symptoms, and patient perception of recovery (Ludman et al., 2016).

**Working definition.** Kawi (2012) undertook the task of conceptually analyzing SMS in chronic illness care and elicited a definition of SMS:

SMS is a comprehensive approach toward improving outcomes in chronic illness care that consists of three major attributes: patient-centered attributes (involving patients as active partners in care, providing diverse, innovative educational modalities specific to patients’ needs, and individualizing patient care), provider
attributes (health care providers possessing adequate knowledge, skills, and attitudes in chronic illness care), and organizational attributes (putting an organized system of care in place to address patient needs, having a multidisciplinary team approach, and using tangible/social support for patients).

(p. 116)

While this definition encapsulates many of the key attributes of SMS, it fails to address some of the nuances specific to pediatric chronic health care and mental health care required for students with PNES as well as many of the details gleaned from SMS research. Therefore, prior to analyzing data from the fieldwork phase, the following working definition for SMS in the context of school nursing was developed:

School nurse SMS is a comprehensive approach toward improving outcomes in chronic condition and mental health care that consists of three major attributes: student/family-centered attributes (involving students and families as active partners in care; providing diverse, innovative educational modalities specific to students’ and families’ needs, including the use of technology; and individualizing student care based on disease stage and developmental level), school nurse attributes (possessing adequate knowledge, skills, and attitudes in chronic condition and mental health care), and organizational attributes (coordinating an organized system of care, including school and home, to address student and family needs and using tangible/social support, including peers, school personnel, and even pets). School nurse SMS addresses behavioral, educational, psychosocial, and clinical needs of students and their families.
Fieldwork Phase

According to Rodgers and Knafl (2000), the fieldwork phase “is aimed at corroborating and refining a concept by extending and integrating the analysis begun in phase one with ongoing empirical observations” (p. 137). To identify school nurse participants for empirical observation, school nurses were approached via email and in-person while attending a school nurse conference. Of 11 school nurses approached, 3 had experience caring for students with PNES. All three school nurses who met this basic selection criteria were willing to be interviewed. The school nurses who participated were from three different school districts within the same Midwestern state. Interviews were conducted by phone, except for one, which was conducted via email per the school nurse’s request. Semi-structured interview questions can be found in Table 4. The information obtained from the interviews aptly addresses SMS from a different point of view than any of the publications by coming from school nurses and addressing SMS for students with PNES.

Table 4

Fieldwork Phase Semi-Structured Interview Questions

<table>
<thead>
<tr>
<th>Questions</th>
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<tr>
<td>Tell me about a time when you feel you were able to offer optimal self-management support.</td>
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<tr>
<td>Tell me about a time when you were not able to offer optimal self-management support.</td>
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<tr>
<td>What does “self-management support” mean to you as a school nurse?</td>
</tr>
<tr>
<td>What must be in place before “self-management support” can take place?</td>
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<tr>
<td>What can happen as a result of your “self-management support”?</td>
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<tr>
<td>What have you done as a school nurse to provide “self-management support” for students with PNES?</td>
</tr>
<tr>
<td>How can we measure the work you do to offer “self-management support” for students with PNES?</td>
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</table>
How can we measure the effect your “self-management support” has on your student’s quality of life and academic success?

**Meanings.** Many definitions of SMS were derived from the semi-structured interviews. School nurses’ SMS definitions included:

- “How to empower the student without discounting the parent’s concerns for her soon-to-be unsupervised student”

- “Assistance to any student experiencing a health issue which becomes evident in their lives to the detriment of participating fully in life at school, (i.e., attention in class, participation in class or socialization, field trips, extra-curricular activities) to not only improve their health and ability to participate more fully in school, but instill the confidence in the student to recognize signs and symptoms of their health issue and address them personally or with the assistance of others in a timely manner to lessen the negative impact their health issue has on their life. This assistance can be in many forms, including assessment, education, case management, treatment, access, empowering and evaluation.”

- “It means to help the student get to the optimal place where he can learn, feel safe, and be able to participate in his education plan.”

- “Teach kids about how to manage their problems, to head things off, before they get urgent, recognize the signs and symptoms of a problem early so they can intervene, becoming more self-sufficient.”

The definitions provided by the interviewed school nurses aligned with the behavioral, education, psychosocial, and educational attributes of SMS mentioned during
the interviews. All tasks and attributes that school nurses considered to be part of SMS were able to be categorized into one of these four categories.

**Behavioral.** School nurses reported various tasks that school nurses do or roles that school nurses assume that constitute SMS. Plan development was mentioned by all three school nurses and included such activities as exploring options, ascribing a Likert-type scale for students to communicate anxiety or stress level, and setting boundaries. One nurse explained that her student’s plan included, “Stop, deep breathe, find what the triggers were and what can help de-escalate what was going on either with himself, mentally, or the stressors inside the classroom”. Another school nurse described her role in developing a Section 504 plan or modifying an IEP, both legally binding school accommodation plans, to allow “time out”—exiting class to come to the clinic at onset of anxiety symptoms to listen to music, use a calming smartphone application, or call a mental health caseworker to talk. Allowing extra time to complete school assignments to decrease stress or to compensate for time spent in the health office or seeking mental health care outside of school was another accommodation mentioned. Nurses described these plans and accommodations being developed with both the student and the parent’s involvement, and often also involved the teacher or other school personnel.

In addition to developing a plan of care, two of the three school nurses likened their role to a coach. They described coaching students to talk to their teachers when they felt in crisis or to implement a pre-determined plan if they felt an impending event. They also coached students on making health choices, such as getting enough sleep and keeping mental health care appointments. One school nurse also mentioned “walking
through the situation” with the student to discover what parts of their plan worked and what could be done differently in the future to improve the student’s outcome.

A key task in plan development and coaching students is communication. School nurses reported communicating with their students about the health care action plan developed with their health care providers and about “triggers leading to full-blown anxiety attack that turn into PNES”. One school nurse mentioned talking with her student about “what happened”, the “why”, and what worked to deescalate himself. Only one nurse mentioned communicating with the student with PNES to affirm success after following the plan of care to decrease PNES episodes. In addition to communicating with students, school nurses identified communication with parents or guardians as an SMS activity. Two of the three interviewed school nurses mentioned making follow-up phone calls to a parent or guardian to report how a student’s self-management activities were impacting their PNES experience. Yet another key communication activity included the school nurse debriefing with the student, staff, and parent/guardian after a PNES event to discuss any strategies that helped improve the situation or were not effective before, during, or after the event.

Educational. School nurses reported several educationally aimed activities. Activities within the realm of education included assessing both student and parent knowledge of the condition, sharing information, providing tools, and using a written plan from the diagnosing health care provider to provide one-on-one education with the student about PNES. Two of the three school nurses discussed the importance of sharing information about the PNES diagnosis with teachers and school personnel.
**Psychosocial.** Because PNES is a mental health condition that presents as a seizure, several themes arose related to the psychological nature of the condition. One school nurse declared the importance of her SMS role in helping students with PNES increase their confidence in advocating for themselves and find balance between parent concern and student’s desire for “freedom”. Another school nurse SMS task involved building a relationship with the parents/guardians with the hope that parents/guardians would trust the school nurse as well as begin to trust the students’ ability to self-manage their condition.

Other psychosocially oriented tasks were more specific, including providing students with alternative “safe places” or “outs” when they felt a PNES event might occur, offering a calm environment with dimmed lights and calm music, talking with the student as a way to keep anxiety from escalating, and allowing the student with increasing anxiety to assist another student as a distraction tactic. One school nurse described her SMS activity as “helping the student be able to do the steps in his own head mentally…before it gets to the point where the anxiety is too much that he shuts down and the only thing he can do to handle the stress is to have a PNES because he is no longer in control of the situation.” All school nurses agreed that their role was not just focusing on the physical aspects of the seizure activity, but on the anxiety or stress that triggered the PNES.

**Clinical.** The clinical attributes of SMS received less attention from school nurses than the other attributes. However, school nurses did discuss their concerns regarding the long-term effects of not seeking appropriate care, keeping mental health care appointments, and acquiring medications to treat co-morbid conditions. One school nurse
also cited speaking with a student’s other health care providers about tools to help the student.

**Measurement.** School nurses were not aware of any tools that measured SMS for students with PNES. However, they were able to identify several measures that they felt exemplified key indicators for SMS success. All three interviewed nurses identified positive academic gains (either through improved grades or increased completion of coursework) and improved school attendance as key measures of SMS success. Two of the three nurses also mentioned measuring number of visits to the health office and/or length of time spent in one-on-one care with the school nurse. Other student measure suggestions included level of willingness to participate in SMS activities, confidence level in self-managing the condition, number of mental health care visits completed, high school graduation rates, and QOL. Measures that could be completed by a parent/guardian, teacher, or school nurse include level of student involvement in advocating for self (to prevent a trigger from leading to a PNES event), number of PNES events at home and at school, number of days sent home early from school related to PNES, number of hours of class time missed for PNES (time spent in health office for PNES), teacher understanding of condition, and parent/guardian QOL. Suggested health care measures include number of hospital visits and health care costs.

**Antecedents.** When asked what needed to be in place before school nurses could provide SMS, the answers were varied. Some responses reflected a means of knowing SMS was needed, including evidence of poor self-management in the past or poor school attendance due to the health condition. Other responses reflected a state of student- or family-readiness to receive SMS, such as being willing to participate, being motivated to
change, or having mutual respect between student and nurse or parent and nurse. Other antecedents involved the student being under the care of a mental health care provider to confirm diagnosis, prescribe medication for anxiety or other co-morbid condition as appropriate, and provide a health care action plan to inform the school nurse’s care at school. The school nurse having confidence in presenting material about the condition and confidence in expecting positive outcomes in students’ self-management capabilities was also an antecedent to SMS mentioned in a school nurse interview.

**Consequences.** The school nurses interviewed witnessed fewer and/or less severe exacerbations of illness, better attendance in school, better academic outcomes, better social relationships, more participation in life activities, happier disposition, improved confidence, improved self-advocacy, and reduction in fear of being “different” or “out of control.” Students used tools gained through SMS to control the anxiety response to stress resulting in fewer visits to the health office. For a student wrongly diagnosed with epilepsy, once the correct diagnosis of PNES was delivered and a health care action plan appropriate for PNES was provided to the school nurse, a decrease in number of seizures was noted. School nurses also cited observing students express understanding of their condition, greater comfort taking action steps when feeling a PNES event approaching, and greater sense of control over their education plan and stressors at school.

**Analytic Phase**

During the final analytic phase, Rodgers and Knafl (2000) recommend answering the following questions:

1. How much is the concept applicable and important to [school] nursing?
2. Does the initial selection of the concept seem justified?
3. To what extent do the review of literature, theoretical analysis, and empirical findings support the presence and frequency of this concept within the population selected for empirical study? (p. 147)

After completing theoretical and fieldwork phases, it is evident that SMS is both applicable and important for school nurses caring for students with PNES. The selection of SMS as a concept is extremely relevant, especially considering that there are no published findings in school nurse, medical, or psychological journals to guide school nurses in the care they provide students with PNES; additionally, school nurses report struggling to identify appropriate interventions to support students with PNES. The review of literature, theoretical analysis, and empirical findings suggest much more emphasis should be placed on supporting students with PNES in school, and school nurses providing SMS is a practical solution for addressing the greatest concerns of children with PNES—school relationships, attendance, and performance (Morgan & Buchhalter, 2015).

**Meaning.** The analysis phase is also for “interfacing the initial theoretical analysis with insights gained from the empirical observations” (Rodgers & Knafl, 2000, p. 132). When comparing SMS meanings found in literature and provided by school nurses, similarity was found between school nurses’ definition and Cahill and colleagues’ (2016) definition focusing on the transition between parent management and student management. Henry and Schor (2015) reflected school nurses’ experience in their emphasis on the family’s role in health promotion and the family’s need for confidence in providing care; however, Henry and Schor (2015) failed to recognize the combined role of family and child together managing a health condition. Van Hooft and colleagues
(2017) offered a definition similar to that of school nurses that addressed coaching the patient in self-management skills. Reviewing key findings within the behavioral, educational, psychosocial, and clinical attribute categories of SMS highlights further variability in conceptual attributes between literature and reality for school nurses.

**Behavioral.** The importance of goal setting and having a written plan was an integral part of SMS in both literature and in the field. The role of coaching was also a key element, although the person in the role of coach within the literature was a community health worker, mental health care specialist, or peer with similar condition or ethnic background; in the field, the school nurse was the person considered to be the coach. School nurses had not considered utilizing any other person to coach students with PNES; instead, they used their own relationship with the student to build a coaching relationship. Communication through follow up calls or “check-ins” was a theme through both literature and school nurse interviews.

**Educational.** The patient-centered approach recommended by Shomaker and DeVeau-Rosen (2016) and the individual-paced approach of Ammerlaan and colleagues (2017) compliment the school nurses’ one-on-one education approach for students with PNES. One very distinct difference is that no authors, even those conducting pediatric SMS research, reported providing any education for teachers. This oversight is concerning when school-aged children likely spend more time with their teacher(s) than their parents for large portions of each year. School nurses consistently mentioned the importance of educating teachers regarding their students’ health conditions.

**Psychosocial.** Within the theoretical phase, relationships were a fundamental theme. Henry and Schor (2015) emphasized the importance of the relationship between
the child, parent, and health care provider while Lozano and Houtrow (2018) discussed the parent-child relationship in the context of “shared management.” Similarly, in the fieldwork phase, school nurses identified critical relationships in the SMS process but included themselves in this relationship unit as well as the student’s teacher. One untapped social strategy for school nurses may be utilizing peer support, which was strongly supported in literature (Henry & Schor, 2015; Hensel et al., 2016; Marjolijn et al., 2016), but was only mentioned once by school nurses in the context of a student with PNES helping brighten the day of a student with a different health condition.

Within trusting relationships with health care providers or peers, students can learn valuable psychological skills. In the literature, Marjolijn and colleagues (2016) mentioned cognitive restructuring as a SMS activity. On the other hand, school nurses focused on teaching coping strategies and coaching students with PNES in the use of these strategies, especially in regard to anxiety and stress response. Interestingly, while literature identified bullying as a concern for students with PNES (Morgan & Buchhalter, 2015), none of the school nurses interviewed identified bullying as a concern, although one school nurse did mention “stressors in the classroom” which could indicate stress from a teacher interaction, student interaction, or learning/homework difficulty.

Clinical. Much of the rhetoric from the theoretical and fieldwork phases that addressed clinical attributes was analogous. One noticeable difference is that school nurses did not explicitly discuss incorporating day-to-day life topics, which was a recommendation for SMS within the literature (Been-Dahmen et al., 2015; Brooks et al., 2016; Henry & Schor, 2015). One explanation is that school nurses are performing SMS outside of the health care setting, making their interactions more “day-to-day” focused
than SMS that may occur in the health care setting. One additional distinction noted between the phases is that school nurses often mentioned communicating directly with the health care provider as a part of SMS; no mention was made in any pediatric oriented literature about health care providers reciprocally reaching out to school nurses to ensure continuity of care outside the health care setting.

**Contextual Boundaries.** The current definition of SMS is applicable to the specialty of school nursing and the care school nurses provide for students age 3-22. This care is provided outside of the typical health care setting and can occur in schools, school health offices, and in students’ homes or other outpatient settings. SMS offered by school nurses falls well within the scope and standards of practice for school nurses, although certain aspects of SMS explored in the literature, such as CBT, would require additional training above and beyond what nurses would learn in current nursing curricula.

**Concept Analysis Discussion**

**School Nurse-Informed Working Definition**

Taking into consideration information gained from literature regarding chronic condition, mental health, and pediatric SMS and from school nurses, the working definition of SMS in the context of school nursing can be evaluated. The working definition provided in the theoretical phase fully encompasses the major themes discussed and does not need adjusted based upon information gathered in the fieldwork phase. With this well-informed definition, further research can be conducted.

**Theoretical and Scientific Implications**

After comparing the theoretical underpinnings of the theoretical and fieldwork phases, the theories or models that resonate most with school nurse SMS include
cognitive behavioral theory (Marjolijn et al., 2016), behavior change theory (Shomaker & DeVeau-Rosen, 2016; Van Bragt et al., 2015), motivational interviewing (Shomaker & DeVeau-Rosen, 2016), shared decision making (Van Bragt et al., 2015), and pediatric self-management model (Lozano & Houtrow, 2018). School nurses focused on coaching students to challenge anxiety-inducing thoughts, employ calming behaviors, use aspects of motivational interviewing to identify and reach goals through a written plan, and share the decision making process. By employing pediatric-focused strategies and involving the family in these processes, school nurses are addressing many theoretical models. Future research should clearly identify theories or models applicable to the tested interventions and expected outcomes to aid in replication and future school nurse guideline development.

**What Theoretical Perspectives are Applicable to Understanding Adolescent Psychogenic Nonepileptic Seizures?**

Previous PNES research has been conducted primarily in the absence of clearly identified theoretical underpinnings. To ensure the advancement of science, this dissertation was designed with not only gaps in knowledge but also several pertinent frameworks and theories in mind. Theories and frameworks related to the school environment, self- and family-management processes, and perceptions of PNES shaped this dissertation. These theories and frameworks, including concepts that have informed a guiding framework for this study, are discussed in the remainder of this section.

**Bronfenbrenner’s Bioecological Framework**

Children with PNES report a variety of school-related concerns. These concerns include learning difficulties, academic achievement, school attendance, bullying, and
relationships with peers and teachers (Alhafez & Masri, 2019; Asadi-Pooya, Myers, et al., 2019; Doss et al., 2017; Dunne et al., 2019; Uzun et al., 2019; Valente & Alessi, 2014; Y. Yi. et al., 2014). Bronfenbrenner’s Bioecological Model of Child Development identifies connections between the various contexts (environments) and processes (interactions) through which children develop and learn (Bronfenbrenner & Morris, 2006). Many studies have used Bronfenbrenner’s Model to explore and explain school-based phenomena (Beck-Cross & Cooper, 2015; O’Donoghue & Guerin, 2017) as well as self-management decisions in adults with PNES (A. Green et al., 2004) and adolescents with epilepsy (Rizou et al., 2017). Within the model, the student is centered amid concentric systems or spheres of influence. Surrounding the student is a system in which the student interacts directly with parents, peers, and teachers. These interactions could be positive or negative, leading to positive or negative consequences in growth and development. In the outer-most system surrounding the student, Bronfenbrenner places school policies, attitudes, and beliefs. These concepts are integral to the understanding of attending school with PNES amid school policies that inappropriately require calling 911 when PNES events occur at school. Attitudes and beliefs are also relevant in qualitative discussions of teachers, students, and parents believing PNES events are “fake” seizures purposefully elicited by students for attention or to avoid tests.

**Framework for 21st Century School Nursing Practice**

Bronfenbrenner’s Bioecological Framework highlights the integral role the school environment and school interactions play in students’ development. The Framework for 21st Century School Nursing Practice, subsequently, highlights the role school nurses play in impacting the school environment and interactions (National Association of
School Nurses, 2016). Like Bronfenbrenner’s Framework, the Framework for 21st Century School Nursing Practice places the student surrounded by family and school community in the center. Overlapping key principals of care coordination, community/public health, leadership, and quality improvement encircled by the school nursing’s scope and standards of practice emphasize the array of intervention and evaluation opportunities for nurses practicing in the school environment. A recent integrative review demonstrated the Framework as an effective tool for categorizing school nurse interventions, although most interventions consisted of care coordination tasks—specifically motivational interviewing and counseling—with a need for greater emphasis on student health and academic outcomes (Best et al., 2018).

**Self- and Family-Management Framework**

The Self- and Family-management Framework (Grey et al., 2015) offers a deeper look at the relationship between children with PNES and their caregivers outside the school setting. Because students often need the assistance of their parents or caregivers to attend mental health care appointments, seek academic support through federal law that requires public schools to provide Individuals with Disabilities Education Act (IDEA) special education services or through Section 504 plans for students who do not qualify under IDEA, or simply remain safe during PNES events, PNES research must examine children’s needs at both the individual and caregiver levels. The Self- and Family-management Framework details the antecedents, including facilitators and barriers at the individual and family level, to disease management. These antecedents affect the processes of self- and family-management activities. The ability to carry out these processes will impact proximal outcomes (such as frequency of PNES events and number
of school days missed because of PNES) and distal outcomes (such as PNES QOL and academic performance). The Self- and Family-management Framework has been tested in the context of Portuguese adolescents with type 1 diabetes and was adequate for explaining the relationship between school support, parental coping, illness representation, and disease management outcomes (Almeida et al., 2020). These framework relationships echo the fieldwork phase findings from school nurses in the development of the conceptual definition of school nurse SMS.

**Common Sense Model of Self-Regulation**

The understanding of PNES management in the context of school and family is amplified by examining PNES management through the lens of a behavioral health model, specifically Leventhal’s Common Sense Model of Self-regulation (CSM; Leventhal, Brissette, & Leventhal, 2003). The concepts and relationships within CSM begin with a perceived health threat (when one identifies a difference between one’s perception of health and current signs/symptoms indicating a change in health). For children with PNES, a perceived health threat could be a PNES event. Following the health threat, the individual develops an illness representation, or set of beliefs about the health threat. Illness representation includes five different characteristics: 1) identity (signs and symptoms one attributes to the illness—unconsciousness, uncontrollable movements), 2) cause (what one believes to cause the condition or acute episodes within a condition—stress, ever-growing homework load, academic underachievement, bullying), 3) consequence (the effects of the illness on one’s life—poor school attendance, being escorted by teaching assistant between classes, injury), 4) controllability/curability (the ability to control the condition or be cured-successfully
using such techniques as deep breathing or mindfulness to stop an impending PNES event), and 5) timeline (beliefs regarding how long the condition will last, with experimental pediatric PNES research revealing 66-75% remission rates for children; Kozlowska et al., 2018b; Yadav et al., 2015).

In addition to conceptualizing health threat and illness representation, Leventhal and colleagues (2003) postulate a series of relationships within the CSM. An individual’s illness representation will influence the use of coping strategies to manage the health threat. Following the use of selected coping strategies, the individual will appraise the effectiveness or helpfulness of the coping strategy. If the coping strategy is found to be effective or helpful, the individual may alter the illness representation and/or coping strategies. This process becomes a feedback loop of coping, appraisal, and updating of illness beliefs or illness representation. In a study of adults with PNES, individuals who focused on the cognitive or objective aspects of the health threat were more likely to select problem-solving coping strategies. Use of problem-solving coping strategies tended to result in better health outcomes (A. Green et al., 2004). In this same study, those who focused on emotional aspects of the health threat were more likely to use solitary-venting coping strategies and have poorer health outcomes. This research may not be applicable to children. Although researchers have not investigated illness representations in children with PNES, a study of children with type 1 diabetes revealed children with better blood sugar control held more emotion-focused illness representations. This seems to contradict the adult PNES study findings. However, the many differences between the biomedical condition of type 1 diabetes and mental health condition of PNES may make this comparison impractical. While the hypothesized
relationships may not be consistent between conditions, evidence supports the usefulness of CSM in better understanding PNES in children.

**Summary and Critique**

**State of the Science of Adolescent Psychogenic Nonepileptic Seizure Management**

Having PNES drastically impacts the lives of adolescents with PNES. Mounting evidence in literature presented from a health care system perspective reveals that adolescents with PNES have school-related struggles, often described as predisposing, precipitating, and perpetuating factors. However, scant evidence presented school-related struggles from the student, family, or school perspectives or as consequences of PNES. The enormity of the school-related struggles for adolescents with PNES suggests a need for interventions to address the struggles. Current school-based recommendations for adolescents with PNES simply address how to respond to PNES events occurring at school. However, no reported interventions explicitly address school-specific characteristics or outcomes for adolescents. A number of studies targeted school-based interventions for students with a variety of mental health concerns, including one-time to weekly individual, group, and universal cognitive behavioral interventions. When considering intervention development for adolescents with PNES, one concept that has emerged from the literature and the field of school nurses is a need for self-management support, which includes student, family, school nurse, and organizational attributes that influence behavioral, educational, psychosocial, and clinical needs of students and families. A number of theories, models, and frameworks amply tackle these particular attributes and influences at the individual, family, school nurse, and organization levels.
Existing research has failed to consider adolescents’ perspectives regarding their school-related struggles. Much of the pediatric PNES research has consisted of evaluating medical records of children and adolescents who have received care at epilepsy centers. While this descriptive quantitative research is beneficial to understanding characteristics of those with PNES, this clinical perspective does not consider the relevance of these characteristics to the lives of the adolescents. A small number of studies have examined the effectiveness of pediatric PNES interventions; however, none have targeted the oft mentioned school-based concerns that plague adolescents with PNES. In the absence of school-centric PNES intervention research, an examination of school-based mental health interventions is a logical starting point. However, it is unclear how applicable general mental health interventions are for understanding the effectiveness of PNES-specific interventions, especially with the unique physical manifestations of the condition. Additionally, school nurses are uniquely positioned to provide school-based interventions but have not been previously considered in existing research for the contributions they could make in the improving the academic, QOL, and mental health outcomes.

**Need for Current Study**

A number of gaps in pediatric PNES research have been identified. Current research lacks a student perspective for understanding the many school struggles adolescents with PNES face. The extant pediatric PNES research lacks a strong tie to a theoretical framework or model of related concepts. Therefore, theoretically guided, student-centered research is needed to begin to understand the experience of attending school as an adolescent with PNES, the role self- and family-management support may play in overcoming school struggles, and how school environment characteristics may
impact the school experience for adolescents with PNES. Before the commencement of intervention development, greater insight from adolescents with PNES should be sought through a qualitative approach.
CHAPTER III
METHODOLOGY

After determining the gaps in literature and the need for understanding adolescents’ experience of attending school while attempting to self-manage PNES, a research method appropriate to address this gap in understanding was identified. This chapter will detail the selected research method, including the specific design and rationale, the sampling and recruitment methods, methods and instruments used to generate data, and data management and preparation strategies. Additionally, this chapter provides a detailed explanation of the data analysis process.

Research Design

Background and Description of the Qualitative Descriptive Method

Investigating adolescents’ experiences self-managing PNES in the school context requires a research method that allows for investigation of more than what can be extrapolated from electronic medical records. While researching the number of adolescents with PNES with academic and school-related challenges and their electronic medical record data has identified a population in need of intervention (Caplan et al., 2017; Doss et al., 2017; Plioplys et al., 2014, 2016), the experience of facing those school challenges and their meaning to adolescents has not been reported in literature. Therefore, a qualitative research method was selected to answer the research questions. Qualitative research overcomes certain limitations of quantitative research, specifically that of “coding the social world according to preordained operational variables,” which “destroys valuable data by imposing limited worldview on the subjects” (Marshall & Rossman, 2016, p. 101). Qualitative research also is appropriate when attempting to
explore complex issues, empower individuals, understand the contexts in which individuals address a targeted problem, explain quantitative findings, and/or develop a theory to address current gaps in understanding (Creswell & Poth, 2018).

A specific qualitative method, qualitative content analysis, was selected to achieve a greater understanding of the complexities of adolescent PNES. Content analysis has been used to measure the frequency of words’ appearances in written text since the 1930’s, and the frequency of concepts and relationships since the 1950’s (Busch et al., 2012). Today, content analysis can be used to investigate entire mental models (Busch et al., 2012) and patterns within the “bigger picture” (Erlingsson & Brysiewicz, 2017).

**Rationale for Approach**

Qualitative research was determined the most appropriate method for a number of reasons. Attending school and self-managing PNES as an adolescent is a complex issue requiring adolescent empowerment and an understanding of overcoming PNES self-management barriers. Bringing “bigger picture” understanding to previous PNES quantitative findings and developing a theory or framework to address gaps in understanding are applicable goals that further support the selection of a qualitative method for this study.

In particular, qualitative content analysis can be used to “explore mental models,” including their “affective, cognitive, social” significance (Busch et al., 2012, p. 3) by focusing on concepts and semantic relationships. Because no literature was identified in which the authors explored this particular phenomenon of attending school with PNES, starting with a qualitative study is necessary to understand the experience before proceeding with a program of developing and testing interventions for adolescents with
PNES. To answer the proposed research questions regarding the thoughts, feelings, and self-management actions and interactions of students with PNES, both inductive and deductive qualitative content analysis were used. Further rationale and description of this particular analysis method is provided in the Data Analysis section.

Sample

Sampling Method

Conducting qualitative research requires a sampling method that produces a sample of participants who can adequately add to the understanding of the research problem. Selecting a sampling method involves considering people, actions, events, or processes that will most purposefully inform the project (Creswell & Poth, 2018). For this study, purposive sampling was used to identify adolescents who had experienced attending school with PNES, could describe experiencing PNES events at school, and could articulate the process of self-managing PNES in the school context. A goal of maximum variation—including but not limited to geographic region, disease severity, and academic ability—was sought amidst the timesaving, targeted convenience sampling strategy used. An a priori sample size was not determined; instead, sampling and interviewing was continued until a sense of data saturation, or repetition of themes or patterns (Marshall & Rossman, 2016), was identified in the participants’ responses.

Inclusion/Exclusion Criteria

Purposive convenience sampling for this study included carefully selected inclusion and exclusion criteria to best meet the study’s goals. To participate in the study, participants were required to have a diagnosis of PNES verified by self-report of video-EEG (as verbalized by the adolescent), current or recent in-person attendance at school
with other students and school personnel, age between 12 and 19 years, ability to speak and understand English, and ability to discuss the experience of attending school as a student with PNES. The only exclusion criterion was lack of adolescent assent to participate in the study.

**Sample Size**

The desired sample size for this study was not determined a priori but was instead identified at the point of data saturation. Determining the point of data saturation and conclusion of data collection included scrutinizing the data for evidence of both inductive thematic saturation (the point at which no new codes or themes emerged in the inductive analysis process) and a priori thematic saturation (the point at which all pre-determined themes were exemplified in the deductive analysis process) within the data (Saunders et al., 2018). The data were also examined to ensure negative instances of thematic patterns existed as an additional sign of data saturation (Marshall & Rossman, 2016). For example, evidence of both positive and negative school experiences and both effective and ineffective self-management strategies were identified before the conclusion of data collection. Based on these strategies for detecting data saturation, data collection ceased after ten participants were interviewed.

**Recruitment**

Recruitment for this study involved multiple strategies, including the sharing of flyers through four methods:

1. School nurses contacted via the National Association of School Nurses (NASN) SchoolNurseNet listserv
2. School nurses contacted via NASN state affiliate email lists
3. Other health care providers contacted via contact information provided on a PNES referral site (https://nonepilepticseizures.com/epilepsy-psychogenic-NES-information-referral-sites.php)

4. PNES information-sharing and support groups on Facebook, with permission from page administrators.

Recruitment occurred September 10, 2019 to October 20, 2020 according to the above-listed strategies approved by the Indiana University Institutional Review Board (see Appendix A). The use of varied recruitment approaches resulted in one participant from a flyer shared by a school nurse who was reached via a NASN state affiliate email list and the remaining nine participants from the flyer (accompanied by a brief video introduction by the researcher) being shared via PNES Facebook groups. The flyer used for recruitment can be found in Appendix B.

**Ethical Considerations**

Each phase of the research process was planned with ethical considerations in mind. Prior to the design of this study, the researcher participated in a course regarding the responsible conduct of research and completed human protection training required by the Institutional Review Board. The research design was reviewed and approved by the Institutional Review Board. Upon approval, each step of the research process was conducted paying special attention to ensuring the protection of participants as well as their information.

During the recruitment process, all communication with participants was conducted via email, phone, or text on password protected electrical devices. No identifiable participant information was collected. Both parents/guardians and the
adolescents were provided with detailed information regarding the voluntary nature of the study and the opportunity to end their participation at any time. Adolescents were again asked for their assent to participate immediately prior to data collection and were reminded that they could refuse to answer any question that made them feel uncomfortable or end their participation at any time during the interview.

Once data collection began, additional measures were implemented to ensure the protection of participants. Participants and their parents/guardians were encouraged to participate in interviews in a secure area where others would not be able to hear information regarding their diagnosis or any other personal information. Additionally, parents/guardians were asked to ensure adolescents participated in interviews in a safe location in case a PNES event occurred during the interview. In the event the researcher detected the interview had a negative impact on a participant’s mental health, the researcher was prepared to notify the parent/guardian of a need to contact a mental health professional.

After data collection was complete, the data were protected using multiple strategies. Video and audio recordings were deleted upon transcription and verified accuracy of transcripts. No identifiable information was connected or saved with the transcripts. Transcripts were saved in a password-protected online storage account accessed only on a password-protected computer. Information within the transcripts were shared only with research team members (dissertation committee) and did not include any identifiable information. Finally, within the reporting of research results, the words of participants were treated with continued attention to protecting identity. Quotes were selected and shared without any identifying information.
Data Generation

Instrumentation

A variety of tools were used to collect data from participants. Within qualitative research, the researcher serves as an instrument, as “it is through the researcher’s facilitative interaction that a conversational space is created where respondents share rich information about their lives” (Pezalla et al., 2012, p. 182). In addition to rich data generation through semi-structured interviews, additional supportive data were collected using a modified QOL questionnaire. Finally, demographic data were collected. An explanation of each instrument is provided in the following sections.

Semi-Structured Interview

A semi-structured interview was used to gather information regarding adolescents’ experience attending school with PNES and self-managing their condition in the school context (see Appendix C). Questions were designed to ensure sufficient data would be generated to answer the study’s research questions. One data generating question was used to initiate the one-to-one video-conferencing interviews (Ryan et al., 2009). Techniques such as building rapport, asking open-ended questions, and asking probing or clarifying questions when needed were used (Marshall & Rossman, 2016). The initial interviews were exploratory in nature; however, as data collection continued, more pointed probing questions were used to support or refute budding themes in the data analysis process (Ryan et al., 2009).

PNES Quality of Life Questionnaire

Those with psychogenic nonepileptic seizures (PNES) report disturbingly low quality of life (QOL) scores—lower than sufferers of potentially debilitating conditions
such as epilepsy and Parkinson’s Disease (Anderson et al., 2007; Szaflarski et al., 2003). The few studies conducted to better understand pediatric PNES reveal as many as 65-84% of school-aged children with PNES have unusually high levels of stress and anxiety while 44-55% have symptoms of depression (Plioplys et al., 2014; Sawchuk & Buchhalter, 2015a). Children and adolescents with PNES are also much more likely to express physical complaints, such as headaches, dizziness, weakness, and difficulty walking (Plioplys et al., 2014). They also experience higher rates of bullying, increased school absenteeism, greater likelihood of learning problems, and decreased quality of life (QOL), especially in the domain of school functioning (Akdemir et al., 2013; Morgan & Buchhalter, 2015; Plioplys et al., 2014).

Despite many condition-specific factors affecting quality of life, few studies have examined the QOL of children and adolescents with PNES. Researchers of QOL in adults with PNES have used the Quality of Life in Epilepsy Inventory (QOLIE-31), which assessed many constructs pertinent to PNES including emotional, social, and cognitive functioning and seizure worry (Myers et al., 2012). Instruments that measure QOL for adults lack attention to pediatric-specific concerns such as school functioning; therefore, researchers of QOL in pediatric PNES have used the Pediatric Quality of Life Inventory (PedsQL; Akdemir et al., 2013). Although this often used general pediatric QOL measure captures physical and psychosocial health as well as emotional, social, and school functioning scores, it still fails to hone in on the challenges specific to experiencing PNES. PNES episodes can be sporadic, unexpected, embarrassing, and debilitating (McWilliams et al., 2016). Pediatric QOL measures for epilepsy, such as the PedsQL Epilepsy Module (Modi et al., 2017) can more specifically identify effects of seizure-
specific concerns. However, even this tool fails to address how children’s QOL can be uniquely affected by seizures associated with PNES, including feelings of confusion, uncertainty, and being misunderstood by teachers and peers (McWilliams et al., 2016), which can impact school attendance, anxiety and depression symptoms, and somatic complaints (Akdemir et al., 2013; Morgan & Buchhalter, 2015; Plioplys et al., 2014).

Because children with PNES experience greater anxiety, depression, psychosomatic complaints, and academic struggles than their peers (Akdemir et al., 2013; Morgan & Buchhalter, 2015; Plioplys et al., 2014; Sawchuk & Buchhalter, 2015), imagining and testing interventions that address these concerns is critical to their QOL. To test such interventions, a QOL measure that is sensitive to change in the condition as a response to intervention and can discriminate between sub-groups is necessary.

To address the need for a pediatric QOL measure that can assess the unique QOL concerns for children and adolescents with PNES, the Quality of Life Index: Pediatric PNES Version was developed. See Appendix D for the complete instrument. This measure operates under the following conceptual definition of QOL: “Subjective well-being related to how happy or satisfied someone is with life as a whole” (Ferrans et al., 2005, p. 340). Items for the newly developed instrument were created based upon the existing Ferrans and Powers Quality of Life Index: Epilepsy Version-III (Ferrans & Powers, 1984). Ferrans and colleagues’ (2005) causal model of health-related QOL provides six complex and interrelated areas of QOL. These six areas, in conjunction with constructs from Bronfenbrenner’s Bioecological Model, formed the basis for individual items of the Quality of Life Index: Pediatric PNES Version. Refer to Table 5 for a depiction of the six QOL areas and the item numbers that correspond to the QOL areas.
Table 5

Quality of Life Areas and Corresponding Items

<table>
<thead>
<tr>
<th>Quality of Life Area</th>
<th>Item Numbers</th>
<th>Sample Item Wording</th>
</tr>
</thead>
<tbody>
<tr>
<td>Individual and environmental characteristics</td>
<td>3, 9, 10, 11, 12, 14, 15, 17, 21, 22, 23, 24, 26, 27, 30, 33, 37</td>
<td>How HAPPY are you with: How well your doctors, family, and school work together to help you?</td>
</tr>
<tr>
<td>(including school, home, family, neighborhood)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Biological functions (molecular to organ level</td>
<td>4, 5, 25</td>
<td>The amount of energy you have for required activities like school work?</td>
</tr>
<tr>
<td>involvement)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Symptoms (physical and psychological)</td>
<td>6, 7, 13, 29, 32</td>
<td>How well you can tell a seizure might happen soon?</td>
</tr>
<tr>
<td>Functional status (ability to perform physical,</td>
<td>4, 5, 6, 8, 13, 16, 18, 20, 24, 25, 28, 29, 34</td>
<td>How well you get along with others when you feel sad or stressed?</td>
</tr>
<tr>
<td>social, role, or psychological tasks)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>General health perceptions</td>
<td>1, 2, 4, 5, 14, 15, 29, 37</td>
<td>How doctors, nurses, and counselors take care of your health?</td>
</tr>
<tr>
<td>Overall quality of life</td>
<td>19, 31, 35, 36, 38</td>
<td>Your life overall?</td>
</tr>
</tbody>
</table>

While the Quality of Life Index: Epilepsy Version-III effectively captures general and seizure-specific QOL concerns, it fails to measure pediatric PNES-specific concerns. Therefore, QOL and qualitative literature provided content for additional items. Based upon McWilliams and colleagues’ qualitative study (2017), Item 3 was added to address the perceived need of a partnership between the pediatric clinician and school liaison to ensure all needs, including QOL needs, are adequately met. Item 13 regarding how well one “gets along with others when sad or stressed” was added as a result of a PNES QOL study identifying relationship quality as a predictor of anxiety and depression levels,
which in turn affect QOL (Green et al., 2017). A qualitative study by Rawlings and Reuber (2016) offered support for Items 14, 16, and 17 through identified QOL themes surrounding negative reactions from others upon learning of the PNES diagnosis, negative perceptions of the cause of PNES events, and concern about how well others understand the cause of PNES events. Item 20 alludes to associations found between alexithymia (ones’ inability to identify and articulate internal feelings or emotions) and poorer QOL for those with seizures, both PNES and epileptic seizures (Wolf et al., 2015). Finally, Item 28 is in reference to critical review findings that suggest school-related difficulties are the most common precipitating stressor for children and adolescents with PNES, which could negatively impact QOL (Reilly et al., 2013).

This newly developed tool has yet to be psychometrically tested. Before such a rigorous pilot study can be designed for psychometric testing, the tool needs to be evaluated for face validity. Face validity does not establish validity of an instrument, but does provide laymen’s perceptions of the instrument’s ability to measure the construct of interest (Waltz et al., 2017). Face validity of the newly developed Quality of Life Index: Pediatric PNES Version was assessed during the interviews to ensure it is user-friendly and comprehended by those aged 12 to 19 years (Netemeyer et al., 2003). Additionally, data generated through the face validity assessment were used to quantify and depict the magnitude of perceptions regarding PNES experiences. This use of quantitative data from the instrument will be discussed in greater detail in the description of data analysis. Due to the small sample size, the power of the study was too low to calculate any statistical relationships between QOL and other variables.
**Demographics**

Some demographic data points have been investigated across a number of adolescent PNES studies and were found to be relevant for this study. Age at time of study and age at onset of PNES have been associated with variances in outcomes and PNES presentation (Alessi et al., 2013; Asadi-Pooya & Ziyaee, 2018; Reilly et al., 2013). Earlier age at onset of PNES may lead to longer time before diagnosis (Valente et al., 2017), which can also impact outcomes related to seizure reduction or remission. Gender was also included in demographic data collection because PNES presentation and precipitating stressors have been found to vary by gender (Say et al., 2015). Investigating these demographics allow a comparison of the participants in this study to those of previous studies.

Additional information regarding diagnosis, care following diagnosis, and seizure outcomes are critical to understanding an adolescent’s PNES experience. Video EEG has been identified as the gold-standard for PNES diagnosis (Gedzelman & LaRoche, 2014), and confirming this method of diagnosis is helpful to ensure the information gathered in this study is applicable to adolescents with PNES. Asking about care from a seizure specialist brings understanding of the adolescent diagnosis and care experience, as transition from neurology care to mental health care can impact adherence and treatment success (Kozlowska et al., 2018b). Additionally, gathering data regarding whether each adolescent is under the care of a mental health care professional further defines the adolescent’s experience, especially because such care has been associated with improved pediatric outcomes for health care utilization and seizure frequency (Sawchuk et al., 2020). Seizure frequency is a common outcome measured in PNES research with
decreased frequency used as a common indicator of condition improvement (De Rinaldis et al., 2015; Sawchuk et al., 2020; Yadav et al., 2015).

Subsequent prompts and follow-up questions provided additional details to describe the experience of attending school with PNES and managing the condition in the school context. Asking about whether participants have an aura or warning prior to seizures offered insight into opportunities for participants to self-manage the condition through taking action in an attempt to prevent a seizure or protect oneself from harm during a PNES event. Little has been reported regarding auras in PNES (Madaan et al., 2018); however, the ability to predict PNES events and respond appropriately may impact one’s illness representation and QOL. Investigating this topic allowed a better understanding of potential conceptual relationships.

Another avenue for understanding the school experience is asking participants if they have experienced bullying or other stressors. Many researchers have identified bullying as a common etiology of PNES (Alhafez & Masri, 2019; Valente & Alessi, 2014). Other reported stressors for adolescents with PNES include acute and chronic issues within the family and school (Sawchuk et al., 2020; Say et al., 2015; Valente & Alessi, 2014). One additional stressor that has not been investigated in current literature but was identified as a potential stressor in a secondary analysis and subsequently included in this investigation is the stress of changing schools (Tanner, 2019). In light of these many stressors, participants were asked to share their perceptions of their grades and school attendance to identify any potential relationships between school experience and academic outcomes. Academic and attendance concerns have been reported in
previous adolescent PNES research (Akdemir et al., 2013; Dunne et al., 2019; Madaan et al., 2018; Say et al., 2015; Valente & Alessi, 2014).

In an attempt to understand schools’ response to the needs of adolescents with PNES, participants were asked about school-related accommodations. Legally binding school accommodations can include an IEP or Section 504 plan (Cole et al., 2014; Doss et al., 2017). Participants with such accommodations were asked if the accommodations existed prior to or after the diagnosis of PNES.

While most demographic details were included in the interview based on existing literature findings, some questions were included that have not been commonly included in existing research, including region of the United States where participants reside, type of school setting (such as public, private, charter, online, or homeschool) and type of program (including full day or partial day). Because of the important role school nurses could play in adolescents’ school experience managing PNES, participants were asked about the presence (all day, partial days, some days, or never) and role of the school nurse. While unprecedented in PNES research, the responses to these questions provided a more detailed understanding of the school environment and the relationship it might have to the school experience for adolescents with PNES.

**Settings and Procedures**

The setting and procedures used in this study were specifically selected to enhance the data collection process. After permission was given via email, text, or verbally over the phone by a parent/guardian (as approved by IRB), a date and time was agreed upon with the adolescent and parent/guardian. At the agreed upon time, the researcher and each adolescent connected via Zoom web conferencing platform. This
method of connection for individual interviews allowed for long-distance interviews to occur at no cost to the researcher or participants. Meeting via Zoom also allowed the researcher to visualize the adolescents during the interviews, making the data collection process richer than if the interviews had occurred via phone. Before the interview began, the researcher explained the study and the meaning of voluntary participation to each adolescent and asked for assent. Once assent was granted, the researcher asked each adolescent for permission to record the interview. To initiate the interview, the researcher read a data generating prompt (see Appendix C). As each adolescent responded to the prompt, the researcher asked clarifying questions to gain richer data and additional insight. The interview continued with the researcher following the semi-structured interview script (see Appendix C) and ensuring all questions were addressed in the adolescents’ responses. At the completion of the open-ended interview questions, the demographic questions were asked (see Appendix C), followed by verbally conducting the Quality of Life Index: Epilepsy Version-III (see Appendix D) while displaying the visual response options on the shared Zoom screen. At the conclusion of the interview, the researcher thanked each adolescent and sent a message of gratitude to the parents/guardians for allowing the adolescents to participate.

Interviews lasted 35-70 minutes, except for one interview that lasted only 2 minutes and was ended when an adolescent began crying while explaining her school experience and was unable to finish the interview. For this adolescent, the researcher communicated with the adolescent’s parent and confirmed the adolescent’s safety and access to a mental health care provider to discuss the emotional response to the interview.
Data Preparation, Management, and Analysis

Data Preparation and Management

Data obtained during the interviews were prepared and managed in a secure, confidential manner. Audio recordings of each interview were transcribed by a transcription service and saved as a word document in a secure, password-protected online storage account. Each transcript was proofread by the researcher to ensure accuracy. Then, the words within the transcripts were broken down into phrases called meaning units in preparation for the analysis process (Bengtsson, 2016; Erlingsson & Brysiewicz, 2017; Graneheim et al., 2017). These meaning units were entered into a Microsoft Excel spreadsheet. Additionally, results from demographic questions and the Quality of Life Index: Epilepsy Version-III were entered into the Microsoft Excel spreadsheet, which contained no identifiable information, and saved on a password-protected computer. The spreadsheet was organized with columns dedicated to following: participant number attributed to each meaning unit, each broad interview question, each demographic category, and each questionnaire item. Each row was dedicated to the responses of a single adolescent. A separate sheet was created for each overarching theme. The organization of this spreadsheet design aided the data analysis process.

Data Analysis

Articulating the steps of the content analysis process, both for inductive and deductive analyses, is difficult; content analysis is lauded for researchers’ feelings of uncertainty, frustration, and confusion regarding what happens “between steps” (Erlingsson & Brysiewicz, 2017 p. 93). Therefore, a step-by-step analysis plan was adapted from processes described by Erlingsson and Brysiewicz (2017) and Bengtsson.
that clearly detailed the commonly known steps as well as what happens “between steps.”

**Content Analysis Steps**

The analysis phase included a sequential process of content analysis. First, the transcripts were reviewed three times to become immersed in the data while beginning to inductively open code (identify potential categories or themes that were not identified a priori) and ensure a priori themes deductively derived from the study’s conceptual framework were appropriate “buckets” for initial organization of data (Marshall & Rossman, 2016). Second, the data organization template was modified and used to organize participant responses to interview questions according to newly identified (inductive) and predetermined (deductive) overarching themes separated into columns (see the next section for more information about inductive and deductive analysis). Lastly, thematically related meaning units from each column were reviewed, advanced through levels of abstraction, and compiled into meaningful conclusions. See Figure 2 for a summary of the content analysis process based upon previous researchers’ detailed accounts of content analysis (Bengtsson, 2016; Erlingsson & Brysiewicz, 2017; Marshall & Rossman, 2016).

**Figure 2**

**Content Analysis Steps**

1. Read transcripts three times to open code and ensure a priori themes appropriate
2. Create template and distribute interview responses
3. Advance through levels of abstraction to draw conclusions
**Inductive vs. Deductive Theme Selection**

To appreciate the steps of content analysis within this study, one must understand the difference between inductive and deductive theme selection and the reason for each approach’s use in advancing the understanding of adolescents’ experience attending school with PNES. To organize data, researchers may take an inductive approach (developing an organization system of categories or themes only after they emerge from the many readings of the text) or a deductive approach (developing a priori themes to organize data; Sandelowski, 1995). Because so little is reported about the school experience for students with PNES, it would be difficult and reckless to solely determine a priori categories regarding this phenomenon. However, existing research and application of theory to the PNES experience provide some initial understanding. Based on the previously reported review of literature and relevant theories, a conceptual framework was created (see Figure 3) to guide the semi-structured interview and certain predetermined themes.
Using this conceptual framework, themes were deductively predetermined based upon constructs examined in similar research. This resulted in an initial matrix in which comments from interview transcripts were coded and categorized based upon exemplifying the conceptual definition of each category (Elo et al., 2014). Sandelowski (1995), regarding the use of a priori frameworks, explained, “key concepts of this framework can also serve as an organizing framework for analysis of the data” as long as the predetermined theme matrix does not “prematurely close off recognition of other ways of organizing the data that are truer to them and more illuminating” (p. 375).
Therefore, by simultaneously coding according to a pre-determined theme matrix as well as allowing the emergence of additional themes, the researcher honored the creativity of
qualitative inductive analysis while also using a skeleton of preformed ideas to bring order through the deductive analysis process. Authors of content analysis guidance agree inductive and deductive content analysis can occur in tandem within one study (Kibiswa, 2019). See Table 6 for a summary of both theme selection approaches used in this study.

**Table 6**

*Theme Selection Approaches*

<table>
<thead>
<tr>
<th></th>
<th>Inductive</th>
<th>Deductive</th>
</tr>
</thead>
<tbody>
<tr>
<td>Definition</td>
<td>developing an organization system of categories/themes after they emerge from multiple readings</td>
<td>developing a priori themes to organize data prior to readings</td>
</tr>
<tr>
<td>Basis</td>
<td>immersing self in interviews</td>
<td>reviewing literature and theories, creating a conceptual framework</td>
</tr>
<tr>
<td>Limitations</td>
<td>researcher’s perceptions may allow analysis to diverge from original data, context, or participants’ intended meaning</td>
<td>“prematurely close off recognition of other ways of organizing data that are truer to them and more illuminating” (Sandelowski, 1995)</td>
</tr>
</tbody>
</table>

**Template Utilization**

Central to the analysis of data was the creation and consistent utilization of a template for organizing miscellaneous phrases into organized and meaningful themes that inform conclusions. As described in the data management section, a Microsoft Excel spreadsheet was created based upon both inductively and deductively determined themes. A separate sheet was created for each theme. Each sheet included the process of abstraction, which will be described in the next section. See Figure 4 for a depiction of template utilization within the data analysis phase.
The crux of content analysis is the process of moving text from transcripts through a process of abstraction and describing the process in enough detail to ensure credibility and authenticity of the results (Graneheim et al., 2017). An abstraction process developed by combining processes detailed by multiple qualitative researchers (Bengtsson, 2016; Erlingsson & Brysiewicz, 2017) was used to guide this qualitative content analysis. First, the process began with decontextualizing interview content into meaning units (phrases or sentences that expresses a particular phenomenon). Second, the meaning units were recontextualized or condensed into shorter phrases that still maintained the original meaning but lacked extra, unnecessary words. Third, the condensed meaning units were organized by using codes or organizational categories to identify similar meaning units. Fourth, the codes were further categorized into category clusters. Fifth, the category clusters were compiled into overarching conclusions about the underlying meaning behind the collection of meaning units within the theme. See
Table 7 for a summary of advancement through the levels of abstraction and Figure 5 for a depiction of using a template to organize the abstraction process.

**Table 7**

**Advancement through Levels of Abstraction**

<table>
<thead>
<tr>
<th>Level of abstraction</th>
<th>Example statement under Illness Representation</th>
<th>Consequences of Illness theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>Least</td>
<td>1. Decontextualizing the data into meaning units (phrases or sentences that together express a phenomenon)</td>
<td>“A lot of people judge me. And that bothers me. They tell me I'm faking it.”</td>
</tr>
<tr>
<td></td>
<td>2. Recontextualizing, or condensing, meaning units into shortened text while maintaining meaning</td>
<td>Judgment, people believe faking</td>
</tr>
<tr>
<td></td>
<td>3. Coding, or organizing, condensed meaning units</td>
<td>Peer judgment</td>
</tr>
<tr>
<td></td>
<td>4. Categorization by clustering codes that belong together to describe what is obvious in the data</td>
<td>Social effects</td>
</tr>
<tr>
<td></td>
<td>5. Compilation, or drawing conclusions about underlying meaning</td>
<td>Loss (encompassing loss of control, function, respect, and freedom)</td>
</tr>
</tbody>
</table>

**Figure 5**

**Template Utilization for Organizing Abstraction Process**

![Template Utilization for Organizing Abstraction Process](image-url)
**Magnitude Coding Displays**

Magnitude coding is a unique approach of using quantitative data to enhance a qualitative study. Magnitude coding can be used to indicate a code, category, or theme’s “intensity, frequency, direction, presence, or evaluative content” (Saldana, 2012, p. 58). Displaying frequency of statements (such as statements pertaining to self-management or family-management) or presence or absence of comments (such as acknowledgement or lack of acknowledgement of illness perception characteristics) can allow a clearer understanding of the phenomenon as well as characteristics of the sample (Sandelowski, 2001). Such phenomena as students’ perceptions of effectiveness of self- or family-management activities or coping strategies were coded using numbers for perceived strength of effectiveness and symbols for direction of effect (such as + for positive/helpful effects and – for negative/harmful effects; Saldana, 2012).

Additional data gathered from the QOL questionnaire aided potential pattern recognition (Sandelowski, 2001). The following table (see Table 8) demonstrates an example of magnitude coding with data obtained through student interviews. By using magnitude coding, the effects of self-management strategies became more evident, revealing the following: 1) no self-management strategies had a negative effect; 2) there existed a 50/50 chance of self-management strategies having a positive effect on impending seizures; 3) the ability to tell when a seizure may occur does not necessarily relate to employing effective self-management strategies; and 4) no participants felt they had control once a seizure began.
Table 8

Magnitude Coding Example

<table>
<thead>
<tr>
<th>Participant</th>
<th>Self-management strategy</th>
<th>Effect on avoiding impending seizure</th>
<th>“How well you can tell a seizure might happen soon?” (1=very unhappy-6=very happy)</th>
<th>“The amount of control that you have when you have a seizure?” (1=very unhappy-6=very happy)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Hum classical music</td>
<td>+</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>2</td>
<td>Meditation, grounding</td>
<td>+</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>3</td>
<td>Breathing techniques, mindfulness</td>
<td>0</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>4</td>
<td>Self-talk “Not here, not now”</td>
<td>+</td>
<td>5</td>
<td>1</td>
</tr>
<tr>
<td>5</td>
<td>Call mom</td>
<td>0</td>
<td>5</td>
<td>1</td>
</tr>
<tr>
<td>6</td>
<td>Tell school how to handle seizure, text mom</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>7</td>
<td>Unable to complete interview, crying</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>8</td>
<td>Go to health office, decompress</td>
<td>0</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>9</td>
<td>Laying down, breathing, telling friends</td>
<td>+</td>
<td>6</td>
<td>1</td>
</tr>
</tbody>
</table>

Data Interpretation

“Interpretation means attaching significance to what was found, making sense of the findings, offering explanations, drawing conclusions, extrapolating lessons, making inferences, considering meanings, and otherwise imposing order” (Patton, 2002, p. 480).

An audit trail was maintained during the data analysis phase to capture potential explanations, conclusions, inferences, and meanings. At the conclusion of the abstraction process, the compilations were combined to create a “larger meaning” of the data.
Erlingsson and Brysiewicz (2017) identified compilation, the final step in the analysis phase, as a step in data interpretation. This particular step involves articulating themes that help answer questions such as “why, how, in what way, or by what means?” (Erlingsson & Brysiewicz, 2017, p. 94). In this study, the data interpretation phase resulted in answers to several questions not initially posited as research questions, such as:

1. Why do adolescents with PNES have poorer school attendance?
2. How do adolescents with PNES respond when sensing an aura or seizure warning?
3. In what way do school nurses impact the school experience for adolescents with PNES?
4. By what means do schools interfere with adolescents’ legal right to a free appropriate public education (FAPE) when they experience PNES at school?

Once the abstracted data have been interpreted, the results must be presented in a useful format. Elo and colleagues (2014) recommend reporting the results systematically, making clear connections between the raw data and organized results. Unlike other qualitative research approaches, such as phenomenology or grounded theory, content analysis does not provide a prescribed technique for connecting concepts (Elo et al., 2014). Elo and colleagues (2014) suggest reporting results in such a way that similarities within categories and differences between categories are apparent. Quotations were utilized sparingly and only when needed as representative citations for enhanced
credibility or opportunities for the participants’ voices to be heard over that of the researcher (Graneheim et al., 2017).

Validity

The validity, or trustworthiness, of the results of this study were substantiated through attention to credibility, dependability, confirmability, and transferability (Lincoln & Guba, 1985). Credibility is the confidence a researcher has in the ‘truth’ of the research findings (Elo et al., 2014). The credibility of the findings was supported by identifying a sample appropriate for addressing phenomenon. A number of recruitment strategies were employed to ensure participants were adolescents who understood and could convey the experience of attending school with PNES (Graneheim et al., 2017). Care was taken to obtain a large enough sample for variability in findings to occur (such as both positive and negative school experiences). Another important strategy to confirm credibility was examining negative, or opposing, cases such as opposing school experiences (Lincoln & Guba, 1985). Triangulation, a process of employing multiple methods or sources of information, was used to gain a more comprehensive understanding of attending school with PNES (Marshall & Rossman, 2016). Information was gleaned from existing literature, hybrid concept analysis with school nurse interviews, interviews with adolescents, and a QOL questionnaire to gain a more well-rounded understanding of adolescents’ experience. Finally, peer debriefing with dissertation committee members allowed the researcher to discuss preliminary findings and seek an external evaluation of the content analysis and interpretation process.

Dependability refers to showing that the research findings are consistent and repeatable (Lincoln & Guba, 1985). To demonstrate dependability, clear rules were
followed for category and theme development and designation (Graneheim et al., 2017). Definitions for obscure categories and themes were included in the column headings on the Microsoft Excel spreadsheet to ensure consistency in analysis. The researcher also used peer debriefing with dissertation committee members, including a discussion of the researcher’s pre-understandings, to bolster dependability (Graneheim et al., 2017). A written audit trail was also used to capture the researcher’s data analysis thoughts and interpretation research findings.

Similar strategies were implemented to support confirmability of findings. Confirmability is the degree of neutrality used to interpret findings so that other researchers could confirm the results (Lincoln & Guba, 1985). The researcher ensured findings were shaped by the adolescents rather than by the researcher’s bias. An audit trail, including reflexive journaling, was used to make any researcher bias explicit (Lincoln & Guba, 1985). Because the researcher has had previous experience with adolescents attending school with PNES, it was important to acknowledge this perspective.

It is also necessary to acknowledge the limitations of transferability of the research findings from this study to other contexts. Some traditional researchers claim a weakness of qualitative research is the lack of generalizability, or external validity (Marshall & Rossman, 2016). However, by using a theory-driven conceptual model to guide this research design, audiences of this study can identify the connection between this study and the theories that guided it (Marshall & Rossman, 2016). This increases the transferability of these research findings to work related to the school environment, self- and family-management, and illness-representation. A thorough reporting of the data,
sample characteristics, and data analysis process provided the audience with the tools necessary to conclude how transferable the results are to other contexts (Elo et al., 2014).

**Summary**

This qualitative descriptive study was designed to answer a number of research questions derived from a theory-guided conceptual framework. The strong influence of theory and previous literature, an appropriate sampling method to answer the research questions, and evidence-supported data generation methods bolster the validity of this study’s findings. Also boosting validity is a well-articulated data analysis process detailing the approach for data abstraction, interpretation, and presentation through compilations of themes and magnitude coding. The increased understanding of adolescents’ experience of attending school with PNES gained from this study will shape future research and interventions for self-, family-, and school-management.
CHAPTER IV

RESULTS

Rich data were obtained through semi-structured interviews with students diagnosed with PNES. As described in Chapter 3, students’ responses were transcribed and broken down into meaning units, condensed, coded, categorized, and compiled into overarching themes or conclusions. In this chapter, characteristics of the adolescents are presented. Next, results of the data analysis are presented, organized by research question. Additional themes that inductively emerged during the analysis process are addressed in subsequent sections.

Sample Characteristics

Ten adolescents participated in the study. Adolescents ranged in age from 12 to 19 years, with a mean age of 15.8 years. Eight adolescents were White (80%) and two were Black or African American (20%). While efforts were made to recruit both male and female participants, all 10 adolescents (100%) were female. Age at diagnosis ranged from 10 to 18 years, with a mean of 14.4 years. Adolescents in the study had been diagnosed with PNES on average 1.5 years (range 0.66-4 years). Seven adolescents (70%) were from the Midwest, while two (20%) were from the Northeast and one (10%) was from the Southeast.

In addition to demographic information, to better understand adolescents’ experiences, characteristics pertaining to adolescents’ school and PNES management experiences were evaluated. Eight adolescents (80%) reported receiving mental health care, one (10%) reported not receiving mental health care, and one (10%) ended the interview before disclosing this detail. All students receiving mental health care also
reported receiving school accommodations for PNES (80%), six via Section 504 plans and two via IEPs. The adolescent who reported not receiving mental health care also reported not receiving documented school accommodations. Of the eight students with accommodations, five adolescents did not begin receiving school accommodations until after their PNES diagnosis, while three had comorbid diagnoses (ADHD, depression, and history of concussion) already qualifying them for school accommodations.

Adolescents’ school environments varied in a number of ways that potentially influenced their school experience. All adolescents attended public schools, but the program type varied, based on PNES care needs, from homebound instruction (n = 1, 10%) to partial day (n = 4, 40%) or full day (n = 5, 50%). Their schools varied in PNES response protocols: five schools represented in the study (50%) did not call 911 for each PNES event, three schools (30%) had protocols or policies requiring calling 911 for each PNES event, and two adolescents (20%) were unsure or did not specify their schools’ PNES response plan for calling 911. School environments also differed according to school nurse presence. Forty percent (n = 4) of adolescents reported having a school nurse at their school full time each day. Another 40% (n = 4) reported having a school nurse partial days or some days each week. One adolescent (10%) reported having no school nurse at her school. Worth noting is the single adolescent without a school nurse was also the only adolescent known to not have school accommodations through either a Section 504 plan or IEP. Yet another characteristic of school environments was a climate of bullying. The term “bullying” was not defined for adolescents; rather they were allowed to share any experiences they felt involved bullying. Six adolescents (60%) reported experiencing bullying at school and four (40%) did not.
Similar to the deeply personal and individualized experience of school bullying, there were a number of individual characteristics that were important to examine in conjunction with qualitative findings. To better understand adolescents’ ability to identify impending PNES events, adolescents were asked about experiencing an aura, or warning, prior to PNES events: eight (80%) responded they did experience a warning while one (10%) did not have any indication of impending PNES event and one (10%) did not provide a response. Adolescents also described their PNES event frequency ranging from six seizures per day to zero seizures in the past two months. Adolescents also approximated their school attendance, which ranged from missing 10 days of a 45 day quarter to “most days.” Despite the general poor school attendance of all adolescents, seven (70%) described their school performance as good (A’s and B’s or equivalent GPA) and only one (10%) described school performance or grades as poor. Also related to interaction with school environments, 40% of adolescents noted changing schools during their school-aged years. See Table 9 for participant demographics, school environment characteristics, and individual condition and academic characteristics.

Table 9

Demographic, School, and Individual Characteristics of the Sample

<table>
<thead>
<tr>
<th>Variable</th>
<th>n = 10</th>
<th>Percentage</th>
<th>M (SD)</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (in years)</td>
<td></td>
<td></td>
<td>15.8 (2.04)</td>
<td>12-19</td>
</tr>
<tr>
<td>Age at diagnosis (in years)</td>
<td></td>
<td></td>
<td>14.4 (2.06)</td>
<td>10-18</td>
</tr>
<tr>
<td>Time since diagnosis (in years)</td>
<td></td>
<td></td>
<td>1.5 (1.06)</td>
<td>0.66-4</td>
</tr>
<tr>
<td>Quality of Life Index: Pediatric PNES</td>
<td></td>
<td></td>
<td>4.1 (0.65)</td>
<td>2.62-4.78</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>0</td>
<td>0%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>10</td>
<td>100%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>8</td>
<td>80%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Category</td>
<td>Value</td>
<td>Percentage</td>
<td></td>
<td></td>
</tr>
<tr>
<td>----------------------------------</td>
<td>-------</td>
<td>------------</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Black/African American</td>
<td>2</td>
<td>20%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Location</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Midwest</td>
<td>7</td>
<td>70%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Northeast</td>
<td>2</td>
<td>20%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Southeast</td>
<td>1</td>
<td>10%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Receiving of mental health care</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>8</td>
<td>80%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>1</td>
<td>10%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unknown</td>
<td>1</td>
<td>10%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>School accommodations</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Section 504</td>
<td>6</td>
<td>60%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>IEP</td>
<td>2</td>
<td>20%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>1</td>
<td>10%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unknown</td>
<td>1</td>
<td>10%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Initiation of accommodations</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Before PNES diagnosis</td>
<td>5</td>
<td>50%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>After PNES diagnosis</td>
<td>3</td>
<td>30%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>School type</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Public</td>
<td>10</td>
<td>100%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Private</td>
<td>0</td>
<td>0%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Charter</td>
<td>0</td>
<td>0%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Program type</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Homebound</td>
<td>1</td>
<td>10%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Partial day</td>
<td>4</td>
<td>40%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Full day</td>
<td>5</td>
<td>50%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>School 911 protocol</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Did not call for every seizure</td>
<td>5</td>
<td>50%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Did call for every seizure</td>
<td>3</td>
<td>30%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unknown</td>
<td>2</td>
<td>20%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>School nurse presence</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>4</td>
<td>40%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Partial day/week</td>
<td>4</td>
<td>40%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Full time</td>
<td>1</td>
<td>10%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unknown</td>
<td>1</td>
<td>10%</td>
<td></td>
<td></td>
</tr>
<tr>
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<td></td>
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</tr>
<tr>
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<td>6</td>
<td>60%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>4</td>
<td>40%</td>
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</table>
Research Question 1: Experience of Attending School as an Adolescent with Psychogenic Nonepileptic Seizures

When asked about their experience attending school with PNES, the majority of adolescents immediately responded with variations of, “It’s hard!” Two adolescents began by recounting their experience of having their first seizures at school while others shared the details of what made attending school with PNES so challenging. Bronfenbrenner’s Bioecological Model (Bronfenbrenner & Morris, 2006) and its concentric influences of child development shaped the analysis of adolescents’ school
experiences. In the retelling of seizure experiences and what makes attending school with PNES so challenging, themes of stressors, bullying, accusations of “faking it,” and feeling left out arose.

**Stressors**

Adolescence can be a stressful time for all students. Attending school as an adolescent with a mental health condition that presents as fear-inducing seizure activity can be even more stressful, as evidenced by responses from the initial data-generating question. Adolescents identified a number of internal and external stressors that defined their school experience.

**Internal**

Three adolescents distinguished internal stressors that influenced their school experience. Those internal stressors included co-morbid mental health conditions including post-traumatic stress disorder and anxiety. Feelings of intense emotions, including anger, grief, and being overwhelmed were identified as internal stressors. Bronfenbrenner’s Bioecological Model depicts the impact internal stressors can have on external situations.

**External**

All interviewed adolescents discussed external stressors. Through the lens of Bronfenbrenner’s Bioecological Model, bidirectional interactions between adolescents and their school or extra-curricular lives shaped the resulting categories. Envisioning the concentric circles surrounding a child in the model during the content analysis process, stressors were considered as either originating from adolescents’ involvement with school or having an impact on their school experience.
School-Related Stressors. All adolescents responded with school-related stressors that impacted their school experience. They discussed the sense of feeling overwhelmed by school deadlines, being behind in the completion of school work related to missing school, and academic struggles in one or more subject areas. However, not all academic struggles were related to intellectual difficulties; instead, three adolescents experienced school struggles related to taking Advanced Placement or challenging courses. Adolescents also noted test anxiety as a school-related stressor.

Beyond the stressors linked to school-related challenges, adolescents identified a number of additional stressors. Two adolescents described experiencing school stress, but not having seizures in the most stressful classes; rather, they experienced seizures in a particular class where they felt more safe or relaxed. Not all students identified feeling any aspect of school was safe or relaxing for them, instead describing general school environment concerns including others talking about their seizure activity inappropriately. One student even attributed her seizures and school-related stress to racism expressed by fellow classmates. Another student described the school environment in terms of difficult interactions with a teacher.

Examining stressors outside the confines of the school environment, adolescents also experienced stress as they journeyed from childhood into adulthood while having PNES. One adolescent described the stress related to balancing both school and work. While she experienced more seizures at school than at work, both were stressful environments that impacted her overall school experience. Yet another adolescent detailed the stress she experienced related to planning for college in light of having poor grades.
Stressors Impacting School. Not all stress surrounding the school experience was considered by adolescents to be caused by attending school. On the contrary, adolescents mentioned stressors external to the school environment, including family interactions in which the student was providing for the parent’s needs rather than the parent meeting the adolescents needs. Another adolescent noted “money concerns” as a stressor that impacted her school experience. Two adolescents considered one of their primary school stressors to be having PNES and experiencing seizures at school, with one stating, “Seizures themselves are stressful.” The stress of having seizures weighed heavily on one adolescent’s transition into adulthood as she declared, “I actually felt stressed by not being able to have a job and not being able to drive. I felt like I lost my sense of being an adult.”

Bullying

When asked directly about their experiences with bullying as a part of their school experience, a range of responses ensued. Four of the adolescents denied experiencing bullying initially. However, after each interview was completed, only one adolescent still maintained she did not experience bullying. The adolescents listed a number of reasons others chose to bully them, forms in which bullying was delivered, and perpetrators of the bullying.

Reasons

Adolescents’ responses revealed a number of reasons others bullied them, with many, but not all, reasons relating to their seizures. Adolescents described being bullied for “stupid things” and for “things I couldn’t help.” One student identified bullying that
was targeted at her race rather than her seizures. However, all adolescents pinpointed seizure-related reasons for at least some of the bullying they endured.

The bullying rooted in response to adolescents’ seizures was multifocal. One adolescent recounted being bullied for the attention she received due to seizures, saying, “They called me attention-whore and things like that.” The same adolescent also described rude comments from students regarding her frequent absences from school, with such comments as, “If you wanna leave school so badly, instead of having a seizure, why don’t you just drop out?” Derogatory comments from peers also pertained to perceptions of unfairness when the adolescent with PNES was allowed to attend a school trip despite having poor attendance. Yet another aspect of bullying was experienced after this described event: “This kid has made a post about the whole seizure and how the school wasn’t treating me right and it ended all over Facebook. And then we had to deal with the legal troubles.” Other instances of bullying involved peer comments such as, “You’re the seizure girl. You can’t do this or that” and school personnel telling an adolescent with PNES that she was scaring other children.

Another aspect of bullying came in the form of accusations that adolescents were faking their seizures. This was such a prominent theme in adolescents’ responses that an entire section is devoted to peers’ and school employees’ remarks regarding accusations of faking seizures in a future section. It is also important to note not all bullying took place in the school setting; one student described being bullied by peers regarding having seizures while residing as an in-patient in a mental hospital.
Forms

Just as bullying took place in multiple locations, bullying also came in many forms. The previously mentioned accounts of bullying were primarily in spoken form. However, one adolescent’s experience was a result of a digital social media post. Another adolescent explained her experience of bullying via written word received on and in her locker. What seemed to have an even greater impact on the school experience of adolescents was bullying that occurred in the form of exclusion from the activities of peers and even acts of violence. One adolescent’s harrowing experience was described in this way:

I had stuff thrown at me, things like that. I had one kid throw probably the biggest rock I had ever seen at me one day when I was getting in my sister-in-law's car, and yelled at me that if a brain injury started all of this, maybe another one could cure it.

Perpetrators

Lastly, to understand adolescents’ experience with bullying, it was important to realize the perpetrators of such bullying. As detailed in the previous accounts, peers at school were the primary offenders reported by eight different adolescents. Peers in the mental hospital were the perpetrators at a mental hospital. However, school personnel charged with identifying, reporting, and addressing bullying were also identified as perpetrators in bullying through their words and actions, especially those conveyed out of an assumption that adolescents were faking their seizures.
Faking It: Multisector Misunderstandings

One particular concept arose amidst adolescents’ discussions surrounding bullying and their school experience in general, the accusations of “faking it.” One participant pointed out the term “pseudoseizure,” formerly used for PNES, conjured the impression that the seizures are “not real.” Six of the ten adolescents interviewed described at least one person who had accused them of faking their seizures. While two adolescents specifically identified peers or friends as the accusers, the accusations were primarily cast by various members of both the health care sector and education sector.

Health Care

Adolescents described a number of disconcerting interactions with a number of health care personnel. One adolescent described doctors in the hospital conveying the accusation of faking seizures because they did not understand the condition. Another adolescent quoted her diagnosing physician, saying, “And then they did an EEG and that's when they came up saying, it was PNES. She's faking it. Send her home. There's nothing we can do.” A hospital nurse was overheard later repeating the words of this physician. Yet another adolescent quoted an emergency medical service personnel: “Sign these papers quickly because we have somebody with real chest pain to go get to.”

Education

Although members from the health care sector, namely school nurses, exist within the education setting, their presence did not improve the understanding of education personnel for some students. Unfortunately, not all school nurses had or conveyed an accurate understanding of PNES. One school nurse was reported as being overheard saying to other school personnel during a participant’s seizure, “She only does this in
front of certain people.” Adolescents reported overhearing school personnel refer to their seizures as “attention episodes” acted out purposefully “to get out of school” and a principal reporting to his staff that “they’re faked for attention.” Classmates, even those thought to be friends, tended to follow the example set by their teachers and school leaders by echoing their remarks regarding faked seizures.

**Left Out**

The negative thoughts and comments from school personnel and students created an environment where adolescents expressed feeling “left out” in myriad ways. This theme arose from various school interactions at various levels. Seven participants reported feelings of isolation or exclusion, with six of the participants citing their school environment being the cause of such feelings.

**By School**

Adolescents with PNES attributed their feelings of school isolation and exclusion to a number of school-related factors. One adolescent described a lack of time to connect with others:

Every second that I had that I wasn't insanely stressed or worried about having a seizure or actually having a seizure was spent frantically trying to catch up on the work. I was either having seizures, or I was catching up as much as possible, and I was always behind. So yeah, I didn't really have any time to talk to people in the hallways or anything.

In addition to schoolwork and seizure worries preventing time with friends, another adolescent described the experience of having an adult escort at all times decreasing the likelihood that she could interact with peers. Another school decision that had a similar
effect was placing a student on a half-day schedule, which decreased the number of classes she had with peers as well as access to the recreational opportunities school offered. Five different adolescents described situations in which they were prohibited from attending school-related extracurricular events—a course after normal school hours, school spirit week, choir contest, field trip, football games, or homecoming—because of the chaos an untimely seizure might cause. One adolescent also explained that her school would not allow her to participate in physical education class with her peers because the gym was located in a separate building from the main school building.

**By Peers**

School decision makers had a role in creating a sense of exclusion or isolation for adolescents with PNES, as did peers in the school setting. Adolescents expressed peers’ fear of seizures and avoidance of those different than themselves as reasons for feeling left out. One commented, “They [peers] treat us like we’re out-casters in a way,” while another articulated, “They had just kicked me out of everything…they would call me crazy.” One adolescent used a social media poll to gain understanding of how others viewed her, resulting in 48 responding they viewed her differently because of her condition and 8 responding their view of her was unchanged.

**By Others**

Beyond the feeling of being excluded by peers, multiple adolescents sensed a lack of access to caring people, both at school and in health care settings. One adolescent described her inability to try out for cheerleading because the urgent care where she attempted to obtain a school physical would not examine her due to her having “unexplained seizures.” She later learned that other health care providers might have
performed a physical, but that information was received too late for her to try out for cheerleading. The health care system was also a source of isolation for an adolescent when a neurologist provided the diagnosis of PNES without any subsequent transition follow-up care. She said, “I…felt like I was just pushed out to sea and left to build a raft on my own.”

**Self-Inflicted**

Adolescents voiced that they were the source of some of their feelings of exclusion or isolation. Feelings of having to orchestrate life around PNES because of the fear of impending seizures happening at school and the need to avoid seizure triggers were expressed by those interviewed. One adolescent described being involved in the decision with school leaders to isolate in the health office rather than attend school spirit week events. Another adolescent expressed a desire to separate herself from others who do not have PNES, stating, “I just wanna go to a school where everyone has the same disorders as me, so they could treat me the same.”

**Summary**

The adolescents interviewed for this study expressed the great hardship it is to attend school with PNES. They described a number of stressors, including feeling overwhelmed by school work and looming deadlines, planning for college and adulthood, and enduring racist comments from peers. Bullying experienced by the adolescents ranged from negative comments and name-calling to violent acts and was delivered by not only peers but also school and health care personnel. The greatest insult that peers, school personnel, and health care providers hurled was the accusation of adolescents faking their seizures. These words and actions resulted in adolescents often feeling
excluded from the enjoyable aspects of school and isolated from peers who could have a normalizing effect for adolescents with PNES. To quantify some of the adolescents’ perceptions regarding stressors, bullying, and the misunderstandings of health care and school team members, Table 10 displays the scores for QOL items related to these themes. The entire spectrum of responses, from 1 (very unhappy) to 6 (very happy), were used to rate adolescents’ happiness with the various aspects of QOL with PNES. Consistently poorer scores resulted from questions regarding their level of happiness with how people act when they find out they have seizures, how people act during their seizures, and how well others understand the cause of their seizures.

Table 10

School Experience Themes and Related QOL Items

<table>
<thead>
<tr>
<th>Participants</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
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</thead>
<tbody>
<tr>
<td>Stressors</td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
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<td>3</td>
<td>1</td>
<td>4</td>
<td>1</td>
<td>3</td>
<td>?</td>
<td>3</td>
<td>?</td>
<td>4</td>
</tr>
<tr>
<td>Bullying &amp; Left Out</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>QOL People Act about Seizures</td>
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<td>4</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>3</td>
<td>?</td>
<td>4</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>QOL People Act during Seizures</td>
<td>2</td>
<td>1</td>
<td>1</td>
<td>3</td>
<td>1</td>
<td>2</td>
<td>?</td>
<td>3</td>
<td>3</td>
<td>6</td>
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<td>QOL Get Along with Students</td>
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<td>4</td>
<td>6</td>
<td>1</td>
<td>3</td>
<td>5</td>
<td>?</td>
<td>5</td>
<td>?</td>
<td>5</td>
</tr>
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<td>Multisector Misunderstanding</td>
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<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
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<tr>
<td>QOL How Health Care Cares</td>
<td>3</td>
<td>6</td>
<td>1</td>
<td>2</td>
<td>4</td>
<td>4</td>
<td>?</td>
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<td>3</td>
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<td>4</td>
<td>?</td>
<td>5</td>
<td>?</td>
<td>5</td>
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<tr>
<td>QOL Others’ Understanding Cause</td>
<td>2</td>
<td>6</td>
<td>1</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>?</td>
<td>2</td>
<td>?</td>
<td>3</td>
</tr>
</tbody>
</table>

Note. QOL = quality of life; ? = unknown/unavailable response

Research Question 2: Adolescent Self-Management of Psychogenic Nonepileptic Seizures

Adolescent participants offered insight into what constitutes PNES self-management, especially as it pertained to attending school with PNES. A number of strategies were outlined under the overarching theme of self-management, resulting in two sub-themes: 1) proactive self-management strategies used to prevent seizures and
address seizure triggers and 2) reactive self-management strategies used to respond to seizure warning signs or seizure aftermath.

**Proactive Self-Management Strategies**

Sixty-two meaning units were derived for proactive self-management strategies from interviews with adolescents. Some of the comments resulted without prompting while many were only generated after the interviewer specifically asked adolescents about how they managed or took care of their condition. Through the compilation of codes and categories, the adolescents’ responses were grouped according to activities that provided themselves protection, demonstrated personal perseverance, or involved progress monitoring.

**Protection**

Four adolescents described proactive self-management strategies that involved protecting themselves from harm. These activities included carrying a backpack at all times while at school that contained supplies, such as a pillow to protect her head during seizures. This adolescent also reported routinely wearing a coat with a hood everywhere she went for added head protection. Another adolescent described keeping a sack with a jacket in her locker that could be grabbed to protect her head if she sensed an impending seizure. Other protective strategies included finding a safe place where future seizures could occur out of the way and out of the sight of others. Another adolescent obtained a service animal. She explained, “I do have a service dog and she senses, she alerts in response to my seizures…she will alert and I’ll have up to 10 minutes [of warning]. I used to only have a few seconds warning.” At the root of every protective strategy was
the development and implementation of a plan for ensuring safety, especially protection
of one’s head, during seizures.

Perseverance

The vast majority of self-management strategies were considered acts of
perseverance, or ways of learning how to continue trying to attend school despite the
difficulties brought on by PNES. Perseverance strategies were reported by all ten
participants. These strategies included planning for seizures, living life despite seizures,
using coping strategies, seeking treatment, and advocating for oneself.

Adolescents described a number of self-management strategies that involved
making plans for themselves. Several discussed making preparations to respond when
seizure auras, or warnings, occurred, with the primary goal of needing as little assistance
from others as possible. However, others mentioned involving a select group of people in
the plan, such as friends who had become knowledgeable about the condition and how to
respond when seizures occurred. Adolescents also explained including their friends’
parents in planning for their assistance in the event of a seizure. Planning included not
only whose assistance was needed and what care was required during the seizure, but also
the care that might be required after the seizure.

The planning efforts allowed adolescents an opportunity to continue living their
lives, albeit drastically affected by PNES. Specific self-management strategies were
described that focused on “trying to keep going throughout the day.” One adolescent
described keeping a schedule to ensure she left the house each day, avoiding the tendency
to simply stay home and avoid others. Another adolescent discussed remaining at school
after seizures instead of going home after each seizure. One adolescent explained how she learned sign language to adapt to her inability to speak after seizures. Adolescents had a spirit of focusing on the aspects of their lives they could control, as conveyed by one of the participants:

I'm just gonna make it to the classes I can make it to. I'm gonna work my job and go to school. I can't drive, but I'm gonna find a ride. I'm gonna get to school third period, I'm gonna get picked up after sixth. I'm gonna get to work at four and then just whatever I gotta do.

Adolescents also described a number of coping strategies they used as a part of self-managing PNES. Meditation, grounding skills, mindfulness, deep breathing, and thought exercises were named by adolescents as coping strategies they routinely used, especially during moments of increased stress. One student identified an application on her smart phone that she used to implement all of the mentioned coping strategies. Another student found a calming room within her school building to be a helpful environment for practicing coping strategies.

In addition to coping strategies useful in moments of increased stress, other strategies were used to lower general stress levels. Two adolescents described creating artwork and displaying the pieces as a reminder of their healing journey. Other strategies for decreasing general stress levels included lifting weights, applying face masks, using a journaling smart phone application, using positive self-talk, and purposefully taking time for self-care.

Another proactive self-management strategy involved interacting with others to manage their stress. Adolescents sought comfort by engaging with a pet or family
members and understanding support group members. One adolescent also used humor, making jokes about herself after recovering from a seizure to decrease the awkwardness she and bystanders felt.

A common component of self-management is the concept of treatment adherence. Adolescents mentioned routinely visiting a therapist, working through the process of CBT. A commonly mentioned part of PNES treatment was working through finding the stressors that tended to precipitate seizures as well as the stressors that were potential predisposing factors for PNES. Two adolescents also mentioned taking medication as a part of their PNES self-management.

Especially important in the school setting was the ability and confidence to advocate for one’s needs while self-managing PNES. Adolescents recognized a number of ways to advocate for their PNES needs, including actively seeking assistance from school personnel, making concerns heard, reporting inappropriate school nurse behavior to a school administrator, talking to teachers and peers about PNES and how to respond when a seizure occurs, and asking teachers for help with makeup work from seizure-related absences. Through more formalized methods, adolescents advocated for themselves by obtaining written care plans from health care providers. One adolescent wrote a letter to her Section 504 team to express her desired accommodations when she was not invited to attend the meeting herself. Another adolescent advocated for certain seizure response accommodations to be added to her Section 504 plan. All advocacy efforts supported adolescents’ efforts to persevere through school despite their PNES diagnosis.
Progress Monitoring

Another aspect of self-management mentioned by adolescents was tracking their PNES progress. Because decrease in seizure frequency is a common measure of condition improvement, several adolescents described tracking their seizures. Whether through a written record keeping system, phone application, or texting each seizure’s details to a parent, adolescents used seizure tracking to monitor their condition or treatment progress.

Reactive Self-Management Strategies

With 62 meaning units displaying proactive self-management strategies and half as many reactive strategies, it is clear both strategies are integral to the self-management of adolescents’ PNES. Although adolescents make a concerted effort to prevent seizures and plan ahead to provide for their safety, adolescents must also self-manage their PNES through reactive strategies. Reactive strategies included those activities adolescents did in response to a warning that a seizure may occur soon or in response to having a seizure. Not all participants had an aura or warning sign, so the information in this section pertains to the eight adolescents who did experience an aura. Strategies with a desired result of protection and perseverance were prominent in adolescents’ descriptions of the school experience with PNES.

Protection

All eight participants who experienced auras expressed using protective strategies as a part of their PNES self-management. The most commonly stated protective strategy was assuming a position of safety by either sitting or lying down. The next most common strategies were seeking a friend, classmate, or teacher for assistance and a private
location for the seizure to occur, such as a restroom or behind the desk of an understanding teacher. One adolescent described having enough forewarning that she would make arrangements with her mother to stay home that day. When feeling that she was not in a safe or private space for a seizure, one adolescent described her attempts to stave off the seizure: “I can push it off. It feels like it gets harder to not resist, it's something that's pulling but it feels like it's getting harder and harder to just let go and just have the seizure.”

**Perseverance**

The theme of perseverance continued through the voices of the adolescents as they described their reactive self-management strategies. One adolescent who did not experience auras described her attitude after having a seizure as “brush it off and keep going.” For adolescents who experienced auras, they too utilized strategies that allowed them to “keep going” despite sensing an impending seizure. Adolescents detailed a number of calming strategies, the most popular among them being deep breathing, mindfulness, thinking positive thoughts, decompressing in the health office, grounding oneself by slapping the floor, and distracting oneself with humming, repetitive phrases, or being around children were also names as strategies. An adolescent with a significant amount of warning time reacted to the warning in this way:

I would walk to a quiet place. Maybe put in some music or read a book but if I'm here at home I would light a candle and play music, or watch a movie, or something to bring myself back a little bit.
Effectiveness

When prompted, adolescents described the effectiveness of their self-management attempts, and a variety of answers followed. Their responses reflected a general sense of effectiveness for their proactive self-management strategies. For example, one adolescent who described implementing measures to ensure her head was protected during seizures explained she has been able to protect her head with the supplies she packed or coat she wore. Adolescents responded in more detail with the effectiveness of their reactive self-management strategies. Another adolescent who took steps to have privacy successfully did so through going to a stairway or behind an understanding teacher’s desk. Advocating for her school needs by being open with teachers about her condition resulted in positive outcomes for one adolescent: "All my teachers have been super kind, super thoughtful and they're... They've just been really caring." Decreased embarrassment from seizures, teacher adherence to her Section 504 plan, peer awareness of seizures, and normalization of the condition were the results of another adolescent advocating for herself. On the other hand, one adolescent described her attempts at self-advocacy through talking with school personnel about her seizure plan as “just like talking to a brick wall.”

Adolescents also provided details regarding the effectiveness of their reactive self-management strategies. They primarily described their ability, or inability, to postpone or stop a seizure from occurring when they experienced an aura. Four adolescents expressed being able to use strategies successfully to stop a seizure, while one was unable to stop a seizure with her implemented strategy. Those having success with stopping a seizure used such strategies as distraction, meditation, grounding skills, mindfulness, and breathing techniques. The one adolescent who specifically stated she
could not suspend a seizure used sitting down and breathing as her response to feeling an impending seizure.

**Summary**

Adolescents’ self-management of PNES involved a number of strategies to proactively address living life with PNES (see Table 11) and reactively responding to a looming seizure (see Table 12). Much greater emphasis was placed on proactive strategies used to plan for the protection of one’s body, privacy, and dignity. Adolescents demonstrated a strong spirit of perseverance through their efforts to plan their days, prepare for worst case scenarios, cope with uncertainty, invest time in mental health care, advocate for school needs, and monitor the effectiveness of their efforts. Many of the strategies were deemed effective except when unable to convince other school personnel to provide the care they needed during school. Through magnitude coding and reflecting upon pertinent QOL items, it was evident adolescents’ proactive self-management strategies were considered effective at reaching goals of safety and improved mental health. The preponderance of high QOL item scores (4-6) related to talking about their feelings (a common activity in mental health therapy) and reaching goals align with adolescents’ perceptions of self-management effectiveness.

Adolescents reactively put into action the protective plans they had made and skills they had learned in mental health treatment for coping with stress (see Table 12). Table 12 illustrates adolescents found no reactive self-management strategies to have a negative effect and 50% of their reactive strategies to have some effect in preventing or holding off impending seizures. Half of participants were happy with their level of ability to sense a looming seizure, but none of the adolescents were happy with their sense of
control once a seizure began. With the great benefits adolescents found in caring for themselves with proactive and reactive self-management strategies, a greater understanding of the facilitators and barriers to adolescent self-management of PNES is needed.

Table 11

_Proactive Self-Management Strategies, Effectiveness, and Related QOL Item Responses_

<table>
<thead>
<tr>
<th>Participant</th>
<th>Proactive self-management strategy</th>
<th>Effect on caring for condition</th>
<th>“How well you can talk about your feelings?” (1=very unhappy-6=very happy)</th>
<th>“How well you are reaching your goals?” (1=very unhappy-6=very happy)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Carry backpack, pillow, or coat to protect head</td>
<td>+</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>2</td>
<td>Actively participate in therapy, use coping strategies, decrease stress with art and weight-lifting</td>
<td>+</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>3</td>
<td>Use coping strategies, connect with pet and family, identify and avoid triggers</td>
<td>+</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td>4</td>
<td>Plan to leave class with friend</td>
<td>+</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>5</td>
<td>Carry backpack to protect head, connect with other adolescents with PNES in support group</td>
<td>+</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>6</td>
<td>Talk openly with staff about needs, use humor, track seizures</td>
<td>+</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>7</td>
<td>Use coping strategies</td>
<td>?/-</td>
<td>?</td>
<td>?</td>
</tr>
<tr>
<td>8</td>
<td>Attend therapy, use CBT workbook, decrease stress with art, take medication, use app for coping</td>
<td>+</td>
<td>5</td>
<td>4</td>
</tr>
</tbody>
</table>
strategies, voice  
Section 504 plan  
wishes, talk openly  
with staff  

| 9 | Advocate for Section 504 plan accommodations, obtain seizure alert dog, adapt to loss of speech with sign language, openly share about condition with peers | + | ? | ? |

10 | Develop a safety plan, take time to rest/relax, take medication, track seizures, identify and avoid triggers | + | 4 | 5 |

*Note.* + = positive effect; - = negative effect; ? = unknown/unavailable response; QOL = quality of life; CBT = cognitive behavioral therapy

**Table 12**

*Reactive Self-Management Strategies, Effectiveness, and Related QOL Item Responses*

<table>
<thead>
<tr>
<th>Participant</th>
<th>Reactive self-management strategy</th>
<th>Effect on avoiding impending seizure</th>
<th>“How well you can tell a seizure might happen soon?” (1=very unhappy-6=very happy)</th>
<th>“The amount of control that you have when you have a seizure?” (1=very unhappy-6=very happy)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Hum classical music</td>
<td>+</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>2</td>
<td>Meditation, grounding</td>
<td>+</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>3</td>
<td>Breathing techniques, mindfulness</td>
<td>0</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>4</td>
<td>Self-talk “Not here, not now”</td>
<td>+</td>
<td>5</td>
<td>1</td>
</tr>
<tr>
<td>5</td>
<td>Call mom</td>
<td>0</td>
<td>5</td>
<td>1</td>
</tr>
<tr>
<td>6</td>
<td>Tell school how to handle seizure, text mom</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>
Unable to complete interview, crying
Go to health office, decompress
Lay down, breathing, telling friends
Breathing techniques, sit/lay down

<table>
<thead>
<tr>
<th></th>
<th>Note. + = positive effect; 0 = neutral effect; ? = unknown/unavailable response; QOL = quality of life</th>
</tr>
</thead>
<tbody>
<tr>
<td>7</td>
<td>Unable to complete interview, crying ? ? ?</td>
</tr>
<tr>
<td>8</td>
<td>Go to health office, decompress 0 4 1</td>
</tr>
<tr>
<td>9</td>
<td>Lay down, breathing, telling friends + 6 1</td>
</tr>
<tr>
<td>10</td>
<td>Breathing techniques, sit/lay down 0 4 2</td>
</tr>
</tbody>
</table>

**Research Question 3: Facilitators and Barriers of Adolescent Psychogenic Nonepileptic Seizures Self-Management**

A number of facilitators and barriers of PNES self-management emerged during the content analysis. Some themes related to facilitating or impeding self-management surfaced from adolescents being asked directly about what helped them or made it harder for them to manage their condition; other themes materialized from adolescents’ responses to other questions related to their overall school experience. The overarching facilitators and barriers were intertwined in a number of overlapping themes. Several factors appeared as both facilitators and barriers.

**Facilitators**

Adolescents identified a number of acts by a variety of people that assisted their self-management efforts. Adolescents did not identify any internal characteristics that contributed to their self-management efforts. Instead, they identified the actions of their school nurses, family members, friends as facilitators.

**School Nurse Involvement**

Adolescents with supportive school nurses expressed appreciation for their direct assistance as well as their role in supporting their own PNES self-management. School
nurses supported adolescents’ PNES self-management through simply being present during seizures and offering a safe place to rest or wait for a family member to arrive. Five adolescents described acts of caring from their school nurses, including expressing interest in learning more about PNES, building rapport, listening, developing a common language surrounding PNES, and sensing when an adolescent was disappointed in herself. Five adolescents also noted school nurses taking action that supported their self-management—training school personnel on how to properly respond to seizures, teaching adolescents with PNES about how to respond when sensing an impending seizure, coordinating seizure response and Section 504 plans that ensured 911 would not be called, providing reassurance when calling 911 was necessary, providing snacks and resources necessary for adolescents to respond to or recover from seizures, and sharing information about this study. One adolescent summarized effective school nurse self-management support in this way:

I don't know what I would have done at school without her [the school nurse]. She's certainly been a big influence on it. She actually helped me set up because I have a 504 in place now. She's helped me teach myself if I feel it coming on that I can just go to her room, decompress.

**Family Involvement**

Much of what adolescents described regarding family involvement was categorized as family-management, which will be discussed in an upcoming section. However, adolescents provided insight into certain family actions that supported their own PNES self-management. One adolescent detailed the strategy her parents used for supporting her self-management rather than managing the condition themselves: “The
way my family is is if you have a problem at school, Mom and Dad will let you handle it until you come to them and tell them that you can't anymore.” Another adolescent shared her experience of expressing concerns to her mother and her mother joining her to speak with school leaders. One family brought a letter with their daughter’s school care wishes when the adolescent was not invited to attend the Section 504 meeting where PNES management was discussed.

Friend Involvement

Six of the interviewed adolescents emphatically professed the integral role friends played in their PNES management. While many of the meaning units attributed to the theme of friend involvement appeared to be the role friends played in managing PNES rather than their facilitation of self-management, adolescents were the orchestrators of the PNES management strategies implemented by their friends. Adolescents presented examples of how they taught their friends to ensure their safety, alert school personnel of impending seizures, escort them to a place to calm or recover, and distract them when a seizure felt imminent.

Barriers

While all participants reported myriad facilitators to their PNES self-management, they also shared many barriers to their self-management. Many people groups involved in self-management facilitation for some adolescents also served as barriers for other adolescents.

School Nurse Involvement

Half of the adolescents discussed ways in which school nurse involvement was a barrier to their PNES self-management. Four adolescents described school nurses who
were uninvolved with their school experience, providing a broken link in the health-education connection. Two adolescents presented examples of school nurses responding in harmful ways, including being non-intervening bystanders, instructing others to be non-intervening bystanders, and telling bystanders “it’s all in her brain, she’s doing this to herself.” One school nurse also used the threat of calling 911 in an attempt to force a student to stop her seizure.

**School Personnel Involvement**

In addition to school nurses, other school personnel also contributed to hindering PNES self-management. The lack of training of school personnel, including one-on-one aides, left multiple adolescents unable to activate their own self-management strategies. The preconception that adolescents were faking their seizures led teachers and other school personnel to cast negative glances and express their desire to not have students with PNES in their classes because of the distracting nature of seizures. Other adolescents described the efforts of school personnel to avoid litigation, resulting in personnel treating nonepileptic seizures like epileptic seizures, with one adolescent describing a substitute teacher performed a painful sternal rub in an attempt to determine an adolescent’s level of consciousness. Other adolescents described school personnel’s unwillingness to adhere to adolescents’ plans for self-management or not including adolescents’ input in developing a seizure response plan.

**School Building Design**

School building design was previously mentioned as a tool for PNES self-management strategies, especially when a location was dedicated to calming oneself. Alternatively, one adolescent acknowledged the school building design as a barrier for
PNES self-management. By attending a school in a two-story building, the adolescent used stairs throughout the school day. She retold an event involving falling down the stairs during a seizure, resulting in multiple injuries. Following the event, school administrators required she use an elevator, which was a safer but socially isolating accommodation.

**Family Involvement**

Certain aspects of family involvement supported adolescents’ self-management efforts. On the contrary, families’ struggle to believe the PNES diagnosis, removing adolescents from classes with friends, secluding adolescents through homebound instruction, and threatening an adolescent with not being allowed to attend college out of town if seizures persisted served as barriers to their self-management attempts.

**Peer Involvement**

There were a number of peer interactions that were identified as barriers to adolescent’s PNES self-management. The mocking responses and statements of disbelief regarding the involuntary nature of the seizures served as barriers to adolescents exercising self-management strategies or perceiving them as being effective. Furthermore, one adolescent communicated a particular time a classmate video recorded her seizures and shared the videos on social media. This act and the community response to the social media post that ensued made it difficult for the adolescent to effectively communicate with school personnel about her seizure care needs.

**Personal Involvement**

While not a shared experience among multiple adolescents, one adolescent conveyed how her own feelings of being overwhelmed restricted her ability to remember
or focus on self-management strategies. All previously discussed barriers were external factors for adolescents; this admission of personal involvement revealed that internal barriers also existed for at least one adolescent.

**Summary**

In general, adolescents looked to the people closest to them for sources of self-management support or facilitation; adolescents also saw those closest to them serving as barriers to their self-management. Facilitators of self-management came in the form of school nurses, family members, and friends being present, expressing interest in understanding their condition, and being willing to teach, learn, or implement skills that would help adolescents self-manage PNES. Adolescents found barriers to their PNES self-management to include school nurses and other personnel, family members, and peers not believing seizures to be out of their control, refusing to assist or allow others to assist during seizures, and separating adolescents from their supportive peer group. Adolescents also felt hindered when the school building was unsafe or lacked a safe place for calming and when they personally felt so overwhelmed that they could not mentally access self-management strategies.

**Other Findings**

Through the use of a data-generating question regarding the experience of attending school with PNES, adolescents provided a wealth of rich data used to answer the three research questions. Their responses regarding attending school and self-managing their condition revealed adolescent PNES self-management required layers of management outside of themselves. Because PNES involves periods of inability to care for oneself—immediately prior to, during, and after seizures—and because adolescence is
a developmental stage requiring some level of dependence on the adults in their lives, adolescent PNES management requires varying levels of dependence on others. This source of dependence upon as well as influence from others was highlighted in two themes, family-management and school-management. Without prompting, throughout adolescents’ depictions of self-, family-, and school-management, the ten adolescent participants provided vivid details of their illness representation as well as their visions of an “ideal” school experience.

**Family-Management**

In the previous section, the role of family in facilitating self-management was discussed. In this section, the role families played in managing adolescents’ PNES outside the control of the adolescents is discussed. Within the overarching theme of family-management, compiled attributes included positive family-management activities that provided protection for adolescents, supported adolescents’ perseverance, and pushed for the needs of adolescents to be met in education and health care settings. The few negative family-management experiences that adolescents noted were categorized as family members being passive and patronizing.

**Protection**

Mothers, fathers, grandmothers, brother, sister-in-law, and foster father made the list of family members offering protection for adolescents. As a part of family-management of adolescent PNES, family members were noted to transport adolescents to home after having a seizure, as well as to school and mental health care appointments even after adolescents reached the age of being able to drive themselves. One grandmother raising her adolescent granddaughter quit her job to be able to bring her
granddaughter home from school after seizures. Family-management also included teaching adolescents’ friends and school personnel how to keep adolescents safe during seizures and ensuring school meetings happened to develop safety plans and prepare appropriate school personnel for their role in seizure response. One adolescent recounted how her mother accompanied her on an out-of-state school trip and attempted carrying her after the adolescent had a seizure. Another adolescent described how her mother and sister would avoid talking about certain topics in front of her in an attempt to protect her from seizure-triggering emotions.

**Perseverance**

Parents and guardians in particular were mentioned by adolescents for their role in finding ways to persevere as a family and assist adolescents in persevering despite having PNES. Parents returned assignments completed at home when adolescents were sent or kept home related to seizures. Adolescents also described the efforts of parents and guardians to encourage school attendance whenever possible, even to the point of not telling an adolescent she had a seizure during the night in hopes she would feel well enough to attend school the next day. Parents and guardians also learned as much as they could about the condition from health care providers, books, and support groups for loved ones of people with PNES.

**Push**

Parents and guardians also participated in a number of family-management activities that advocated, or pushed, for adolescents’ physical and academic needs to be met. Parents and guardians drove long distances for care from PNES experts. They also signed documents that allowed communication between PNES experts and school
personnel and obtained statements for health care providers to support their wishes for their adolescents’ care. When school personnel insisted upon calling 911 despite written plans or health care provider orders, parents and guardians refused ambulance transport. In response to school personnel refusing to adhere to written school plans, parents and guardians would intervene by talking with school administrators or the school board. In addition to advocating for the physical needs of students, parents and guardians pushed schools to create legally compliant Section 504 plans, which ensured students did not experience discrimination at school or school-related activities for having PNES. Furthermore, one mother and father were attributed with pushing their adolescent to advocate for herself to the greatest extent possible.

**Passive and Patronizing**

Two adolescents described the role their parents played in PNES family-management as passive or patronizing. Passiveness, a result of parents’ fear of the seizures, was described by one adolescent who was already living on her own with her husband: “It's gotten to the point that I will not go over to my parents unless I have had a couple [seizures] at the house already, and then I'm good to go.” Another adolescent described her parents’ patronizing nature as they removed her from her preferred high school classes. She also explained, “My parents, they have an interesting perspective on my PNES. And, so basically, they've kind of put the stress on me by saying if I'm continuing the seizures, I won't be allowed to go to college.”

Both adolescents with negative family-management characteristics were older adolescents at diagnosis (17 and 18 years) and had Section 504 plans prior to being diagnosed with PNES (one for depression and the other for concussion). They both were
in schools where 911 was called for seizures despite current best practice recommending 911 not be called. Both had several seizures per week, missed significant school, and reported very good grades.

**Family-Management and Family-Related Quality of Life**

An exercise in magnitude coding demonstrated the mostly positive perceptions adolescents held regarding family-management of PNES and its effectiveness. All ten adolescents identified positive aspects of family-management with only two identifying any negative qualities. Seven considered the family-management strategies employed to be effective or beneficial. Of note is how highly all participants, even those reporting passive or patronizing family-management, rated their happiness with their family and with their family’s response when they are sad or stressed within QOL items responses. See Table 13 for a depiction of the magnitude of family-management characteristics and QOL item responses.

**Table 13**

*Adolescent and Family-Management Characteristics and Related QOL Item Responses*

<table>
<thead>
<tr>
<th>Participants</th>
<th>1</th>
<th>2</th>
<th>3</th>
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<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family-Management Perception</td>
<td>+</td>
<td>+</td>
<td>+</td>
<td>+/-</td>
<td>+</td>
<td>+</td>
<td>+</td>
<td>+/-</td>
<td>+</td>
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<tr>
<td>Family-Management Perceived Effectiveness</td>
<td>+</td>
<td>+</td>
<td>+</td>
<td>-</td>
<td>+</td>
<td>+</td>
<td>+/-</td>
<td>?</td>
<td>-</td>
<td>+</td>
</tr>
<tr>
<td>QOL Help from Family when Sad/Stressed</td>
<td>4</td>
<td>6</td>
<td>6</td>
<td>6</td>
<td>6</td>
<td>6</td>
<td>?</td>
<td>4</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>QOL Family</td>
<td>5</td>
<td>6</td>
<td>6</td>
<td>6</td>
<td>6</td>
<td>6</td>
<td>?</td>
<td>4</td>
<td>4</td>
<td>6</td>
</tr>
</tbody>
</table>
Note. +/- = both positive and negative family-management attributes; + = positive family-management attributes; - = negative family-management attributes; ? = unknown/unavailable response; QOL = Quality of Life Index item

School-Management

When adolescents were asked to speak about their school experience with PNES, a prominent theme that emerged through the inductive content analysis was school-management. Out of 64 meaning units, 38 were negative attributes of school-management offered by 9 adolescents and 26 were positive attributes contributed by 8 adolescents, with 7 adolescents experiencing both positive and negative school-management of PNES during their school experience. Two adolescents had only negative school-management experiences to share while one had only positive experiences to share. Myriad school accommodations and responses shaped adolescents’ perceptions of their school experiences, both positive and negative.

Positive School-Management

School-management that adolescents considered beneficial was categorized as student-centered and safety-centered. Accommodations of positive school-management included notifying adolescents in advance of seizure triggers such as fire alarms, allowing early dismissal from class to avoid large crowds, extending time to complete homework or tests to decrease stress, permitting tests to be taken at home when seizures prevented attendance, adhering to a student-informed Section 504 plan with seizure response action steps, making improvements to seizure response processes based on learning from previous seizures, utilizing a team approach for responding to seizures, and employing effective teacher-student communication. Supportive school-management also involved
having a space for adolescents with PNES to calm when experiencing heightened stress levels and transitioning adolescents to homebound instruction when seizure frequency made school attendance too difficult. Additionally, school-management would not occur without the action of individuals; individuals’ responses to adolescents with PNES shaped their view of school. Adolescents described the importance of knowing there was at least one person at school who expressed interest in understanding PNES and could be trusted.

**Negative School-Management**

When describing negative school-management of PNES, adolescents identified school-management as liability-driven, seizure-defined, schoolwork-distracting, ever-changing, increasingly restrictive, others-centered, teacher-led, pain-inducing, and fear-driven. Adolescents listed numerous school-management activities that shaded their school experience, including being placed with a one-on-one instructional assistant, being placed in homebound instruction when unable to physically get out of bed to participate in the instruction, being excluded from classes because of seizures, and being required to participate in emotion check-ins with a counselor so the school could gauge the likelihood of a seizure each day. School personnel negatively contributed to school-management when they guessed how to respond to adolescents’ needs rather than following an action plan, immediately calling parents to pick up adolescents after each seizure, parading adolescents via wheelchair throughout the school, attempting to calm adolescents when they were not feeling the need for calming, and cluelessly mishandling seizures through such actions as “put[ing] a pencil in my mouth at one point to keep it open and apart.” Adolescents were negatively affected by responses from school
personnel, as one explained, “I fell and hit my head, and had a seizure. And they didn't really do anything, they just said, ‘Oh, okay, go back to class.’” Another student shared, “Nobody cared that I was seizing until I started bleeding.” Having even just one teacher who responded negatively to their condition made adolescents’ view of their school experience negative.

**School Management and Student Outcomes**

Through magnitude coding, a number of patterns arose related to the school management meaning units and student outcomes. The sole adolescent who only had positive comments regarding her school’s management of PNES was also the only adolescent who missed fewer than 25% of school days. The one adolescent who had only negative comments and completed the entire interview reported missing between 25% and 50% of school days and responded with as a little unhappy regarding how well her health care team, family members, and school team worked together to help the adolescent and how well the adolescent performed in school. One adolescent that had both positive and negative school management experiences was the only student to report a negative perceived academic performance, was one of five adolescents to miss over half of her school days, and rated all aspects of her school experience or outcomes as a little, sort of, or very unhappy. See Table 14 for a summation of adolescent and school management characteristics and responses to QOL items related to these characteristics.

**Table 14**

*Adolescent and School-Management Characteristics and Related QOL Item Responses*

<table>
<thead>
<tr>
<th>Participant</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>School-Management Perception</td>
<td>+/-</td>
<td>+/-</td>
<td>+/-</td>
<td>+/-</td>
<td>-</td>
<td>-</td>
<td>+/-</td>
<td>+/-</td>
<td>+</td>
<td>-</td>
</tr>
</tbody>
</table>
Illness Representation in Adolescent with PNES

Adolescents’ experiences at school shaped their perceptions of their condition. Illness representation is the mental representation one forms in response to a health threat that can motivate one’s use of coping strategies (Diefenbach, 2008; Leventhal et al.,...
Illness representation in the context of PNES includes adolescents’ beliefs surrounding the following: 1) cause of the condition as a whole and each PNES event; 2) physical, social, and emotional consequences of having PNES; 3) sense of control over or curability of PNES; 4) identity, or label, and perceptions of PNES symptoms; and 5) timeline, or duration, of the condition. For adolescents, having PNES conjures many beliefs and expectations about the condition. During the semi-structured interviews, the characteristics of illness representation surfaced as prominent themes without any prompting during the interviews.

**Identity**

The compilation of adolescents’ perceptions regarding PNES identity resulted in a theme of *clashing labels*. One adolescent described the condition and the contradictory nature of nonepileptic seizures: “I go through these very real seizures. And, just because they’re not epileptic does not mean they’re not real.” Throughout the interviews, the realness of the diagnosis and seizures was a consistent concern for adolescents. One adolescent denoted her PNES episodes as “pseudo, but they are not fake,” referring to the term “pseudoseizures” once commonly used as another name for PNES. The very label adolescents gave PNES events differed, with two specifically calling them seizures, three calling them pseudoseizures, and one specifying that the events are not seizures. Adolescents also highlighted the contradictory nature of PNES as a mental condition versus a medical condition, with one explaining, “It was relieving, yet not, to hear that nothing’s wrong with you, that I’m healthy. But…for everyone to say that you’re healthy, but to feel like you’re not, that’s such a big transition.” Five adolescents referred to their diagnosis as a mental condition, juxtaposed with a medical, or “real,” condition such as
epilepsy, with two adolescents detailing the experience of multiple EEGs demonstrating no abnormal brainwave activity.

When using PNES symptoms as a means of describing PNES identity, the result of compilation was the theme *mind-body façade*. One adolescent explained the bodily symptoms of PNES: “What my grandma tells me…it’s the same as a grand mal seizure. Twitching, eye rolling, and foaming from the mouth.” However, another adolescent detailed the mental symptoms of PNES, explaining, “It was really scary ‘cause it got to the point where, in the middle of my seizure, I would dissociate and I would get up and run.” Descriptions of both mind and body events were articulated as comparisons to more widely understood conditions, such as epilepsy and dissociative disorder.

**Cause**

Another characteristic of illness representation that was prominent in adolescents’ discussions was the cause of their condition as well as the cause of each PNES event. All ten adolescents pinpointed stress as the cause of the PNES condition. However, the source of the stress varied, with mentions of post-traumatic stress disorder, history of abuse, and school. One adolescent described her moment of PNES diagnosis, explaining, “All they said [after EEG was completed] was that I needed to work on my stress.” Another adolescent acknowledged understanding that stress was the cause of PNES, but could not identify the source of her stress, stating, “I don’t really feel like I’m a stressed person, and I don’t really have a lot of the characteristics that other people that have been diagnosed with psychogenic nonepileptic seizures have. So, it’s really…it’s confusing.”

Just as adolescents identified stress as the cause of the PNES condition, they pinpointed stressors as the triggers for PNES events. One adolescent was unable to
identify a particular stressor or a trigger. However, the remainder of respondents provided a compilation of triggers that fell into the following categories: physical, school-based, environmental, and emotional. Physical triggers involved feelings of physical exhaustion. School-based triggers included school deadlines, school pressures, certain classes, and being in the school nurses’ office. Loud noises, flashing lights, crowds, and sudden movements made the list of environmental triggers. For emotional triggers, four adolescents noted such triggers as seeing reminders of an abuser, talking with an emotionally abusive parent, feeling anxiety, and overthinking situations.

**Consequences**

Forty-one meaning units were attributed to the illness representation characteristic of PNES consequences. The meaning units were compiled into an overarching theme of *loss*. Of the 41 meaning units, one meaning unit was a positive consequence, or gain, the newly formed positive relationship with a school nurse. However, this was the single exception to the theme of loss. All ten participants listed losses in their lives as a consequence of having PNES. Categories of loss, listed in order of meaning unit frequency per category (with number of meaning units in parentheses), included physical control (11), access to school or school related activities (8), cognitive function (5), independence (4), social connection (4), academic standing (3), privacy (2), confidence (1), future plans (1) and identity (1). A high school student explained the loss of physical control during seizures in this way:

I was having moments where I'd just faint in the middle of the track. I'd start falling and I'd be shaking a lot. I'd fall and hurt my head and maybe bust it, or last time I sprung my arm. People have seen that I've been going to the hospital, and
I've been having blood coming down my face, I've fallen and hit my elbow, or sprung my arm. My lip was busted, my eye had a big bruise and stuff, and I was actually coughing up blood. I fell off my bed. Then I hit my head again and then started bleeding more.

The danger that can result from this loss of physical control resulted in some adolescents requiring one-on-one assistance from school personnel. The presence of an assistant drastically impacted independence, privacy, and social connections with friends. The significance of the loss of school and academic standing experienced by one adolescent was captured in her response:

I was supposed to take this honors analysis math class. It was gonna knock out a college credit for me junior year and I have an F on my transcript simply because my attendance. I could not be there to learn the material and I had to drop out of the class and I failed out of it…I won't even get my honors diploma, simply for attendance reasons, for medical reasons.

The described loss of academic standing was interconnected with descriptions of loss of access to academic opportunities, future plans based on academic performance, and one’s identity as a strong student.

Control

Despite PNES being a condition that results in uncontrolled seizure activity, adolescents described a mixed experience of control and lack of control. Four adolescents described having or attempting control over their seizures, through such methods as “calm myself down,” “sit down by myself to bring myself back together,” or repeating a phrase such as, “Not here, not now.” Conversely, five adolescents detailed a lack of
control over seizures, with one proclaiming, “Deep down I know I wasn’t in control of it.” Yet another adolescent clarified any sense of control was only temporary:

I feel like the longer I let myself remain conscious, like when I’m focusing so hard to stay conscious, I just feel all the muscles just tying up and it's searing and eventually just gets too much and I just feel like I just have to let go and just wake up an hour, hour and a half later.

While adolescents discussed the topic of controlling seizures, no one commented on the illness representation characteristic of curability of PNES. One adolescent broached the concept, saying, “There’s nothing you could do. There is no medicine you could really take for it.” Later in the interview, the same adolescent described what can improve PNES outcomes as “therapy-mind type of working out.” Another adolescent retold her diagnosis experience when the diagnostician said, “It’s up to you now,” when explaining treatment for PNES.

Timeline

Analogous to the lack of adolescent expression of perceived seizure curability was the absence of perceived PNES condition timeline. Six of the ten adolescents interviewed did not comment on the timeline of their condition or the possibility of being seizure free at any point in the future. Among the four adolescents who did comment on a timeline, three indicated a belief there was no end of seizures in sight. Only one adolescent expressed learning that there could be an end to PNES events. This adolescent had a neurologist that said, “This [PNES] isn’t something I normally cover. I want you to know that you are going to get better.” The same adolescent viewed her PNES healing differently than the other adolescents, stating, “It’s like I almost feel like my process time
of healing is being put on a time scale. And, if I don’t reach it [PNES remission], I’m not gonna be able to accomplish the goals that I want to accomplish.” Another student compared her seizure timeline to her school timeline, deducing that she experienced seizure freedom when receiving homebound instruction, but experienced the return of seizures when returning to in-person learning. The absence or presence of PNES timeline perspectives in combination with identity, cause, consequence, and controllability/curability inform the PNES illness representation of adolescents.

**Magnitude of Illness Representation Characteristics in Responses**

The following table was constructed to visualize the number of adolescents who, with prompting, commented on each illness representation characteristic. Table 15 demonstrates every adolescent who completed a full interview (all but Participant 7) provided details regarding their illness identity (through condition label and/or through symptoms), cause (through cause of the condition as a whole and/or through cause of seizure events), consequence, and control (through comments pertaining to having some sense of control over the condition or an inability to control the condition). The only illness representation characteristic that was not discussed by all participants completing interviews was timeline. Only four participants mentioned their condition’s timeline, with three of the four believing there was no end to their PNES struggle.

Table 15 also depicts the participants’ responses to QOL items pertaining to illness representation. When asked about their happiness with their overall health, responses varied from 2 (sort of unhappy) to 6 (very happy), with no obvious pattern between illness representation characteristics and QOL item response. There also did not seem to be congruence between adolescents’ comments regarding a future without PNES
and the QOL item response for how happy the adolescent was regarding her chances for a happy future; the three adolescents who believed there was no end to PNES responded with 5 (*sort of happy*) while the one who believed there could be an end to PNES responded with a lower score of 4 (*a little happy*).

**Table 15**

*Illness Representation Characteristics and Related QOL Item Responses*

<table>
<thead>
<tr>
<th>Participant</th>
<th>1</th>
<th>2</th>
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<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identity</td>
<td></td>
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<td>QOL Chance Happy Future</td>
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Note. X = concept mentioned by adolescent; ? = unknown/unavailable response; QOL = Quality of Life Index item

The Ideal

Near the end of each interview, the researcher ascertained what each adolescent envisioned as the ideal school experience while having PNES. Adolescents’ responses addressed ideal circumstances regarding life, school, and bystander responses to seizures. One adolescent remarked about life in general, “I would just be able to go and do stuff without having to perfectly orchestrate it.” Two adolescents wished they could experience life without being accused of faking their seizures and one hoped for a life free of fearing seizures. Specific to school, adolescents hoped to be able to remain in class despite seizures while the teacher continued to teach class. One desired having just one friend assist her during seizures rather than a team of school personnel bringing attention to the seizures. Another expressed a desire for “perfect attendance” and “perfect grades.” The ideal bystander response included responding in confidence rather than fear, with knowledge, with reassurance, with a motherly instinct, and without assumptions of the seizures being faked. One adolescent eloquently stated the desire for mutual understanding between the adolescent and the bystander:

I feel like just as it’s scary for me, of course, it’s also scary for them. I feel like if people recognize the fear in both accounts, it would help a lot of situations that I had to go through.
Summary

The combination of content analysis and magnitude coding resulted in an understanding of adolescents’ experience attending school and self-managing PNES. Adolescents faced a number of stressors, including bullying and academic pressures. They have a number of effective self-management strategies at their disposal, with a multitude of facilitators and barriers to their employment of self-management. However, their condition and developmental stage render adolescents with PNES dependent to a certain extent on family-management and school-management for their safety and advocacy needs. The perceptions of their self-, family-, and school-management experiences may influence or be influenced by adolescents’ PNES illness representation. While adolescents spoke openly of their PNES identity, cause, consequence, and control, adolescents did not often mention an understanding of their condition timeline. These results may have a number of implications for future nursing research.
CHAPTER V
DISCUSSION

Adolescents with PNES, along with their families, health care providers, and school leaders, struggle with how to best address their academic and mental health needs, both of which affect their QOL. The school environment has been documented as a contributing stressor that may cause PNES or induce PNES events, but with evidence-informed interventions, may also serve a supportive role as a facilitator of self-, family, and school-management. This study provided an opportunity to examine the school experience from the perspective of adolescents with PNES, identify strategies adolescents use to self-manage PNES, identify facilitators and barriers to their self-management efforts, and ascertain the potential influence of family-management, school-management, and illness representation on the school and self-management experiences.

A review of literature provided a glimpse into the extant knowledge of life with PNES for adolescents. Little was known about adolescents’ experience attending school while self-managing PNES beyond statistical data that suggested the school environment presented a number of academic and relationship challenges either before, during, or after PNES diagnosis. School nurses were noted in a hybrid concept analysis as key contributors to linking the health care and academic needs of adolescents with PNES and as capable of providing self-management support through school-based interventions addressing the behavioral, educational, psychosocial, and clinical needs of adolescents. By combining extant research findings with theoretical underpinnings from school nursing, bioecological, self- and family-management, and self-regulation frameworks or theories, a conceptual framework was developed that guided the development of this
studies’ research questions (see Figure 3). This study not only offered rich, robust answers to the proposed research questions, but also supported the use of the conceptual framework in future school nursing self-management support intervention development and testing.

The following sections provide a discussion of the importance of the research findings from this study. The discussion is organized by research question and additional emergent themes. Next, limitations of this study are examined. Finally, future research needs as well as education, practice, and policy recommendations for health care and education settings are presented.

Discussion of Findings

Research Question 1: Experience of Attending School as an Adolescent with Psychogenic Nonepileptic Seizures

The experiences of adolescents with PNES resulted in themes laden with stressors, bullying, accusations of faking seizures, and feeling left out. The following discussion offers contextualization for the current study’s findings from extant research that informs this study’s interpretation of findings. Knowledge from past studies as well as the current study should inform future endeavors to address the negative impact of the school experience for adolescents with PNES.

Stressors

Gaining insight into life stressors is a common exercise in assessing and diagnosing adolescents with PNES. Stressors most commonly identified by PNES researchers have included school, peer, and family problems (Madaan et al., 2018; Yadav et al., 2015). One PNES research team has used these stressors as a part of diagnostic
formulation to describe the cause and treatment plan (Kozlowska et al., 2018a). The overlapping stressors with bi-directional influence identified in PNES research are reminiscent of the child development influences depicted in Bronfenbrenner’s Bioecological Model (Bronfenbrenner & Morris, 2006). For example, one adolescent from this study described her parents’ beliefs about her seizures affected her schools’ insistence upon homebound instruction and her overall school experience. Another adolescent described her classmates’ verbal and physical bullying related to her seizures affected her desire to attend school, which led to missing assignments and poorer grades.

While adolescents in this study expressed stressors including diminishing academic standing and the amount of makeup work that accumulated when they had seizure-related school absences, 80% of adolescents in this study expressed their grades as at least average to above average, many considering themselves strong students. These findings do not fully align with the child and adolescent PNES research indicating students with PNES were more likely to have academic struggles. It is also important to note extant non-experimental, cross-sectional research was not designed to suggest which came first, the academic struggles or the seizures.

In addition to the stressors of academics and school attendance, the descriptions of adolescents’ school experience revealed a stress-seizure cycle not addressed in existing research. Some adolescents described specific stressors that triggered seizures while others identified seizures as a stressor themselves. Experiencing seizures, especially at school, increased some adolescents’ stress level, which they believed led to additional seizures. Identifying a mechanism by which the stress-seizure cycle could be broken would be beneficial for many adolescents.
Bullying

Bullying has been considered a part of PNES etiology (Alhafez & Masri, 2019), a predictor of learning problems in children and adolescents with PNES (Doss et al., 2017), and common childhood traumatic event prior to first PNES event (Valente & Alessi, 2014), with 38% of children and adolescents in one study reporting being bullied (Kozlowska et al., 2018a). PNES researchers did not articulate in their publications if or how they defined bullying for their participants. As noted in Chapter 3, students in this study were not provided with a definition of bullying; rather they were simply asked if they had experienced bullying. Most adolescents who attend school are familiar with the term bullying through education supported by bullying laws in all 50 states and District of Columbia (U.S. Department of Health & Human Services, 2018). Such bullying education uses a common definition: “Bullying is unwanted, aggressive behavior among school aged children that involves a real or perceived power imbalance. The behavior is repeated, or has the potential to be repeated, over time.” (U.S. Department of Health & Human Services, 2020, p. 1). Possibly because no definition was provided when asked about any bullying experiences, four students denied experiencing bullying; however, three of the four who denied experiencing bullying provided details of experiences at school that met the above definition of bullying.

Adolescents interviewed in this study also described instances of aggression that did not meet the definition of bullying. For instance, many adolescents described bullying behavior from teachers, school nurses, and other school personnel, but the definition of bullying in schools only applies to school aged children as perpetrators, not adults. Authors of existing PNES research have not always clarified the definition of bullying.
used in their research, but when articulated, the definition indicated bullying by a peer (Doss et al., 2017) and did not take into account bullying by school personnel. Whether perpetrated by peers or adults, federal law forbids harassment (from peers and adults) that is based on race (Title VI of the Civil Rights Act of 1964) or disability (Section 504 and the Americans with Disabilities Act), which was the case for many participants. Additionally, all 50 states and the District of Columbia have laws that require anti-bullying polices within their discipline codes (McCarthy et al., 2019). Many of the instances of bullying that the participants described would likely fall into the categories of bullying or harassment that schools are legally obligated to address within their discipline codes.

Multiple adolescents also highlighted that disability-related bullying and harassment impacted their school attendance. Similar to the stress-seizure cycle noted by adolescents, some noted a more complicated cycle of bullying, seizures, school absences, increased seizure frequency, and escalated bullying. Although adolescents were not prompted to discuss their response to bullying, one adolescent with better school attendance than most participants indicated her response to bullying might have broken the cycle. This coping response suggests the concept of resilience, defined as “one's ability to bounce back or recover from adversity,” (Garcia-dia et al., 2013, p. 267) should be examined further in relation to PNES outcomes and the self-regulation process noted in the Common Sense Model. This study adds to the understanding of adolescents’ experience with PNES by, for the first time, gathering insight from adolescents not simply in the context of diagnosis but in the context of understanding and improving the school experience.
Faking It

Adolescents spent considerable time in their interviews addressing the impact of others believing their PNES events were “faking it” rather than a valid diagnosis involving a physical presentation of seizure activity not under the control of the adolescents. The role of others perceiving PNES events as “faking” seizures is reported by researchers in pediatric patients (Doss & Plioplys, 2018; McWilliams et al., 2016), adult patients (Karterud et al., 2010; Rawlings et al., 2018), and for those with PNES in South Africa (Pretorius & Sparrow, 2015). Misconceptions regarding the diagnosis or seizure validity have led to families seeking a second opinion, further delaying diagnosis (Valente et al., 2017). What is not noted in the literature is the horrific school experience that can exist for adolescents who repeatedly hear the comments from those in their sphere of influence that seizures are faked; for the adolescents in this study, these words were heard from peers/bystanders ($n = 5$), school personnel ($n = 6$), and health care providers ($n = 4$).

While most adolescents only focused on the role of others making comments about faking seizures, one adolescent turned her focus to articulating her role in explaining the diagnosis to peers and school personnel. She expressed seeing a resultant change in others’ behavior during subsequent PNES events. If given the tools and confidence to address aggressors in this way, other adolescents may also be able to change their perceptions of the school experience, increase school attendance, and improve quality of life.
Left Out

By definition, bullying could include being left out by peers. However, for adolescents in this study, the feeling of being left out extended beyond the actions of peers and also included the school environment, health care system, and adolescents’ own actions. While disturbing, the adolescents’ perceptions of being left out by the health care system is not isolated to this study. In a qualitative thematic comparison of written accounts of people with epilepsy and PNES, a theme of feeling ostracized by health care providers arose (Rawlings et al., 2018), and children with PNES and their families also reported feeling isolated or marginalized by health care professionals (McWilliams et al., 2016).

Amidst mounting evidence of health care-related isolation or marginalization of those with PNES, extant literature did not address the feelings of “left out” by those outside the health care environment. In this study, only two adolescents identified health care providers as the cause for their isolation. Instead, six of the seven adolescents mentioning such perceptions identified school-based factors. School leaders’ decisions meant to ensure the adolescents’ safety, such as homebound instruction or one-one-one adult supervision, often contributed to exclusion from school and school related activities.

School personnel and peers also played a role in adolescents’ feelings of being “left out.” Adolescents in this study did not use the term stigma to describe their experiences of isolation and exclusion. However, their experiences met the definition of stigma: “a social process or related personal experience characterized by exclusion, rejection, blame, or devaluation that results from experience or reasonable anticipation of
an adverse social judgment about a person or group identified with a particular health problem” (Weiss & Ramakrishna, 2006). In fact, one study compared the stigma perceptions of those with PNES and those with epilepsy, with results indicating 87% of people with PNES experience perceived stigma (Rawlings et al., 2017a). Furthermore, those with PNES were at a 42% greater risk than those with epilepsy to experience perceived stigma (Rawlings et al., 2017a).

In addition to creating a stigmatizing environment, school professionals and peers both contributed to the stigma through behaviors that expressed a lack of caring and lack of attention to adolescents’ feelings of being left out. This sense of caring that adolescents mentioned desiring is referred to in academic literature as school connectedness, defined by the CDC as the “belief held by students that the adults and peers in their school care about their learning as well as about them as individuals” (Centers for Disease Control and Prevention, 2009, p. 1). A case study of adolescent females with emotional and behavioral disorders indicated even having one caring adult at school made a positive impact on the school experience (Whitlow et al., 2019). Based upon this current study, school connectedness may be an appropriate school environment concept to consider in future research.

In addition to the potential benefits of the school environment fostering school connectedness for adolescents with PNES, adolescents demonstrated a need for coping skills to address social exclusion. One school-based mental health study identified mediating and moderating effects of a resilience skill called academic self-regulation on affective well-being amidst social exclusion (Arslan, 2018). Similar to self-regulation described in the Common Sense Model (Leventhal et al., 2016), academic self-regulation
is learning to “regulate their thoughts, emotions, and behaviors, as well as be successful in their school experiences” (Arslan, 2018, p. 265). The author recommended a coping intervention for adolescents as well as strategies to increase school connectedness between adolescents and teachers. For adolescents with PNES, a school environment that is sensitive to both illness self-regulation and academic self-regulation may improve the school experience and improve both mental health and academic disparities they described.

**Research Question 2: Adolescent Self-Management of Psychogenic Nonepileptic Seizures**

The hybrid concept analysis of self-management support revealed self-management is not a term readily present in PNES research but is present in literature for adolescent care of a variety of other chronic health concerns (Lozano & Houtrow, 2018; Sattoe et al., 2015). Self-management for general mental health (Sharpe et al., 2017) and following a mental health crisis (Milton et al., 2017) has also been studied, but not specifically examined in adolescents. While the concept of self-management for adolescents is complicated due to their age and condition-related reliance on others, there were a number of proactive and reactive self-management strategies noted by adolescents, referred to as the “Ps of PNES self-management” including protection, perseverance, and progress.

Some self-management strategies mentioned by adolescents in this study were used as proactive strategies in routine self-care as well as reactive strategies in attempting to stop an oncoming seizure. One such strategy was the most commonly stated coping skill, deep breathing exercises. This coping skill may be beneficial for more than simply a
general calming technique, according to research on hyperventilation and oxygen-carbon dioxide levels prior to seizures. The role of hyperventilation at baseline or during stressors and the effectiveness of biofeedback training to improve PNES seizure frequency has been investigated with promising results (Kozlowska et al., 2017, 2018a; Sawchuk & Buchhalter, 2019). While no adolescent acknowledged receiving training in biofeedback using breathing techniques to control seizures, several had been taught by mental health care professionals to use deep breathing as a stress or anxiety coping mechanism. Additionally, evidence suggests school nurses can also effectively deliver deep breathing exercise training to adolescents, with one study’s results indicating an improvement in anxiety symptoms for children (Muggeo et al., 2017).

**Proactive Self-Management Strategies**

School nurses can play a role in supporting adolescents’ self-management through myriad strategies in addition to deep breathing techniques. A variety of self-management strategies were described by adolescents including making a plan, ensuring their safety, learning and using coping strategies, seeking mental health treatment, taking prescribed medications, advocating for their school needs, finding a way to continue living life, and monitoring progress through seizure frequency tracking. Table 16 illustrates the many ways school nurses can support these self-management efforts.

**Table 16**

*Proactive Self-Management Strategies and Potential School Nurse Role*

<table>
<thead>
<tr>
<th>Category</th>
<th>Strategy</th>
<th>Potential School Nurse Role in Supporting</th>
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</table>
| Protect  | Making a plan that ensures safety | • Participate in child find<sup>a</sup>, referral<sup>b</sup>, and evaluation<sup>c</sup> for Section 504 or IDEA eligibility  
• Create an Individualized Health Care Plan<sup>d</sup> with student input |
### Perseverance

| Learning/using coping strategies | • Teach coping strategies |
|Seeking mental health treatment | • Coordinate with school mental health team to identify appropriate mental health care, remove barriers such as transportation |
|Taking medication | • Ensure adolescent has access to medication, reminder system for routinely taking medication |
|Advocating to meet school needs | • Support adolescent in voicing concerns, guide adolescent to appropriate personnel to hear/address concerns |
|Finding ways to continue living life | • Engage adolescent in conversation about life outside of PNES, address barriers |

### Progress

| Seizure tracking | • Assist adolescent in identifying/using seizure tracking tool (phone application, journal) |

*Note.*

- ^a^ Mandate under IDEA for each state to identify and evaluate all children with disabilities;
- ^b^ Referral process to initiate evaluation under IDEA or Section 504 can be requested by anyone, including school nurses identifying health concerns impacting learning and participation in educational programs;
- ^c^ Process of determining eligibility and students’ educational needs;
- ^d^ Plan developed by school nurses for students’ whose health needs require complex school nursing services

**Reactive Self-Management Strategies**

All adolescents can participate in proactive self-management strategies; however, adolescents’ use of reactive self-management strategies in this study was reliant upon detecting an aura or warning sign that a seizure may soon occur. Only one adolescent explicitly stated she experienced no warning at all. This was also the one adolescent with no mental health care, legally-motivated school accommodations, or school nurse presence. She also reported the lowest grades of any participant. Although a single case is insufficient to make assumptions about other adolescents with PNES, it does provoke
several future research questions: 1) Would having mental health and school supports provide students with a keener awareness of body sensations that help predict and respond to impending seizures? 2) Could having mental health and school supports increase the likelihood of positive academic outcomes? 3) Could the presence of a school nurse increase the likelihood of adolescents with PNES accessing mental health care and binding school accommodations?

Within adolescents’ reactive responses, protection came in two different forms—protection of physical self (safety) and protection of privacy. More adolescents expressed strategies promoting safety than privacy, but some opted for privacy over safety, despite eliciting concern or receiving discipline from teachers or parents. Their perceptions of stigma may sway their decision to choose privacy over safety, as adolescents with the lowest QOL item scores regarding others’ response to their seizures (see Table 10) were the adolescents employing self-management strategies that provided privacy during seizures.

Beyond adolescents’ experiences of seeking protection and privacy prior to a seizure, adolescents described strategies for returning to life as normal after seizures. The current guidance of AES and PNES experts is for adolescents to return to class as soon as possible following each seizure (American Epilepsy Society, 2018; Caplan et al., 2017). Some adolescents described trying to remain at school if their school allowed it; however, several adolescents reported going home after seizures, whether by choice or by school leaders’ insistence. Further investigation of post-seizure management strategies is warranted based on the differences between current recommendations and school practices reported in this study.
**Effectiveness**

Other than some adolescents describing their advocation efforts with school personnel as “talking to a brick wall,” adolescents, in general, perceived their proactive self-management strategies as relatively effective. They felt their efforts to protect their head and body during seizures and to seek privacy allowed them to reach their safety and privacy goals. Reports were mixed regarding the effectiveness of reactive self-management strategies (see Table 12), but little is known about the training adolescents had in implementing such strategies. For instance, three adolescents named deep breathing as a reactive self-management strategy, but only one considered the strategy to be beneficial and no adolescents reported receiving breathing biofeedback training. As previously described, breathing biofeedback interventions hold promise in decreasing or preventing seizures through self-regulation of physiological arousal during identified moments of stress (De Rinaldis et al., 2015; Sawchuk & Buchhalter, 2019). While deep breathing mentioned by many adolescents may be helpful for anxiety and general stress-management, a more exact regiment of breathing control may be needed to increase effectiveness of this targeted physiological arousal response in adolescents with PNES.

Through this example and others, this study demonstrates many opportunities for greater proactive and reactive self-management support for adolescents with PNES.

**Research Question 3: Facilitators and Barriers of Adolescent Psychogenic Nonepileptic Seizures Self-Management**

As there is minimal evidence regarding PNES self-management, there is also little to no extant literature regarding PNES self-management facilitators and barriers. Studies regarding other conditions revealed adolescents with type 1 diabetes considered having
school personnel and peers who knew how to respond to their diabetes care needs, having the support of school nurses, and having parent involvement as facilitators to self-management (Sinisterra et al., 2020). The same adolescents listed the difficulty of informing or involving peers and parent involvement (such as nagging reminders) as barriers to their self-management (Sinisterra et al., 2020). Adolescents and young adults following stem cell transplant noted positive attitude, social support, organization, motivation, and information as self-management facilitators and listed physical and psychological symptoms, isolation, and having a bad attitude as barriers to self-management (C. Morrison et al., 2018). Similar facilitators and barriers were noted in this study for adolescents with PNES; however, adolescents with PNES identified few barriers within themselves (such as having a bad attitude for adolescents post-stem cell transplant) and looked outwardly toward those around them for barriers to their self-management. Despite the school nurse being a facilitator of diabetes self-management, one very concerning barrier to PNES self-management was the school nurse for some adolescents in this study. A number of ways school nurses could support self-management was previously listed (see Table 16); however, one school nurse was identified as a barrier to self-management through the use of threats of sending the adolescent to the hospital if a seizure continued. Other school personnel were the source of several identified barriers, including making decisions to protect the school from litigation rather than protect the physical and mental health of students, making decisions about a student’s acceptance into a class out of fear and misunderstandings regarding seizures, and responding with painful tactics in an attempt to bring students out of seizures. Specifically asked about internal barriers, adolescents with PNES may be able
to identify internal factors that impact their self-management; however, the absence of this ability to self-reflect is noteworthy since adolescents’ internal responses to these external forces might impact their ability to self-manage PNES.

**Other Findings**

*Family-Management*

Related to self-management, the theme of family-management resulted in categorical responses reflecting strategies that supported the adolescents’ protection and perseverance. Additionally, family-management functioned as a “push” to get adolescents’ needs met. Multiple adolescents lived with and experienced family-management with people other than their biological parents (including a grandmother, foster father, husband, and brother and sister-law), highlighting the importance of education and health care teams assessing and including not only biological parents in their family-management support or interventions.

The topic of families’ involvement with PNES care did not arise for most adolescents without the researcher specifically asking about the role adolescents’ families played in their care. Their responses were not thorough, even with additional prompts, but they were primarily positive. Adolescents considered their families’ management strategies to be effective except for those intended to advocate for certain school accommodations. While some adolescents experienced positive effects from their families’ advocacy efforts, some adolescents did not see the desired changes in their schools’ response to seizures.

The negative aspects of family-management were the passive or patronizing responses of family members. One adolescent reported her family being overwhelmed by
her seizures, causing her to avoid visiting them until after she had had a seizure and felt no additional seizures would occur for several hours. Another adolescent detailed her family’s disbelief of her diagnosis and their threats of prohibiting her from attending her desired college if the seizures continued. It is notable that both adolescents who expressed undesirable family-management experiences demonstrated strong self-management and self-advocacy skills in the absence of effective family-management. Both adolescents articulated confidence in speaking up for their needs with teachers, peers, and school administrators.

One family purposely remained less involved in their adolescent’s PNES management. This family allowed their adolescent to advocate for herself at school until she reached a point at which she needed assistance. This specific case provided an interesting look into the transition of care from family-management to self-management that has been discussed in other chronic health condition literature (C. Yi & Gan, 2019), especially epilepsy literature (Thompson et al., 2020). Just as there is an overlap between adolescent self-management and family-management, these two concepts also intersect within a new concept, school-management.

School-Management

For adolescents with PNES, the impact of self-management and family-management was surpassed by the impact of their schools’ management of PNES. More students discussed negative school-management experiences than positive, although seven adolescents described both positive and negative school-management experiences. This theme of school-management was built upon a number of experiences that were perceived differently among adolescents. For instance, some adolescents felt transitioning
from in-person learning to homebound instruction or having a one-on-one aide or adult escort was a positive aspect of their school-management, while other adolescents felt these accommodations were forced upon them by their school or family and were perceived as isolating, even punitive, in nature. Adolescents also had differing experiences with school personnel’s adherence to their Section 504 plans, ranging from teachers who “blew it off” to school personnel making student-centered changes upon debriefing after each seizure.

As evidenced by the experiences of some adolescents in the study, school nurses can play a pivotal role in school-management. School nurses were attributed with advocating for student-centered accommodations, ensuring Section 504 plan accommodations were implemented, serving as a liaison for improved student-teacher communication, and including friends or classmates in seizure response plans. There are a number of ways school nurses can support school-management for an improved school experience (see Table 17).

**Table 17**

*Positive School-Management Strategies and Potential School Nurse Role*

<table>
<thead>
<tr>
<th>Category</th>
<th>Strategy</th>
<th>Potential School Nurse Role in Supporting</th>
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<tbody>
<tr>
<td>Protect</td>
<td>Transitioning to homebound instruction</td>
<td>• With administration team, develop trained seizure response team</td>
</tr>
<tr>
<td></td>
<td>Using school elevator</td>
<td>• Ensure student safety addressed in plans</td>
</tr>
<tr>
<td></td>
<td>Having classroom evacuation and hallway traffic rerouting plan</td>
<td>• Identify students who need accommodations/supports and advocate for accommodations that minimize triggers/risks</td>
</tr>
<tr>
<td></td>
<td>Having a seizure response team</td>
<td></td>
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<td></td>
<td>Making safety-centered decisions</td>
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<tr>
<td></td>
<td>Providing advanced warning for triggers</td>
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<td></td>
<td>Allowing early class dismissal to avoid crowds</td>
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</table>
Perseverance
Making student-centered decisions
Having school calming room
Improving accommodations with each seizure
Allowing extra time or test-taking at home
Adhering to Section 504 plan accommodations
Communicating effectively between teacher and student
Including friends/classmates in seizure response plan

• Involve student in planning and accommodation decisions
• Debrief after seizures with student and response team to identify needed improvements to plans
• Initiate communication between student and teacher
• Include peers in plans if safe to do so

Amidst the positive school-management experiences, interview responses revealed a common concern of adolescents—an overwhelming amount of makeup work related to their many absences. As the majority of adolescents noted already having accommodations that are required under federal law, either through an IEP or Section 504 plan, adolescents may experience even greater benefit from accommodations related to the amount and timeline for turning in makeup assignments. School nurses, as members of the IEP or Section 504 teams, could advocate for such accommodations, citing evidence of the stress-seizure relationship.

**Illness Representation**

The Common Sense Model of Self-Regulation (Leventhal et al., 2016) asserts that the representation of a health threat motivates people to take health action and can predict activation and adherence to condition self-management. The concepts within this model were vividly present in adolescents’ descriptions of PNES self-, family-, and school-management. However, a number of issues arise when applying the relationships between concepts from the Common Sense Model to adolescent PNES self-management. For conditions warranting a coping response in which people must make their own internal
response plan, a health care provider must deliver a clear action plan for identifying the problem, responding appropriately to the problem with a treatment plan, and evaluating if the treatment plan is working to address the problem. This is straightforward for conditions such as type 1 diabetes. With type 1 diabetes, the problem of low blood glucose level identified as a glucometer reading of <70 mg/dL warrants the appropriate response of eating 15 grams of carbohydrates followed by evaluation of the treatment plan by re-checking blood glucose levels in 15 minutes to ensure blood glucose levels have risen above 70 mg/dL. In PNES, this iterative process is much more challenging, yet just as imperative, for self-management. First, the identity of the health threat is perplexing. Adolescents readily identify the symptoms of their condition as seizure etiology and appropriately respond to threats of a seizure with a safety plan. They evaluate the effectiveness of their plan by reporting that they remain safe from injury and embarrassment when they activate their plan. However, the underlying health threat that causes PNES for adolescents is stress and a physiological stress response. To truly self-manage PNES, adolescents must understand the identity of the stress, not just the identity of the seizures. Adolescents overwhelmingly noted the cause of their PNES to be stress but did not commonly use the stress as a reason for action-planning.

To better understand how adolescents with PNES use characteristics of self-regulation to move from health threat to action-planning and self-management, researchers must gain insight into how adolescents perceive their condition identity, cause, consequence, control, and timeline. This study is the first of its kind to investigate these concepts in adolescents’ own words.
Identity. The compilation of categories and themes from this study resulted in an overarching theme of mind-body façade. Most descriptions of PNES symptoms consisted of a comparison of their little-understood condition of PNES to the better-understood condition of epilepsy. This aspect of PNES truly troubled adolescents as they could only use other conditions to describe their own condition. Also perplexing for adolescents was how to describe to others that their internal mental health status resulted in the outwardly visible physical response of seizure activity. The difficulty in understanding and helping others understand the unique brain-body connection is likely related to adolescents’ perceptions that peers, school personnel, family members, and health care providers may not believe the diagnosis. This perception of misunderstanding was reflected in this study in the QOL index item responses related to how happy adolescents were with how others understood their seizures (see Table 10); this particular item received the lowest average score of all items, with a 2.25. On the other hand, the item regarding adolescents’ happiness with their own understanding of their condition received a much more favorable average score of 3.89 (see Table 15).

Also contributing to the difficulty in understanding or believing the PNES diagnosis is the many conflicting details regarding PNES. Adolescents with PNES conveyed their identity through a number of contradictory statements: PNES as a mental versus physical condition, PNES events as seizures versus not seizures, and others’ perceptions of PNES events as emergency versus non-emergency situations. The combination of these paradoxical views held by adolescents, families, health care providers, and school personnel resulted in a dueling PNES identity as a real versus faked condition.
**Cause.** Adolescents unanimously identified stress as the cause of their condition. All but one adolescent was able to name known or potential triggers or stressors that occur prior to their PNES events. Their ability to identify a cause for their condition and for individual PNES events allows for adolescents to develop an action plan for addressing the cause, cope with the cause, and evaluate the effectiveness of coping actions. When examining the QOL item responses for how happy adolescents were with their understanding of the cause of their seizures (see Table 15), results were varied with some very unhappy \((n = 2)\), some somewhat to very happy \((n = 5)\), and some somewhere between \((n = 2)\). Unambiguously, adolescents knew the medical explanation for the cause of their condition was stress, but their confidence or satisfaction with that explanation was less evident, with a mean response of 2.62 (a little to somewhat unhappy).

**Consequence.** Adolescents made 40 different comments regarding the losses they experienced as a result of PNES, ranging from loss of cognitive or physical functions to their academic standing and identity. These losses invaded many aspects of adolescents’ lives and could serve as motivation for action planning and health behaviors according to the Common Sense Model (Leventhal et al., 2016). When consequences are considered severe or too difficult to handle, people have a tendency to have poorer outcomes and respond with avoidance (Hagger & Orbell, 2003). For this reason, helping adolescents identify ways to mitigate losses and focus on any gains may improve outcomes.

One adolescent identified something gained through her PNES journey—a relationship with her school nurse. After discussing the ways school nurses could serve as barriers to self-management, it is important to note the supportive role school nurses can play in the school experience and self-management support for adolescents with PNES.
As previously discussed in the hybrid concept analysis regarding school nurse self-management support, school nurses familiar with PNES have identified a number of ways they support adolescents’ self-management of PNES. School nurses without experience caring for adolescents with PNES would benefit from learning from school nurses with experience providing self-management support for this condition.

**Control.** Just as severity of PNES can be appraised by adolescents’ perceptions of consequences, it can also be considered in terms of adolescents’ perceptions of control over PNES. With PNES, control is limited up to the point a seizure begins. At the point of seizure onset, adolescents reported that any sense of control is absent. In a qualitative study of adults with PNES who were asked explicitly regarding elements of illness representation, adults lacked a sense of control over seizures or their condition (A. Green et al., 2004). Similar to adults with PNES, adolescents in this study failed to mention having any hope of a cure for their condition, despite evidence that, with appropriate mental health care, partial or full remission was achievable for children and adolescents in a recent study documenting a 96% decrease in monthly seizures (Sawchuk et al., 2020). Unlike the adults, adolescents in the current study expressed a greater sense of control to hold off seizures, at least temporarily, than the adults in Green and colleagues’ (2004) study.

**Timeline.** Only nine meaning units from interviews with adolescents could be attributed to the illness representation characteristic of timeline, considerably less than the number of meaning units attributed to identity (39), cause (31), consequence (41), and control (15). Similar to lacking perceived controllability or curability, adolescents lacked responses that demonstrated connecting their condition with a timeline that might include
a future free of seizures. These findings are similar to that of adult PNES researchers (A. Green et al., 2004). Green and colleagues (2004) suggested people with PNES hold beliefs regarding both control and timeline that depend upon their views of PNES identity and cause. Future interventions should be developed with these potential relationships in mind.

**Limitations**

A number of limitations exist within this study. First, the purposive sampling and recruitment methods may have produced a sample that is not representative of the general population of adolescents with PNES. By purposefully seeking adolescents who were interested in discussing their school experience, this study may have included a disproportionate number of adolescents who held very strong views, potentially overwhelmingly negative, regarding their school experience. However, attempts were made to ensure opposing views were discovered in the content analysis before concluding that saturation had been reached (Marshall & Rossman, 2016).

Second, this study lacked variability in gender, race, and school type. Only female adolescents or their families responded to the various recruitment methods. PNES researchers indicate more females than males are diagnosed with PNES (Asadi-Pooya & Sperling, 2015; Say et al., 2015); however, the findings would be much more representative if male perspectives were included. As previously mentioned in the literature review, many publications of PNES research findings did not include race, and adolescents with PNES are reported as predominantly Caucasian/White. Therefore, it is unclear how racially representative this study’s sample was. This study would also be more representative of the general population if it included participants from private or
charter schools rather than only public schools. However, a benefit to only interviewing adolescents in public schools is that legal expectations for disability-related accommodations were consistent for all participants.

Third, the most successful recruitment method used in this study was accessing participants or their guardians through PNES support groups on Facebook. By eight of the ten adolescents being recruited via an online platform, there is a chance that adolescents without internet access or family use of social media were inadvertently excluded from this study. It is unknown what differences, including social determinants of health, may exist between adolescents with and without internet access or social media-savvy families and adolescents. These differences may also have impacted school experiences and the layers of influence as depicted in Bronfenbrenner’s Bioecological Model (Bronfenbrenner & Morris, 2006). Similar differences might have also been elicited in a comparison of family income, school free/reduced lunch rates, and school location (rural, urban, or suburban); unfortunately, these demographic variables were not collected in this study.

Fourth, recruiting via Facebook support groups may have increased the likelihood of recruiting adolescents or family members who have heightened concerns or greater advocacy tendencies. Those seeking support groups may have different illness representations and school experiences than those who do not use seeking the support of others as a proactive self- or family-management strategy. Those seeking support may have had more pronounced negative experiences related to their condition that motivated them to look for people with similar experiences. Or, those engaging with support groups may have a greater likelihood of engaging in self- or family-management than those who
do not engage with others with the same condition. These differences may provide the participants of this study with different perspectives than those who do not participate in online support groups.

Finally, this study included the use of a QOL instrument that has yet to be validated or evaluated for reliability. This renders any results from its use simply an exercise in evaluating face validity and an early step in a pilot study for examining validity and reliability.

**Recommendations**

**Future Research**

This study confirmed that the guiding conceptual framework’s concepts were pertinent to the experience of the interviewed adolescents attending school with PNES. The next step in this program of research is to establish methods of measurement of the key concepts and test the relationships between concepts proposed in the framework (see Figure 3). Additionally, further examination of the appropriateness of illness representation as a mediator for a school nurse-led PNES self-management support intervention is needed. Upon the recommendation of multiple adolescents, an additional study should include a qualitative examination of their families’ experience of sending their adolescent to school with PNES. Prior to developing an intervention for family-management support, family input is needed in combination with the adolescents’ input to determine the support families need, what facilitators and barriers to family-management exist, and if illness representation may serve as a mediator in family-management success. With this additional knowledge, a future self- and family-management support intervention study may be designed using the proposed conceptual
framework (see Figure 6) to examine the short-term impact of the intervention on proximal outcomes and select distal outcomes (school attendance and number of PNES events). Upon the pilot study’s success, a longitudinal study would follow to examine the long-term impact on proximal and distal outcomes (QOL and academic performance).

**Figure 6**

*PNES Self- and Family-Management Support Intervention Conceptual Framework*

Note. * Policies/procedures refer to school practices in calling 911, adhering to IEP/Section 504 plans, and school connectedness; You-IPQ-R student/caregiver = Illness Perception Questionnaire Adolescent and Caregiver Versions; UCLA-A = Utrecht Coping List for Adolescents; CHIPS = Coping Health Inventory for Parents; SEMCC = Promis® Measure Self-Efficacy for Managing Chronic Conditions – Managing Emotions; RSCS = Revised Scale for Caregiver Self-efficacy; PAM-13 = Patient Activation Measure; FaMM = Family Management Measure Section 1

The future intervention will be informed by the themes from this study as well as data obtained from future exploratory studies. Based upon this study’s findings regarding
the potential role illness representation characteristics may play in self-management strategy selection and activation, further reflection on an intervention that targets this potential mediator is warranted. The prevalence of meaning units that addressed an understanding of PNES control and timeline was drastically less than the meaning units addressing PNES identity, consequence, and cause. Although untested in adolescent PNES, adolescents with epilepsy benefited from a brief self-regulation CBT and relaxation stress management intervention based on illness representation from the Common Sense Model (Rizou et al., 2017). While epilepsy control and timeline perceptions did not improve through this one time, 4-hour self-regulation intervention, valuable lessons were learned including the difficulty of getting parents to bring children and adolescents to a health care setting for multiple sessions.

School nurses can and have delivered brief CBT interventions and have been able to overcome such barriers as parent motivation and transportation by offering the service in school (Tanner et al., 2020). Trained school nurses and other school-based mental health professionals could partner to deliver a CBT intervention similar to that of Rizou and colleagues (2017) in schools or via an online conferencing platform with individuals or small groups, such as those delivered for adolescents with anxiety (Stjerneklar et al., 2018). Because school nurses have identified time and poor staffing as barriers for implementing various interventions (Tanner et al., 2020), it could also be beneficial for a school nurse expert to develop and implement a standardized nation-wide online intervention. An online video conferencing group psychoeducational and skill-building CBT intervention could benefit adolescents and their families from multiple schools at one time. A school nurse-led training intervention could also be developed after
additional exploratory research to address school-management needs. Through this program of research, we may identify a profession poised and ready to expand the reach of the mental health care system as we know it, using new delivery methods, for PNES and expandable to other mental health concerns that affect adolescents.

**Practical Implications**

Three overarching practical implications arose as a result of this current study. First, numerous educational needs of school nurses and health care providers outside the school setting surfaced. Second, myriad school nursing and health care practice issues that affect adolescents with PNES appeared throughout interviews. Third, adolescents consistently addressed health care and education policy concerns, which have school nurse and health care legal literacy implications.

**Education**

School nurses interviewed in the hybrid concept analysis and several school nurses described by adolescents in this study demonstrated some general understanding of PNES or a caring, therapeutic relationship with adolescents with PNES. Unfortunately, this study revealed there are school nurses who lack understanding of the condition and may respond in ways harmful to adolescents with this particular mental health condition. It has been estimated that school nurses spend 33% of their time providing care related to students’ mental health (Bobo & Shubert, 2013; Ravenna & Cleaver, 2016). However, school nurses have reported needing additional training for providing care for students with mental health conditions (Bohnenkamp et al., 2019). The current study’s findings support the need for a school nurse education program that prepares school nurses to identify and respond to mental health concerns, especially PNES and similar mental
health concerns considered conversion disorders. School nurses also expressed needing training on specific brief interventions that could be implemented during their sporadic encounters with students (Bohenenkamp et al., 2019).

In addition to a clear need for school nurse mental health care training, school nurses also need legal literacy training. As key players in the identification, evaluation, and planning team for adolescents who may qualify for accommodations under federal law through an IEP or Section 504 plan, school nurses need training in this role. Both mental health and legal literacy skills may not be fully, if at all, addressed in nurses’ education prior to the initiation of their school nurse careers. Even school principals and teachers suffer from legal illiteracy and benefit from school law education (Decker et al., 2019). Therefore, while education in pre-licensure nursing education could offer support in these training areas, it is most likely that nurses would seek this training after entering the school nursing specialty. Principals should ensure school nurses are included in legal literacy trainings offered to teachers and other school personnel. It is imperative that school nurses understand their role in responding to known instances of peer or employee harassment based on disability or race as well as raising awareness within IEP/Section 504 teams that bullying must be addressed to ensure students’ receipt of FAPE is not affected.

As noted, many of the educational implications of this study directly apply to school nurses. However, professionals in the fields of neurology and psychology could also benefit from training regarding the school experience of adolescents with mental health conditions such as PNES. Furthermore, health care professionals could benefit from educational offerings regarding school nurses’ role in school-based mental health
care, how to effectively participate in care coordination with school personnel and family members, and the need for their advocacy for school accommodations that are required by federal law.

Practice

Ideally, increased awareness through education efforts will lead to improvements in school nursing and health care practice. First, with increased understanding, school nurses could ensure they are not a barrier to self-management or a hinderance to school connectedness. Instead, they should aim to express care and connect adolescents with other school personnel and peers who can build school connectedness for adolescents with PNES. While coordinating school-management of PNES, school nurses should not overlook their role in supporting adolescents’ self-management. This should include a balance of adolescents self-advocating for their school needs with school nurses or health care professionals advocating for appropriate legal accommodations for school. Advocacy efforts may also include school nurses and health care professionals educating the school professionals that work closely with adolescents with PNES.

The need for school nurses and health care professionals to educate school professionals while advocating for the educational rights of adolescents with PNES highlights the importance of school-management from not just a school perspective, but also a health care perspective. School personnel, including school nurses, rely on health care providers for guidance on the management of student health concerns. Without such guidance, school personnel are left to use their own perceptions of a health condition to make school decisions. In the case of PNES, with little understanding of PNES, some basic understanding of epilepsy, and PNES events closely resembling epilepsy, many
school leaders and school personnel use their understanding of how to manage epilepsy in school and apply it to their management decisions for PNES, including decisions to call 911. From the responses of adolescents, school personnel often lack knowledge of how to appropriately handle epileptic seizures or PNES events, using painful stimuli and holding down students during seizures as seizure response strategies. Therefore, clear guidance from a health care provider is needed to eradicate the use of inappropriate, harmful responses to seizures.

Cole and colleagues (2014) addressed the ethical dilemmas health care providers and school personnel face when choosing to “override school procedures” typical to seizure response (p. 148). Cole and colleagues (2014) reported school leaders have a greater tolerance for erring on the side of calling 911 when it is not needed than the antithesis. The repercussion of school leaders opting to not call 911 or to not respond as one would to an epileptic seizure was highlighted in this study as one adolescent described peers videoing school personnel’s response. Classmates perceived the lack of seizure response as negligent and shared the video on social media, where the school received backlash from community members for their perceived inaction. Cole and colleagues (2014) encouraged health care providers to advocate for their pediatric and adolescent patients with PNES by equipping parents and guardians with the knowledge of their role in negotiating an IEP or Section 504 plan for students meeting criteria of disability. Because the definition of disability under Section 504 is so broad, it is often misunderstood, especially by parents and students.

In the testing of a clinical pathway for children and adolescents with PNES, Sawchuk and colleagues (2020) devised a pathway that included early health care
provider consultation and school care planning with school personnel found to be effective in decreasing or eliminating PNES events. The authors did not provide details regarding the guidance or care plan to be provided to school personnel, but cited the treatment guide by Caplan and colleagues (2017) in which the following school recommendations were offered for seizure response: 1) move student to back of classroom, 2) monitor student until seizure ends without speaking to student, 3) instruct class to resume their classroom activities, 4) notify parent of the event, and 5) avoid transporting in a wheelchair or calling 911. Similar to Cole and colleagues (2014), Caplan and colleagues (2017) recommended health care providers of children and adolescents with PNES advocate for their patients to be evaluated for an IEP or Section 504 plan.

What is currently lacking is an understanding of adolescents’ and school personnel’s receipt and understanding of the above seizure response guidance. Within the current study, adolescents provided details of many school experiences that demonstrated they themselves did not know this was the recommended guidance nor did the school personnel providing their seizure response care. Adolescents described wanting privacy and did not want their seizures to be witnessed by classmates. They also expressed wanting to be comforted during their seizures, especially when they were able to hear during them. The accounts of school personnel not interacting with the adolescents as suggested by the guidance often involved school personnel standing within earshot of the adolescents making comments regarding their disbelief of the seizures’ validity. The differences between adolescents’ ideal school experience with PNES and the current
PNES response guidance (see Table 18) underscore the practice implications for compassionate, collaborative care for adolescents.

Table 18

Current PNES Response Guidelines vs. Adolescents’ Ideal PNES Response

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<tr>
<th>Current PNES Response Guideline</th>
<th>Adolescents’ Ideal PNES Response</th>
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<tr>
<td>1. Encourage those around adolescent to not interact with adolescent during seizure</td>
<td>“make sure their airway is opened” “protect their head” “talk to them and tell them that it's going to be okay and that they are gonna be fine” “be there like a mother would be there” “the teacher to continue with what they're teaching”</td>
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<tr>
<td>2. Do not call 911</td>
<td>“plan to not call 911”</td>
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<tr>
<td>3. Encourage student to return to normal activities as soon as possible</td>
<td>“Maybe have one friend look after me” “Knowing that I'm not going to get in trouble for having a seizure or for being absent” “Not having people bully because of seizures”</td>
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*Note.* Guidelines according to American Epilepsy Society (2018)

**Health Care and Education Policy**

As several states have adopted seizure management in school legislation, the accompanying legislated training and support focuses primarily on epileptic seizures. PNES experts should advocate for existing legislation to be applicable to both epileptic and nonepileptic seizures. Similarly, current clinical practice guidelines for school management of seizures (Lepkowski & Maughan, 2018) are only applicable to epileptic seizures; a need exists for evidence-based clinical practice guidelines for the school management of nonepileptic seizures. Such guidelines could assist schools in developing seizure response policies and procedures that are sensitive to the unique needs of children.
and adolescents with PNES. Likewise, appropriately applying constitutional and special education laws for adolescents with PNES could drastically improve their school experience and related outcomes.

Disability Discrimination Law. Due to Fourteenth Amendment constitutional rights, students with PNES and other mental health concerns are protected by the Equal Protection Clause and Due Process Clause. The Equal Protection Clause protects adolescents with PNES and other mental health concerns from discrimination based upon their disability (McCarthy et al., 2019). Because of the Due Process Clause, compulsory school attendance laws grant students with disabilities a property right to attend school despite their condition. Therefore, no matter the disability, the disruptive nature of the disability, or the cost the students’ care might incur, adolescents with PNES have the right to attend school (McCarthy et al., 2019). All adolescents interviewed in this study expressed real or potential threats to their Fourteenth Amendment rights through discrimination or harassment based upon their condition. They also experienced potentially illegal prohibition from attending in-person learning or school-related activities because of the disruptive nature of their seizures. School nurses and other health care professionals can serve as advocates by educating adolescents and their families regarding disability-related protections provided by Section 504/ADA surrounding attending school with PNES. Furthermore, school leaders and school nurses could benefit from training in legal literacy, or being “able to spot legal issues, identify applicable laws or legal standards, and apply relevant legal rules to solve legal dilemmas” (Decker & Brady, 2016).
**Special Education Law.** Based on the impact PNES has on school attendance and classwork completion, many adolescents with PNES may qualify for special education services under IDEA. As mentioned previously, adolescents with PNES may qualify for special education services if they have at least one of 13 disabilities listed within the IDEA. Most common for adolescents with PNES are disability classifications of Emotional Disturbance or Other Health Impaired. To qualify for special education services, a student must not only have a disability, but also experience an interference with educational progress because of the disability. This does not require a student to have poor grades or standardized test scores to qualify. Rather, students may qualify under IDEA if their disability hinders progress in their education program based upon functional and developmental information in addition to academic information (20 U. S. Code § 1414). The adolescents in this study predominantly had above average grades, but expressed struggling functionally and developmentally in the school setting. Both IDEA and Section 504 can be used to determine that students are legally entitled to special education services and to ensure schools provide students with disabilities a FAPE. Students receiving services under either law are protected from disability-based discrimination under Section 504 (McCarthy et al., 2019). The relationship between IDEA and Section 504 are highlighted in the following case that emphasizes the importance of legal literacy related to special education law.

A Pennsylvania federal district court highlighted in *Pocono Mt. Sch. Dist. v. T.D.*, 2018 U.S. Dist. highlighted the tendency some schools have in too narrowly applying IDEA by focusing solely on academic achievement (Golembiewski, 2016). T. D., an elementary school student, was touched on the genitals by a fellow student on multiple
occasions while at school. Soon after these events, T. D. developed unexplainable vision changes, began visiting the school nurse frequently, and received discipline for behavioral concerns with teachers and classmates. The school district evaluated T. D. for special education services and determined T. D. was not eligible. As T. D.’s vision and behavioral concerns continued during the next school year, his parents arranged for a neuropsychological evaluation, during which T. D. received diagnoses of conversion disorder and anxiety disorder. The following school year, T. D. attended a private school and was evaluated by the private school psychologist, who stated T. D. appeared to have an emotional disturbance qualifying him for special education services. However, the public school, after completing another evaluation, found T. D. not eligible under IDEA because his grades had not been impacted by his disability, but eligible under Section 504. In administrative proceedings, the Hearing Officer maintained that T. D. was eligible for a FAPE under Section 504 but not IDEA and that the school district failed to provide FAPE, resulting in the district funding 26 hours of compensatory education and tuition reimbursement for the last two years of private school education. T. D.’s appealed the Hearing Officer’s opinion on T. D.’s eligibility for services under IDEA and the school district appealed claiming that it had not acted with deliberate indifference providing a FAPE. The Pennsylvania district court analyzed IDEA and relevant cases regarding students with mental health concerns in the absence of academic decline qualifying for special education services, and ultimately found that T. D. was eligible for FAPE under both IDEA and Section 504.

Just as T.D.’s school was accused of too narrowly applying IDEA in Pocono Mt. Sch. Dist. v. T.D., (2018), courts also have been accused of too narrowly applying IDEA
to cases involving students with mental health concerns such as PNES (Golembiewski, 2016). This narrow interpretation of IDEA has resulted in discrimination, under-identification of students with mental health conditions through mandated “child find” initiatives, overutilization of academic assessments and underutilization of social-emotional measures for eligibility determination, and too few opportunities to provide psychological services as a part of related services under IDEA (Golembiewski, 2016). This short-sighted approach results in students with mental health disabilities being robbed of equal education opportunities. Within this study, only two of the ten interviewed adolescents were receiving special education services and were entitled to a FAPE under IDEA (while six adolescents were entitled to a FAPE under 504). Interviews were not designed to determine the appropriateness of the special education designation; however, future research investigating this variable could inform future advocacy interventions for adolescents, their families, and their schools.

**Section 504.** For students who do not meet the criteria for receiving special education services under IDEA, they may still qualify for school accommodations under Section 504 if the school receives federal funds from the U. S. Department of Education. Disability is defined differently under Section 504, with those with PNES qualifying based upon their physical/mental impairment or mental/psychological disorder which “substantially limits one or more major life activities” including caring for oneself, performing manual tasks, walking, seeing, hearing, and learning before, during, or after PNES events. Six of the adolescents participating in this study were receiving school accommodations under Section 504. Some considered the accommodations within their Section 504 plan to be helpful while others did not believe school personnel followed the
accommodations in their plan. Although health care providers are encouraged to advocate for patients with PNES to be evaluated for qualification for services under IDEA or Section 504 (Caplan et al., 2017; Cole et al., 2014), they may also need to advocate for school personnel to provide special education services and/or accommodations that are mandated by federal law through either the IEP or Section 504 team.

**Conclusion**

The research within this dissertation has included a review of literature and identification of a gap in knowledge surrounding the experience of adolescents attending school with PNES and self-managing their condition. The qualitative content analysis and related magnitude coding revealed adolescents’ school experience was greatly affected by poor school-management but was tempered by positive experiences resulting from school connections with caring staff and peers and effective self-, family-, and school-management strategies. School nurses and other health care professionals can and do play a role in supporting all three levels of PNES management but could benefit from a greater understanding of PNES illness representation, potential school-based interventions that can further support adolescents’ self-management proactively and reactively, and legal literacy to prevent disability related discrimination. As this program of research expands to address the education, practice, and policy recommendations from this study, adolescents’ voices from this study will continue to guide instrument and intervention development. Interdisciplinary action must be taken to make adolescents’ school experience less “hard” and their futures brighter through improved academic outcomes, mental health, and quality of life.
## Appendix A

### IRB Approval

![Indiana University Logo]

**INDIANA UNIVERSITY**
**Office of the Vice President for Research**
**Office of Research Compliance**

### NOTICE OF EXPEDITED APPROVAL - NEW PROTOCOL

<table>
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<tr>
<th>DATE:</th>
<th>September 03, 2019</th>
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| TO:       | Wendy Miller, Principal Investigator  
            NURSING |
| FROM:     | Turk, Michael A  
            Chair - IRB-04 |
| RE:       | Protocol #: 1908403332  
            Protocol Type: Expedited  
            Protocol Title: A Mixed Methods Examination of Attending School with Psychogenic Non-epileptic Seizures  
            Funding Source: None |

The Indiana University Institutional Review Board (IRB) IRB 0000219 | IRB-04 recently reviewed and approved the above-reference protocol. Approval of this protocol is based on your agreement to abide by the policies and procedures of the Indiana University Human Research Protection Program (HRPP) and does not replace any other approvals that may be required. Relevant HRPP policies and procedures governing Human Subject Research can be found at: [https://research.iu.edu/compliance/human-subjects/guidance/index.html](https://research.iu.edu/compliance/human-subjects/guidance/index.html).

### Submission and Review Information:

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<tr>
<td>Level of Review:</td>
<td>Expedited</td>
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<tr>
<td>Expedited Category(ies), if applicable:</td>
<td>Category 6: Collection of data from voice, video, digital, or image recordings made for research purposes. Category 7: Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies. (NOTE: Some research in this category may be exempt from the HHIS regulations for the protection of human subjects. 45 CFR 46.101(b)(2) and (b)(3). This listing refers only to research that is not exempt.)</td>
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| Approval Date of Submission: | September 03, 2019 |
| Expiration Date:             |                  |
| Authorized IRB Signature     |                  |

### Regulatory Determinations:

- Study meets the criteria for approval defined by the HRPP Policy on IRB Review Process
- Minimal Risk
- Waiver of documentation of informed consent granted per the IU IRPP Policy on Informed Consent.
- The plan for inclusion of children is appropriate.
- Research meets the criteria for Category 404 involving children: research not involving greater than minimal risk.
- Some or all children are capable of providing assent and the plan for soliciting and documenting assent from those children is appropriate.
- Adequate provisions are made for soliciting the permission of each child’s parent or guardians per the IU HRPP Policy on Children in Research.
- Waiver of documentation of parental/guardian permission granted per the IU HRPP Policy on Children in Research

Documents Approved with this Submission (for Amendments and Renewals, documents appearing in bold were either added or replaced with the submission):

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<td>Data Collection Instrument - Semi-Structured Interview Script</td>
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<td>Data Collection Instrument - QOL instrument</td>
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**NOTE:** If you submitted and/or are required to provide subjects with an informed consent document, please ensure you are using the most recent version of the document to consent subjects.

The following key personnel are approved to participate in the above titled research activities:

<table>
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<tr>
<th>Investigator Name</th>
<th>Role</th>
<th>Training</th>
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<tbody>
<tr>
<td>Wendy Miller</td>
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<td>Andrea Tanser</td>
<td>Key Personnel</td>
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Organizations:

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You should retain a copy of this letter and all associated approved study documents for your records. Please refer to the assigned study number and exact study title in future correspondence with our office. Additional information is available on our website at https://research.ia.edu/compliance/human-subjects/guidance/index.html.

If you have any questions or require further information, please contact the HSO via email at info@ia.edu or via phone at (317)774-8289.
NOTICE OF EXPEDITED APPROVAL - AMENDMENT

<table>
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<th>DATE:</th>
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<tr>
<td>TO:</td>
<td>Wendy Miller, Principal Investigator</td>
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<tr>
<td></td>
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<tr>
<td>FROM:</td>
<td>Tutik, Michael A</td>
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<td>Chair - IRB-04</td>
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<td>RE:</td>
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<td></td>
<td>Funding Source: None</td>
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The Indiana University Institutional Review Board (IRB) IRB 00000219 | IRB-04 recently reviewed and approved the above-reference protocol. Approval of this protocol is based on your agreement to abide by the policies and procedures of the Indiana University Human Research Protection Program (HRPP) and does not replace any other approvals that may be required. Relevant HRPP policies and procedures governing Human Subject Research can be found at: https://research.iu.edu/compliance/human-subjects/guidance/index.html

Submission and Review Information:

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<td>Expedited Category(ies), if applicable:</td>
<td>Category 6: Collection of data from voice, video, digital, or image recordings made for research purposes. Category 7: Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies. (NOTE: Some research in this category may be exempt from the HHS regulations for the protection of human subjects. 45 CFR 46.101(b)(2) and (b)(3). This listing refers only to research that is not exempt.)</td>
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Regulatory Determinations:

- Study continues to meet the criteria for approval defined by the HRPP Policy on IRB Review Process.

Documents Approved with this Submission (for Amendments and Renewals, documents appearing in bold were either added or replaced with the submission):

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If you have any questions or require further information, please contact the HSO via email at irb@iu.edu or via phone at (317)274-8289.
Appendix B

Recruitment Flyer

DOES YOUR CHILD HAVE NON-EPILEPTIC SEIZURES?

I am a school nurse wanting to learn about what it is like to attend school with PNES (non-epileptic seizures or events).

IF YOUR CHILD WOULD BE INTERESTED IN VIDEO CHATTING WITH A SCHOOL NURSE FOR ABOUT 1 HOUR TO SHARE THE EXPERIENCE OF COMING TO SCHOOL WITH THIS CONDITION, PLEASE CONTACT:

ANDREA TANNER, RN AT ANDRTANN@IU.EDU
Appendix C

Semi-Structured Interview Script

-I am going to start recording now. Is that ok with you?

-I’ve started recording. Do you have any last-minute questions for me before we begin?

-“Tell me about what it is like to come to school as a student with PNES. Describe any experiences that seem important, as well as your thoughts and feelings. Continue to describe your experiences until you feel you have fully described what it is like to be a student at school with PNES.”

Possible follow up questions:

Who has been a part of your PNES at school?

When did episodes occur? Not occur?

Where did episodes occur? Not occur?

How does your experience in school compare to other students who don’t have PNES?

What is most helpful to you at school as a student with PNES?

What is most harmful at school for you as student with PNES?

What do you do to help you manage your PNES?

What has or could the school nurse do to help you manage your PNES?

Demographics and Quality of Life questions:

How old are you right now?

How old were you when you were diagnosed with PNES?

How were you diagnosed? Was a video EEG done?

Are you under care of mental health care professional right now? Have you ever been?

Are you under the care of a seizure specialist right now? Have you ever been?
Are you still experiencing PNES spells? Time since last one? How often (times per day, week, month)?

Do you experience any aura/warning/clue that you might have a seizure? Type? How do you respond when you have an aura?

Have you experienced bullying? At school or outside of school? Before or after dx?

What things in your life cause you to feel more stress than usual?

How are you doing in school? How are your grades? Have you ever changed schools?

How is your school attendance? How many days of school have you missed this school year?

Do you have an IEP? 504 plan? Before or after dx?

What region of us?

Type of school setting? Public, private, charter, online, homeschool

Type of program? Full day, partial day

School nurse present? All day, partial day every day, some days, never

To help me understand your quality of life, I’ll ask you a series of questions. (See Quality of Life Index: Pediatric PNES Version.)
Appendix D

Quality of Life Index: Pediatric PNES Version

Directions: Please put an X in the box next to each question that shows how happy you are with that area of your life. There are no right or wrong answers.

HOW HAPPY ARE YOU WITH:

1. Your health?
2. How doctors, nurses, and counselors take care of your health?
3. How well your doctors, family, and school work together to help you? (McWilliams et al., 2016)
4. The amount of energy you have for required activities like school work?
5. The amount of energy you have for fun activities?
6. How well you can tell a seizure might happen soon?
7. The amount of control that you have when you have a seizure?
8. The amount of control you have over your life?
9. The help you get from your family when you feel sad or stressed?
10. Your friends?
11. Your family?
12. The help you get from other people when you feel sad or stressed?
13. How well you get along with others when you feel sad or stressed? (Green et al., 2017)
HOW HAPPY ARE YOU WITH:

14 *How people act when they find out you have seizures?* (Rawlings et al., 2017)...........................
15 How people act when you have a seizure?...........................................................
16 *Your understanding of what causes your seizures?* (Rawlings et al., 2018)
17 *How well others understand what causes your seizures?* (Rawlings et al., 2018)............................
18 *How helpful you are to others?* ...........................................................
19 The amount of worries in your life?............................................................
20 *How well you can talk about your feelings?* (Wolf et al., 2015)...........................
21 The neighborhood where you live?...........................
22 Your home, apartment, or place where you live?...................................
23 *Where you spend your time before or after school?*...................................
24 Your job (if you have a job)?...........................
25 How well you learn?...........................................................
26 *How teachers get along with you?*...........................................................
27 *How other students get along with you?*...........................................................
28 *How well you do in school?* (Reilly et al., 2013)...........................
29 *How many school days you feel well enough to go to school?*...........................
30 The things you do for fun?...........................................................
31 Your chances for a happy future?...........................................................
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<td>How peaceful your life is?</td>
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<td>Your faith in God?</td>
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<td>How well you are reaching your goals?</td>
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<td>How you look?</td>
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Page 3/3  Thank you for taking the time to help us know more about you and how we may help you with your diagnosis of PNES!

Normal type=items from original Quality of Life Index Epilepsy Version III

Bold type=items revamped from original Quality of Life Index Epilepsy Version III to reflect pediatric level of understanding and PNES-specific concerns

*Bold type with asterisk=new items created to reflect PNES QOL literature and theoretical underpinnings
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https://doi.org/10.1080/088704403100081321


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R., LaFrance Jr, W. C., Laptook, R., Shaw, R. J., Weisbrot, D. M., Willis, M. D., &
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CURRICULUM VITAE

Andrea Lynn Tanner

Education

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<td>Murray State University</td>
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<tr>
<td>University of Missouri</td>
<td>School/Public Health Clinical Nurse Specialist</td>
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<td>Indiana University at IUPUI</td>
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<td>Barbary J. Kenneth W. Levy Nursing Fellowship University of Missouri</td>
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<td>Ethel C. J. &amp; Rhonda J. Lemonds Brown Master’s Scholarship University of Missouri</td>
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<td>Indiana School Nurse Administrator of the Year</td>
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<td>Robert Wood Johnson Foundation Future of Nursing Scholar</td>
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Professional Societies

National Association of School Nurses
Indiana Association of School Nurses
American Epilepsy Society
American Thoracic Society
Academy Health
Midwest Nursing Research Society

Publications


Presentations

Tanner, A. (2016). *Flipping the classroom and other strategies to creating effective trainings*. Presented at National Association of School Nurses Conference, Indianapolis, IN.

Tanner, A. (2016). *Leading from within: Using trainings to establish leadership in the education system*. Presented at National Association of School Nurses Conference, Indianapolis, IN.

Tanner, A. (2016). *Flipping the classroom; Creating trainings that work*. Presented at Indiana School Nurse Association State Conference, Indianapolis, IN.

Tanner, A. (2017). *The past, present, and future of school nursing as a hub for community culture of health*. Presented at Indiana Center for Nursing, Indianapolis, IN.


Speaking Engagements

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<td>Academy Health/Robert Wood Johnson Foundation Campaign for Action Listening Session</td>
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<td>Presented and co-led national post-town hall event for school health leaders</td>
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