21ˢᵗ Century School Nurses' Role in Addressing Functional Neurological Disorder at School

Andrea Tanner, PhD, RN, NCSN

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There are no relevant financial relationships with ineligible companies for those involved with the ability to control the content of this activity.

A bit about the presenter…

- School nurse for two decades

- School nurse leader for one decade

- Clinical Nurse Specialist in School/Public Health

- PhD in Nursing Science with minor in Education Law

- Postdoctoral fellow in self-management intervention research at Indiana University School of Nursing

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Objectives

As a result of participating in this educational activity, learners will be able to . . .

- describe functional seizures and their effects on students' school experience.

- articulate at least four themes pertaining to students' experiences attending school and self-managing functional seizures.

- collaborate with students with functional seizures, their families, their school community, and health care teams.
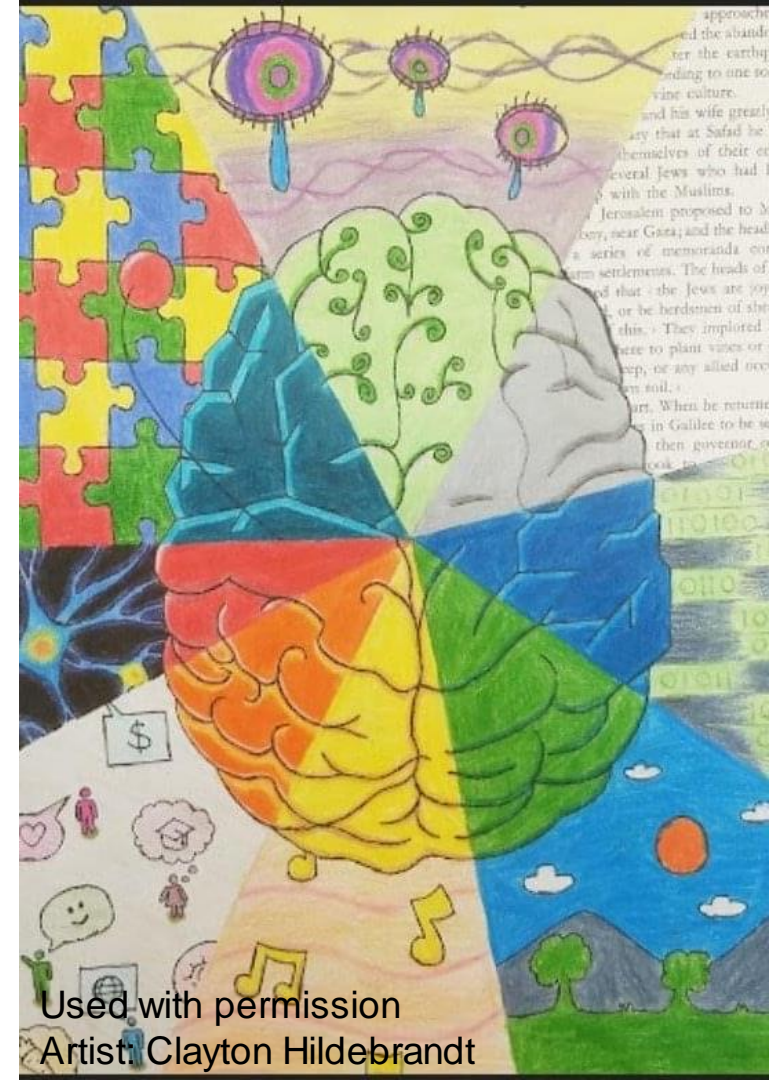
Identifying a Problem

Problem → Methodology → Results → Innovative Opportunities

Background

- PNES among top three neuropsychiatric problems (Kanemoto et al., 2017)

- Mental health condition (conversion/functional neurological disorder)

- Physical response to perceived stress, like headaches or stomachaches

- Not intentional or faked

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Artist: Clayton Hildebrandt

Background

- Diagnosed by video-EEG with absence of abnormal brainwave activity (Allendorfer et al., 2019)

- Prevalence rates 59.5/100,000 (Villagran et al., 2021)

- Treatment-cognitive and behavioral

  o Stress management (deep breathing, distraction, mindfulness, biofeedback)

  o Challenging cognitive distortions (unhelpful thinking patterns)

  63-95% of children/adolescents treated become seizure/symptom free!!!
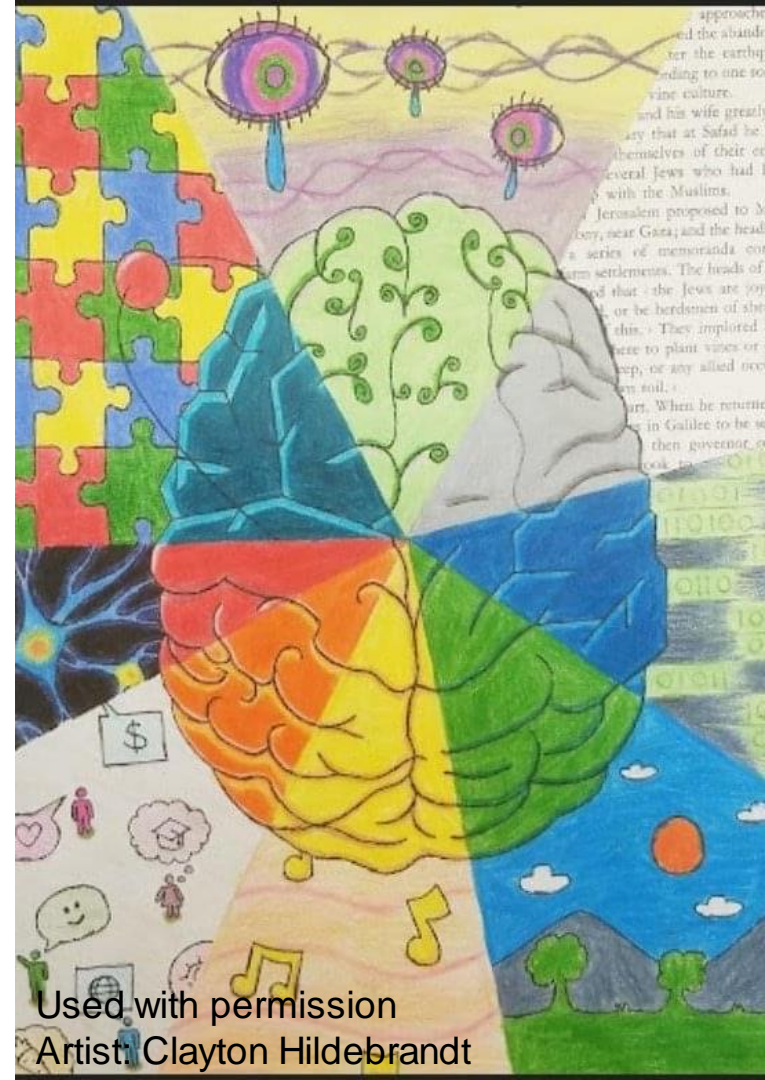
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PNES and School

School experience serves as a predisposing, precipitating, and perpetuating factor for PNES

- Learning disabilities

- Social concerns/bullying

- Poor relationships with teachers

- Poor school attendance

(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)

PNES and School

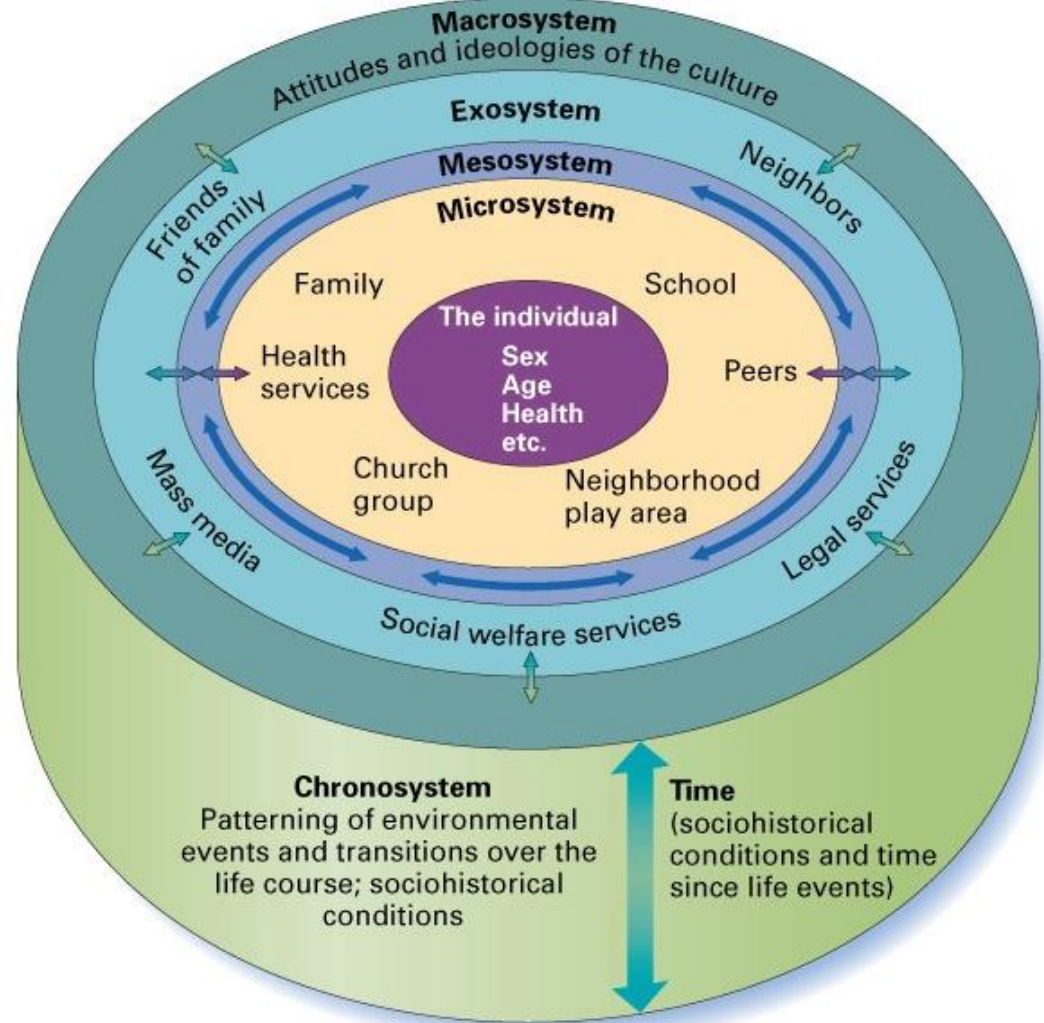Schools are challenged by PNES

- Procedural (Tanner et al., 2020)

- Ethical

- Legal

  o Individualized Education Plan (IEP)

  o Section 504 Plan (Cole et al., 2014)

Schools lack guidance to address the challenges and adolescents' perspective (Terry et al., 2020)

Theoretical Considerations
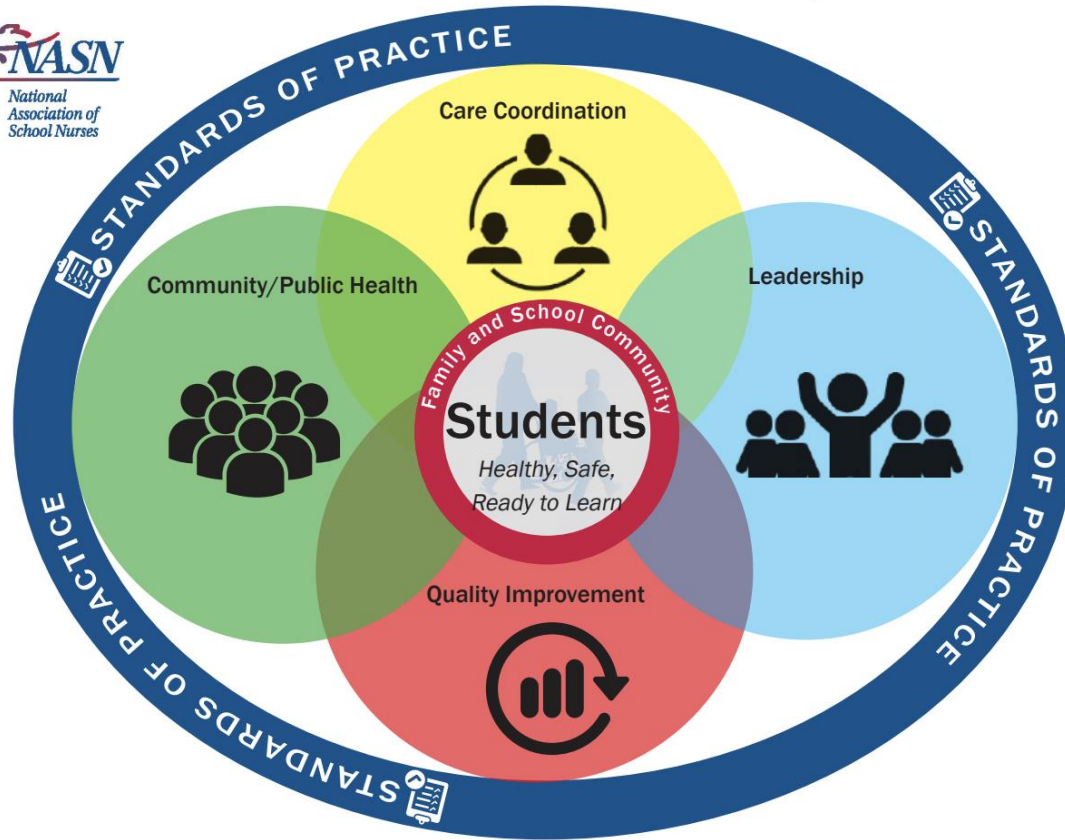
- Bronfenbrenner's Bioecological Model

Think it through…

- Take 2 minutes

- Discuss at your table

When you discover a school nursing issue, what steps do you take to address it?

Framework for 21st Century School Nursing Practice™

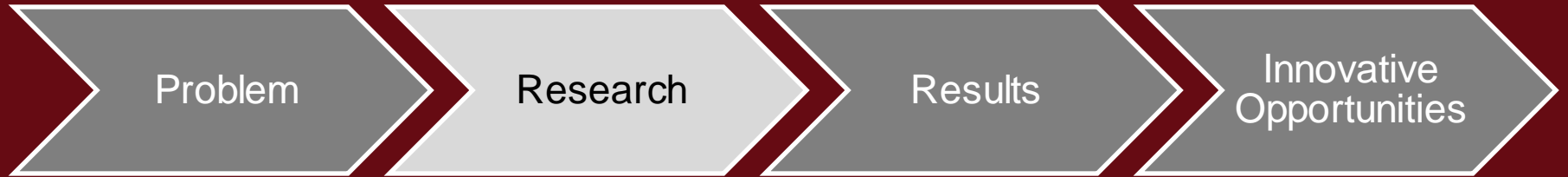# Framework for 21st Century School Nursing Practice™

NASN's *Framework for 21st Century School Nursing Practice™* (the *Framework*) provides structure and focus for the key principles and components of current day, evidence-based school nursing practice. It is aligned with the Whole School, Whole Community, Whole Child model that calls for a collaborative approach to learning and health (ASCD & CDC, 2014). Central to the *Framework* is student-centered nursing care that occurs within the context of the students' family and school community. Surrounding the students, family, and school community are the non-hierarchical, overlapping key principles of *Care Coordination, Leadership, Quality Improvement,* and *Community/Public Health*. These principles are surrounded by the fifth principle, *Standards of Practice*, which is foundational for evidence-based, clinically competent, quality care. School nurses daily use the skills outlined in the practice components of each principle to help students be healthy, safe, and ready to learn.

Standards of Practice	Care Coordination	Leadership	Quality Improvement	Community/ Public Health
• Clinical Competence • Clinical Guidelines • Code of Ethics • Critical Thinking • Evidence-based Practice • NASN Position Statements • Nurse Practice Acts • Scope and Standards of Practice	• Case Management • Chronic Disease Management • Collaborative Communication • Direct Care • Education • Interdisciplinary Teams • Motivational Interviewing/ Counseling • Nursing Delegation • Student Care Plans • Student-centered Care • Student Self-empowerment • Transition Planning	• Advocacy • Change Agents • Education Reform • Funding and Reimbursement • Healthcare Reform • Lifelong Learner • Models of Practice • Technology • Policy Development and Implementation • Professionalism • Systems-level Leadership	• Continuous Quality Improvement • Documentation/Data Collection • Evaluation • Meaningful Health/ Academic Outcomes • Appraisal • Research • Uniform Data	• Access to Care • Cultural Competency • Disease Prevention • Environmental Health • Health Education • Health Equity • Healthy People 2020 • Health Promotion • Outreach • Population-based Care • Risk Reduction • Screenings/Referral/ Follow-up • Social Determinants of Health • Surveillance

ASCD & CDC. (2014). *Whole school whole community whole child: A collaborative approach to learning and health.* Retrieved from http://www.ascd.org/ASCD/pdf/siteASCD/publications/wholechild/wscc-a-collaborative-approach.pdf

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Research

Problem → Research → Results → Innovative Opportunities

Hybrid Concept Analysis of Self-Management Support: School Nurses Supporting Students with Psychogenic Nonepileptic Seizures

Andrea Tanner, PhD, RN, NCSN (iD)**, Jane von Gaudecker, PhD, RN, AGCNS, Janice M. Buelow, PhD, RN, FAAN, and Wendy R. Miller, PhD, RN, CNS, CCRN, FAAN**

Abstract

Self-management support has been identified as an effective nursing intervention for improving outcomes for people with chronic conditions, yet this concept lacks a clear definition. Furthermore, the concept has not been used in school nursing literature despite the clear connection between school nursing practice and tenets of self-management support. Additionally, the concept has not been explored in the context of difficult-to-manage mental health concerns, such as psychogenic non-

Purpose of Study

Investigate the following:

- the experience of students attending school with PNES

- students' expressions of concepts applicable to the development of a conceptual framework

- opportunities for mental health care and school alignment in supporting self-, family-, and school-management
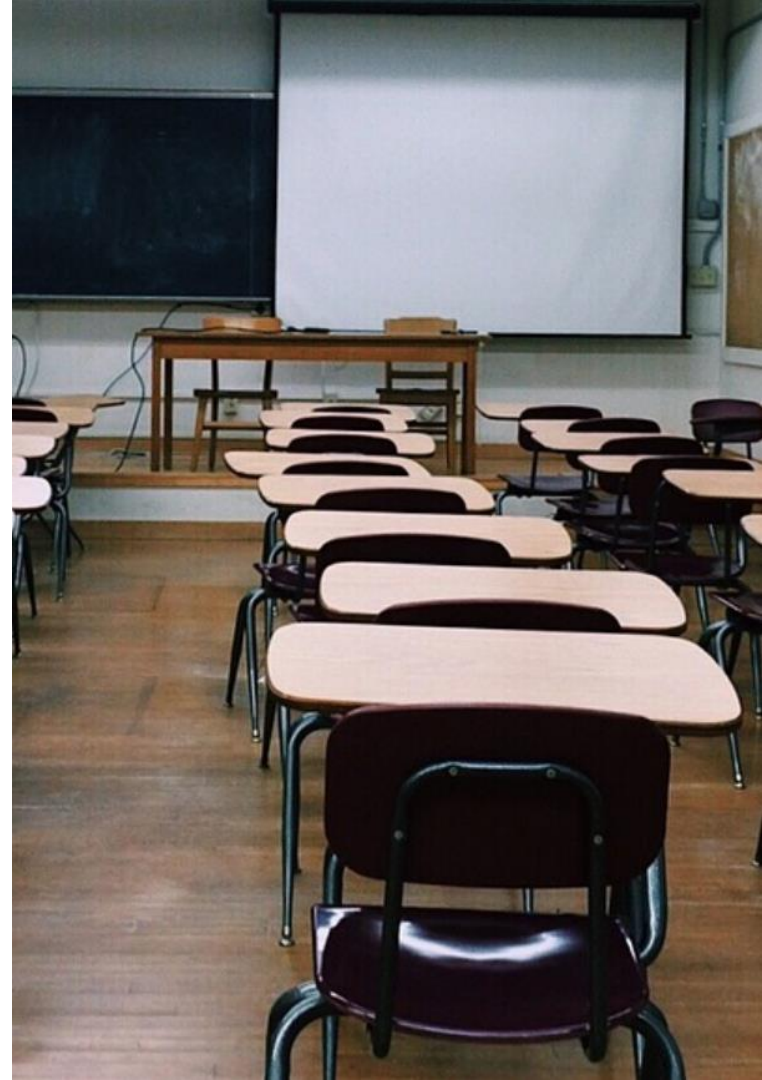
Research Questions

- What is the experience of attending school as an adolescent with PNES?

- What do adolescents do to self-manage their condition?

- What are facilitators and barriers for PNES self-management?

Design & Sample

- **Qualitative content analysis**

- **Sample**
  - Purposive sampling
  - Inclusion-age 12-19 years, self-report of VEEG, recent in-person school attendance, English speaking, ability to discuss school experience
  - Recruited via flyer shared by school nurses, mental health care professionals, and Facebook support groups

Data Generation

- Semi-structured interview

- PNES Quality of Life Questionnaire

- Demographics

Data collected until reaching data saturation

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

Page 1/3   Please turn the page →

Advancement through Levels of Abstraction

Level of abstraction	Example statement under *Faking It* theme:	
Least ↓ Greatest	1. Decontextualizing the data into meaning units (phrases or sentences that together express a phenomenon)	"They (school personnel) thought I was faking the whole thing to get out of school."
	2. Recontextualizing, or condensing, meaning units into shortened text while maintaining meaning	School personnel thought seizures faked to get out of school
	3. Coding, or organizing, condensed meaning units	School personnel
	4. Categorization by clustering codes that belong together to describe what is obvious in the data	School sector
	5. Compilation, or drawing conclusions about underlying meaning	Multisector misunderstandings

Magnitude Coding

- Unique approach of using quantitative data to enhance a qualitative study

- Indicate a code, category, or theme's "intensity, frequency, direction, presence, or evaluative content" (Saldana, 2012, p. 58)

Results

Problem → Research → Results → Innovative Opportunities
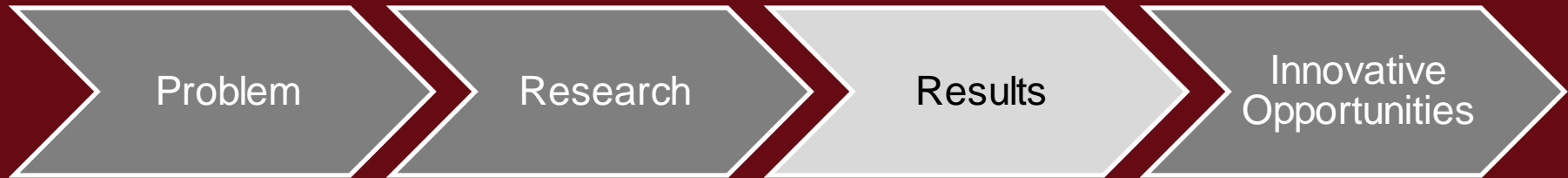
Participant Demographics

Variable	Participants ($n = 10$)
Age	Range 12-19; Mean 15.8 (SD 2.04)
Gender	Female = 10, Male = 0
Race	White = 8, Black = 2
Location	MW = 7, NE = 2, SE = 1
Receipt of mental health care	Yes = 8, No = 1, Unknown = 1

Participant School Characteristics

Variable	Participants (n = 10)
Accommodations	504 = 6, IEP = 2, None = 1, ? = 1
Initiation of accommodations	Before PNES = 5, After PNES = 3
School type	Public = 10, Private/Charter = 0
Program type	Full day = 5, Partial day = 4, HB = 1
School 911 protocol	No call = 5, Call = 3, ? = 2
School nurse presence	None = 1, PT = 4, FT = 4, ? = 1

PNES-School Experience

Variable	Participants (*n* = 10)
Experienced bullying	Yes = 6, No = 4
Experienced aura	Yes = 8, No = 1, ? = 1
PNES event frequency	Daily = 3, Weekly = 3, Monthly = 2, Bimonthly = 1, ? = 1
Missed school days (%)	<25 = 1, 25-50 = 3, >50 = 5, ? = 1
Changed schools	Yes = 4, No = 4, ? = 2
Perceived academic performance	S = 8, U = 1, ? = 1

Research Question 1: Experience of Attending School as an Adolescent with PNES

1. **Stressors**

   "Being behind in work, in school, as I missed so much school"

   "Attendance and make-up work has been the biggest thing"

   "I'm stressed 'cause I'm like, "Well, what about my future? I'll never get into a college with these kind of grades."

   "Seizures themselves are stressful."

Research Question 1: Experience of Attending School as an Adolescent with PNES

2. **Bullying**

"They called me attention-whore and 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."

Research Question 1: Experience of Attending School as an Adolescent with PNES

3. **Faking It: Multidisciplinary Misunderstandings**

   Hospital: "She's faking it. Send her home. There's nothing we can do."

   EMS: "Sign these papers quickly because we have somebody with real chest pain to go get to."

   School nurse: "She only does this in front of certain people."

Research Question 1: Experience of Attending School as an Adolescent with PNES

4. **Left Out**

   At school: "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."

   After neurologist delivered diagnosis: "I…felt like I was just pushed out to sea and left to build a raft on my own."

Pair and Share

What are four themes that describe adolescents' school experience in this study?

1. Stressors

2. Bullying

3. Accusations of "faking it"

4. Left out

Research Question 2: Adolescent Self-Management of PNES

1. **Proactive Self-Management**

   Protection: I kept a pillow in my backpack that I usually had enough time to get out.

   "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]."

   Perseverance: "Trying to keep going throughout the day."

   Progress monitoring: "Keeping track of [seizures]"

Proactive Self-Management Strategies, Effectiveness, and Related QOL Item Responses

Part	Proactive self-management strategy	Effect on caring for condition	"How well you can talk about your feelings?"	"How well you are reaching your goals?"
1	Carry backpack, pillow, or coat to protect head	+	3	2
2	Actively participate in therapy, use coping strategies, decrease stress with art and weight-lifting	+	3	5
3	Use coping strategies, connect with pet and family, identify and avoid triggers	+	6	5
4	Plan to leave class with friend	+	6	6
5	Carry backpack to protect head, connect with other adolescents with PNES in support group	+	5	6

Proactive Self-Management Strategies, Effectiveness, and Related QOL Item Responses

Part	Proactive self-management strategy	Effect on caring for condition	"How well you can talk about your feelings?"	"How well you are reaching your goals?"
6	Talk openly with staff about needs, use humor, track seizures	+	5	5
7	Use coping strategies	?/-	?	?
8	Attend therapy, use CBT workbook, decrease stress with art, take medication, use app for coping strategies, voice Section 504 plan wishes, talk openly with staff	+	5	4
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

Research Question 2: Adolescent Self-Management of PNES

2. **Reactive Self-Management**

Protection: "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: "Brush it off and keep going."

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

Part	Reactive self-management strategy	Effect on avoiding impending seizure	"How well you can tell a seizure might happen soon?"	"The amount of control that you have when you have a seizure?"
1	Hum classical music	+	3	1
2	Meditation, grounding	+	3	1
3	Breathing techniques, mindfulness	0	3	1
4	Self-talk "Not here, not now"	+	5	1
5	Call mom	0	5	1
6	Tell school how to handle seizure, text mom	0	1	1
7	Unable to complete interview, crying	?	?	?
8	Go to health office, decompress	0	4	1
9	Lay down, breathing, telling friends	+	6	1
10	Breathing techniques, sit/lay down	0	4	2

Mini-Quiz Time!

What are four strategies adolescents can use to help manage their PNES condition. Jot them down in your notes…

1. Have a written plan

2. Keep supplies handy to stay safe

3. Use coping strategies (mindfulness, breathing, grounding, distraction)

4. Participate in mental health care (cognitive behavioral therapy)

Research Question 3: Facilitators and Barriers to PNES Self-Management

School Personnel:

- "One-on-one aides that aren't trained"
- "The looks from teachers and staff that don't understand"
- "School CYA"
- "Teachers telling me I can be a distraction"
- "People who don't believe me"
- "A substitute teacher doing a sternal rub"

School Nurse:

- "School nurse's response. She threated to send me to the hospital."

Other Findings: School Management

- 64 meaning units: 38 negative, 26 positive, 53 related to accommodations
- **Positive accommodations**:
  - student-centered, safety-centered decisions
  - elevator and calm room
  - classroom evacuation and hallway traffic plan
  - seizure response team
  - seizure debrief
  - advanced warning for triggers
  - early dismissal from class
  - extended time for assignments and tests at home
  - inclusion of friends/classmates in plan

Other Findings: The School Ideal

- "I'm a perfectionist and I just wanted to do everything perfectly and I wanted to have perfect attendance and get perfect grades and I never wanted to have to talk to the attendance officer"

- "I would want them to respond kind of not in fear but in confidence of knowing what they could do, like the basic necessity."

- "If they can hear, talk to them and tell them that it's going to be okay and that they are gonna be fine and reassure them they're not alone."

Limitations

- May not be representative of general population

- Lack of variability in gender and school type

- Lack of access to and measurement of SES variability

- Access to most vocal and frustrated
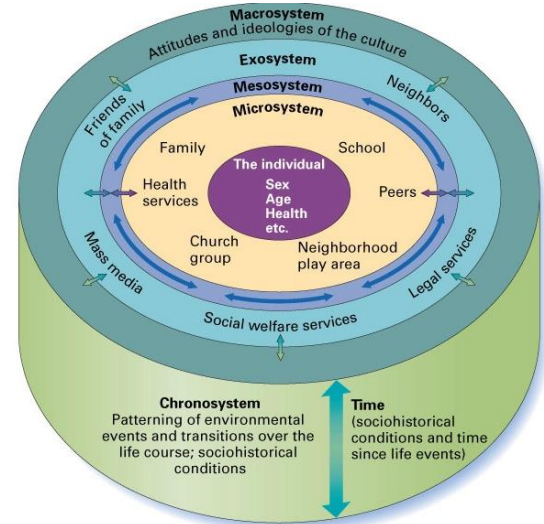
21ˢᵗ Century School Nurse Care

Problem → Research → Results → 21ˢᵗ Century School Nurse Care

Be ready to help others understand…

1 → **2** → **3**

1. Ecological stressors

2. Bullying described vs. reported

3. Accusation of faking and stigma at every turn

Macrosystem
Attitudes and ideologies of the culture

Exosystem

Mesosystem

Microsystem

Friends of family

Neighbors

Family

School

Health services

The individual
Sex
Age
Health
etc.

Peers

Mass media

Church group

Neighborhood play area

Legal services

Social welfare services

Chronosystem
Patterning of environmental events and transitions over the life course; sociohistorical conditions

Time
(sociohistorical conditions and time since life events)

Offer self-management support and care coordination…

Framework for 21st Century School Nursing Practice™

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1

2

3

4

Coping strategies

Identifying triggers and aura

Planning for safety vs. privacy

Educating school and health personnel
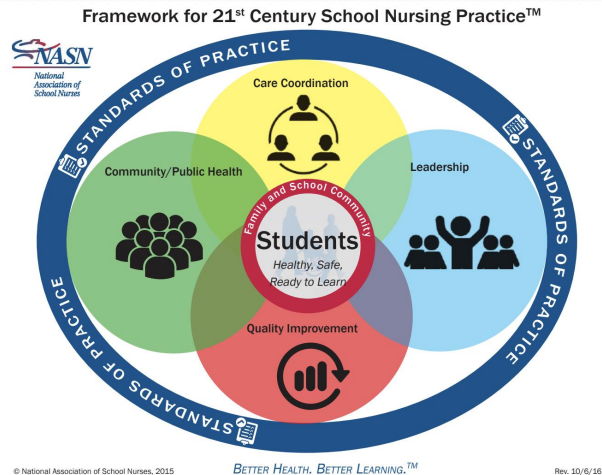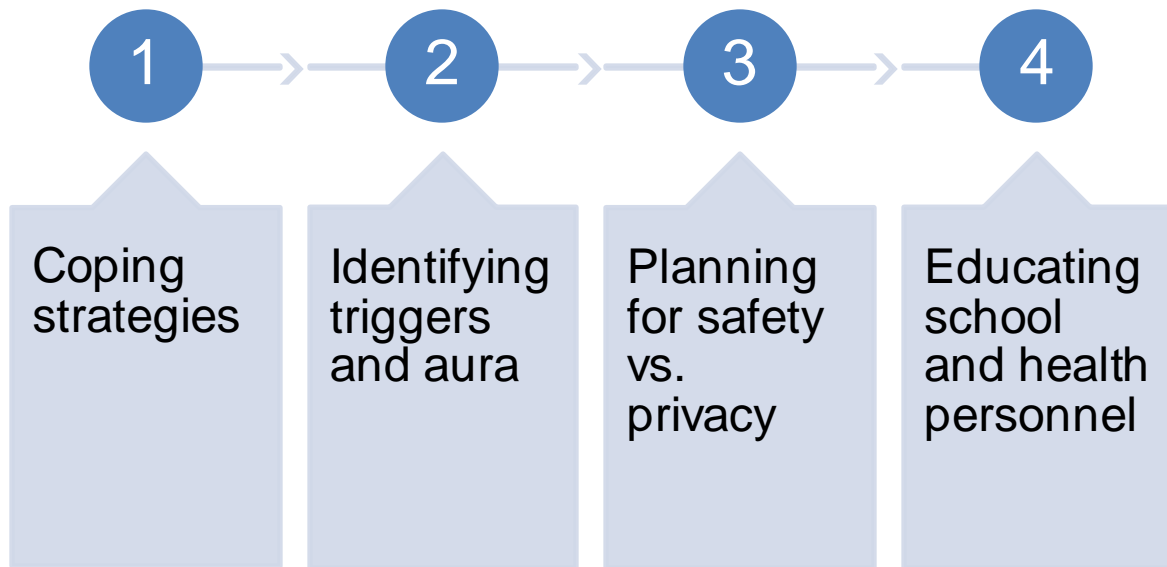
The case of collaboration

Nick is a 13-year-old boy newly diagnosed with functional seizures. Most seizure events happen at school. He misses 2-3 school days per week. When he is at school, teachers comment that he just needs to go on homebound. The assistant principal and SRO believe 911 should be called for each seizure event because they last longer than 5 minutes. When EMS comes, they comment on how often this student is faking seizures to get out of school. What can you do to support self-management and care coordination?

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Post comments/questions in discussion below presentation video and speaker information to continue an online discussion.

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