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Adolescents' Perceptions of Functional Seizure Self-Management Strategies, Facilitators, and Barriers in the School Environment

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Abstract

Adolescents with functional (psychogenic nonepileptic) seizures encounter many struggles within the school environment, including stress, bullying, stigmatization, and accusations of faking seizure events. Mental health nurses and school personnel are poised to support school-based self-management; unfortunately, to date, no evidence exists to detail effective school-based self-management strategies for adolescents with functional seizures. Therefore, in the current qualitative study, we examined adolescents' functional seizure self-management, perceived effectiveness, and facilitators and barriers using semi-structured interviews analyzed using content analysis. We interviewed 10 adolescent females aged 12 to 19 years. Themes of proactive (prior to seizure warning symptoms) and reactive (after seizure warning symptoms) self-management, involving protection, perseverance, and progress monitoring, emerged. Adolescents perceived proactive strategies as primarily effective, whereas reactive strategies were less effective. Adolescents identified school nurses and personnel, family, and peers as facilitators and barriers to self-management. Mental health nurses are positioned to provide care, co-create plans, and advocate for adolescents with functional seizures in collaboration with school nurses and personnel.

Adolescents with a mental health condition known as functional seizures (also known as psychogenic nonepileptic seizures, nonepileptic attack disorder, or dissociative seizures) endure a multitude of school-related challenges. Adolescents with functional seizures

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experience stress, bullying, isolation, accusations of faking seizure events, and poor school attendance (Tanner et al., 2022). Given that these negative school-related experiences serve as predisposing, precipitating, and perpetuating factors for stress-induced functional seizures, it is important to examine adolescents' perceptions of self-management of the condition within the school context to inform nurse-led self-management support activities.

Although functional seizures are not associated with abnormal brainwave activity, as epileptic seizures are, functional seizures require much of the same planning for seizure events as epileptic seizure disorders. Pediatric epilepsy self-management constructs of adherence and self-efficacy are modifiable cognitive and behavioral targets of intervention (Smith et al., 2018), but knowing what to adhere to and believing one has the capability to reach certain goals requires action planning that has not been a documented aspect of functional seizure self-management. Self-management for functional seizures also includes a multitude of stress-reducing coping strategies practiced with the goal of preventing or reducing the number of seizure events (Tanner et al., 2021). One tool for identifying and appropriately responding to stress is cognitive-behavioral therapy (CBT), the gold standard treatment for functional seizures in adults (Goldstein et al., 2010; LaFrance et al., 2009), which has also been found effective in adolescents (McFarlane et al., 2019; McWilliams et al., 2019). CBT requires adhering to a schedule of consistent therapy sessions and homework or skills practice as part of the self-management process (American Psychological Association, 2018; Beck, 1976).

When considered through the lens of Bronfenbrenner's Bioecological Model (Bronfenbrenner & Morris, 2006), adolescent self-management of functional seizures occurs within many spheres of developmental influence. Factors, such as internal attributes, family and school attributes, interactions with school personnel and peers, access to mental health services, and school policies and climate, may all influence adolescents' self-management and may serve as facilitators or barriers (Tanner et al., 2022). A middle-range explanatory theory of self-management behaviors also classifies strategies as *proactive*, such as creating a plan, and *reactive*, such as acting on a change in health status in response to a plan (Blok, 2017). The Common Sense Model of Self-Regulation posits that perceiving a proactive action plan as helpful in addressing a health threat (e.g., stress or functional seizures) can inform a feedback loop that changes condition perception and future self-management behaviors (Leventhal et al., 2016).

Nurses are equipped to support adolescents in developing individualized plans with appropriate goals and enhancing self-efficacy. Having a plan and the confidence to follow the plan, especially at school, could allow adolescents with functional seizures to cope with stressors more effectively, achieve seizure reduction or freedom (Fobian et al., 2020), and improve school attendance and make the transition into adulthood stronger and healthier (Robert Wood Johnson Foundation, 2016). However, little is known about adolescents' experiences self-managing functional seizures within the school environment and the collaborative role personnel within the school and mental health nurses external to the school can play in supporting self-management.

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The purpose of the current study was to gain an understanding of adolescents' experiences of self-managing functional seizures in the school environment and inform nursing interventions that support self-management, health, and academic outcomes. This goal was achieved by answering the following research questions: (1) While attending school, what do adolescents do to self-manage functional seizures, and are identified strategies perceived as effective? (2) What are the facilitators and barriers of adolescent functional seizure self-management?

METHOD

We have detailed the study methods and published initial findings—adolescents' experience attending school with functional seizures—from this study's dataset in a prior publication (Tanner et al., 2022). The current constructs of interest were not included in the prior analysis from this Institutional Review Board (IRB)–approved qualitative study.

Participants

The study included recruiting adolescents with functional seizures through the sharing of a flyer via school nurses, mental health care providers, and social media support groups for those with functional seizures and/or their families. Inclusion criteria were: (a) self-reported diagnosis of functional seizures by a health care provider, (b) recent experience attending school with functional seizures, (c) aged 12 to 19 years, (d) ability to comprehend and answer questions in English, and (e) ability to articulate experiences of meeting functional seizure care needs (as reported by the consenting individual).

Data Collection

The first author (A.L.T.) conducted audio-recorded interviews with participants via Zoom. After transcription, the first author organized responses within a Microsoft® Excel spreadsheet by semi-structured interview questions, which included: (1) What do you do to help you manage your functional seizures? What is most helpful to you at school as a student with functional seizures? What is most harmful at school for you as a student with functional seizures? and (4) Who has been a part of your functional seizures at school? Nine interviews lasted 35 to 70 minutes, and one interview ended after 2 minutes when the adolescent became too upset to continue. Following this halted interview, the first author followed a distress protocol of contacting the consenting parent to ensure the adolescent was safe and had access to appropriate mental health services if needed.

Data Analysis

Content analysis of adolescents' responses allowed for greater understanding of the experience of self-managing functional seizures within the school environment. Through the sequential steps described by Erlingsson and Brysiewicz (2017), the first author deconstructed transcribed interview responses into meaning units (i.e., phrases that express a phenomenon), organized meaning units into a coding system of subthemes, and categorized subthemes into themes (Tanner et al., 2022). Three research team members (J.R.v.G., J.M.B., W.R.M.) met with the first author weekly during the content analysis process to ensure rigor and trustworthiness. In addition to debriefing meetings with the research team,

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tools used to ensure rigor and trustworthiness included bracketing preconceptions, audit trails, and triangulation of findings with theory and existing evidence (Elo et al., 2014; Graneheim & Lundman, 2004; Lincoln & Guba, 1985; Tufford & Newman, 2012).

Ethics

This study was reviewed and approved by the Indiana University Institutional Review Board (#1908403332). Research was conducted in accordance with the principles embodied in the Declaration of Helsinki and with local statutory requirements. All participants aged 18 years or parents/guardians of participants aged <18 years gave informed consent to participate in the study. All participants aged <18 years gave verbal assent to participate in the study.

RESULTS

Demographic, Condition, and School Characteristics

Of 10 participants aged 12 to 19 years (mean = 15.8 years, *SD* = 2.04 years), 100% self-reported as female and 80% as white. Time since diagnosis was 0.66 to 4 years (mean = 1.5 years, *SD* = 1.06 years). Adolescents resided in the Midwest (70%), Northeast (20%), and Southeast (10%) of the United States. Eighty percent of participants reported receiving mental health services; the same 80% also received school accommodations through either a Section 504 plan (i.e., a formalized school plan for accommodations to the learning environment that support students with a disability in accordance with Section 504 of the Rehabilitation Act of 1973) or Individualized Education Program (IEP; i.e., a formalized school plan for special education and related services in accordance with the Individuals with Disabilities Act) and had access to a school nurse at least part time. In addition, 80% of participants experienced an aura, or advanced warning of an impending seizure, which provided reactive self-management opportunities. Furthermore, 30% of adolescents experienced seizure events daily, 30% weekly, 20% monthly, and 10% bimonthly (with 10% unknown due to the interview ending abruptly prior to completion).

Self-Management

Participants offered insight into what constitutes functional seizure self-management, especially as it pertained to attending school with functional seizures, and their overall plan for self-management. Two subthemes emerged: (1) proactive self-management strategies used to prevent seizures and avoid or address seizure triggers, and (2) reactive self-management strategies used to respond to seizure warning signs or seizure aftermath. In this section, we will also explain the facilitators and barriers of functional seizure self-management identified by participants. We provide select supportive quotes below and additional quotes to support theme and category selection are shown in Table A (available in the online version of this article).

Proactive Self-Management Strategies

Sixty-two meaning units encompassed proactive self-management activities engaged to address the overall condition or plan for seizure events. Some of the comments resulted without prompting, whereas many surfaced after the interviewer specifically asked

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adolescents how they managed or took care of their condition. Adolescents' responses comprised three categories of proactive self-management strategies: providing themselves protection, demonstrating personal perseverance, or monitoring progress.

Protection.—Four adolescents described proactive self-management strategies that involved protecting themselves, and especially their heads, from harm. These activities included always carrying a backpack while at school that contained supplies, such as a pillow, or routinely wearing a coat with a hood everywhere to protect the head during seizures. Other protective strategies included "trying to get to a safe place" where future seizures could occur out of the way and sight of others, such as a restroom or stairwell. Another adolescent obtained a service animal, which "alerts in response to my seizures" providing minutes of forewarning, rather than the seconds of warning she had with an aura.

Perseverance.—Most self-management strategies entailed acts of perseverance, or ways of learning how to remain in school despite the difficulties brought on by functional seizures, exemplified by one adolescent's efforts: "I don't like to go home after seizures, 'cause I did that last year and I just missed like half the school year. So now, I'm just trying to keep going throughout the day." All participants reported perseverance strategies. Adolescents described numerous self-management strategies that involved making plans for themselves and others during and after seizure events. Several discussed preparing 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 or friends' parents.

Adolescents' planning efforts allowed them an opportunity to continue living their lives, "trying to keep going throughout the day," albeit drastically affected by functional seizures. 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 to rest. 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, such as staying in one class at a time.

Adolescents also described coping strategies, such as meditation, grounding skills, mindfulness, deep breathing, and "thought exercises" when self-managing functional seizures and stress. One student identified an application (app) on her smartphone that she used to implement coping strategies. Another student found a calming room within her school building to be a helpful environment for practicing coping strategies. Adolescents also described creating artwork and displaying the pieces as a reminder of their healing journey, lifting weights, applying face masks, using a journaling smartphone app, and using positive self-talk.

Another proactive self-management strategy involved interacting with others to manage their stress. Adolescents sought comfort by engaging with pets, family, and 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.

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A common component of self-management is the concept of treatment adherence. Adolescents mentioned routinely visiting a therapist to work through the process of CBT. A commonly mentioned part of functional seizure treatment was working through finding the stressors that tended to precipitate seizures. Two adolescents also mentioned taking medication as a part of their self-management (to treat comorbid mental health conditions).

Especially important in the school setting was the ability and confidence to advocate for one's needs while self-managing functional seizures. Adolescents recognized several ways to advocate for their functional seizure 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 functional seizures and how to respond when a seizure occurs, and asking teachers for help with make-up work from seizure-related school absences. Through more formalized methods, adolescents advocated for themselves by obtaining written care plans from health care providers, writing a letter to the Section 504 team to express her desired accommodations when not invited to the Section 504 team meeting, and requesting specific seizure response accommodations to be added to the Section 504 plan.

Progress Monitoring.—Because decreased seizure frequency is a common measure of condition improvement, several adolescents described tracking their seizures. Whether through a written record keeping system, phone app, or texting event details to a parent, adolescents used seizure tracking to monitor their condition or treatment progress.

Reactive Self-Management Strategies

Although adolescents made a concerted effort to prevent seizures and plan for their safety, adolescents also self-managed their functional seizures through reactive strategies. Thirty-six meaning units represented reactive self-management strategies implemented in response to a seizure aura. Not all participants had an aura or warning sign, so aura-response strategies in this section pertained to the eight adolescents who reported experiencing an aura. Reactive strategies prominent in adolescents' descriptions of the school experience with functional seizures encompassed two reactive strategy categories—protection and perseverance.

Protection.—All eight participants who experienced auras expressed using protective strategies as a part of their functional seizures self-management. The most stated protective strategy was assuming a position of safety sitting or lying down. The next most common strategies encompassed seeking a friend, classmate, or teacher for assistance and a secluded location for the seizure to occur, such as a restroom stall or behind the desk of an understanding teacher. One adolescent described having enough forewarning that she would adjust plans for the day, stating, "We would just stay at home, make sure we're not out and about or if we do, either we would still kind of be in the car or we would be somewhere close to where she could get me to sit down or something." When feeling that she was not in a safe or private space, one adolescent described her attempts to stave off the seizure until reaching such a space.

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Perseverance.—The theme of perseverance continued through adolescents' voices as they described their reactive self-management strategies. Adolescents with and without auras described attitudes after having a seizure as "brush it off and keep going." Adolescents described using calming strategies, the most popular among them being deep breathing. Other reactive strategies included mindfulness, thinking positive thoughts, decompressing in the health office, grounding oneself by slapping the floor, and distracting oneself with repetitive phrases or visiting a classroom with younger children after seizure warning signs began. One adolescent detailed the use of humming as a distraction: "I found the perfect thing is to hum different sections of Pachelbel's Canon. The cello part, then the viola part, then the violin part."

Effectiveness of Self-Management Attempts

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, including successful avoidance of head injury when keeping a pillow or coat available and assurance of privacy when implementing plans to relocate to a restroom or behind a teacher's desk. Advocating for school needs by being open with teachers and classmates about the condition resulted in positive outcomes for two adolescents, including decreased embarrassment from seizures, teachers' kindness, school personnel's adherence to Section 504 plan accommodations, peers' awareness of seizures, and normalization of the condition. An adolescent explained the effectiveness of telling peers about her condition: "The more of them [peers] that know the better it is for me, 'cause if … I go down, she may know, 'Hey, just don't let me hit my head.'" On the other hand, one adolescent described her attempts at self-advocacy with school personnel 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 their ability to use strategies successfully to stop a seizure, whereas 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. Adolescents described the effectiveness of such strategies, with one proclaiming, "It's some type of control, and sometimes it works. It doesn't completely make them go away." The one adolescent who specifically stated she could not suspend a seizure used sitting down and breathing as her aura response plan. Table 1 and Table 2 provide lists of proactive and reactive self-management strategies as well as adolescents' perceived effectiveness.

Self-Management Facilitators and Barriers

Adolescents identified numerous facilitators and barriers of functional seizure self-management. Adolescents did not identify any internal characteristics that contributed to their self-management efforts. Instead, they identified the actions of those in their developmental sphere of influence, including school nurses, family members, and friends, as facilitators. Many of these influential people appeared as facilitators and barriers.

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Facilitators.

School Nurse Involvement.: Adolescents with supportive school nurses expressed appreciation for their direct assistance as well as their role in supporting self-management. School nurses supported adolescents' functional seizure self-management through caring actions—being present during seizures, offering a safe place to rest or wait for a family member to arrive, expressing interest in learning more about functional seizures, building rapport, listening, developing a common language surrounding functional seizures, and sensing when an adolescent was disappointed in themselves. Adolescents also noted school nurses taking action that supported their self-management—training school personnel on how to properly respond to seizures, teaching adolescents coping strategies to use when sensing an impending seizure, and coordinating "the plan not to call 911."

Family Involvement.: Adolescents provided insight into certain family actions that supported their own functional seizure self-management, which is different than family management. One adolescent detailed her parents' self-management support strategy of allowing her to "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.

Friend Involvement.: Six adolescents emphatically professed the integral role friends played in their functional seizure management. Although many meaning units reflected the role friends played in managing functional seizures rather than their facilitation of self-management, adolescents orchestrated the functional seizure management strategies implemented by their friends. Adolescents presented examples of how they taught their friends to ensure their safety: "They just hold my head, they clear everything away from me, so I don't hit anything." Friends also alerted school personnel of impending seizures, escorted adolescents to a place to calm or recover, and distracted them when a seizure felt imminent.

Barriers.—School Nurse Involvement. One half of adolescents enumerated ways in which school nurses were a barrier to their functional seizure self-management. Four adolescents described school nurses who did not play an active role in their school experience, providing a broken link in the health-education connection. Two adolescents described school nurses responding in what adolescents perceived as harmful ways, including being non-intervening bystanders, instructing others to not intervene, and telling bystanders, "It's all in her brain, she's doing this to herself." One school nurse threatened to call 911 to coerce a student to stop her seizure.

School Personnel Involvement.: In addition to school nurses, other school personnel also contributed to hindering functional seizure self-management. 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 faked their seizures led teachers and other school personnel to cast negative glances and express their desire

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to not have students with functional seizures 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 functional seizures like epileptic seizures, with one adolescent describing a substitute teacher performing a painful sternal rub to determine an adolescent's level of consciousness. One adolescent, describing school personnel as a barrier to self-management and school attendance, declared, "They would send me home right away and so I was leaving first period every single day." Other adolescents described school personnel's unwillingness to adhere to an action plan for self-management or not including adolescents' input in developing a seizure response plan.

School Building Design.: One adolescent acknowledged the school building design as a barrier for functional seizure self-management. By attending a school in a two-story building, the adolescent used stairs throughout the school day. After incurring severe injuries from falling down the stairs during a seizure, 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 functional seizure diagnosis, removing adolescents from classes with friends, secluding adolescents through homebound instruction, and threatening an adolescent with not attending college out of town if seizures persisted served as barriers to their self-management attempts. One adolescent summed up the negative aspect of family involvement by stating, "They've kind of put the stress on me."

Peer Involvement.: The mocking responses and statements of disbelief from peers regarding the involuntary nature of the seizures served as barriers to adolescents exercising self-management strategies or perceiving them as effective. One adolescent described the result of such responses as, "I stopped showing up to school." 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 made it difficult for the adolescent to effectively communicate with school personnel about her seizure care needs.

DISCUSSION

Adolescents' responses indicate a desire for a proactive seizure plan, especially a plan that will protect not only their physical health but also their emotional or mental well-being. Although adolescents deemed their proactive self-management strategies and some reactive strategies targeting personal safety as effective, not all self-management strategies identified by adolescents are recommended or considered safe. For example, plans that included not alerting a trusted adult or escaping to a locked restroom stall may place adolescents in danger. Adolescents desire co-created self-management plans that reflect their wishes, and school personnel desire student safety and risk mitigation. Therefore, mental health nurses, school nurses, and school personnel must consider the practicalities of school safety and condition monitoring when co-creating self-management plans. Because functional seizure literature has not addressed self-management aspects of this condition, it is important to

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apply findings from the current study with what is known about self-management of other seizure and mental health conditions. Multiple implications for psychosocial and mental health nursing arise from better understanding adolescents' perceptions of self-management.

Study Findings and Self-Management Literature

Although more commonly considered an intervention for chronic physical conditions, such as diabetes or heart disease, self-management is also an integral part of mental health care. Despite functional seizures being a symptom of a mental health condition, adolescents in the current study placed a heavy emphasis on self-management strategies that provided protection of their heads and bodies during seizure events. This desire is understandably absent from mental health literature but is not reflected even in epilepsy self-management literature. Instead, existing pediatric epilepsy self-management interventions have targeted treatment adherence, trigger avoidance, and self-efficacy (Ayar et al., 2020; Smith et al., 2018).

Most adolescents in the current study also expressed a desire to involve a friend in their functional seizure plan. Integration of a friend in a functional seizure response plan was included in a randomized control trial testing a retraining and control therapy (ReACT), which resulted in significant reduction in number of functional seizures (Fobian et al., 2020). The authors provided no details of the role a supportive peer played in the functional seizure action plan; therefore, insight from our study may provide ideas for use of supportive peers in action planning until further intervention testing is reported.

In our study, multiple adolescents described using apps and text messaging as coping strategies and to document seizure events, triggers, or emotions and stressors that impact the condition. Although the usefulness of technology found in this study was consistent with documented self-management interventions for mental health support, technology in previous research benefitted co-creation of goals and self-management practices with a mental health care provider (Williams et al., 2019), rather than simply an electronic diary or calming tool. This may be a gap that psychosocial and mental health nurses could explore.

In the current study, adolescents described many facilitators of self-management. Facilitators were considered people's actions that supported self-management, such as school nurses teaching school personnel about the condition and the appropriate response plan or equipping adolescents with new coping strategies. Several self-management support interventions noted in a hybrid concept analysis were consistent with adolescents' desired self-management support strategies in this study—working together to set goals and develop a plan, coaching regarding coping strategies for anxiety and stress, and collaborating with school and health care team members to address day-to-day life needs (Tanner et al., 2021).

Adolescents in the current study also identified several barriers to self-management, including stigmatization and negative relationships with school personnel. These school climate factors serve as risk factors for students developing additional comorbid mental disorders (Mofatteh, 2021). Among children and adolescents with functional seizures, 39.1% develop comorbid mental health disorders after being diagnosed with functional seizures (Hansen et al., 2021). Mental health nurses caring for adolescents with functional

seizures should assess for comorbidities and mitigate risk factors through education of school personnel.

LIMITATIONS

Despite efforts to recruit male and female participants, and interest expressed by two males, only female participants completed the current study. Although a limitation, at least three times as many females as males are affected by functional seizures (Kozlowska et al., 2018; Villagrán et al., 2021). Although racial diversity may be an additional limitation of this study, few studies of pediatric functional seizures have reported race and those that have yielded varied results. The proportion of white participants in this study (80%) was consistent with a recent retrospective chart review study that did not require recruitment (79%; Sawchuk et al., 2020) and greater than that in a recent prospective study requiring recruitment (59%; Stager et al., 2022). In addition, although we used multiple recruitment strategies, most participants responded to a flyer shared via social media support groups. Adolescents and families who seek support groups may speak out more about concerns or better understand the condition than those not participating in such groups. Furthermore, the authors asked adolescents self-management questions in the context of the school experience. Additional self-management strategies may require exploration of life outside of school and school-related activities and for younger children.

IMPLICATIONS FOR PSYCHOSOCIAL AND MENTAL HEALTH NURSES

Mental health nurses are positioned to provide direct services for adolescents with functional seizures. Although CBT is the gold standard treatment for functional seizures, clinical mental health nurses at all levels of training can support self-management through co-creating appropriate seizure event response plans and proactive care plans, teaching coping strategies, and advocating for legal, safe school-management of the condition. For adolescents with access to a school nurse, mental health nurses should collaborate with the school nurse to ensure adolescents are considered for either a Section 504 Plan or IEP. Mental health nurses can also work with school nurses (and other school personnel for schools without a school nurse) to support appropriate school policies, procedures, and environments that can alleviate school stress, bullying, accusations of faking, and isolation/exclusion that so frequently plague adolescents with functional seizures and increase risks for additional mental disorders. Through a strong connection between mental health and school health teams, adolescents can set and achieve goals that lead to improved health and academic outcomes, which can lead to a healthier adulthood.

CONCLUSION

Adolescents with functional seizures practice self-management strategies that help them manage their day-to-day life with the condition as well as moments when a seizure event feels imminent. Many people—school nurses and personnel, family members, and peers—play a role in facilitating these self-management strategies; however, many of these same people serve as barriers to adolescent self-management in the school environment. Adolescents identified co-creating a plan for safety and coping with school personnel as

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key to their self-management. Adolescents also felt better equipped to self-manage their functional seizures when school personnel and peers gained understanding of the condition. Mental health nurses are well-positioned to support adolescents in their self-management efforts and support those who may serve as facilitators and barriers to self-management.

Acknowledgment:

The authors thank the incredibly brave adolescents who shared their experiences attending school and self-managing functional/psychogenic nonepileptic seizures.

Table A: Self-Management Themes, Categories, and Additional Exemplar Statements

Theme	Category	Exemplar Statement
Proactive	Protection	"There was a couple places that I would go. Mostly near the stairwells…. It wasn't as, like, out in the open. And specifically, under a stairwell was very good, 'cause no one could see me just walking by." "I kept a pillow in my backpack that I usually had enough time to get out… I was actually able to handle the seizures on my own."
	Perseverance	"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." "I take the time; I ask teachers if I can stay after school because of this time I miss." "I would rather be open about it since I know I've already lost that control to be private, I'd rather be open, so everyone has the facts rather than some mixed up thing."
	Progress monitoring	"Keeping track of them could be a part of [managing functional seizures]" "Okay, so usually I text my mom and that's my way of recording it, 'cause then I can just go up and see all the text messages."
Reactive	Protection	"I found the perfect thing is to hum different sections of Pachelbel's Canon. The cello part, then the viola part, then the violin part." "Well, I sit down, and I start breathing." "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 way I deal with it is just like kind of brush it off and keep going." "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	Effective	"All my teachers have been super kind, super thoughtful and they're… They've just been really caring" (after being open with teachers about condition).
	Ineffective	"It's just like talking to a brick wall" (when trying to proactively explain to school personnel how to respond to seizures). "Let's just be honest, those don't help me when I'm in a seizure, nothing can get me out of one" (when trying to reactively respond to seizure warnings).
Facilitators	School nurse involvement	"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."

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Theme	Category	Exemplar Statement
	Family involvement	“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.”
	Friend involvement	“I’d look at her, give her this look, because I’m one of the lucky ones that get anywhere from a three to five-minute warning, and we would leave class without saying a word.” “They [friends] are more open about knowing what it is, so they listen a lot more and they’re scared, but for some reason, the school is more scared than my friends are, so they know how to handle it and they’re a lot more calm about it.”
Barriers	School nurse involvement	“She threatens me. ‘If you don’t get out of this, then you’re going to go to the hospital.’”
	School personnel involvement	“Teachers not wanting me in their class and kind of verbalizing that to me, and teachers telling me that I can be a distraction sometimes.” “I also had a substitute teacher sternum rub me while I was wide awake. And completely bruise my chest from it, even though I was screaming for him to stop.”
	School building design	“I was going up the stairs and I fell down the stairs and my whole hip and my ribs were bruised up. The principal did make me ride the elevator for the next year though which really did upset me.”
	Family involvement	“They’ve [parents] kind of put the stress on me by saying if I’m continuing the seizures I won’t be allowed to go to college.”
	Peer involvement	“They [classmates] just point and laugh.” “This kid has made a post about the whole seizure [on social media] and how the school wasn’t treating me right.”

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TABLE 1

PROACTIVE SELF-MANAGEMENT STRATEGIES AND PERCEIVED EFFECTIVENESS

Participant	Proactive Strategy	Effect on Caring for Condition
1	Carry backpack, pillow, or coat to protect head	+
2	Actively participate in therapy, use coping strategies, decrease stress with art and weightlifting	+
3	Use coping strategies, connect with pet and family, and identify and avoid triggers	+
4	Plan to leave class with friend	+
5	Carry backpack to protect head, connect with other adolescents with functional seizures in support group	+
6	Talk openly with staff about needs, use humor, track seizures	+
7	Use coping strategies	?
8	Attend therapy, use cognitive-behavioral therapy workbook, decrease stress with art, take medication for comorbid conditions, use phone app for coping 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 for comorbid conditions, track seizures, identify and avoid triggers	+

Note. + = positive; ? = unknown/unavailable response.

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TABLE 2

REACTIVE SELF-MANAGEMENT STRATEGIES AND PERCEIVED EFFECTIVENESS

Participant	Reactive Strategy	Effect on Caring for Condition
1	Hum classical music	+
2	Meditation, grounding	+
3	Breathing techniques, mindfulness	0
4	Self-talk "Not here, not now"	+
5	Call mom	0
6	Tell school how to handle seizure, text mom	0
7	Unable to complete interview, crying	?
8	Go to health office, decompress	0
9	Lay down, breathing, telling friends	+
10	Breathing techniques, sit/lay down	0

Note. + = positive effect; 0 = neutral effect; ? = unknown/unavailable response.