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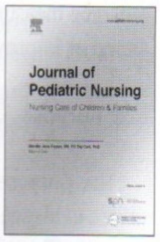

Improving the self-efficacy of caregivers of children with seizures using evidence-based practice

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ABSTRACT

Background: Epilepsy is considered a widespread chronic illness; it is estimated that approximately 1% of all children have the condition. Parents and caregivers of children with seizures experience fear and anxiety relative to their perceived confidence to manage their child's seizures after leaving the hospital. Evidence supports the use of simulation to educate caregivers to improve their perceived level of self-efficacy.

Methods: The evidence-based practice project examined the impact of utilizing a simulation training session on the self-efficacy of caregivers of children with seizures at a large pediatric medical center in the southern United States. Caregivers of children with newly diagnosed seizures or with a recent change to their seizure treatment plan attended a simulation training session individualized to their discharge instructions. Demographic data, pre- and post-training self-efficacy measurements, and program satisfaction data were collected.

Findings: The 31 caregivers who participated during the 3-month implementation period experienced a statistically significant increase in self-efficacy ($p < .0001$ to 0.002) and reported being satisfied with the simulation education training.

Discussion: The project outcomes suggested simulation training was an effective method for improving the self-efficacy of caregivers of children with seizures and could be a feasible practice change at organizations with access to simulation technology.

Application to practice: The outcomes of the project aligned with the evidence available in the literature. The results reinforced that education that includes simulated learning opportunities was generally well-received by caregivers and may improve their confidence to care for their child after discharge.

Background

Epilepsy is considered a widespread chronic illness; it is estimated that approximately 1% of all children have the condition (Hamaad & Alseraty, 2019). A diagnosis of epilepsy in childhood has a substantial psychological impact on the family (Hamaad & Alseraty, 2019; O'Dell et al., 2007). When children with epilepsy are discharged from the hospital, customarily parents are tasked with resuming their role as caregivers and are responsible for managing the response to any seizures that may ensue (Dumeier et al., 2017; O'Dell et al., 2007). Aware that their child may still suffer seizures despite receiving treatment, caregivers of children with seizures experience persistent fear (O'Dell et al., 2007). These caregivers also experience increased stress and anxiety, often related to fear and perceived low self-efficacy (Hamaad & Alseraty, 2019). Prompt and effective treatment of seizures significantly reduces the chance of admission to the hospital (Dumeier et al., 2017). Therefore, lack of confidence or self-efficacy to respond appropriately in the event of a seizure may negatively impact a caregiver's ability to rescue their child and result in a child experiencing a prolonged seizure, severe harm, or even death (Dumeier et al., 2017; O'Dell et al., 2007).

Self-efficacy is a significantly related factor to caregivers' experiences (Hamaad & Alseraty, 2019; Vance et al., 2021; Wooldridge & Carter, 2021). It has consistently been noted that caregivers of children with seizures who report higher levels of self-efficacy experience improved well-being for themselves and their children (Hamaad & Alseraty, 2019; Vance et al., 2021; Wooldridge & Carter, 2021). A review of the literature suggested that the self-efficacy of caregivers of children with seizures may be predictive of their ability to respond to a seizure outside of the hospital environment and to achieve positive outcomes for themselves and their children (Dumeier et al., 2017; Hamaad & Alseraty, 2019; O'Dell et al., 2007; Vance et al., 2021; Wooldridge & Carter, 2021). This highlights self-efficacy as a potential and meaningful

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outcome measure when implementing evidence-based practice changes aimed at improving the care of this population.

EBP purpose

The purpose of the evidence-based practice (EBP) project was to utilize evidence from the literature and available resources to improve the self-efficacy of caregivers of children with seizures at a large pediatric medical center in the southern United States. Nurses in the neurology and epilepsy monitoring unit had expressed concern for caregivers' confidence in responding to a seizure upon discharge home. A Likert-type survey showed that 58.3% of nurses rated caregiver comfort with responding to a seizure at home as only somewhat comfortable, and 37.5% rated caregivers as uncomfortable to very uncomfortable. When asked how often caregivers expressed anxiety, fear, or stress related to their child having a seizure at home, 50% of nurses reported this happens often, and 29.1% reported this happens very often. In addition to survey responses from nurses, additional evidence of the practice problem included readmission data. Of all readmissions to the neurology and epilepsy monitoring unit, 39.2% were seizure-related. Although this data did not specifically address caregiver confidence or self-efficacy, it highlighted the likelihood that caregivers of children with seizures will experience their child requiring seizure care in the home environment.

Literature synthesis

A search of the literature to discover the best practices for improving the self-efficacy of caregivers of children with seizures to respond to a seizure in the home environment revealed two categories: educational interventions and psychological interventions. Educational interventions included simulation training and didactic modules with discussion (Arnold & Diaz, 2016; Diaz & Arnold, 2021; El-Esrigy et al., 2021; Fleeman & Bradley, 2018; Gürhopur & Dalgiç, 2018; Hamaad & Alseraty, 2019; Jafari et al., 2020; Kızılay et al., 2017; Kumar et al., 2019; Sigalet et al., 2014; Silva et al., 2021). Psychological interventions included empowerment, support groups, and counseling (Fleeman & Bradley, 2018; Jafari et al., 2020; Jahri Sheijani et al., 2020; Ji & Shim, 2020; Sartore et al., 2021). A systematic review of psychologically supportive interventions and education through didactic modules with discussion revealed that the impact of these interventions was limited, but they did not cause harm and were generally well-received by caregivers (Fleeman & Bradley, 2018). Alternatively, education involving simulation training significantly improved confidence and self-efficacy and was well-received by caregivers (Arnold & Diaz, 2016; Diaz & Arnold, 2021; Hamaad & Alseraty, 2019; Sigalet et al., 2014; Silva et al., 2021).

A synthesis of the literature focused on simulation training for caregivers of children with medically-complex conditions included research and non-research evidence. Research evidence included a systematic analysis, a meta-analysis, and quantitative and qualitative research studies such as quasi-experimental interventional studies, randomized control trials, and descriptive-exploratory studies (Franklin & Lee, 2014; Hamaad & Alseraty, 2019; Mundell et al., 2013; Prickett et al., 2019; Sigalet et al., 2014; Silva et al., 2021). Non-research evidence included position statements, a quality improvement project, and clinical practice guidelines (Arnold & Diaz, 2016; Diaz & Arnold, 2021; Mednick et al., 2021; Wooldridge & Carter, 2021). Major findings and recommendations from the synthesis of the literature supported utilizing simulation for caregivers of children with seizures and other complex conditions. Specifically, caregivers who received simulation training in addition to traditional education reported higher levels of self-efficacy, confidence, knowledge, relief, and competence (Diaz & Arnold, 2021; Franklin & Lee, 2014; Hamaad & Alseraty, 2019; Mundell et al., 2013; Prickett et al., 2019; Sigalet et al., 2014; Wooldridge & Carter, 2021). Despite some initial anxiety when participating in simulation training, caregivers reported feeling relieved and self-confident after the training (Silva et al., 2021). Lastly, simulation training supported patient-family-centered care and had the potential to improve the quality of education when compared with other teaching modalities (Arnold & Diaz, 2016).

EBP conceptual framework

The Johns Hopkins Nursing Evidence-Based Practice (JHEBP) Model was used as the conceptual framework to guide the planning, implementation, and evaluation of the EBP project. The JHEBP Model is utilized by interprofessional teams to develop an answerable practice question, to gather and appraise available evidence to make a practice change recommendation, and to create an action plan for translating the recommended practice change to the organization (Dang et al., 2021). The model is inquiry-based and breaks down the EBP process into three phases, outlined in 20 steps, to provide a clear pathway for nurses to identify practice problems and solve or mitigate them using EBP (Dang et al., 2021).

Methods

Sample and setting

A sample of 31 caregivers who were to be sent home with a seizure rescue medication for their children who were either recently diagnosed with seizures or who had incurred a change to their seizure treatment plan, participated in an evidence-based educational simulation intervention prior to their child's release from the hospital. Caregivers were identified and scheduled for training through collaboration between nurse practitioners, a clinical nurse leader, and bedside nursing staff. Caregivers included English or Spanish-speaking adults who may be alone with the child or responsible for responding in the event of a seizure after discharge from the hospital. The project was carried out over a 3-month pilot period.

Intervention

Caregiver simulation education sessions took place in a private treatment room on the unit, but away from the child's bedside, and lasted approximately 45 min to 1.5 h. Each session was adapted to align with the individual child's seizure treatment plan and discharge instructions. The clinical nurse leader would review seizure first aid and appropriate administration of rescue medication and allow caregivers time to ask questions or request clarifications. Caregivers were also able to touch and handle their home rescue medication. After the standard education was completed, caregivers were introduced to the human-patient simulator and instructed to observe the manikin for any seizure-like behavior. The human-patient simulator was able to display a combination of blinking, head twitching, upper extremity tone, or generalized shaking to best depict the child's seizure. Caregivers were expected to respond with appropriate seizure first aid interventions and correctly administer the rescue medication, after which the manikin would transition to post-ictal behavior. After completion of the simulation, caregivers were offered guidance on responses that needed improvement and praise for correct responses. At the closing of the session, caregivers were once again provided with an opportunity to ask questions and request clarifications. There was no cost to caregivers who participated in the training and no associated financial burden to the organization as the facilitators completed the trainings during their regularly scheduled work hours.

Measures

The data collected during the EBP project included all elements of the KidSIM-ASPIRE Parent Seizure Self-efficacy Questionnaire (Sigalet et al., 2014). The questionnaire included 12 items that addressed the caregiver's perception of their own ability to perform seizure rescue actions. The questionnaire was specifically designed to measure self-efficacy, and was authored and psychometrically established by Sigalet et al. (2014) with a reliability coefficient of α = 0.92. Dr. Sigalet approved the copyright permissions request of the intent to use the questionnaire for this project. In addition to caregiver self-efficacy data, the project team collected demographic information (caregiver's relation to the patient, age, gender, level of education, race, ethnicity, and marital status) and program satisfaction responses.

Statistical analysis

Statistical analyses of the project data and outcomes included descriptive statistics (means, standard deviations, medians, percentages, and/or frequencies) for caregiver demographic data, all items of the KidSIM-ASPIRE Parent Seizure Self-efficacy Questionnaire, and post-training program satisfaction responses. A Wilcoxon signed-rank test, for ordinal data, was calculated to compare pre- and post-caregiver simulation session self-efficacy Likert-style responses for each of the 12 items on the KidSIM-ASPIRE Parent Seizure Self-efficacy Questionnaire. Qualitative data from the open-ended question related to program satisfaction were reviewed for themes to evaluate the caregivers' experiences with the simulation training session.

Ethical considerations

A detailed written project proposal explaining the practice problem and the suggested practice change was sent to the Director of Human Subject Protections in the organization's Institutional Review Board (IRB) department. The director reviewed the abstract and determined the evidence-based practice project did not require IRB oversight. The project team received an IRB exemption and the Director of Nursing Research and Evidence-Based Practice served as the project team's executive contact for ethical considerations. Caregiver participation in the project was entirely optional and voluntary. There were no consequences, such as a change to their child's care or discharge timeline, for choosing not to participate. In order to protect the privacy of participants and the collected data, the project team adhered to a data stewardship plan. Every participant was assigned a number that was used to label each of their questionnaires. Their personal information such as name, date of birth, and address was not collected. Completed questionnaires and data analysis documents were stored on the organization's private server in locked and password-protected storage that could only be accessed by the project team. The project and data collection began on January 11th 2023 and concluded on April 5th 2023.

Findings

Demographics

Ages of the participating caregivers ranged from 21 to 71 years, with a mean of 43.3 (SD = 13.41) years and a median of 42 years. The majority of participants were women (58.1%), and the remaining participants were men (41.9%). None of the participants reported being non-binary, transgender, or preferred not to respond. The level of education completed by caregivers ranged from grade school to master's degree, with 9.7% having attended grade school, 32.3% having completed a high school diploma or GED, 29% who attended some college, 22.6% having completed a bachelor's degree, and 6.45% who completed a master's degree. Most participants were married (71%), followed by never married (22.6%), and a small number were either divorced (3.2%) or widowed (3.2%). The majority of caregivers were White (61.3%), followed by Asian caregivers (12.9%), Black caregivers (9.7%), those who reported some other race (9.7%), and one caregiver (3.2%) who did not respond. Most caregivers were not Hispanic or Latino (74.2%), but approximately a quarter of participants (25.8%) did report being of Hispanic or Latino ethnicity. The caregivers' relation to the patient included mothers (35.5%), grandparents (29%), fathers (25.8%), and other relatives (6.5%). Only one participant (3.2%) did not respond.

Self-efficacy

A statistical comparison of the pre- and post-KidSIM-ASPIRE Parent Seizure Self-efficacy Questionnaire responses, presented in Table 1, suggested participation in the simulation training increased caregiver self-efficacy to respond to a seizure in the home environment. A Wilcoxon signed-rank test revealed a statistically significant increase in caregiver self-efficacy on each of the twelve items on the questionnaire, $z = -3.236$ to -4.662, $p < .0001$ to 0.002, with a moderate to large effect size ($r = 0.39$ to 0.59) (Cohen, 1988). The median score for all survey items increased from pre-simulation education to post-simulation

Table 1
KidSIM-ASPIRE parent seizure self-efficacy questionnaire pre- and post-intervention analysis.

Item	Pre-simulation median	Post-simulation median	z-score	p value	Effect size (r)
A. How sure are you that you know when your child is having a seizure?	3.0	5.0	−3.533	< 0.0001	0.45
B. How sure are you that you can manage your child's seizure at home rather than calling 911 or driving your child to the emergency department?	3.0	4.0	−4.662	< 0.0001	0.59
C. How sure are you that you know when to call 911 or drive your child to the emergency department when they are having a seizure?	3.0	5.0	−3.236	0.001	0.41
D. How sure are you that you can protect your child from harm when having a seizure?	3.0	5.0	−4.182	< 0.0001	0.53
E. How sure are you that you can place your child in the recovery position?	3.0	5.0	−4.283	< 0.0001	0.54
F. How sure are you that you will carry the rescue medications on you at all times?	4.0	5.0	−3.07	0.002	0.39
G. How sure are you that you can follow the directions for administering the rescue medication correctly?	4.0	5.0	−3.619	< 0.0001	0.46
H. How sure are you that you can draw up the correct dose of rescue medication when your child is having a seizure?	3.0	5.0	−3.915	< 0.0001	0.50
I. How sure are you that you can administer your child's rescue medications during a seizure?	3.0	5.0	−4.065	< 0.0001	0.52
J. How sure are you that you can administer the rescue medication if your child has a seizure for longer than 5 min?	3.0	5.0	−4.312	< 0.0001	0.55
K. How sure are you that you know the common/emergent side effects of your child's rescue medications?	1.0	5.0	−4.641	< 0.0001	0.59
L. How sure are you that you can assess your child's breathing during a seizure?	2.0	5.0	−4.381	< 0.0001	0.56

Note. Item column reflects questions included on the KidSIM-ASPIRE Parent Seizure Self-efficacy Questionnaire (Sigalet et al., 2014). $p \leq 0.05$. small effect size (r) = 0.1, medium effect size (r) = 0.3, large effect size (r) = 0.5 (Cohen, 1988).

education, with a median increase of at least 1 full point higher and up to 4 full points higher. The largest change from pre- to post-simulation training was reported on the questionnaire items related to managing the seizure at home instead of calling 911, knowledge of medication side effects, and assessing their child's breathing status.

Program satisfaction

The analysis of program satisfaction responses from caregivers of children with seizures favored the use of simulation training. All caregivers who completed the program satisfaction survey ($n = 30$) reported the training was very to extremely helpful and that they were very to extremely satisfied with the training and education. Additionally, all caregivers reported they would recommend this training to other caregivers. Themes from responses to the open-ended question asking if caregivers would like to share anything with the project team included no feedback ($n = 16$), gratitude ($n = 7$), knowledge acquisition (n = 7), and increased confidence ($n = 4$). Examples of comments from caregivers included expressions of gratitude such as "Thank you," and statements like "I learned more about how to give rescue medications," and "I am much more comfortable in caring for (my child) in case of any long seizures."

Discussion

The results of the project suggested simulation training significantly improved the self-efficacy of caregivers of children with seizures to respond to a seizure in the home environment. Caregivers were satisfied with the training they received and found it to be helpful. They reported they would recommend the training to other caregivers of children with seizures and expressed gratitude for the opportunity to receive this training. At the conclusion of the project pilot, the practice change was accepted by the organization and integrated into discharge education for caregivers of children with seizures.

Retrospective analysis of implementation

A reflective look at the implementation of the practice change highlighted the importance of strategy and logistics. Prior to implementation, the project team obtained approval from the Human Subject Protections liaison and from department leadership. They assessed risks, such as facilitator burnout, availability of training space, and caregiver scheduling conflicts, and made plans for avoiding or mitigating their potential negative impact on the successful rollout of the project. The project team also analyzed the power and interest of each project stakeholder while considering potential strengths, weaknesses, opportunities, and threats to the practice change implementation. Communication was imperative to the successful implementation. The project team advertised the upcoming practice change with bedside nursing staff and nurse practitioners who managed the care of children with seizures and followed up weekly to assist in identifying and scheduling caregivers for training.

The primary challenge faced during implementation included the inability of the project team to provide the simulation education to every caregiver who was appropriate to receive the training. The brief nature of admission and discharge for patients with seizures and the competing demands of the primary roles of the intervention facilitators resulted in missed opportunities. An analysis of hospital discharges among children conducted by Macy et al. (2009) found seizure-related diagnoses to be among the top ten diagnosis-related groups with high turnover stays (hospitalizations with lengths of stay of 0 to 1 night) over a ten-year period. This insight has prompted the project team to begin considering how to resolve this issue with organizational support. It is possible that a new position with a large portion of their role dedicated to providing this education could improve the organization's ability to provide training to all appropriate caregivers.

Evidence application to practice

The successful implementation of the EBP project suggested it is feasible to utilize simulation as a tool to improve the self-efficacy of caregivers of children with seizures within organizations with access to simulation technology and with the capacity to obtain adequate facilitator support. The outcomes of the project aligned with the evidence available in the literature and reinforced that education including opportunities to learn using simulation is generally well-received and may improve the confidence to care for their child after discharge across a diverse demographic group of caregivers (Arnold & Diaz, 2016; Diaz & Arnold, 2021; Hamaad & Alseraty, 2019; Sigalet et al., 2014; Silva et al., 2021). In addition to a positive reception of simulation training by caregivers and increased self-efficacy or confidence, evidence in the literature also suggested simulation training may increase knowledge, competence, and relief, and improve the quality of caregiver education (Arnold & Diaz, 2016; Diaz & Arnold, 2021; Franklin & Lee, 2014; Hamaad & Alseraty, 2019; Mundell et al., 2013; Prickett et al., 2019; Sigalet et al., 2014; Silva et al., 2021; Wooldridge & Carter, 2021). Application to practice of the knowledge gained from the outcomes of the EBP project, and the existing body of evidence, may include the development of caregiver education programs that standardize the use of simulation training.

Research implications

The success of this evidence-based practice project and the positive results of prior research investigating the use of simulation for caregivers of children with medically-complex conditions, including seizures, asthma, diabetes, and tracheostomy dependency, suggest research investigating the use of simulation to support caregivers of children with other types of complex conditions that are managed at home should be pursued (Diaz & Arnold, 2021; Drummond et al., 2017; Hamaad & Alseraty, 2019; Prickett et al., 2019; Ramchandani et al., 2016; Sigalet et al., 2014). The project team is also interested in investigating the impact of the evidence-based practice change on seizure-related readmissions and communication between the caregiver and their neurology provider over time.

Limitations

Limitations noted by the project team include a small group of participants with varying levels of prior experience with and knowledge of seizures. Some caregivers attended training due to a change in their child's seizure treatment plan, and others attended class after their child was newly diagnosed with seizures. It is likely that the caregivers' differing levels of experience may have influenced their responses to the project surveys. Due to logistical challenges, the project team was unable to provide training and education for every family who met the project criteria. The inclusion of all caregivers who met the criteria would have increased the number of responses and may have affected the project results. Lastly, some caregivers verbally reported to the project team confusion about questions when completing the pre-survey. They would request clarification about the meaning of the question or would express concern about reporting that they were not confident to care for their child. The project team would provide clarification so that caregivers understood the questions prior to answering. Project team members also reassured the caregivers that their responses to both the pre- and post-surveys were anonymous and would not impact their ability to take their child home.

Conclusions

The ongoing evaluation of this practice change and the impact of this project could include quality improvement considerations such as a comparison of the readmission rate of those patients whose caregivers participated in the training and those who did not. Reflection on the implementation, outcomes, and research implications of this evidence-based practice project includes the significant impact of experiential simulation education on the self-efficacy of caregivers of children with seizures and the potential for this intervention to support caregivers of children with other medically-complex conditions. This impact is a call to pediatric nurses and healthcare organizations to take intentional action to provide these educational opportunities to caregivers in a purposeful effort to decrease their fear and increase their ability to enjoy life at home with their child.

CRediT authorship contribution statement

Malorie Brooks: Conceptualization, Formal analysis, Writing – original draft, Investigation, Project administration. **Natalie Palau:** Conceptualization, Investigation, Project administration, Writing – review & editing.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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