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Development of an Epilepsy Nursing Communication Tool: Improving the Quality of Interactions Between Nurses and Patients With Seizures

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ABSTRACT

Background: Nurses have become increasingly involved in overseeing the management of patients with complex medical conditions, including those with epilepsy. Nurses who are not specialists in epilepsy can play a central role in providing optimal care, education, and support to their patients with epilepsy, given the proper tools. **Objective:** Our objective was to create a tool that can be used by nurses in the clinic setting to help facilitate discussion of topics relevant to enhancing medical care and management of patients with epilepsy. To address this need, a panel of epilepsy nursing experts used a patient-centered care approach to develop an Epilepsy Nursing Communication Tool (ENCT). **Methods:** An initial set of topics and questions was created based on findings from a literature review. Eight nurse experts reviewed and revised the ENCT using focus groups and discussion forums. The revised ENCT was provided to nurses who care for patients with epilepsy but had not been involved in ENCT development. Nurses were asked to rate the usability and feasibility on a 5-point scale to assess whether the tool captured important topics and was easy to use. **Results:** Ten nurses provided usability and feasibility assessments. Results indicated strong tool utility, with median scores of 4.5, 4, and 4 for usefulness, ease of use, and acceptability, respectively. **Conclusions:** The preliminary ENCT shows promise in providing a tool that nurses can use in their interactions with patients with epilepsy to help address the complexity of disease management, which may help improve overall patient care.

Keywords: communication, epilepsy, nursing care, tool

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Epilepsy is a chronic disease that affects 1% of the population and can be associated with significant physical and psychosocial sequelae.¹ A person with epilepsy often has comorbid conditions and must carefully manage their epilepsy and comorbid diseases, as well as navigate how their life is affected by their diseases.² Developing self-management strategies in epilepsy requires ongoing, effective patient-provider communication to ensure treatment adherence and optimize outcomes (via patient-centered care). Patients with epilepsy report that they want to be an active participant in their own self-management,³ but the patient-provider dynamic is often fraught with difficulties. Time limitations and lack of patient-centered communication techniques often interfere with patient-provider goal setting and hamper patient management recommendations.⁴ Patients with epilepsy have reported feeling inadequately informed regarding aspects of disease treatment or management,^{2,5} despite healthcare quality indicators for epilepsy providers designed to ensure that parameters of patient care are addressed.⁶ The quality indicators cover topics to ensure patients understand their disease, treatment, side effects, and safety issues, but they do not thoroughly address equally important lifestyle

issues, such as getting sufficient sleep and engaging in stress reduction activities.¹

In this challenging environment with an increased emphasis on quality care, nurses are uniquely positioned to facilitate effective communication with patients, because they typically provide the first interaction during an office visit and perform initial assessments of patient conditions and needs. In addition, patients with chronic disease may be more likely to contact and discuss care issues with nurses than physicians,⁷ providing an opportunity for nurses to develop a trusting patient-provider relationship that supports active communication and allows patients to identify both self-management priorities and barriers. Indeed, patients note that conversations are more open and unhurried when they are active participants in discussing their own care needs.⁷

Although epilepsy care is a specialized field and formal training opportunities are available, many nurses who care for patients with epilepsy may not have formal education in this area.⁸ Therefore, resources that help nurses assess and assist their patients are needed.⁹ Nursing guidelines for the care and education of patients with epilepsy are a critical first step to expand one's knowledge on epilepsy diagnosis and treatment, patient self-management, and psychosocial aspects of care.^{9–11} A tool providing discussion topics important to patients with epilepsy would also empower nurses without epilepsy-specific training, regardless of their geographic location or clinical setting, who may directly care for patients with epilepsy.¹⁰

The benefit of nurse-led interventions to improve patient knowledge of disease and effective self-management strategies has been reported across a number of chronic conditions,⁷ including in managing patients with epilepsy.¹² In epilepsy, these benefits include improved patient satisfaction with knowledge and coping skills,¹ improved emotional well-being, confidence and treatment adherence, lower costs, and shorter inpatient stays.⁸ Although studies have not reported significant impact on quality of life measures or clinical outcomes, a recent study has reported on improved quality of care provided by nurse-physician teams compared with physician-only care.¹³ These findings parallel the reported benefit of nurses educating patients to improve disease management and in their role of identifying patients for further management of disease or treatment goals in a variety of other chronic diseases.¹⁴

Given that nurses without epilepsy specialization will increasingly encounter and provide care for patients with epilepsy, we sought to create a tool to help improve nurse-patient communications and positively affect a nurse's approach to care for people with epilepsy using the model of patient-centered care.² With this model, patient care is customized according to

The ENCT has 40 questions
covering: seizures, medications,
side effects, and normal
daily activity.

patient needs and values, with the patient as the source of control.¹⁰ Knowledge and information are freely shared between patients and their healthcare providers, patient needs are anticipated, and treatment decisions are made based on the best available evidence.

Methods

ENCT Development

The Epilepsy Nursing Communication Tool (ENCT) was developed in 3 phases, in alignment with qualitative research recommendations (see Figure, Supplemental Digital Content 1, available at <http://links.lww.com/JNN/A117>).¹⁵ Phase 1 entailed a thorough review of the PubMed literature, searched on June 2015 (limited to humans and English language) to identify publications pertaining to patient surveys or questionnaires, interview guides (limited to 2013–2015), and satisfaction with such assessments with nurses or patients with epilepsy. Of 544 returns, 127 were identified as possibly relevant. The studies were reviewed for topics that were of importance (or deficient) to the management of patients with epilepsy. After this thorough literature search, survey questions and topics for the preliminary ENCT were developed by the 2 nursing authors, both experts in epilepsy care. Open-ended questions were formulated to address topics considered important to patients to allow nurses and patients the ability to explore patient care needs.²

In phase 2, survey items were refined based on feedback from expert nurses.¹⁶ We recruited the expert nurses through the American Epilepsy Society and through the American Association of Neuroscience Nursing. Eight nurses were recruited: 7 were experts in epilepsy and 1 was an expert in patient communication techniques. Of the 7 with epilepsy expertise, 6 have master's degrees in nursing and 1 has a bachelor's degree in nursing, with epilepsy experience ranging from 5 to 25 years, and all work in epilepsy-specific clinical settings. The patient communication expert has a PhD in nursing. After recruitment, the experts were asked to review the original tool for completeness and to provide input for additional content using a secure Web-based digital platform. This platform provided support for an online discussion forum where the experts could share their thoughts providing context for future discussions. After review, each nurse

was asked to comment in each area, and the comments were recorded on the digital platform. Nurses were given 2 weeks to respond both to the individual ENCT items and also to others' comments. A real-time discussion (via phone) was held providing the nurses a chance to openly critique the strengths and weaknesses of the tool. The authors analyzed the feedback and revised the ENCT based on the discussions and their analyses; the tool was resubmitted to the 8 nurses for further review and comment via the digital platform. Eight questions regarding the ENCT were provided to initiate discussion. All nurses fully participated in the discussion forums over the 2-week review period. After the 2-week comment period on the digital platform, the authors reviewed feedback and revised the ENCT, followed by a second discussion forum. A final version was completed after the second forum.

Ease of Use

In phase 3, the ENCT was assessed for ease of use and utility.¹⁵ The finalized tool was submitted to a separate panel of 15 nurses who primarily worked in either hospitals or clinics, cared for patients with epilepsy, and had at least 1 but fewer than 5 years of experience. The 15 panelists were asked to assess feasibility and usability on a 5-point scale (1, strongly disagree, to 5, strongly agree with positive statements) for 11 statements.¹⁷ The scores were tallied, and further revisions to the ENCT were made based on those findings. The tool was then given to the original 8 nurse experts for final comments, which were then considered by the authors before making the final revisions.

Results

ENCT Development

The final ENCT resulting from phase 3 development is shown in Table 1. Forty questions were categorized under the main topics of seizures, medications, side effects, and normal daily activity. The patient-centered questions were developed to encourage full patient engagement and were generally posed as open-ended questions or requests that patients freely describe or talk about concerning an issue, topic, situation, or concern. The initial ENCT also contained a list of problem-specific cues that aligned with category questions. These cues were included to help nurses prompt their patients for more information when initial answers are lacking in detail or depth.

Ease of Use

During phase 3, an evaluation form with a series of 11 statements probing the feasibility and usability of the ENCT was provided to 15 nurses. Of these, 10 nurses (66.7%) returned the form with their ratings. The

median values for usefulness (4.5), ease of use (4), and acceptability (4) support strong tool utility (Table 2). The ENCT was refined based on feedback, and additional testing is ongoing.

Discussion

In this study, the initial ENCT was developed and then submitted to 15 nurses who rated the tool as having clinical utility and feasibility for the care of patients with epilepsy. Because one-third of the surveys were not returned, the robustness of the rating is limited. The ENCT will next be expanded to include best practices. Further refinement will improve the ENCT, which could provide a useful tool for nurses to help improve patient-provider communication and support quality improvement efforts.

Epilepsy-specific tools are available to assess seizure risk and management strategies, identify comorbid depression or anxiety, and capture patient-reported quality of life¹⁸ or changes in quality of life,¹⁹ but none to date have been developed specifically to improve the communication interface between nurses and their patients with epilepsy. By prompting and capturing topics of concern to patients, nurses may directly provide instruction, education, and referrals, as well as identify areas in need of further attention. Recommendations for effective communication with patients include providing straightforward, specific, and repetitive information; using open-ended questions; paraphrasing responses to confirm patient understanding; addressing vital topics first; and providing written instructions.⁴

Recommendations from the American Academy of Neurology to improve the quality of care for patients with epilepsy cover 8 overarching topics, including assessing seizure type and frequency, reviewing results of imaging tests, providing counsel on antiepileptic drug side effects and safety issues, and how treatment may affect women with respect to childbearing.⁶ Although these quality indicators are important, they do not fully address other essential areas of patient care such as the discussion of how life is affected by epilepsy. Furthermore, the quality indicators do not holistically reflect quality care because they are more physician oriented. Finally, quality of care is often suboptimal when measured against a variety of care processes, which may indicate that additional quality measures are needed that may involve care delivery from allied health professions.²⁰ In the case of epilepsy, nurses are essential to improving the quality of care by engaging patients in more detail on the topics of greatest concern, including antiepileptic drug side effects and epilepsy-related safety issues such as supporting development of a clear seizure management plan for unforeseen events.

TABLE 1. Final ENCT: Every Interaction Begins With Patients Identifying Main Problems

| Patient-centered Questions | Problem-specific Cues |
|---|---|
| Seizures | |
| Tell me about your seizures since your last visit. | Frequency Severity Impact |
| Describe your seizure. | Postictal effect in 24 h Did somebody see it—who? Do you fall? Can you understand what people are saying? Do you remember your seizure? Do you lose sense of time? |
| Talk about how you felt right before and right after your last seizure. | Are there stomach changes (rising, etc)? Characteristics (changes) included are... |
| Talk about how seizures affect you. | Forgetful, dizzy, tired? |
| Tell me about things that you think might cause your seizures. | Triggers: sleep deprivation, alcohol, missed medications, urinary tract infection or other infections, high stress, other drugs, menses. |
| Tell me about when they occur (time of day). | |
| Talk about how long it takes you to recover. | |
| Tell me about time you may have injured yourself. | Is there blood, change in vision, incontinence, laughing, chewing, jerking, or stiffness? |
| Talk about fears, worries, or concerns. | Do you experience pain, anxiety, fear, frustration, exhaustion, or crying? |
| Talk about any changes in seizures or seizure patterns. | |
| Are there behaviors that may cause your loved one or significant other any concerns? | Behavior cues: agitation, prolonged somnolence |
| Do all of your seizures look the same? | |
| Do you have concerns about pregnancy and your epilepsy? | |
| Talk about what you do if you have a different or prolonged seizure or more than 3 seizures in a day? | |
| Medications | |
| What medications are you taking? | Consider asking about: Timeline |
| What medications are you taking that are not for your seizures, including supplements? | What time of day do you take the medications? |
| Do you take any other medications or supplements to help control your seizures? | Do you take them with food? |
| Tell me what you know about your medications, and also tell me what you would like to know. | |
| Do you ever miss your medications? | Issues with compliance Paying for medications Getting medications Remembering to take medications Concern or drug interactions |
| And if so, why? | |
| Talk about any problems you have had with your medications. | How do you tell them apart? Do you wish you had a wallet-sized card to remember what you are taking? |

(continues)

TABLE 1. Final ENCT: Every Interaction Begins With Patients Identifying Main Problems, Continued

| Patient-centered Questions | Problem-specific Cues |
|---|--|
| Talk about how you obtain your seizure medications (mail, drug store). | Do you get a 3-mo supply or month-to-month? Does it come to your home, or do you have to pick them up locally? |
| Talk about how you remember to take your medications. | What types of systems do you have in place to help you remember to take your medications? |
| Talk about what you would do if you forgot your medication? | |
| Do you have a plan? | |
| Side effects | |
| Talk about any medication side effects that you are experiencing. | Consider asking about: Description |
| Talk about how you manage medication side effects to keep them from interfering with your daily life. | Frequency |
| Talk about side effects that you can live with, those that you cannot live with, and the side effects that are deal breakers. | Timeline |
| | Impact |
| | Effect on their compliance |
| Normal daily activities | |
| Talk about how your seizures are affecting your daily life. | Consider asking about: School or work |
| Tell me about how you spend a typical day. | Transportation |
| Tell me about how you feel after having a seizure. | Fulfilling responsibilities |
| Do you feel that your family, friends, or significant others are able to manage your seizures? | Quality of life |
| Do you have a plan for a seizure event at work, at school, or in public? | Relationships |
| Do you have a plan for a seizure event or seizures if they are unusual or more frequent? | |
| Do you have to get help to get to your appointment? | |
| Do your seizures interfere with any of your activities or your relationships? | |
| Talk about the people in your life and how they make you feel safe when you have a seizure. | |
| Tell me about a time when you had to change your activities because of seizures. | |
| Describe what you would consider to be a good day of epilepsy management. | |
| If you had a glimpse into your life in 6 mo, what would you really like to be doing? | |
| What are the baby steps that would make that a reality? | |

Abbreviation: ENCT, Epilepsy Nursing Communication Tool.

TABLE 2. Ease-of-Use Survey Statements and Median Scores for the ENCT^a (N = 10 Nurses Providing Responses)

| Category Survey Statement (n = 10 for each statement) | Median Score (Q1, Q3) |
|---|-----------------------|
| Usefulness (n = 50) | 4.5 (4, 5) |
| I believe the ENCT will assist me in clearly communicating with my patients | 4.5 (4, 5) |
| I believe the ENCT will work well for me | 4 (3, 5) |
| I believe the ENCT addresses issues important to my patients | 5 (5, 5) |
| I believe the ENCT will help me identify issues important to my patients | 5 (4, 5) |
| I believe the ENCT will help my patients get the resources they need to be better at self-managing their epilepsy | 4 (3, 4) |
| Ease of use (n = 30) | 4 (3, 5) |
| The ENCT appears easy to use | 4 (4, 5) |
| ENCT appears convenient to use | 4 (3, 4) |
| I would like to use the ENCT in communicating with my patients | 4 (3, 5) |
| Acceptability (n = 30) | 4 (4, 5) |
| I like the ENCT | 4 (4, 5) |
| I like the way content is presented to me in the ENCT | 4 (3, 5) |
| I would enjoy using the ENCT | 4 (3, 5) |

Abbreviation: ENCT, Epilepsy Nursing Communication Tool.

^aScore options were 1, strongly disagree; 2, disagree; 3, unsure; 4, agree; and 5, strongly agree.

Conclusion and Nursing Implications

The goal of the ENCT is to help nurses, particularly those without epilepsy-specific training, have more thorough and constructive conversations with their patients with epilepsy. Patients require epilepsy-related information regarding the impact of the disease on comorbid conditions, short- and long-term side effects of antiepileptic drug treatments, repeated discussions on topics due to memory issues, referral to social services, and honesty regarding the challenges of finding optimal treatment combinations for their individual disease.²⁰ The ENCT is designed to facilitate these discussions. By providing a format that encourages patients to discuss issues that are not routinely covered, this tool may assist nurses in capturing and addressing a range of patient needs and enhance patient-provider communication and decision-making. Further refinement of the tool is ongoing, with the goal of improving the quality of interactions between patients with epilepsy and their providers to ensure optimal management of epilepsy.

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References

1. Bautista RED. Understanding the self-management skills of persons with epilepsy. *Epilepsy Behav.* 2017;69:7–11.
2. Miller WR, Bakas T, Buelow JM. Problems, needs, and useful strategies in older adults self-managing epilepsy: implications for patient education and future intervention programs. *Epilepsy Behav.* 2014;31:25–30.
3. Bellon M, Pfeiffer W, Maurici V. Choice and control: how involved are people with epilepsy and their families in the management of their epilepsy? Results from an Australian survey in the disability sector. *Epilepsy Behav.* 2014;37:227–232.
4. Beverly EA, Worley MF, Court AB, Prokopakis KE, Ivanov NN. Patient-physician communication and diabetes self-care. *J Clin Outcomes Manag.* 2016;23(11):509–518.
5. Groenewegen A, Tofighy A, Ryvlin P, Steinhoff BJ, Dedeken P. Measures for improving treatment outcomes for patients with epilepsy—results from a large multinational patient-physician survey. *Epilepsy Behav.* 2014;34:58–67.
6. Fountain NB, Van Ness PC, Swain-Eng R, Tonn S, Bever CT Jr, and for the American Academy of Neurology Epilepsy Measure Development Panel and the American Medical Association–Convened Physician Consortium for Performance Improvement Independent Measure Development Process. Quality of improvement in neurology: AAN epilepsy quality measures: report of the Quality Measurement and Reporting Subcommittee of the American Academy of Neurology. *Neurology.* 2011;76(1):94–99.
7. Rees S, Williams A. Promoting and supporting self-management for adults living in the community with physical chronic illness: a systematic review of the effectiveness and meaningfulness of the patient-practitioner encounter. *JBI Libr Syst Rev.* 2009;7(13):492–582.

8. Risdale L, McCrone P, Morgan M, Goldstein L, Seed P, Noble A. Can an epilepsy nurse specialist-led self-management intervention reduce attendance at emergency departments and promote well-being for people with severe epilepsy? A non-randomised trial with a nested qualitative phase. *Health Serv Deliv Res*. 2013;1(9).
9. Smith G, Wagner JL, Edwards JC. Epilepsy update, part 2: nursing care and evidence-based treatment. *Am J Nurs*. 2015; 115(6):34–44.
10. England MJ, Liverman CT, Schultz AM, Strawbridge LM. Epilepsy across the spectrum: promoting health and understanding. A summary of the Institute of Medicine report. *Epilepsy Behav*. 2012;25(2):266–276.
11. Ozuna J, Stecker M, Walter SM, Maytum J, Krause A. *Care of Adults and Children With Seizures and Epilepsy: A.A.N.N. Clinical Practice Guideline Series*. Chicago, IL: American Association of Neuroscience Nurses; 2016.
12. Bradley PM, Lindsay B, Fleeman N. Care delivery and self management strategies for adults with epilepsy. *Cochrane Database Syst Rev*. 2016;2:CD006244.
13. Hill CE, Thomas B, Sansalone K, et al. Improved availability and quality of care with epilepsy nurse practitioners. *Neurol Clin Pract*. 2017;7(2):109–117.
14. Health Quality Ontario. Specialized nursing practice for chronic disease management in the primary care setting: an evidence-based analysis. *Ont Health Technol Assess Ser*. 2013; 13(10):1–66.
15. Lynn MR. Determination and quantification of content validity. *Nurs Res*. 1986;35(6):382–385.
16. Hasson F, Keeney S, McKenna H. Research guidelines for the Delphi survey technique. *J Adv Nurs*. 2000;32(4): 1008–1015.
17. Bakas T, Champion V, Perkins SM, Farran CJ, Williams LS. Psychometric testing of the revised 15-item Bakas Caregiving Outcomes Scale. *Nurs Res*. 2006;55(5):346–355.
18. Jacoby A, Baker GA, Crossley J, Schachter S. Tools for assessing quality of life in epilepsy patients. *Expert Rev Neurother*. 2013;13(12):1355–1369.
19. Miller WR, Bakas T, Weaver MT, Buelow JM, Sabau D. The life changes in epilepsy scale: development and establishment of content and face validity. *Clin Nurse Spec*. 2015;29(2): 95–99.
20. Pugh MJ, Berlowitz DR, Montouris G, et al. What constitutes high quality of care for adults with epilepsy? *Neurology*. 2007; 69(21):2020–2027.