Standardized Screening for Depression in Pediatric Epilepsy

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ABSTRACT

Introduction: Depression is a common comorbidity of epilepsy that is under-recognized and under-diagnosed. To improve recognition, a brief screening tool, the Neurological Disorders Depression Inventory-Epilepsy-Youth (NDDI-E-Y) was implemented in a level-IV pediatric epilepsy clinic.

Method: This quality improvement is a pre-post design measuring the impact of standardized depression screening, via the NDDI-E-Y tool, in youth 12-17 years with epilepsy. Those with positive screens, scores > 32, received social work evaluation and mental health resources. Education was provided to all patients in standard discharge paperwork.

Results: Of N = 176 patients evaluated, n = 112 met criteria to complete the NDDI-E-Y. Fifteen percent (n = 17) of patients had positive screens, suggesting that they are at risk for depression.

Discussion: Depression is a challenge when managing patients with epilepsy and may impact their quality of life and seizure control. Routine depression screening is recommended and feasible in the outpatient setting with a standardized work process. J Pediatr Health Care. (2020) 34, 47–53

KEY WORDS

Epilepsy, depression, quality improvement, pediatric epilepsy

Epilepsy is a common neurological disorder of childhood, with the most recent prevalence estimated at 1% in the United States, and is associated with a number of comorbid conditions, including depression (Russ, Larson, & Halton, 2012; Zack & Kobau, 2017). Among adolescents with epilepsy, 10–30% have clinical depression (Caplan et al., 2005; Russ et al., 2012). Depression is also the most significant risk factor for suicide, with one study reporting 11.9% of epilepsy patients with depression endorsing suicidal ideation within the past 2 weeks (Hecimovic et al., 2012). A confounding factor in diagnosis is that many medication side effects may mimic symptoms of depression, specifically fatigue, sleep disturbance, and mood lability (Kanner et al., 2012). This underlines the need for population-specific tools when evaluating for depression.

Depression in this population is a complex issue that is affected by patients’ underlying neurologic disorder, social stigma associated with epilepsy, patient perception of seizures, seizure burden, as well as impact of anti-epileptic drugs on suicidal ideation and mood changes. Depression may negatively impact quality of life and contribute to poor seizure control (GUILFOYLE, Monahan, WESOLOWSKI, & MODI, 2015). Additionally, access to mental health services is challenging, contributing to only one third of those with symptoms receiving mental health treatment (Caplan et al., 2005). It is important to note that depression-associated symptoms and suicidal ideation may occur at any time during the disease course; therefore, patients should undergo routine screening, even if previous screenings were negative (GUILFOYLE et al., 2015). However, individuals with comorbid conditions that increase the risk of depression may benefit from more routine follow-up and evaluation (GUILFOYLE, Wagner, Smith, & MODI, 2012).
A negative perception of epilepsy and mental health by the patient and family have also been associated with an increased risk for depression as well as the patient’s willingness to obtain mental health services (Dunn, Austin, & Huster, 1999; Vona, Siddarth, Sankar, & Caplan, 2009). Providing families with routine education about mental health and available services may positively improve their attitude toward mental health (Vona et al., 2009).

Studies reviewed overwhelmingly demonstrate the need for appropriate depression screening in patients with epilepsy. However, there are a variety of tools available, making comparisons of data difficult. The Children’s Depression Inventory-2 (CDI-2) is considered the gold standard for pediatric depression screening. This 27-question tool requires a trained professional to administer and may be costly for some practices, typically costing between $1–$2 per administration (Kellermann et al., 2017; Wagner et al., 2016).

The Neurological Disorders Depression Inventory-Epilepsy (NDDI-E) has been shown to be effective in screening adult epilepsy patients for depression (Rampling et al., 2012). When compared with the Diagnostic and Statistical Manual of Mental Disorders, 4th edition, it demonstrated reliability in screening for depression (Rampling et al., 2012). Later, the Neurological Disorders Depression Inventory-Epilepsy for Youth (NDDI-E-Y) was created based on the NDDI-E, as well as validated pediatric measures, with the intention of developing an effective tool for use in the pediatric population (Wagner et al., 2016). The goal of the NDDI-E and NDDI-E-Y is to appropriately screen patients with epilepsy for depression, while minimizing symptoms that can be caused by medication side effects and interactions (Wagner, Smith, Ferguson, & Fedele, 2013). Early testing demonstrated a sensitivity of 0.8 and specificity of 0.71 (Wagner et al., 2013). When compared with the CDI-2, the NDDI-E-Y scores positively correlated to the CDI-2 scores ($r = .70, p < .001$), demonstrating that the NDDI-E-Y is a reliable alternative to the CDI-2 (Wagner et al., 2016). The NDDI-E-Y has also been compared with the Neuro-Quality of Life assessment, an 8-item scale used to assess quality of life, and the NDDI-E-Y was shown to be a stronger predictor of depression (Kellermann et al., 2017). The NDDI-E-Y is a validated 11-item tool that is completed by the patient, focuses on internalizing symptoms of depression, and minimizes focus on symptoms that may be related to use of anti-seizure medications, such as fatigue, and is available for free of charge (Wagner et al., 2016). Therefore, this tool is a reliable, brief, and free alternative for screening of depression in pediatric epilepsy.

Despite the known association of depression and epilepsy, as well as the impact on quality of life and suicide risk, the regular assessment for depressive symptoms may not routinely occur in the outpatient neurological clinical setting. Therefore, implementation of a standardized, population-specific, depression screening tool will improve screening for depression symptoms in patients presenting for routine epilepsy care in the neurology clinic. Validated, brief, depression screening tools exist, specifically the NDDI-E-Y, to assess symptoms of depression. Families that receive education on the importance of mental health and risk of depression have improved attitudes toward mental health. However, identification of a need and evidence-based guidelines are just the first steps in creating change. The transition of evidence-based guidelines into practice takes time and early support and defining a clear process of implementation is vital for its success. Identification of the problem and the acquisition of knowledge are key components to this transition (Mitchell, Fisher, Hastings, Silverman, & Wallen, 2010). This implies that all involved in the change must have a clear understanding of the need and rationale for the solution. Therefore, it is essential that clinics are identifying need and utilizing available resources to assess and provide appropriate referrals and education for youth with epilepsy.

**PROJECT AIM**

Because of the increased risk for depression in pediatric epilepsy and the lack of screening, the primary goal of the project was to implement the routine screening for depression in youth with epilepsy with the use of a standardized, validated, population-specific screening tool. Therefore, the project aimed to screen those children and teens 12–17 years of age with epilepsy that met screening criteria with the NDDI-E-Y when presenting for chronic care visits. Additionally, those with scores $≥ 32$ on the NDDI-E-Y, indicating a high likelihood of clinical depression, would receive mental health referrals through utilization of a full-time clinic social worker. Finally, all patients 12–17 years of age, regardless of their ability to complete the screening, and their families would receive standardized education, based on content from the Epilepsy Foundation website, on the risk of depression in youth with epilepsy at each visit (Vosburgh & Obsorne Shafer, 2018).

**PROJECT DESIGN**

This is a pre-post study measuring the percentage completion of standardized depression screening, via the NDDI-E-Y tool, in patients with epilepsy and aged 12–17 years, as compared with a pre-implementation rate of zero. These are reported as percentages of patients who completed the screening. Additionally, descriptive statistics are reported for the NDDI-E-Y scores. Questionnaire and NDDI-E-Y results were managed using the REDCap electronic secure data management system (Harris et al., 2009). No private health information was collected. This quality-improvement project has been formally evaluated using a quality-improvement checklist as well as reviewed by a hospital institutional review board and determined not to be human subject research.

Additionally, providers, clinic nurses, and care assistants completed a post-implementation survey via a secure REDCap link to assess attitudes toward implementation and areas for improvement.
SAMPLE

Patients with a diagnosis of epilepsy aged 12–17 years, presenting for routine epilepsy care with their primary epilepsy provider, were evaluated for screening. To complete the screening, patients must have a current diagnosis of epilepsy; therefore, new patients were screened at the direction of the physician or nurse practitioner. Epilepsy was defined according to the standard International League Against Epilepsy definition including generalized, focal, and intractable epilepsies. Patients were English speaking/reading without severe cognitive disability, which for the purpose of implementation was defined as being able to read at a 5th-grade reading level. Children without an individualized education program (IEP) were assumed to be reading at grade level. Parents of children with an IEP were asked for a reading level based on the most recent IEP meeting, as reading level is often included in an IEP. Patients lived in rural, suburban, and urban environments and were referred from several states in the Midwest.

IMPLEMENTATION PLAN

Staff buy-in and preparation is vital to the success of a new process (Greenhalgh et al., 2008). After identification of the need for depression screening, interviews with key stakeholders, specifically clinic nurses, social workers, and providers were completed to identify primary concerns. Key stakeholders also all needed to have an equal understanding of the problem and mastery of the available literature. This was accomplished with the use of educational sessions for stakeholders. Additionally, a champion was identified to support staff and assist in ongoing implementation.

Interviews with key stakeholders and an end-user demonstrated that the primary concerns with implementation included time, resources, and interpretation of testing results. Addressing these concerns during staff education and in the project design improves organizational change and staff readiness for change.

During interviews, clinic nurses had concerns about the time screening would take and impact on clinic flow. The NDDI-E-Y is to be independently completed by the patient, allowing the nurse to complete additional clinic tasks, thereby reducing impact on the clinic nurse flow. The survey requires additional time from the provider to analyze scoring; however, the majority of the additional time spent falls with the clinic social worker who would provide additional resources and discussion with the patient and families. Overall, it was anticipated that there would be an additional time need for clinic space and the social worker, but no significant time change for the rest of the clinic staff, thus alleviating some of this concern. Since there was no significant time burden or alteration in clinic flow anticipated, no changes were made to provider schedules prior to or during implementation.

The primary concern of providers was the availability of psychological and psychiatric resources as well as response to any patient who may be actively suicidal. Wait lists of 4–6 months are not uncommon for mental health services and patient insurance coverage may provide additional concern regarding service accessibility. However, a clear concern is demonstrated in the literature regarding depression in youth with epilepsy; therefore, it is vital that it is addressed. Resources of local psychological and psychiatric services, from a variety of insurance payors, were kept readily available in the clinic. These were compiled from online sources as well as current social work resources. Additionally, the clinic is located within a hospital with an emergency department for any child with active suicidal ideation or current risk to self/others. Hospital policy also clearly outlines clinic staff response for any patient who is actively suicidal, activating a one-to-one staffing and social work response which follows a clear plan for identification of admission and safety plan.

Finally, stakeholders had concerns regarding who would be responsible for interpretation of results and discussion of results with family. The NDDI-E-Y does not require specialized training for interpretation. However, to alleviate time burden on nursing staff and to improve discussion regarding results, providers were identified as the responsible party for the interpretation and discussion of testing results with the patient and their family. For those with positive test results, this discussion was also supported by the clinic social worker. The clinic has one licensed clinical social worker; therefore, additional licensed clinical social workers that support the hospital were identified as support resources in the event the clinic social worker is unavailable.

Based on the concerns outlined, as well as the need for screening, a standardized implementation workflow was created (Figure 1). Patients were identified for the day, based on age, prior to start of the clinic. Epilepsy diagnosis was identified based on the provider-created diagnosis list in the computerized medical record. Once a patient arrived at the clinic, nursing staff completed a short electronic questionnaire on an iPad, or on a clinic computer if an iPad was unavailable. The purpose of this questionnaire was to ensure that all appropriate patients were screened. Patient’s age category (12–14 or 15–17) was collected as well as confirmation that the patient was English speaking, could read at a 5th-grade level, and had a diagnosis of epilepsy. After completion of the questionnaire, the NDDI-E-Y screening was activated based on questionnaire response. The nursing staff then passed the NDDI-E-Y screening onto the patient for independent completion. Once the patient had completed all questions the survey prompted return of the iPad to the nursing staff. The nursing staff then submitted the survey for scoring. Scoring was completed automatically via REDCap, based on the scoring instructions for the NDDI-E-Y as updated in an erratum, ranging from 1 (never) to 4 (always; Wagner et al., 2016). Nursing staff would then be prompted, based on the score, regarding the next steps.

For those with positive scores, defined as ≥ 32, nursing updated provider and called clinic social work to provide resources and counseling. For those with scores < 32,
nursing staff notified the provider of completion of the NDDI-E-Y and the score. The provider would then complete their clinic visit. At the completion of the visit, all patients were provided with standardized education on clinic discharge paperwork, which included information about the risk of depression, symptoms, as well as a social work number to call with any concerns.

Building the innovation into the existing workflow improves the effectiveness of the intervention. Providing ongoing feedback to the team can also improve the effectiveness (Marchionni, & Ritchie, 2008). A registered nurse champion provided ongoing feedback to nursing peers while an advance practice registered nurse provided feedback to the provider team on a weekly basis.

FIGURE 1. Clinic flow for NDDI-E-Y implementation.

(This figure appears in color online at www.jpedhc.org.)
RESULTS

Over an 8-week implementation period, \( N = 176 \) patients were evaluated and \( n = 112 \) met the criteria for completion of the NDDI-E-Y. 59.7% (\( n = 105 \)) of patients evaluated were male and 62.5% (\( n = 110 \)) were 12−14 years of age (Table 1). All qualified patients (\( n = 112 \)) completed screening (100%). The most common reason patients were unable to complete the NDDI-E-Y was cognitive limitations (30.2%, \( n = 52 \)). An additional 2.8% (\( n = 5 \)) of patients were excluded because of being non-English speaking.

A positive screen was identified in 15% (\( n = 17 \)) of patients, defined as scores ≥ 32, suggesting that these patients had a high likelihood of having a diagnosis of depression. All 17 patients with a positive screen were evaluated by social work and, if needed, received mental health referrals. However, an additional two patients were referred to social work because of concern by the provider, despite scores below 32 (one score was 29 and the other 31). Of those with scores ≥ 32, \( n = 10 \) had already established care with a mental health provider while \( n = 7 \) were provided with referrals.

Evaluation of the NDDI-E-Y demonstrated that 14.3% of respondents reported that they always or often felt sorry about things and 43.8% reported that they sometimes feel frustrated (Figure 2). Overall, 10.7% reported that they sometimes think about dying or killing themselves. During implementation, no patients were actively suicidal.

All patients, 12−17 years of age and seen in the epilepsy center during implementation (100% [\( n = 176 \)]), received standard depression education that was provided as a part of the standard clinic discharge process.

Staff surveys were sent out intermittently during implementation and 13 surveys were completed. These were brief 4-question surveys including an opportunity to leave comments that focused on perceived benefit, implementation process, as well as impact on clinic flow. Survey respondents were a mix of nurses (\( n = 5 \), 38.5%), care assistant (\( n = 1 \), 7.7%), nurse practitioners (\( n = 5 \), 38.5%), and physicians (\( n = 2 \), 15.4%). Staff overwhelmingly agreed that depression screening, while potentially time consuming, was beneficial to patient care (Table 2). Comments included “great project, so needed right now,” “the NDDI-E-Y should be given to the patient as soon as vitals are done,” and “this tool even without positive screens has encouraged much needed conversation between the patients and myself.” Data regarding patient time in clinic pre- and post-implementation or time for NDDI-E-Y completion was not collected.

DISCUSSION

Implementation of the NDDI-E-Y demonstrated that 15% of our population would likely qualify for a diagnosis of depression, which is consistent with previously reported statistics (Russ et al., 2012). Of those identified, 66% (\( n = 10 \)) had already established care with a mental health provider, which may suggest that the NDDI-E-Y positively correlates with a clinical diagnosis of depression. However, the number of children identified by the tool who were already established with mental health services (\( n = 10 \)) may suggest that

<table>
<thead>
<tr>
<th>TABLE 1. Demographic breakdown of sample</th>
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<tr>
<td>Demographic Characteristics</td>
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<tr>
<td>Gender</td>
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<td>Age</td>
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<tr>
<td>Cognition</td>
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![FIGURE 2. Percentage reporting always or often and sometimes to each NDDI-E-Y item.](image-url)
this tool identifies children with more severe symptoms and may not appropriately identify patients with mild symptoms, who may also benefit from counseling services. In one instance the provider remarked “that should have been a positive screen” on a patient who scored 29. Alternatively, this may reflect an increased awareness and self-reporting of symptoms in those already receiving therapies. Consideration should be given to further evaluation of the cutoff for positive scores, which may allow for a higher false positive rate, but may also improve screening for those at risk of depressive symptoms.

Standardization of the implementation process as well as staff buy-in to the importance of the intervention assisted in achieving a 100% compliance rate with the process. All children 12–17 years of age completed a questionnaire upon arrival to the clinic, which helped in the identification of patients who were able to complete the NDDI-E-Y. This was done electronically and triggered the NDDI-E-Y automatically for those that qualified, reducing burden on staff to complete a chart review or other assessment to determine appropriateness of the tool.

Staff commented that the survey sparked positive conversations between families and staff about risk for depression. Additionally, nursing staff adopted a strategy to assist in identification of patients on their daily clinic list, drawing a sad face next to the appointment time to help highlight those in need of screening.

Utilization of the REDCap system, which eliminated the need for paper scoring sheets and automatically scored the NDDI-E-Y, also reduced time burden on nursing staff. Having this system available on the clinic iPads as well as the desktop computers ensured that it was always accessible. Downtime papers and scoring sheets were available but were not needed during this implementation time. In the future, with approval from an institutional review board, this system could be merged with the medical record to further streamline documentation, social work consults, and referrals for mental health services.

A significant challenge of assessing this population for depression is the rate of cognitive disabilities in youth with epilepsy. Given that 30.2% of patients seen during implementation were excluded because of cognitive limitations, strong consideration should be given to the development and implementation of a tool that allows for assessment of those with cognitive disabilities.

### CONCLUSION

Depression is a common comorbidity of epilepsy and patients should be routinely assessed for symptoms throughout the course of the disease. Screening can be successfully implemented in the outpatient setting by using standardization in workflow and implementation of brief and validated tools. Depression negatively impacts quality of life and seizure control; therefore, routine screening and intervention are vital to patient management.

Findings from the current quality-improvement project suggest standardized depression screening is a necessary and feasible component of patient care in the epilepsy center. Considerations for future research may include further assessment into different presentations of depression in youth with epilepsy; impact on quality of life, seizure control, and risk factors associated with specific epilepsy subtypes as well as medications. Longitudinal evaluation of the rate of follow-up for mental health referrals provided as well as wait times to establish care may also improve the success of further interventions. Finally, given the proportion of patients who were unable to complete the survey because of cognitive limitations, evaluation into appropriate depression screening for these patients may be beneficial in assessment and evaluation in the future.

### REFERENCES


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**TABLE 2. Staff survey results**

<table>
<thead>
<tr>
<th>Question</th>
<th>Response</th>
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<tbody>
<tr>
<td>What do you think of the implementation process?</td>
<td>It’s great (n = 11, 84.6%)</td>
</tr>
<tr>
<td>Does the NDDI-E-Y impact clinic flow?</td>
<td>No (n = 11, 84.6%)</td>
</tr>
<tr>
<td>Is the NDDI-E-Y beneficial?</td>
<td>Yes (n = 12, 100%)</td>
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Note. NDDI-E-Y, Neurological Disorders Depression Inventory-Epilepsy for Youth.


