



# The EpiLing-Tool: A new tool to distinguish epileptic seizures from dissociative seizures in the first encounter between physician and patient

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## ABSTRACT

**Purpose:** Studies have shown that conversation analysis of doctor-patient-encounters can help with the distinction of accounts of epileptic seizures (ES) and dissociative seizures (DS). We were keen to make these linguistic insights available to clinicians.

**Methods:** We analyzed 80 doctor-patient-encounters with young seizure patients (aged 6.1 to 17.9 years, mean 13.9 years). The conversations followed a guideline highlighting the importance of open invitations for patients to talk.

Based on previous studies, we created the EpiLing-Tool: a scoring-table with two sets of eight items – either favoring a diagnosis of ES or DS. The items focus on how patients describe the seizures, on their attitude towards the seizures, seizure interruption strategies and the course of the conversation.

In two one-day-training sessions clinicians blinded to the medical diagnosis used the EpiLing-Tool on recordings of patient interviews. In one session 50 participants rated eleven recordings, in the other session 25 participants rated ten different recordings.

**Results:** A mean of 30.8 EpiLing-Tools (range 9 to 49) were completed for every recording. In the eight patients with DS, the correct diagnostic conclusion was documented in 206 of 237 ratings using the EpiLing-Tool (sensitivity 86.9 %). In the ES group, the correct diagnosis was identified in 364 of 409 ratings (sensitivity 89.0 %); the sensitivity of the tool did not differ between the five patients with focal ES (sensitivity 88.6 %), and the eight patients with generalized ES (sensitivity 89.2 %).

**Conclusions:** The EpiLing-Tool is a simple and promising scoring table that can help clinicians to recognize DS when they first take the history of children and adolescents with seizures.

## 1. Introduction

Dissociative seizures (DS), also known as functional or psychogenic non-epileptic seizures (PNES), can easily be mistaken for epileptic seizures (ES) [1,2]. The idea to use Conversation Analysis to distinguish DS from ES was initially generated in a collaboration between clinicians at the Bethel Epilepsy Center and researchers at the University of Bielefeld in 1999 [3]. At this point the approach was purely qualitative. Subsequently, the method was developed further in Bethel [4] and in the

United Kingdom [5–8]. This approach was then replicated in a number of countries but required labour-intensive analysis by CA trained linguists. Studies in Italy [9], China [10], France [11] and Russia [12] also confirmed that linguistic observations can help to distinguish between patients describing ES or DS by thorough analysis of transcripts and recordings of doctor-patient encounters.

This process of analysis requires a great deal of linguistic expertise and time. Therefore, we sought to find ways of making the method more readily accessible to doctors. Reuber was the first to propose the so

*Abbreviations:* CA, conversation analysis; DS, dissociative seizures; ES, epileptic seizure; PNES, psychogenic non-epileptic seizure; PPV, positive predictive value.

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called “Diagnostic Scoring Aid”, a table with seventeen criteria supporting either the diagnose of ES oder DS [13].

Jenkins et al. showed in 2016 that neurologists can learn to identify linguistic features during routine clinical interactions with adults after a one-day teaching intervention [14]. She proposed the use of a short questionnaire to support the diagnosis.

In a study by Beghi et al. four researchers without experience in the field underwent a one-day training based on the linguistic differences between self-reports of DS and ES. After training, seven recordings of linguistic interview were evaluated by the four researchers (SD, GH, GM, DP) blinded to the gold standard video-EEG diagnosis. By using a simple scoring table with five criteria both for ES and DS, two raters reached 100 % correct diagnosis: in the worst case, the error rate was 25 %.

Inspired by the catalog of criteria used by Reuber et al. [13] our working group identified those eight criteria that allow DS to be recognized with the highest sensitivity and specificity during the consultation with the doctor. We juxtaposed these criteria with eight criteria which we had found to be typical of communication with patients with ES in our data. We created a scoring table, the so-called EpiLing-Tool (Table 1), which formulates the criteria so concisely that they fit on a single page (see supplement for the German Version of the EpiLing-Tool). This study was conducted to evaluate the diagnostic accuracy of this scoring tool.

## 2. Methods

### 2.1. Development of the Epiling-Tool

From 2013 to 2022 we recorded 80 doctor-patient encounters with young patients (aged 6.1 to 17.9 years, mean 13.9 years) who presented

**Table 1**  
The EpiLing-Tool. Items on the left side suggest ES, items on the right suggest DS.

EpiLing-Tool	
<b>Seizure description</b>	
1. The subjective seizure experiences are presented as relevant	Holistic statements and denials (“I’m gone”, “I can’t remember anything”) are used in relation to the course of the seizure
2. Symptoms are integrated in a sequential account of seizure experiences	Range of symptoms without clear placement in a seizure sequence
3. Formulation effort; struggle to communicate a comprehensible account of the course of the seizure, if necessary, through the use of gestures	Incoherent statements; blurring strategies: symptoms named initially are relativized to the point of retraction; focusing resistance
4. Beginning and end of gaps in consciousness are marked linguistically; gaps in recollection may be reconstructed using witness accounts	Being “completely out” is repeatedly stressed; Environmental details do not contribute to understanding of the seizure experience
5. Typical epileptic seizure symptoms such as open eyes, short duration, lateral tongue bite, postictal impairment.	Typical dissociative seizure symptoms such as closed eyes, long duration, undulating course, symptoms not consistent with epileptic seizures or other pathophysiologically mediated disorders such as syncope
<b>Display of attitude towards seizures</b>	
6. Confident, relatively unimpaired (“I’m in control.”)	Helplessly at the mercy of the seizure, seizures represent a heavy burden (“This could happen at any time”)
<b>Seizure interruption strategies</b>	
7. Openness to the topic, may actively bring it up	Topic not discussed or negated
<b>Course of conversation</b>	
8. A clear picture of the course of the seizure emerges	Generates increasing irritation on the part of the physician. No clear picture of the course of the seizure emerges
<b>Sum of ticked items favoring epileptic seizures: ____</b>	<b>Sum of ticked items favoring dissociative seizures: ____</b>

at our hospital for a diagnostic workup of paroxysmal events. The conversations followed a standardized guideline (see 2.2.).

17 recordings were excluded because patients were ultimately found to have neither ES nor DS, and 4 were excluded because no diagnosis could be confirmed. Two patients with both ES and DS were also excluded. 57 recordings were included: 36 Patients with ES vs. 21 patients with DS.

A group of linguists analyzed the audio or video recordings and verbatim transcriptions. The linguistic analysis followed a standard three-step method (sequential conversation analysis, feature elicitation and quantitative evaluation of the features).

As a starting point, we applied the Diagnostic Scoring Aid published by Reuber et al. in 2009 [13] and the questionnaire published by Jenkins (2016) [14] to our recordings. Of the given criteria, we concentrated on those that emerged as most discriminatory when a pilot version of the EpiLing Tool was used in the context of a one-day-training with clinicians in 2016 [14] (please see [supplement for details](#)). During the analysis, we developed different wordings for each criterion. These wordings were discussed with linguists as well as neurologists and subsequently revised for accuracy, clarity, and brevity.

Our analyses confirmed that most conversational profile characteristics typically associated with diagnoses of ES or DS described previously [13] could also be identified in conversations with our young seizure patients. The main differences lie in the fact that children and adolescents are still in the process of developing narrative routines and broadening their vocabulary. These challenges are particularly evident in those young people who have only experienced very few seizures when they present for an initial diagnosis. This explains why adolescents may not show all of the differentiating characteristics evident in the more extensive narratives or descriptions which adults tend to provide.

Plug et al. had shown that seizure metaphors differ in patients’ accounts of ES and DS [15]. We found that the use of metaphors is more likely in adults, which is why we have not included the items “metaphoric seizure description” and “external/internal conceptualization of seizures” which were of diagnostic value in adults in our scoring table. A recent study showed that the use of metaphors cannot distinguish between ES and DS [16].

On the other hand, some of the characteristics are particularly striking in the histories provided by young patients: holistic statements about seizure events (item 1 (DS), see Table 1) and the blurring of previously mentioned seizure elements (item 3 (DS)). These two features require a brief explanation:

Item 1 (DS): Young patients with DS very often give extremely brief, semantically empty, and evasive answers to questions about the seizure event. Such holistic statements are frequently used with negations, for example: “I don’t notice anything,” “I’m just not there,” “I know nothing.”

Item 3 (DS): We use the term “blurring” for response sequences in which descriptions of seizure perceptions that have already been mentioned are blurred immediately afterward. This happens through repeated self-interruptions, restatements, and chains of reformulations, whereby the original statement becomes increasingly vague and indistinct in terms of content, but also syntactically and phonetically, until its meaning is completely lost. These blurring sequences often result in longer pauses and a change of topic.

Both items contribute significantly to the irritation and confusion that the physicians may experience when they hear such accounts. Therefore, we added it as a new criterion (item 8 (DS) Table 1).

We added a criterion in which the symptoms described by the patient were to be rated from a medical point of view (item 5 in Table 1). The symptoms listed are typical for both young and adult patients [17].

We ended up with the so-called EpiLing-Tool, a scoring table with 8 items each favouring ES or DS (see Table 1). Items 1, 3, 4 and 5 are not dichotomous. Participants can therefore mark no item, one item or both

items in a row as applicable.

### 2.2. Interview guidelines

To enable the patient to display the interactional and linguistic markers that help to differentiate between ES and DS it is necessary, that the doctor uses a nondirective conversational approach [18]. For this reason we provided users with brief interview guidelines:

- a) Begin the conversation with an open invitation to talk without specifying the topic or mentioning seizures. Openings could be: “What is going on?“, “What’s up?“ or “How can we help?“.
- b) Only questions that do not provide new thematic impulses are allowed by the interviewer.
- c) The interviewer should only mention symptoms or descriptions of seizures if the child or adolescent has used them before, for example to show interest and encourage descriptions. Child: “I feel dizzy sometimes.“ Interviewer: “Can you describe what you mean by dizzy?“
- d) Ask about the first, last, and worst seizure to encourage more talk about seizure experiences after the initial open phase of the interview has ended.

### 2.3. Evaluation process

For the evaluation of the EpiLing-Tool, we selected recordings of interviews with 21 patients with a confirmed diagnosis (Table 2). Eight patients had DS. According to the criteria published by LaFrance [19] two had possible DS, four had clinically established DS and two had documented DS.

In February and September 2022, we held two online workshops with a total of 75 participants. All participants were given the opportunity to familiarize themselves in advance with the comprehensive manual for using the EpiLing-Tool. In the workshop we first explained the EpiLing-Tool and then presented the aforementioned recordings of patients with ES and DS in random order. For each recording we asked the participants to use the EpiLing-Tool. In the first workshop with 50 participants, we presented eleven recordings. In the second workshop (25 participants) we presented ten different recordings. Right after the scoring we explained the answers based on formal Conversation Analysis of the recordings and discussed the ratings. We wanted to make sure that the participants did not only learn which items to endorse, but also why these items represent specific communicative behaviors and how to recognize them in talk. After the workshop participants sent us their filled-out EpiLing-Tools.

**Table 2**  
Clinical data of patients who were included in the evaluation. ED: epileptiform discharges.

Patients	DS	ES	
		Focal	Generalized
No of pts.	8	5	8
Age	14;0 to 16;2	9;8 to 16;0	7;5 to 16;7
Sex m/f/d	0/8/0	1/4/0	7/1/0
Mental retardation	3	0	0
Psychiatric comorbidity	8	1	0
History of possible sexual assault	4	0	0
No of seizures (median)	2 to >100 (10)	5 to >100 (10)	1 to >100 (2)
EEG-recording: Normal/ED*)	8/0	0/5	2/6
Time between 1st seizure and encounter (median)	2wks to 3yrs (80d)	10month to 4yrs (1 yr)	1d to 10yrs (12d)
Time between last seizure and encounter (median)	0d to 3d (1d)	0d to 350d (3d)	0d to 4d (1,5d)

### 2.4. Statistical analysis

First, we examined the sensitivity and specificity of the eight items favouring DS and the eight items favouring ES. We assigned one point for each item that had been marked on the EpiLing-Tool. We defined the difference between the sum items ticked supporting a diagnosis of DS and the sum of items pointing to ES as the final score of the EpiLing-Tool. This final score ranges between -8 and 8. A difference  $\geq 1$  was attributed as DS; a difference  $\leq 1$  was attributed as ES; a difference of 0 was attributed as “inconclusive”. We calculated the sensitivity and specificity and positive predictive values of the final score with these attributions. We then checked whether other cut-offs lead to higher sensitivity or higher positive predictive values. As we included only patients with either ES or DS the positive predictive value of the EpiLing-Tool for ES equals the negative predictive value for DS and vice versa.

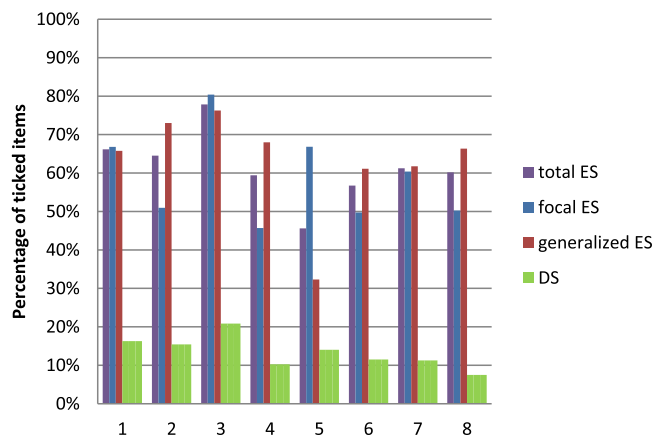
In order to investigate whether the distribution of the sum of the item ratings given by the raters differs from the distribution that would be expected if the items in both scales had been ticked randomly, we calculated the expected distribution and compared it with the observed distribution. The calculations are explained in the Supplement.

All calculations were carried out using EXCEL.

### 3. Results

A mean of 30.8 completed EpiLing-Tools per recording were submitted for analysis (range 9 to 49). A total of 646 EpiLing-Tools could be evaluated: 409 for the 13 patients with ES (132 for the five patients with focal ES, 277 for the eight patients with generalized ES) and 237 for the eight patients with DS. and 2 show the percentage of respondents ticking items 1 to 8. The sensitivity of the eight items associated with a diagnosis of ES ranged from 46 % to 78 %, the specificity from 79 % to 93 % (Fig. 1). The sensitivity of the eight items indicating a diagnosis of DS ranged from 45 % to 69 %, the specificity from 83 % to 96 % (Fig. 2).

When we compared the final scores with expert diagnoses based on all available clinical evidence, we found that the EpiLing-Tool ratings suggested the correct diagnosis in 364 of the 409 of the ES patents (89.0 %, 95 % confidence interval 85,8 - 91.8 %). The sensitivity of the tool was near identical for patients with focal ES (88.6 %) and generalized ES (89.2 %). In the eight patients with DS the sensitivity of the tool was 86.9 % (206/237 completed EpiLing-Tools, 95 % confidence interval 82.3 % - 90.9 %). The positive predictive value of the EpiLing-Tool for ES was 93.8 %, for DS it was 86.6 %, 27 of the 75 participants arrived at the correct diagnosis with every EpiLing-Tool they completed. 25 had one incorrect rating, 19 had two, two had three and two had four final scores



**Fig. 1.** Percentages of the 8 EpiLing-items favoring epileptic seizures (ES) ticked in patients with dissociative seizures (DS), focal ES, generalized ES, and in the total group of patients with focal or generalized seizures (total ES). Each of the 8 items of the EpiLing-Tool favoring ES was selected much more often in patients with ES compared to patients with DS.

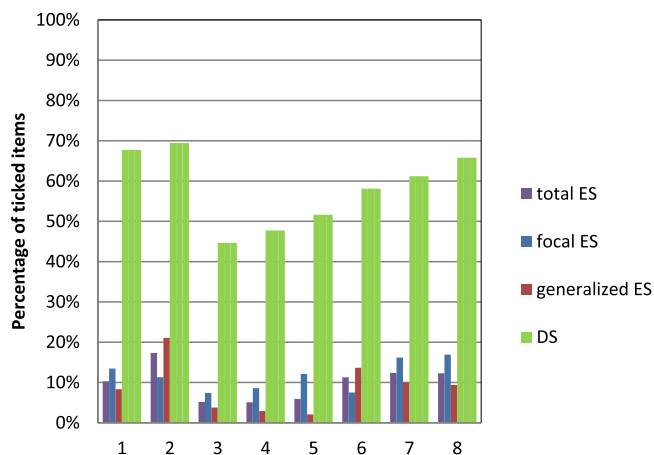


Fig. 2. Percentages of the 8 EpiLing-items favoring dissociative seizures (DS) ticked in patients with DS, focal epileptic seizures (focal ES), generalized epileptic seizures (generalized ES), and in the total group of patients with focal or generalized seizures (total ES). Each of the 8 items of the EpiLing-Tool favoring DS was ticked clearly more often in patients with DS compared to patients with ES.

not matching the best possible medical diagnosis.

Fig. 3 demonstrates that the observed distribution of the final scores of the EpiLing tool is clearly skewed to the left in ES patients and clearly skewed to the right in DS patients. This indicates a tendency for extreme final results, once raters assume that they correctly classified a seizure as ES or DS. However, there is also a slight bimodality in the observed distributions of final scores, which indicated a tendency towards (wrong) extreme final results when raters incorrectly classify a seizure as ES or DS. The supplement describes in detail which distributions would have been expected (under certain conditions) and how these expected distributions deviate from the observed distributions.

We initially only classified an EpiLing-Tool score of 0 as inconclusive. In a retrospective analysis, we then tested whether other cut-off values could increase the positive predictive value (PPV) of the questionnaire. We found that an increase in PPV is possible if, in addition, those EpiLing-Tools were rated as inconclusive for which the sum of criteria for both ES and DS was equal or greater than 2 (Table 3).

36 of the 75 participants stated the number of years they had been

Table 3 Sensitivity and PPV of the EpiLing-Tool with different attributions of the final score.

Criteria defining the inconclusive result of the EpiLing-Tool:	- Final score=0		- Final score = 0 - both the sums of criteria for ES and DS are $\geq 2$	
	ES	DS	ES	DS
<b>Clinical diagnosis</b>				
EpiLing-Tool rated as ES	364	24	357	9
EpiLing-Tool rated as DS	32	206	18	201
Inconclusive	13	7	34	27
Sensitivity for ES	89.0 %		87.3 %	
Sensitivity for DS		86.9 %		84.8 %
PPV for ES	93.8 %		97.5 %	
PPV for DS		86.6 %		91.8 %

working with seizure patients (0–35 years). The number of errors in the EpiLing-Tool showed no correlation with years of experience.

Our assumption that training is necessary to avoid misdiagnoses with the EpiLing-Tool was confirmed by the written feedback from participants. In particular, they articulated the need for further explanation concerning the different types of negations and for the meaning of "blurring". Accordingly, in our following workshops, we focused on these phrases and items and supported our explanations with additional audio material. Written information on the items can be found in the detailed manual for the EpiLing-Tool, which also provides many additional examples.

#### 4. Discussion

##### 4.1. Sensitivity of the EpiLing-Tool

Most previous studies that used linguistic criteria to distinguish ES from DS used an approach involving one or two experts in conversation analysis rating recordings and detailed transcripts. Only Jenkins et al. asked clinicians who participated in a one-day training to complete a rating tool immediately after they had spoken to adults presenting with seizures [14]. As they had not defined cutoff values in advance, they only state that, with a cutoff value that was optimized in retrospect, their

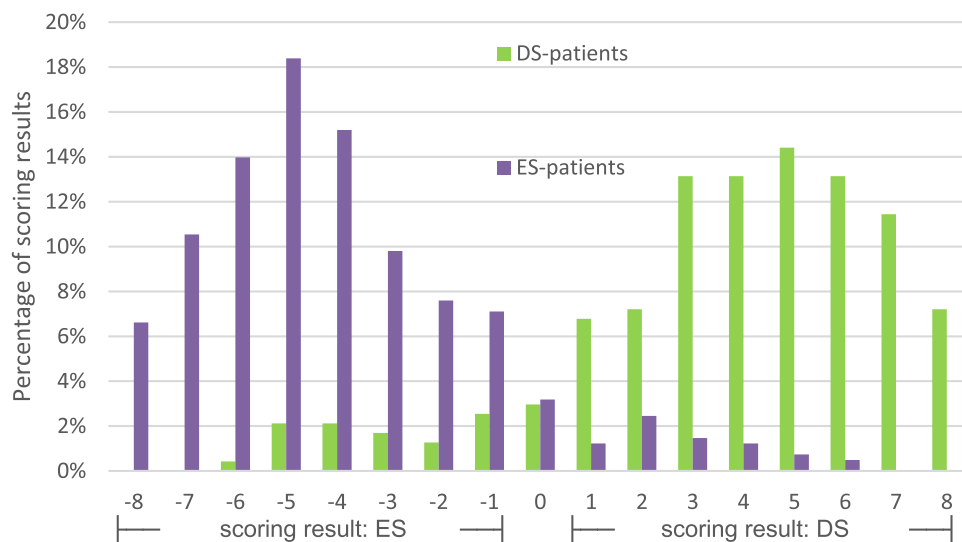


Fig. 3. Distributions of the final scores of the EpiLing-Tool calculated as difference between the sum of ticked items supporting a diagnosis of dissociative seizures (DS) and the sum of items pointing to epileptic seizures (ES). In the vast majority of cases, patients with DS can be differentiated by EpiLing-Tool from patients with ES (final score > 0, sensitivity 86.9 %, positive predictive 86.6 %).

scoring table would classify 81,8 % of the individuals correctly. The sensitivity of the scoring table we present is higher (86.9 % to 89.0 %).

One reason might be that the EpiLing-Tool is not only based on linguistic knowledge but also makes use of the medical knowledge of the participants, as we ask whether the patient mentioned any symptoms likely to point to diagnoses of ES or DS (item 5 in Table 1).

Another reason could be that we used the results of Jenkins [14] when we designed our scoring table. Thus, we started our work with criteria that had already proven to help participants in differentiating DS from ES.

Most of our patients had little routine in talking about their seizures: they were recruited in a secondary epilepsy center where they had typically been admitted because of an acute seizure. Most had a very brief history of seizures (median of 10 seizures in patients with DS, 10 seizures in patients with focal ES, and 2 seizures in patients with generalized ES). Some of our features may emerge more clearly in formulations generated “on the spot” rather than in practiced verbal expressions.

Our evaluation shows that the ratings tended to extreme final scores: regardless of whether the final diagnosis suggested by the EpiLing-Tool was correct or incorrect, high (positive or negative) sum scores were seen more frequently than expected if the items of the ES and DS scales were answered independently. We hypothesize that once participants had concluded that the patient had either ES or DS based on some items (or even without reference to the EpiLing-Tool), they tended to rate other items to fit with their initial diagnostic hypothesis. This may help to explain why doctors without previous linguistic training were able to achieve very high correct “hit rates” for linguistic items.

The trend towards high sum scores may also have been reinforced by the layout of the EpiLing-Tool: All items suggesting ES are in one column, contrasting with items suggesting DS in the other. A random arrangement of the items might have encouraged users to score different items more independently of each other. However, our arrangement makes it easier to understand the basic principle and how to use the tool.

With only females in our DS group, female sex had a high predictive value for DS (eight out of eight patients with DS were female versus five out of 13 patients with ES,  $p = 0.0063$ , exact Fisher test). We did not include this as a pointer in the EpiLing-Tool, because we wanted to focus on the linguistic observations in this study.

Our findings relate to observations made during naturally occurring interaction between clinicians and patients. Other means of data collection, for instance questionnaires, would be likely to yield different findings [20]. A recent paper examined subjective seizure symptom reporting in DS and ES using an open questioning followed by structured closed questioning using possible symptom prompts. They found that prompting generates more detailed ictal symptom profiles [21].

#### 4.2. Generalized ES vs focal ES

Most previous studies exploring the diagnostic value of conversation analysis were exclusively based on contrasts between patients with focal epileptic or dissociative seizures [11,12,14,22,23]. We expected the EpiLing-Tool to show poorer performance in the detection of generalized ES compared to focal seizures since the patients with generalized seizures typically lose consciousness without warning and may be able to describe fewer subjective seizure symptoms than those with focal epilepsies (items 1 (ES) and 2 (ES)). Additionally, the patients cannot rely on their memory for the experience of the seizure itself. Therefore, we expected items 1 (DS) and 4 (DS) to be rated false positive. We were therefore surprised that the EpiLing-Tool detects diagnoses of generalized ES just as readily as of focal ES. Here, it seems crucial to us that it is not the number of details and symptoms described by the patient that are assessed, but his or her formulation effort (item 3 (ES)).

#### 4.3. Young patients vs adult patients

The EpiLing-Tool was developed with knowledge that was gained from young patients and adult patients [24], but the evaluation was only carried out with recordings from encounters with children and adolescents. However, we believe that the EpiLing-Tool can be used in adult patients with similar levels of accuracy for the following reason: All criteria that proved to distinguish between ES and DS in Jenkins' work on a significant level [14] are also included in the EpiLing-Tool.

#### 4.4. Clinical use

The EpiLing-Tool can be directly applied in the first encounter and should help to raise clinicians' awareness of a possible diagnosis of DS. It is easy to administer after an introductory training, does not require any technical equipment and is therefore cost-effective. In case of doubt about the diagnosis of DS the standard diagnostic workup including video-monitoring is still necessary [25].

#### 4.5. Limitations

Items 1–3 of the EpiLing-Tool can only be evaluated if the doctor succeeds in getting the patient to speak freely without the clinician asking questions that specify topics. In our study 20 of the 21 interviews were conducted by the same doctor. He is not only a specialist in pediatric epileptology with 35 years of professional experience, but also an analytical psychotherapist. Conversations with less experienced doctors could weaken the diagnostic quality of the EpiLing-Tool.

The EpiLing-Tool is not self-explanatory: In our experience, the use of the EpiLing-Tool must be learned in a training session involving examples of real recordings. For professionals who are not used to read transcripts it is necessary to hear the recording.

The evaluation of the EpiLing-Tool took place in one day training sessions where the participants could concentrate fully on the records of the doctor patient encounters. In real life the physician is very much absorbed with the talking and the documentation. In view of this clinicians may be less able to watch out for the conversational behavior of the patient. Therefore, we evaluate the usefulness of the EpiLing-Tool in clinical practice in a multicenter study. Data collection takes place from December 2023 to December 2025.

We cannot tell how the EpiLing-Tool works in patients with both DS and ES as we excluded those patients. In theory, patients should show the typical DS features when reporting DS and the typical ES features when reporting ES. However, it may not be possible to differentiate between the two, as the patients themselves do not usually recognize clearly distinguishable seizure forms.

#### 4.6. Prospects

Recent research has shown that artificial intelligence can be used to distinguish between ES and DS with increasing accuracy [8,26]. The accuracy depends to a large extent on the quality of the criteria with which large learning models are trained. Our 16 items of proven discriminatory value may provide a good basis for the future use of AI in this clinical context. Conclusion

The EpiLing-Tool is a simple and promising scoring table designed to assist clinicians in recognizing diagnostic markers of ES and DS when they first take the history from children and adolescents with seizures.

Our study demonstrates that the tool achieves high sensitivity and specificity, aiding in accurate diagnosis when used by trained professionals. The tool's effectiveness is attributed to its integration of linguistic markers and medical insights, making it a valuable resource in clinical settings.

Our findings underscore the importance of allowing patients sufficient opportunity for free expression during consultations, which is critical for capturing the nuances that the EpiLing-Tool aims to

highlight. Overall, the EpiLing-Tool is offering clinicians an accessible method to improve diagnostic accuracy and patient outcomes.

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### Declaration of competing interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests:

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### Supplementary materials

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