

## Impact of epilepsy in adolescence: A UK controlled study

Gus A. Baker<sup>a,\*</sup>, Shiri Spector<sup>b</sup>, Yuko McGrath<sup>a</sup>, Helen Soteriou<sup>b</sup>

<sup>a</sup> *Department of Neurological Science, University of Liverpool, Walton Hospital, Liverpool, UK*

<sup>b</sup> *Psychotherapy Support Team, King's College Hospital, London, UK*

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### Abstract

**Purpose.** The goals of the work described here were to investigate the psychological and social impact of epilepsy on adolescents and to identify to what degree clinical and demographic variables and knowledge of epilepsy could influence psychosocial functioning.

**Methods.** Seventy adolescents with epilepsy were compared with healthy controls (matched for age, sex, and reading ability) on measures of self-esteem, social adjustment, depression, and obsession. Within the epilepsy group, the impact of seizure frequency, seizure severity, and knowledge of epilepsy on the above measures was also determined.

**Results.** Adolescents with epilepsy showed significantly higher levels of depression, anhedonia, and social anxiety and significantly higher numbers of obsessive symptoms than the adolescents without epilepsy. Among the adolescents with epilepsy, high seizure frequency was significantly associated with low self-esteem, and tonic-clonic seizures were specifically associated with higher levels of depression. Finally, low levels of epilepsy knowledge were significantly associated with higher levels of depression, lower levels of self-esteem, and higher levels of social anxiety.

**Conclusions.** Epilepsy has a significant psychosocial impact on adolescents at this difficult time of life. Social support and access to appropriate information about epilepsy could be of help.

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### 1. Introduction

Adolescence is a turbulent period of development marked by identity formation and self-definition [1], a period when individuals pay particular attention to peer norms and beliefs [2]. Adolescents engage in social activities and begin to prepare for employment, relationships, and driving [3,4]. These are all important aspects in the move toward achieving independence [5]. It is thus recognized as a crucial time for the acquisition of knowl-

edge and social skills that allow for natural integration into society [6].

The majority of individuals emerge from this transitional period with a positive self-image, a strong sense of self-identity, and an ability to interact positively with their friends, family, and society as a whole [6]. Epilepsy is the most common neurological disorder in adolescents, with a prevalence of 1.5–2% [2,7,8]. Its presence can impact on the formation of such independence through its social, educational, emotional, and behavioral consequences [5]. Recent studies have demonstrated that for the adolescent with epilepsy, this particular period may be difficult to negotiate [9–11]. This can be explained by the prohibitive impact that epilepsy can have on many aspects of the adolescent's life, including schoolwork, sports, employment, and driving [12].

\* Corresponding author. Present address: University Department of Neurosciences, Clinical Sciences Centre for Education and Research, Lower Lane, Fazakerley, Liverpool L9 7LJ, UK. Fax: +44 151 529 5503.

E-mail address: [g.baker@liv.ac.uk](mailto:g.baker@liv.ac.uk) (G.A. Baker).

A study investigating the relationship between stigma and self-esteem in adolescents [13] using a multivariate approach found that low self-esteem could be predicted by high seizure frequency and the belief that epilepsy was stigmatizing. Studies have shown that children with epilepsy have poorer perception of control, as well as lower self-esteem, than those without epilepsy [14]. Austin and Dunn [15] found that children with epilepsy were concerned about seizures, their effects, their timing, and what restrictions they would impose on their day-to-day activities. They also reported fear of seizures, concern about why they had them and whether they would be the subject of bullying or teasing, and guilt about the anxiety their parents experienced. These findings suggest that children with epilepsy may be at greater risk from anxiety and depression as a consequence of the fear of the reactions of others. A number of studies have identified individual predictors of adjustment to epilepsy in children and adolescents with the condition. These include being a boy [16], seizure control, polytherapy/monotherapy, and parental marital status [17], and seizure frequency [18].

Few studies, however, have examined whether the psychosocial problems associated with adolescents with epilepsy can be observed in adolescents without the condition to a similar or lesser degree. One study of adolescents with epilepsy (AWE) who were matched for age and sex with controls reported that the AWE group was more likely to report problems with transport and behavior in class, and had lower reading abilities, than the control group [19].

This study set out to examine whether the psychological difficulties observed in adolescents with epilepsy are unique or can be observed in populations without significant health problems and whether possessing knowledge of epilepsy is likely to ameliorate the effects of the condition on psychological functioning. The aims of this study were twofold: (1) to investigate psychological adjustment of adolescents with epilepsy in comparison to healthy control subjects (matched for age, sex, and reading ability); (2) to identify whether clinical and demographic variables and knowledge of epilepsy could influence psychological functioning in adolescents with epilepsy.

## 2. Methods

This study was a matched, controlled study. Adolescents aged between 12 and 18 with epilepsy were matched by age, sex, and reading ability (a surrogate for intellectual functioning) with adolescents who do not suffer from any physical or psychological health problems. Adolescents with epilepsy were recruited from two major epilepsy centers in the United Kingdom (London and Liverpool, where specialist adolescent epi-

lepsy clinics have been established). The control group was recruited from adolescents attending local schools selected at random. The headmaster or headmistress at each school was contacted by telephone, and this was followed by a face-to-face interview with the principal investigator to explain the nature of the study and obtain the necessary consent.

Demographic details, including information on age, gender, current status, and year at school, were collected. For adolescents with epilepsy, clinical details, including age at onset, age at the last attack, seizure types and seizure frequency during the past year, and details of their antiepileptic medication, were also collected.

### 2.1. Battery of well-validated questionnaires used for all adolescents

#### 2.1.1. The Rosenberg Self-Esteem Scale

This 10-item scale is used to measure levels of self-esteem [20]. The scoring for each item ranges from 1 to 4. Higher scores indicate higher levels of self-esteem of the respondent.

#### 2.1.2. The Social Avoidance and Distress Scale (SADS)

This 28-item scale is designed to measure the degree of social anxiety [21]. There are 14 true and 14 false items. The higher the number of questions on which the respondent answers false to false items and true to true items, the greater the degree of his or her social anxiety. The validity of the scale was also documented [21].

#### 2.1.3. The Birlson Depression Scale (BDS)

This 18-item scale is used to measure the degree of depressive feelings in children. Each item has three options to choose from; these are scored 2 (“most of the time”), 1 (“sometimes”), and 0 (“never”). A score greater than 17 indicates clinical depression. The validity of this scale has been reported [22].

#### 2.1.4. The Leyton Obsessional Inventory (LOI)—Child Version

This 20-item scale measures the degree of obsessive symptoms, and was adapted from the 44-item Leyton Obsessional Inventory—Child Version for this study. It has excellent reliability and validity [23].

#### 2.1.5. The Children's Depression Inventory (CDI)

This scale consists of 27 items designed to measure the level of depression in children [24]. Its five subscales measure categories of depression: negative mood, interpersonal problems, ineffectiveness, anhedonia, and negative self-esteem. For each item there are three statements, and the individual is asked to choose the statement that best describes her or his experience in the past 2 weeks. The score for each item ranges from

0 to 3. Scores greater than 65 indicate clinical depression.

### 2.1.6. The Schonell Reading Test

In this test, each individual is given a stimulus card with 100 words printed on it and asked to read aloud each word until he or she makes 10 consecutive mistakes [25]. The number of correct responses indicates his or her reading age. Reading ability has been significantly correlated with intellectual functioning.

## 2.2. Two additional questionnaires used for adolescents with epilepsy

### 2.2.1. The impact of epilepsy scale

This 10-item scale was developed to assess the impact of epilepsy and antiepileptic drug therapy on an individual's relationship with friends and family, social life, employment, health, self-esteem, plans for the future, and standard of living. It is scored on a Likert scoring system. Acceptable levels of reliability and validity of the scale have been reported elsewhere [26]. The wording has been amended to be appropriate for adolescent use.

### 2.2.2. Adolescents' Knowledge of Epilepsy Questionnaire (AKE)

This questionnaire consists of 51 questions about epilepsy, which are all based on knowledge rather than attitude. Questions 1 to 50 are answered by choosing one of the following options: true, false, and don't know. Question 51 asks for an estimation of prevalence by choosing one answer from a choice of five. Evidence of the scale's psychometric properties is still being constructed; however, initial results suggest that it has good evidence of reliability and validity [27].

## 2.3. Statistical methods

Data were analyzed with the SPSS for Windows Version 10.0.  $\chi^2$  tests and one-way ANOVAs were conducted for within-data analyses and *t* tests were carried out for between-group comparisons.

## 3. Results

Of the 305 adolescents with epilepsy who attended epilepsy clinics at the two centers, 126 were not considered suitable (learning difficulties, non-English-speaking, other severe medical and/or mental disabilities). Of the remaining 179, only 42% (75) agreed to participate. Participants were matched by age, sex, and reading age. Of the 75 adolescents, 5 could not be matched with any of the controls for reading age and, thus, were not included in the between-group analysis.

## 3.1. Demographic characteristics

The mean age of the adolescents with epilepsy and the control group was 15. Fifty percent of all adolescents were male. Eighty-nine percent of the adolescents with epilepsy were students, 9% were in paid employment, and 2% were unemployed; likewise, 91% of the controls were students and 9% were in paid employment. Thirty-one percent of the adolescents with epilepsy and 24% of the controls had a boyfriend or girlfriend. There were no significant differences between the groups with respect to any of the demographic features.

## 3.2. Clinical characteristics

The mean age at the onset of epilepsy was 9, and the mean age at which they had their last seizure episode was 14. Thirty-three percent experienced only tonic-clonic seizures, 29% had both tonic-clonic and other types of seizures, and the remaining 38% experienced only other types. During the preceding 12 months, 29% experienced no seizures, 36% had less than one seizure per month, and 35% had more than one seizure per month. Eighty-eight percent of adolescents with epilepsy were on antiepileptic drugs (AEDs), with 75% on monotherapy and 25% on polytherapy. Forty-five percent of the subjects who were on AED therapy were taking lamotrigine; 37% sodium valproate; 20% carbamazepine; 9% topiramate; 3% clobazam, phenytoin, gabapentin, or levetiracetam; and 2% ethosuximide or sabril. Sixty-one percent reported that their medications were controlling their seizures very well, 32% fairly well, and 7% not very well. Approximately half of the subjects (53%) reported that they never missed taking their medication, 32% missed their medication less often than once a month, 14% missed their medication more often than once a month but less often than once a week, and 1% missed their medication once a week or more.

## 3.3. Psychological measures

The mean scores of each scale were compared between the adolescents with epilepsy and the controls (see Table 1). There were significant differences in the mean scores for four scales, with adolescents with epilepsy reporting higher levels than adolescents without epilepsy for the CDI subscales Interpersonal Problems ( $P = 0.03$ ) and Anhedonia ( $P = 0.02$ ), the SADS ( $P = 0.04$ ), and the LOI "yes" (obsessional symptoms) responses ( $P = 0.03$ ).

A series of one-way ANOVA analyses and Tukey post hoc tests were conducted to examine the effects of seizure frequency and seizure severity and knowledge on psychological functioning (see Table 2). The self-esteem score was the only variable that was significantly influenced by seizure frequency, with those with

Table 1  
Mean scores on questionnaires for adolescents with epilepsy and controls

	Mean (95% confidence interval)		
	Adolescents with epilepsy	Controls	<i>P</i> value
CDI			
Total	48 (46–50)	46 (44–49)	0.07
Negative Mood Subscale	48 (46–51)	49 (46–51)	0.19
Interpersonal Problems	49 (47–51)	47 (45–49)	0.03 <sup>a</sup>
Ineffectiveness	48 (45–50)	47 (45–50)	0.18
Anhedonia	47 (45–49)	45 (43–47)	0.02 <sup>a</sup>
Negative Self-Esteem	48 (46–50)	49 (47–51)	0.06
BDS	9 (8–10)	8 (7–9)	0.07
Self-Esteem Scale	32 (30–33)	31 (30–32)	0.08
SADS	8 (7–9)	7 (5–8)	0.04 <sup>a</sup>
LOI	20 (17–23)	20 (16–22)	0.16
LOI number of “yes” responses	10 (8–11)	9 (8–10)	0.03 <sup>a</sup>
LOI interference	10 (8–12)	9 (8–10)	0.12

<sup>a</sup> Significant at  $P < 0.05$ .

frequent seizures more likely to report lower levels of self-esteem than those with no seizures. Similarly, only scores on the Anhedonia subscale of the CDI were influenced by seizure type. The level of anhedonia was significantly higher in those who had both tonic-clonic and other types of seizures than in those who had only seizures other than tonic-clonic ( $P < 0.01$ ).

The mean score on the AKE was 30 (range: 19–43), with 60% of the questions being answered correctly. To analyze the effects of knowledge on psychological functioning, scores on the AKE were divided into three groups, according to 33 and 66 percentiles of the scores. Therefore, scores between 19 and 27, 28 and 34, and 35 and 42 were classified as low, medium, and high, respec-

tively. The degree of depressive feeling was significantly higher in the low knowledge group, in comparison to the high knowledge group ( $P = 0.039$ ). Although the levels of self-esteem in the medium and high knowledge groups were not significantly different, the medium and high knowledge groups exhibited significantly higher levels of self-esteem than the low knowledge group ( $P = 0.026$  and  $P < 0.001$ ). The level of social anxiety was significantly lower for those who had high knowledge than those who had low knowledge ( $P = 0.039$ ).

Table 3  
Mean scores of each scale as a function of levels of knowledge on epilepsy

	Mean (95% confidence interval) level of knowledge on epilepsy		
	Low (95% CI)	Medium (95% CI)	High (95% CI)
CDI			
Total	49 (46–52)	49 (45–52)	46 (42–49)
Negative Mood	49 (46–52)	49 (45–53)	46 (42–50)
Interpersonal Problems	50 (47–53)	48 (44–51)	49 (46–53)
Ineffectiveness	50 (46–54)	46 (41–51)	48 (44–53)
Anhedonia	49 (45–52)	48 (44–52)	45 (42–48)
Negative Self-Esteem	49 (45–53)	47 (44–50)	47 (43–52)
BDS	10 <sup>a</sup> (8–12)	8 (6–10)	7 <sup>a</sup> (5–9)
Impact of epilepsy	17 (14–20)	16 (13–18)	14 (12–16)
Self-Esteem	29 <sup>b,c</sup> (27–31)	33 <sup>b</sup> (31–34)	35 <sup>c</sup> (33–37)
SADS	11 <sup>d,e</sup> (9–14)	7 <sup>d</sup> (5–9)	5 <sup>c</sup> (3–7)
LOI	21 (16–26)	19 (15–23)	17 (11–22)
LOI “yes” responses	10 (8–12)	10 (8–11)	10 (6–11)
LOI interference	11 (6–15)	10 (7–12)	7 (8–11)

<sup>a</sup>  $P = 0.039$ .

<sup>b</sup>  $P = 0.026$ .

<sup>c</sup>  $P = 0.000$ .

<sup>d</sup>  $P = 0.039$ .

<sup>e</sup>  $P = 0.000$ .

Table 2  
Mean scores of each measure as a function of seizure frequency and type

	Mean (95% confidence interval)					
	None	<One/month	>One/month	Tonic-clonic	Tonic-clonic + other	Other
CDI						
Total	46 (43–48)	49 (45–52)	49 (45–52)	48 (44–51)	46 (42–49)	49 (46–50)
Negative Mood	47 (44–50)	48 (45–52)	50 (46–54)	48 (44–53)	48 (45–51)	48 (45–52)
Interpersonal Problems	49 (46–52)	50 (46–53)	48 (45–52)	51 (47–54)	47 (44–50)	49 (46–52)
Ineffectiveness	44 (41–47)	51 (47–55)	48 (44–53)	51 (45–56)	46 (42–49)	48 (44–52)
Anhedonia	47 (44–50)	47 (44–51)	48 (45–51)	46 (43–48)	45 <sup>b</sup> (42–48)	51 <sup>c</sup> (47–54)
Negative Self-Esteem	45 (42–48)	49 (46–53)	49 (45–53)	47 (44–51)	46 (42–50)	50 (46–53)
BDS	8 (6–10)	9 (7–11)	9 (7–11)	8 (6–9)	8 (6–10)	10 (8–12)
Impact of Epilepsy	14 (10–17)	16 (14–19)	17 (15–19)	15 (13–18)	15 (12–18)	17 (14–20)
Knowledge of Epilepsy				31 (28–34)	30 (27–32)	31 (29–32)
Self-Esteem Scale	35 <sup>a</sup> (33–37)	30 <sup>a</sup> (28–33)	31 <sup>a</sup> (29–33)	33 (31–35)	33 (30–35)	31 (29–33)
SADS	8 (6–10)	9 (6–12)	8 (6–10)	8 (6–10)	7 (4–10)	9 (7–12)
LOI	20 (15–24)	19.26 (14–24)	18 (13–23)	20 (15–25)	18 (13–24)	19 (14–22)
LOI “yes” responses	10 (9–12)	9 (7–12)	9 (6–11)	10 (8–12)	9 (6–11)	9 (7–11)
LOI interference	9 (6–13)	8 (6–13)	9 (6–12)	10 (6–13)	9 (5–13)	10 (7–12)

<sup>a</sup> Significant at  $P < 0.05$ .

<sup>b</sup>  $P = 0.003$ .

<sup>c</sup>  $P = 0.01$ .

Also, those who had low knowledge demonstrated significantly higher levels of social anxiety, in comparison to those who had medium knowledge (see Table 3).

#### 4. Discussion

The aims of this study were twofold: (1) to investigate psychological adjustment of adolescents with epilepsy in comparison to healthy control subjects (matched for age, sex, and reading ability); (2) to identify whether clinical and demographic variables and knowledge of epilepsy could influence psychological functioning in adolescents with epilepsy.

Adolescents with epilepsy had significantly higher levels of depression relating to interpersonal problems and anhedonia, as measured by two of the five subscales of the CDI. This group also reported significantly higher levels of social anxiety, as measured by the SADS, and a significantly larger number of obsessive symptoms than the adolescents without epilepsy. The results also demonstrated that, among the adolescents with epilepsy, high seizure frequency was significantly associated with low self-esteem. Tonic-clonic seizures were found to be specifically associated with higher levels of depression associated with anhedonia. Finally, low levels of epilepsy knowledge were significantly associated with higher levels of depression, lower levels of self-esteem, and higher levels of social anxiety.

These results confirm that epilepsy does take a significant psychological toll on adolescents. This seems to revolve predominantly around the social aspect of the adolescent's life, and manifests in elevated social anxiety levels. Given the enormous importance that social life and relationships with peers play at this stage of life, and the nature of epilepsy as a stigmatizing and "unsocial" condition, this link is not surprising. Earlier studies identified that young people with epilepsy are particularly susceptible to the psychosocial impact of epilepsy [27,28]. Evidence from previous studies also demonstrated that epilepsy could have social, educational, emotional, and behavioral consequences leading to increased rates of depression in adolescents with epilepsy compared with adolescents without epilepsy [5,10,29,30].

However, the relationship between adolescents with epilepsy and psychosocial problems is likely to be mediated by a number of other factors including seizure frequency and type, adverse effects of AEDs, the family, school, and society at large [31]. Eklund and Sivberg [12] found that some aspects of the disorder, namely, seizures, limitations on social activities, side effects from medications, and feelings of being different, placed particular strains on the adolescent. These effects may continue into adulthood, with reports suggesting that adults with epilepsy may experience a poor sense of control or mastery associated with increased psychosocial prob-

lems, including depressive feelings, difficulties with peer relationships, poor self-confidence, poor self-esteem, social maladjustment, and absence of friendship [27,32,33].

This study highlights the importance of knowledge of epilepsy in terms of psychological adjustment, specifically in relation to depression, self-esteem, and social anxiety, and the importance of seizure control in terms of self-esteem. Adolescents with increased levels of knowledge were less likely to report psychosocial problems than those with less knowledge. This is consistent with the findings of a previously published study of adults with epilepsy [34]. There is also evidence to suggest that adolescents with higher levels of knowledge were less likely to be depressed. Whether greater knowledge acts as a barrier to depression cannot be established as a consequence of the design of the study, but it is clearly worthy of further research.

One of the reasons why adolescents may not possess high levels of knowledge about their condition is their desire not to acknowledge its existence for fear of being stigmatized. Westbrook et al. [35] compared the social functioning of adolescents with epilepsy, adolescents with other chronic illnesses, and adolescents without a chronic illness. The results of the study showed that adolescents with epilepsy were significantly more likely to report that they rarely discussed their disorder with others. Only 15% of the respondents with epilepsy said that all of their friends knew about their disorder, as compared with 59% of the adolescents with other chronic illnesses. Thus, the findings indicate that disclosing their diagnosis to others was more limited for adolescents with epilepsy than for those with other chronic illnesses. Limited disclosure was also replicated in a later study [36] in which 70% of adolescents rarely or never talked to anyone about their epilepsy.

The findings outlined above suggest that adolescents with epilepsy face social isolation as a result of their diagnosis [37,38]. To avoid the social embarrassment of experiencing a seizure in public, the adolescent may increasingly withdraw from social activities [39]. In addition, adolescents appear to deal with their diagnosis on their own because they are afraid of the way in which friends and family will perceive them [2]. Thus, it seems that stereotypes and attitudes can cause more pain for adolescents than the seizure itself [40]. Once this negative label has been applied to people who experience seizures, the person is faced with negative societal reactions and these can have a deleterious effect on self-esteem [41]. The stigmatizing effect of this chronic condition can generate poor psychosocial health-related outcomes (worry, negative feelings about life, depression) and increase the risk that adolescents fail to achieve their social, educational, and vocational goals [2].

Stigma and social discrimination in relation to epilepsy may be associated with a lack of knowledge and understanding about the condition. In a survey of

19,441 adolescents in the general population of the United States, Austin et al. [42] found support for this idea. The sample was recruited from the general population and ranged in age from 13 to 18. Results from the survey indicated that adolescents in the general population were not familiar with epilepsy, possessed inaccurate or incomplete information about the disorder, and held perceptions about epilepsy that reflected stigma. This lack of knowledge generated distortions and misconceptions that could have heightened the stigma surrounding the disorder. Therefore, even though epilepsy is the most common neurological disorder in adolescents, few adolescents in the general population are familiar with it.

The effects of seizure activity and medication on cognitive functioning can place additional pressures on adolescents at a crucial stage in their educational development [39,41,42]. Teenagers with epilepsy may also experience vocational concerns about the possible restrictions their diagnosis may place on their career choice [5]. Often the support structures that should be in place to buffer the effects of these added strains are insufficient. Galletti et al. [29] found that adolescents with epilepsy felt discriminated in school by both teachers and peers.

In contrast to these findings outlining the negative psychosocial impact of epilepsy in the adolescent population, several studies have generated conflicting results. Reeve and Lincoln [10] found no significant differences between adolescents with epilepsy and a control group on measures of self-esteem, affect, and self-efficacy. Similarly, Westbrook et al. [13] found that the majority of the adolescents in their study did not report feeling stigmatized by their epilepsy. Sixty-nine percent said that having epilepsy did not affect whether they were invited to go out on dates or their willingness to attend a party, and 89% believed that people with epilepsy could have sexual relationships just like people without epilepsy. But adolescents who felt stigmatized by their disorder were more likely to report low self-esteem than adolescents who did not feel stigmatized.

There are a number of limitations to this study that the authors are aware of and these include the following: (1) The adolescents with epilepsy were recruited from those attending a specialist epilepsy clinic and, as a consequence, are more likely to present with more difficult-to-manage epilepsy. This may limit potentially the generalizability of the sample to the broader population of adolescents with epilepsy. (2) We relied on the responses of the participants and did not have access to a proper psychiatric evaluation of the participants. This may have led to an under- or overestimation of the psychological problems presented. (3) Although we found significant differences between the groups, the relative sample size was small and therefore some caution should be used when interpreting the results; however, there still

appears to be a significant negative trend with respect to adolescents with epilepsy.

Despite the limitations of this study a diagnosis of epilepsy appears to impact negatively on the global psychological adjustment of the adolescent across multiple domains. Behavioral, social, emotional, and educational effects of epilepsy must be approached by providing support to the individual to enable her or him to feel in “control” of the epilepsy as well as life [5]. Teenagers must be provided with the specialist epilepsy services they require. Currently they find themselves caught between pediatric and adult services, with neither service being able to fully support them during this difficult period of transition [5,9]. It seems that adolescents could benefit from being able to gain accurate information and discuss important issues with those around them [12]. Therefore, sufficient social support from health professionals, teachers, parents, and friends can serve to alleviate strains on the adolescent with epilepsy [5,41]. This support should be combined with educational programs aimed at reducing negative societal attitudes and providing individuals with accurate information on which to draw [42].

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