



# Clinical characteristics associated with psychosocial functioning among patients with uncomplicated epilepsy in Spain

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## KEYWORDS

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## Summary

**Objective:** To identify the clinical characteristics associated with poor psychosocial functioning among Spanish patients with epilepsy but no other neurological or psychiatric disorder.

**Methods:** Between May and September 2001 a survey among patients with epilepsy was carried out in 32 Spanish health care centres. The selection criteria of patients were attendance to a routine neurologist visit, to be aged between 25 and 64 and not having another additional neurological handicap ( $n = 812$ ). Psychosocial function was

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elicited through six indicators: educational level, marital status, unemployment status, restricted car driving, self-perception of epilepsy as an important limiting factor in the educational level achieved and, among unemployed, as the cause of their unemployment. Multiple logistic regression models were fitted in order to calculate adjusted odds ratios (aOR) and their 95% confidence intervals.

*Results:* After simultaneously adjusting for socio-demographic variables and clinical characteristics, the six outcomes analysed increased with seizure frequency. Moreover, all the outcomes except low educational level were also related to early age at onset of epilepsy. Although no relation with objective educational level was found, there was a strong association between early age at onset of symptoms and self-perception of epilepsy as an important limiting factor of educational achievement. *Conclusion:* These findings emphasize the need for more effective treatment of epilepsy and also highlight the importance of a psychosocial approach to management of epilepsy for patients with an early onset of symptoms in order to prevent social limitations in adult life.

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## Introduction

Epilepsy is not just a clinical disorder but a social label<sup>1</sup> and a number of studies support the view that the social prognosis of epilepsy may be less optimistic than the clinical one.<sup>2</sup> Although it is a generally benign disorder with excellent clinical prognosis<sup>3</sup> it is associated with a wide range of markers of social and economic disadvantage, including poor academic achievement, unemployment, underemployment, low income and lower marriage rates.<sup>4–7</sup> People with epilepsy are generally considered more likely to be socially dysfunctional than people without epilepsy but the reasons for this continue to be a focus for debate. Studies have identified several factors related to clinical course and poor psychosocial functioning, including aetiology, seizure type, seizure frequency, age at onset of seizures and an abnormal neurological examination, but results are not consistent.<sup>8</sup>

A limitation of previous research about the impact of epilepsy on social functioning is the lack of consideration of some confounders such as mental retardation or concomitant neurological deficits,<sup>9,10</sup> and the failure to simultaneously take into account several clinical and social variables as predictors. According to an extensive revision, the evidence from the various studies is often contradictory because in many studies the different risk factors have been treated as independent although they actually may be interrelated.<sup>11</sup>

Additionally, the socio-political environment and country-specific factors associated with history, policies, legal rights and institutions attitudes impact people's health, thus leading to an expectation that the nature of social and economic variations in social opportunities for people with chronic diseases will differ between societies. For example, cross-cultural differences have been found between levels of

stigma reported by people with epilepsy across Europe, with Spanish respondents reporting the lowest levels, and French respondents, the highest.<sup>12</sup> However, most European studies about the impact of epilepsy on poor social adjustment have been carried out in northern European countries and the UK, but little is known about the impact of epilepsy in social function in Mediterranean countries, such as Spain.

The objective of this study is to identify the clinical characteristics of epilepsy associated with poor psychosocial functioning among Spanish patients with epilepsy but no other neurological or psychiatric disorder.

## Methods

### Data

Between May and September 2001, the Epilepsy Group of the Spanish Society of Neurology (SEN) launched a survey that aimed at analysing quality of life and social limitations among epileptic patients with no additional psychiatric or neurological disorders and without known learning disability. The announcement of this initiative and the description of the main characteristics of the study were made during the 2000 Congress of the Spanish Society of Neurology, and all members of the Epilepsy Study Group were invited to participate. An anonymous questionnaire was developed by neurologists, experts in epilepsy and a social epidemiologist. The final version of the questionnaire, and the instructions about the study, as well as a presentation letter signed by the coordinator and the secretary of the Epilepsy Study Group, were made available at the SEN website (<http://www.sen.es/>) and the participation was opened to all members of the Epilepsy Group.

The instructions specified the study population as all patients older than 16 with no additional psychiatric or neurological disorders, who attended for a routine medical visit to their neurologist between May 15 and September 15 of 2001. Patients were asked to fill out a self-administered questionnaire covering socio-demographic questions, family characteristics, and questions related to their employment status and working conditions. Additional questions about clinical characteristics such as seizure type, age at onset, seizure frequency, antiepileptic drugs used and side effects of medication were collected by the neurologist during the medical visit. Thirty-six neurologists from 32 Spanish health care centres (tertiary hospitals, small regional hospitals and primary health care centres with a full time neurologist) participated in the study. Only 4% of the patients who were proposed to participate refused to answer the questionnaire. For the purposes of this study the sample was restricted to people aged 25–64 ( $n = 812$ ). We selected this group because this is the age when people have usually finished their main formal education and fully develop their family and employment roles.

## Study variables

Measures of psychosocial function:

- *Educational status*: This variable was dichotomised into low educational level (compulsory schooling or less) and high educational level.
- *Marital status*: was categorised into single versus married. Although being single can be a personal option, it can also be an indicator of difficulties for making up a family. For this outcome, the analysis was restricted to single and married people (761 persons). Previous research indicates that there may be factors specific to the psychosocial processes of epilepsy that reduce the likelihood that an epileptic person will marry and, among those who do, the stress of living with a chronic illness, particularly a stigmatising one, may increase the risk of marital breakdown. In our view, these issues are quite distinct processes and that is the reason why we restricted the population to single and married people, as we were interested in the limitations imposed by epilepsy for partnership formation.
- *Employment status*: For this outcome the analysis was restricted to the active population, i.e. employed and unemployed who were actively seeking a job (532 persons). We excluded from the analysis full-time homemakers (19.0%) because most of them were women (99.3%) and the examination of this situation would require

discussing gender issues that are beyond the objectives of this study. We also excluded students (0.7%) and people whose current situation was defined as “others” (9.7%). Therefore, we focused our interest on the impact of epilepsy on unemployment among the active population.

- *Not driving as a consequence of epilepsy*: This variable was elicited through two questions. People who answered that they did not drive (63.1%) were additionally asked whether epilepsy was the reason or not. Epilepsy was more likely to be mentioned as the reason for not driving among men (73.7% versus 47.9%).

Additionally two indicators of self-perceived impact of epilepsy on two aspects of psychosocial functioning were analysed:

- Extent to which epilepsy is perceived as a factor limiting the educational status. This variable that originally had four categories (definitely, quite a lot, a little and not at all) was dichotomised by considering the answers “definitely” and “quite a lot” as perception of limitations.
- Extent to which epilepsy is perceived as a cause of being unemployed. This variable, that only applied to unemployed people ( $n = 83$ ), had also four categories and was dichotomised. Categories “definitely” and “quite a lot” were considered as having had limitations.

Clinical characteristics of epilepsy:

- *Age at epilepsy onset*. This variable was classified into three categories: Before 15, 16–30 and after 30.
- *Seizure type*: Generalised seizures, simple partial seizures, complex partial seizures, partial seizures evolving to secondary generalised seizures and other.<sup>13</sup>
- *Seizure frequency during last year*: Seizure free, less than 1 seizure per month and more than 1 seizure per month.

## Data analysis

First, frequencies for categorical variables and mean and standard deviation (S.D.) for age were calculated. Multiple logistic regression models with all clinical characteristics of epilepsy, sex and age (continuous variable) as independent variables were fitted in order to examine the association between clinical characteristics and each outcome. For all the outcomes analysed, except low educational status the analysis was additionally

controlled for educational status with three categories: Primary school or less, secondary school and university degree. Adjusted odds ratios (aOR) were used as a measure of the magnitude of the independent association between a predictor variable and the risk of the measured outcome.<sup>14</sup> The 95 percent confidence intervals were also calculated from the logistic regression models. Goodness of fit was obtained using the Hosmer Lemeshow test.<sup>15</sup> The SPSS statistical package was used for the analysis.

## Results

### General characteristics of the sample

Table 1 shows the general characteristics of the study sample. The proportion of men and women was similar and the mean age was 40.3 years (S.D. = 10.8). About half of the persons had primary education or less, 11% were unemployed, 35.2% were single and 33.7% did not drive because of epilepsy. One-fifth of patients considered that epilepsy had limited their educational opportunities quite a lot or absolutely, whereas the proportion of unemployed who reported that epilepsy had relation with their employment status was even higher (43.1%).

Regarding clinical characteristics, in 42.7% of patients, onset of symptoms occurred before 15 years of age and the most frequent seizure types were partial with secondary generalisation (31.8%) and generalised (26.4%). Almost half of the patients had been seizure-free in the year previous to the medical visit.

### Factors associated with limitations in psychosocial functioning

Table 2 shows factors associated with objective psychosocial limitations. The likelihood of remaining single, being unemployed and non-driving because of epilepsy increased with early age of symptoms and with seizures frequency. The aORs associated with having one or more seizures a month in the year previous to the medical visit as compared with being seizure free were 1.84 (95%CI = 1.12–3.01) for being single, 3.23 (95%CI = 1.63–6.41) for being unemployed and 7.71 (95%CI = 4.85–12.24) for not driving because of epilepsy. As compared with persons with the onset after 30, those patients starting symptoms before 15 had a higher risk of being single (aOR = 2.72; 95%CI = 1.49–4.97), being unemployed (aOR = 2.77; 95%CI = 1.10–6.93) and of not driving because of epilepsy (aOR = 2.56;

**Table 1** General characteristics of the study sample (%)

Variables	Percentage (n = 812)
Sex	
Men	48.0
Women	52.0
Age (mean and standard deviation)	40.3 (10.8)
Educational status	
Primary school or less	54.2
Secondary school	31.9
University	13.9
Employment status	
Employed	59.6
Unemployed	11.0
Housewives	19.0
Students	0.7
Other	9.7
Marital status	
Single	35.2
Married or cohabiting	58.8
Separated or divorced	3.8
Widow	2.1
Age at onset of epilepsy	
After 30 years	23.4
Between 15 and 30 years	33.8
Before 15 years	42.8
Type of seizures	
Generalised	26.4
Simple partial	6.0
Complex partial	19.1
Partial with secondary generalisation	31.8
Mixed	16.0
Other	0.7
Seizures frequency last year	
None	46.9
Less than one a month	29.0
One or more a month	24.1
Non driving because of epilepsy	33.7
Extent to which epilepsy is perceived as a limiting factor for the educational level	
Absolutely	5.3
Quite a lot	14.7
A little	15.7
Nothing	64.3
Extent to which epilepsy is perceived as cause of unemployment <sup>a</sup>	
Absolutely	27.2
Quite a lot	15.9
A little	15.5
Nothing	41.4

<sup>a</sup> Only unemployed workers who are actively seeking a job.

**Table 2** Factors associated with poor psychosocial functioning

Variables	Low educational level <sup>a</sup>		Single <sup>b</sup>		Unemployed <sup>c</sup>		Non-driving because of epilepsy	
	(%)	aOR (95%CI)	(%)	aOR (95%CI)	(%)	aOR (95%CI)	(%)	aOR (95%CI)
Sex								
Men	50.4	1	45.5	1	14.8	1	32.6	1
Women	47.9	1.35 (1.00–1.82)	29.3	0.37 (0.88–0.92)	16.7	1.06 (0.64–1.75)	34.7	0.98 (0.70–1.38)
Age (continuous)	–	1.06 (1.04–1.08) <sup>***</sup>	–	0.90 (0.88–0.92)	–	1.02 (0.99–1.05)	–	0.99 (0.98–1.01)
Educational level								
University	–		51.9	1	10.3	1	26.2	1
Secondary school	–		39.8	0.46 (0.27–0.79) <sup>**</sup>	18.6	1.67 (0.76–3.63)	32.5	0.87 (0.50–1.54)
Primary school or less	–		31.7	0.50 (0.30–0.85) <sup>**</sup>	15.6	1.34 (0.61–2.92)	34.9	1.00 (0.58–1.72)
Age at onset of epilepsy								
After 30 years	61.0	1	13.3	1	8.0	1	19.9	1
Between 15 and 30 years	48.0	1.10 (0.70–1.74)	41.2	1.76 (0.94–3.27)	17.4	2.73 (1.08–6.90) <sup>*</sup>	32.2	1.63 (0.95–2.79)
Before 15 years	55.8	1.51 (0.96–2.64)	47.1	2.72 (1.49–4.97) <sup>**</sup>	18.6	2.77 (1.10–6.93) <sup>*</sup>	44.2	2.56 (1.52–4.31) <sup>**</sup>
Type of seizures <sup>d</sup>								
Generalised	51.0	1	38.2	1	17.5	1	27.1	1
Simple partial	43.8	0.61 (0.31–1.20)	37.5	1.22 (0.56–2.67)	16.1	0.64 (0.21–1.93)	26.5	0.58 (0.27–1.27)
Complex partial	55.1	0.88 (0.55–1.41)	36.2	1.04 (0.60–1.82)	17.0	0.59 (0.27–1.26)	45.2	1.36 (0.81–2.29)
Partial with secondary generalisation	56.6	1.07 (0.72–1.59)	31.8	0.81 (0.50–1.29)	12.0	0.55 (0.29–1.06)	30.6	0.97 (0.61–1.53)
Mixed	58.6	1.08 (0.63–1.84)	49.2	1.27 (0.15–10.83)	18.4	0.72 (0.31–1.68)	39.2	1.40 (0.78–2.50)
Seizures frequency last year								
None	49.1	1	33.8	1	10.7	1	15.5	1
Less than one a month	58.6	1.41 (0.93–2.13)	37.0	1.60 (1.02–2.48) <sup>*</sup>	16.8	1.76 (0.96–3.22)	43.8	5.04 (3.32–7.65) <sup>***</sup>
One or more a month	57.9	1.47 (1.02–2.12) <sup>*</sup>	45.1	1.84 (1.12–3.01) <sup>*</sup>	27.3	3.23 (1.63–6.41) <sup>**</sup>	61.3	7.71 (4.85–12.24) <sup>***</sup>

Adjusted odds ratios (aOR) and 95% confidence intervals (CI). <sup>a</sup>Low educational level is primary school or less. <sup>b</sup>Previously married people are excluded. Only single vs. married or cohabiting persons are compared. <sup>c</sup>Only people with a paid work and unemployed actively seeking a job included. <sup>d</sup>Category "Others" is excluded because of less than 10 individuals in the cell. <sup>e</sup>\*\*\*<0.001; \*\*<0.01; \*<0.05.

**Table 3** Factors associated with considering epilepsy as responsible for limitations in the educational status and of unemployment

Variables	Low educational level		Unemployment <sup>a</sup>	
	(%)	aOR (95%CI)	(%)	aOR (95%CI)
<b>Sex</b>				
Men	33.9	1	59.5	1
Women	37.1	1.04 (0.74–1.46)	57.5	0.96 (0.53–1.75)
Age (mean and standard D.E.)	—	1.01 (1.00–1.03)		1.01 (0.98–1.04)
<b>Educational level</b>				
University	16.7	1	45.8	1
Secondary school	35.9	2.27 (1.22–4.23) <sup>*</sup>	57.1	1.09 (0.39–3.03)
Primary school or less	39.5	2.60 (1.46–4.84) <sup>**</sup>	61.4	1.50 (0.57–3.98)
<b>Age at onset of epilepsy</b>				
After 30 years	14.7	1	42.6	1
Between 15 and 30 years	28.0	2.50 (1.38–4.53) <sup>**</sup>	60.8	2.54 (1.05–6.14) <sup>*</sup>
Before 15 years	51.6	6.10 (3.44–10.82) <sup>***</sup>	62.2	2.50 (1.08–5.79) <sup>*</sup>
<b>Type of seizures<sup>b</sup></b>				
Generalised	32.7	1	53.1	1
Simple partial	30.0	0.87 (0.38–1.98)	42.1	0.43 (0.13–1.45)
Complex partial	42.9	0.94 (0.56–1.59)	68.2	0.96 (0.36–2.61)
Partial with secondary generalisation	32.5	0.90 (0.57–1.40)	57.5	1.12 (0.51–2.45)
Mixed	33.3	0.93 (0.52–1.68)	65.8	1.35 (0.49–3.68)
<b>Seizures frequency last year</b>				
None	25.4	1	39.1	1
Less than one a month	34.0	1.50 (0.99–2.28)	61.9	2.61 (1.29–5.29) <sup>**</sup>
One or more a month	57.4	3.17 (2.02–4.97) <sup>***</sup>	76.9	6.55 (2.91–14.72) <sup>***</sup>

Adjusted odds ratios (aOR) and 95% confidence intervals (CI). <sup>a</sup>Only unemployed actively seeking an occupation are included.

<sup>b</sup>Category "Others" is excluded because of less than 10 individuals in the cell. <sup>c</sup>\*\*\* <0.001; \*\* <0.01; \* <0.05.

95%CI = 1.52–4.31). Additionally, they were more likely to have low educational status (aOR = 1.51; 95%CI = 0.96–2.64).

As with objective social limitations, the risk of perceiving epilepsy as a social limiting factor increased with seizure frequency and with early age of epilepsy onset (Table 3). People with one or more seizures a month in the year previous to the medical visit had an aOR = 3.17 (95%CI = 2.02–4.97) of perceiving epilepsy as a limiting factor of their educational status and an aOR = 6.55 (95%CI = 2.91–14.72) of considering this condition as a cause of their unemployment situation, compared with those who were seizure free. Patients whose symptoms started before 15 had a higher risk of perceiving epilepsy as a limiting factor for their educational attainment (aOR = 6.10; 95%CI = 3.44–10.82) and as the cause of their being unemployed (aOR = 2.50; 95%CI = 1.08–5.79).

## Discussion

Within the framework of a large cross-sectional study of individuals with epilepsy with no additional

neurological or psychiatric handicap, and with a high response rate, we have simultaneously examined the contribution of several different clinical variables in the limitations of psychosocial functioning in Spain. Our study has produced three main findings. First, both early age at onset of epilepsy and seizures frequency are associated with five of six psychosocial outcomes analysed and this association is independent of age, sex and educational status. Second, seizures frequency is also associated with low educational status. Finally, although no association was found between early age at onset of epilepsy and low educational status, a strong association was found between early age of symptoms and self-perception of epilepsy as an important limiting factor of educational achievement.

Unlike Baker et al.<sup>16</sup> who observed a consistent association between seizure type and several psychosocial outcomes, in our study seizure type was not associated with any psychosocial outcome analysed. This inconsistency between the two studies may be explained by the lack of consideration of the correlations between variables in the exclusively bivariate analysis of Baker et al.<sup>16</sup> Actually, in our study, we found statistically significant correlations between



age at onset of epilepsy and seizure frequency with seizure type ( $p < 0.01$ ). Our results are also consistent with those of Jacoby et al.<sup>17</sup> who, after adjusting for different clinical variables, found seizure type associated with only one out of the seven psychosocial outcomes analysed.

Our results are consistent with other studies reporting that patients with "epilepsy only" beginning in childhood have significant social adjustment and competence problems in adulthood.<sup>18,19</sup> However, unlike these studies, in ours, the association between early age at onset of epilepsy and low educational level was only marginally significant ( $p = 0.07$ ) and the magnitude of the association (aOR = 1.51) very weak. This finding is very important because the onset of symptoms at ages older than 30 cannot too much affect basic or vocational education, but the onset at childhood may do. These inconsistencies between studies could be related to cultural differences between countries – Finland and Spain, in this case – although this is only a speculation that deserves further research. It is also important to remark that a strong association was found between age at onset of epilepsy and perception of epilepsy as related to low educational achievement with an aOR of 6.10 among people starting with symptoms before 15. This disparity between objective and self-perceived limitations may well be related to the strong experience of epilepsy as an stigmatising condition that permeates the whole social life from childhood, although it is not consistent with objective educational achievement.

We found that both objective unemployment status and perception of epilepsy as the main cause of unemployment were positively related to seizure frequency and negatively associated with age at epilepsy onset. Moreover, this finding was independent of the educational level. Although it has been reported that people with well-controlled epilepsy and uncomplicated by other handicap, do not generally experience problems with employment<sup>5</sup> our results show the importance of age at onset of epilepsy, independently of seizure activity and of educational level, as a factor associated with unemployment. This result is consistent with the reported high concern of employers regarding epilepsy, including the likelihood of it being linked to a work-related accident.<sup>20</sup>

Whereas, as well as in the present study, Jacoby et al.<sup>17</sup> found an association between employment status and seizure activity, age at onset of epilepsy was not associated with unemployment in that study carried out in the UK. These inconsistent results can be related to cultural, social, political and economical differences between countries, with Spain, for

example, having the highest unemployment rates in the European Union in recent years, and emphasize the need to analyse psychosocial consequences of epilepsy in different cultural contexts.

It has been reported that childhood onset of epilepsy is related to higher rates of unemployment and lower socio-economic status and that these differences are not accounted for by differences in educational attainments or seizure frequency.<sup>21</sup> Although it has been suggested that social limitations among young adults with epilepsy during childhood are largely explained by neurological or learning disabilities,<sup>22</sup> in our study people with neurological or psychiatric disorders were not included in the sample and yet low psychosocial functioning was still found to be associated with early age at onset of symptoms. Moreover, the association remained after adjusting for educational level. Parental lower expectations compared with their healthy children and overprotection have been suggested as the main reason for social limitations among people whose symptoms started during childhood.<sup>23,24</sup> For example, in a study of young adults with epilepsy during their childhood, even subjects with normal mental capacity and idiopathic disease were more tied to their parents and home, lived at home more often, and had retarded sexual maturation compared with the controls.<sup>22</sup>

It has been reported that rates of marriage are lower among people with epilepsy.<sup>25,26</sup> Jalava et al.<sup>18</sup> attributed this fact to social factors such as prejudice, stigma and fear of having an abnormal child. Our results show, again, that factors associated with lower marriage rates were early age at onset of epilepsy and seizure frequency. These findings are only partially consistent with those of Jacoby et al.<sup>17</sup> in the UK. Whereas they also found an association between marital status and age at onset of epilepsy, no relation observed with seizure frequency. However, a study carried out in Japan reported that among patients who had not informed their spouses about the disease, witnessing seizures was associated with divorce.<sup>27</sup> It seems reasonable to think that, at least in some cultural contexts, having uncontrolled epilepsy represents a difficulty for marriage, although we cannot rule out cultural differences among countries as the reason for these different patterns.

The risk of driving limitations because of epilepsy was associated with higher seizure frequency and earlier age at onset. It is not surprising that there is an association with seizure frequency. However, it is important to emphasize, once again, age at onset of epilepsy as one of the factors related to not driving. Overprotection by parents during childhood can be related to more passive behaviours in daily life, such

as the delay in the age of leaving their parents,<sup>22</sup> not having a driving license or more passive attitudes in social relations.

## Limitations

Although the sample analysed is not representative of Spanish patients with epilepsy, considering the large sample size, the heterogeneity of health care centres included in the study (from tertiary hospitals to primary health care centres) and that they are distributed throughout the Spanish territory, it is reasonable to think that our results are generalizable to the Spanish context. Unlike many studies based on an overall measure of quality of life we have used six indicators of social functioning that provide a more concrete identification of the social dimensions affected by epilepsy, therefore suggesting specific actions to address specific domains for intervention.

## Conclusions

This study shows a consistent association between age at epilepsy onset and seizure frequency across a broad range of outcomes, both objective limitations and self-perception of epilepsy as a limiting factor for social functioning among patients with “epilepsy only”. Moreover, the associations were found after adjusting for age, sex, and educational status. Although an association was found between age at onset of epilepsy and perception of epilepsy as related to low educational achievement, no relation was observed with objective low educational status, thus probably reflecting the strong experience of epilepsy as an stigmatising condition related to limitations in different social domains, although it is not consistent with objective educational achievement.

Establishing the relative contribution of different potential risk factors is clearly important for developing appropriate interventions aimed at reducing poor psychosocial functioning. Our findings emphasize the need for more effective treatment of epilepsy and highlight the need for a psychosocial as well as a medical approach to management of epilepsy. There is a need for psychological and counselling services to address the issues related to an early onset of epilepsy. Moreover, efforts should be made to include educating people with epilepsy and their families to address the relation between knowledge, stigma and adjustment,<sup>28,29</sup> as well as targeting the general public and the various organisations with which people with epilepsy connect.<sup>30</sup>

## Conflict of interests

None.

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