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Therapeutic itinerary of children living with epilepsy in Kinshasa: Features, determinants, and relationships with behavioral problems and cognitive impairment

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ABSTRACT

Background: Epilepsy mostly affects children in sub-Saharan Africa. However, little is known about the therapeutic itinerary of these children living with epilepsy (CWE). This study aimed to describe the therapeutic itinerary of CWE in Kinshasa and to analyze its relationships with clinical features, behavioral problems, and cognitive impairment.
Methods: This hospital-based study has included 104 CWE aged 6 to 17 years. The features of their therapeutic itinerary and their relationship with clinical features, behavioral problems, and cognitive impairment were analyzed.
Results: The vast majority of CWE (87%) has started their therapeutic itinerary by the Western medicine. The first source of information about epilepsy as well as the type of antiepileptic treatment varied with the socioeconomic status of families of CWE. The total duration of the therapeutic itinerary was shorter for the CWE who were living with both their parents ($P = .038$), who had generalized seizures ($P = .0073$) or who had no family history of epileptic seizures ($P = .019$). The CWE who had total behavioral problem, compared with the others, were putting more time ($P = .021$) to reach the Centre de Santé Mentale Telema (CSMT) after the suspicion or the diagnostic of epilepsy. The total duration of CWE who had cognitive impairment ($P = .021$) was longer than that of CWE who had not cognitive impairment.
Conclusion: The therapeutic itinerary of CWE in Kinshasa began with Western medicine. The remainder of this therapeutic itinerary looks like what is described in sub-Saharan literature with the majority of CWE seeking the healing based on beliefs. This study also shows that the therapeutic itinerary of CWE was associated with socioeconomic conditions, clinical features, behavioral problems, and cognitive impairment.

1. Introduction

Analysis of the therapeutic itinerary is important to understand the determinants of the quest of the care for a disease. In sub-Saharan Africa, only a small number of studies have been devoted to the therapeutic itinerary of people living with epilepsy (PWE). These studies describe a therapeutic itinerary of PWE that passes successively or simultaneously through three types of treatment: Western medicine, traditional medicine, and prayer [1–4].

Traditional medicine is often the first step in the quest for care of sub-Saharan Africa's PWE [2,3,5]. Its geographical, economic, and cultural accessibility pleads in its favor [3,5]. In sub-Saharan Africa, treatment with Western medicine is not the first choice of PWE [2,3,5,6]. Only one-third of PWE arriving in a neurological structure has ever received antiepileptic medication [6–8]. Although very little documented, prayer is also used as a therapeutic means [1,2,4].

The therapeutic itinerary of PWE in sub-Saharan Africa is responsible for late arrival of patients in appropriate health facilities [6]. Birbeck [6] has found that the PWE in sub-Saharan Africa take up to 4.7 years to

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reach an appropriate structure for the care of epilepsy. This delay has consequences on clinical characteristics, cognitive performances, and the psychic functioning of the PWE. For children, for example, delay in the diagnosis and, consequently, in the management of the epilepsy aggravates it [9].

While epilepsy, in sub-Saharan Africa, more frequently affects children [8,10,11], we have not found studies specifically devoted to the therapeutic itinerary of children living with epilepsy (CWE). Thus, this study aimed to describe the therapeutic itinerary of CWE, to identify its determinants, and to analyze its relationships with behavior problems and cognitive impairment. This study is complementary to another one on behavioral problems and cognitive impairment in CWE of Kinshasa [12].

2. Methods

2.1. Nature, period of study, and study setting

The present study is a cross-sectional hospital-based study. The inclusion of CWE, by a convenience sampling, was done two times, from April to May 2013 and from November to December 2013. The '*Centre de Santé Mentale Telema*' (CSMT or Mental Health Center Telema) located in the city of Kinshasa (capital of the Democratic Republic of the Congo) was the framework of this study [12]. This neurological and psychiatric of ambulatory care health center is situated in the eastern part of the city of Kinshasa. Its geographic location, the relatively low cost of the care, and the high influx of person with neurological disease or mental disorder are its main assets. The CSMT performs more than 30,000 consultations annually. Based on guidelines, western medicine cares are provided daily by 4 or 5 nurses. The second author, a neuropsychiatrist (in the Democratic Republic of the Congo [DRC], the training in neurology and psychiatry are combined) of the department of psychiatry of University of Kinshasa supervises the center once per week. He consults the cases complex for the nurses. The CSMT has 2 video electroencephalographs and a pharmacy that sells psychotropic drugs at a low price.

2.2. Children with epilepsy

This study has included active CWE aged 6 to 17 years. These CWE had presented at least two unprovoked epileptic seizures separated by a 24-hour interval, the last of which had occurred in the last 5 years [13]. Seizures have been classified according to the recommendations of the International League Against Epilepsy [14]. The description of seizures was collected from eye witnesses of epileptic seizures.

2.3. Characteristics of the therapeutic itinerary

The determinants of the therapeutic itinerary have been analyzed from four variables: the types of consultations prior to the first arrival at the CSMT, the first source of suspicion or of diagnosis of epilepsy, the type of antiepileptic treatment prior to the first consultation at the CSMT, and the duration of the therapeutic itinerary.

The types of consultations prior to the first arrival at CSMT included Western medicine (regardless of care provider quality), traditional medicine, and prayer. In the DRC, as in numerous sub-Saharan African countries [15], Western medical cares more often are provided by nurses. The CWE for which information was lacking to fit into one of these three categories were included in a category named "other".

The first source of suspicion or of diagnosis of epilepsy was the first source who suspected or diagnosed epilepsy as the child's disease; it could be a family member or a relative, a care provider of Western medicine, or a traditional healer. In this study, the family is understood in the broader sense and not in the sense of the nuclear family.

The type of antiepileptic treatment prior to the first consultation at the CSMT was considered. The types of antiepileptic treatment were as follows: antiepileptic drugs (AEDs), traditional therapy (TT), and the combination of AEDs and TT (AEDs-TT). In this study, the combination does not require the simultaneous use of both types of treatment.

The duration of the therapeutic itinerary was divided into three: i) Duration I: between the first seizure and the suspicion or the diagnosis of epilepsy; ii) Duration II: between the suspicion or the diagnosis of epilepsy and the first consultation at the CSMT; and iii) Total duration: between the first epileptic seizure and the first consultation at the CSMT.

2.4. Sociodemographic variables

The following variables were taken into account: the age, the gender, the family type (child living with both parents or other), the father's age, the mother's age, the household size, and the estimation of the equivalent amount of money in United States dollars ($) usually spent on daily household needs and per household member.

2.5. Epileptic features

The following variables were considered: the age at first seizure, the history of epileptic seizure in the family, the type of epileptic seizures, and the estimated monthly epileptic seizure frequency. The type of epileptic seizures was dichotomized into generalized and other seizures (focal seizures and spasms). The unclassified crises were omitted from statistical analyzes. The monthly seizure frequency was categorized into two: <2 seizures per month and ≥ 2 seizures per month.

2.6. Behavioral problems

The behavioral assessment was performed with the Achenbach child behavior checklist (CBCL). The behavioral problems (internalized, externalized, and total) in the CWE included in this study were the subject of a previous publication [12].

2.7. Cognitive impairment

The cognitive performance was assessed using the short version (2 subtests) of the Wechsler Nonverbal (WNV) scale of ability. The cognitive impairment was defined as a score of less than 70 on the WNV or the inability of the CWE to respond to WNV items coupled with a clinical history of intellectual disability. The cognitive impairment of CWE included in this study was the subject of a previous publication [12].

2.8. Missing data

To complete the missing pieces of information for some CWE, according to the case, we conducted telephone calls or used medical files for CWE followed at the CSMT [12]. Missing data are indicated in the tables of results.

2.9. Statistical analyses

The analyses of the data were performed with the software Statistica 13 and SPSS 20. Associations between categorical variables were searched by the Pearson chi-square test eventually followed by analysis of standardized residuals as "post hoc" after Bonferroni corrections ($\alpha_{cor} = 0.05/(\text{number of rows} \times \text{number of columns})$).

The normality of the quantitative data was assessed by the Shapiro test. The homoscedasticity was evaluated by the Levene's test. Parametric statistical tests were used for quantitative variables that have met at least equality of variances and did not exhibit important asymmetry. For the previous antiepileptic treatment and the source of the suspicion or the diagnostic of epilepsy, the means of groups were compared by planned orthogonal linear contrast tests (see supplementary materials). Nonparametric tests were performed for quantitative variables that did not meet at least the equality of variances or had exhibited a high asymmetry. Mann–Whitney *U* tests, the Kruskal–Wallis test, eventually followed by multiple comparisons of mean ranks, and Spearman correlations were used depending on the situation.

The graphics have been plotted with software R 3.1.2. (R Core Team, 2014).

2.10. Ethical approval

The present research has obtained the agreement of the Ethics Committee of the School of Public Health of the University of Kinshasa (ESP/CE/018/13). The inclusion in the study was conditioned upon the signing of an informed consent form by an adult accompanying the CWE.

3. Results

3.1. Characteristics of CWE

This study had included 104 CWE (Table 1). Their characteristics were described previously [12].

3.2. Characteristics of the therapeutic itinerary

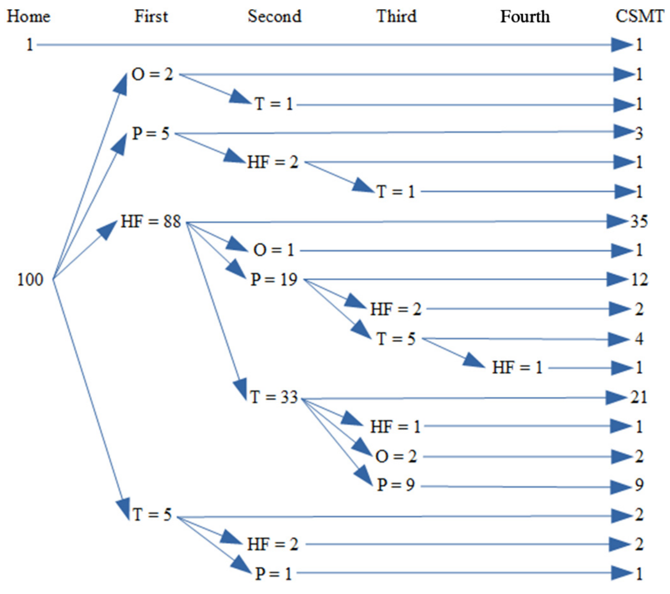

Diagram 1. Types of successive consultations. CSMT: Centre de santé mentale Telema. HF: Health Facility. P: Prayer. O: Other. T: Traditional.

Diagram 1 traces and details the therapeutic itinerary of 101 CWE. The Western medicine was the first step of treatment for 88 (87.1%) CWE. These CWE who had started with Western medicine then moved on to the CSMT (35/88 or 39.8%), to a traditional healer (33/88 or 37.5%), or to prayer (19/88 or 21.6%). Thus, 59.1% (52/88) families of the CWE seen in the health facilities have sought thereafter for the healing based on beliefs. Both traditional medicine and prayer were the first consultations for five CWE (5.0%). The CSMT was the first step of the therapeutic itinerary for only one child living with epilepsy (1.0%). One of the two children who had started their therapeutic itinerary with an "other" structure had taken an antiepileptic drug by self-medication.

Finally, during their therapeutic itinerary, 92 (91.1%), 45 (44.6%), and 34 (33.7%) CWE have passed, respectively, toward the Western medicine, the traditional medicine, and prayer, before arriving at the CSMT. Overall, Western medicine had preceded, directly or indirectly, belief-based treatment in 67 (66.3%) CWE, with traditional medicine for 39 (38.6%) CWE, and prayer for 28 (27.7%) CWE.

During their therapeutic itinerary, the CWE have consulted successively up to four different types of consultations (Table 2). Three quarters (76.3%) of the CWE had arrived at the CSMT with no suspicion or diagnosis of epilepsy (43.3%) or with suspicion from family or relatives (33.0%). The majority (55.9%) of the CWE had previously received antiepileptic treatment with antiepileptic drugs (13.7%), traditional medicine (29.4%), or both (12.8%). Thus, 26.5% of CWE had previously received antiepileptic drug and 42.2% a traditional treatment. Among the 15 (15.5%) CWE who had their diagnoses in health facilities, 6 (5.8%) received AEDS.

Table 1
General characteristics of CWE.

Variable	n (%) or mean ± SD
Age, years	12.0 ± 3.2
Male	61 (58.6%)
Father's age, years (N = 91)	48.9 ± 8.0
Mother's age, years (N = 97)	41.5 ± 7.0
Lives with both parents (N = 98)	74 (75.5%)
Size of household (N = 102)	7.2 ± 2.6
Household daily expenditures, $ (N = 98)	8.04 ± 4.14
Individual daily expenditures, $ (N = 98)	1.24 ± 0.72
History of epileptic seizure in family	42 (40.4%)
Age of onset, (years)	6.9 ± 4.0
Generalized seizure (N = 96)	35 (36.4%)
≥ 2 seizure/month (N = 103)	59 (57.3%)
Cognitive impairment (N = 90)	66 (73.3%)
Internalized behavioral problem	24 (23.1%)
Externalized behavioral problem	28 (26.9%)
Total behavioral problem	30 (28.8%)

The suspicion or the diagnosis of epilepsy had occurred 1 (0–2.5) year after the first seizure. Thereafter, the CWE took less than a year (0 [0–2.5] year) to arrive at the CSMT. The total duration of the therapeutic itinerary, from the first epileptic seizure to the arrival to the CSMT, was 2 (1–6) years.

3.3. Reciprocal relationship between the therapeutic itinerary features

There was a statistically significant relationship between the first source of suspicion or diagnosis of epilepsy and the type of treatment (Khi2 = 40.4, df = 9, P = .00001; Table 3). The threshold α for the posthoc assessment to independence deviations was of 0.05/(4 × 4) or 0.003125. The CWE who had their diagnoses by traditional healers

Table 2
Characteristics of the therapeutic itinerary.

Variable	n (%) or median (IQR)
Number of type of previous consultation (101)	
- None	1 (1.0%)
- One	41 (40.6%)
- Two	39 (38.6%)
- Three	19 (18.8%)
- Four	1 (1.0%)
First source of suspicion/diagnostic (N = 97)	
- None	42 (43.3%)
- Family/relatives	32 (33.0%)
- Traditional healer	8 (8.2%)
- Health facilities	15 (15.5%)
Type of previous antiepileptic treatment (N = 102)	
- None	45 (44.1%)
- Traditional treatment	30 (29.4%)
- Antiepileptic drugs + Traditional treatment	13 (12.7%)
- Antiepileptic drugs	14 (13.7%)
Duration	
- Duration I (year)	1 (0–2.5)
- Duration II (year)	0 (0–2.5)
- Total duration (years)	2 (1–6)

CSMT: Centre de Santé Mentale Telema

Table 3
First source of suspicion/diagnostic and antiepileptic treatment (with their adjusted residuals).

	First source of suspicion or diagnostic				
	None	Family/ relatives	TH	HF	P
Antiepileptic treatment					<.001
None	25 (2.9)	13 (−0.6)	0 (−2.7)	5 (−1.0)	
Traditional	8 (−1.7)	11 (0.7)	**8 (4.6)**	1 (−2.1)	
AED + Traditional treatment	1 (−2.2)	6 (1.9)	0 (−1.0)	3 (1.3)	
AED	6 (0.1)	2 (−1.7)	0 (−1.2)	**6 (3.0)**	

AED: antiepileptic drug. TH: traditional healer. HF: Health facility.

were more likely to receive traditional treatment (P = .0000048), and the CWE who had their diagnoses in health facilities were more likely to receive AED alone (P = .0026).

Duration I did not vary with the source of the suspicion or the diagnosis of epilepsy (H (3, N = 97) = 0.9, P = .82).

There was a relationship between the source of the suspicion or the diagnosis of epilepsy and duration II of the therapeutic itinerary (H (3, N = 97) = 48.7, P < .001, Fig. 1A). The group of CWE who had arrived at the CSMT without suspicion or diagnosis of epilepsy (0 (0–0) year) had shorter duration II than those who had the suspicion or the diagnosis by family or relatives (2 (1–4) years, P < .000001), traditional healers (2 (0.5–4.5) years, P = .0073), or care providers of Western medicine (1 (0–5) year, P = .0048).

The total duration of the therapeutic itinerary was varied according to the source of suspicion or diagnosis of epilepsy (H (3, N = 97) = 15.2, P = .001, Fig. 1B). The CWE who did not had suspicion or diagnosis of epilepsy (1 (0–2) year) were arriving faster at the CSMT than the CWE for whom suspicion was emanating from family or relatives (4 (2–8) years, P = .0021).

Duration I did not vary with the type of the previous treatment (H (3, N = 102) = 3.7, P = .29).

There was a relationship between the type of the previous treatment and the duration II of the therapeutic itinerary (H (3, N = 102) = 14.7, P = .002, Fig. 1C). The CWE who had not previously received antiepileptic treatment (0 (0–0) year) had a duration II shorter than the CWE treated with AED combined with traditional treatment (2 (1–3) years; P = .041) and the CWE treated with traditional treatment alone (1 (0–4) year, P = .027).

The total duration was also varied with the types of antiepileptic treatment (H (3, N = 102) = 8.5, P = .037, Fig. 1D), but the multiple comparisons of mean ranks failed to find which groups were different.

3.4. Analysis of characteristic of the therapeutic itinerary according to sociodemographic characteristics and characteristics of epilepsy

The per capita daily expenditures of the CWE's families without suspicion nor diagnosis of epilepsy (1.45 ± 0.70 $) were higher (t = 2.1, P = .035, Fig. 2A) than those of the families of the CWE whose epilepsy had been suspected or diagnosed by the traditional healers (1.00 ± 0.66 $) taken together with those of the families of the CWE whose epilepsy had been suspected by a family member or a relative (1.09 ± 0.73 $).

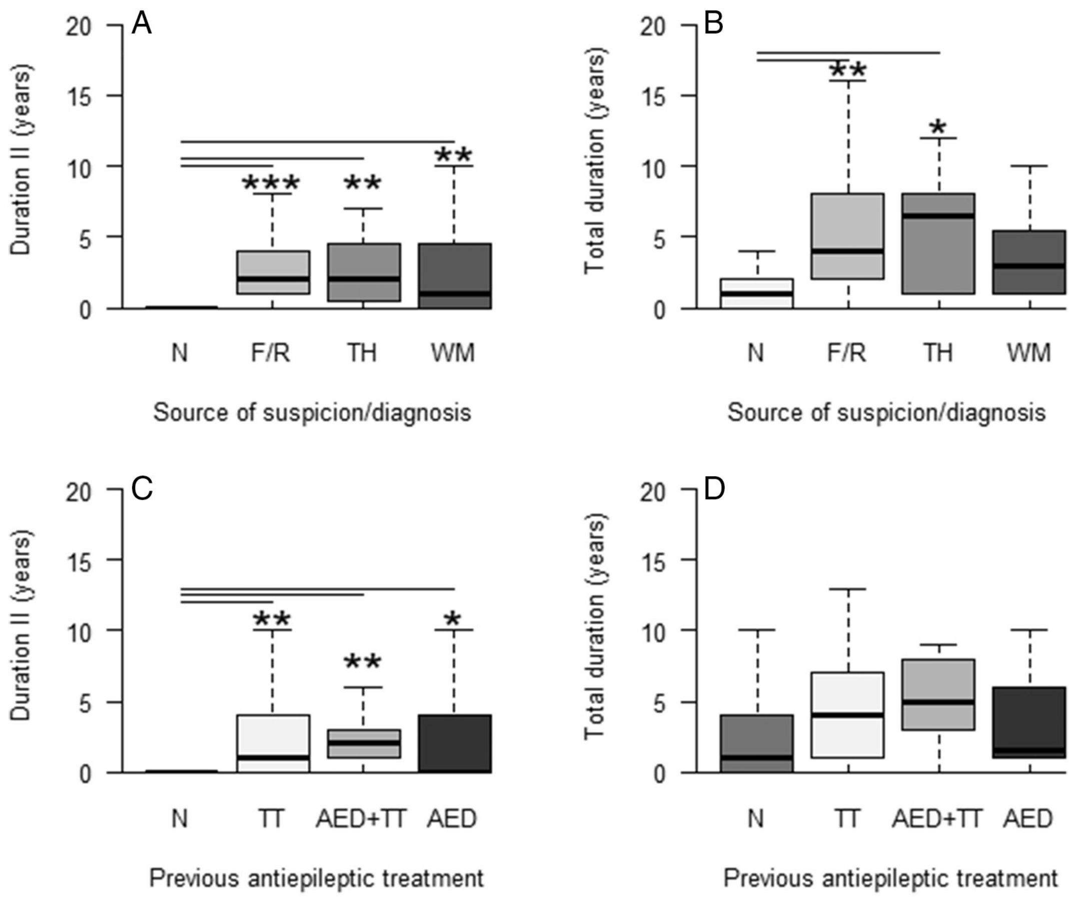

Fig. 1. Duration of the therapeutic itinerary according to the first source of suspicion or diagnosis of epilepsy and the type of antiepileptic treatment. N = none; F/R = family or relatives; TH = Traditional healer; WM = Western Medicine; TT = traditional treatment; AED + TT = antiepileptic drug and traditional treatment; AED = antiepileptic drug. *: P < .05; **: P < .01; ***: P < .001.

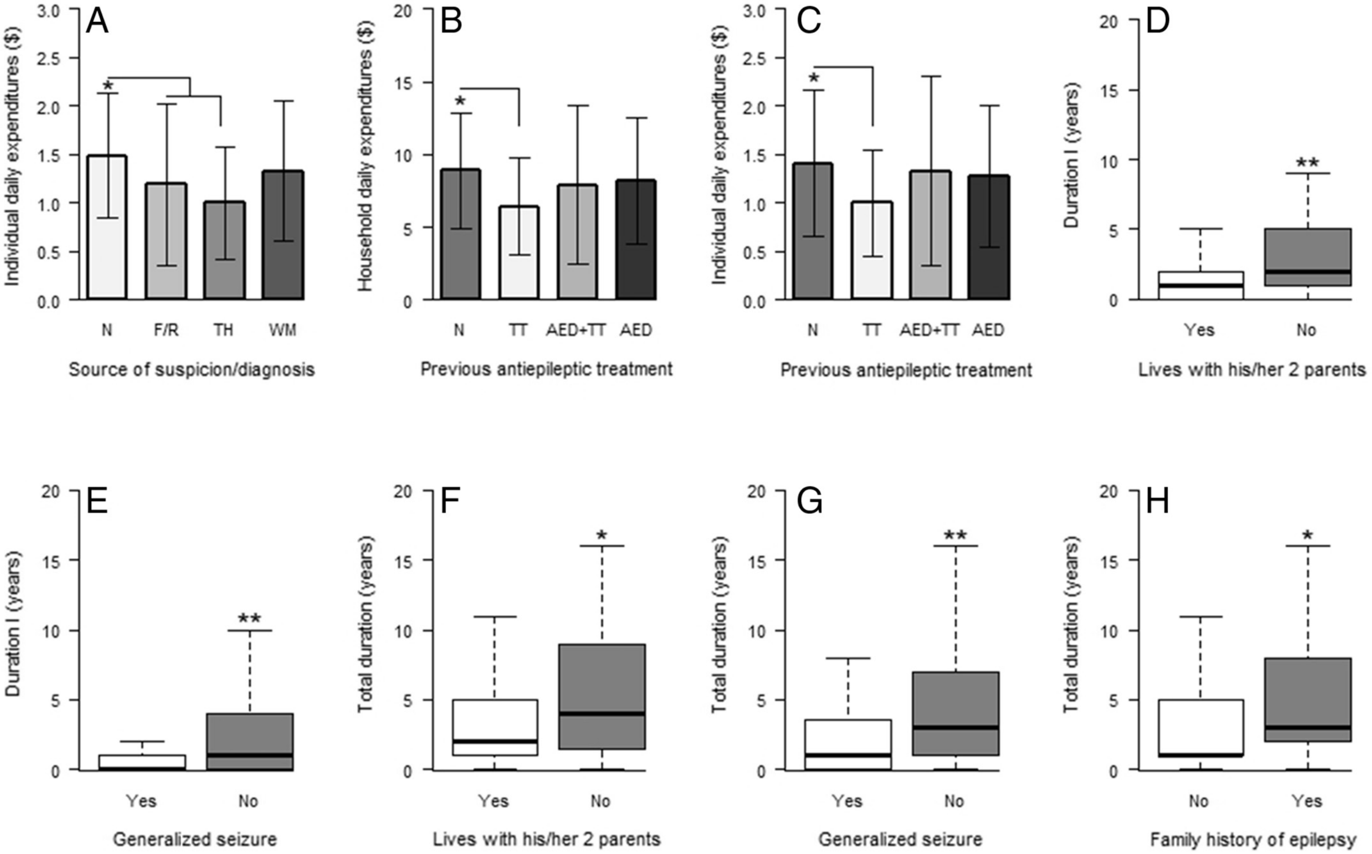

Fig. 2. The features of the therapeutic itinerary and sociodemographic and clinical characteristics of children living with epilepsy. N = none; F/R = family or relatives; T = traditional healer; WM = Western medicine. TT = traditional treatment; AED + TT = antiepileptic drug combined with traditional treatment; AED = antiepileptic drug. *: P < .05; **: P < .01; ***: P < .001.

The families of CWE previously traditionally treated had daily expenditures per household (6.42 ± 3.26 $ versus 8.80 ± 3.97 $, t = 2.4, P = .018) and per individual (0.99 ± 0.58 $ versus 1.37 ± 0.71 $, t = 2.2, P = .029) lower than those of previously untreated CWE (Fig. 2B and 2C).

The CWE who were living with both of their parents had a shorter duration I than the other CWE (1 (0–2) year versus 2 (1–5) years, N = 98, *U* = 550.5, P = .0037, Fig. 2D). Duration I was shorter for the CWE with generalized seizures than for the CWE with other types of seizures (0 (0–1) year versus 1 (0–4) year, N = 96, *U* = 697.0, P = .0032, Fig. 2E). Duration I was negatively correlated with age at first epileptic seizure (ρ = −0.41, P = .000016, Table 4).

Duration II was positively correlated with age (ρ = 0.22, P = .026, Table 4). This duration was negatively correlated with the age at the first seizure (ρ = −0.21, P = .032), the family's daily expenditures per household (N = 98, ρ = −0.22, P = .026), and daily expenditures per individual of household (N = 98, ρ = −0.26, P = .0097).

The total duration was shorter for CWE who were living with both of their parents (2 (1–5) years versus 4 (1.5–9) years, N = 98, *U* = 638.5, P = .038, Fig. 2F), who had generalized seizures (1 (0–4) year versus 3 (1–7) years, N = 96, *U* = 718.5, P = .0073, Fig. 2G), or who did not have a history of epilepsy in their family (1 (1–5) year versus 3 (2–8) years, *U* = 950.0, P = .019, Fig. 2H). The total duration was positively correlated with age (ρ = 0.33, P = .00064, Table 4) and negatively correlated with age at first epileptic seizure (ρ = −0.54, P < .000001).

Table 4
Matrix of correlations of the durations of the therapeutic itinerary.

	Age		Age of onset		DEH		DEI	
	ρ	P	ρ	P	ρ	P	ρ	P
Duration I	0.179	.068	−0.409	<.001	0.066	.52	0.171	.093
Duration II	0.218	.026	−0.210	.032	−0.225	.026	−0.260	.0097
Total duration	0.329	<.001	−0.539	<.001	−0.163	.11	−0.097	.34

DEH: Daily expenditures per household. DEI: Daily expenditures per individual.

3.5. Relationship between the therapeutic itinerary, the behavioral problems, and the cognitive impairment

There was no relationship between the first source of suspicion and the externalized behavioral problem (Chi-square = 1.3, df = 3, P = .73) and between the first source of suspicion and the total behavioral problem (Chi-square = 2.7, df = 3, P = .44). There was a relationship between internalized behavioral problem and the first source of suspicion or diagnosis of epilepsy (Chi-square = 8.5, df = 3, P = .036; see supplementary materials). Compared with that of the other groups, the proportion of the internalized problem was higher among the CWE who had been suspected of having epilepsy by family or by relatives (P = .0060; α corrected 0.05/(4 × 2) = 0.00625).

The previous antiepileptic treatment was neither associated with the externalized behavioral problem (Chi-square = 4.5, df = 3, P = .21), with the internalized behavioral problem (Chi-square = 4.4, df = 3, P = .22), nor with total behavioral problem (Chi-square = 5.2, df = 3, P = .15).

Except for the relationship between duration II and the total behavioral problem, all the durations were similar for the CWE with behavioral problems and those without behavioral problems (all P > .05). Indeed, the CWE with a total behavioral problem had a duration II (1.5 (0–4) year versus 0 (0–2.0) year, *U* = 821.5, P = .021) greater than those of the CWE without total behavioral problem (Fig. 3A).

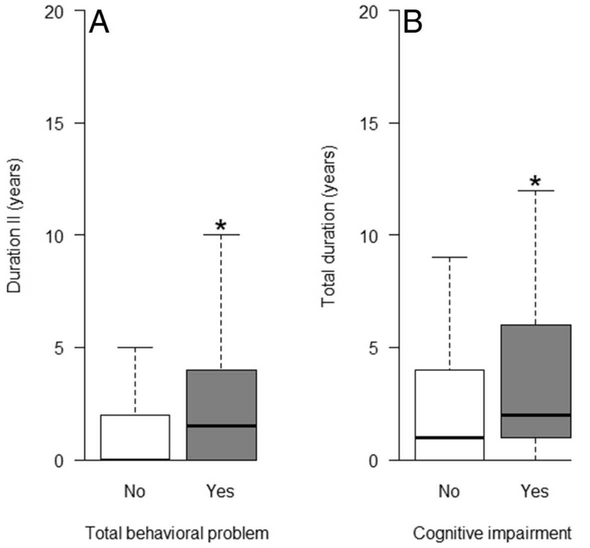

Fig. 3. Behavioral disorder, cognitive impairment, and the duration of therapeutic itinerary. *: P < .05; **: P < .01; ***: P < .001.

Cognitive impairment was neither associated with the first source of suspicion or diagnosis (Chi-square = 2.9, df = 3, P = .41) nor with the previous antiepileptic treatment (Chi-square = 4.3, df = 3, P = .23). The CWE with cognitive impairment had the same durations I (1 (0–2) year versus 0 (0–1.5) year, $U = 647.5$, P = .17) and II (0 (0–3) year versus 0 (0–0.5) year, $U = 602.5$, P = .051) compared with the CWE without cognitive impairment. On the other side, the CWE with cognitive impairment had a longer total duration of the therapeutic itinerary than the CWE who did not have cognitive impairment (2 (1–6) years versus 1 (0–4) years, N = 90, $U = 541.0$, P = .021, and Fig. 3B).

4. Discussion

4.1. Characteristics of the therapeutic itinerary

The first goal of this study was to describe the therapeutic itinerary of the CWE. The results of this study, as observed by very few authors [16], have shown that the first consultation unfold mainly in a Western medicine structure. This result is in contradiction with the vast majority of data from the sub-Saharan African literature describing therapeutic itinerary that begins with traditional medicine or prayer [1–3]. These studies have included only adults [1,2] or both adults and children [3]. The therapeutic itinerary of CWE could differ from that of adults living with epilepsy. Probably, at the first consultation, the CWE are treated as suffering from other common diseases in Africa, such as cerebral malaria and meningoencephalitis, which can be manifested by epileptic seizures. It has been observed that some CWE were treated with antimalarials and/or antibiotics [7,17].

After the first type of consultation, the therapeutic itinerary was closer to that described in the sub-Saharan Africa literature [2]. The trigger for this change would be the suspicion or the diagnosis of epilepsy. Indeed, in sub-Saharan Africa, epilepsy is considered as having a spiritual origin [1,16]. In Kinshasa, epilepsy is described by the population as "*maladi ya ndeke*" (bird disease). This name does not apply to epileptic seizures of other clinical entities such as cerebral malaria or meningitis. Aujoulat et al. [18] have shown that in sub-Saharan Africa the name of a disease influences the choice of the type of treatment. These researchers have observed that according to its name, the same disease is treated either by Western medicine or by traditional treatment. This could explain why the families of children with epilepsy who had the information by the family or by the relatives had turned more often to traditional medicine. Conversely, families of children with epilepsy who did not suspect "maladi ya ndeke" as the disease of their child went to CSMT or to other health facilities.

As elsewhere in sub-Saharan Africa, the total duration of the therapeutic itinerary of CWE observed in this study was very long. It was similar to the average duration of 2.2 years observed by Doumbia-Ouattara et al. [3] in Ivory Coast. Moreover, these authors have described that PWE spend up to 3.6 years before taking an antiepileptic drug. However, the total duration of the therapeutic itinerary observed in our study was much lower than the 4.7 years observed in Zambia [6].

This therapeutic itinerary beginning in Western medical structures and then moving on to antiepileptic treatments based on beliefs, highlights the difficulties of the health facilities in diagnosing and in managing epilepsy. This motivates the struggle of many researchers in sub-Saharan Africa for a better training of healthcare workers at the primary level of the healthcare pyramid [15,19].

4.2. Relationships between the characteristics of the therapeutic itinerary

The results of this study have shown that the first source of suspicion or diagnosis, the previous antiepileptic treatment, and the duration (duration II and total duration) of the therapeutic itinerary were statistically associated. These characteristics express the different facets of the therapeutic itinerary. The associations among these features could be summed up in a simplistic way; the more the first source of information about the disease was not accurate, the more the families consulted many actors and took different types of treatment, and this was lengthening the time before reaching a care structure appropriate to manage epilepsy [1]. For example, Koba Bora et al. [7] in Lumbumbashi, another city of the DRC, have noted that PWE spent fifteen months between their first visit to a traditional healer and their arrival in an appropriate health facility. Moreover, Birbeck [6], in Zambia, has found that the average 4.7 years of total duration of the therapeutic itinerary grows to 9 years for the PWE who have resorted care to traditional healers.

4.3. Therapeutic itinerary, sociodemographic, and clinical characteristics

This study has observed, like many other studies, that the type of antiepileptic treatment was associated with the socioeconomic conditions of the CWE's families [3,7,10,16]. The socioeconomic conditions were one of the main factors that were guiding the choice of the traditional treatment. Families of CWE who had benefited from the traditional treatment had less financial means and could not equally afford the current antiepileptic treatment. Matonda et al. [17] have found that these CWE had clinical outcomes more severe than the CWE that did not received antiepileptic treatment prior their arrival at the CSMT.

Few factors were associated with the duration I. As observed by others authors, this duration was reducing with generalized seizures [9] and was increasing with an early onset [1]. The children who were living with both of their parents had suspicion or diagnosis of epilepsy more rapidly. The reason is not clear to us. Perhaps the level of education would have played a role [1,3,9]. Is it because, in the DRC, men have higher level of education than women? The CWE who were living with their fathers could thus receive the suspicion or diagnosis of epilepsy earlier. It may also be that keeping in touch with the families of both parents could increase the number of "experts" of the disease, or the fact that the parents are together reduces the time for consultation and/or fundraising for CWE's care. Be that as it may, this has reduced the total duration of the therapeutic itinerary for the children who were living with both parents.

In this study, several factors were associated with the total duration of the therapeutic itinerary. Like other authors [1,9], this study has found that nongeneralized seizures, young age, and early onset have lengthened the total duration of the therapeutic itinerary. These variables would reflect the difficulties of diagnosing epilepsy, particularly in toddlers [9]. Moreover, at this age, many conditions, such as cerebral malaria and meningitis, that can also manifest themselves by epileptic seizures may have increased the difficulty of diagnosing epilepsy.

The existence of a family history of epilepsy had lengthened, paradoxically, the total duration of the therapeutic itinerary. Probably, those who had a history of epilepsy in the family were wasting time seeking treatment based on belief. Two elements could explain this paradox. On the one hand, it is difficult for sub-Saharan Africans to accept the chronicity of a disease as being natural [16,18], and on the other hand, a failure, real or perceived as such, of a drug treatment in the other family member suffering from epilepsy may explain the gravitation toward belief-based treatment [16,18]. Moreover, the families do not exclude that epilepsy may be cured without the use of any antiepileptic drug, particularly for cultural beliefs [10,16].

4.4. Therapeutic itinerary, behavioral problems, and cognitive impairment

The results of this study showed that internalized behavioral problem was more common among the CWE who had received the first information about their illness from a relative. Thus, the CWE would be sensitive to whoever first suspected or diagnosed their illness or to what was said to them the first time about epilepsy. Conversely, receiving the suspicion or the diagnosis by the different caregivers, from Western medicine as well as from traditional healers, does not increase the internalized behavior problem more than the ignorance of the disease. These caregivers seem to be holding a nontraumatic communication or nontraumatic attitudes for the CWE. Particularly for traditional medicine, this finding echoes the observation of the authors who have examined the beneficial role of traditional healers on the psyche of the patients [20]. Thus, one can conclude that the traditional medicine would have no side effect on the psyche of CWE. However, by lengthening of the total duration of the therapeutic itinerary, the traditional medicine would have side effects on the other clinical features of CWE [6,9].

In this study, the CWE with total behavior problem compared with the other CWE had greater duration II. These relationships seem to highlight the crucial role of the announcement of and the period after the suspicion or the diagnosis of epilepsy. This goes in the same sense for the association between the internalized behavioral problem and the first source of suspicion or diagnosis of epilepsy. Some factors associated with duration II, example socioeconomic situation, have been shown to favor behavior problems [21].

Among the different characteristics of the therapeutic itinerary, only the total duration of the therapeutic itinerary was associated with cognitive impairment. Our result is consistent with that of researchers working on the consequences of delayed diagnosis and management of epilepsy [9]. This relationship between the total duration of the therapeutic itinerary and the cognitive impairment is very important. As the care pathway begin in the health facilities, the improvement of the ability of these care providers to manage epilepsy could reduce the total duration of the therapeutic itinerary and therefore could reduce the occurrence of cognitive impairments.

4.5. Limits

This study is a hospital-based study, and thus, the CWE included in this study are not representative of all the CWE of Kinshasa. Nevertheless, most of our results are consistent with the literature data. Moreover, to our knowledge, this study is the first one devoted to the therapeutic itinerary of CWE. It raises several interrogations that could be subjects of others studies on the therapeutic itinerary of these children.

5. Conclusion

This study, contrariwise to the results of the vast majority of studies, has found that the therapeutic itinerary of the CWE has begun with Western medicine. This could highlight the difficulties of the health structures to diagnose and to manage epilepsy. The rest of the therapeutic itinerary, with belief-based treatments, was similar to what is reported in the sub-Saharan literature. This therapeutic itinerary was closely related to the clinical characteristics and socioeconomic conditions in where the CWE live. This therapeutic itinerary was also associated with behavioral problems and cognitive impairment.

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Disclosures

The authors do not have any conflicts of interest to disclose.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.yebeh.2018.11.035.

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