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ABSTRACT

A multicentre face-to-face interview was conducted to identify factors contributing to the marital status of people with epilepsy (PWE) in Korea. The marriage rate of PWEs was only 80% and the divorce rate was more than double that in the general population. Among the single subjects, 34% replied that they were unmarried because of epilepsy, and 76% of divorced PWEs replied that epilepsy was the cause of the divorce. The factors affecting the single and divorced status in PWEs included gender, an earlier onset of seizure and seizure onset before marriage. Not informing the spouse of the disease before marriage for fear of discrimination was not related to disadvantage in marriage negotiation or to divorce. Social stigmatization of epilepsy continues and impacts on the marital status of PWEs in Korea. However, there is no correlation between the perceived and the enacted stigmas of epilepsy.

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1. Introduction

Epilepsy has serious adverse effects on various aspects of social life. It is generally agreed that people with epilepsy (PWE) are less likely to marry and more likely to divorce than the general population.^{1–5} Such an undesirable social phenomenon affecting PWEs can be attributed largely to the social stigmatization of epilepsy. The social effects of the stigma on PWEs varies from culture-to-culture and from country-to-country, as demonstrated in a previous study.^{4–7}

A distinction can be made between perceived and enacted stigma. Perceived stigma refers to the shame of being epileptic and the fear of encountering epilepsy-linked enacted stigmata; whereas enacted stigma refers to actual episodes of discrimination.⁶ In this context, it might be typical behaviour of perceived stigmatized PWEs such that the majority do not inform the spouse about their illness before marriage for fear of any disadvantage in the process of marriage negotiation.^{4–6} Unfortunately, the dishonest behaviour caused by the perceived stigmatization offers the spouse a legitimate reason for divorce as an extreme result of enacted stigmatization of epilepsy.^{4–6}

There have been few studies worldwide of the potential contributors to an undesirable marital status of PWEs and the influence of stigmatization of epilepsy on marital life of PWEs.

2. Subjects and methods

A multicentre, cross-sectional design was used in an attempt to approximate a national sample, to acquire basic data on and to clarify factors that contribute to the marital status of Korean PWEs. A face-to-face interview with a standardized questionnaire was conducted in 2007 at 9 regional epilepsy centres that cover 3 of the 5 large geographic and administrative areas in Korea: 3 in Seoul, the capital city; 3 in the Honam district, which includes the cities of Gwangju and Iksan; and 3 in the district of Youngnam, which include the cities of Busan, Daegu and Jinju.

The criteria for inclusion in the study were: treated for at least 1 year at an epilepsy clinic; not mentally impaired ($IQ \ge 70$); between 20 and 60 years of age. The survey questionnaire was designed to gather information about demographic and clinical features, including marital status of PWEs and contained 7 questions to define how the epilepsy-linked perceived or enacted stigma influenced the married life of PWEs (Appendix A). The medical records of the study participants were reviewed retrospectively at each centre to characterize clinical features.





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Table 1	
Characteristics	of subjects.

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	Men	Women	<i>p</i> -value
Age (years)	(<i>n</i> =276)	(<i>n</i> =308)	
Mean \pm SD	${\bf 35.84 \pm 10.517}$	$\textbf{35.76} \pm \textbf{9.982}$	0.925
Age range (years)	(n = 276)	(<i>n</i> =308)	
20–29	91(32.1%)	99(32.1%)	0.928
30–39	89(32.2%)	107(34.7%)	
40-49	60(21.7%)	65(21.1%)	
50-60	36(13.0%)	37(12.0%)	
Age of seizure onset (years)	(<i>n</i> =276)	(<i>n</i> =308)	
Mean \pm SD	21.47 ± 12.084	20.07 ± 10.869	0.152
Age at first marriage ^a	(<i>n</i> =131)	(<i>n</i> =202)	
	29.17 ± 3.922	25.79 ± 3.610	0.000
Level of education (years)	(<i>n</i> =265)	(<i>n</i> =297)	
0	7(2.6%)	14(4.7%)	0.236
1–6	21(7.9%)	26(8.8%)	
7–12	119(44.9%)	147(49.5%)	
>12	118(44.5%)	110(37.0%)	
Seizure classification	(n=263)	(<i>n</i> =294)	
IGE	25(10.1%)	32(12.0%)	0.809
SPS/CPS only	75(30.2%)	78(29.2%)	
Second. GTCS	148(59.7%)	157(58.8%)	
Unclassified ^b	15	27	
Remission status	(n=263)	(<i>n</i> =295)	
Remission	105(42.3%)	125(45.3%)	0.537
Not in remission	143(57.7%)	151(54.7%)	
Undetermined ^b	15	19	

n: number of respondents to the corresponding question; SD: standard deviation; IGE: idiopathic generalized epilepsy; SPS/CPS: simple/complex partial seizure; Second. GTCS: secondary generalized tonic-clonic seizure.

^a Data for the married only.

^b Not included in the statistical analysis.

With respect to the remission status of epilepsy, refractory epilepsy was defined as the occurrence of more than one unprovoked seizure a year in the course of treatment of epilepsy, with trials of two or more appropriate anti-epileptic drugs (AEDs) at maximal tolerated doses, which were established on the basis of the occurrence of clinical side-effects at supramaximal doses. Responsive epilepsy was defined as treatment with an appropriate AED with complete freedom from seizures for at least 1 year before the beginning of the study. The recurrence of seizures during a planned AED withdrawal period or an AED changing period was considered as suitable inclusion criteria for AED responsiveness. PWEs who were frequently in poor compliance with AED therapy and those who had reported seizures with a questionable semiology were classified as undetermined with respect to AED responsiveness. The marital status at the beginning of the survey was defined as: single for a subject who was not and had not been married; married for a subject who was or had been married; bereaved for a subject whose spouse had died. The study was approved by the Ethical Committee of Chonnam National University Hospital, and informed consent was obtained from all subjects.

All statistical analysis was done with SPSS software (version 17.0 for Windows; SPSS Inc., Chicago, IL) and included the use of Student's *t*-test for independent samples, Pearson's χ^2 -test, and Fisher's exact test to evaluate the statistical significance of the differences in the survey responses. Univariate or multivariate logistic regression analysis was used in attempts to clarify the potential contributing factors affecting the current marital status of PWEs, while avoiding the possible influence of confounders on the results. The level of statistical significance was set as p < 0.05.

3. Results

3.1. Demographic and clinical characteristics

The demographic and clinical characteristics of the subjects are given in Table 1. In brief, 584 Korean PWEs (276 men and 308 women) were recruited and there was no significant difference between genders for: mean age at the start of the survey; mean age at seizure onset; educational career; seizure classification; or remission status. The overall rate of refusal to participate in the study was 15.7%.

3.2. Marital status in Korean PWEs

Of the 584 PWEs in the present study, 251 were single. The marriage rate among subjects aged 20–60 years was 0.57, which is 80.4% of that expected in the general population according to the 2005 Korean Statistical Information Service data (http://www.ko-sis.kr/domestic/). Men with epilepsy (47.5%) were less likely to marry than women with epilepsy (65.6%; Table 2). The divorce rate among PWEs aged 20–60 years was 11.4%, which is more than double the 5.1% value among the general population in the same age range (2005 Korean Statistical Information Service data; http://www.kosis.kr/domestic/; Table 2). Of the 38 divorced subjects, 15.8% had a second marriage (Table 2).

3.3. The potential contributory factors affecting the marital status of Korean PWEs

Among the single subjects (n = 251), 34.4% replied that they were unmarried because of epilepsy. A multivariate logistic regression analysis showed that the potential contributors

Table 2	
Marital status	of Korean PWEs.

	Total	Men (<i>n</i> =276)	Women (<i>n</i> = 308)
Single	251(43.0%)	145(52.5%)	106(34.4%)
Married	333(57.0%)	131(47.5%)	202(65.6%)
Divorced	38(11.4%) ^a	14(10.7%)	24(11.9%)
Second marriage	6(15.8%) ^b	0(0%)	6(100%)
Bereaved	5(1.5%) ^a	0(0%)	5(100%)

PWE: people with epilepsy.

^a Proportion in the married (n = 333).

^b Proportion in the divorced (n=38).

95%CI	
	95%Cl

Table 3

	AOR	95%CI	<i>p</i> -value	Adjusted factor
Gender				
Women	1	-	-	Age
Men	3.4476	2.214-5.460	<0.001	
Age of seizure onset (years)				
>20	1	-	-	Gender
≤ 20	2.567	1.786-3.690	<0.001	
Women>20	1	-	-	Gender
Men≤20	5.536	3.224-9.506	<0.001	

PWE: people with epilepsy; AOR: adjusted odds ratio; CI: confidence interval.

Coded as 'single' = 1 and 'married' = 0.

affecting the single status in PWEs were gender and age of seizure onset; a 3.5-fold greater probability of being single for men than for women (95% confidence interval (CI) = 2.108–5.767, *p* < 0.001; adjusted for age) and a 2.6-fold greater probability for PWEs with seizure onset before 20 years of age than for PWEs with seizure onset after 20 years of age (95% CI = 1.786-3.690, p < 0.001; adjusted for gender). In particular, the probability of being single for men with seizure onset \leq 20 years of age was 5.5-fold greater than that for women with seizure onset >20 years of age (95% CI = 3.224–9.506, *p* < 0.001; Table 3).

About 76% of the divorced PWEs (n = 38) said that epilepsy was the cause of the divorce. Table 4 summarizes the demographic and clinical characteristics of the divorced PWEs and the results of logistic regression analysis to clarify the potential contributors affecting the status of divorce. For the divorced subjects, the age at the beginning of the survey was 39.5 ± 7.78 years and at the time of the first marriage it was 26.7 \pm 4.56 years, which was similar to the age of PWEs who were still married (p > 0.05).

The potential contributors affecting the status of divorce in Korean PWEs were: earlier onset of seizure; seizure onset before marriage; absence of offspring in married life with ex-spouse; and a lower level of education. The odds of divorce were: 0.96-fold less in PWEs who had seizure onset at >20 years of age than in PWEs who had seizure onset at <20 years of age (95% CI = 0.929–0.991, *p* = 0.012; adjusted for gender); 4.5-fold greater in PWEs who had seizure onset before marriage than in PWEs who had seizure onset after marriage (95% CI = 1.465 - 13.624, p = 0.009; adjusted for gender and age); 4-fold greater in PWEs who had no offspring than in PWEs who had offspring (95% CI = 1.771 - 9.755, p = 0.001; adjusted for gender and age); and the PWEs who had >12 years of formal education were less likely to be divorced than the PWEs

Table 4

The potential contributing factors affecting the status of divorce in Korean PWEs.

Factors (number of respondents)	Divorce (%)		Logistic re	Logistic regression, multivariate ^a		
	Yes	No	AOR	95% CI	p-value	Adjusted factor
Gender (333)						
Women	24(11.9)	178(88.1)	1	-	-	Age
Men	14(10.7)	117(89.3)	0.96	0.47-1.96	0.961	
Age, mean \pm SD, year (333)						
20-39	20(52.6)	133(45.1)	1	-	-	Gender
≥ 40	18(47.4)	162(54.9)	0.75	0.38-1.49	0.408	
Age of seizure onset, year (321)						
≤20	23(62.2)	136(47.9)	1	-	-	Gender
>20	14(37.8)	148(52.1)	0.96	0.93-0.99	0.012	
Seizure onset (294)						
After marriage	4(11.8)	101(38.8)	1	-	-	Age, Gender
Before marriage	30(88.2)	159(61.2)	4.47	1.47-13.62	0.009	
Type of marriage (298)						
Arranged marriage	9(5.7)	150(94.3)	1	-	-	Age, Gender
Non-arranged marriage	17(12.2)	122(87.8)	2.13	0.87-5.20	0.098	-
Level of education, year (320)						
0	3(7.9)	15(5.3)	1	-	-	Age, Gender
1-6	5(13.2)	29(10.3)	1.22	0.25-5.88	0.804	
7–12	24(63.2)	136(48.2)	0.80	0.27-2.38	0.687	
>12	6(15.8)	102(36.2)	0.26	0.07-0.96	0.044	
Remission status (323)						
Remission	13(34.2)	128(44.9)	1	-	-	Age, Gender
Not in remission	24(63.2)	135(47.4)	1.74	0.85-3.57	0.133	
Undetermined ^b	1(2.6)	22(7.7)	-	-	-	-
Spouse's awareness (321)						
After marriage	19(50.0)	195(65.4)	1	-	-	Age, Gender
Before marriage	19(50.0)	98(34.6)	1.79	0.87-3.68	0.113	-
Number of children (304)						
≥1	22(66.7)	244(90.0)	1	-	-	Age, Gender
0	11(33.3)	27(10.0)	4.16	1.77-9.76	0.001	

PWE: people with epilepsy; AOR: adjusted odds ratio; CI: confidence interval; SD: standard deviation.

Coded as divorced = 1 and not = 0.

^b Not included in statistical analysis.

Table	5
n 1	

Relationship among perceived and enacted stigmata and divorce rate.

Questions (%)	Divorce rate (%)	<i>p</i> -value	Spouse's awareness before marria	age ^a
Spouse made aware before marriage,	<i>n</i> = 186 ^b			
Yes, 107(57.5)	15.0	0.688	Yes	No
No, 79(42.5)	17.7		p-value	
Disadvantageous in marriage negotia	ion, $n = 186^{b}$			
Yes, 28(15.1)	28.6	0.001	18(16.8%)	10(12.7%)
No, 158(84.9)	13.9		0.535	
Suffered unreasonable treatment by s	pouse, <i>n</i> = 321			
Yes, 54(16.8)	27.8	0.000	24(20.5%)	30(14.7%)
No, 267(83.2)	8.3		0.215	
Spouse filed for divorce, $n = 321$				
Yes, 29(9.0)	69.0	0.000	14(12.0%)	15(7.4%)
No, 292(91.0)	6.0		0.224	
Disadvantageous in raising children, 1	= 321			
Yes, 62(19.3)	14.5	0.384	26(22.2%)	36(17.6%)
No, 259(80.7)	10.8		0.378	
Spouse understands the illness well, n=321				
Yes, 200(62.3)	2.4	0.000	86(73.5%)	114(55.9%)
No, 121(37.7)	27.3		0.002	
Content with current married life, n=	276			
Yes, 179(64.9)	2.7	0.000	73(65.2%)	106(64.6%)
No, 97(35.1)	19.2		0.310	

^a Concerns only respondents who replied "yes" to questions in the far left column.

^b Concerns only respondents with seizure onset before marriage; *n*: number of respondents.

who were not educated at all (OR = 0.097, 95% CI = 0.071–0.964, p = 0.044; adjusted for gender and age). However, gender, age, type of marriage (arranged or not arranged), remission status of epilepsy, and spouse's awareness before marriage, did not affect the status of divorce in Korean PWEs (Table 4).

3.4. The effect of epilepsy-linked stigma on the married life of PWEs

About 43% of 186 subjects who had seizure onset before marriage replied that they had not informed their spouse of epilepsy before marriage for fear of discrimination in the marriage negotiation (perceived stigma). With respect to epilepsy-linked enacted discrimination, 16.8% of 186 respondents who had seizure onset before marriage replied that this factor had been disadvantageous in the marriage negotiation, 8.8% of married respondents replied that they had filed for divorce, 16.5% had suffered unreasonable treatment by the spouse, and 18.7% had been at a disadvantage in raising their children because of the illness itself. About 64% of the respondents said that the spouse had a good comprehension of their illness and 65.5% said that they were content with their current married life (Table 5). No gender difference was noted in suffering resulting from enacted discrimination; however, men with epilepsy were more likely to be content with their married life than women with epilepsy (73.1% vs. 60.9%, p = 0.04).

Only 186 respondents who had a seizure before marriage were included in the analysis designed to clarify the influence of epilepsy-linked perceived stigma on the enacted stigmata that PWEs had actually experienced. Only 16.8% among 107 PWEs who had informed their spouse about the epilepsy before marriage said that they had actually experienced disadvantages in the marriage negotiation, while 12.7% among 79 PWEs who had not informed their spouse about the epilepsy said that they had experienced disadvantages in the marriage negotiation (p = 0.535). There was no difference in enacted stigmata between PWEs who had and those who had not informed the spouse before marriage, except with respect to the level of contentment with current married life, which was significantly higher for PWEs who had than for the PWEs who had not informed the spouse of epilepsy before marriage (p = 0.005; Table 5).

With regard to the influence of seizure onset before or during marriage on the enacted stigmata, PWEs who had seizure onset before marriage were more likely to file for divorce and to have difficulty in raising children than those who had seizure onset while married (13.3% vs. 3.0%, p = 0.006 and 24.3% vs. 12.6%, p = 0.022, respectively). However, there was no difference in the degree of contentment with current married life (p = 0.180) between PWEs who had seizure before marriage and those who had seizure during married life.

The divorce rate among PWEs who had not informed their spouse about epilepsy was 15%, which was similar to that among PWEs who had informed their spouse about epilepsy (17.7%). However, the divorce rate for the PWEs who had experienced an epilepsy-linked enacted discrimination was significantly higher than those who had not; specifically, 32.3% vs. 9.7% (p = 0.001) with respect to a disadvantage in the marriage negotiation, 69.0% vs. 6.0% (p < 0.001) in filing for divorce, 27.8% vs. 8.3% for suffering unreasonable treatment by their spouse, 27.3% vs. 2.4% (p < 0.001) in spouse's comprehension of epilepsy, and 19.2% vs. 2.7% (p < 0.001) in contentment with married life. Epilepsy-linked disadvantages in raising children did not affect the divorce rate of PWEs (p = 0.384; Table 5).

4. Discussion

Recent studies worldwide have reported improvements in the public's attitude toward epilepsy,^{7,8} yet negative public attitude toward PWEs persist. Many people believe that PWEs should not marry and that they would object to their child marrying a PWE, even when seizures are well controlled. Not surprisingly, discrimination against PWEs is shared to different degrees worldwide, regardless of ethnicity, culture or country.^{7,9–12} In addition to direct social discrimination against PWEs (an enacted or externalized stigma), the public's negative attitude can be attributed to the perceived stigmatization of epilepsy in PWEs based on fear of encountering negative experiences in the marriage negotiation (internalized stigma), as suggested in an earlier study.⁶ Therefore, it appears to be reasonable that the interaction between externalized and internalized stigmata of epilepsy can influence the marital status of PWEs.

In the present study, the marriage rate among PWEs was only 80% and the divorce rate was more than twice as high as that in the general population. About one-third of the single and three-fourths of the divorced PWEs ascribed their undesirable marital status to epilepsy *per se*. Seizure-related clinical characteristics of PWEs, such as seizure classification and remission status, did not appear to exert a negative influence on the current marital status, in agreement with earlier studies.^{5,13} In a study conducted recently in Seoul, more than half of those questioned were opposed to marriage of their children to a PWE and to childbearing by women with epilepsy.¹⁴ These results suggest that epilepsy-linked internalized or externalized stigmata or both, rather than epilepsy *per se*, influence the marital status of PWEs in Korea.

In the current study, after adjusting for the confounding effects of gender and/or age, on which the marital status of an individual is highly dependent, men with seizures of an earlier onset were more likely to be single, and PWEs who had seizures of an earlier onset, primarily before marriage, a lower level of education, and PWEs who had no children in their married life before divorce, were more likely to be divorced. A lower rate of marriage for males with seizures of earlier onset seems to be a global phenomenon.^{3,4,15} It has been stated that childhood-onset epilepsy might have indirect adverse effects on personality, psychosocial maturation, and academic achievement of an individual, which can be conveyed through lower parental expectations, ambivalent overprotection, or negative peer group attitude, some of which might persist even when the epilepsy is in remission.¹³ In addition, these interpersonal stigmata that occur in interactions with others, both within and external to the family system, might cause significantly higher rates of unemployment and lower socioeconomic status,¹³ which is an unfavourable condition, especially for men of marriageable age. The present study revealed that a higher rate of divorce in PWEs can be attributed, in part, to the adverse effects of an earlier onset of seizures; however, the adverse effects can be overcome by a higher academic achievement in PWEs of school ages and a contented married life with children.

Studies conducted in Asian countries have reported that not informing the spouse of disease before marriage for fear of discrimination in various marital aspects, a common behaviour due to the perceived stigmatization of epilepsy, was the direct cause of divorce in PWEs and that the main victims of an undesirable result of the perceived stigmatized behaviour were women with epilepsy or PWEs who had entered an arranged marriage.^{4,5} Given the fact that women have been socially underprivileged in some Asian countries, such as India where men are thought to be superior to women,⁴ it seems natural that women with epilepsy are an easy target of social stigmatization of epilepsy and was much greater in those who concealed their illness before marriage. Even in developed countries, like Japan, the perceived stigmatized PWEs who enter an arranged marriage were more likely to be divorced than non-PWEs.⁵ However, in the present study, it was noted that the divorce rate among PWEs was not correlated with the perceived stigma that PWEs had before marriage, as well as the difference in gender or the type of marriage. In addition, the direct relationship of the perceived stigma with an enacted stigma that PWEs had encountered during their married life was not evident in the present study: thus. PWEs who disclosed their illness before marriage did not always suffer a more serious social discrimination in the matter of preserving a contented married life than PWEs who concealed their illness and vice versa. Instead, PWEs who had experienced an enacted stigmatization of epilepsy were significantly more likely to be divorced than those who had not. Gender discrimination is not causative of divorce or preserving a contented married life; rather, issues before or at the time of marriage are more important factors for Korean PWEs in avoiding divorce.

About 65% of married PWEs said that they were satisfied with their current married life. The degree of marital satisfaction of PWEs appears to be very similar to that of the general population in Korea; According to the Korean Longitudinal Survey of Women and Family in 2007 (http://klowf.kwdi.re.kr/ko/proceedingview), about 68% of the general population aged between 30 and 65 years old said that they were satisfied with their current married life. In the present study, there was no difference in the degree of contentment with current married life between PWEs who had seizure before the marriage or during married life. These results suggest that epilepsy *per se* is not a major factor affecting marriage of PWEs.

In conclusion, social stigmatization of epilepsy, including the perceived stigma of patients, continues and impacts on the marital status of PWEs in Korea. However, it is evident that there is no difference between the perceived and the enacted stigmata of epilepsy, such as disadvantage in the marriage negotiation or divorce. Therefore, there should be greater concerted public efforts to enable PWEs to come out of the shadow of the stigma of epilepsy and to create a more acceptable environment in which PWEs can be supported to deal with perceived stigma, as well as the social stigma, and to preserve a contented married life. Also, a public medical policy favourable to PWEs for early treatment with better seizure control will help in marital matters, and family counselling is needed for those facing marital conflicts and those at risk of marital discord and dissolution.

Author disclosure statement

The author declares that there are no competing financial interests.

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Appendix A. Questionnaire

[Seizure aspect]

- 1. Age at seizure onset; D years old
- 2. Seizure classification
 - □ Idiopathic generalized epilepsy
 - Simple or complex partial seizures or both
 - Secondary generalized tonic-clonic seizure
 - Unclassified
- 3. Remission status of epilepsy
 - Drug-responsive epilepsy (complete freedom from seizures with an appropriate AED)
 - Drug-refractory epilepsy (> 1 unprovoked seizure per year in the course of treatment of epilepsy with trials of > 2 appropriate AEDs at maximal tolerated doses)
 - □ Others (frequently in poor compliance or with vague semiology)

[Marital status]

- 4. Current marital status
 - □ I have never been married
 - \rightarrow If yes, due to \square Epilepsy *per se* \square Others \rightarrow end study
 - □ I have been married
 - \rightarrow If yes, type of marriage? \square Love \square Arranged
 - □ I have been divorced
 - \rightarrow If yes, due to \square Epilepsy *per se* \square Others
 - I have been remarried (for only those who have been divorced)
 - □ I have been bereaved

[Questions for those who have been married only]

- 5. Age at first marriage; □□ years old
- 6. Number of children from the first marriage; $\Box \Box$
- 7. I have informed my spouse of epilepsy before marriage; \Box Yes \Box No
- I have experienced disadvantages in marriage negotiation due to epilepsy;
 □Yes □ No
- 9. I have been treated inappropriately by my spouse due to epilepsy; □Yes □No
- 10. I have had divorce filed by my spouse due to epilepsy; \Box Yes \Box No
- 11. I have had disadvantages in raising children due to epilepsy; □Yes □No
- 12. The spouse comprehends my illness; Yes No
- 13. I am content with my current marriage life; \Box Yes \Box No

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