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From the Centers for Disease Control and Prevention Managing Epilepsy Well Network

Depression and quality of life among African Americans with epilepsy: Findings from the Managing Epilepsy Well (MEW) Network integrated database☆

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ABSTRACT

Depression and worse quality of life (QOL) are significantly associated with epilepsy. However, limited descriptive data on depression and quality of life among African Americans with epilepsy are available. This study sought to describe the prevalence of depression among African Americans with epilepsy participating in self-management studies and to examine the relationship between depression and QOL. Using data from the Managing Epilepsy Well (MEW) research network, a subgroup of African Americans with epilepsy were selected for the analytic sample. Descriptive statistics indicated the prevalence of depression (Patient Health Questionnaire-9 [PHQ-9]) and reports of epilepsy-specific QOL (Quality of Life in Epilepsy-10 [QOLIE-10]) in the sample. Multiple linear regression examined the relationship between depression and QOL while controlling for sociodemographic characteristics and seizure frequency. The prevalence of depression (PHQ-9 ≥; 10) was 47.7%. Quality of life was the only variable significantly associated with depressive symptoms in multivariable analyses, suggesting that depressive symptoms have a stronger relationship with QOL than seizure frequency. With the high levels of depression and the significant relationship with QOL, regular screening of depression is needed among African Americans with epilepsy. Self-management programs that improve mood may also play an important role in improving the lives of African Americans with epilepsy.

1. Introduction

People with epilepsy (PWE) report worse mental health and quality of life (QOL) compared with those without epilepsy [1]. Depression is among the most common comorbid mental health problems experienced by PWE [2]. While reports of depression among PWE range widely depending on the assessment method, a recent meta-analysis reports that clinically diagnosed depressive disorders are prevalent in about 23% of PWE [3]. However, the prevalence varied greatly across studies, ranging from 4.5%–84.2% [3]. Compared with people without epilepsy, PWE are 2.5-times more likely to report depression [4]. While more research is needed to understand risk factors for depression among PWE [5,6], a complex set of biological and social factors appear to contribute to depressive symptom severity (e.g., [7,8]). For instance, employment status [8], medication side effects [9], and other factors may contribute to depressive symptoms. These factors also contribute to QOL, which is linked to depressive symptom severity among PWE [10–16]. Moreover, QOL may be more strongly associated with depressive symptoms than other epilepsy-related variables, such as seizure severity or frequency [13,14]. While depression in the general population of PWE has been relatively well-studied; there is very limited research specific to depression and QOL among African Americans with epilepsy.

National estimates suggest that rates of epilepsy are similar across racial and ethnic groups [17–19]. However, estimates from select

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populations (e.g., Washington, DC; Medicare; and elderly and low-income) suggest that African Americans may have a higher prevalence rate of epilepsy [20–23]. Additionally, disparities in experiences of epilepsy exist for African Americans. For instance, African Americans are 30% less likely to obtain care from outpatient neurologists and more likely to receive care in emergency departments [24]. Furthermore, mortality rates are greater for African Americans with epilepsy compared with that of PWE from other racial and ethnic groups [25]. These disparities, in turn, could contribute to depressive symptoms and worse QOL.

Although some research suggests that African Americans with epilepsy have similar rates of depression compared to other racial and ethnic groups [26], in one recent study, African Americans with chronic medical conditions were found to be more likely to report depression compared with non-Hispanic white people with chronic medical conditions [27]. In the general population, African Americans are less likely to report depressive symptoms [28], but the burden of depressive disorders may be greater for African Americans compared with other racial and ethnic groups [29]. African Americans who experience depression are more likely to experience persistent depression and more likely to report that depression severely impairs their functioning [29].

Quality of life is significantly worse for PWE compared to those without epilepsy [1]. Epilepsy-specific QOL includes several domains including seizure worry, social function, and cognition [30]. Quality of life among PWE is significantly associated with seizure frequency [15], seizure severity [15,31], and adverse medication effects [16], as well as psychiatric comorbidities [10–16]. Studies have assessed QOL in PWE across racial and ethnic groups; some studies found limited differences in reports of QOL by race and ethnicity among PWE [12,26]. However, small sample sizes may have restricted the ability to detect differences across racial and ethnic groups [12]. In the general population, studies examining QOL among African Americans report mixed results, and sociodemographic variables explain much of the difference compared with non-Hispanic whites [32].

Given the very limited data on both depressive symptoms and QOL among African Americans living with epilepsy, this secondary analysis from an integrated database of a U.S. national research collaborative network provides novel descriptive data. The specific foci in this analysis included identification of the burden of depression among African Americans with epilepsy, investigation of the relationship between epilepsy QOL and depressive symptom severity in this subgroup, and exploration of the relationship between depressive symptom severity and specific components of epilepsy QOL. Understanding these relationships may inform specific intervention areas for African Americans with epilepsy.

2. Materials and methods

2.1. Dataset

The Managing Epilepsy Well (MEW) Network was established by the Centers for Disease Control and Prevention in 2007 and is comprised of eight research institutions, each with primary projects related to epilepsy self-management [33,34]. One of the aims within the network is the development of new research and dissemination projects focused on underserved groups, including African Americans. The MEW Network research sites contribute data to a combined data repository, allowing for integration and larger-scale analyses such as those in the current study [35,36]. Sahoo et al. [35,36] describe the process for integrating the data from across the studies. All studies included in the database obtained informed consent from all participants prior to submitting data to the database.

We included data from all studies within the MEW Network Database (MEW DB) that evaluated depression using the Patient Health Questionnaire-9 (PHQ-9, [37,38]) and QOL using the 10-item QOL in epilepsy (Quality of Life in Epilepsy Inventory-10 [QOLIE-10]) among African Americans with epilepsy. Baseline data from the following seven studies were accessed: WebEase [39]; FOCUS (pilot study and randomized controlled trial); TIME [40]; MORE [41]; PACES [42]; and SMART (Ongoing; PI: Sajatovic) [34,43]. Table 1 provides more details about each study.

2.2. Measures

2.2.1. Depressive symptoms

Depressive symptoms were measured with the PHQ-9 [37,38]. The PHQ-9 contains nine items that ask about the frequency of depressive symptoms, such as “trouble concentrating on things” and “little interest or pleasure in doing things” [37,38]. The PHQ-9 has been tested with African American populations and has demonstrated good reliability and validity [44,45]. A score greater than 9 is used as the cutoff for likely depression; score ranges of mild (5–9), moderate (10–14), moderately severe (15–19), and severe (20–27) have also been used to characterize depression severity [37]. For the multivariable analysis, a continuous depression symptom severity score was calculated ranging from 0 to 27. Cronbach's alpha was good for the PHQ-9 (alpha = 0.86).

2.2.2. Quality of life in epilepsy

Quality of life was measured with the 10-item QOLIE-10 questionnaire [30]. The measure assesses QOL with seven self-reported subcomponents including seizure worry, emotional wellbeing, energy-fatigue, cognitive functioning, medication effects, social functioning, and overall QOL. Some studies in the MEW DB used the 31-item version of the QOLIE, which includes the 10 questions in the QOLIE-10. Given slightly different versions of the QOLIE-10 questions across studies in the MEW DB, scores were calibrated to yield a total possible score range of 1–5, with lower scores indicating better QOL and fewer problems related to epilepsy. Cronbach's alpha was good for the QOLIE-10 (alpha = 0.79).

2.2.3. Seizure frequency

In addition to these variables, we examined self-reported seizure frequency over the past 30 days.

2.2.4. Sociodemographic variables

Sociodemographic variables included in the analysis were age, gender (male/female), education (high school education or less; some college; college or higher), employment status (employed, unemployed, unable to work, and other), income (less than $25,000 and $25,000 or more), and marital status (married or cohabitating, single, never married, and divorced, separated, or widowed).

2.3. Analyses

First, basic descriptive analyses were completed to describe the frequencies and sample means for each variable. Then, bivariate analyses, including *t*-test, analysis of variance, and Spearman-rank correlations, were conducted to identify sociodemographic variables significantly associated with depressive symptoms and QOL. Multivariable linear regression was used to assess the strength of the relationship between depressive symptoms and QOL, while controlling for seizure frequency and sociodemographic variables significantly related to depressive symptoms or QOL. Lastly, Spearman correlation and Wilcoxon Rank-Sum test analyses examined the components of QOL significantly associated with depressive symptoms. To complete the analysis, SAS 9.4 was used. A Type I error level of 0.05 was adopted for all tests.

3. Results

3.1. Overall sample description

This analysis of the MEW DB includes 155 African Americans with epilepsy (92.3% of total African Americans in the MEW DB). Over

Table 1
Details about studies included in the analysis.

Study title [Reference]	Acronym details	Target audience	Study focus
WebEase [39] n = 2	Epilepsy, Awareness, Support and Education	Adults with epilepsy taking antiepileptic medication	Randomized controlled trial (RCT) of a web-based self-management program focused on medication adherence, stress reduction, and sleep management
FOCUS Pilot Study: n = 5 RCT: n = 17	Figure out the problem or the issue, Observe your routine, Connect your observations and choose a goal, Undertake a change strategy, Study the results	Adults with epilepsy and their support providers. (Only data from the adults with epilepsy were included in this analysis)	Pilot study and RCT of an in-person self-management program focused on building skills for self-regulation and targeted social support.
TIME [40] n = 25	Targeted Self-Management for Epilepsy and Serious Mental Illness	Adults with comorbid epilepsy and mental illness Mental illnesses included schizophrenia, schizoaffective disorder, bipolar disorder, or chronic/recurrent major depressive disorder	RCT of an in-person, group intervention that includes education, behavioral modeling, and group support.
MORE [41] n = 10	Management of Risks in Epilepsy	Adults with epilepsy from an urban, public hospital	Cross-sectional study examining medication adherence in a low-income and ethnically diverse sample
PACES [42] n = 22	Program for Active Consumer Engagement in Self-Management	Adults with epilepsy	RCT of an in-person, group self-management program tailored to individual needs, including stress, mood, and cognitive functioning
SMART [34,43] n = 74	Self-management and Recovery Training	Adults with epilepsy who experienced a negative health event, such as seizures, hospitalization, emergency department visit, or self-harm attempt	RCT of a web-based intervention that uses group- and individual-delivery group self-management program

80% of African American participants come from four MEW Network studies: SMART (47.7%), TIME (16.1%), PACES (14.2%), and FOCUS (14.2%). Table 2 provides the characteristics of the African American participants included in the MEW DB who had PHQ-9 or QOL data. The mean age was 40.6 (SD = 12.5). About two-thirds of participants were women. Few participants (12.3%) completed college, with most reporting completing some college (47.7%) or high school education or less (40.0%). Some participants (36.6%) were unable to work, and almost 90% reported incomes less than $25,000. On average, participants reported slightly more than three seizures per 30 days (range = 0–75.7; $\bar{x}$ = 3.10, SD = 9.3).

Table 2
Descriptive details of the African American participants included in the Managing Epilepsy Well (MEW) Network Database.

Variable	Total sample	% or Mean (standard deviation)
Gender	154	
Male	52	33.77%
Female	102	66.23%
Education	155	
College \= ;≥4 yrs	19	12.26%
College <1–3 yrs	74	47.74%
High school education or less	62	40.00%
Employment	112	
Employed	31	27.68%
Unemployed	30	26.79%
Unable to work	41	36.61%
Other	10	8.93%
Income	127	
<$25 K	113	88.98%
=;≥$25	14	11.02%
Marital Status	133	
Married or Partnered	26	19.55%
Single Never Married	80	60.15%
Divorced, Separated, or Widowed	27	20.30%
30-day seizure frequency	109	3.10 (9.3)
QOLIE-10 Total Score (Range 1 to 5)	131	2.88 (0.8)
QOLIE-10 Components		
Seizure worry	133	2.67 (1.2)
Emotional wellbeing	132	2.95 (1.5)
Energy-Fatigue	132	3.71 (1.4)
Cognitive Function	133	3.62 (1.4)
Medication Effects	133	2.57 (1.3)
Social Functioning	132	2.79 (1.2)
Overall QOL	133	2.85 (1.0)
PHQ-9 (Range 0 to 27)	132	10.01 (6.9)
Level of Depressive Symptoms (PHQ-9)		
Minimal (scores 0–4)	33	25.00%
Mild (scores 5–9)	36	27.30%
Moderate (scores 10–14)	30	22.70%
Moderately severe (scores 15–19)	17	12.90%
Severe (scores 20–27)	16	12.10%

The mean QOLIE-10 total score was 2.88 (SD = 0.8). The subscales of the QOLIE-10 with the poorest QOL scores included energy ($\bar{x}$ = 3.71, SD = 1.4) and cognition ($\bar{x}$ = 3.62, SD = 1.4). The mean depression symptom severity score was 10.01 (SD = 6.9). Three-quarters of the sample reported at least mild depressive symptoms (PHQ-9 ;≥ 5) with 27.3% reporting mild symptoms (PHQ-9 = 5–9), 22.7% reporting moderate symptoms (PHQ-9 score = 10–14), and 25.0% reporting moderately severe to severe symptoms (PHQ-9 score ;≥ 15).

Table 3 presents the bivariate results. Variables significantly associated with depressive symptoms included female gender (t(129) = −2.66, p = .009) and seizure frequency (r = 0.32, p = .009). Women ($\bar{x}$ = 11.1, SD = 6.6) had higher mean depressive symptoms scores compared with men ($\bar{x}$ = 7.8, SD = 7.1). Seizure frequency was positively correlated with depressive symptoms. Women ($\bar{x}$ = 3.1, SD = 0.9) also reported worse depressive symptom scores compared with men ($\bar{x}$ = 2.4, SD = 0.8). Seizure frequency (r = 0.43, p ;≤ .0001) was positively correlated with poorer QOL. In addition, age was significantly positively correlated with poorer QOL (r = 0.18, p = .04). No other sociodemographic variables were significantly associated with depressive symptoms or QOL.

Table 4 displays the multiple linear regression results. The sample for the multivariable analyses consisted of 103 participants because of missing data. The model was significant $F(4, 98) = 24.00$, p ;≤ .001 and explained 49% of the variance in depressive symptoms. Quality of life was significantly associated with depressive symptoms (t = 9.13, p < .0001) when adjusting for age, gender, and seizure frequency. No other variables remained significantly associated with depressive symptoms.

Depressive symptoms were significantly correlated with each subscale of the QOLIE-10 (Table 5). The strongest correlation was between depressive symptoms and emotional wellbeing (r = 0.66, p ;≤ .0001). Functional status also was moderately correlated with depressive symptoms (r = 0.56, p ;≤ .0001). Fig. 1 illustrates the difference in the QOLIE-10 subscales by depressive symptom status with each subscale demonstrating significantly poorer QOL for those with depression compared with those without depression.

Table 3
Bivariate relationships between demographic characteristics and depression severity and QOLIE-10 for African Americans with Epilepsy.

		PHQ-9			QOLIE-10	
Variable	n	Mean (SD)	*p*-value	n	Mean (SD)	*p*-value
Gender			.009			.023
Male	42	7.8 (7.1)		41	2.6 (0.75)	
Female	89	11.1 (6.6)		89	3.0 (0.85)	
Education			.063			.672
College >4 yrs	14	7.6 (7.3)		15	2.9 (0.9)	
College <1–3 yrs	62	9.2 (6.5)		64	2.8 (0.9)	
High school education or less	56	11.5 (7.0)		52	3.0 (0.8)	
Employment			.097			.059
Employed	25	7.5(6.5)		24	2.4 (0.8)	
Unemployed	26	10.6 (6.3)		28	2.9 (0.8)	
Unable to work	36	11.6 (7.5)		39	3.0 (0.8)	
Other	7	8.7 (9.4)		8	2.6 (1.0)	
Income			.272			.942
< $25 K	106	10.5 (6.8)		101	2.9 (0.8)	
=; ≥$25	13	8.7 (7.9)		11	2.9 (0.9)	
Marital Status			.551			.557
Married or Cohabiting	21	10.2 (6.2)		24	2.8 (0.9)	
Single, Never Married	68	9.9 (7.0)		66	2.8 (0.8)	
Divorced, Separated, or Widowed	21	12.0 (7.7)		20	3.0 (0.7)	
Age (spearman correlation coefficient r, *p*-value)			.116, .189			.181, .040
30-day seizure frequency (spearman correlation coefficient, *p*-value)			.317, .0009			.425, <.0001

4. Discussion

This analysis from a pooled epilepsy research database examined the relationship between depressive symptom severity, sociodemographic and clinical variables, and QOL in African Americans with epilepsy, an understudied subgroup of PWE. The analysis found 47.7% of African Americans with epilepsy in this sample reported depressive symptoms in the moderate to severe range. Findings are fairly similar to a recent analysis of the MEW DB that examined correlates of depressive symptoms (also using the PHQ-9) in a general population of PWE. Of the 770 PWE in that analysis (mean age = 42.4, SD = 13.0 years), the mean total PHQ-9 score was 9.4 (SD = 6.6), and 334 subjects (43.4%) had moderate to severe depressive symptoms (PHQ-9 ≥ 10), and depressive symptom scores were not significantly different by race/ethnicity [46].

In addition to underscoring the relatively high prevalence of depression in African Americans with epilepsy in this sample, this analysis also found that QOL and depression are significantly associated. Being female and having more frequent seizures were associated with worse depressive symptoms in bivariate analysis, but in multivariable analysis, QOL was the only variable significantly associated with depressive symptoms. This indicates that QOL has a stronger association with depressive symptoms than seizure frequency. These results are in line with similar findings on the relationship between QOL and depression in PWE [10–14]. A non-MEW Network study that analyzed individuals with poorly controlled epilepsy found that in the order of large to small magnitude: depression, low self-mastery, anxiety, stigma, medical and psychiatric comorbidity, poor medication adherence, and more frequent seizures were associated with worse QOL [47].

These results also confirm the association of QOLIE-10 subscales with depressive symptoms within the African American population [11]. Each one of the QOLIE-10 subscales was significantly associated with depressive symptom severity. Similar to the general literature on PWE, these findings in African Americans with epilepsy confirm that depression is not only common, but is associated with powerful negative effects [14,48,49].

The findings of this analysis in African Americans with epilepsy have several implications. First, given the high proportion of African Americans with epilepsy who have depression, depression screening should be a standard component of care. The PHQ-9, used in this analysis, can both screen for depression and monitor outcomes over time. Other screening tools for depression in epilepsy include the Neurological Disorders Depression Inventory for Epilepsy [50] and the Beck Depression Inventory [51].

Additionally, recent research in a general population of PWE found an association between fewer self-management behaviors and increased levels of depressive symptoms and reduced QOL [52]. Epilepsy self-management programs seek to help PWE improve health outcomes through behavioral approaches. These programs address a variety of behaviors, such as medication management and stress management. By teaching these techniques, self-management programs developed by the MEW Network, such as Project UPLIFT [53,54], PEARLS [55], and TIME [40], may help African Americans with epilepsy to reduce depressive symptoms and improve QOL. A key focus of more recent work by the MEW Network has been scaling up epilepsy self-management approaches and increasing the proportion of racial and ethnic minorities enrolled in self-management studies [33,56]. For instance, Project UPLIFT, a self-management program to treat and prevent depression among PWE, is currently being tested among African Americans with epilepsy through a randomized controlled trial [57].

Table 4
Multiple linear regression assessing the strength of relationship between depression severity (continuous measure) and QOLIE-10, controlling for gender, age and seizure frequency. (n = 103).

Variables	B	SE B	Beta
QOLIE-10, total	5.56	0.61	0.69***
Age	0.01	0.04	0.03
Women	1.42	1.13	0.09
Seizure Frequency, 30 days	0.06	0.06	−0.08

*** $p < .0001$, $F(4, 98) = 24.00$, p ;≤ .001, $R^2 = 0.49$.

Table 5
The Spearman correlation (pho and *p*-value) between discrete PHQ-9 and QOLIE-10 subscale components.

Variables	Correlation with depressive symptoms (r)
Energy-Fatigue	0.48***
Emotional-Wellbeing	0.66***
Social Functioning	0.56***
Cognitive Functioning	0.46***
Medication Effects	0.37***
Seizure Worry	0.42***
Overall QOL	0.46***

*** $p < .0001$.

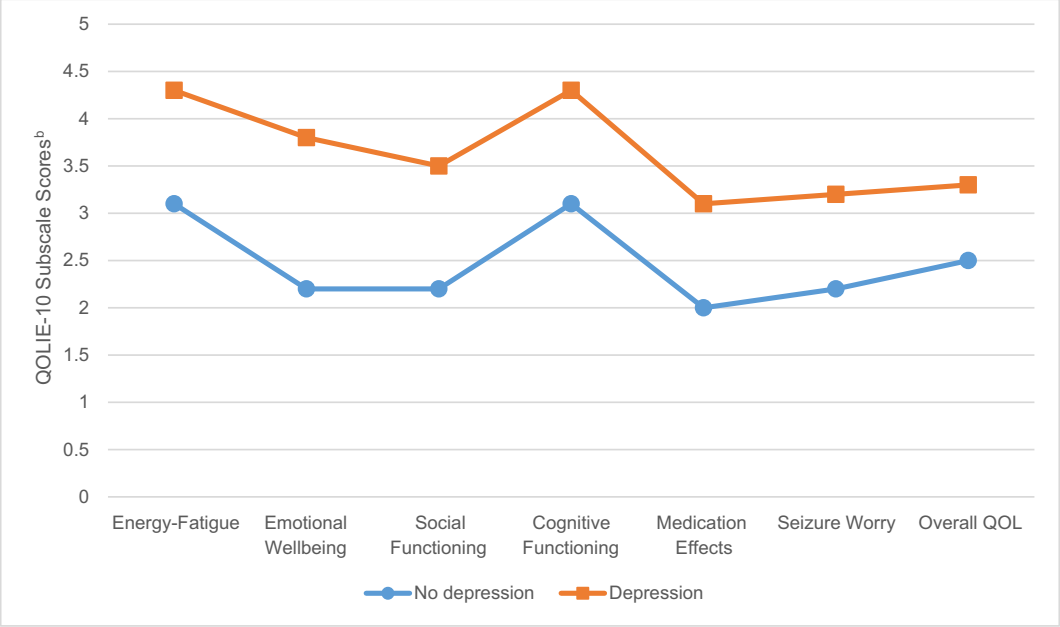

Fig. 1. The relationship between categorical depression and QOLIE-10 subscale components[a]. [a]:Wilcoxon Rank-Sum test; all variables $p < .0001$; [b]:higher scores indicate worse QOL.

The present analysis has a number of limitations including the cross-sectional design and sample composition. The high prevalence of depression in this sample may be due to the composition of the sample. The interventions from where the data come from focus on self-management with a particular emphasis on psychosocial factors. For instance, the TIME intervention focused on adults with comorbid epilepsy and mental illness, and 25 participants in this analysis come from that study. Therefore, more people with depressive symptoms may have been eligible or interested to participate in the intervention studies represented in this sample. Additionally, African Americans with epilepsy who volunteer to be in research studies may not be representative of the larger population of African Americans with epilepsy. Because of missing data and a small sample size, the data were insufficient to further explore the relationship between depressive symptom severity and specific components of QOL accounting for covariates. Moreover, the QOLIE-10 has not been validated specifically in African Americans. We were unable to include additional variables, such as coping or social support, in our analysis, because of the limitations of the database. While each study included in the database uses similar measures of depression and QOL, there is more variation in the scales used to assess other psychosocial variables. Lastly, age was assumed to be a linear variable in the analyses, but depressive symptoms may decrease after reaching a certain age [58]. However, the pooled cross-regional nature of the sample and focus on depression comorbidity and QOL provide insight that is often not available in standard clinical trials.

In conclusion, subgroup analysis from a national research network found that moderate to severe depression is common in this sample of African Americans with epilepsy and is significantly associated with worse QOL across multiple domains. Future research should examine the prevalence of depression among a representative population of African Americans with epilepsy. To better understand these psychosocial outcomes among African Americans, future research could compare depression and QOL scores among African Americans and other races and ethnicities. This study focuses specifically on the African American population, rather than comparing with other races and ethnicities, because of the lack of research examining experiences of epilepsy among African Americans. To inform interventions seeking to improve the lives of African Americans with epilepsy, future studies should examine how social support or coping influences the relationship between depression and quality of life [59,60]. As self-management programs continue to be delivered in the future, it is important to examine changes in QOL and depression for African Americans in these programs to understand successful interventions and strategies that could be effective. Given the high prevalence of depression in this sample, healthcare providers need to regularly assess depression among PWE.

Conflicts of interest

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