

Epidemiology

Quick screening tool for patients with severe negative emotional reactions to chronic illness: psychometric study of the negative emotions due to chronic illness screening test (NECIS)

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Abstract

Background. Severe negative emotional reactions to chronic illness are maladaptive to patients and they need to be addressed in a primary care setting.

Objective. The psychometric properties of a quick screening tool—the Negative Emotions due to Chronic Illness Screening Test (NECIS)—for general emotional problems among patients with chronic illness being treated in a primary care setting was investigated.

Method. Three studies including 375 of patients with chronic illness were used to assess and analyze internal consistency, test–retest reliability, criterion-related validity, a cut-off point for distinguishing maladaptive emotions and clinical application validity of NECIS. Self-report questionnaires were used.

Results. Internal consistency (Cronbach's α) ranged from 0.78 to 0.82, and the test–retest reliability was 0.71 ($P < 0.001$). Criterion-related validity was 0.51 ($P < 0.001$). Based on the 'severe maladaptation' and 'moderate maladaptation' groups defined by using the 'Worsening due to Chronic Illness' index as the analysis reference, the receiver-operating characteristic curve analysis revealed an area under the curve of 0.81 and 0.82 ($ps < 0.001$), and a cut-off point of 19/20 was the most satisfactory for distinguishing those with overly negative emotions, with a sensitivity and specificity of 83.3 and 69.0%, and 68.5 and 83.0%, respectively. The clinical application validity analysis revealed that low NECIS group showed significantly better adaptation to chronic illness on the scales of subjective health, general satisfaction with life, self-efficacy of self-care for disease, illness perception and stressors in everyday life.

Conclusion. The NECIS has satisfactory psychometric properties for use in the primary care setting.

Key words: Behavior Rating Scale, Chronic disease, comprehensive health care, emotions, emotional adaptation, primary health care.

Introduction

Negative emotional reactions among patients with chronic illness include anxiety, anger, worry and depression (1). Functional emotional reactions are essentially adaptive; however, hyper-reactive emotions could become dysfunctional (2) and worsen chronic illness. Compared to patients merely suffering from chronic illness, patients experiencing comorbid depression/anxiety exhibited higher use of medical resources, longer absences from work (3), less compliant (4) and poorer psychophysiological functioning (5). In sum, maladaptive psychological and physical outcomes are important indices when assessing maladaptive negative emotions.

Several screening instruments have been used to examine negative emotions in the medical setting; however, a screening tool for assessing general negative emotional experiences among patients with chronic illness in the primary care setting is lacking in Taiwan. The five-item Brief Symptom Rating Scale (BSRS-5) is widely used to screen for psychiatric disorders and/or suicidal ideation with different populations in Taiwan owing to its good statistical and diagnostic properties (6). However, as it screens for psychiatric disorders, its use in the primary care setting is limited. Many patients with chronic illness do not meet the diagnostic criteria for a psychiatric disorder; however, these patients still experience enough distress that necessitates professional help (7). The 10-item Center for Epidemiological Studies Depression Scale (8) and the 20-item Zung's Self-Rating Depression Scale (9) are excellent screening tools for a variety of participant samples. Nevertheless, these instruments are too long and are designed specifically for depression; thus, the undifferentiated nature of negative emotional experience among patients with chronic illness in a clinical setting is not reflected (10).

Emotional problems are difficult to address in the primary care setting in Taiwan because of the high patient load in clinics. The average number of visits to any kind of clinics (e.g. family medicine, pediatrics) in a year was about 15.14 times per person in 2015 (11,12), and the duration of discussion with the physician during each consultation was relatively short (3–5 min). Such visits are generally rushed, involve a long waiting time, and the waiting environment is crowded. This situation is mostly due to that an appropriate gate-keeping system is not well implemented, neither referrals nor the appointments are necessary for visiting almost any clinics affiliated to hospitals or in the community. In other words, almost all clinics in Taiwan ultimately function as walk-in clinics of primary care.

To address aforementioned limitations, a screening tool for assessing general emotional disturbance in patients with chronic illness that can be easily implemented in the clinical setting is necessary. Such an instrument should be in the self-report format, it should be conceptually simple but should address a wide range of negative emotional experiences among patients with chronic illness, and it should be easy to respond to and score. Accordingly, we developed the eight-item Negative Emotions due to Chronic Illness Screening Test (NECIS), which can be administered within 1–2 min by any medical staff, with minimal training.

The reliability, criterion-validity, cut-off point and the clinical application of the NECIS were analyzed in the present study using samples from walk-in clinics of primary care affiliated to hospitals or from clinics in the community in Taiwan (Most outpatient clinics of Taiwan, whether in the community or at any level in hospitals, are available for patients without referral. Clinics of primary care are widely distributed and present in almost every department in a hospital, which is a very different system from most developed nations where a patient referral and appointment system is usually

implemented.). Due to the conditions mentioned earlier, patients in these clinics had little time. Therefore, the researchers had to divide the study into three sub-studies to reduce the time each participant was required to spend.

Method

General procedure for the three studies

Recruitment of participants

The selection criteria were as follows: (i) being above 20 years old; (ii) having been diagnosed with any irreversible chronic illness that requires life-long active control; (iii) being able to communicate and (iv) absence of any severe physical or mental disorder (e.g. dementia, schizophrenia). Physicians would ask patients who met the criteria and seemed to be available at that time, to participate the study. After the patients agreed to participate, research personnel obtained informed consent and administered the questionnaires. All patients referred by the physicians participated in this study. However, it was not recorded who refused to participate when the physician invited them, to protect their privacy. There was no overlap in the participants of the three studies.

Data analysis

Descriptive statistics and internal consistency using Cronbach's α were computed in all three studies.

Study 1: construction of the NECIS and its criterion-related validity

Construction of the NECIS

This eight-item scale contains overall negative emotional experience and troublesome feelings regarding daily disease control requirements. Using a five-point Likert-type scale (1 = never, 5 = always), respondents rate how often they experience the following negative emotions: (1) nervousness or anxiety, (2) sorrow accompanied by crying, (3) sadness or depression, (4) anger and (5) worry or fear; and how often they feel troubled by the following daily disease control requirements: (1) medication, (2) diet and (3) exercise. A higher total score (computed by summing scores on the eight items: 8–40) indicates more severe emotional disturbance. These emotions and disease control domains were selected and combined from Chen's findings (10) and from the findings of our pilot interview that assessed 100 patients with chronic illness. We revealed that patients often describe their emotional reactions in a globally negative manner, hardly expressing their feelings in distinct emotional terms. Therefore, the NECIS items have been designed to assess similar emotions in one item to avoid patient confusion.

The questionnaires were in the self-report format; however, for participants with blurred vision and/or those who were unable to read due to their educational level, a structured interview was conducted by reading the items aloud and recording the rating points that were expressed.

Subjects and setting of recruitment

In total, 72 patients with chronic illness were recruited from an outpatient clinic affiliated with a medical center and two clinics in communities in northern Taiwan.

Measures

The NECIS, Demographic Data and Zung's Self-Rating Depression Scale (ZSDS) were utilized.

Demographic data

Information regarding participants' gender, age, educational background and diagnosis was collected via self-report.

Zung's self-rating depression scale (ZSDS)

It is the only instrument that has been used in empirical studies focusing on emotional problems among patients with chronic illness in the primary care setting in Taiwan (9). Respondents rate 20 items regarding depressive symptoms using a five-point Likert-type scale (1 = never, 5 = always); the total score ranges from 20 to 80. The Cronbach's α for the ZSDS was 0.82.

Data analysis

Criterion-related validity was examined using the Pearson's correlation test.

Study 2: cut-off point analysis of the NECIS

Subjects and setting of recruitment

This study comprised 120 patients with chronic illness recruited from one outpatient clinic affiliated to a medical center and two clinics in communities in northern Taiwan.

Measures

In addition to the NECIS and Demographic Data, subjective perception of the impact of chronic illness on everyday life was assessed using the Worsening Due to Chronic Illness index, which is the gold standard among tools used for this purpose.

Gold standard for the cut-off point analysis: worsening due to chronic illness

This instrument was developed according to the opinions of primary care physicians and clinical psychologists who work mainly with patients with chronic illness. Primary care clinicians often observed that patients with chronic illness complained about feeling worse regarding various life domains. These domains included 'energetic feelings,' 'ability to perform daily activities,' 'working ability/efficiency,' 'interactions with family and friends,' 'sleep' and 'self-perception.' Therefore, in this tool, these six domains are rated on a five-point Likert-type scale (1 = never, 5 = always). A sum of the scores on these six items is used as the index (range = 6–30). The Cronbach's α for this scale was 0.84 (13).

Data analysis

A score of above the 67th and 50th percentiles on the Worsening Due to Chronic Illness index indicated 'severe maladaptation' and 'moderate maladaptation,' respectively. The receiver-operating characteristic (ROC) curve was analyzed to define the appropriate NECIS cut-off point.

Study 3: clinical application analysis and test-retest reliability of the NECIS

Subjects and setting of recruitment

This study comprised 183 patients with chronic illness recruited from four outpatient clinics in communities in mid Taiwan; 44 patients among them were also included in the retest phase to examine the test-retest reliability of the tool.

For the retest phase, data were collected during the next visit as per the appointment made by the doctor based on the patient's chronic illness condition, typically after 3 months.

Measures

In addition to the NECIS and Demographic Data, the following questionnaires were implemented for the clinical application analysis.

Subjective health

This two-item instrument assesses participants' present subjective health compared to that from 6 months ago, as well as their health perceptions relative to others of a similar age. These items are scored on a five-point Likert-type scale (1 = much worse, 5 = much better).

General satisfaction with life

This one-item instrument assesses participants' present general satisfaction with life compared to that from 6 months ago. Participants rate this item using a five-point Likert-type scale (1 = much worse, 5 = much better).

Self-efficacy of self-care for disease

This instrument assesses participants' confidence in performing the everyday life tasks: executing self-designed health-related plans or goals, taking medications on time, diet control, exercising regularly and regulating emotions in response to their disease. Items are rated on a five-point Likert-type scale (1 = extremely unconfident, 5 = extremely confident). A total index is calculated by summing the scores on the five items. The Cronbach's α for this scale was 0.73 (13).

Illness perception

This instrument assesses participants' perception of their own disease condition. This measure includes the following three subscales: 'Positive Illness Perception' (10 items), 'Confusion about the Illness' (1 item) and 'Pessimism about the Illness' (1 item). Positive Illness Perception measures participants' positive attitudes toward their illness. Items were rated on a five-point Likert-type scale (1 = never, 5 = always). The Positive Illness Perception index is calculated as the sum of the scores on the 10 items, and the Cronbach's α for this subscale was 0.82 (13). The Confusion about the Illness and Pessimism about the Illness indices are used as raw scores from the respective individual items.

Stressors in everyday life

This instrument measures the extent to which participants feel stressed with reference to the following four domains: finance, work, family and friends/social life. Participants rate the items using a five-point Likert-type scale (1 = extremely unstressed, 5 = extremely stressed). An index is calculated as the sum of the scores on the four items, and the Cronbach's α of this tool was 0.81 (13).

Data analysis

Using the NECIS's discriminatory cut-off point from Study 2, participants in Study 3 were divided into 'high emotional disturbance' and 'low emotional disturbance' groups. Differences between the two groups with regard to the aforementioned measures were analyzed using the chi-square and *t*-tests. Test-retest reliability was examined using the Pearson's correlation test. To explore the possible influences of ways of responding (i.e. self-report versus structured interview), we also compared the differences in the age, number of diagnosed chronic diseases, and the NECIS scores between the subjects who responded in the two ways using a *t*-test.

Results

Results across the three studies: Subjects and internal consistency

Description of demographic data and the NECIS scores of the samples of three studies have been presented in Table 1. Gender ($\chi^2 = 8.92$,

Table 1. Description of demographic data and NECIS scores of samples of: study 1 'criterion-related validity', study 2 'cut-off point analysis', study 3.1 'clinical application analysis' and study 3.2 'test-retest reliability'

Variables	Study 1	Study 2	Study 3.1	Study 3.2
	N (%)	N (%)	N (%)	N (%)
Gender				
Male	44 (61.1)	57 (47.5)	74 (40.4)	18 (40.9)
Female	28 (38.9)	63 (52.5)	109 (59.6)	26 (59.1)
Educational background				
Elementary school or below	11 (15.3)	15 (12.8)	87 (47.5)	19 (44.2)
Junior high school	10 (13.9)	14 (12.0)	29 (15.8)	4 (9.3)
Senior high school or occupational school	23 (31.9)	38 (32.5)	34 (18.6)	13 (30.2)
College or above	28 (38.9)	50 (42.7)	32 (17.5)	7 (16.3)
Diagnosis of chronic illness				
Diabetes mellitus	35 (48.6)	37 (30.8)	71 (38.8)	16 (36.4)
Hypertension	49 (68.1)	70 (58.3)	103 (56.3)	22 (50.0)
Hyperlipidemia	24 (33.3)	34 (28.3)	28 (15.3)	9 (20.5)
Gout	7 (9.7)	10 (8.3)	26 (14.2)	6 (13.6)
Others	9 (12.5)	26 (21.7)	52 (28.4)	13 (29.5)
Number of chronic illnesses diagnosed				
One	33 (45.8)	78 (65.0)	112 (61.2)	28 (63.6)
Two	29 (40.3)	28 (23.3)	48 (26.2)	11 (25.0)
Three	7 (9.7)	13 (10.8)	20 (10.9)	4 (9.1)
Four	3 (4.2)	1 (0.8)	3 (1.6)	1 (2.3)
Variables	Mean \pm SD	Mean \pm SD	Mean \pm SD	Mean \pm SD
Age	56.64 \pm 12.20	59.89 \pm 11.62	59.00 \pm 13.31	56.50 \pm 14.60
NECIS score (1st)	16.46 \pm 5.03	18.24 \pm 6.06	19.42 \pm 5.60	20.30 \pm 6.29
NECIS (2nd)	—	—	—	18.70 \pm 5.78

* $P < 0.05$, ** $P < 0.01$, *** $P < 0.001$.

$P < 0.05$), educational background ($\chi^2 = 60.63$, $P < 0.001$), diagnosis of diabetes mellitus ($\chi^2 = 6.09$, $P < 0.05$), hyperlipidemia ($\chi^2 = 12.42$, $P < 0.05$) and other chronic illness ($\chi^2 = 7.58$, $P < 0.05$), and the NECIS scores ($F = 7.26$, $P < 0.01$) were different across three study samples. According to the post hoc test by the Bonferroni t , the mean NECIS score of the sample of Study 3 (clinical application analysis) was higher than that of the sample of Study 2 (criterion-related validity) ($P < 0.01$). The Cronbach's α coefficients for the NECIS were with 0.82, 0.82, 0.80, 0.82 and 0.78 for the single tests for Studies 1–3 and for the first and second test for the test-retest study sample in Study 3, respectively).

Study 1: criterion-related validity of the NECIS

The correlation between the NECIS and ZSDS was 0.51 ($P < 0.001$).

Study 2: cut-off point analysis of the NECIS

According to the 'severe maladaptation' and 'moderate maladaptation' groups, which were defined using the 'Worsening Due to Chronic Illness' index, the ROC analysis revealed an area under the curve (AUC) of 0.82 and 0.81 (both $ps < 0.001$; Fig. 1).

The sensitivity and specificity of the different cut-off points have been listed in Table 2. A cut-off point of 19/20 was the most satisfactory for discriminating the 'severe maladaptation' group from the non-cases and it was satisfactory for identifying the 'moderate maladaptation' group. The sensitivity and specificity of this cut-off point for the 'severe maladaptation' group was 83.3 and 69.0%, respectively; for the 'moderate maladaptation' group, sensitivity and specificity was 68.5 and 83.0%, respectively.

Study 3: clinical application analysis and test-retest reliability of the NECIS

Based on the results of Study 2, subjects were divided into the 'high emotional disturbance group' (NECIS score ≥ 20 , $n = 98$)

and 'low emotional disturbance group' (NECIS score ≤ 19 , $n = 85$). A demographic description of these two groups has been shown in Table 3. The high emotional disturbance group was younger and had a higher ratio of participants with 'other chronic illnesses.'

Compared to the high emotional disturbance group, the low emotional disturbance group had better current subjective health, general satisfaction with life, self-efficacy of self-care for disease and positive illness perception; the high emotional disturbance group scored higher on confusion about the illness, pessimism about the illness and stressors in everyday life (Table 3).

The NECIS scores were not statistically different between the subjects who responded by self-report ($N = 100$, $M = 18.88$) and structured interview ($N = 83$, $M = 20.07$). Meanwhile the subjects who needed assistance with the questionnaire were significantly older ($t = 8.48$, $P < 0.001$), and they reported having more kinds of chronic diseases ($t = 3.58$, $P < 0.001$).

Neither the demographic data nor the NECIS score were significantly different between the sample of 44 participants included in the retest phase and the original whole sample of Study 3 ($N = 183$). The test-retest reliability of the tool was 0.71 ($P < 0.001$), with an average test-retest interval of 4.10 months ($SD = 1.73$ months).

Discussion

Summary of the main findings

Results revealed that the NECIS has satisfactory internal consistency, test-retest reliability and criterion-related validity. The instrument has good sensitivity and specificity for distinguishing respondents with severe maladaptation, and it exhibited satisfactory clinical application. Comparison between subjects using self-report and structured interview showed that ways of responding did not result

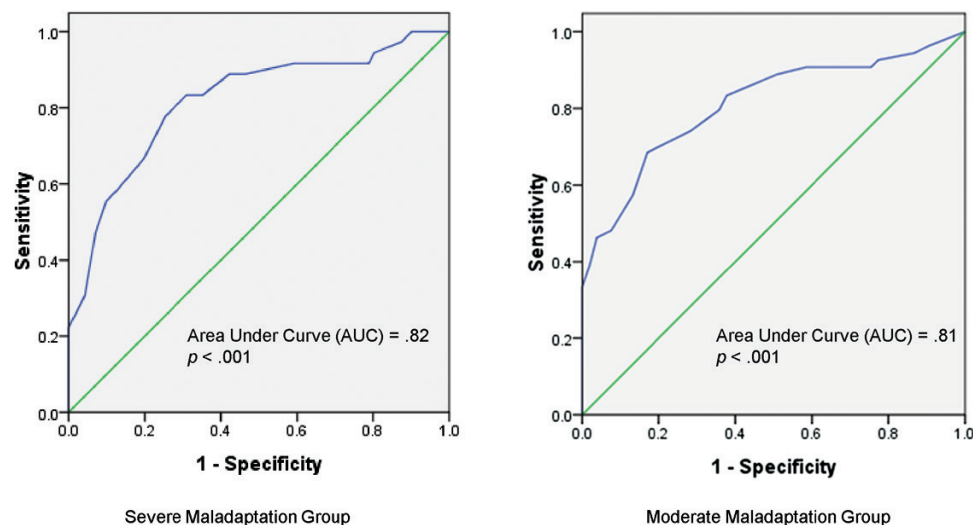


Figure 1. NECIS ROC curves for the two groups created based on the worsening due to chronic illness index.

Table 2. Sensitivity and specificity of discriminatory cut-off points for severe maladaptation and moderate maladaptation groups defined by worsening due to chronic illness in study 2

Cut-off point	Worsening due to chronic illness			
	Severe maladaptation		Moderate maladaptation	
	Sensitivity (%)	Specificity (%)	Sensitivity (%)	Specificity (%)
15	91.7	33.8	88.9	49.1
16	91.7	40.8	83.3	62.3
17	88.9	53.5	79.6	64.2
18	88.9	57.7	74.1	71.7
19	83.3	64.8	72.2	75.5
20	83.3	69.0	68.5	83.0
21	77.8	74.6	57.4	86.8
22	66.7	80.3	48.1	92.5
23	58.3	87.3	46.3	96.2
24	55.6	90.1	38.9	98.1

in significant differences in the NECIS scores, thus increasing the clinical utility of the NECIS.

Results in comparison to the literature

There may be more patients with chronic illness in the primary care setting who need assistance concerning emotional problems than we have noticed. Anseau *et al.* (14), found that the prevalence of generalized anxiety and major depression in primary care was 8.3 and 6.3%, respectively. However, the prevalence was much higher when considering multiple mental disorders simultaneously (9,15). Anseau *et al.* (15), found that 42.5% of patients had at least one mental disorder, 31.0% patients had mood disorders, and 19.0% had anxiety disorders. In comparison, we found that 53.6% of the patients in Study 3 fell into high emotional disturbance group. However, emotional disturbances that do not meet the criteria of a mental disorder still need professional attention; thus, this study alerted us that more patients need help in adjusting to their chronic illness than we previously thought.

Strength, limitations and implications for practice and research

An important strength of the NECIS as compared to other screening tools concerning emotional disturbances is that it included

subjective judgments in regard to disease-control requirements, while other tools mainly concern 'how I feel.' (6,8,9) Various studies suggested that avoidance or inhibition of emotional expression is associated with maladaptive outcomes (16). In Taiwan, negative emotion expression is not encouraged. The items of disease-control requirements can bypass this culturally demanded avoidance by expressing their 'judgments/feelings' regarding required activities, which is a less threatening way of expressing emotions.

There are several limitations in this study. Due to the limited research resources (e.g. high patient load), all of the measures used in this study could not be administrated together and three studies with different samples were designed. However, by collecting data in outpatient clinics with various characteristics, including city prosperity, area socioeconomic status, and levels within the gate-keeping system, the ecological validity of this study was increased. To maximize the clinical utility, the Worsening Due to Chronic Illness was used for the cut-off point analysis. As a subjective measure designed according to physicians' and psychologists' opinions, it might decrease the validity of the cut-off analysis. However, it reflects and combines important concerns of previous research on adjustment to chronic illness. 'Inactivity,' as reflected in Items 1–3, has been regarded as risky in chronic illness adaptation (17). 'Impaired interpersonal relationship,' (18) 'sleep disturbance' (19) and 'self-perception' (20) are

Table 3. Description and comparison of demographic data of high and low emotional disturbance groups from study 3

Variables	NECIS score		χ^2	P
	Low	High		
	N (%)	N (%)		
Gender				
Male	45 (45.9)	29 (34.1)	2.63	0.105
Female	53 (54.1)	56 (65.9)		
Educational background				
Elementary school or below	47 (48.0)	40 (47.6)	0.97	0.808
Junior high school	17 (17.3)	12 (14.3)		
Senior high school or occupational school	16 (16.3)	18 (21.4)		
College or higher	18 (18.4)	14 (16.7)		
Diagnosis of chronic illness				
Diabetes mellitus	42 (42.9)	29 (34.1)	1.46	0.226
Hypertension	56 (57.1)	47 (55.3)	0.06	0.801
Hyper lipid	15 (15.3)	13 (15.3)	0.00	0.998
Gout	19 (19.4)	7 (8.2)	4.66	0.031
Others	19 (19.4)	33 (38.8)	8.45	0.004
Number of chronic illnesses diagnosed				
One	59 (60.2)	53 (62.4)	0.48	0.922
Two	27 (27.6)	21 (24.7)		
Three	10 (10.2)	10 (11.8)		
Four	2 (2.0)	1 (1.2)		
Variables	Mean \pm SD	Mean \pm SD	t	P
Age	61.57 \pm 10.86	56.00 \pm 15.22	2.78	0.006
Subjective health (compared to 6 months ago)	2.76 \pm 0.67	2.46 \pm 0.82	2.64	0.009
Subjective health (compared to others of a similar age)	3.04 \pm 0.86	2.41 \pm 0.95	4.69	0.000
General satisfaction with life	3.06 \pm 0.74	2.65 \pm 0.81	3.58	0.000
Self-efficacy of self-care for disease	17.53 \pm 3.91	15.99 \pm 3.40	2.82	0.005
Positive illness perception	34.43 \pm 7.43	30.79 \pm 6.24	3.55	0.000
Confusion about illness	2.14 \pm 0.99	2.86 \pm 1.21	-4.33	0.000
Pessimism about illness	2.13 \pm 1.43	2.59 \pm 1.38	-2.17	0.031
Stressors in everyday life	6.39 \pm 2.81	8.67 \pm 2.85	-5.43	0.000

also considered to evidence maladaptation in patients with chronic illness, these three were assessed in Items 4–6 of the Worsening Due to Chronic Illness. Yet, this measure needs standardization through a well-designed study in the future.

Future research could examine the utility of the NECIS in relation to other subjective and objective criteria such as other negative emotions, life satisfaction, frailty and emergency use.

Conclusion

Improving the mental health of patients with chronic illness is important in treating the disease. However, it is frequently overlooked in the primary care setting due to the lack of opportunity for patients to report their feelings. The NECIS fills this gap because of its ease of application to every patient within a few minutes during consultations.

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Declaration

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