## **Original Article**

## Significance of Psychological Stress Response and Health-related Quality of Life in Spouses of Cancer Patients When Given Bad News

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## ABSTRACT

Objective: This study illuminates the degree of psychological stress response experienced by spouses of cancer patients when given bad news at three different times (notification of the name of the disease, notification of recurrence, and notification of terminality) as well as the factors that influence the response and the health status of the spouse as measured by health-related quality of life (QOL). Methods: A total of 203 individuals (57 men and 146 women) who had received the three types of news were surveyed using a self-report questionnaire on psychological stress response, marital satisfaction, and health-related QOL scales. Results: The degree of the psychological stress response was the highest for notification of terminality, followed by notification of the name of the disease, and notification of recurrence. The

influencing factors varied depending on the notification period. Although no significant difference was observed for health-related QOL among the three notification types, significant differences were observed for certain items when compared with national standard values. **Conclusions:** When a notification of terminality, which produced the highest psychological stress response, is given, providing care that considers health-related QOL is necessary not only for patients but also for their spouses.

**Key words:** Bad news, health-related quality of life, marital satisfaction, psychological stress response, spouses of cancer patients

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## Introduction

At present, cancer is considered as a chronic disease that follows a long course.<sup>[1]</sup> In cancer diagnoses and over the course of treatment, receiving bad news is commonplace. For spouses who were with patients at the time of notifications, the first piece of bad news (notification of the disease) creates significant stress.<sup>[2,3]</sup> The primary emotion spouses experience at the time of notification is identification with the patient and their own helplessness.<sup>[4]</sup>

This study aims to quantitatively analyze the stress level and health status of spouses at the three notification periods throughout the course of the patient's cancer treatment.

The present study measured and compared the degree of the psychological stress response to three different notifications: Notification of the name of the disease, of recurrence, and of terminality. The subjects were the spouses of cancer patients, and they helped to illuminate the significance between the factors that influence psychological stress response and health-related quality of life (QOL) for each notification period. Although the three notifications could be combined, the psychological stress response and health-related QOL of the spouses might differ in each notification period. We anticipate that suggestions for appropriate nursing support concerning the health of spouses throughout the course of cancer treatment can be obtained through the present study.

## **Methods**

## Subjects

We conducted our survey at five medical institutions, including three cooperative cancer treatment facilities in Saga Prefecture: Saga University Hospital, Saga-ken Medical Center Koseikan, NHO Ureshino Medical Center, NHO Saga National Hospital, and Saga City Fuji-Yamato Spa Hospital. After receiving approval from the Ethics Review Board of each hospital, we considered as eligible subjects, the spouses of all patients diagnosed with cancer (regardless of stage) from 2011 to 2014, excluding those of patients with malignant hematological tumors. Among these subjects, 203 spouses consented to participate. They were given an explanation of the study's objective, significance, and methods, as well as the voluntary nature of participation/nonparticipation, their ability to withdraw consent at any time, the method for asking for clarification, and the fact that no disadvantageous treatment would be given if they chose not to participate. Written consent was obtained. In addition, the mental state of the subjects was considered seriously. They were informed that if they experienced significant psychological distress during the study, they could immediately discontinue their participation.

#### **Ethics**

This study was approved in advance by the Institutional Review Board of each hospital.

#### **Procedure**

First, the objective, significance, and methods were explained to the attending physicians. Then, after the attending physicians provided a simple explanation of the study to the subjects, the researchers explained the study in detail and obtained consent.

Evaluations were conducted for the following three notification instances: (1) "notification of the name of the disease," when the patients and their spouses were informed of the definite diagnosis of cancer and a treatment plan for the first time; (2) "notification of recurrence," when cancer recurred within the course of treatment, and active treatment was resumed; and (3) "notification of terminality," when the cancer treatment stopped achieving results, active treatment was stopped, and treatment began to focus on alleviating the patient's pain. For each notification period, spouses recalled the emotional changes they experienced 2–3 days after they received the bad news and submitted a completed self-report questionnaire within 4 weeks.

#### **Evaluation items**

### Spouse and patient characteristics

Spouses were surveyed regarding age, sex, caregiving experience, employment, family structure, whether they had discussed cancer with the patient while the patient was healthy, the presence of family or friends other than their spouse from whom they could seek advice, and anxiety caused by financial difficulties. We collected information from medical records on patients' age, sex, disease name, disease stage, bad news notification period, number of recurrences, copayment for medical expenses, and number of days the patient suffered from the disease.

Among the 203 subjects, 57 were men and 146 were women; 48 individuals (20 men, 28 women) were in the notification of disease name period, 42 (7 men, 35 women) were in the notification of recurrence period, and 113 (30 men, 83 women) were in the notification of terminality period. Their average age was 66.9 years. The average age of spouses in the notification of recurrence period was lower than that in the other periods. The rate of caregiving experience was higher for spouses in the recurrence period and the disease name period. The spouses in the disease name period were more than those in the other periods.

#### Psychological stress response scale

The stress response scale-18 (SRS-18)<sup>[5]</sup> is capable of multifaceted measurement of the psychological stress experienced over the previous 2–3 days. Psychological stress

response is divided into affective reactions (e.g., depression, anxiety, and anger), cognitive responses (e.g., apathy and difficulty concentrating), and behavioral reactions (e.g., reduced efficiency at work). The SRS-18 contains 18 questions. A higher score indicates greater psychological stress. [6] The reliability and validity of the SRS-18 have been confirmed, and this scale has been used in intervention research on patients with early gastric cancer who have undergone gastrectomy. [7] and to explore factors relating to postoperative QOL in patients with adult-onset breast cancer. [8] Cronbach's  $\alpha$  coefficient index of reliability in this study was 0.917.

#### Marital satisfaction scale

The marital satisfaction scale is the Japanese-language version of the Quality of Marriage Index, [9-11] which is composed of items reflecting the overall quality of marital relationships. The questionnaire has six items sufficiently confirmed for reliability and validity. [12] Cronbach's  $\alpha$  coefficient in this study was 0.927.

## Health-related quality of life (scale short form-8 Japanese-language version)

The Japanese-language version of the health-related QOL scale short form (SF)-8<sup>[13]</sup> is a comprehensive scale that measures health-related QOL. An abridged version of the SF-36, the Japanese-language questionnaire includes one item to measure each of the eight health concepts. For all subscales, norm-based scoring was calculated. The questionnaire is used in large-scale epidemiological studies<sup>[14-16]</sup> and has confirmed reliability and validity. The Cronbach's  $\alpha$  coefficient in this study was 0.853.

#### Statistical analysis

Statistical analyses were conducted using IBM SPSS Statistics version 20 (Chicago, IL, USA). The Mann–Whitney U-test, Kruskal–Wallis, one-sample t-test, and Chi-squared tests were conducted and the results are presented in Tables 1-4. Multiple regression analysis (stepwise method) was conducted and the result is presented in Table 5. Tests with a P < 0.05 were considered statistically significant.

### Results

#### Spouse and patient characteristics

The average total score on the marital satisfaction scale was  $20.1 \pm 4.1$  points. No significant differences were observed between periods. For the disease name group, 114 individuals (56.2% of the total number) had lung cancer; 46 (22.7%) had gastrointestinal cancer; and 43 (21.2%) had breast, uterine, urinary system, or other types of cancer. The most common stage was Stage IV (74 individuals; 36.5%) [Table 1].

The average patient age was 68.2 years. A significant difference was found between the disease name  $(18.9 \pm 13.8)$  and terminality periods  $(14.0 \pm 11.3)$  for the time from bad news reception until the day of the survey [Table 1]. With regard to the medical expense burden, 31.6% of the patients (largely those who were 70 years of age or older) accounted for 10% of the burden, and 38.9% (those younger than 70 years or those 70 years and older who were high-income earners) accounted for 30% of the burden. For the recurrence group, this was the first recurrence for 12 individuals (46.2%) and the second for 8 (30.8%).

### Psychological stress response

The total average psychological stress response score for spouses of cancer patients was  $19.8 \pm 12.2$  points. For individuals in the disease name, recurrence, and terminality periods, the averages were  $18.9 \pm 12.9$ ,  $17.1 \pm 11.8$ , and  $21.2 \pm 11.9$  points, respectively. A significant difference was observed between the recurrence and terminality periods. In addition, a significant difference was observed between the recurrence and terminality periods for the psychological stress response subscale item "apathy."

# Health-related quality of life scale (short form-8 Japanese-language version)

Health-related QOL using the SF-8 questionnaire was measured for 159 of the 203 spouses. No significant differences were found between the groups [Table 2]. Nonetheless, compared to the Japanese national standard value that was obtained using stratified, multistage randomly sampled specimens from all over Japan, in the one-sample t-test, significant differences were observed for some items of the health-related QOL. For the notification of the disease name period, the seven health-related QOL subscales of the SF-8, such as "role physical," "general health perception," "vitality," "social functioning," "role emotional," "mental health," and "mental component summary," were significantly lower than the national standard value [Table 3]. For the notification of recurrence period, the seven items "physical functioning," "general health perception," "vitality," "social functioning," "role emotional," "mental health," and "mental component summary" were significantly lower than the national standard value [Table 3]. For the notification of terminality period, the nine items of the SF-8, such as "physical functioning," "role physical," "bodily pain," "general health perception," "vitality," "social functioning," "role emotional," "mental health," and "mental component summary," were significantly lower than the national standard value [Table 3].

Cancer patients were classified into three site-specific groups in descending order, that is, three groups for lung

Characteristics	All subjects	Notification of	Notification	Notification of	P
	,	disease name	of recurrence	terminality	
Spouses of patients	n=203	n=48	n=42	n=113	
Male	57 (28.1)	20 (41.7)*	7 (16.7)*	30 (26.5)	<0.05°,*
Female	146 (71.9)	28 (58.3)	35 (83.3)	83 (73.5)	NSc
Age, years mean±SD	66.9±9.2	$66.2 \pm 10.2$	$64.2 \pm 8.7^*$	68.2±8.8*	<0.05 <sup>b</sup> ,*
Caregiving experience	99 (49.0)	15 (31.9)***	29 (69.0)****,*	55 (48.7)*	<0.001°,**** <0.05°,*
Employment	79 (39.1)	26 (55.3)*,*+	13 (31.0)*	40 (35.4)* ,*+	<0.05°,* <0.05°,*+
Family structure (only married couple)	81 (40.1)	15 (31.9)	18 (42.9)	48 (42.5)	NSc
Talking about cancer with the patient while they were healthy	129 (63.5)	35 (72.9)	23 (54.8)	71 (62.8)	NSc
Presence of family or friends other than their spouse from whom they could seek advice	181 (89.2)	42 (87.5)	40 (95.2)	99 (87.6)	NS <sup>c</sup>
Anxiety due to financial difficulties	161 (79.3)	34 (70.8)	33 (78.6)	94 (83.2)	NSc
Marital satisfaction scale means±SD	$20.1 \pm 4.1$	$20.0 \pm 4.0$	19.9±3.7	$20.2 \pm 4.3$	$NS^{a}$
Patients (mean±SD)					
Age, years	68.2±9.3	$66.1 \pm 11.1$	66.3±8.1	69.4±8.9	$NS^a$
Number of days with the disease	$764.2 \pm 1065.7$	82.0±83.2 <sup>(10)(1)</sup> , (10)(1)+	762.6±748.2****	973.4±1209.5****,****	<0.001 <sup>b</sup> ,****
Bad news notification period	15.6±12.8	$18.9 \pm 13.8^*$	$18.0 \pm 15.9$	14.0±11.3*	< 0.05b*
Disease name $(n=203)$ (%)					
Lung cancer			114 (56.2)		
Gastrointestinal cancer <sup>d</sup>			46 (22.7)		
Breast/uterine/urinary system/other cancerse			43 (21.2)		
Disease stage ( $n=203$ ) (%)					
Stage I			18 (8.9)		
Stage II			17 (8.4)		
Stage III			28 (13.8)		
Stage IV			74 (36.5)		
Unknown			66 (32.5)		

<sup>a</sup>Kruskal-Wallis test, <sup>b</sup>Mann-Whitney U-test, <sup>c</sup>Chi-squared test, <sup>a</sup>Gastrointestinal cancer: Stomach/colon/pancreas/esophagus/liver/gallbladder cancers, <sup>a</sup>Breast/uterine/urinary system/other cancers: Breast/uterine/prostate/kidney/bladder/laryngeal cancers, <sup>\*</sup>P<0.05, \*\*P<0.01, \*\*\*P<0.001, \*\*\*P<0.05 and \*\*\*\*\*P<0.001: Statistical significance between study groups at each period. SD: Standard deviation

Table 2: Comparison between psychological stress response stress response scale-18 and health-related quality of life (short form-8) in spouses of cancer patients given bad news (mean±standard deviation)

Psychological stress response SRS-18	All subjects (n=203)	Notification of disease name (n=48)	Notification of recurrence $(n=42)$	Notification of terminality (n=113)	P
Total score	19.8±12.2	18.9±12.9	17.1±11.8*	21.2±11.9*	<0.05a,*
Depression/anxiety	$8.7 \pm 4.6$	$8.4 \pm 4.9$	$7.7 \pm 4.5$	9.2±4.6	
Displeasure/anger	$5.5 \pm 4.4$	5.5±4.4	$4.8 \pm 4.4$	$5.7 \pm 4.4$	
Apathy	$5.6 \pm 4.5$	$5.0 \pm 4.8$	$4.6 \pm 4.0^*$	6.2±4.5*	
Health-related QOL SF-8	All subjects (n=159)	Notification of disease name (n=31)	Notification of recurrence $(n=27)$	Notification of terminality (n=101)	
PCS-8	47.7±8.0	48.7±6.5	46.5±9.3	47.7±8.1	
MCS-8	43.1±9.6	44.0±7.3	46.2±9.0	41.9±10.2	

<sup>a</sup>Mann-Whitney U-test, \*Statistical significance between study groups at each period. SD: Standard deviation, QOL: Quality of life, SRS-18: Stress response scale-18, SF-8: Short form-8, PCS-8: Physical Component Summary-8, MCS-8: Mental Component summary-8

cancer, gastrointestinal cancer, and other types of cancer. When health-related QOL of the SF-8 was compared between site-specific groups (lung, gastrointestinal, and breast/uterine/urinary system/other), "physical functioning" was lower among the spouses of patients with lung cancer. Significant difference was observed for the "physical component summary" between the spouses of

the lung and breast/uterine/urinary system/other cancer groups [Table 4].

# Factors that influence psychological stress response score on stress response scale-18

Multiple regression analysis was conducted using the stepwise method with items of the SF-8 for which

Table 3: Comparison between health-related quality of life (short form-8) and the Japanese national standard value in spouses of cancer patients

Subscale item	National standard values (n=152)	Notification of disease name (n=31)	P		Notification of recurrence (n=27)	P		Notification of terminality (n=101)	P	
Physical functioning	50.05	48.9±7.1	0.369	NS	$47.3 \pm 6.3$	0.033	< 0.05*	47.6±7.4	0.001	< 0.01***
Role physical	50.22	$47.4 \pm 6.6$	0.022	< 0.05*	$47.0 \pm 9.0$	0.072	NS	$47.3 \pm 7.9$	0.000	< 0.001****
Bodily pain	51.27	$50.4 \pm 8.5$	0.573	NS	$47.9 \pm 10.1$	0.097	NS	$48.8 \pm 9.6$	0.011	< 0.05*
General health perception	50.59	$46.9 \pm 7.7$	0.012	< 0.05*	$46.7 \pm 7.1$	0.009	< 0.01***	$44.3 \pm 7.6$	0.000	< 0.001****
Vitality	52.40	49.2±5.9	0.005	< 0.01***	$48.9 \pm 5.5$	0.002	< 0.01***	$47.6 \pm 7.2$	0.000	< 0.001****
Social functioning	50.19	45.2±9.7	0.007	< 0.01**	$45.8 \pm 10.0$	0.031	< 0.05*	41.6±12.0	0.000	< 0.001***
Role emotional	51.30	$45.5 \pm 7.3$	0.000	< 0.001***	$46.3 \pm 7.5$	0.002	< 0.01***	$44.1 \pm 10.4$	0.000	< 0.001****
Mental health	53.29	$45.7 \pm 8.3$	0.000	< 0.001***	$47.2 \pm 6.7$	0.000	< 0.001****	$44.1 \pm 7.7$	0.000	< 0.001****
Physical component summary	48.47	$48.7 \pm 6.5$	0.824	NS	46.5±9.3	0.283	NS	$47.7 \pm 8.1$	0.323	NS
Mental component summary	51.97	$44.0 \pm 7.3$	0.000	< 0.001***	46.2±9.0	0.002	< 0.05*	$41.9 \pm 10.2$	0.000	< 0.001***

P: One sample t-test with the Japanese national standard value as the population mean, \*P<0.05, \*\*P<0.01, \*\*\*P<0.001: Statistical significance between study groups. NS: Not significant

Table 4: Comparison of health-related quality of life (short form-8) between cancer groups in spouses of cancer patients given bad news (mean ± standard deviation)

Subscale items	Lung cancer $(n=70)$	Gastrointestinal cancer <sup>c</sup> (n=46)	Breast/uterine/urinary system/other cancers <sup>d</sup> (n=43)	P
Physical functioning	47.3±6.7*	46.8±8.3	49.7±6.1*	<0.05b*
Role physical	$46.7 \pm 8.4$	$47.1 \pm 7.9$	48.3±6.7	$NS^a$
Bodily pain	48.4±9.5	$48.6 \pm 8.9$	$50.2 \pm 10.0$	$NS^a$
General health perception	45.3±7.6	43.8±7.3	46.4±7.8	$NS^a$
Vitality	48.4±6.1	$46.5 \pm 7.7$	49.3±6.3	$NS^a$
Social functioning	$44.0 \pm 10.5$	$41.1 \pm 12.2$	43.6±11.7	$NS^a$
Role emotional	44.8±9.7	44.7±9.2	44.6±9.3	$NS^a$
Mental health	45.8±7.2	44.5±8.3	43.8±7.8	$NS^a$
Physical component summary	$46.8 \pm 8.2^*$	46.8±7.5*+	50.0±8.0°,°+	<0.05 <sup>b</sup> ,* <0.05b,**
Mental component summary	44.2±9.4	42.3±9.5	$42.0 \pm 10.0$	$NS^a$

"Kruskal-Wallis test, "Mann-Whitney U-test, Gastrointestinal cancer: Stomach/colon/pancreas/esophagus/liver/gallbladder cancers, \*Statistical significance (P<0.05) between lung cancer and other cancers, \*Statistical significance (P<0.05) between gastrointestinal cancer and other cancers, Breast/uterine/urinary system/other cancers: Breast/uterine/prostate/kidney/bladder/laryngeal cancers. NS: Not significant

Table 5: Factors influencing on the psychological stress response score of the stress response scale-18 after the notification of bad news

Dependent variable	All subjects $(n=203)$					
	Independent variable (SF-8)	Standardized β coefficient	Adjusted R <sup>2</sup>			
Psychological stress response total score SRS-18	Mental health	-0.393ª	0.302ª			
	Role emotional	-0.209 <sup>a</sup>				
<sup>®</sup> Multiple regression analysis SRS-18: Stress response scale-18. SF-8: Short form-8						

a correlation was observed in each period based on Spearman's rank correlation coefficient as independent variables and "psychological stress response total score" of the SRS-18 as the dependent variable. In all periods, "mental health" (measures whether it was always nervous and sluggish) and "role emotional" (measures whether a problem for psychological reasons when performing work or usual activities) on the SF-8 were significant influencing factors [Table 5].

## Discussion

The psychological stress response was highest in the notification of terminality period, followed by the notification of the disease name and recurrence periods. A notification of terminality in cancer treatment entails a discontinuation of the cancer treatment performed up until that point and worsening of symptoms and life expectancy, giving the spouse a glimpse of the coming loss. Depressive symptoms among caregivers increase as the patient's death approaches.<sup>[17,18]</sup> Moreover, caregivers of patients who have just been admitted to the hospice have high levels of depression.<sup>[19]</sup> In this study, the "apathy" subscale of psychological stress response was significantly higher in the notification of terminality period than in the other two periods. In the notification of terminality period, the patient's coming death is inferred to influence

the psychological stress response of his or her spouse, and apathy and depression emerge.

Our conjecture is that spouses in the notification of recurrence group (those showing the lowest psychological stress response) hold out hope for the next treatment. Facing the bad news of cancer recurrence, the spouses are aware that new treatments may be tried. Previous research has reported a significant need for hope among the families of cancer patients.<sup>[20]</sup> This fact may explain why spouses in the notification of recurrence period have lower levels of psychological stress response than those in the other two periods.

As shown in Table 1, factors that influence psychological stress response after bad news differ by the notification period. In particular, "role emotional," "mental health," and "economic anxiety" in the notification of the terminality period gradually increased as influencing factors although no statistically significant difference exists. Female spouses, especially in the notification of terminality period, begin to consider restructuring their family roles as the head of the family. This condition likely has a large influence on their psychological stress response. Furthermore, economic anxieties brought on by the patient's death regarding what to do specifically about medical costs and future living expenses significantly influence the psychological stress response of the spouse. The economic difficulties faced by the families of cancer patients have a significant influence throughout every step of cancer treatment.[21-24] In this study, 83.2% of the spouses of patients in the notification of terminality period responded that they had "economic anxiety," which has a possible significant influence particularly on the psychological stress responses of female spouses in the notification of terminality period.

Moreover, the notification of bad news affects the physical state of spouses. Previous research has reported that younger caregivers show a greater influence in the physical aspects of health-related QOL<sup>[25]</sup> and that male spouses of breast cancer patients have increased fatigue and stress. <sup>[26]</sup> In addition, lung and colon cancer caregivers provide care while facing their own health problems, <sup>[27]</sup> and at least 33% of the caregivers have experienced their own physical health issues as a result of caregiving. <sup>[28]</sup>

In the spouse's health-related QOL in the present study, "role physical" in the notification of disease name period and "physical functioning" in the notification of recurrence period were significantly lower than the national standard value. Presumably, the decrease in "role physical" for spouses in the notification of disease name period is brought on by the expansion of the range of behaviors required to resolve the changes in family roles accompanying the

patient's hospitalization, economic challenges caused by missing work, and so on.

In addition, during the notification of recurrence period, the initial treatment is complete, and patients often return to their homes and take responsibility for their family roles to a certain degree. Nonetheless, their fight against the disease drags on, and the spouse's accumulated physical fatigue has a deteriorating effect on the physical aspects of their QOL. In addition, regarding the physical aspects of health-related QOL for spouses in the notification of terminality period, a significant difference was observed for "bodily pain." Over the course of cancer treatment, bad news is repeatedly received from the attending physician, and the spouse, at the side of the long-suffering patient, is susceptible to chronic exhaustion and continuous psychological stress. This type of chronic exhaustion is surmised to be accompanied by musculoskeletal pain. The average number of days suffered by patients during the notification of terminality period in this study was 973, a relatively long period. During the patient's course from onset to repeated recurrence, arthritis and chronic lower-back pain onset in the initial period of caregiving and development of heart disease in the long term are reported as widespread. [29]

Furthermore, in site-specific divisions (lung, gastrointestinal, breast/uterine/urinary system/other cancers), physical QOL was lower in the lung and gastrointestinal cancer groups. Patients with lung and gastrointestinal cancer are often male, and we can assume that their female spouses are constantly concerned about the patient and provide care. In addition to bearing the burden of care throughout hospitalization and commuting to the hospital for treatment, female spouses take responsibility for housework. This condition is considered to be connected to the physical exhaustion and reduction in the health-related QOL of the spouse.

#### Limitations

That can be addressed in the future include selection bias, as subject selection was entrusted to attending physicians. Large differences in the number of cases for each notification period existed. The SF-8 has certain limitations, that is, the recall memory may not accurately reflect the real emotional changes. Furthermore, as the survey was administered during outpatient visits, we cannot be certain if it was conducted in a calm and quiet environment. This factor possibly affected the psychological stress response and health-related QOL because both are easily influenced by the environment. In the future, continued research on spousal psychological stress response and health-related QOL will be necessary and should consider the effect of the survey environment.

## Conclusion

Throughout the course of cancer treatment, the psychological stress of spouses of patients who receive bad news is highest in the notification of terminality period. During this period, offering caregiving support that considers the spouse's health-related QOL and financial worries is particularly important. In addition, attention should be directed to the decrease in the physical aspects of QOL related to caregiving and housework burden and the economic challenges faced by the female spouses of patients with lung or gastrointestinal cancer.

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### **Conflicts of interest**

There are no conflicts of interest.

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