

# Associated Factors of Psychological Distress among Japanese NICU Nurses in Supporting Bereaved Families Who Have Lost Children

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**Purpose:** This study aimed (1) to examine the current status of psychological distress experienced by neonatal intensive care unit (NICU) nurses in supporting bereaved families, (2) to identify the factors associated with psychological distress, and (3) to understand the professional characteristics of nurses experiencing high psychological distress by comparing the study results with those of pediatricians. **Methods:** We sent questionnaires to 64 NICUs. The psychological distress of nurses was classified into two groups based on the frequency of psychological distress experienced and analyzed using the  $\chi^2$  test and Fisher's exact test. A multiple logistic regression analysis was used to investigate the factors related to psychological distress. **Results:** Of the 384 nurse respondents, 190 (49.5%) reported having supported bereaved families, 169 of who were included in the analysis. A total of 123 nurses (72.8%) reported high levels of psychological distress. Our study revealed that the use of coping methods is associated with high psychological distress. The comparison with pediatricians revealed that nurses were significantly more likely to be female and had fewer years of working experience. Nurses were also significantly more likely to use coping methods and to experience high psychological distress. **Conclusion:** Clarifying the coping methods for psychological distress in supporting bereaved families may be necessary, and nurses need to identify appropriate coping methods. In nursing education, information on psychological distress related to children's deaths and bereavement care should be conveyed from the early stage and nurses must obtain preliminary knowledge. The creation of a bereavement follow-up system is recommended.

## INTRODUCTION

Infants with extremely low birth weight or severe congenital disease survive their neonatal days nowadays owing to the development of medical equipment and management systems. In 2015, World Health Organization Reports revealed that Japan had the lowest neonatal mortality rate and infant mortality rate worldwide (22).

The Japanese perinatal medical system started in the 1970s. The system has helped decrease the neonatal and perinatal mortality rate and is composed of two types of facilities, Comprehensive Perinatal Medical Centers and Regional Perinatal Medical Centers. The two facilities provide different levels of treatment based on their size. Increasing survival rates and neurologically intact survival is one of their goals. However, in recent years, not only active treatment but also palliative care has received attention. However, no clear standards for neonatal palliative care or end-of-life (EOL) care have been defined in Japan. To address this situation, in 2003, the "Guidelines for Healthcare Providers and Parents to Determine the Medical Care of Newborns with Severe Disease" were created by the research team commissioned by National Center for Child Health and Development. However, even now, each neonatal intensive care unit (NICU) follows its own standards, and no uniform standard has been established for EOL care. Because there is no clarity about the growth limit and there are no unified standards, NICU is said to be a ward that is likely to pose an ethical dilemma (3).

Further, the death of a child is a traumatic event for the parents, and the impact of the event is immeasurable (2; 6; 8). In addition, caring for dying children can be seriously stressful for healthcare providers (17; 20; 25). At times, healthcare providers have to face the stressful situation of supporting bereaved families following children's deaths (11; 14; 25). In a survey of pediatricians conducted by Setou, many pediatricians were found to continue maintaining a relationship with bereaved families following children's deaths. The survey identified female gender,

fewer years of working experience, lack of coping methods, and feeling of helplessness as risk factors for psychological distress in pediatricians (18). Similar to pediatricians, nurses are also potentially exposed to distress and helplessness because nurses more frequently visit and provide physical and mental care to dying children and their families (16). In addition, nurses who care for children are at risk of developing compassion fatigue (1). Compassion fatigue is a physical, psychological, and spiritual depletion that nurses face when caring for patients (13). A few studies conducted in Europe and the USA revealed that the years of experience as a nurse and bereavement care education are related to nurses' comfort of providing care (4; 25). However, the historical and cultural backgrounds of these countries differ extensively from Asian countries including Japan. Therefore, it is not always possible to directly apply the research results of each country to Japanese nurses.

We conducted a questionnaire survey in NICUs to examine the psychological distress experienced by nurses in supporting families who had lost children and examined the factors of psychological distress involved in providing bereavement support. In addition, we compared these results with those of pediatricians to understand the professional characteristics of nurses experiencing high psychological distress in supporting bereaved families and examined strategies to reduce the psychological distress of NICU nurses.

## METHODS

### Participants and data collection

One hundred and twenty facilities belonging to the Japan Neonatal Follow-up Study Group were invited to participate in this survey through a letter. This is a multi-field study group of professionals that is focused on contributing to the dissemination and improvement of follow-up of children with high risk of long-term prognosis. We sent questionnaires to the NICUs that consented to participate in this study from November to December 2014. Several nurses were selected to participate from each NICU by the respective administrators. The participants' nurses were full-time with no mental illness. These participants were selected from perinatal medical centers throughout Japan. They were asked to fill out the survey forms individually. Participants either returned the questionnaires themselves or via the administrators.

### Contents of questionnaire

The questionnaire used in this study included questions on the following: (1) demographic characteristics of participants (8 items: gender, age, years of working experience, etc.); (2) presence/absence (and details) of official bereavement care to support families who have lost children (2 items); (3) current situation of support for bereaved families (14 items: the type of support provided for the families, experience of patient loss during the past year, how often they experienced psychological distress and how they coped with it at the time, availability of a professional advisor, and experience of professional education for bereavement care, etc.), (4) consciousness of supporting bereaved families (11 items: concern about bereavement care, lack of knowledge about bereavement care, etc.).

These questionnaire items were created based on the previous survey by Setou (18). Regarding Item (4), consciousness of supporting bereaved families, participants answered using a 5-point Likert scale ranging from 1 ("strongly agree") to 5 ("strongly disagree"). "Experience of patient loss" means that the participants have experienced caring for a dying patient. Regarding how often nurses experienced psychological distress and how they coped with it at the time, participants selected one or more from "Talking to colleagues, friends, and family", "Accepting the death of babies as their fate and considering it as part of my job", "Resting, distraction", and "Other."

### Data analysis

Nurses' psychological distress was assessed by asking how often they experienced psychological distress in relation to supporting bereaved families. The psychological distress was classified with two grades. Namely, those who answered the question that they "always" or "often" experienced distress in relation to bereavement care were classified as the high distress group, while those who answered "sometimes," "rarely," or "never" were classified as low distress group. The  $\chi^2$  test and Fisher's exact test were utilized to compare variables such as attributes, experience of education, and consciousness of supporting bereaved families between the two groups.

A multiple logistic regression analysis was employed to investigate the factors related to psychological distress. Items with *p*-values less than 0.2 in the  $\chi^2$  test and Fisher's exact test were added as independent variables, and odds ratios (ORs) were calculated using the backward elimination (likelihood ratio) method. To quantify multicollinearity, variance inflation factors was computed.  $VIF > 10$  was set as multicollinearity.

Furthermore, to analyze the characteristic factors of nurses' psychological distress,  $\chi^2$  tests and Fisher's exact test were conducted to compare the results of the present study with those of pediatricians (from the previous

survey) on all common items. Data analysis was conducted using SPSS Statistics ver. 24, and the level of significance was set at 0.05.

### **Ethical consideration**

With regard to ethical considerations, the questionnaire included information on the purpose of the research, clarified that refusing to participate would not lead to any disadvantages, and explained the confidentiality obligation to the target NICU and individual nurses. In addition, it was stated clearly that answering/returning the questionnaire would be considered as providing consent to participate.

This study was conducted with the approval of the Ethics Committee of the Graduate School of Health Sciences, Kobe University, and with permission from the permanent executive board of the Japan Neonatal Follow-up Study Group.

## **RESULTS**

### **Nurses' psychological distress related to providing support to bereaved families**

A total of 384 questionnaires were completed and returned from the 64 NICUs. Of the 384 respondents, 190 (49.5%) reported having experiences of providing support for bereaved families, and 169 provided data with errors/omissions on two items or less and were thus included in the analysis. The actual support provided to bereaved families included "listening, conversations, consultations" (28%), "letter exchange" (25%), and "funeral attendance" (16%).

Regarding the level of psychological distress, 123 nurses (72.8%) were classified as the high distress group. Of the high distress group, 97 nurses (78.9%) had experienced patient loss during the past year, and 116 nurses (94.3%) had used coping methods.

### **Factors associated with high psychological distress related to providing support to bereaved families**

Table I shows the demographic characteristics of participants, presence/absence of official bereavement care to support families who have lost children, and current situation of support for bereaved families. Nurses in the high distress group had more frequently experienced patient loss during the past year ( $p = 0.036$ ). A greater number of nurses in this group used coping methods ( $p = 0.005$ ), and they used a greater number of coping methods ( $p = 0.014$ ). Table II shows the results pertaining to consciousness of providing support to bereaved families for both groups. However, the differences in consciousness of providing support to bereaved families between the two groups were not significant.

To investigate the factors related to high or low psychological distress, a logistic regression analysis was performed with the seven independent variables (Table I and II) whose  $p$ -values were less than 0.2 (experience of patient loss during the past year, use of coping methods, number of coping methods to be used, belief that nurses should provide care to bereaved families, anxiety, fatigue, and desire for training on bereavement care). Not using coping methods was found to be the only factor significantly associated with nurses' psychological distress. When nurses did not use coping methods, the psychological distress was lower (OR = 0.217, 95% confidence interval = 0.074–0.638). Collinearity analysis among variables included in the final model demonstrated a low level of multicollinearity (maximum VIF for the final model = 3.05). The result of the Hosmer-Lemeshow test indicated a good fit ( $p = 0.804$ ), and the discriminant predictive value was 76.2%. Additionally, there were no outliers with a predicted value exceeding  $\pm 3$  SD with respect to the measured value (Table III). Of the 164 participants, 82 (50%) selected "Talking to colleagues, friends, and family", 33 (20%) selected "Accepting the death of babies as their fate and considering it as part of my job", 33 (20%) selected "Resting, distraction", and 16 (10%) selected "Other" as their coping methods.

### **Comparison of results between nurses and pediatricians**

A total of 13 of 20 items exhibited significant differences ( $p < 0.05$ ) between pediatricians and nurses (Table IV). Compared with pediatricians, a greater number of nurses were females ( $p < 0.001$ ). Nurses also had fewer years of working experience ( $p < 0.001$ ), had high proportion of high distress ( $p = 0.001$ ), had provided official bereavement care ( $p = 0.001$ ), had experienced patient loss during the past year ( $p = 0.001$ ), had used coping methods ( $p < 0.001$ ), had a professional advisor available ( $p = 0.043$ ), had experienced professional education for bereavement care ( $p < 0.001$ ), believed that bereaved family care should be provided by their profession ( $p < 0.001$ ), were concerned about bereavement care ( $p = 0.006$ ), had high anxiety ( $p < 0.001$ ), had high helplessness ( $p = 0.013$ ), and expressed desire for training on bereavement care ( $p < 0.001$ ).

Table I. Demographic characteristics, current situation of bereavement care, and experience of education

	n = 169	%	High Distress		Low Distress		p-value
			n = 123	%	n = 46	%	
<b>Gender</b>							
Male	2	0.2	1	0.8	1	2.2	0.471
Female	167	98.8	122	99.2	45	97.8	
<b>Years of working experience as an NICU nurse</b>							
<5 years	55	32.6	39	31.7	16	34.8	0.815
6~10 years	60	35.5	45	36.6	15	32.6	
11~15 years	32	18.9	23	18.7	9	19.6	
16~20 years	19	11.2	13	10.6	6	13.0	
21~25 years	3	1.8	3	2.4	0	0	
<b>Official bereavement care (self-help group etc.)</b>							
Presence	152	90.0	112	91.1	40	87.0	0.299
Absence	17	10.0	11	8.9	6	13.0	
<b>Experience of patient loss during the past year *</b>							
Yes	126	74.6	97	78.9	29	63.0	0.036
No	43	25.4	26	21.1	17	37.0	
<b>† Coping methods **</b>							
Use	148	87.8	116	94.3	32	78.0	0.005
Do not use	16	12.2	7	5.7	9	22.0	
<b>†Number of coping methods used *</b>							
Do not use	16	9.7	7	5.7	9	21.9	0.014
One	80	48.9	60	48.8	20	48.8	
Two	52	31.7	42	34.1	10	24.4	
More three	16	9.7	14	11.4	2	4.9	
<b>Professional advisor</b>							
Available	68	40.2	52	42.3	16	34.8	0.377
Not available	101	59.8	71	57.7	30	65.2	
<b>Experience of professional education for bereavement care</b>							
Yes	101	59.8	75	61.0	26	56.5	0.599
No	68	40.2	48	39.0	20	43.5	
<b>Should nurses provide bereavement care to bereaved families?</b>							
Agree	116	68.6	89	72.4	27	58.7	0.168
Agree but difficult to do	52	30.8	33	26.8	19	41.3	
Disagree	1	0.6	1	0.8	0	0	

Each item was  $\chi^2$  tested and Fisher's exact test between the two groups.

\* :  $p < 0.05$  \*\* :  $p < 0.01$

Indicated sum of the items is different from the actual sum due to the number of blank responses.

† : The total responses obtained for this category was 164, of which 41 responses belonged to the low-distress group.

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Table II. NICU nurses' consciousness of supporting bereaved families

	n = 169		High Distress		Low Distress		p-value
	n	%	n = 123	%	n = 46	%	
<b>Bereavement care is meaningful</b>							
Yes	164	97.0	120	97.6	44	95.7	0.414
No	5	3.0	3	2.4	2	4.3	
<b>Concern about bereavement care</b>							
Yes	150	88.8	110	89.4	40	87.0	0.650
No	19	11.2	13	10.6	6	13.0	
<b>Lack of knowledge about bereavement care</b>							
Yes	136	80.5	99	80.5	37	80.4	0.994
No	33	19.5	24	19.5	9	19.6	
<b>Lack of skills for bereavement care (communication skill etc.)</b>							
Yes	124	73.4	90	73.2	34	73.9	0.923
No	45	26.6	33	26.8	12	26.1	
<b>Lack of information about bereavement support (self-help group etc.)</b>							
Yes	141	83.4	104	84.6	37	80.4	0.522
No	28	16.6	19	15.4	9	19.6	
<b>Anxiety about hurting the bereaved families</b>							
Yes	125	74.0	95	77.2	30	65.2	0.113
No	44	26.0	28	22.8	16	34.8	
<b>Avoiding children's deaths and bereavement if possible</b>							
Yes	63	37.3	49	39.8	14	30.4	0.261
No	106	62.7	74	60.2	32	69.6	
<b>Feeling of helplessness in bereavement care</b>							
Yes	91	53.8	69	56.1	22	47.8	0.337
No	78	46.2	54	43.9	24	52.2	
<b>Increase of fatigue during bereavement care</b>							
Yes	107	63.3	82	66.7	25	54.3	0.139
No	62	36.7	41	33.3	21	45.7	
<b>Desire to study bereavement care</b>							
Yes	152	89.9	114	92.7	38	82.6	0.054
No	17	10.1	9	7.3	8	17.4	
<b>Necessity of cooperating with professionals</b>							
Yes	139	82.2	103	83.7	36	78.3	0.407
No	30	17.8	20	16.3	10	21.7	

For each item, "strongly agree" and "agree" are represented by "Yes."

"Neither agree or disagree," "disagree," and "strongly disagree" are represented by "No."

Table III. Factors associated with high psychological distress of NICU nurses related to providing support to bereaved families

n = 164	Regression coefficient	p-value	Odds ratio	95% CI	
				Lower Confidence Limit	Upper Confidence Limit
<b>Did not use coping methods</b>	-1.527	0.005	0.217	0.074	0.638
<b>Did not experience patient loss</b>	-0.753	0.063	0.471	0.213	1.040
<b>Constant</b>	1.500	0.000			

Table IV. Comparison of results between nurses and pediatricians

	n = 344		Nurses		Pediatrician		p-value
	n = 344	%	n = 169	%	n = 175	%	
<b>Gender ***</b>							
Male	99	28.8	2	1.2	97	55.4	< 0.001
Female	245	71.2	167	98.8	78	44.5	
<b>Years of working experience ***</b>							
≤ 14 years	155	49.8	141	83.4	47	26.8	< 0.001
15~22 years	70	22.5	27	16.0	43	24.6	
23~29 years	50	16.1	1	0.6	49	28.0	
≥ 30 years	36	11.6	0	0	36	20.6	
<b>Frequency of psychological distress **</b>							
High Distress group	220	64.0	123	72.8	97	55.4	0.001
Low Distress group	124	36.0	46	27.2	78	44.6	
<b>†<sup>1</sup>Official bereavement care (self-help group etc.) ***</b>							
Presence	194	56.6	152	89.9	42	24.1	< 0.001
Absence	149	43.4	17	10.1	132	75.9	
<b>†<sup>2</sup>Experience of patient loss during past year **</b>							
Yes	223	65.8	126	74.6	97	57.1	0.001
No	116	34.2	43	25.4	73	42.9	
<b>†<sup>3</sup>Coping methods **</b>							
Have	220	64.9	144	87.8	76	43.4	< 0.001
Have not	119	35.1	20	12.2	99	56.6	
<b>Professional advisor *</b>							
Available	120	34.9	68	40.2	52	29.7	0.043
Not available	224	65.1	101	59.8	123	70.3	
<b>Experience of professional education for bereavement care ***</b>							
Yes	147	42.7	101	59.8	46	26.3	< 0.001
No	197	57.3	68	40.2	129	73.7	
<b>†<sup>1</sup>Should the professional provide bereavement care to bereaved families? ***</b>							
Agree	193	56.3	116	68.6	77	44.3	< 0.001
Agree but difficult to do	132	38.5	52	30.8	80	46.0	
Disagree	18	5.2	1	0.6	17	9.7	
<b>Concern about bereavement care **</b>							
Yes	285	82.8	150	88.8	135	77.1	0.006
No	59	17.2	19	11.2	40	22.9	
<b>Anxiety about hurting the bereaved families ***</b>							
Yes	221	64.2	125	74.0	96	54.9	< 0.001
No	123	35.8	44	26.0	79	45.1	
<b>†<sup>1</sup>Feeling of helplessness in bereavement care *</b>							
Yes	161	46.9	91	53.8	70	40.2	0.013
No	182	53.1	78	46.2	104	59.8	
<b>Desire to study bereavement care ***</b>							
Yes	275	79.9	152	89.9	123	70.3	< 0.001
No	69	20.1	17	10.1	52	29.7	

Each item was  $\chi^2$  tested and Fisher's exact test between the two groups.

\* :  $p < 0.05$  \*\* :  $p < 0.01$  \*\*\* :  $p < 0.001$

Indicated sum of the items is different from the actual sum due to the number of blank responses.

The total number of responses obtained was different for some categories. These are indicated below:

†<sup>1</sup> : pediatricians' n = 174, †<sup>2</sup> : pediatricians' n = 170, †<sup>3</sup> : nurses' n = 164.

## DISCUSSION

### **Nurses' psychological distress related to providing support to bereaved families**

Our study revealed that high psychological distress was related to experiencing patient loss during the past year, use of coping methods, and number of coping methods used.

Most (72.8%) nurses experienced high psychological distress in providing support to bereaved families. Nurses who cared for families who had lost children in the perinatal period reported feeling severe distress frequently (11; 14; 25). Our results are consistent with the results of those reports.

Seventy-nine percent of nurses in the high distress group experienced patient loss during the past year. High frequency of nurses' experience of patient loss suggests that the death of young infants in NICU is still not rare in Japan. In addition, nurses usually provide EOL care and bereavement care (12; 14). Such roles of nurses might be related to the cause of psychological distress in NICU nurses.

According to the Almanac of Data on Japanese Children 2017, the death of infants occupied 39.6% of the total deaths of children, and 47% of them occurred in newborn days (within 4 weeks after birth). The majority of children's deaths in Japan is suspected to occur in NICUs. After a child's death, NICU nurses usually provide bereavement care for families in private rooms (12), and they care for the deceased child's body together with the family members (12; 25). Children's deaths are mostly a traumatic event for the families themselves (2; 6; 8). In addition, it is widely recognized that the death of children causes complex grief in families (7; 8; 10; 19; 24). Therefore, the accumulated fatigue due to experiences of patient loss and providing bereavement care for families may increase psychological distress in nurses.

### **Factors associated with high psychological distress related to providing support to bereaved families**

Logistic regression analysis revealed that the factor associated with high psychological distress is the use of coping methods. In the high distress group, nurses used coping methods more frequently. Generally, coping methods help to avoid or alleviate stress (5; 9). Even if the same event was experienced, the extent of stress experienced could differ according to individuals (9). The results of the present study revealed that high psychological distress was related to using coping methods. This may be because the nurses who perceive that providing bereavement care for families as a stressful event might experience an increase in the desire for a suitable coping method to deal with the distress.

Half of the nurses selected "Talking to colleagues, friends, and family" as their used coping method. This coping method is classified as emotional-focused coping. Lazarus divided coping methods into the two groups, emotion-focused coping and problem-focused coping. Emotion-focused coping is a conscious effort and action that involves stopping thoughts about the distressing event and makes efforts to adjust emotions, and problem-focused coping is a conscious effort to think about the cause about the distress and how to solve it (9). In this survey, most of the coping methods used by the nurses belonged to the emotion-focused coping group. A previous study reported that emotion-focused coping methods did not reduce the psychological distress of nurses in palliative care (21). On the other hand, problem-focused coping methods were effective to help palliative care nurses manage distress (15). From these results, for the distress of nurses in EOL care and bereavement care, problem-focused coping methods were considered to be more suitable than emotion-focused ones. In addition, selection of the contents of coping methods might be important. The contents should be appropriate for any situation and suitable to the sensitivity of each nurse. The relationship between the distress of individual nurses and used coping methods will require analysis in the future. A more appropriate approach to psychological distress can perhaps be achieved.

### **Comparison of results between nurses and pediatricians**

A total of 13 of 20 items of comparison exhibited significant differences ( $p < 0.05$ ) between pediatricians and nurses. In the previous study by Setou, four factors were found to be related to pediatricians' high psychological distress: female gender, fewer years of working experience, lack of coping methods, and feeling of helplessness (18). The nurses in our study were significantly more likely to be female and had fewer years of working experience. The risk of psychological distress might be greater for nurses than for pediatricians with regard to supporting bereaved families. Therefore, as part of nursing education or at the earliest after nurses are employed, it is important to convey information on psychological distress related to children's deaths and bereavement care and ensure that nurses obtain preliminary knowledge. It is necessary to improve the educational environment so that nurses who are experienced in EOL care can provide information to novice nurses.

Nurses who used coping methods were more likely to experience psychological distress. The results of using coping methods were exactly opposite between the nurses and the pediatricians. Depending on how they interact with children and families, the relationship of different medical practitioners, such as pediatricians, nurses, and other co-medical staff, with bereaved families is different. Therefore, different types of coping methods for providing support to bereaved families may be required based on the characteristics of each job category.

Furthermore, compared with pediatricians, nurses were significantly more likely to use coping methods and to experience high psychological distress. Therefore, this suggests the limitations of individuals in coping by themselves. According to Vachon (23), occupational stress among hospice and palliative care providers has been found to develop due to environmental and personal factors, and it may be possible to reduce stress by addressing both of these types of factors. Therefore, it is necessary to create a system to reduce the psychological distress of NICU health care providers related to supporting bereaved families as a whole hospital. The system must support all health care providers by offering multiple perspectives.

### LIMITATIONS

The facilities in which pediatricians participating in the Japan Neonatal Follow-up Study Group are working took part in this study. Therefore, the institutions and participants were limited, as other perinatal medical centers throughout Japan could not be involved. Second, nurses working in wards other than NICUs could not be compared. Future surveys should include different hospitals and target groups. Third, the results of NICU nurses were compared with those of pediatric neurologists and neonatologists; therefore, differences in patients' diseases and wards may have affected the results. Fourth, since we did not investigate individual resilience and stress tolerance, these individual characteristics could not be compared. Finally, in the questionnaire used in this study, no problem-focused coping options were provided for "coping methods."

### CONCLUSION

Most nurses experienced high psychological distress in providing support to bereaved families, which is associated with the use of coping methods. Therefore, it may be necessary to clarify the coping methods for psychological distress in supporting bereaved families, and nurses need to identify appropriate coping methods.

Comparison with pediatricians revealed that nurses were significantly more likely to be female and had fewer years of working experience, and there is a possibility that nurses are more likely to experience high psychological distress. Therefore, as a part of nursing education, information on psychological distress related to children's deaths and bereavement care should be conveyed from the early stage, and nurses must obtain preliminary knowledge.

Although NICU nurses used coping methods to counter psychological distress, their suffering did not reduce, suggesting the limitations of individuals in coping by themselves. Therefore, considering the approach from environmental factors, a bereavement follow-up system consisting of a multidisciplinary team having different perspectives should be created.

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