



# The Lived Experiences of Living with LPD among CKD Patients in Southern Taiwan

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## ABSTRACT

### Aim

To explore the experience of patients with chronic kidney disease with regard to adopting a low-protein diet.

### Background

Chronic kidney disease is a serious and increasingly prevalent global health problem. A low-protein diet helps delay the progression of the disease and decreases associated complications. However, many patients with chronic kidney disease have difficulties adhering to a low-protein diet, even after several consultations.

### Design

A phenomenological study.

### Methods

This study used a phenomenological inquiry based on Colaizzi's phenomenological analysis. Participants with chronic kidney disease were recruited from a nephrology unit at a local district hospital in southern Taiwan.

### Results

Fifteen Taiwanese adults with stages 3b-5 chronic kidney disease participated in this study. More than half (53%) were men, the mean age was 57 years, and the mean duration of chronic kidney disease was nine (range, 2-19) years. Most participants reported that the diet education they received from health care providers was inconsistent and confusing. Four themes emerged from participant experiences: confusion about eating restrictions, struggling with the daily diet, concerns about quality of life and mortality, and a fresh look at life and motivation to adhere to the low-protein diet. With diet management, these participants had maintained their minimum kidney function for many years.

### Conclusion

This study highlights the substantial problems faced by chronic kidney disease patients while self-managing a low-protein diet. Also, we found some tips to manage the patients' diet which all professional health practitioners could learn from them.

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### Relevance to clinical practice

A low-protein diet plays an important role in controlling the progression of chronic kidney disease. Without aggressive treatment, chronic kidney disease can progress to end-stage renal disease and cause lifelong hemodialysis. This paper provides simple tips and integrated education strategies to support individuals in adopting a low-protein diet.

### Keywords

Chronic kidney disease, Nutrition, Renal nursing

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### Background

Chronic kidney disease (CKD) is a progressive chronic disease that, if left untreated, can quickly progress to end-stage renal disease (ESRD) and cause lifelong hemodialysis. Obesity, diabetes, and hypertension are important factors for ESRD [1]. CKD causes a high global medical burden. The World Health Organization [2] reported that in 2010, CKD was the fourth largest cause of death worldwide. The prevalence of CKD in Taiwan was 9.8% in 1997 and 11.9% in 2006 [3]. The medical expense for ESRD was more than 1 billion USD, which accounted for 7% of the annual total health expenditure of the national health insurance [4]. In order to avoid complications of CKD and reduce medical expenses, it is important to prioritize effective strategies to control the progression of CKD and reduce the incidence of ESRD.

According to the definition of the [5], CKD is a long-term condition involving the gradual loss of kidney function over time and is associated with an estimated glomerular filtration rate (eGFR) of  $<60$  ml/min/1.73 m<sup>2</sup>. The eGFR is a good indicator of kidney function and is affected by diet. Therefore, CKD is categorized into five stages on the basis of the eGFR: stage 0,  $>100$  ml/min/1.73 m<sup>2</sup>; stage 1,  $\geq 90$  ml/min/1.73 m<sup>2</sup>; stage 2, 60-89 ml/min/1.73 m<sup>2</sup>; stage 3, 30-59 ml/min/1.73 m<sup>2</sup>; stage 4, 15-29 ml/min/1.73 m<sup>2</sup>; and stage 5,  $<15$  ml/min/1.73 m<sup>2</sup> (NKF, 2013). The eGFR is commonly estimated using equations that adjust the serum creatinine concentrations for age, race, and gender [5,6], but can also be determined using an abbreviated prediction equation.

To control the progression of CKD and reduce the incidence of ESRD, strategies should focus on improving patients' knowledge about controlling of their diet required for kidney disease and enforcing healthy lifestyles, such as appropriate diet planning and positive lifestyles [5,7]. Some

studies have shown that a low-protein diet (LPD) plays an important role in reducing the progression of CKD [8-11], as it can maintain the nitrogen balance and assist with tissue repair in the body [11,12]. In general, the minimum daily protein requirement for adults is 0.8-1.0 g/kg/day. A high protein dietary intake is related to glomerular pressure and high filtration rate. Controlling the protein intake could decrease the blood urea nitrogen level, urinary toxins, and phosphorus accumulation, and improve the symptoms of anemia. In addition, studies have indicated that adherence to LPD, with a protein intake of 0.6-0.8 g/kg weight/per day, could preserve the serum albumin, reduce proteinuria and albuminuria, prevent uremic symptoms [11,12], and reduce phosphorus and C-reactive protein concentrations [13]. In addition, LPD could be important in delaying CKD progress [14-16]. The diet of patients with CKD is easily affected by lifestyle. Although studies show that LPD is significantly associated with a decline in CKD progression, diet modification and low adherence are observed in many CKD patients [9,17]. Therefore, it is important to understand how to educate patients about incorporating a LPD into their daily life and determine what the patient's diet was before and after adoption of the LPD.

LPD is beneficial for maintaining a good lifestyle in CKD patients. However, very few studies have elaborated on why patients with CKD cannot properly comply with a LPD.

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### Design

#### ■ Research question

What do patients with CKD experiences regarding adopting a LPD in their daily life?

#### ■ Methodology

This was a phenomenological inquiry based on Colaizzi's [18] phenomenological analysis. Phenomenology, which explores a phenomenon

and describes it, was used as the theoretical basis for this study to explore CKD patient's experience of LPD [19].

Purposive sampling was used in this study. The sample setting was a nephrology clinic of a regional hospital in southern Taiwan and the study took place between December 2014 and March 2015. The inclusion criteria were as follows: (a) diagnosis of CKD with treatment but not receiving hemodialysis, (b) receipt of education on LPD by case managers and dietitians, (c) ability to communicate in Mandarin or Taiwanese, (d) age > 20 years, (e) eGFR of 10-45 ml/min/1.73 m<sup>2</sup>, and (f) agreement to participate in interviews and share his/her own experiences.

## ■ Methods

### Procedures and ethical consideration

Two nephrology case managers and one nephrologist arranged the meeting between the participants and the researcher. In general routine, the nephrology clinic provided the contents of health counseling for CKD patients by case managers included (a) assessing the comorbidity of patient's health condition and medication compliance, e.g., diabetes, hypertension, obesity; (b) assessing and providing lifestyle modification for each patient, e.g., cigarette cessation, physical activity, such as 30 minutes or 150 minutes of exercise ever day or each week, and weight loss education; (c) using the food models to demonstrate the amount of protein and other kinds of ingredients; (d) assessing adopting food contents and amount for each patient during the diet counseling. The interview included the following questions: (1) Please describe your thoughts on health-education guidance for a LPD provided by a health educator; (2) Please share your own experiences about LPD intake; and (3) Please share your own strategies that helped you maintain the LPD.

This study was approved by Hospital Institute Review Board (IRB No: B10304014) before conducting the interview. Fifteen participants agreed to take part in the study. They were informed that if they felt uncomfortable during the interviews, they were allowed to leave the study at any time. All interviews were recorded. In order to protect the interviewees' privacy, the study used abbreviated patient names and all recorded data were secured.

## ■ Data analysis

The study employed Colaizzi's [18] phenomenological data analysis in seven steps. Based on the data collection and context analysis provided by Lincoln & Guba [20], the sample size was determined when there was no new data obtained from the participants. Overall, 15 participants were included in this study.

## Results

A total of 15 participants (**Table 1**) were involved in this study, which included eight men and seven women aged 22-82 years (mean, 57). Five had stage 3b CKD, four had stage 4 CKD, and six had stage 5 CKD. The majority reported the presence of hypertension (80%), diabetes (33%), or both (20%). The duration of diagnosis of CKD was 2-19 (mean, 9) years. The experiences of adopting LPD could be categorized into four main groups: confusion about eating restrictions, struggling with the daily diet, concerns about quality of life and mortality, and a fresh look at life and motivation to adhere to the LPD.

### ■ Confusion about eating restrictions

The CKD participants were typically diagnosed without any symptoms or discomfort at an early stage. All the health education information provided by the CKD case manager in the hospital was only simple diet information. Most patients were shocked and no idea what should they eat without professional advices. They were totally confused about diet restrictions in their life.

Mrs. H said: *"I was diagnosed with kidney problems and abnormal blood pressure at the clinic. However, I really didn't have any problems with my health or body at that time; therefore, I didn't pay extra attention to the diagnosis. Later, when I went to hospital for treatment of a cold, I was astonished when I was advised to begin kidney dialysis and needed to have diet control. The nurse and doctor only told to me eat less protein; what was protein? I had no idea about less protein diet."*

Mrs. L kept her daily life for whole life; Mrs. L stated, *"I didn't know the severity of this disease when I was initially diagnosed. I didn't control my diet or pay any special attention to it. I was a housewife and worked at hospital as a caregiver. I prepared my family's diet every day. Corn flour*

**Table 1: Characteristics of the interviewees.**

No	Alias	Age	Education	CKD years	Diet <sup>1</sup> years	eGFR <sup>2</sup>	eGFR <sup>3</sup>	eGFR <sup>4</sup>	eGFR <sup>5</sup>	eGFR <sup>6</sup>	Occupation	No of diet counseling <sup>4</sup>
1	Mr. C	70	High school	3	2	37.66	33.73	30.27	32.55	32.55	Coordinator	15
2	Mrs. T	82	Illiterate	14	4	28.92	33.05	32.96	31.73	23.63	Volunteer	25
3	Mrs. L	66	Primary school	11	8	44.71	40.09	44.41	25.45	28.90	No	37
4	Mr. L	49	PhD	19	6	77.64	69.91	53.79	49.71	25.42	Professor	28
5	Mrs. H	55	Primary school	6	5	9.91	9.74	7.43	8.51	4.75	Farmer	45
6	Mr. T	68	High school	14	8	15.9	15.90	16.79	14.56	8.78	No	48
7	Mr. M	41	Primary school	12	4	34.18	37.76	30.71	31.57	32.66	Carpenter	25
8	Mrs. L	68	Primary school	15	8	25.71	24.28	20.88	15.65	10.88	No	62
9	Mrs. T	58	Secondary school	2	2	25.54	20.72	15.75	19.49	19.49	Dancing teacher	13
10	Mr. S	60	Illiterate	5	5	16.18	17.76	15.63	12.33	11.42	Boss	40
11	Mrs. C	68	Illiterate	16	8	34.83	37.52	30.30	30.20	10.30	No	49
12	Mr. N	61	Primary school	4	4	39.03	41.40	31.09	32.79	36.49	Farmer	21
13	Mr. H	22	High school	4	3	32.52	25.80	32.61	32.74	34.34	Driver	20
14	Mr. T	37	High school	4	3	38.62	36.60	38.90	40.61	40.03	Boss	19
15	Mrs. L	55	High school	8	5	22.71	22.62	11.81	13.62	11.94	Part time	38

<sup>1</sup> receiving education of low protein diet years by case manager;

<sup>2</sup> eGFR: estimated glomerular filtration rate; first time received diet education by case manager.

<sup>3</sup> eGFR~<sup>2</sup>eGFR: estimated glomerular filtration rate; data from chart per 3 month before the interview.

<sup>6</sup> eGFR: interview period, December 2014 and March 2015.

<sup>4</sup> Total number of receiving counseling by case manager.

*was my family’s daily breakfast. I ate it every day until one day one dietitian told me: Do not eat corn flour.... Actually, I had added only two spoons of rice bran or corn flour into milk for my breakfast in case of easily hungry due to heavy job; I really didn’t know who exactly was correct? Honestly speaking, I sometimes still ate corn flour for my breakfast because no one told me that I could not eat rice bran or corn flour.”*

Mr. N had a similar response: *“I was diagnosed with this disease in 2003, but I did not have any symptoms, and no one had ever instructed me about how to control the disease. I was always overeating, especially meat. I was a meat lover. No doctor or nurse told me how to eat my diet, and what Low-protein diet was. I was confused about the diet.”*

Although most participants were instructed by professional healthcare workers, everyone had their individual interpretation about diet inclusions and quantity, due to the different information received.

Mr. C said: *“The dietitians gave me too much information, which was too complicated for me to understand and remember. For instance, they said not to eat foods that are too oily, to eat less seafood,*

*to completely stop eating animal organs, etc. I could not follow so many regulations in my diet. The information was too much. I could not remember it, especially for older people.”*

**■ Struggling with the daily diet**

All participants struggled with their daily diet, as they found the diet hard to prepare, and it was also difficult to make changes to their daily diet.

Mr. N had a similar response: *“They told me too many things to remember. I only remembered that bean curd was protein, and I should eat more vegetables and less meat, around five or six small pieces per day. My wife did not know how to prepare for me. I was struggled with the daily diet.”* Mrs. H said, *“The dietitians instructed me to eat only the white part of the egg, not the yolk, and only eat one egg per day. Starfruits and soups were forbidden due to their high potassium content, which could cause itching. They also asked me to drink soya bean milk when I was hungry, but I always drank milk with lotus root powder instead of soya bean milk, because I did not like soya bean milk. It was difficult to change my daily habit.”*

Many participants still worked outside home and had a social life. Participants found it hard to spending time with friends or colleagues, as LPD adherence was difficult.

Mr. C said: *“Although I intended to try my best to follow the low-protein diet, there were many difficult situations, particularly when I was involved in business. It was really hard for me to reject my customers’ invitations and social occasions. I did not want to lose the opportunity to get along with the customers and friends. I couldn’t refuse to eat the meals that they ordered at such occasions, because I wanted to maintain the relationship.”* Mr. M had a similar experience: *“Sometimes, when having dinner with my friends or relatives, I was unable to control my diet. Even the dietitians kept reminding me not to eat too much.”*

Mr. T commented: *“My job was different from others, and my working shift was not steady. I usually ate outside; hence, it was difficult for me to strictly follow the low-protein diet. Moreover, I did not like to bother others. If they ordered a lunch box, I only ate what I could eat from the items in the box.”* Mrs. L also described: *“Once I ate outside, everything went out of control. It was really difficult to ask any restaurant or convenience stores to prepare the particular diet only for me. I just ate what they sold to general customers without special limitations. It was really impossible for me to follow the doctor and dietician’s advice. What I could do was drink more water; not eat fried food; and eat less sugar, less potassium, and more vegetable protein. Nevertheless, in daily life, it was extremely hard to adopt a low-protein diet.”*

### ■ Concerns about quality of life and mortality

Many participants felt scared and concerned about their life after they changed their diet. However, the life changes pushed the participants to a better lifestyle.

Mr. H said, *“I was so afraid of passing away due to the accidental myocarditis caused by viral infection without any faith they’d recovered, and my mother was also extremely worried. Therefore, to prevent any serious disease again, I started to pay more attention to my daily diet.”* Mr. T further stated, *“I was hospitalized for over ten days to gain control of my cardiac edema as a priority and as a remedy for my kidney condition. Because of my poor health, I was able to persuade myself to follow the doctor’s directions and thereafter I began taking care of my health.”*

Mr. M was hospitalized 3 years ago due to a cerebral vascular accident, and he expressed his grief about his 12-year history of kidney disease: *“I was unscrupulously overeating, no matter what the dietitians told me. Until I had a cerebral hemorrhage, for which I was hospitalized for a while and that saved my life, I would never have cared about my daily diet.”* Mr. C made the similar comments: *“I always overate seafood without control. I knew that it could lead to various problems, such as leg pain, due to its various components like uric acid and high blood sugar. But, I never paid attention to it until I was diagnosed with kidney disease. I regretted indulging myself in luxury diets that affected my kidney and health. Since I had learnt the lesson, I finally realized the importance of controlling my diet with low protein content.”*

Pain and discomfort made the participants changes their daily diet to be healthy. Mr. N said: *“I used to eat everything without any limitations, but at the moment, I care about my daily appropriate diet to avoid the pain.”* Mrs. C was hospitalized several times and almost had kidney dialysis. She was very scared and said: *“I was hospitalized due to kidney disease, and I almost needed dialysis treatment. After that horrible experience, I always remain alert about my daily diet and control it strictly to avoid all forbidden food such as oatmeal, starch, and flour.”*

Mr. L started to change his diet because of his daughter and wife: *“My daughter supported me, so I won’t let her down. I look forward to seeing her grow up. Three years ago, I was abruptly hospitalized due to a cerebrovascular accident, and I didn’t pay any attention to diet control before hospitalization. At that moment, my wife and daughter cried and told me not to give up. Therefore, I usually remind myself of my young daughter and keep my diet healthy. I have controlled my diet for the last three years.”*

Family support helped these participants maintain LPD. Mr. M said: *“We didn’t cook at home before our baby was born, but I started to prepare food more frequently because I would like to live longer for my baby.”*

The participants did not want their parents to be scared and worried. Mr. H commented: *“When I was sent to the intensive care unit and my parents were notified about my critical condition by the hospital, my mother was very scared and worried about my health. Fortunately, I felt better and*

*thereafter strictly controlled my daily diet because I didn't want to scare my mother anymore."*

#### ■ A fresh look at life and motivation to adhere to LPD

Many participants accepted the diagnosis and started to live with the disease more than 10-20 years after the diagnosis. They faced many difficulties in the process and started taking a fresh look at life. These participants did not want to concentrate on the diet too much, because they found that after controlling the diet, life was as normal for them as it was for other people.

Mrs. L stated: *"On initial discovery of the disease, I didn't realize its severity and did not pay attention to the daily low-protein diet. The dietitians kept reminding me what I should not eat and what was good for my health. I have gradually adopted strict diet control in recent years."* Mr. T further said: *"When my creatinine level increased, I usually went back to the hospital to check if anything was wrong with my kidney. My visits to the hospital became a regular occurrence to monitor my creatinine levels quarterly, but life was the same as always."*

Self-reminding and personal willpower seemed become the participants' motivation to help them keep their life healthy and live a quality life. Mrs. L found that willpower was very important in following the diet: *"The more nutritious the food, the less I should eat, because my kidneys cannot absorb so much nutritious food. Dietitians also reminded me not to eat too many eggs or much meat, and I seriously followed this advice to keep my life healthier and live a quality life."* Mrs. L also kept reminding herself not to eat fast food and maintain her health: *"I ate less meat, less salt, low protein, and less unhealthy meals by strictly adjusting my own daily diet habits. I always reminded myself not to eat fried foods and visceral meat and eat less meat, more fish, and boiled vegetables to modify my original diet habits and it worked."*

#### Discussion

Although many studies have focused on the beneficial effects of LPD in CKD and its cost-effectiveness in reducing its medical burden [13,16,21], only a few studies have elaborated on the reasons for and barriers to LPD adherence [8]. It is important to understand why CKD patients do not practice LPD. This

study revealed CKD patients' experiences of significant barriers to adopting LPD from the beginning of diagnosis, until they accepted and controlled their daily diet. As such, their four main experiences were as follows: confusion about eating restrictions, struggling with the daily diet, concerns about quality of life and mortality, and a fresh look at life and motivation to adhere to the LPD.

Some interviewees were originally perceived to be healthy without any symptoms of CKD, but after health checks were suddenly notified that they needed to control their CKD. Although the medical team provided proper diet modification, the symptoms of the disease should be were obvious and the LPD specification should be was too complex to be implemented precisely. These phenomena are similar to those reported in previous studies, wherein patients did not feel any physical discomfort and did not sense the presence of any disease threat; therefore, they were not serious about the diet, and did not cooperate in controlling the condition at the early stage [22]. However, when diagnosed with sudden severe kidney disease, such as stage 5 CKD, patients often felt uncomfortable and were prone to depressive symptoms. This phenomenon is similar to the finding of Ramer [23]. Therefore, it is necessary to early detect the emotional symptoms for those stage 5 CKD suffers. Notably, many participants in the current study were concerned about their creatinine level and directly linked this to their diet control. Future studies should focus on how to initiate awareness of adopting LPD at early stages of CKD. Comparing changes in biomarkers such as eGFR and creatinine for CKD during each clinic visit and explaining the benefits of LPD to patients could be an efficient method to encourage them to adopt a diet modification.

A significant finding of this study was the inconsistency in diet education and confusing information provided by different health care providers. This result was similar to a study from Australia, Tong [24] found that many patients appreciated specialist care, but felt that the health care system was not integrated; they received insufficient information and psychosocial support. These phenomena might consequently affect their diet modification about the LPD. A nationally representative survey by Hsu *et al.* [22] reported that awareness of CKD in Taiwan is quite low: the awareness of stage 3 CKD is only 8%, stage 4 is 25%, and stage 5 is 71%. Therefore, it is important to spread

awareness about CKD in order to initiate early changes in dietary habits upon diagnosis, and to encourage the early adoption of the principles of a proper diet to assist with self-management. In addition, the provision of a simplified dietary approach and simple tips from one integrated case manager or dietician could reduce the confusion involved with adopting a LPD. Pisani [10] conducted a randomized trial in Italy using a new strategy consisting of six clear points that could easily be managed by patients with CKD. This strategy improved the metabolic profile of renal disease and patients' adherence. Further, in Brazil, Paes-Barreto [17] used an intense nutrition-education program and found that it contributed to a reduction in protein intake in patients with stages 3-5 CKD. Therefore, it is necessary for future studies to establish a Taiwanese culture-tailored and personalized dietary intervention for LPD, especially for patients who have limited knowledge about CKD.

The results of the current study are consistent with those of previous studies [21,25,26] that showed that early diet intervention allowed patients to better understand the LPD concept, and that a slower decline of eGFR was effective. For example, six years ago, Mrs. H was diagnosed with stage 5 CKD with an eGFR of 9.91 ml/min and started to follow the diet advised by the CKD case manager. After five years (during the interview), her eGFR was maintained at 4.75 ml/min and she still did not require dialysis. Due to adoption of the LPD, the progression of CKD was delayed; she now has a better understanding of the LPD and shows good performance. Another interviewee, Mr. T, had an eGFR of 38.62 ml/min (stage 3b) three years ago. During the interview, his eGFR remained at 40.03 ml/min (stage 3b). The results showed that when patients are initially diagnosed with CKD without any symptoms, they should immediately be educated about the required diet modification.

From the perspectives of participants, the market of eating outside contained rich of protein food, many participants described if they want to keep LPD in their daily diet, it is difficult for them to maintain a good relationships with colleagues or friends, because they don't want to bother others. Although LPD is considered difficult to

maintain, better nutrition and diet provide better results among patients with kidney diseases. Health practitioners, who care for patients with CKD, should be reappraised the diet for helping them keep better quality of life.

Moreover, this finding highlighted an important issue: many participants struggled with the diet during work or social outings. This issues associated with adhering to the diet were seen in the form of difficulties in relationships with their colleagues or friends, interruption of their social interaction, and psychological distress. Thus, it is hoped that this finding will encourage the local government to develop a policy for commercial production of a LPD. Further study is required to establish a social support system in each teaching hospital and local district for CKD patients and their families [27-29].

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## Conclusion

This phenomenological study explored the experience of CKD patients with regard to adopting a LPD. The four main experiences of patients with CKD were confusion about eating restrictions, struggling with the daily diet, concerns about quality of life and mortality, and a fresh look at life and motivation to adhere to the LPD. To reduce the barriers of adopting LPD and the progression of CKD in people with limited health literacy, clinicians need to understand the difficulties these patient face, establish a tailored culture and simple tips for adopting LPD, and empower the patients and their families to adopt diet modification in the early stages of CKD.

Without aggressive treatment, chronic kidney disease can progress to end-stage renal disease and cause lifelong hemodialysis. Low-protein diet plays an important role in controlling the progression of chronic kidney disease. Few studies have explored the barriers to diet adherence among patients with chronic kidney disease. Many participants reported that diet education provided by their health care provider was confusing and inconsistent.

All participants experienced chaos due to the sudden change in diet and struggled with adoption of the diet. After managing their diet, the participants have maintained their minimum kidney function for many years.

### ■ Relevance to Clinical Practice

There is an urgent need to establish simple tips and integrate education strategies to support individuals to adopt a low-protein diet. It is important to implement methods for early detection of chronic kidney disease, provide adequate information to the patients, and establish support groups to enhance diet adherence through community-based health promotion programs.

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### Conflict of interest

There are no conflicts of interest for all authors in this study.

### Author Contributions

All authors have agreed on the final version and meet at least one of the following criteria [recommended by the ICMJE (<http://www.icmje.org/recommendations/>)]:

- Substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data;
- Drafting the article or revising it critically for important intellectual content.

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