QUALITATIVE PAPER

Dyadic appraisal and coping with illness among older Chinese adults with type 2 diabetes mellitus: a qualitative study

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Abstract

Introduction: Diabetes management permeates patients' daily routines and interacts with their living context. Less is known about how older Chinese couples view their supportive roles and the allocation of the management responsibility between them.

Objectives: To explore dyadic appraisal, coping and the barriers to diabetes management shared by older Chinese couples. **Methods:** A qualitative study of older couples where at least one partner had type 2 diabetes mellitus was implemented in four communities of Guangzhou, China. Four focus groups containing 11 couples, and ten in-depth interviews with individual couples were conducted sequentially. All of the data were coded with Nvivo 11 using thematic analysis.

Results: The majority of the older couples interviewed appraised diabetes as a shared problem, taking part in monitoring and altering each other's health status and behaviour. Limited knowledge and a lack of accurate information about diabetes negatively impacted the patients' self-management and their spouse's ability to support them. A female dominated-care pattern was evident that female spouses, regardless of their health status, were actively involved in or fully responsible for managing their husband's health. Older couples' management practices were also shaped by family responsibilities and their living environment.

Conclusions: Our study provides first-hand evidence of older Chinese couples' daily interactions and the main barriers to diabetes management. It is vital to provide health education directly to older couples to empower them to access adequate mutual support when managing chronic diseases.

Keywords: diabetes management, Chinese, dyadic coping, adherence, qualitative research, older people, qualitative research

Key Points

- Most older Chinese couples appraised diabetes as a shared problem, but wives were more engaged in managing partner's health.
- Older couples' limited knowledge and lack of accurate information on diabetes hindered their management practices.
- Long-term adherence to multiple medications, diet control and regular exercise was nominated as the main management barriers.
- Commitment to family obligations, and constraints in living environment affected older Chinese couples' diabetes management.
- Improving information and access to effective professional support was important in maintaining older couples' well-being.

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Introduction

China has the world's largest number of older adults with diabetes: estimated at 36 million of those aged 65 years and above in 2019, and will rise to 54 million in 2030 [1]. Despite the progress made in diabetes detection and treatment since China's health reform in 2009 [2], the healthcare system remains underprepared for the escalating burden of the older population: as indicated by a nationwide survey, only 44% of older adults identified as diabetic were aware of their condition and only 38% received treatment [3]. Management gaps result from not only insufficient healthcare resources [2], but also patients' lack of self-management awareness [4,5]. Diabetes management is complex, as selfcare regimens permeate patients' daily routines, and interact with their living context. Improvements in the adherence to self-management require the identification of modifiable factors to overcome behavioural and environmental barriers.

Given self-management takes place within the context of the family, family members, especially the spouse, play a pivotal role in diabetes management [6,7]. Marital obligation makes the spouse the number one supporter for his/her partner, providing practical and emotional support to the loved one [6]. Moreover, the shared living environment and daily interaction over long term may lead to similar lifestyles for the couple, which is best managed jointly [8].

Several couple-based dyadic coping frameworks have been proposed [9,10]. Among which, Berg and Upchurch's (2007) developmental-contextual model provides a more systematic and dynamic view of couples' appraisal and how they cope with stressors surrounding chronic illness [11]. It constructs two mutually influenced components of couple interactions in illness management: a dyadic appraisal of illness severity, ownership and management responsibility (i.e. whether the illness is a stress for the patient, the partner or shared by the couple); as well as dyadic coping, ranging from uninvolved (the patient copes alone), supportive (the spouse plays a supportive role), collaborative (the couple copes jointly) to controlling (the spouse dominates the care responsibility) [10]. The model examines the couples' interactions by developmental stages over life course and illness progression, and against sociocultural contexts.

There is scarce evidence on how older Chinese couples view their supportive roles and the allocation of illness management tasks. Collaborative resources for older adults are crucial, considering the greater frequency of chronic illness and increased dependency in later life [11]. Spousal support may be particularly relevant to disease management in fastageing China, whereby the collectivistic culture has been fundamentally challenged by sharp decreasing family size and lessening filial duty [12]. It is thus worth exploring the coping styles related to diabetes among older Chinese couples and identify the unique ways that spouses can promote patients' self-management. Guided by the developmental-contextual model, our study aimed to explore: i) how is the cause and management responsibility for diabetes appraised by older Chinese couples? ii) What are their main barriers

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in daily care activities? and iii) Is there any gender-specific pattern associated with diabetes management?

Methods

Design

Our study employs a qualitative design to explore older couples' lived experiences regarding diabetes management. Community-based interviews were conducted between March and August 2019 in two steps: first, focus groups consisting of two to three couples were held to generate common themes related to their shared beliefs and behaviour regarding diabetes; second, in-depth interviews with each couple were undertaken to explore the dyadic appraisal and coping strategies. Couples were chosen as the unit of analysis, to explore their communal experiences and interactions in diabetes management.

Setting and participants

The study was implemented in Guangzhou, Guangdong, China. Guangzhou is ageing rapidly, with 18.3% of the total population aged 60+, reaching 1.69 million by 2018 [13]. Four community healthcare centres of four districts were purposively selected, covering urban and rural districts. Older couples living in the catchment areas of these healthcare centres, aged 60+, where at least one partner had type 2 diabetes mellitus (T2DM), were referred by healthcare workers and invited to take part in the study. The study was approved by the Sun Yat-sen University Institutional Review Board (Approval no. 2019–064). All participants will read and sign the written informed consent approved by the institutional review board prior to participation.

Data collection

Four focus groups were conducted, each lasting approximately ninety minutes. The focus groups were open-ended to obtain a broad range of information on couples' management practices and were facilitated by three research assistants: a moderator responsible for the inquiry, a recorder and an observer taking field notes to catch key information plus facial expressions and body language of the interviewed couples.

Based on the findings of the focus groups, we developed an interview guide to explore older couples' more delicate daily interactions and negotiations regarding diabetes management (Appendix A1). The couples of the focus groups all accepted the invitation to attend an in-depth interview, except for one couple, who was unavailable. In-depth interviews were carried out at the couples' home or another place of their choosing. The interviews were facilitated by two researchers (one moderator and one recorder), and lasted between ninety minutes and two hours. After holding four focus groups with 11 couples and 10 in-depth interviews with 10 couples, no new study themes were emerging,

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Table 1. Characteristics of couples participated in the study

Couple ID	Role	Diabetes	Diabetes History (Years)	Multiple Diseases	Age (Years)	Educational level	Occupation	Retired	Living with family
1	W	NO	/	NO	64	Senior high school	Midwife	YES	YES
1	Н	YES	3	YES	65	Senior high school	Government official	YES	
2	W	YES	2	NO	62	Junior high school	Cleaner	YES	NO
2	Н	YES	2	YES	62	Senior high school	Bus driver	YES	
3	W	NO	/	NO	61	Junior high school	Factory technician	YES	NO
3	Н	YES	3	NO	64	Junior high school	Factory manager	YES	
4	W	YES	7	YES	69	Senior high school	Commercial worker	YES	NO
4	Н	YES	18	YES	79	College or Uni	Military personnel	YES	
5	W	YES	10	YES	65	Senior high school	Nurse	YES	YES
5	Н	NO	/	YES	65	Senior high school	Clerk	YES	
6	W	YES	10	NO	66	Senior high school	Office staff (Factory)	YES	NO
6	Н	NO	/	NO	71	Senior high school	Office staff (Factory)	YES	
7	W	YES	5	YES	76	Senior high school	Technician	YES	NO
7	Н	NO	/	YES	83	College or Uni	Government official	YES	
8	W	NO	/	NO	60	Senior high school	Bus driver	YES	NO
8	Н	YES	3	YES	64	Senior high school	Service worker	YES	
9	W	YES	5	YES	60	Senior high school	Industrial worker	YES	YES
9	Н	YES	5	NO	60	Senior high school	Driver	NO	
10	W	NO	/	NO	72	≤Primary School	Housewife	YES	NO
10	Н	YES	10	YES	78	Junior high school	Craftsman	YES	
11ª	W	NO	/	NO	61	≤Primary School	Industrial worker	YES	NO
11 ^a	Н	YES	3	YES	64	Senior high school	Bus driver	YES	

W: wife; H: Husband; Uni, university. ^aCouple 11 did not take part in the in-depth interview.

indicating that information saturation had been reached [14].

Data analysis

The research team discussed and summarised the interviews, as suggested by Krueger [15]. The focus group and indepth interviews were audio-recorded and transcribed verbatim. Transcripts derived from both sources were coded with Nvivo 11 using thematic analysis [16], to provide a rich thematic description of the entire dataset. A general inductive approach was adopted to capture key concepts of the transcripts. Guided by our research questions, codes were created and clustered into relevant (sub)themes (Appendix A2). The data were coded independently by two researchers (J.T., J.L.). All of the themes and categories identified were discussed and scrutinised by the research team.

Results

Participant characteristics

The couples interviewed had a mean age of 67, and the husbands were older than their wives by an average of four years (Table 1). The majority of them were retired blue-collar workers, with an education level of senior high school. In five of the couples, the husband had diabetes, in three the wives, and in three cases, both partners were diabetic. The husbands' average diagnosis year was one year longer than the wives.

Older Chinese couples' appraisal of diabetes

A 'we' broblem

Ten of the 11 couples interviewed regarded diabetes as a shared problem, using terms like 'we', 'our' and 'ours' up to 226 times during the interviews. The couples echoed and reinforced each other's views about diabetes by nodding and providing examples. Two females even provided all of the information about their husbands' diabetes and were fully responsible for their husbands' daily care, as one commented 'I know far more about his condition than he does himself!'. Only in one pair (Couple 6) did the husband feel that diabetes was entirely his wife's (patient) affair and he rarely got involved, while the wife still took care of her husband's health.

Multiple causes and factors outside individua <u>l's control</u>

The couples interviewed mainly associated the cause of diabetes with dietary habits (seven out of the 11 couples, i.e. 7/11), insufficient exercise (4/11), alcohol consumption (2/11), smoking (1/11) and genetic factors (3/11). They commented that their similarities and differences regarding these factors may have resulted in their same or different health conditions. Some male patients alluded to the idea that most of these factors lay outside their control, attributing unhealthy lifestyles to their past occupations and social lives. Their dietary habits were also related to the abundant food available in contemporary society.

A non-life-threatening condition and a sense of ambiguity

Many of the interviewees did not consider diabetes a lifethreatening illness, but a natural process of ageing that all

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older adults developed sooner or later. Hence, they rarely felt stressed about diabetes. Some may have felt concerned when first diagnosed, but they gradually got used to the condition. They stated that as long as they did not feel uncomfortable, they would ignore diabetes. Instead, they were more concerned about other, 'more serious' conditions, like cardiovascular disease or the comorbidity of diabetes. It was also evident that their understanding of diabetes was unclear. Many of the interviewees were unsure about the standard diabetes diagnosis and had insufficient knowledge about diabetes prevention and management, while others complained that their doctor was not bothered to provide them with adequate information.

Most doctors only prescribe medication and hardly explain anything to you. They're very busy, with a lot of patients waiting for them. There isn't much opportunity for you to ask questions'. (Couple 3, Husband, 64, Patient)

Daily management interactions and barriers encountered by older couples

Although the majority of couples appraised diabetes as a shared problem, the extent to which the spouse became involved in the patient's daily management varied by gender, disease severity and the pre-existing divisions of family responsibility.

Adherence to long-term & multiple medications and blood glucose monitoring

Most of the diabetic patients interviewed (11/14) reported that they adhered to their medication regime, yet misunderstandings about the medication still prevailed. Some believed that medicine had many side effects, and taking too many drugs would damage their liver and kidneys. They feared long-term medication use, and tried to avoid taking medicine or reduced the dosage once their condition improved, without consulting their doctor. In these cases, the spouse would not intervene, who might hold a similar understanding or simply lack knowledge, until the patients' health condition deteriorated.

Moreover, many of the older patients had multiple chronic conditions, requiring them to take several medications. The spouse played an important role in reminding the patient to take medicine and helped to monitor the blood glucose level from time to time. The older couples tended to be concerned about high blood glucose levels, but were less aware of the risks associated with low blood glucose.

W: 'He takes too many medications! Oh my God, one handful after another . . . '

H: 'We become forgetful as we age. Sometimes, she can remember things very clearly while I can't and, sometimes, I can remember but she can't, so we remind each other.' (Couple 7, Wife, 76, Patient; Husband, 83, Spouse).

Diet control

The couples had consciously controlled their food choices and consumption since diabetes diagnosis. They had a rough idea about which food they should and should not eat, and tried to comply with this. It was often the wife who prepared the meals either alone (6/11) or with their husband (3/11). The wives, thus, were mainly involved in monitoring and controlling their husband's diet, and intentionally adjusted their meal plans to comply with the doctors' suggestions.

Nevertheless, their limited knowledge about a healthy diet made diet control one of the most difficult types of behaviour to change, particularly for the male diabetic patients, who normally had a strong preference for meat over vegetables, and were ignorant about fruit choices. Two of the male patients had been drinking alcohol for decades. They insisted that it was necessary for them to consume alcohol, as this was associated with their social activities or self-well-being. Their wives tried to control their drinking behaviour, but could not prevent them drinking. The patients' past life experiences and life-long eating and drinking habits impacted on their dietary compliance fundamentally.

H: 'Sometimes, my old colleagues gather together, I have to drink just out of politeness...'.

W: 'Your colleagues are just being polite to toast to you, but you can still let them know your health condition. You know your condition better than anyone else. You need to have self-control. (Sighs, and turns to the interviewers) I've told him so many times'.

H: 'I'm so old. It doesn't matter if I eat or drink more. Life's unpredictable, and I will die anyway...' (Couple 4, Husband, 79; Wife, 69, Both Patients)

Moreover, living with family, it may be difficult to prepare meals that suit the needs of diabetic patients only, especially when dining with adult children or grandchildren, who prefer larger meals. Although only three of the older couples interviewed live with their extended family, seven regularly ate with other family members. Among families where the food preparation centred on the needs of the younger generation, the diet control of older diabetic adults was even harder to achieve.

Regular exercise

The interviewees acknowledged the importance of exercise, and exercised more regularly (mostly walking) after their diagnosis. They had their own understanding of exercise, which included shopping, doing housework and climbing stairs. Counting these daily activities as exercise, they often overlooked the matter of exercise intensity. Some of the interviewees indicated that they had other physical or ageing conditions (e.g. rheumatoid arthritis), which limited their mobility.

Family obligations also took away the older adults' time and energy to exercise, especially for female patients undertaking housework. Many of the older adults (5/11) additionally had an obligation to care for their grandchildren, which left them with less time to manage their own chronic condition. Some mentioned that unfriendly living environment

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for older adults prevented them from undertaking regular exercise.

W: 'I need to cook when he brings back the food, right? I also need to do the cleaning and laundry (H: All the housework.) I stay at home to cook for him!... Live on the fifth floor, getting up and down is tiring, and my eyesight isn't good'.

H: 'There's no elevator in our building'.

W: 'There're many cars in our community. They are parked everywhere. Besides, my eyesight isn't good; I don't dare to (exercise)...' (Couple 5, Wife, 65, Patient; Husband, 65, Spouse)

Gender-specific patterns within diabetes management among older Chinese couples

Mutual influence between couples

Except for one couple, where the patient remained relatively independent regarding her diabetes management (Couple 6), all of the other ten couples were more or less involved in each other's illness management. They were familiar with each other's physical condition and lifestyle, and spent an increasing amount of time together after retirement. Three females and one male checked their partners' diabetes state via blood glucose levels on the patient's behalf. The wives were more likely to express concerns about the male patients' health, became cautious about their diet, urged the patients to attend check-ups regularly while consciously checking their own blood glucose along with the patients. In two of the three couples where both had diabetes, the spouses were diagnosed immediately after their partner was. The spouse's lifestyle, especially diet, was impacted by the patient's lifestyle changes.

'I was worried, of course! And I was thinking how to ensure that he (the patient) can take care about his lifestyle... We then adjusted our meals to be light, (with) less oil and salt'. (Couple 1, Wife, 61, Both Patients)

The female as the carer

In nearly all of the couples, the female played the main role in monitoring and controlling the condition of her husband, regardless of her own health status. Females dominated the illness management in 6 of the 11 couples while, in the other four pairs, the husband and wife collaborated in illness management. The female interviewees generally viewed taking care of their partner as a natural obligation.

'We're a couple, which means we should take care of each other, and supervise each other regarding an unhealthy lifestyle'. (Couple 9, Wife, 60, Patient).

Compared to the wives' involvement, the males tended to be less involved in their wife's illness management. In Couple 6, the husband expressed an attitude of indifference towards his wife's diabetes management. Meanwhile, the wife still actively participated in controlling her husband's high blood pressure.

Constant negotiation

The interviewees often mentioned their negotiations regarding diet control. The wives complained about their husband's failure to engage in diet control. In one in-depth interview, the wife recounted in detail how the husband resisted her restrictions and insisted on eating all kinds of unhealthy food, while the husband listened silently, simply occasionally adding, 'I'm OK' and 'I know my body'. During another interview, the couple argued slightly.

H: 'I only drink one day per week the amount of a tea cup. How much more do you want me to reduce it to?... If I stop drinking alcohol for a week, my blood pressure rises to 130/90. Once I drink a cup of liquor, it immediately falls to between 115-120 and less than 70!'

W: 'How absurd! Are you saying drinking alcohol can low your blood pressure? (H: Yes, yes.) That's so ridiculous! He's making this up...I persuaded him to see the doctor, even dragged him to the hospital.

H: 'They all push me, my daughter, daughter-in-law, my wife . . . 'You should see the doctor', they always say. Just piss off, I won't go'. (Couple 3, Husband, 65, Patient; Wife, 64, Spouse)

Although occasional tension was observed, the tone and facial expressions of the couples suggested that the argument was mild, and rather a way to express concern. The male patients interpreted being monitored as being cared for. They treated it more as love and care from others than as a restriction on their individual autonomy. 'The more control (attention), the better', one male patient joked. Hence, a strong resistance to or negative rejection of spousal support was rarely expressed by the patients within the couples interviewed.

Discussion

Guided by the dyadic developmental-contextual model of chronic illness management [11], our study explored the dyadic appraisal and daily interactions between older Chinese couples regarding diabetes management. We found that the majority of the older couples interviewed appraised diabetes as a shared problem, while the wives were more actively involved in or fully responsible for managing their husband's illness. Misunderstandings and limited knowledge about diabetes negatively impacted on the patients' selfmanagement and their spouses' ability to support them.

By interviewing the couple dyad together, our study provided first-hand evidence on older Chinese couples' dyadic appraisal of diabetes and the related care responsibility. Nearly, all of the interviewed couples appraised diabetes as a shared problem. The frequent use of 'we-language' was found among couples who shared a common understanding of diabetes. This is consistent with evidence that a long-term marriage, characterised by shared experiences and a strong knowledge of each other, is associated with a

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communal appraisal of the stressors and greater collaborative involvement [11,17]. More 'we-language', as an implicit marker of communal coping, was related to reduced distress and improved self-care behaviour among couples with newly diagnosed diabetes [18]. Our finding may be further rooted in the Chinese family duty-oriented morality, whereby the family (usually the spouse) is heavily involved in patients' medical decision-making [19] and committed to informal caregiving [20].

The older couple's shared appraisal of diabetes impacted on their interactions in daily management. In line with prior studies [21], the couples interviewed indicated that their mutual reminders to take medication, check blood glucose levels and visit the doctor were frequent and important, particularly as they became older and more forgetful, and were compelled to handle multiple medications [22]. Gendered patterns in T2DM management were evident in our study, as the female interviewees were predominately involved in monitoring their husband's health, whereas the males tended to pay less attention to their wife's illness management. The stronger female spousal control over food-related behaviour changes, as reported previously [23,24], may be attributed to the male patients' lower self-control regarding diet and alcohol, and their high dependence on their wife for meal preparation. Against the Chinese background, the gendered care pattern is further reinforced by the traditional femaledominated responsibility for domestic chores and caregiving, as well as the couple's demographic profile, whereby wives are generally younger and healthier than their husband [12]. Although constant negotiations between the older couples were found, as in prior studies [23-25], our interviewees interpreted spousal involvement positively. They considered it more an expression of love and care rather than control for autonomy, as reported by Western studies [11,21,25]. This difference may reflect the interdependency over independency in Chinese collectivistic culture [11], which emphasises connectedness and harmonious relationships [19].

Facilitated by the in-depth interviews, our study provides rich information on the main barriers to diabetes management situated in older couples' socio-environmental context. We found that the older couples' appraisal of and measures to cope with diabetes were largely shaped by their life experiences and education levels. The older couples interviewed generally had a vague understanding of diabetes, related it to causes lying outside individual's control or as a normal consequence of ageing, and followed their perceived 'healthy lifestyles' based on their own experience. Their misconceptions resulted from not only the low education level of the older generation in general [26], but also insufficient health education received from health professionals. Many of the interviewees mentioned that, restricted by the limited consultation time, the doctors were simply too busy to talk to them; a problem not only encountered by older adults, but by most patients in various medical institutions in China [27]. Limited knowledge and a lack of authentic information hindered older couples' diabetes management [4], who remained unsure about how to prevent compli-

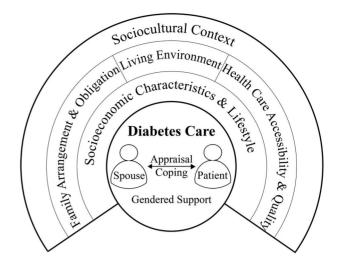


Figure 1. Couple's dyadic appraisal and copying of diabetes in socio-environmental context, adapted from Acheson's model on social determinates of health (1998).

cations like hypo-glycaemia or conduct proper foot care. Their diabetes management was further shaped by strong commitment to family obligations [24]; for instance, dining with family members influenced their diet, and taking care of grandchildren limited their time and energy to exercise. Other socio-environmental factors, such as older people-unfriendly housing and lack of public spaces, additionally inhibit their ability to exercise regularly. We summarise the barriers identified in reference to Acheson's model on the social determinants of health [28] in Figure 1.

Strengths and Limitations

Our study contributes to the literature by its thorough study design guided by a theoretical framework plus fine-grained narrative evidence on the misunderstanding of diabetes and management barriers from the older couples' dyadic perspectives, which are largely overlooked in the current Chinese diabetes-related studies. Several limitations are worth noting. Our study sample was relatively small and was recruited through purposive sampling. The couples interviewed were likely to represent the younger-old, with a satisfying marital relationship. Our findings may underestimate the T2DM management challenges faced by the oldest-old and be biased towards positive spousal interactions and cooperative coping styles. Nonetheless, our findings about the interviewees' insufficient knowledge and management barriers may also hold true among older patients without spousal support and warrant further investigations to identify their dilemma regarding diabetes care considering their specific family context. Furthermore, we interviewed the couple dyad together to gain insights into their interactional processes. Although both spouses were encouraged to participate equally, the discussion was sometimes dominated by one spouse, and the other party may qualify their responses due to their partner's presence.

Implications for research and practice

Diabetes management requires a lifelong commitment to multiple care regimens. The understanding of the patients' family context inspires the design of tailored interventions, targeted at management barriers. Our findings highlight the important role that spouses, particularly wives, play in optimising the patients' diabetes management. Clinicians and health educators should direct therapeutic and educational efforts at the couple by empowering them with sufficient knowledge and management skills, while considering their past experience and lifelong habits. It is crucial to recognise that spouses may not necessarily understand diabetes or its management and may themselves have health conditions that need reciprocal support. Besides, older couples' diabetes management is situated in broader social contexts, such that the whole family's awareness of and support for diabetes management, an ageing-friendly living environment and accessibility to healthcare services all play a role.

Conclusion

Effective chronic disease management programs are required to meet the mounting healthcare needs of China's rapidly ageing population. Our study reveals how older Chinese couples as a unit appraise diabetes, illustrating their daily interactions and barriers regarding diabetes management. Opportunities exist to support older couples by increasing their health literacy and management skills, monitoring couples' health status jointly, and mobilising community-based healthcare and social care resources to empower older couples.

Supplementary Data: Supplementary data mentioned in the text are available to subscribers in *Age and Ageing* online.

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