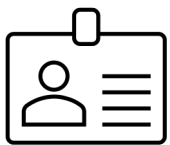
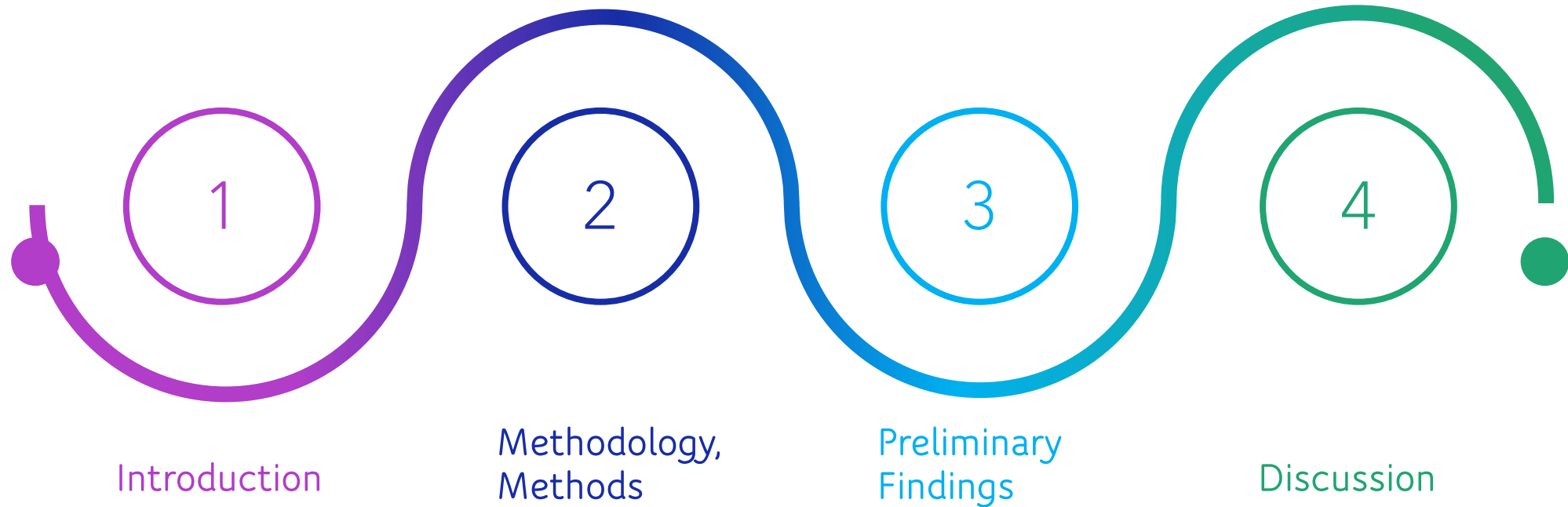


WHAT ARE THE EXPERIENCES OF DIETITIANS PROVIDING NUTRITIONAL CARE FOR PATIENTS WITH CYSTINOSIS?



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1

BACKGROUND: NUTRITION IN CYSTINOSIS

NUTRITIONAL CARE: HOW?

- „cystinosis [all fields]“ on PubMed: 1,658 results (19/06/2022)
- ("cystinosis"[All Fields]) AND ("diet"[All Fields]) on PubMed: 36 results (07/07/2022)

➤ [Acta Paediatr Scand. 1968 Sep;57\(5\):409-16. doi: 10.1111/j.1651-2227.1968.tb07313.x.](#)

Dietary treatment of cystinosis

M S ➤ [Acta Paediatr Scand. 1970 Nov;59\(6\):613-20. doi: 10.1111/j.1651-2227.1970.tb17695.x.](#)

PM **Treatment of cystinosis with a diet poor in cystine and methionine** ➤ [Pediatr Nephrol. 1998 Jun;12\(5\):365-70. doi: 10.1007/s004670050467.](#)

M F Christensen, J A Nielsen, O I

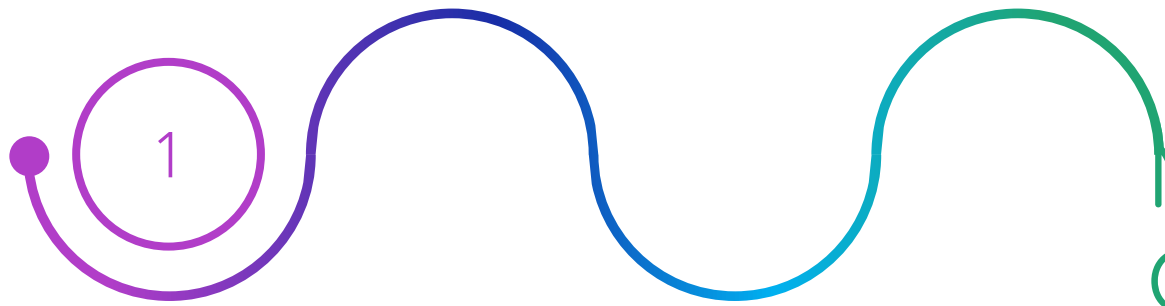
PMID: 5312270 DOI: 10.1111/j.

Feeding problems in cystinosis

E Elenberg ¹, L L Norling, R E Kleinman, J R Ingelfinger

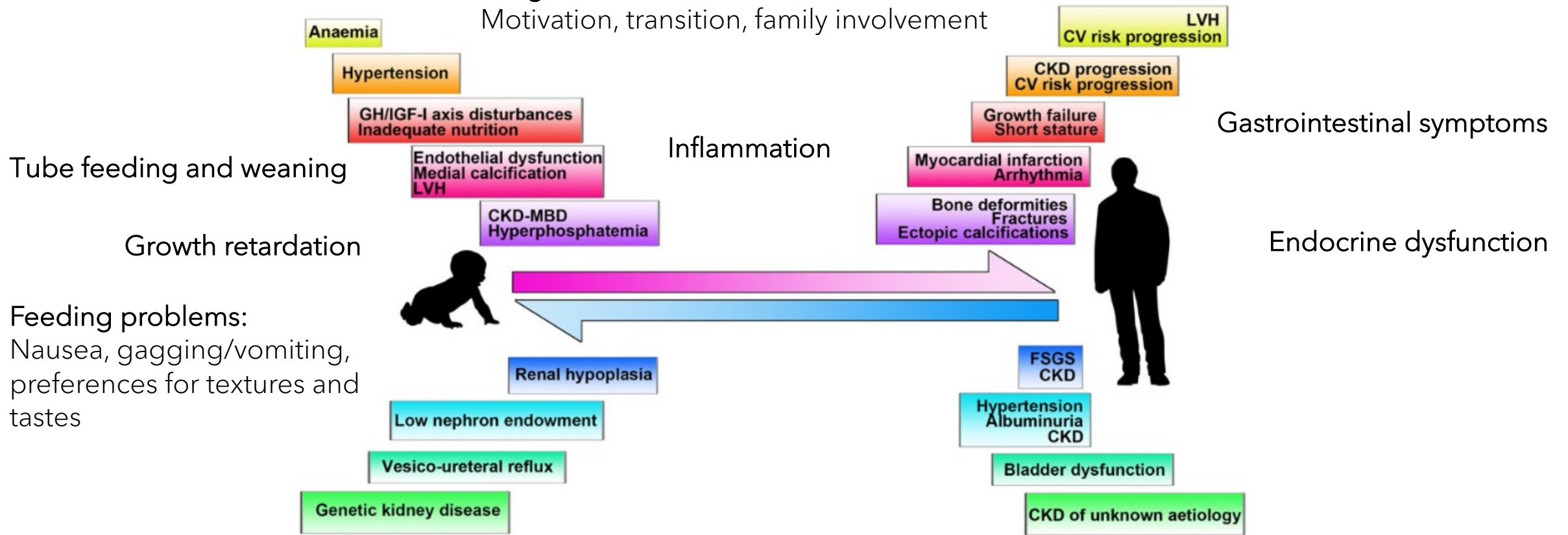
Affiliations + expand

PMID: 9686953 DOI: 10.1007/s004670050467



NUTRITION, CYSTINOSIS, CHRONIC KIDNEY DISEASE

Long-term condition:
Motivation, transition, family involvement



Tube feeding and weaning

Growth retardation

Feeding problems:
Nausea, gagging/vomiting,
preferences for textures and
tastes

Gastrointestinal symptoms

Endocrine dysfunction

(Beccherucci et al., 2016: 588)

(Elenberg et al., 1998; Elmonem et al., 2016; Ariceta et al., 2019; Urbano et al., 2021; Elmonem et al., 2022)

RESEARCH QUESTION:

What are the experiences of dietitians who provide nutritional care for patients with cystinosis?

AIM:

To explore dietitians' experiences of current practice in the nutritional management of patients with cystinosis concluding with recommendations for best practice and service development.

OBJECTIVES:

- to explore dietitians' experiences of current nutritional management for patients with cystinosis
- to understand priorities in the dietetic consultations
- to explore potential obstacles and challenges when supporting patients with cystinosis from dietitians' perspectives
- to undertake thematic analysis to identify patterns or common themes in participants' experiences and responses
- to use the findings to support future development of dietetic services for patients with cystinosis



2

METHODOLOGY, METHODS

METHODOLOGY: QUALITATIVE DESCRIPTIVE STUDY

- To explore and understand the phenomenon of nutritional care and the perspectives of dietitians involved
- Lack of data: Describe perceptions with as little interpretation as possible

(Bradshaw, Atkinson and Doody, 2017)

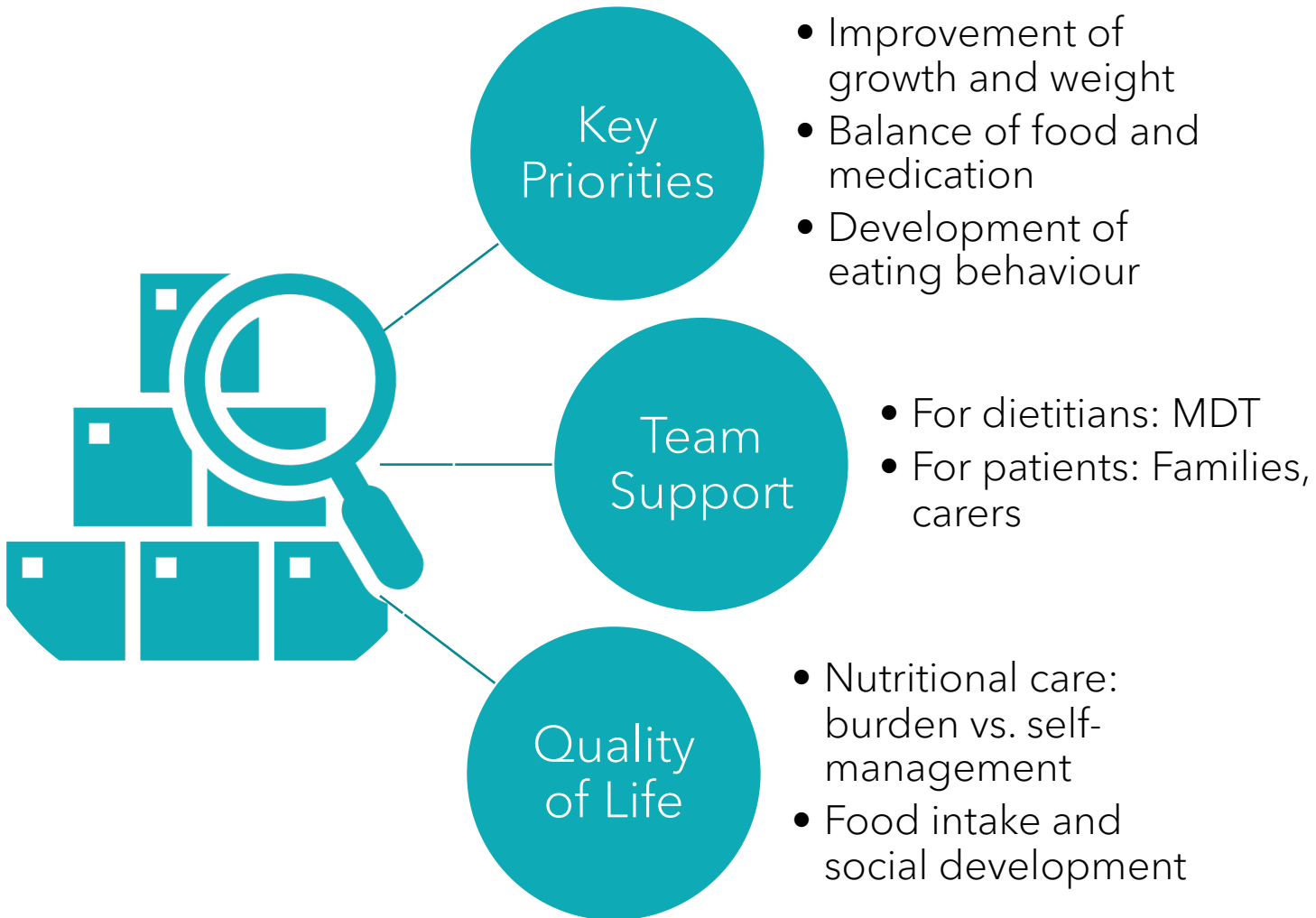
METHODS: SEMI-STRUCTURED INTERVIEWS

- Piloted with a peer-review of the questionnaire
- Purposive and snowball sampling, Cystinosis Network Europe
- Intelligent verbatim transcription
- Inductive computer assisted thematic analysis, to identify and code relevant themes
- Sample size: n=6-10



3

PRELIMINARY RESULTS



Results may change, manuscript to follow.

„We have to be glad with small successes.“

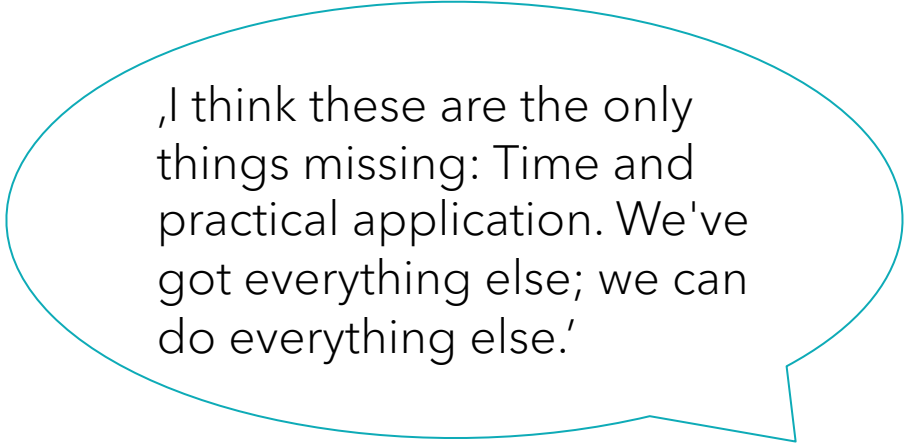


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DISCUSSION

POINTS OF INTEREST

- Dietitians are aware of the severity of the disease – focus on providing patients with sufficient energy despite more options, e.g., alleviating inflammatory processes linked to cystinosis
- Insufficient food intake: Metabolic, hormonal or cell-signalling contribution caused by cystinosis?
- Social and psychological factors: Children with cystinosis sometimes do not want to eat; dietitians experienced better food intake when children ate with their peers



,I think these are the only things missing: Time and practical application. We've got everything else; we can do everything else.'

(Elenberg et al. 1998; Ames and Thoene, 2022; Elmonem, Veys and Prencipe, 2022)



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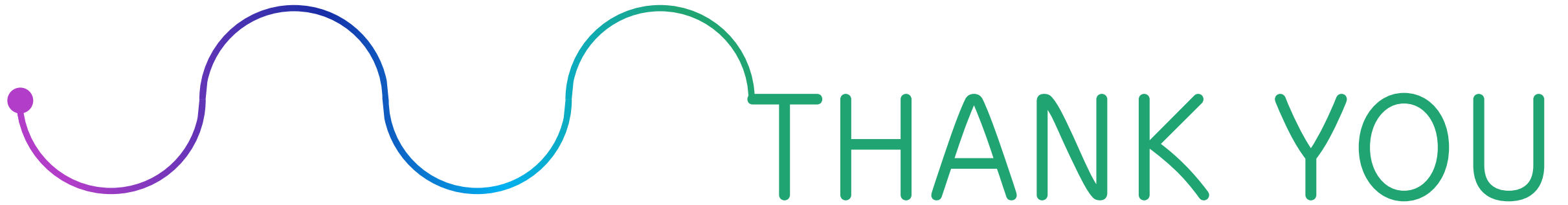
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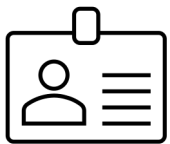
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THANK YOU

ANY QUESTIONS?



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