

Proposal of a new education system for the PKU diet

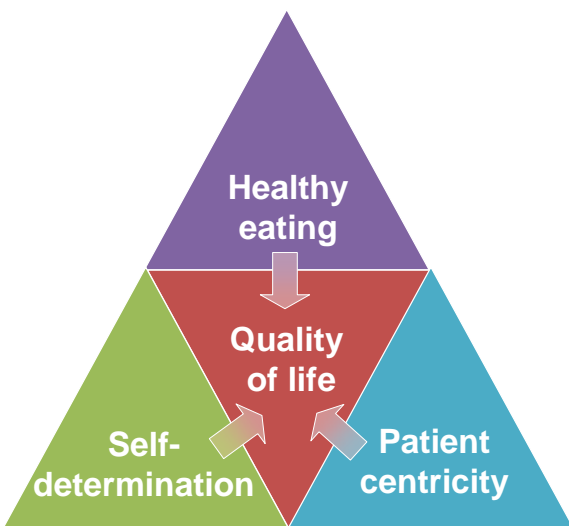
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Background

Joyful and healthy eating is not in the focus in dietary treatment of PKU but rather the controlled intake of natural protein or phenylalanine. This is a burden on the families and the social life of the patients. Even relaxed diets due to increased phe tolerance or concomitant sapropterin therapy are still complex. A working group of German, Austrian and Swiss Dieticians has been developing a new patient education system for strict and relaxed PKU diet.

Aims for education and coaching of the patient



Healthy eating

The pyramid system emphasizes analogies to recommendations for healthy children.

The dietitian specifies the pyramid for each patient (no matter whether on a strict or relaxed diet) by advising on individual allowances.



AAM- amino acid supplement

How does it work in daily practice?

During the conversation with the dietician, the patient indicates with cards of foods what he is typically eating during a day.

Subsequently, the patient puts the cards on the pyramid and can easily find out whether he is eating the "right things in the right amounts".

The dieticians' experience with the new education system

During the workshop the group members stated that they

- need to listen to the patient more carefully
- need to watch attentively what he is doing
- need to "take themselves back"
- have less power or control but keep track easily
- share a common experience with the patient as basis for relationship
- can propose a system aimed at the patient's benefit (his self-control)

Satisfaction with the new education system

During the workshop the group members rated their satisfaction with the system and estimated the patients' satisfaction.

Formal evaluation for the satisfaction of patients is underway.

Evaluation during the workshop

	before	after
	use of pyramid system	
Dietician's satisfaction with her		
Didactic instruments	5.8	+ 2
Own methodical competence	7.8	+/-0
time for the patient	7.8	+ 1
Patient's satisfaction with own		
Quality of life	4.3	+1
Self-determination	4.5	+2
Relationship with dietician	8	+/- 0

1- very low 10 – very high

The new education tool is

- easy to understand and use
- basis for trustful relationship between patients & dieticians
- highly accepted by dieticians and patients
- The system was yet successfully applied in two metabolic centres. Further evaluation is ongoing.