



## LETTER TO THE EDITOR

# The Effect of Phenylketonuria on Family Quality of Life

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The treatment of phenylketonuria is the regulation of phenylalanine levels, which is achieved with a special diet. In hyperphenylalaninemia, patients have a greater tolerance to the intake of foods containing phenylalanin [1]. In the field of health, quality of life is defined as a concept that encompasses a wide range of physical and psychological characteristics as well as limitations, which describe a person's ability to function and derive satisfaction from this function. Although there is no consensus on the definition, most researchers agree that: The concept of quality of life is multidimensional and includes a sense of physical, psychological and social well-being. It should express the patient's own subjective assessment and not the opinion of the therapist or researcher [2]. By the term free time we refer to the activities that people choose to do themselves, to the time they have for themselves and does not have specific characteristics, duration and frequency, it is the balance that remains from the obligations they have, studies, work or other regular activities. The use of free time contributes to the better mental health and balance of the individual, being the trigger for intellectual pre occupations, the individual is socialized and given the opportunity to participate in society [3]. For the evaluation of the quality of life, we chose five scales adapted to the nutritional needs of the child and, by extension, the limitations resulting from the diet, which in turn can affect the quality of life of the family. The five scales that assess the quality of life are, personal time, social life, and activities of daily living, work and entertainment. By social life you define the individual's ability and desire to create social relationships and participate in social events, so as to satisfy their needs for communication, develop

and maintain social relationships and assume social roles. The social life section also examines the degree to which the individual is satisfied or dissatisfied with the social position he holds as a member of the society in which he lives [4]. The term activities of daily living is used in the health and care sector to refer to a person's daily self-care needs either inside their home or outdoors, or both. Health professionals (occupational therapists, social workers, nurses, etc.) usually refer to the ability or inability to perform these activities as a measure of a person's functional status, especially with regard to special social groups, such as patients, people with special needs and the elderly [5]. Work is defined as the systematic effort of man to satisfy individual and social needs and is distinguished into mental and physical, more specifically, work is defined as any activity undertaken by the person, regardless of the remuneration factor, e.g. student, domestic, care of a child [6]. On adolescents with phenylketonuria aged 14-18 years and 110 parents with a phenylketonuric child aged 6-12 years participated in the present study. To record the factors affecting the quality of life of the participants, we structured a questionnaire, with five sections, which consisted of four questions on a five-point scale. The structure of the questionnaire adapted to the needs of special nutrition was based on the WHOQOL questionnaire of the World Health Organization [7]. Data was analyzed using SPSS 20.0 statistical package. Descriptive statistics were utilized for the analysis of the results.

Table 1 describes the limitation caused by the therapeutic needs of the disease in the 5 modules that assess the Quality of Life. The sufferers' free time, social life and entertainment were more affected than

**Table 1:** Comparison Parent patients.

Scales	Parents		Patients		T-test	P- value
	Mean	SD	Mean	SD		
Free time	3.21	1.13	3.54	0.52	2.80	0.006
Social life	3.80	0.98	4.02	0.88	1.75	0.082
Activities of daily living	3.92	0.86	3.70	0.42	2.94	0.004
Work	3.88	0.79	3.77	0.67	1.10	0.275
Entertainment	3.15	0.99	3.96	0.52	7.51	< 0.001

**Table 2:** Severity of disease.

Scales	Parents PKU		Parents HYP		T-test	P- value	Πάσχοντες PKU		Patients HYP		T-test	P- value
	Mean	SD	Mean	SD			Mean	SD	Mean	SD		
Free time	3.38	1.11	2.91	1.10	2.15	0.034	3.53	0.51	3.58	0.55	0.45	0.852
Social life	3.75	1.05	3.89	0.86	0.78	0.436	3.97	0.92	4.13	0.79	0.86	0.391
Activities of daily living	3.92	0.92	4.05	0.75	0.76	0.447	3.66	0.42	3.78	0.43	1.36	0.178
Work	3.84	0.85	3.96	0.68	0.77	0.446	3.83	0.68	3.65	0.62	1.32	0.190
Entertainment	3.26	1.02	2.97	0.92	1.49	0.139	3.94	0.46	3.99	0.63	0.47	0.643

the parents. On the contrary, the activities of everyday life and work affected parents more than teenagers. As we can see in [Table 2](#), free time and entertainment are more affected in parents with a PKU child, compared to parents with a HYP child. Conversely, parents with HYP are more affected in the areas of Social life, Activities of daily living and Work in relation to parents where their child suffers from HYP. Patients with classic PKU state that nutritional needs affect the work domain more than HYP patients. In the other four subcategories, patients with the mildest form of the disease are more affected than patients with the classic form. With the exception of the recreation sector, corner silk and patients, they do not present statistically significant restrictions on the restrictions that nutrition causes on their quality of life. Limitations in quality of life are not determined by the actual limitations caused by the special diet of the disease. The way in which the severity of the disease is represented by the parents and the patients themselves, determines the ability to manage the social restrictions due to nutrition [8]. Quality of life is inherently a dynamic, multi-layered and complex concept, reflecting objective, subjective, macro-social and micro-individual, positive and negative interacting influences [9].

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