

PERCEPTIONS AND EXPECTATIONS OF PATIENTS AND THEIR FAMILIES FOR THE EFFECTS OF GROWTH HORMONE TREATMENT.

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Background

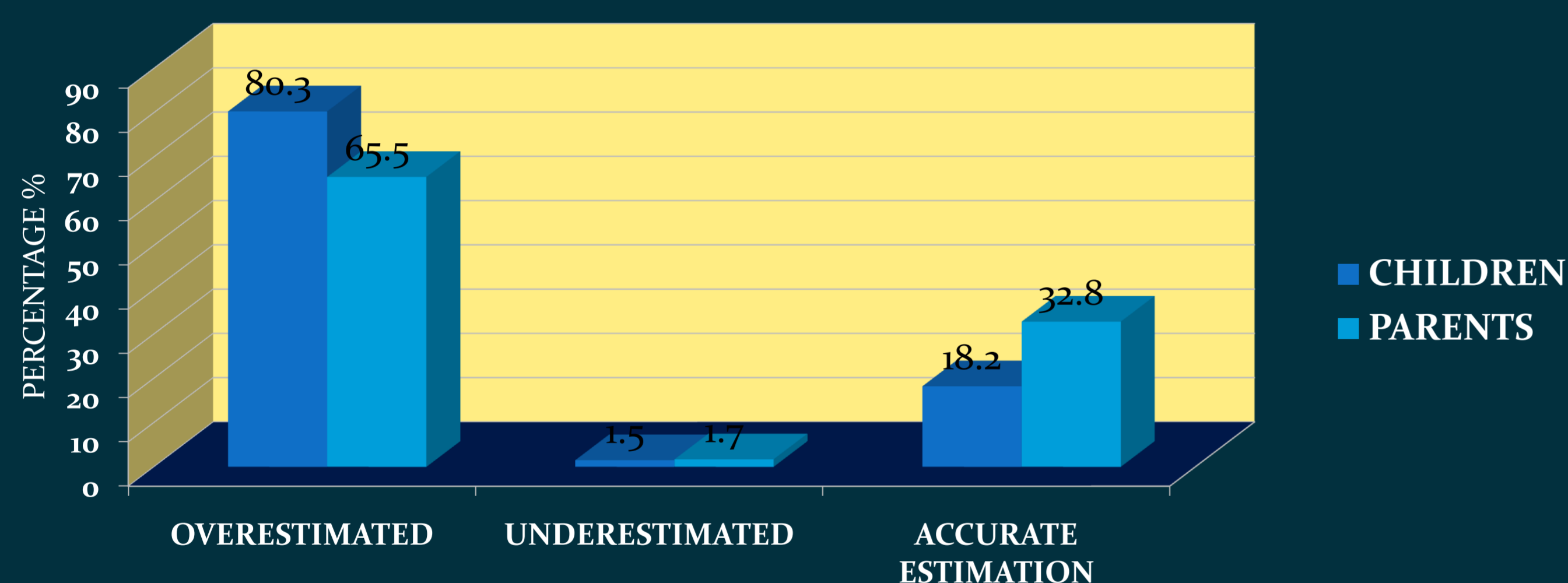
The expectations of patients receiving Growth Hormone (GH) treatment, have been previously assessed, by questioning the children's parents and physicians. However, there are limited data on children's and adolescents' perceptions of their own body size, as compared with that of their age-related peers, as well as on their expectations of their final height.

Methods

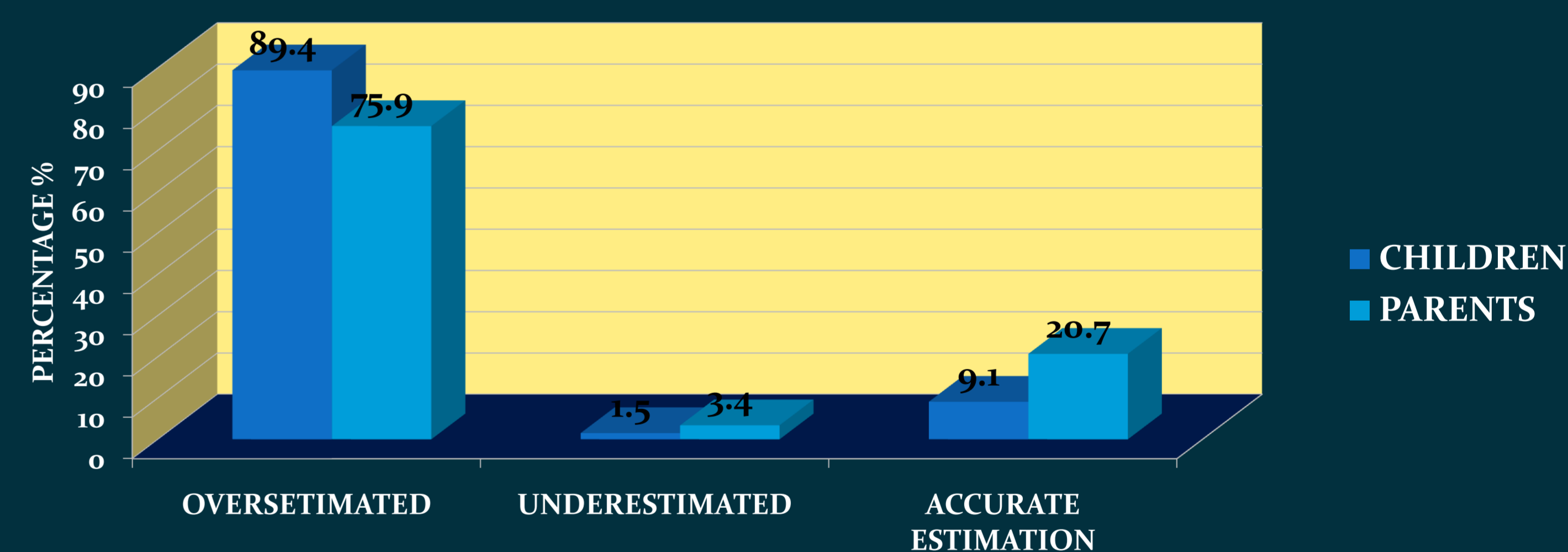
It is a prospective study with the use of validated questionnaires (SAT). The study group consists of 66 children (43 boys and 23 girls) diagnosed with (isolated) Growth Hormone Deficiency (GHD) with no other underlying disease, treated with rhGH for at least six months (prior to the psychological tests). The mean age of the sample is 13.2 years (SD=2.5years) and the mean duration of treatment 3.5 (3.2) years. The study was conducted in the Endocrinology Department of one of the two main Pediatric Hospitals in Athens, from November 2013 to February 2014. For the comparisons of proportions chi-square test was used.

Results

Parents' and children's perceptions for the children's present height



Parents' and children's expectations for the children's future predicted height.



These findings suggest that the majority of children had an inaccurate picture of their present and future predicted height, overestimating it in 80.3% and 89.4% of cases respectively.

Parents' perceptions of their child's height was somehow more realistic, with 65% being more optimistic. Only (20.7%) of parents were found to have realistic expectations for the growth promoting effects of GH treatment.

Mothers with higher level of education (> 12 yrs) have a more realistic perception of their child's height (17.6% vs 52.4%, p=0.004).

The vast majority of parents (80%) stated that their child's physician often/always explains to them everything they need to know about their child's height related problem.

There was a high level of agreement between parents' and children's perceptions (70.7%) and expectations (81%) for the child's present and final height.

A large percentage of the children (87.9%) had a good understanding of the rational for their treatment and 86.3% were convinced of its benefits. Moreover 82.8% of them would continue GH therapy if they had to choose. They mentioned however, non fulfillment of expectations as the main reason for poor compliance or treatment discontinuation.

Conclusions

The majority of growth hormone treated children and their families have overestimated their child's present and predicted height. This happens despite the fact that prior to completing the SAT each of these patients had been examined by a pediatric endocrinologist and had seen their growth data plotted on a growth chart. The high degree of agreement between parents and children's beliefs is probably due to failure of effective communication between the health care providers and the family or reflects denial and misinterpretation of the given information within the family.

Repeated psychoeducational intervention to patients and their families, is needed, so as to help them have more accurate expectations. Furthermore, continuous support of patients' and their families, focusing on specific and concrete questions regarding treatment expectations, will improve compliance and treatment satisfaction.

Objectives

To evaluate-assess

the perceptions of GH treated children and their families for the child's stature as compared to that of their peers

the level of understanding of the aim of GH therapy

the expectations and the degree of satisfaction from it.

Figure 1 : Silhouette Apperception Technique (SAT)

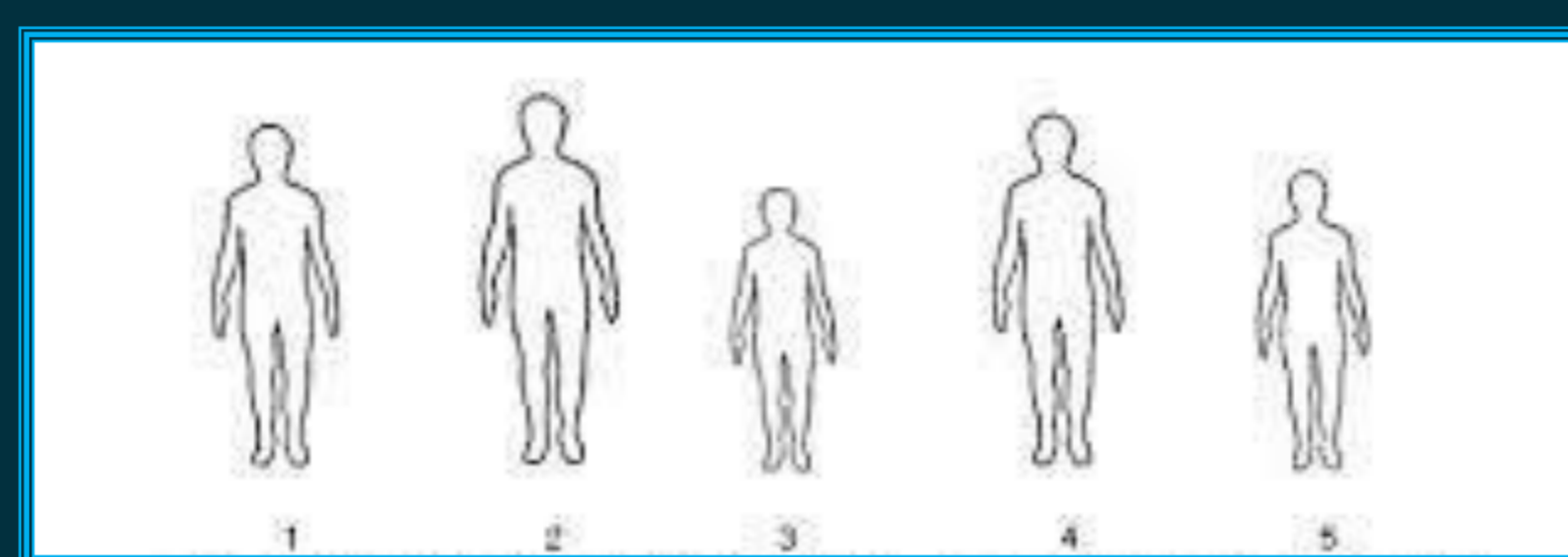


Table1: Demographic characteristics

		N	%
Gender	Boys	43	65.2
	Girls	23	34.8
Maternal educational level	<12 years	40	60.6
	>12 years	26	39.4
Paternal educational level	<12 years	39	59.1
	>12 years	27	40.9
Responding parents' sex	Female	44	66.7
	Male	22	33.3
Age (years), median range ±SD		13.2±2.5	
Duration of GH treatment (years) , median range ±SD		3.5±3.2	