

The assessment of quality of life and new technologies for therapeutic monitoring in a cohort of pediatric patients treated with growth hormone

G. Pruccoli, C. Partenope, M. P. Ferrarello, C. M. Damia, R. Pajno, D. Gallo, S. Osimani, G. Garbetta, G. Weber, G. Pozzobon
Pediatric Department, San Raffaele Hospital, Milan, Italy

Introduction

Short stature may represent a significant psychosocial problem. The rationale for growth hormone (GH) treatment has traditionally relied on the clinical improvement in terms of growth and quality of life. Furthermore adherence to the therapy has a significant relevance referring to the effectiveness of the therapy.

Objectives

In our study we investigated the benefits of GH treatment (Δ Ht SDS). Besides that we analyzed:

- differences between "objective" adherence to the therapy and the reported one
- Health related Quality of Life (HrQoL) concerning short stature and long-time therapy from children and parents' point of view.

Methods

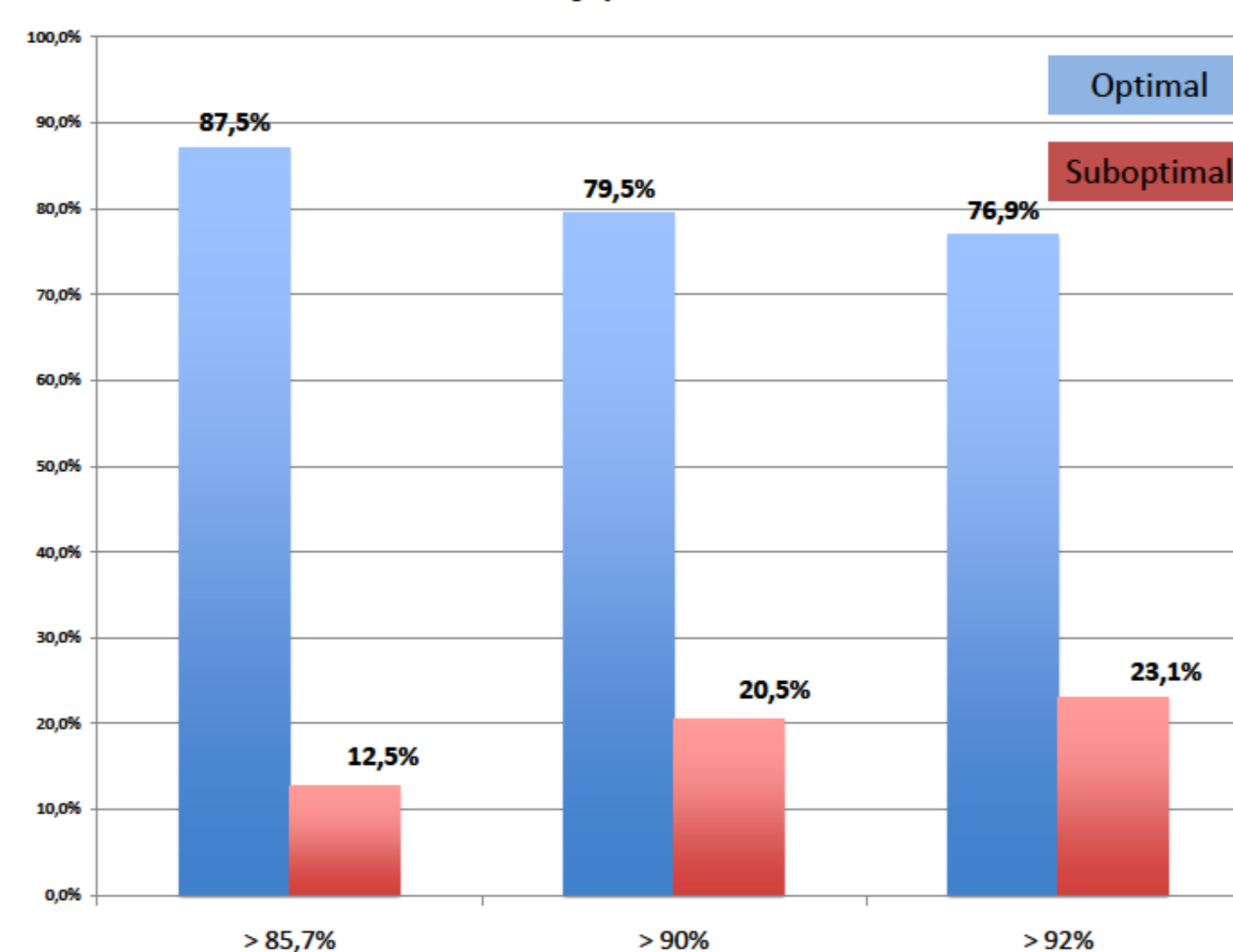
Our population included 40 short stature children and adolescents (28 males, 12 females) with a diagnosis of growth hormone deficiency (GHD) and/or SGA. All patients were treated with GH (medium dose $0,21 \pm 0,02$ mg/kg/week; median age of starting therapy 8.4 ± 3.3) using an electronic device (easypod™) for the administration of the therapy. We evaluated:

- anthropometric parameters
- adherence to therapy automatically recorded by the electronic device
- three different questionnaires answers referring to quality of life (HrQoL), treatment's knowledge and adherence.

Total of patients (M/F)	40 (28/12)
Mean age at the beginning of the therapy	8,4 3,3 years
✓ Diagnosis:	
- GHD	33 (82,5%)
- SGA	4 (10%)
- GHD + SGA	3 (7,5%)
✓ Mean age at the last visit	10,8 3,0 years

Results

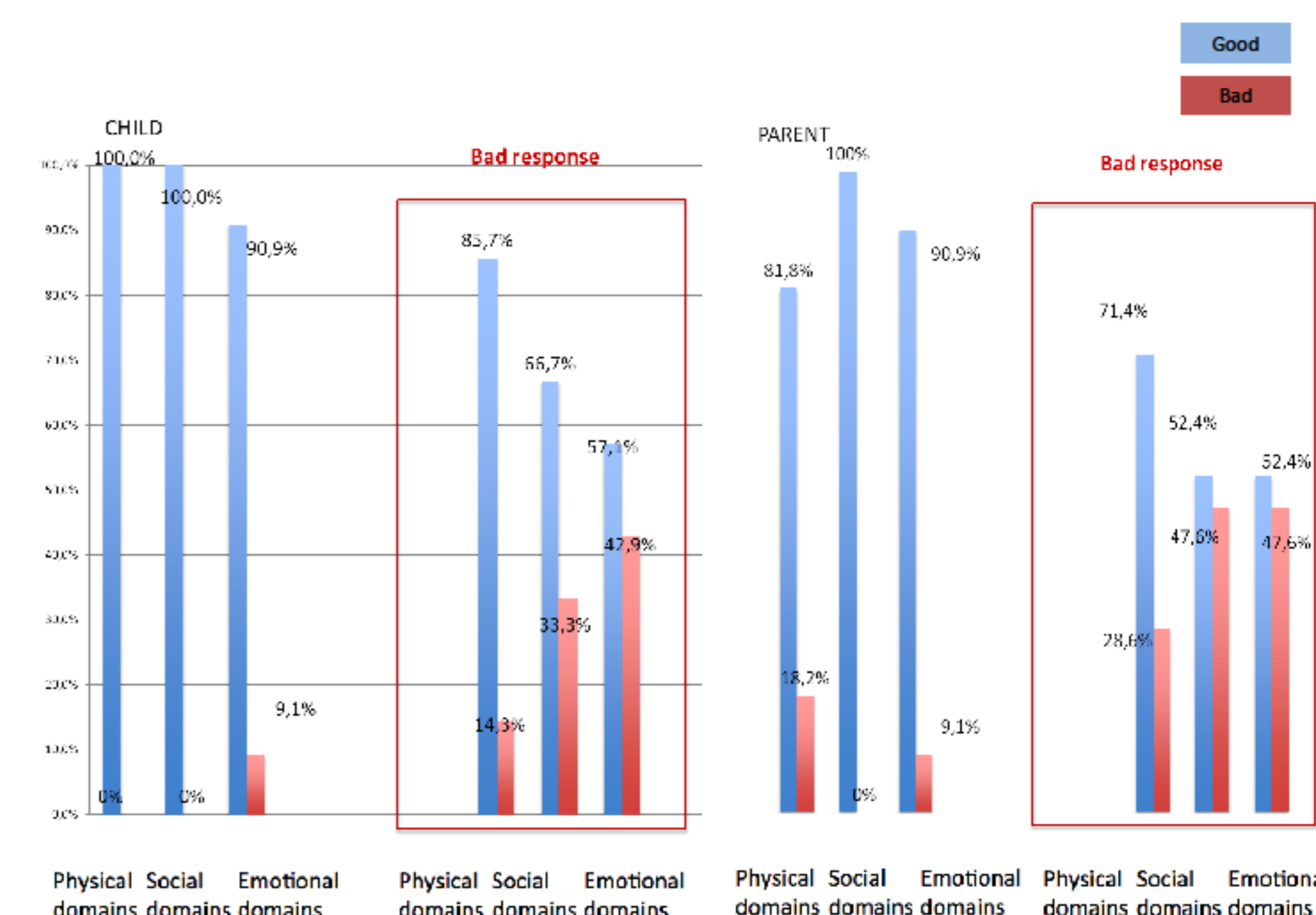
97.5% of patient presented an height improvement after one year of therapy ($+0.4 \pm 0.3$ SDS) and a progressive catch to the genetic target (Δ Ht SDS – midparental SDS - 1.7 ± 0.8 pretreatment; -1.5 ± 0.8 SDS at the first ys of tp; -0.8 ± 0.5 SDS after 5 ys of tp). Adherence to therapy was $94.4 \pm 7.3\%$ in 4 months and $92.1 \pm 8.9\%$ in one year. According to Cutfield/Hartmann criteria, adherence to therapy in 4 months resulted optimal in 87.5% of patients (suboptimal in 12.8%). According to our criteria (optimal adherence 90% equal to less than 3 missed administration/monthly), adherence to therapy in 4 months resulted optimal in 79.5% of patients (suboptimal in 20.5%). No patient demonstrated bad adherence (adherence $<70\%$ equal to 9 or more missed administration/monthly).



Reported adherence resulted higher compared to the recorded one, as shown in the table below:

Recorded adherence	% of patients	Reported adherence	% of patients
100%	35,9%	Never	54,1%
> 90 e < 100%	43,6%	Rarely	32,4%
> 70 e < 90%	20,5%	Once a week	10,8%
< 70%	0,0%	More than once a week	2,7%

We found a good HrQoL in both child (89.7% in physical aspect; 79.5% in social aspect; 74.4% in emotional aspect) and parent's (69% in physical aspect; 62% in social aspect; 62% in emotional aspect) point of view, even if parents generally have a worst opinion of their children's conditions.



Additionally we found better psychological status in patients with higher growth response to therapy in the first year compared to poor responders to treatment.

Conclusions

The GH therapy using an electronic device showed an optimal response in both statural growth and adherence to treatment. Interestingly we noted a significant difference between recorded adherence and reported one.

In the outcome of GH therapy, it is relevant to consider patient's quality of life and not only the auxological parameters. This allows to match benefits and risks of the treatment in a more accurate way, especially in poor responder patients.

References

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