MAJOR IMPROVEMENT IN PARENTAL PERCEPTION OF THEIR CHILDREN’S HEIGHT-SPECIFIC QUALITY OF LIFE AFTER ONE YEAR OF GH TREATMENT

OUR EXPERIENCE WITH THE QOLISSY (Quality of Life in Short Stature Youth) QUESTIONNAIRE

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Background
- Short stature may be a source of social and affective stress in children and their parents, and thus impact negatively on their quality of life (QoL).
- Treatment by growth hormone (GH) may improve QoL through normalization of height.

Aims of the study
To evaluate height-specific and general QoL in short stature children after 1 year of GH treatment

Methods
- Prospective study
- Inclusion criteria: GH started between April 2012 and December 2014, age ≥ 4 y.o and short stature (-2 SDS).
- Exclusion criteria: serious chronic disease, syndromic cause or developmental delay.
- Two questionnaires: general PedsQL 4.0 and height-specific QOLISSY (Quality of Life in Short Stature Youth, Bullinger et al. Health Qual Life Outcomes 2013).
- Questionnaires completed on the day of first GH injection (M0) and one year later (M12), both in parents and in children.
- Paired t-test was used to evaluate changes in QoL.

Population description

336 GH initiation sessions

227 excluded

109 eligible patients

35 questionnaires not filled in

74 M0

GHD (42.1%)

SGA (21.1%)

BD (26.3%)

ISS (10.9%)

GHD: GH deficiency
SGA: small for gestational age
BD: bone dysplasia
ISS: idiopathic short stature

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Results
- Of 74 patients included, 37 (58% boys) have completed up to date the M12 questionnaires.
- Mean age: 10.2 yrs (4.2-16.6), initial height: -2.7 SDS (-2 to -5).
- Gain in height after 1 year: 0.8 SDS (0-2 SDS).

In PedsQL questionnaires, children and parents report improvement of Emotional QoL.

(children: p=0.025, parents: p=0.004).

In QOLISSY questionnaires, children report improvement of social (p=0.045) and emotional (p=0.046) QoL. Beliefs concerning importance of height in life are also improved (p=0.036).

Parents report important improvement of children’s physical (p=0.001), social (p=0.002) and emotional QoL (p=0.001), and of parental stress linked to child’s short stature (p=0.025)

Conclusions
- Our preliminary results show that after one year of treatment, children’s height-specific QoL is significantly improved, according to parental perception (physical, emotional, social) and children’s perception (emotional and social QoL and beliefs).
- Parental QoL is also improved (effects on parents).