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### Putting parental concerns on short stature in perspective

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*Children's Mercy Kansas City*

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## Putting parental concerns on short stature in perspective

**Submitting/Presenting Author (must be a trainee):** Maria Cristina Murano

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**Resident/Psychology Intern**

**Fellow**

**Primary Mentor (one name only):** John Lantos, MD

**Other authors/contributors involved in project:** M. Max Feldt, DO

**IRB Number:** We don't have the IRB approval number, but there was no new data collection at Children's Mercy. All the data collection was completed in Cleveland in 2009.

**Describe role of Submitting/Presenting Trainee in this project (limit 150 words):**

The fellow has analyzed the data collected in 2009 and made a more recent literature review. The fellow wrote a first draft of the abstract and Dr. John Lantos and M. Max Feldt have read it and made suggestions for improvement.

**Background, Objectives/Goal, Methods/Design, Results, Conclusions limited to 500 words**

**Background:**

Some parents consider short stature (SS) as a disadvantage and seek growth hormone (hGH) therapy for their children. No studies exist on how parents attitudes on SS change over time – with or without h GH treatment. The Pediatric Endocrine Society highlights the fact that there is little evidence that short stature causes psychosocial burdens or that hGH reduces this concern.

**Objectives/Goal:**

To understand parents' attitudes about SS over time, hGH treatment, and psychosocial sequelae.

**Methods/Design:**

We surveyed parents about their attitudes regarding their children's SS at the time when they sought endocrinologists evaluation and again 15 years later. We compared parents' retrospective evaluation of the impact of SS on their children with their initial concerns. We surveyed 201 parents whose children (age 5-15 years) had short stature. Of these, 98 had been referred to an endocrinologist for evaluation and 103 were not. Primary variables included perceived suffering due to short stature, overall well-being, and self-esteem. These results were compared with the literature review of recent studies on parents' attitudes towards short stature.

**Results:**

At baseline, referred parents perceived greater suffering in their child due to short stature than did parents who were not referred. 15 year later, referred parents were 3.8 more likely to report improvement in self-esteem, 2.4 times more likely to report improved treatment from peers and 5.7 times more likely to report

overall ability to cope with height than were unreferral parents. Of the children who were referred, only 23.5 % were treated with hGH. Psychological improvement was present in both groups, and greater in both groups than in the control (unreferred) group. The literature review shows that parents tend to overestimate their children's maladaptation in comparison to patients themselves.

**Conclusions:**

This study suggests that referral itself leads parents to perceive psychosocial improvements over time, regardless of whether hGH is prescribed. Given that parents' concerns about short stature might decrease over time and that there are discrepancies with children's perceptions, an ethical approach to shared decision-making on hGH treatment should balance parents and children's attitudes. Future studies should examine the process by which children and parents decide to seek specialists' evaluation and the role that such evaluation plays in their future well-being.