

PEDIATRIC ENDOCRINOLOGY NURSING SOCIETY

Children with Short Stature and
Growth Failure: Heightism, Gender
and Racial Disparities
PhD, CRNP, FAAN

Terri H Lipman, PhD, CRNP, FAAN
Assistant Dean for Community Engagement
Miriam Stiri Endowed Term Professor of Nutrition
Professor of Nursing of Children
University of Pennsylvania School of Nursing

SESSION OBJECTIVES

- Explain the origin and impact of heightism
- Identify gender disparities in the diagnosis and treatment of children with growth failure
- Identify racial disparities in the diagnosis and treatment of children with growth failure

DISCLOSURE

- I have nothing to disclose

INTRODUCTION

- Growth is the single most important indication of the health of a child.
- The American Academy of Pediatrics (AAP) recognizes the importance of somatic growth assessment to diagnose a variety of underlying pathological conditions.
- The AAP recommends that children's heights be measured at 3-5 days, 1,2,4,6,9,12,15,18,24 and 30 months, and then every year thereafter until 21 years of age.

WHAT IS SHORT STATURE?

- Short stature is defined as height that is 2 standard deviations below the mean for age and sex.
- A child does not have to be short to demonstrate growth failure - identified as a growth rate that is below the growth velocity appropriate for age.
- Deviations from the normal growth curve can signal diseases such as hypothyroidism, growth hormone deficiency, inflammatory bowel disease, celiac disease, cystic fibrosis, renal tubular acidosis and HIV infection.
- It may be difficult to identify deviations in rate of growth as most children in pediatric primary care practices are measured inaccurately.

BACKGROUND

- In the past 2 decades, rhGH (recombinant human growth hormone) has been available in the US for growth enhancement based on various FDA-approved indications.
- Between 1993–2000, the FDA-approved rhGH for specific causes of growth failure such as chronic renal insufficiency, Turner syndrome, and Prader-Willi syndrome.

BACKGROUND

- The use of recombinant human growth hormone (rhGF) for ISS was approved for children who were 2 standard deviations below the mean for their chronological age and gender
- The influx of potential patients has challenged the existing system used to refer, diagnose, and treat children with linear growth disorders.

HOW GROWTH HORMONE THERAPY IS USED

- The utilization of growth hormone therapy has been shown to be a multifactorial decision process that is affected by
 - psychosocial concerns
 - parent education
 - physiological growth characteristics
 - economic factors
 - provide beliefs and experience
- Several attempts have been made to standardize the process of diagnosing and treating linear growth disorders, however disparities still exist.

HEIGHTISM

- Heightism is prejudice or discrimination against individuals based on height, and refers to discriminatory treatment against individuals whose height is not within the normal acceptable range of height in a population.
 - Short males are most commonly the target of heightism.
- Studies have found a positive correlation between male height and reproductive success, job promotion and income, dominance, attractiveness and dating/ mate preference, and physical strength.

HEIGHTISM

- The economic and social advantages of being a tall male have been documented as early as 1915
- Height also affects the choice and evaluation of political leaders. Since the advent of televised presidential candidates, there have been 15 presidential elections.
 - In evaluating 14 elections where both candidates were men, the taller candidate has won 79% of the elections.

HEIGHTISM

- Heightism has even been shown to occur prenatally. Advertisements have appeared in Ivy League college newspapers: couples were willing to pay \$50,000 for an egg, provided the donor was at least five feet, ten inches tall.
- Studies have shown detrimental psychosocial effects of short stature on children as small children have been impacted by juvenilization, teasing, bullying, victimization, loss of independence/overprotection and exclusion.

GLOBAL HEIGHTISM

- A study in Germany demonstrated that a 1 cm increase in male height was associated with a 1.6 percentage point increase in the probability of attending college- even when controlling for academic achievement and parental background.
- In China, an advertisement for new staff of the People's Bank of China read: "Male applicants must be above 168 cm in height and female applicants above 155 cm." A law student, who was 165 cm, and his classmates at the Law Department of Sichuan University, brought suit to safeguard their constitutional right—the right to equality.

GENDER DISPARITIES: PARENT PERSPECTIVES

- Although growth hormone therapy has been shown to be relatively safe, parents still express concerns that influence their decision making process related to treatment of growth disorders.
- Parent reports:
 - “I think culturally, if we tell the truth, it’s okay for girls to be small... but it’s not as okay for boys... I think that’s an American thing.”
 - “Like they’re supposed to be manly, you know what I mean. They’re supposed to be manly, there’s that stigma from society, you’re supposed to be a man, you’re supposed to be bigger than the girls, you’re supposed to be, strong and everything else”

GENDER DISPARITIES: HEALTH CARE ACCESS/ PROVIDER BIAS

- Gender disparities exist for referral for evaluation of growth disorders.
- A study examined sex differences among children referred to a division of endocrinology for evaluation of short stature or poor growth.

GENDER DISPARITIES: HEALTH CARE ACCESS/ PROVIDER BIAS

- Examination of all patient charts during a 1-year period revealed that boys were referred nearly twice as often as girls (182 vs. 96; $P < .00005$).
- More boys (72%) than girls (48%) who were referred were of normal height or short but healthy ($P < .0001$).
- Girls were significantly more likely to have identifiable organic causes of short stature compared to boys (41% vs. 15%).

GENDER DISPARITIES: HEALTH CARE ACCESS/ PROVIDER BIAS

- It is important to evaluate whether fewer girls are referred for evaluation because the prevalence of growth-faltering is lower among girls.
- An examination of the prevalence of growth-faltering by gender found
 - An overall prevalence of growth-faltering of 9%, (no difference between males and females) In addition,
 - For those children who were evaluated, GH/insulin-like growth factor (IGF) axis testing was performed twice as often in boys as in girls (1.8% vs. 0.9%; $P < .05$) increasing the likelihood of under diagnosis of growth hormone deficiency in girls.

GENDER DISPARITIES: HEALTH CARE ACCESS/ PROVIDER BIAS

- In a study of almost 60,000 growth hormone treated children that compared gender disparities in the US with those treated globally, it was shown that male predominance was similar to the US in Asia, Europe, Australia and New Zealand.
- In general, gender disparities were most prevalent in the use of growth hormone therapy for treatment of idiopathic short stature.
- US pediatric endocrinologists who evaluated hypothetical case scenarios, were more likely to recommend rhGH treatment for boys than girls in otherwise identical cases.

RACIAL DISPARITIES: PARENT PERSPECTIVES

- ×Parents seeking evaluation for their child's short stature tended to differ demographically
- ×Parents who sought treatment for their children tended to be White ($p < .03$), more affluent ($p < .001$), and college educated ($p < .01$).
- ×Black families had a lower threshold for acceptable adult height

RACIAL DISPARITIES: PARENT PERSPECTIVES

- × African American families described a more spiritual perspective – commenting that that height was divinely ordained and should be accepted without tampering.
- × It was proposed by an African American parent that height is relatively minor issue across racial lines, especially when so many issues already exist within the African-American community.
- × Parental concerns significantly impacted physicians' decisions to refer children for evaluation of short stature

RACIAL DISPARITIES: HEALTH CARE ACCESS/ PROVIDER BIAS

- ❖ In a study of over 2000 children treated with growth hormone, the racial distribution of the patients was 87.8% White, 6.0% Black, 1.0% Asian, and 5.2% other.
- ❖ Black patients also had more severe growth hormone deficiency as demonstrated by their lower maximum GH responses to provocative agents and a three-fold higher prevalence of pretreatment hypoglycemia.

RACIAL DISPARITIES: HEALTH CARE ACCESS/ PROVIDER BIAS

- ❖ Race was one of the most powerful predictors of growth faltering in an urban US population.
- ❖ Black children with growth faltering were less likely to be evaluated by a subspecialist, particularly an endocrinologist.
- ❖ Racial disparities in referral for evaluation of growth failure, and in treatment with growth hormone, are not limited to African American children. Relatively few Asian children are treated with growth hormone.

RACIAL DISPARITIES: HEALTH CARE ACCESS/ PROVIDER BIAS

- In a classic study by Johnston et al, 1985, the growth of a population of 519 Guatemalan children from a disadvantaged urban community was compared to Guatemalan children from a higher SES
 - SES was the strongest predictor of height
- Data from a study of children adopted from Eastern Europe showed linear catch up growth in 62% of the children within six months of adoption

RACIAL DISPARITIES: HEALTH CARE ACCESS/ PROVIDER BIAS

- These data suggest that short stature observed in certain racial/ethnic groups is due to poverty and the environment, not race or ethnicity.
- Therefore, short stature and growth failure should never be ignored- regardless of a child's racial and ethnic background.

ROLE OF PENS NURSES

- PENS nurses can help to ensure equitable care related to growth for all patients by emphasizing the need for children to be measured accurately at yearly primary care visits.
- It is important to incorporate school nurses as a member of the health care team. Arranging conferences for school nurses regarding measuring technique and the importance of identifying children with growth failure can be effective in increasing appropriate referrals.

ROLE OF PENS NURSES

- Employing a uniform approach to asking about teasing or bullying and being aware that growth failure is troubling for both boys and girls are important strategies.
- Education of primary care providers and specialty providers is essential to present data on the disparities in growth evaluations and on the treatment for approved indications for rhGH therapy.

ROLE OF PENS NURSES

- Publishing in scientific journals will advance the dissemination of this important issue.
- It is also necessary to publish in the lay press and on online sites targeted at parents- to educate and alert parents that growth is not merely about stature- but is a crucial indication of a child's health.
- Although it is necessary to acknowledge that heightism exists, it is also necessary to recognize that a number of parents seek growth hormone treatment for shorter than average children- usually boys- in an attempt to prevent bias that may occur because of stature.

ROLE OF PENS NURSES

- PENS nurses are key in providing education regarding normal short stature and when there is no indication for treatment.
- It is also important to note, that although rare, side effects of growth hormone can occur. The risk of side effects are not justified for those in whom rhGH is not indicated.
- PENS nurses' involvement with these children and their families can produce valuable benefits in situations where adaptive measures are more important than medication.

CONCLUSION

"PENS NURSES HAVE A CENTRAL ROLE IN ADVOCATING THAT ALL CHILDREN WHO ARE APPROPRIATE CANDIDATES FOR RHGH THERAPY ARE TREATED, REGARDLESS OF GENDER, RACE, OR SOCIOECONOMIC STATUS, IN PRACTICE AND WHEN WORKING WITH THIRD-PARTY PAYERS AND GROWTH HORMONE COMPANIES."

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