LETTER

Growth attenuation therapy: practice and perspectives of paediatric endocrinologists

For non-ambulatory children with severe physical and cognitive disabilities (SPCD), being lifted and transported become more challenging with increasing size. Reduction in length and overall size for select children with SPCD can be accomplished by growth attenuation therapy (GAT), which reduces linear growth by administering hormones (eg, oestrogen) that accelerate epiphyseal closure. There are no reliable data describing attitudes and practices of paediatric endocrinologists regarding GAT for children with SPCD.

In collaboration with the Pediatric Endocrine Society (PES), an anonymous questionnaire about GAT was emailed to PES physician members (n=1100, 92% from the USA). Responses were stripped of identifiable information. Consent was implied by responding. The study received institutional review board exemption status at the University of Wisconsin–Madison.

Two hundred and eighty-four PES members responded to the survey (response rate=26%). Ninety-nine respondents had either been asked to prescribe or had prescribed GAT to a child with SPCD. Of these, 92 (94%) said requests came from the patient's family and 34 reported seeking ethics consultation.

Thirty-two respondents had prescribed GAT to a child with SPCD, most recalling doing so one to five times (n=28, 88%), yielding a conservative estimate of at least 65 children with SPCD treated. Oral oestrogen was the most common sex hormone therapy used for GAT (n=21, 66%).

Withholding of interventions that suppress precocious puberty in a child with SPCD in order to reduce ultimate linear growth was reported by 130 respondents (46%). Of these, only seven (5%) sought ethics consultation. Key findings are highlighted in figure 1.

Previous surveys of GAT practices[1 2] focused on prescriptions of GAT to healthy tall-statured girls, not on treatment of children with SPCD. Results from this present survey show, for the first time, that instances of prescribing GAT for children with SPCD are not limited to the single existing case report. There is a need for collaborative investigation of therapeutic growth attenuation strategies, reporting of outcomes, and discussion among stakeholders to develop evidence-based guidance for patients and families. The demonstration here that approximately one in three responding paediatric endocrinologists have been asked about GAT for a child with SPCD provides an opportunity for further investigation regarding efficacy of GAT in length reduction, quality of life improvement and the possible risks of therapy.[3]

The main limitations of this study were (1) brevity of the questionnaire, which was designed to optimise ease of participation and therefore maximise the response rate and (2) the possibility that respondents may not be representative of paediatric endocrinologists overall.

In conclusion, paediatric endocrinologists are receiving inquiries regarding GAT from families of children with SPCD more commonly than previously realised and at least 65 children with SPCD have received GAT. Most of the responding paediatric endocrinologists view GAT as an appropriate therapeutic modality in certain circumstances. Systematic investigation of risks and benefits of GAT in children with SPCD would enrich paediatric endocrinologists' guidance for families who are already inquiring about GAT and would assist in developing consensus on a responsible and thoughtful approach to GAT within the paediatric endocrinology community.

Key Findings

Number of respondents who have been asked about GAT for a child with SPCD:	98
Number of respondents who have prescribed GAT for a child with SPCD:	32
Number of children with SPCD treated (minimum calculation):	65
Number of respondents who have withheld treatment of precocious puberty to attenuate growth in a child with SPCD:	130
Percent of respondents who obtained ethics consultation for GAT of children with SPCD:	34%
Percent of respondents who obtained ethics consultation for withholding treatment of precocious puberty in order to attenuate growth in children with SPCD:	5%

Figure 1 Key findings from the study survey. Of note, there were 284 respondents to the questionnaire. GAT, growth attenuation therapy; SPCD, severe physical and cognitive disabilities.

Allison J Pollock, Norman Fost, David B Allen

Department of Pediatrics, University of Wisconsin, Madison, Wisconsin, USA

Correspondence to Dr Allison J Pollock, Department of Pediatrics, University of Wisconsin, Madison, WI 53703, USA; apollock@pediatrics.wisc.edu

Acknowledgements The authors would like to thank Jens Eickhoff, PhD, for his assistance with statistical analysis and the Pediatric Endocrine Society for facilitating distribution of the questionnaire.

Contributors AJP: Conceptualised and designed the study and questionnaire instrument, carried out the initial analyses, drafted the initial manuscript and approved the final manuscript as submitted. NF and DBA: Contributed to the design and analyses, critically reviewed and revised the manuscript and approved the final manuscript as submitted.

Competing interests None declared.

Ethics approval University of Wisconsin Institutional Review Board.

Provenance and peer review Not commissioned; internally peer reviewed.

To cite Pollock AJ, Fost N, Allen DB. *Arch Dis Child* Published Online First: [*please include* Day Month Year] doi:10.1136/archdischild-2015-309130

Accepted 3 July 2015

Arch Dis Child 2015;0:1. doi:10.1136/archdischild-2015-309130

REFERENCES

1 Conte FA, Grumbach MM. Estrogen use in children and adolescents: a survey. *Pediatrics* 1978;62(6 Pt 2):1091–7.
2 Barnard ND, Scialli AR, Bobela S. The current use of estrogens for growth-suppressant therapy in adolescent girls. *J Pediatr Adolesc Gynecol* 2002;15:23–6.
3 Wilfond BS, Miller PS, Korfiatis C, *et al*. Navigating growth attenuation in children with profound disabilities. Children's interests, family decision-making, and community concerns. *Hastings Cent Rep* 2010;40:27–40.

Research #'s

2015

Growth attenuation therapy: practice and perspectives of paediatric endocrinologists

Allison J Pollock, Norman Fost and David B Allen

Arch Dis Child published online July 22, 2015

Growth Attenuation Therapy: Practice & Perspectives of Pediatric Endocrinologists

Allison J Pollock, MD · Norman Fost MD MPH · David B Allen MD · Department of Pediatrics · University of Wisconsin School of Medicine & Public Health

Disclosure: the authors have nothing to disclose.

Background

Growth attenuation therapy (GAT) is administration of exogenous sex steroids before puberty to decrease final height by accelerating epiphysis closure. Treatment of a girl with severe cognitive and physical disabilities in 2006 prompted intense debate. There are no reliable data on GAT prescribing practices and attitudes of pediatric endocrinologists.

Objectives

Determine diagnoses that prompt consideration of GAT

Assess how often pediatric endocrinologists prescribe GAT

Assess pediatric endocrinologists' attitudes about growth attenuation therapy (GAT) in children with severe physical & cognitive disability

Design

Pediatric Endocrine Society (PES) members received questionnaires (~1100). Consent was implied by participating. Anonymity was assured with de-identified data collection.

Results

284 (26%) of ~1100 PES members (74% academic physicians) completed the survey.

62%
OF RESPONDENTS
have been asked
TO PRESCRIBE GAT AND
27%
OF RESPONDENTS
have prescribed
GROWTH ATTENUATION THERAPY

GAT Medications Prescribed
1. Oral estrogen (80%)
2. Transdermal estrogen (13%)
3. Androgens (27%)

How often respondents prescribed GAT for a child with severe physical & cognitive disability	# of respondents
1 time	15
2-5 times	13
6-10 times	4

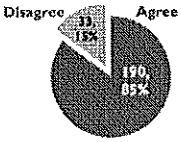
At least 65 children

WITH SEVERE PHYSICAL + COGNITIVE DISABILITY

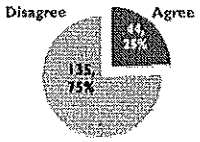
have been treated with GAT to reduce ultimate height

RESPONDENTS' ATTITUDES ABOUT GAT

"Growth attenuation therapy is sometimes appropriate."



"GAT should be actively offered for cases of severe physical and cognitive disability, not just when raised by a parent."

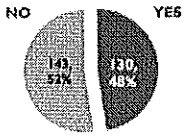


DIAGNOSES PROMPTING GAT INQUIRIES

Reasons respondents did NOT prescribe GAT in children with severe physical & cognitive disability
1. Family decided against (63%)
2. Concern about side effects (43%)
3. Legal concerns (13%)
Concern about publicity (13%)
4. Personal conviction or beliefs (10%)
5. Ethics consultation recommendation (7%)

PASSIVE GAT EXPERIENCE

Have you withheld treatment for precocious puberty in a child with severe physical and cognitive disability to reduce ultimate height?



Conclusions

1. Growth attenuation therapy (GAT) has been prescribed by at least **32** respondents to reduce height in at least **65** children with severe and physical cognitive disability.
2. This therapy is no longer rare. At least 62% (n=175) of respondents have had inquiries for GAT, and 27% (n=74) have prescribed GAT.
3. Severe physical and cognitive disability has replaced tall stature as the main indication for GAT inquiries.
4. More data are needed to assess risks and benefits of GAT by evaluating side effects, linear height reduction and improvement in quality of life.

Acknowledgements Thank you to the University of Wisconsin Department of Pediatrics, the Pediatric Endocrine Society (PES) and Jens Eickhoff, our biostatistician.

Contact Information Allison Pollock MD apollock@uwhealth.org University of Wisconsin - Madison