

TITLE PAGE

Title: The Clinician's Role in Promoting Resiliency for Individuals and Families with Growth Anomalies

Running title (maximum of 50 characters including spaces):
The Clinician's Role in Promoting Resiliency

Authors: Howard D. Silverman, MD MS ^a (Corresponding Author)
Michelle Grunauer, MD, PhD ^b (Co-Author)

Addresses:

^aThe University of Arizona College of Medicine – Phoenix
5895 East Onyx Avenue
Scottsdale, Arizona 85253
howards@email.arizona.edu

^bSchool of Medicine, Universidad San Francisco de Quito, Quito, Ecuador
Pediatric Critical Care Unit, Hospital de los Valles, Quito Ecuador
Phone: +593-099-893-8210
Universidad San Francisco de Quito, Quito, Ecuador
Av. Interoceánica y Florencia, km 12 ½. Edificio de Especialidades Médicas PB.
Escuela de Medicina. Quito-Ecuador.
mgrunauer@usfq.edu.ec

ABSTRACT

Some recent clinic and population-based studies suggest that severe short stature is not associated with significant behavioral and psychological problems, however collectively studies on this topic are variable and frequently contradictory. In light of these contradictory sources, it is important to recognize that there may be some children for whom growth failure is disabling. Many of such children can respond to counseling and support, but there may be occasions in which therapy can be recommended.

Resiliency can be defined as a pattern of positive adaptation in the context of past or present adversity with resiliency in childhood defined as typical development in the face of adverse circumstances that propel others to deleterious outcomes. Several strategies for promoting resilience in short stature patients and their families include 1) conducting a comprehensive psychosocial assessment; 2) recommending psychological strategies to directly address predictable social challenges associated with short stature; 3) discouraging the expectation that taller stature is associated with improvement in quality of life and; 4) discussing treatment efficacy in terms of the degree of certainty and magnitude of effects.

Recognizing time constraints in clinical settings, these approaches can be carried out across multiple visits. Being aware of, honoring, and addressing factors the parent and patient use in making their treatment decisions has the potential to promote resiliency in patients and families. This approach to clinical care can serve to promote resiliency in clinicians as well.

INTRODUCTION

The aims of this presentation were to 1) define and discuss resiliency; 2) briefly review literature on the question of whether significant behavioral and psychological problems are associated with children with short stature; and 3) provide a framework and tools to promote resiliency. The presentation focuses on how this goal can be achieved from the author's perspective as a Family Physician.

WHAT IS RESILIENCY?

The term 'resiliency' has become more prominent in recent years as a more positively oriented term compared to 'burnout'. It has been variously defined as:

1. A pattern of positive adaptation in the context of past or present adversity [1].
2. A set of inner resources, social competencies, and cultural strategies that permit individuals to not only survive, but recover, or even thrive after stressful events, but also to draw from the experience to enhance subsequent functioning [2].

According to the American Psychological Association [3], being resilient does not mean that a person does not experience difficulty or distress. Emotional pain and sadness are common in people who have suffered major adversity or trauma in their lives. In fact, the road to resilience is likely to involve considerable emotional distress. Resilience is not a trait that people either

have or do not have. It involves behaviors, thoughts and actions that can be learned and developed in anyone. Resilience is ordinary, not extraordinary and people commonly demonstrate resilience.

One author noted that “Resiliency in childhood is defined as typical development in the face of adverse circumstances that propel others to deleterious outcomes [4].”

How does resiliency apply to children with short stature?

At the beginning of this talk, the speaker invited all participants (faculty and medical students) to respond to two questions utilizing a web-based polling platform. The results of these polls are depicted in Figure 1. Most (80%) of the respondents indicated they believed that “studies show significant behavioral and psychological problems associated with children with short stature.”

The results were evenly split with regard to the second question of “A recent study of pediatric endocrinologists showed that over 25% reported the emotional well-being of children and adults with short stature as ‘often’ or ‘always’ impaired.”

While a comprehensive analysis of the literature on the topic of behavioral and psychological problems associated with children with short stature was beyond the scope of this communication, a survey of the literature over time provided helpful albeit at times conflicting information. Additionally, studies were often primarily focused on other areas (i.e., treatments and/or growth rates) and not designed explicitly to focus on behavioral and psychological topics. A significant proportion of studies were funded by industry which was understandably less focused on these topics.

The following statements were typical of the literature reviewed:

1. One implicit assumption in the clinical literature is that stature-related stressors, such as teasing or juvenilization, are inevitably associated with psychiatric dysfunction. Instead, what has been observed in clinic- and population-based short stature samples is that such experiences do not necessarily differentiate short youth from others, nor are they generally associated with clinically meaningful effects on overall adaptation [5]
2. Although short children from a population-based sample reported marginally higher levels of self-perceived peer victimization, they did not differ from their non-short peers in a range of social, emotional, and behavioral outcomes [6]
3. Numerous studies on the psychological consequences associated with GH management of children with short stature exist. Findings across studies are variable and frequently contradictory [7]
4. In a national census study of pediatric endocrinologists’ recommendations regarding initiating and discontinuing rhGH (n = 727), more than 50% reported the emotional well-being of children and adults with heights less than the third percentile is “sometimes” impaired, and more than 25% responded it was “often” or “always” impaired [8]

The literature suggests a possible disconnect between the perception of the prevalence of behavioral and psychological problems and several studies which suggest that such problems are neither as deep nor as prevalent as perceptions suggest. Despite these studies, we recognize that there may be some children for whom growth failure is disabling. This raises important questions regarding whether parental and/or clinician concerns regarding short stature may vary significantly from the experience and perceptions of the affected children. While many of such children can respond to counseling and support, but there may be occasions in which therapy can and should be recommended.

PERCEPTION AND BIAS

One possible reason why negative stereotypes regarding short stature are so prevalent is the impact of cognitive biases. Sandberg et al [9,10] describe a known cognitive bias known as ‘The Focusing Illusion’:

- The focusing illusion occurs “when a judgment about an entire object or category is made with attention focused on a subset of that category, . . . whereby the attended subset is over weighted relative to the unattended subset.”
- Assuming that most people believe that short stature is associated with multiple negative characteristics, it then follows that evaluations of the quality of life of an individual that focuses on this isolated trait would be overly negative.
- The existence of a focusing illusion may also serve as a cautionary note for parents and clinicians. There is the possibility that by focusing on height, this characteristic becomes overvalued relative to less noticeable ones.

Additional research in disability beliefs and biases inform three things clinicians should know about disability [11]:

- Quality of life: Numerous studies demonstrate that able-bodied people assume the quality of life experienced by people with disabilities to be lower than they themselves report
- The problem of ableism: Ableism refers to the assumption that the “normal” able body is better than abnormal bodily forms and to the social ramifications of that assumption
- Disability vs disease/illness: To be disabled is not automatically or necessarily to suffer or be in pain or to have an illness or disease. Many people with disabilities do not experience pain and suffering and many are not ill or diseased. It is not a contradiction in terms to be disabled and healthy

PROMOTING RESILIENCY: PRACTICAL TIPS FOR BUSY CLINICIANS

As the expert, the pediatric endocrinologist has the potential to significantly impact the perceptions of patient and family resulting from the diagnosis of short stature as well as the treatment decisions. Clinicians vary widely in the degree to which they provide psychological and emotional support to patients and families depending on their experience, expertise, and degree of comfort in doing so and other considerations related to their practice setting.

Common constraints in counseling patients and families are time and level of clinician comfort and/or expertise in counseling. Certainly not all patients require such counseling at all visits so

an early triage of psychological and behavioral counseling needs can be very helpful in providing some additional time for those patients and families most in need. Furthermore, clinicians can and should develop a professional referral and support network of relevant organizations, qualified psychologists, other parents, families, and teachers. Doing so will allow the busy clinicians to team with members of this network who often have more time and expertise available. Depending on the practice environment, it is also advisable to reserve some longer appointment times to use selectively to work with patients and families who are struggling. This level of interaction with patient and family can be both challenging and tremendously rewarding for patients and families as well as clinicians. Eliciting and honoring the patient's and family's concerns and expanding their community connections and other internal and external resiliency resources can be positively impactful.

Table 1 provides an excellent overview of “Dos and Don'ts” by Sandberg and Colman based on the cited literature and personal clinical experiences [12, 13, 14, 15, 16, 17, 18, 19, 20, 21, 22, 23].

Acknowledgements

The author would like to thank the organizers and supporters of the Third Universidad San Francisco de Quito Biennial Meeting on GH & IGF Research for the invitation to present this paper and acknowledge the input and direction of Drs. Ron Rosenfeld and David Sandberg.

References

- ¹ Wright M.O., Masten A.S. (2005) Resilience Processes in Development. In: Goldstein S., Brooks R.B. (eds) *Handbook of Resilience in Children*. Springer, Boston, MA
- ² Stanton-Salazar, R.D. & Spina, S.U. *The Urban Review* (2000) 32: 227.
<https://doi.org/10.1023/A:1005122211864>, accessed 8/27/2019
- ³ <https://www.apa.org/helpcenter/road-resilience>, accessed 8/27/2019
- ⁴ Deater-Deckard K., Ivy L., Smith J. (2005) Resilience in Gene-Environment Transactions. In: Goldstein S., Brooks R.B. (eds) *Handbook of Resilience in Children*. Springer, Boston, MA
- ⁵ Sandberg DE. Short Stature: Psychosocial Interventions. *Horm Res Paediatr* 2011;76 (suppl 3)
- ⁶ Lee JM, Appugliese D, Coleman SM, Kaciroti N, Corwyn RF, Bradley RH, Sandberg DE, Julie C. Lumeng JC. Short Stature in a Population-Based Cohort: Social, Emotional, and Behavioral Functioning. *Pediatrics* 2009;124:903–910
- ⁷ Gardner M, Boshart ML, Yeguez CE, Desai KM, Sandberg DE. Coming Up Short: Risks of Bias in Assessing Psychological Outcomes in Growth Hormone Therapy for Short Stature. *J Clin Endocrinol Metab* January 2016, 101(1):23–30
- ⁸ Sandberg DE, Gardner, M. Short Stature: Is It a Psychosocial Problem and Does Changing Height Matter Sandberg DE, Bukowski WM, Fung CM, Noll RB. Height and Social Adjustment: Are Extremes a Cause for Concern and Action? *Pediatrics* 2004;114:744-750? *Pediatr Clin N Am* 62 (2015) 963–982
- ⁹ Sandberg DE, Bukowski WM, Fung CM, Noll RB. Height and Social Adjustment: Are Extremes a Cause for Concern and Action? *Pediatrics* 2004;114:744-750
- ¹⁰ Schkade DA, Kahneman D. Does living in California make people happy? A focusing illusion in judgments of life satisfaction. *Psychol Sci*. 1998;9:340–346
- ¹¹ Reynolds JM, Three Things Clinicians Should Know About Disability. *AMA Journal of Ethics, Medicine and Society*, December 2018, <https://journalofethics.ama-assn.org/article/three-things-clinicians-should-know-about-disability/2018-12>, accessed August 28, 2019
- ¹² Sandberg D, E, Colman M: Growth Hormone Treatment of Short Stature: Status of the Quality of Life Rationale. *Horm Res* 2005;63:275-283.
- ¹³ Sandberg DE: Short stature: Intellectual and behavioral aspects; in Lifshitz F (ed): *Pediatric Endocrinology*, ed 3. New York, Dekker, 1996, pp 149–162.
- ¹⁴ Wilson DM, McCauley E, Brown DR, Dudley R: Oxandrolone therapy in constitutionally delayed growth and puberty. Bio-Technology General Corporation Cooperative Study Group. *Pediatrics* 1995; 96: 1095–1100.
- ¹⁵ Eminson DM, Powell RP, Hollis S: Cognitive behavioral interventions with short statured boys: a pilot study; in Stabler B, Underwood LE (eds): *Growth, Stature, and Adaptation*. Chapel Hill, The University of North Carolina at Chapel Hill, 1994, pp 135–150.
- ¹⁶ Rekers-Mombarg LT, Busschbach JJ, Massa GG, Dicke J, Wit JM: Quality of life of young adults with idiopathic short stature: Effect of growth hormone treatment. *Acta Paediatr* 1998; 87: 865–870.

-
- ¹⁷ Theunissen NC, Kamp GA, Koopman HM, Zwinderman KA, Vogels T, Wit JM: Quality of life and self-esteem in children treated for idiopathic short stature. *J Pediatr* 2002; 140: 507–515.
- ¹⁸ Sandberg DE, Bukowski WM, Fung CM, Noll RB: Height and social adjustment: Are extremes a cause for concern and action? *Pediatrics* 2004; 114: 744–750.
- ¹⁹ Downie AB, Mulligan J, McCaughey ES, Stratford RJ, Betts PR, Voss LD: Psychological response to growth hormone treatment in short normal children. *Arch Dis Child* 1996; 75: 32–35.
- ²⁰ Finkelstein BS, Singh J, Silvers JB, Marrero U, Neuhauser D, Cuttler L: Patient attitudes and preferences regarding treatment: GH therapy for childhood short stature. *Horm Res* 1999; 51(suppl 1):67–72.
- ²¹ Singh J, Cuttler L, Shin M, Silvers JB, Neuhauser D: Medical decision-making and the patient: understanding preference patterns for growth hormone therapy using conjoint analysis. *Medical Care* 1998; 36(suppl 8):AS31–AS45.
- ²² Finkelstein BS, Imperiale TF, Speroff T, Marrero U, Radcliffe DJ, Cuttler L: Effect of growth hormone therapy on height in children with idiopathic short stature: A meta-analysis. *Arch Pediatr Adolesc Med* 2002; 156: 230–240.
- ²³ Grimberg A, Kutikov JK, Cucchiara AJ: Sex differences in patients referred for evaluation of poor growth. *J Pediatr* 2005; 146: 212–216.

Declarations of interest: None

Funding: This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

Appendices: None

Figure Legends:

Figure 1: All participants (faculty and medical students) were invited to respond to two questions utilizing a web-based polling platform

Table Legends:

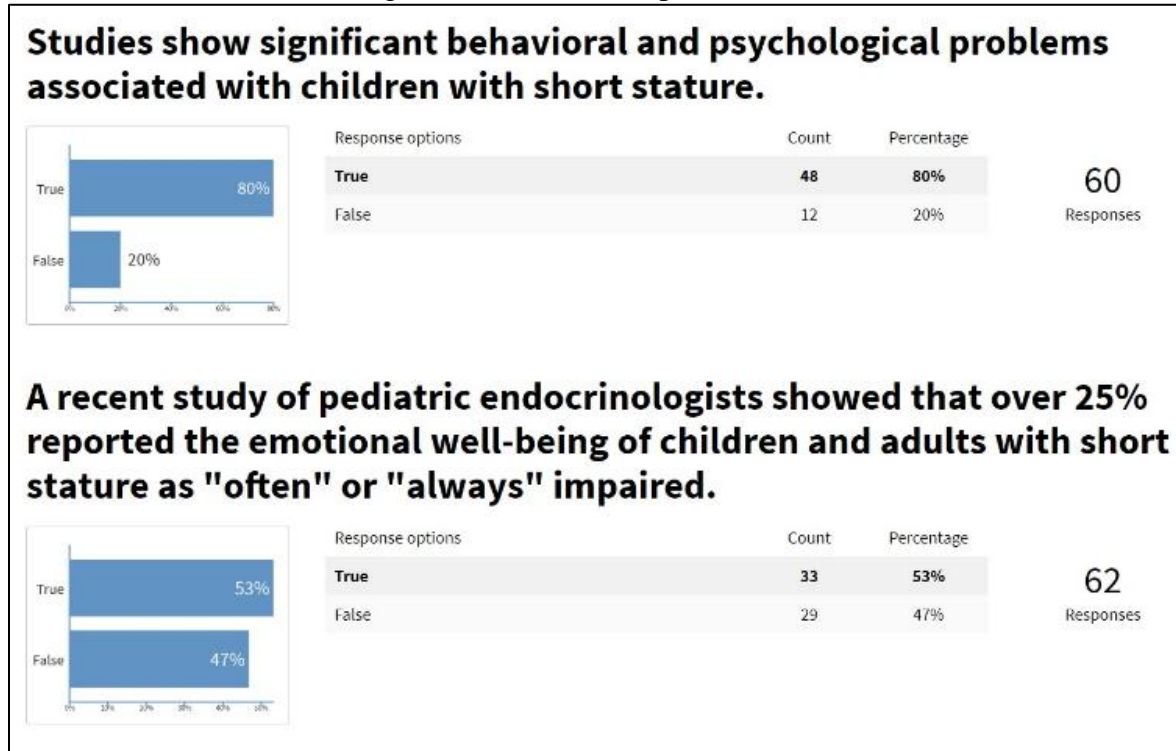
Table 1: “Dos and Don’ts” by Sandberg and Colman based on the literature and personal clinical experiences

Footnotes: None

FIGURES

Figure 1 Legend: All participants (faculty and medical students) were invited to respond to two questions utilizing a web-based polling platform

Figure 1: Audience Response Polls



TABLES

Table 1 Legend: “Dos and Don’ts” by Sandberg and Colman based on the literature and personal clinical experiences

Table 1: Recommendations for clinicians: Do’s, Don’ts, and Practical Tips [a]

| Dos | Don’ts |
|---|--|
| Conduct a comprehensive psychosocial assessment [13, 14] | If problems of psychosocial adaptation are detected, do not assume that these are attributable to short stature |
| Recommend psychological strategies to directly address predictable social challenges associated with short stature [15] | Do not assume the parent or patients wants rhGH therapy |
| Discourage the expectation that taller stature is associated with changes in quality of life [16, 17, 18, 19] | Do not minimize long-term side effects while emphasizing short-term safety |
| Be aware of and address factors the parent and patient use in making their [treatment] decision[s] [20, 21] | Do not minimize potential monetary costs associated with rhGH therapy [b]; discuss these prior to initiating therapy |
| Discuss treatment efficacy in terms of the degree of certainty and magnitude of effects [22] | Do not give the parent or child unrealistic expectations about the growth-promoting benefits of rhGH will achieve Do not delay in evaluating girls with poor growth because of the belief that short stature is less a problem for girls [23] |

[a] Recommendations reflect the authors’ opinions based on the cited literature and personal clinical experiences.

[b] Of greater relevance in the USA.
