Fitting Positive Airway Pressure Adherence into Teenage Life: Don't Push It!

Ignacio E. Tapia and Carole L. Marcus[†]

Sleep Center, Children's Hospital of Philadelphia, Perelman School of Medicine at the University of Pennsylvania, Philadelphia, Pennsylvania

Positive airway pressure (PAP) is an important therapeutic tool for the treatment of the obstructive sleep apnea syndrome (OSAS). However, as with any long-term medical treatment, it requires adherence to be effective. Adolescents are a growing segment of the OSAS population, due in part to the obesity epidemic, improved diagnostics, and increased social awareness of OSAS leading to more sleep center referrals. In addition, adolescents may be less likely to respond to adenotonsillectomy (1), the preferred treatment for OSAS in pediatrics (2), and therefore are often prescribed PAP therapy. In this issue of the *AnnalsATS*, Alebraheem and colleagues (pp. 83–88) present a qualitative study that describes barriers to and facilitators of PAP use in adolescents (3). This is one of the very few studies specifically addressing PAP adherence in adolescents, and it highlights the importance of a very old clinical skill: listening to the patient (4).

Adolescence is a period of transition from childhood to adulthood that is characterized not only by somatic growth and hormonal changes but also by cerebral remodeling (5). Importantly, these changes can occur simultaneously but asynchronously (6). These factors, in addition to the social environment, can lead to dramatic changes in behavior, an important predictor of adherence regardless of the treatment (7, 8). For example, it is not unusual for parents to report that a previously docile child has now become a teenager excelling at limit testing. Therefore, this unique developmental period deserves unique interventions. One important intervention

emphasized by Alebraheem and colleagues is acquiring information directly from the patient. In pediatrics, caregivers frequently take the lead during medical visits, and it is important for providers to remember to actively engage adolescents in their own care (9). Assumptions such as “my adolescent patient can manage PAP independently” may often be misleading. In fact, Alebraheem and colleagues identified the relevance of a dynamic family support in which caregiver involvement varies according to the adolescent's wishes and skills. This requires good communication between caregivers and adolescents, and it is similar to previous findings by Prashad and colleagues that showed the importance of family support and open communication styles as positive factors for PAP adherence in this population (10). Specifically, authoritative parenting styles, which provide structure along with emotional support, were commonly seen in participants with better PAP adherence. This type of parenting, characterized by a balance between adolescents' psychosocial needs and parental monitoring (11), has also been associated with better outcomes in other domains, such as cigarette smoking, depression, and diabetes (12–14). This is possibly due to the fact that authoritative parenting fosters long-term independence and does not push decisions into teenagers' lives. In addition, listening directly to the patient helps build trust, which is particularly important when prescribing chronic medical therapies such as PAP, where the benefits may not be immediately apparent to the patient (10).

The adolescents in the study by Alebraheem and colleagues brought up another important point: device design. Nowadays, no company targeting adolescents would dare to release a product without sound market research. There are several articles in serious news media reporting how headphones, smartphones, and skateboard companies, among others, incorporate prospective users' feedback into their designs. The goal of these companies is to make a high-quality product that is safe; comfortable; and liked in real life and, possibly more importantly, in social media. Similar issues have been brought up by other adolescent patient populations using medical devices. For example, researchers in a qualitative study regarding adherence to a cystic fibrosis physiotherapy device concluded that devices inclusively designed for adolescents may promote adherence (15). Shouldn't this be the norm for all medical devices targeting this age group? After all, manufacturers and adolescent patients alike would benefit from collaboration. One of the goals of the Patient-Centered Outcomes Research Institute is to promote engagement of patient partners in research, and one of the Food and Drug Administration Center for Devices and Radiological Health strategic priorities is to promote a culture of meaningful patient engagement. It is our responsibility as healthcare providers for adolescents to push the envelope further and advocate to include our patients in these initiatives.

(Received in original form August 10, 2017; accepted in final form October 6, 2017)

[†]Deceased.

Supported by National Institutes of Health grants K01 HL130719 (I.E.T.) and U01 HL125295, R01 HL120909, and UL1TR001878 (C.L.M.).

Correspondence and requests for reprints should be addressed to Ignacio E. Tapia, M.D., M.S., Sleep Center, Children's Hospital of Philadelphia, 3400 Civic Center Boulevard, Philadelphia, PA 19104. E-mail: tapia@email.chop.edu.

Ann Am Thorac Soc Vol 15, No 1, pp 22–23, Jan 2018

Copyright © 2018 by the American Thoracic Society

DOI: 10.1513/AnnalsATS.201708-641ED

Internet address: www.atsjournals.org

Qualitative research appears to be a perfectly suited method to study adherence because it prioritizes patient needs and perspectives (16). In fact, predictors of poor adherence such as maternal education (17), as well as some barriers associated with poor PAP adherence such as parenting style and communication, cannot be easily modified by healthcare providers. However, the adolescent perception of the challenges versus benefits obtained from using PAP and the importance of a tailored adjustment period could evolve with the help of an informed healthcare team. Future qualitative and/or mixed methods studies building on current knowledge could be

instrumental to further understanding and enhancing the experience of young PAP users. Data published by Benavides-Vaello and colleagues are a good example of this (18). In their study, a population of underserved women recently diagnosed with type 2 diabetes mellitus informed the healthcare team about more realistic or contextually relevant self-management strategies. Importantly, these strategies were reframed within the women's cultural context. Similar research could be performed in adolescents with known risk factors for poor adherence.

In summary, Alebraheem and colleagues have added important knowledge

to the field and corroborated previous findings in the scarce adolescent sleep literature. It is our opinion that dedicated pediatric sleep centers would benefit from offering psychosocial evaluations to adolescents and their families at the time of PAP initiation to better tailor adherence strategies and to closely listen to the experience of adolescents using PAP at follow-up visits. Most importantly, further promotion of patient engagement in research is needed. ■

Author disclosures are available with the text of this article at www.atsjournals.org.

References

- Bhattacharjee R, Kheirandish-Gozal L, Spruyt K, Mitchell RB, Promchiarak J, Simakajornboon N, et al. Adenotonsillectomy outcomes in treatment of obstructive sleep apnea in children: a multicenter retrospective study. *Am J Respir Crit Care Med* 2010; 182:676–683.
- Marcus CL, Brooks LJ, Draper KA, Gozal D, Halbower AC, Jones J, et al.; American Academy of Pediatrics. Diagnosis and management of childhood obstructive sleep apnea syndrome. *Pediatrics* 2012; 130:e714–e755.
- Alebraheem Z, Toulany A, Baker A, Christian J, Narang I. Facilitators and barriers to positive airway pressure adherence for adolescents: a qualitative study. *Ann Am Thorac Soc* 2018;15:83–88.
- Miles SH. Hippocrates and informed consent. *Lancet* 2009;374: 1322–1323.
- Gogtay N, Giedd JN, Lusk L, Hayashi KM, Greenstein D, Vaituzis AC, et al. Dynamic mapping of human cortical development during childhood through early adulthood. *Proc Natl Acad Sci USA* 2004; 101:8174–8179.
- Blakemore SJ, Burnett S, Dahl RE. The role of puberty in the developing adolescent brain. *Hum Brain Mapp* 2010;31:926–933.
- Cohen DM, Lumley MA, Naar-King S, Partridge T, Cakan N. Child behavior problems and family functioning as predictors of adherence and glycemic control in economically disadvantaged children with type 1 diabetes: a prospective study. *J Pediatr Psychol* 2004;29:171–184.
- Bérubé S, Cloutier-Bergeron A, Amesse C, Sultan S. Understanding adherence to treatment and physical activity in children with hemophilia: the role of psychosocial factors. *Pediatr Hematol Oncol* 2017;34:1–9.
- Cooley WC, Sagerman PJ; American Academy of Pediatrics; American Academy of Family Physicians; American College of Physicians; Transitions Clinical Report Authoring Group. Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics* 2011;128:182–200.
- Prashad PS, Marcus CL, Maggs J, Stettler N, Cornaglia MA, Costa P, et al. Investigating reasons for CPAP adherence in adolescents: a qualitative approach. *J Clin Sleep Med* 2013;9:1303–1313.
- Pettit GS, Laird RD, Dodge KA, Bates JE, Criss MM. Antecedents and behavior-problem outcomes of parental monitoring and psychological control in early adolescence. *Child Dev* 2001;72:583–598.
- Stanton CA, Highland KB, Tercyak KP, Luta G, Niaura RS. Authoritative parenting and cigarette smoking among multiethnic preadolescents: the mediating role of anti-tobacco parenting strategies. *J Pediatr Psychol* 2014;39:109–119.
- Monaghan M, Horn IB, Alvarez V, Cogen FR, Streisand R. Authoritative parenting, parenting stress, and self-care in pre-adolescents with type 1 diabetes. *J Clin Psychol Med Settings* 2012;19:255–261.
- Piko BF, Balázs MA. Control or involvement? Relationship between authoritative parenting style and adolescent depressive symptomatology. *Eur Child Adolesc Psychiatry* 2012;21:149–155.
- Lang AR, Martin JL, Sharples S, Crowe JA. Medical device design for adolescent adherence and developmental goals: a case study of a cystic fibrosis physiotherapy device. *Patient Prefer Adherence* 2014; 8:301–309.
- Vandermause R, Barg FK, Esmail L, Edmundson L, Girard S, Perfetti AR. Qualitative methods in patient-centered outcomes research. *Qual Health Res* 2017;27:434–442.
- DiFeo N, Meltzer LJ, Beck SE, Karamessinis LR, Cornaglia MA, Traylor J, et al. Predictors of positive airway pressure therapy adherence in children: a prospective study. *J Clin Sleep Med* 2012;8:279–286.
- Benavides-Vaello S, Brown SA, Vandermause R. “Can you keep it real?": Practical, and culturally tailored lifestyle recommendations by Mexican American women diagnosed with type 2 diabetes: a qualitative study. *BMC Nurs* 2017;16:36.