### CHALLENGING CASE: ADOLESCENCE

# An Adolescent Who Abruptly Stops His Medication for Attention-Deficit Hyperactivity Disorder\*

#### **CASE**

Robbie was one of those kids pediatricians look forward to seeing in the office. At 11 years old, he was evaluated by his pediatrician for academic underachievement, inattentiveness in the classroom, hyperactivity, and disruptive behavior limited to the classroom. A comprehensive assessment demonstrated a moderate, language-dependent learning disability and attention-deficit hyperactivity disorder (ADHD) without evidence for significant anxiety, depression, or family disharmony. After the initiation of methylphenidate, a tutoring program, and close interactions between his parents and teachers, Robbie's academic performance and interpersonal skills improved dramatically. He tolerated a moderate dose of methylphenidate over the next 5 years.

At 15 years of age, he announced to his parents and his pediatrician that he would no longer take the medication. He said, "I don't need it . . . I'm fine . . . I don't see why I should take it." Robbie denied any medication side effects, other drugs, or alcohol use. His A/B grades were stable. He purposefully did not take the medication for a few weeks and said he could not tell the difference. However, his parents observed that his test results, when off the medication, were below his standard scores. They also noted that he was more distractible and less attentive when doing his homework during that time.

Robbie's pediatrician tried to engage him in a dialogue about the decision to stop medication. His response was limited: "I'm fine . . . I don't need it."

Index terms: Attention-deficit hyperactivity disorder, methylphenidate, adolescence

#### Dr. Martin T. Stein

Compliance with recommended treatments has always been a challenge in pediatric practice. When prescribing a medication for a young child, the parents' investment in the therapy is critical. Factors that impact compliance include their belief that the treatment will be effective, the parents' understanding of the disease and how treatment will alter or ameliorate symptoms, and the quality of the therapeutic alliance between the clinician, child, and parent. For the most part, young children and school-aged children have less effect on compliance compared with their parents. The story begins to change in adoles-

cence. With the quest for greater autonomy and control, the healthy adolescent will reach out for greater participation in medical decision-making. It is both a signal of independence from his parents and a reflection of increasing attention to all body functions and an intense desire to gain control over both the physical self and external influences.

A recent Challenging Case in this journal reviewed a case of a teenager with leukemia that was unresponsive to chemotherapy. When faced with a recommendation for a bone marrow transplant, the youth refused the treatment against the advice of his doctors and family. Medical and ethical implications were reviewed. The present case is of an adolescent who also refused a medical treatment but under different circumstances. He has a condition, attention-deficit hyperactivity disorder, that is common and a treatment that has worked effectively for several years before an abrupt discontinuation of the medication. The case provides an opportunity to discuss compliance issues during mid-adolescence in a patient with a high-prevalence neurobehavioral condition that may have significant effects on developmental tasks.2

The commentaries have been written by a pediatrician and a child-adolescent psychiatrist. **Dr. Mary-Ann Shafer** is Professor of Pediatrics and Associate Director of Adolescent Medicine at the University of California, San Francisco, where she has taught and cared for adolescents for more than two decades. She has directed research projects that have led to a greater understanding of infectious, epidemiological, and behavioral aspects of sexually transmitted diseases among adolescent patients. Dr. Shafer consulted with **Dr. Glen Elliott**, Associate Professor of Psychiatry at her institution, while she developed her response to the case.

**Dr. Saul Levine** is Professor and Director of the Division of Child and Adolescent Psychiatry at the University of California, San Diego, and the Director of the Institute of Behavioral Health at the Children's Hospital and Health Center in San Diego. He has published extensively on aspects of contemporary culture that influence adolescent development.

MARTIN T. STEIN, MD Professor of Pediatrics University of California, San Diego School of Medicine San Diego, California

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# Dr. Mary-Ann Shafer (in consultation with Dr. Glen R. Elliott)

Review of the facts: Robbie was diagnosed at 11 years of age with ADHD and a moderate languagedependent learning disability. He did not have any comorbid psychiatric problems commonly associated with ADHD, his family function seemed intact, and he did not complain of side effects of the medication. What we do not know is whether there was any change in Robbie's affect and behavior before stopping his medication. For example, has his demeanor changed, or has he had any changes in his social life before discontinuance such as new friends, problems with limit-setting, onset of sexual activity, or drug use such as smoking cigarettes or marijuana or other substances? Was Robbie's psychosocial development consistent with a normal middle adolescence up to this point in time? Finally, has he been complaining about having to take the medication at school?

Assumptions: From the case discussion, I will assume that ADHD was the correct diagnosis at age 11 years because he had not been identified with any comorbid conditions such as anxiety or conduct disorder, among others. I will also assume that his dose was titrated to the appropriate dose of methylphenidate and was appropriately monitored by his parents, teachers, and physician. He apparently has had an appropriate diagnosis of a learning disability which has responded to parent and school interventions. Let us discuss this case as a clinician would in the office—addressing some of Robbie's probable concerns.

"I don't need it ... I'm fine." Robbie may have heard something from a teacher or other professional that most kids "outgrow" ADHD by adolescence. However, ADHD is not only a disease of childhood and early adolescence. One third of children with the syndrome continue with obvious symptoms through adolescence and into adulthood; another one third

experience less severe but still significant problems as adults, which can affect their ability to lead happy and productive lives.<sup>1</sup> Although teens may be less "active" and more able to check their self-control than children, the important focus for teens should be on control of impulsivity, inattention, and distractibility.<sup>2</sup> Robbie needs to hear the message that in most cases, ADHD is a life-long challenge that needs attention.

"I don't want to take drugs." This might be one of the motivations why Robbie discontinued his medication. With the emphasis on "zero tolerance" for drug use at school and the numerous messages that drugs are wrong, Robbie, who has a learning disability and is a middle adolescent, might take the messages literally and be quite uncomfortable having to take a multidose drug like methylphenidate during the day at school.

"I don't want to be dependent on a drug—I want to be in control of myself." Robbie has already given you an obvious "hint" that he wants to be in control by doing a self-evaluation and stopping the drug on his own. Robbie is not unlike any middle adolescent with a chronic disease like diabetes mellitus who has been wonderfully compliant under parental supervision until he hits middle adolescence, in which "invulnerability" and need for control of one's life peaks. He has enough knowledge to feel he can safely stop but not enough maturity to understand that his actions may impact his school and social performance and that he needs to discuss his decision with his parents, teachers, and physician. This is normal adolescent development at its finest moment! A useful tool included as a part of counseling parents was developed by Schubiner and Robin<sup>3</sup> and can be duplicated for use in office practice, "Principles for Parenting Adolescents with ADHD" (see Table 1).

The Intervention: Most likely, Robbie's behavior represents normal adolescent development in an adolescent with ADHD. Longitudinal studies of adolescents with ADHD have shown that it hinders school performance, limits participation in extracur-

#### **TABLE 1.** Principles for Parenting Adolescents with ADHD

- Gradually shape appropriate independence-seeking behavior. For example, give the adolescent a half-hour extension on curfew. If the adolescent comes home on time for a month, then extend the curfew another half-hour. Eventually, over several years, the curfew might gradually become several hours later, based on responsible behavior.
- Maintain adequate structure and supervision longer than you think you should. For example, continue to monitor homework through all of high school, even though this may not be necessary for adolescents without ADHD.
- Establish "bottom line" rules for living in your home and enforce them consistently (e.g., no drugs, alcohol, violence, treat people with respect).
- Involve adolescents in decision-making regarding all other issues which are not "bottom lines" through mutual problem-solving and negotiation.
- Use consequences wisely . . . Use incentives before punishments. For example, many parents issue "grounding for life." Not only is this excessive, it is impossible to enforce. Grounding the adolescent for several nights is equally effective. It is important to build in the opportunity to earn positive privileges for appropriate behavior.
- Maintain good communication. Listen to your teenager when her or she wants to talk and guard against bad habits of your own (put-downs, lectures, etc.). Try to practice positive alternative communication behaviors.
- · Focus on the positive by being your adolescent's cheerleading squad and helping your adolescent build on his/her strengths.
- Keep a disability perspective, practice forgiveness, and don't personalize your adolescent's problems.
- Develop reasonable expectations. Don't expect perfection in chores and homework, but do expect responsible behavior and genuine
  effort. Don't predict disaster when you give more freedom, but do expect poor judgment at times.

ADHD, attention-deficit hyperactivity disorder. Adapted from Schubiner HH et al.<sup>3</sup>

ricular activities, increases the delinquency risk, and places at risk social interactions with peers and family; affected adults suffer more psychiatric problems, trouble with the law, including incarceration, and job and marital failures.4 Adolescents seem to be best served by a multimodal approach, including medication, school evaluation and individual planning, and counseling that emphasizes cognitive therapy with life and social skill building techniques.<sup>4</sup> They must be included in the management planning and gradually be given more responsibility over decisions throughout adolescence. It is possible that Robbie was given little say in the development of a management plan. It is important to include Robbie in the anticipatory guidance process from early to late adolescence regarding the need to periodically monitor progress and success and to illustrate to him the fact that this is a lifelong disease.

It is critical for the parents and physician to be cognizant of the concerns that Robbie has about the medication and his problem. Has he had any ongoing counseling as he grows into adulthood and is desperate to be normal? Has anyone talked to him about the possibility of changing drugs so that he could take a one-dose regimen at home using a different medication? Has anyone brought up the possibility that he may be being pressured by some peers to share his drugs? Has anyone over the past few years talked to him as a normal adolescent about sexual activity, substance use (some drugs can potentiate the impact of stimulants, for example), and other risk-taking behaviors? This is important information as one decides about the need versus the risk of stimulant medications. It may be possible to consider the use of an antidepressant to treat his ADHD if an underlying depression is discovered. Ongoing dialogue and anticipatory guidance about his concerns, his adolescence, and possible changes as he becomes older may have avoided the problem that Robbie, his parents, and physician now must face—an adolescent who refuses medication.

At this point, I think it may be necessary to negotiate a contract with Robbie and acknowledge his need to be in control. I would include the following elements in any negotiation:

- Agree to a trial off medication for a specific period of time.
- Develop a written contract with a reassessment date with parents, teacher, and physician with Robbie. Make the endpoints of success or failure of the trial concrete and measurable.
- Include formal checklists to assess ongoing performance at home and at school by parents, teachers, and Robbie,<sup>5</sup> and possibly perform a reassessment of his learning disability.
- Include the need to have ongoing counseling about his concerns and need for taking appropriate control as an adult during this trial period.
- Consider tying the ability to obtain a driver's license with his ability to continue to perform acceptably at home, at school, and socially while off or, if the need is shown by this trial, on appropriate medication since there is increased risk for

- problems with motor vehicle accidents when ADHD is not under control.
- Finally, include Robbie in all phases of planning, assessment, and treatment because it is likely that he will require reinstitution of some medication regime from his history.

The bottom line is that Robbie is an emerging adult who is trying desperately to assert his independence. He needs assistance and guidance to become a healthy, happy, and productive adult. This situation may have been avoided if appropriate anticipatory guidance had been done before the problem arose. However, it is critical now to include Robbie in the information sharing, planning, and management of his ADHD.

> MARY-ANN SHAFER, MD Professor of Pediatrics Associate Director, Adolescent Medicine GLEN R. ELLIOTT, MD Associate Professor of Psychiatry Director, Child Psychiatry University of California, San Francisco San Francisco, California

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#### Dr. Saul Levine

The first thing to recognize is that Robbie is acting in an entirely age-appropriate manner. At the age of 15, feeling and acting well, he is beginning to ask himself the usual existential, identity-related questions of that age. In addition to "Who am I?" and "Where am I going?" and "How do I fit in?" he surely is wondering, "Why do I still have to take this stuff?" and "Am I different?"

He is wrestling with the palpable changes in his soma and psyche, and like many adolescents, "daring" himself to confront his dybbuks and demons. This is a minor variant of risk-taking behavior, but it also entails "testing" to see how far he can push the boundaries of his health and strength, and to what extent he can act autonomously, vis-à-vis his parents. He is also comparing himself to his peers, as all teenagers are wont to do, in the hope that he is at least as good (strong, attractive, desirable, worthy, etc.) as his classmates and friends. He has doubts about himself, but he certainly won't admit that. No wonder then, that he tells his parents and his physician, "No problem," as in, "Get off my back, will ya?"

Merely to push him hard to take the medications at this point will be futile, precipitating a painful conflict over compliance with medication, when that is decidedly *not* the critical issue. And parental "hovering" over an adolescent who in fact has been doing very well—psychologically, socially, physically, and academically—and who is on the threshold of adulthood, is perceived by him as infantilizing, disrespectful, and demeaning. It is also very threatening because, being a bright lad, he knows at some level that his parents *may be right!* 

It may well be that what Robbie's parents are noticing in the areas of attention and concentration are valid, but I would not jump to that conclusion. At times, looking too hard for subtle signs of problems makes the zealous "sleuth" find difficulties that are transient, ephemeral, and even nonexistent. Sometimes abrupt discontinuation of medication results in a brief "rebound" of symptomatology before the body's compensatory mechanisms come into operation. Nor would I base the symptoms entirely on the discontinuation of his medication. After 5 years on methylphenidate, a drug "holiday" and empirical observation and monitoring for a period of time sound like good medical care. Perhaps the discontinuation of the medication could have been done gradually (weaning) and with supervision, but it sounds to me like Robbie made an "informed," albeit impulsive, decision. If Robbie is to be off the methylphenidate for at least a few months, he should be seen by his pediatrician every few weeks for a physical examination and discussion of his mood, relationships, school performance, appetite, sleep, interests—i.e., the "Gestalt" of his being.

If the lack of concentration, inattentiveness, irritability, and decreased school performance are indeed present and of recent vintage, they may be a result of the medication discontinuation, or, as likely, they may be related to preoccupations of Robbie, such as depressive feelings, anxiety, lack of interest in school, work, nascent romance, worries about his attractiveness ("zits," etc.), problems with his parents or friends, or dozens of other variegated sources.

The major point of this is to give Robbie some "space" to make decisions, learn about himself, and even make some mistakes (as we all do). The situation will be clarified within a few months. If all is well, then there is little or nothing to worry about. And, if the inattentiveness persists or gets worse, or if Robbie's grades begin to slide, etc., then that is when a meeting with a professional who is knowledgeable about, sensitive to, experienced with, and interested in adolescents would be in order. He would then be reassessed for his learning problems and medication history, to be sure, but as or more important, he would be generically evaluated for issues related to mood, preoccupations, relationships, self-esteem, etc. If medication is deemed necessary, or if counseling or psychotherapy is indicated, then this can be instituted at that time. The important issue is that Robbie will have had an opportunity to be part of the process of discovery and decision-making, as any young adult should.

All in all, however, and with the caveat that the history presented was very brief, I think that we have cause to be optimistic about Robbie.

SAUL LEVINE, MD
Professor and Director, Child and Adolescent
Psychiatry
University of California, San Diego School of

Medicine

Director, Institute of Behavioral Health Children's Hospital and Health Center, San Diego San Diego, California

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#### Dr. Martin T. Stein

Adolescence is an amazing stage of life for parents, clinicians, and youth. Although change in physical characteristics is predictable from a knowledge of Tanner staging for secondary sexual characteristic, height spurt, and menarche, behavior change may be rapid, insidious, and unpredictable. Several years ago, the child psychologists Eric Erikson and Peter Blos delineated the salient developmental tasks during adolescents.<sup>2,3</sup> Since then, many observers have expanded on their work to include cognitive and moral characteristics of this age. Pediatricians have found that a distillation of theories and empirical observations yield practical recommendations for clinical work with youth. Table 2 illustrates various changes in growth and development that are separated into three chronological groups. Although the early, middle, and late stages overlap in several dimensions, this particular scheme has significant clinical use.

Robbie's journey from an 11-year-old diagnosed with ADHD and a learning disability who was subsequently prescribed methylphenidate to a 15-yearold who made a decision to stop the medication traverses many developmental changes. The predictable move toward independence brings with it a sense of ambivalence about separation from parents and other close family members. A greater capacity in cognitive potential means that at mid-adolescence, many youth have the capability to think in abstract terms. Robbie can now hypothesize "What if I don't take the medicine?" Compared with an earlier phase of development in which control of behavior was mediated by a conscience imbedded in his family values, he no longer has the same restraint on his actions. At mid-adolescence, Robbie is now motivated to try on different ways of responding to authority as he discovers his own sense of self.

Drs. Shafer and Levine responded to Robbie's case history with insights from a developmentally based perspective. That Robbie is "... 'daring' himself to confront his dybbuks and demons and 'testing' to see how far he can push the boundaries of his health ... and to what extent he can act autonomously ..." is

TABLE 2. Growth Tasks in Adolescents by Developmental Phase<sup>a</sup>

| Task              | Early: 10–13 Yr   | Mid: 14–16 Yr   | Late: 17 Yr+   |
|-------------------|---|---|--|
| Independence      | Emotional break from parents; prefers friends to family | Ambivalence about separation                                    | Integration of independence issues                                     |
| Body image        | Adjustment to pubescent changes                         | "Trying on" different images to find real self                  | Integration of a satisfying body image with personality                |
| Sexual drives     | Sexual curiosity; occasional masturbation               | Sexual experimentation;<br>opposite sex viewed as sex<br>object | Beginning of intimacy/caring   |
| Relationships     | Unisex peer group; adult crushes                        | Begin heterosexual peer group;<br>multiple adult role models    | Individual relationships more important than peer group                |
| Career plans      | Vague and unrealistic plan                              | •   | Specific goals/specific steps to implement them                        |
| Conceptualization | Concrete thinking                                       | Fascinated by new capacity for thinking                         | Ability to abstract  |
| Value system      | Drop in superego; testing of moral system of parents    | Self-centered   | Idealism; rigid concepts of right and wrong; other-oriented asceticism |

<sup>&</sup>lt;sup>a</sup> Adapted from Felice ME: Adolescence, in Levine MD, Carey WB, Crocker AC (eds): Developmental-Behavioral Pediatrics, 2nd ed. Philadelphia, PA, W.B. Saunders, 1992, pp 65-73.

Dr. Levine's reminder of the inner conflicts that all adolescents experience. What makes Robbie different from at least 80% of teenagers is that his experience is coupled with a chronic disorder. Dr. Shafer emphasized that approximately 60% of school-age children with ADHD continue to have the core sympof inattentiveness, hyperactivity, impulsivity into adolescence.4 Although the manifest overactivity may no longer persist to the same degree, other ADHD-related symptoms may continue to affect learning, social skills and self-esteem.<sup>5</sup> The use of psychostimulants in adolescents with ADHD is effective in improving core symptoms.<sup>6,7</sup>

As a general rule, it is good medical practice to reevaluate all children and adolescents with ADHD periodically. The need for medication may increase, diminish, or abate. Coexisting conditions such as anxiety, depression, oppositional behaviors, and family discord may evolve and impact the original diagnosis.8 A learning disability that was either not evaluated sufficiently at an earlier stage or has a recent onset associated with higher learning expectations may become apparent.4,9

Many clinicians reassess the need for medication in children and youth with ADHD at least once each year with a trial off of medication for a few weeks. Assessment may include reports from teachers who are blinded to the temporary change in therapy as well as assessing change from the patient's perspec-

Robbie might have been asked at regular follow-up visits, "How do you feel when you take the medicine? In what ways does it help you (with your school work or when you are with friends)? Does it interfere with these activities in any way? Do you think that you should continue the medicine?" This direction of exploration may not only yield useful information to make clinical decisions, but it also provides an opportunity to strengthen and expand the therapeutic alliance. Dr. Shafer emphasized this strategy as a way to include the adolescent in management planning and to go a step further by negotiating a "contract" with specific expectations and consequences. By providing the patient with more sophisticated information about ADHD that is consistent with his expanded cognitive abilities, the clinician will recognize the therapeutic value of joint decision-making and partnering to discover mutual solutions to a challenging clinical problem. At its best, this form of medical practice makes use of the clinical encounter as an opportunity to enhance personal competence and facilitate independence.

> MARTIN T. STEIN, MD Professor of Pediatrics University of California, San Diego School of Medicine San Diego, California

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