CASE

Mr and Mrs Floyd, the parents of Leroy, an 8-year-old child with Asperger syndrome, recently moved from out of state and contacted Dr Stonehill, a primary care pediatrician with experience in developmental-behavioral problems. Dr Stonehill planned for an extended initial office visit. Leroy demonstrated many of the behaviors characteristic of children with Asperger syndrome. He avoided eye contact and was preoccupied with his Yu-Gi-Oh cards. He startled easily and was impulsive and oppositional, particularly during his physical examination. Mrs Floyd informed Dr Stonehill that Leroy had been prescribed a “ton of meds, and none had worked well.” She also brought a long list of specialists whom she had consulted and informed Dr Stonehill that each one had failed to be of any help. She seemed very needy, and initially she responded well to Dr Stonehill’s patient and supportive manner. At the end of the visit, she expressed extreme gratitude for his time and agreed to follow his advice regarding behavioral management.

During the next several months, Mrs Floyd made weekly acute visit appointments with Dr Stonehill to address the cascade of behavioral problems that Leroy demonstrated at home and school. She seemed desperate, and Dr Stonehill reluctantly prescribed a series of psychopharmacologic agents to reduce Leroy’s extreme impulsivity, temper outbursts, and obsessive rigidity. Although Mrs Floyd was initially grateful and deferential to Dr Stonehill, over time, her attitude changed, and she became demanding of Dr Stonehill and his staff. She became enraged when prescriptions were not ready on time or when she had to wait to get an appointment. She frequently called his exchange during off hours and insisted that he do something to help her control Leroy’s complicated behavioral problems. On a few occasions, she yelled at Dr Stonehill’s office staff, who now tried to avoid interacting with her during frequent clinic visits. Dr Stonehill believed that, no matter how hard he tried, he could not please her and that her demands on his time and patience were excessive. He considered telling her that he would no longer serve as her pediatrician, but he worried that there were no other good alternatives in town and that Leroy indeed needed help.

INDEX TERMS: the difficult patient, doctor-patient communication, Asperger syndrome.

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On the best of days, pediatric practice is an extraordinarily fulfilling and enjoyable experience. Our knowledge of medical science is coupled with the skills to apply the most effective diagnostic measures and therapeutic applications to each child. We leave the office, clinic, or hospital with the satisfying feeling that we have contributed to the health and well-being of many children. It is a gift of our profession that we cherish.

On other days, there are numerous events that challenge this feeling of competence and accomplishment. Pressure to see too many patients, scheduling errors when 2 new patients are scheduled at the same time, and endless forms to review and sign are among many examples. Perhaps the most challenging situation occurs with a parent who is demanding of our time, never satisfied with their child’s care, and often angry with us and our staff, which affects our interactions with other patients and staff members. These difficult parent-clinician interactions are not limited to the specialist who sees children with chronic illnesses with no available cures. Primary care pediatricians also must respond to the occasional “difficult parent.”

This case history illustrates many of the challenging moments (and opportunities) that these parents bring to a pediatrician. Dr Leon Eisenberg observed that “time with the patient…[is] the currency of medical care” (personal communication, 2003). But what happens when we are uncertain about how to use the time effectively?

The first commentary is by Dr Michael Jellinek, Professor of Psychiatry and of Pediatrics at Harvard Medical School and Chief of the Child Psychiatry Service at Massachusetts General Hospital. Dr Jellinek is trained in both pediatrics and child psychiatry. His commentary translates many principles of psychiatry and the clinician-parent relationship into the clinical experience of pediatricians. Dr Robert D. Wells is a child and adolescent psychologist who works with both general pediatricians and developmental-behavioral pediatricians. He is Associate Clinical Professor of Pediatrics and Psychiatry at the University of California, San Francisco, and Director of Research and Ethics at the Children’s Hospital Central California in Fresno. Dr Wells also has an active clinical practice.

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Most physicians, especially those with subspecialty interests and skills, probably have uneasy personal experiences similar to the situation described by Dr Stonehill. Pediatricians may be at special risk because of the complexity of dealing with both a desperate, dedicated parent and a child with major needs. Let us look at each of the factors in this story and then discuss early recognition and management.

The pediatrician would like to provide optimal care for every child and especially one with a serious, chronic illness. Most pediatricians are largely successful when dealing with families seeking expert opinions. The specialist will review the situation, spend extra time, modify the treatment plan, and fulfill the reasonable expectations of parents. Pediatricians feel appropriately gratified by being identified as having special skills, making a sacrifice to spend extra time with their patients, and being acknowledged by the patients’ families. The pediatrician’s pride in his or her work and the gratitude of a stressed family are appropriate and deserved rewards. These positive feelings remind us of the special, meaningful, and powerful role pediatricians play in the lives of families and children with chronic illness. Being so valued feels quite good to a busy, harried pediatrician, and thus being overvalued may slip early detection.

The parents are in a vulnerable state, because they are coping day after day with a chronically ill child. Despite recent clinical advances, many chronic diseases cause great suffering and uncertainty. Mental disorders also bring the added stress of stigma, an extra measure of parental guilt, and quite constrained resources for treatment or respite. Parents in their whole-hearted effort to do the best for their child continue to search for new leads and hopes. An appointment with a pediatric subspecialist raises those hopes and expectations. Maybe if the parents or patient are special, then the doctor will use all the resources available (time, expertise, and advocacy) for the child. And if the parents can get that special level of treatment, then and only then have they been good parents or the best parents.

Although not as relevant to circumstances in this vignette because of the child’s difficulty in relating, we should remember the child’s perspective of the physician. The child often sees the physician as critically powerful. And as children get older, they have to face the realities of dependency on the pediatrician while trying to establish autonomy and independence along their developmental trajectory. Gratitude, resentment, frustration, fear, and hope are all features of a long-term relationship between a chronically ill patient and pediatric subspecialist.

Mrs Floyd enters Dr Stonehill’s practice in a typical manner, is seen frequently, elicits his best efforts, and yet is increasingly dissatisfied. There is no cure or profoundly effective mitigation of Asperger syndrome. She becomes angry, demanding, aggressive, and, over time, less trusting rather than grateful and more trusting. From my experience, this behavior indicates several dynamics. Mrs Floyd has not fully grieved the loss of her son’s potential. She has not reevaluated her hopes and expectations. She has not accepted the sad realities of an Asperger diagnosis at this level of severity. Quite possibly there have been other losses in her life, most likely in her childhood, that she could not accept. Was there a severe, chronic circumstance—a discordant divorce, mental illness, abuse, or alcoholism—that was overwhelming and that she could not face? Did she feel as a child that she should have solved her family’s problems and as a result feels guilt and a sense of failure? Does she feel guilty now given her son’s illness? Can she bear this level of sadness and guilt? Can she bear being as “bad” a parent as her parents possibly were? Is her demanding nature and anger the only path available to her in that it relieves the guilt, avoids the sadness, and confirms she is doing the best she can? Will any pediatrician do the best for her child on the basis of professionalism and caring rather than intimidation?

Pediatricians can be slow to recognize the pattern of Mrs Floyd’s behavior. The pattern of behavior builds gradually; pediatricians assume it is temporary parental stress and tend to minimize or feel guilt about any anger they feel toward a demanding parent. The pediatrician expects that by working even harder, trust and gratitude will satisfy the parental demands. But for some parents like Mrs Floyd, this approach hits a personality made rigid by previous, overwhelming losses. However, there are several steps to recognize and possibly predict Mrs Floyd’s behavior:

1. Ask parents (preferably both if at all possible) about how the illness has impacted the family. What were their hopes before the diagnosis, and how have those hopes and expectations changed? How much of a loss did they experience when it became clear that the illness would have a major impact on the child’s or family’s future?

2. Have there been other recent or past losses in the family or in their childhood that were similar or as momentous as what they are facing now with their child’s chronic illness?

3. What in their past relationships with the health care system did they find helpful and not helpful? With physicians, nurses, house staff, and others?

4. At some point early in the process, get the past medical records and talk to the previous pediatrician or subspecialist. If parents want you to be “unbiased” initially, fine. However, at some point after the diagnosis is made and the plan is outlined, insist on contact with previous caretakers and get records.

5. Be aware of changes in your pattern of treating a family, such as special calls or extended appointments beyond the ordinary. Listen to internal feelings of frustration, anger, resentment, or wishes to avoid the family. Your feelings should not be ignored or arouse guilt. These feelings are your personal radar or early warning system for impending difficulties. Feeling inadequate or anger at a parent’s demands or expectations is to be treasured. The feeling should initiate a differential diagnosis—why do I feel this way? Of course the
cause could be in the physician (eg, overwork and personal worries) or be elicited by a parent’s or family’s profound needs.

Once recognized, usually additional consultation is required. The pediatrician will do a great service by defining the parent’s unresolved issues that are interfering with his or her child’s care. Some parents will be able to face their losses through a referral to appropriate mental health services. Others will not; they become agitated and begin another round of “doctor-shopping.” For this latter group, sound documentation is critical both for legal protection and to help the next pediatrician.

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Dr Stonehill is facing a myriad of problems that arise from his attempts to deal with this “difficult parent.” Difficult parents are noted to be intense, demanding, dependent, irritable, and unpredictable. These are temperamental characteristics that have been described extensively in the literature on children. Unfortunately, not much is written or taught about working with difficult parents, although most pediatric health care providers encounter such individuals all too frequently. ¹ You will know that you have met such a parent when you feel frustrated, underappreciated, confused, and helpless. As soon as you hear the parent’s name, a sense of dread appears and you want to hide. None of your colleagues want to see the difficult parent either, but as with Dr Stonehill, you have no place to run or hide.

Studies on difficult adult patients describe them as having a higher incidence of mental disorders, a greater number of somatic complaints, more severe symptoms, poor functional status, more unmet expectations, less satisfaction with care, and a higher use of medical services than patients not meeting the “difficult patient” criteria. ² In pediatrics, it is not uncommon to meet parents who are initially cooperative and excessively complimentary but who later become negative, mistrusting, and chronically dissatisfied.

Dr Stonehill, while working to maintain his therapeutic alliance with Mrs Floyd, must now take steps to diminish her disruptive behaviors. He should consider the many factors that contribute to her sense of frustration. Certainly, taking care of a behaviorally challenged child with serious developmental limitations places her at high risk for depression. The literature on difficult adult patients clearly indicates that depression and other mental disorders are highly prevalent among patients who have difficulty adhering to medical regimens and who are described by their medical providers as difficult. ², ³ It is also likely that Mrs Floyd may have unreasonable expectations about the treatment or function of her son that have not been directly addressed.

Dr Stonehill may be wise to directly discuss these issues with Mrs Floyd. This should not be done while Leroy is in the room. In a firm and caring voice, Dr Stonehill might begin by acknowledging her growing sense of frustration and his concern that he might not be able to meet all her expectations. After listening to her complaints and worries, Dr Stonehill should negotiate some actions that might lead to improved satisfaction and communication. If this is accomplished, Dr Stonehill should then discuss his expectations regarding how he and his staff should be treated by patients and families, and he should describe any method he uses for dealing with grievances in his office. By using empathy, problem-solving, negotiating, and clear limit-setting, Dr Stonehill is likely to mitigate the impact of this difficult parent on his desire to provide effective care for her child.

In some instances, it will be apparent that the difficult parent’s behavior cannot be contained through such direct communication. Mrs Floyd may have an underlying character disorder that may make it difficult for her to maintain reasonably harmonious relationships. The fact that she disliked her previous set of doctors and has already started a pattern of overly valuing and then devaluing others indicates that she may have symptoms found among individuals with borderline personality disorder. ⁴ Such individuals are often angry and enraged. They have a history of very unstable interpersonal relationships and tend to love you one minute and hate you the next. They can be very fearful of abandonment and engage in a lot of push-and-pull behavior, insisting on help solving the problem but rejecting all advice. Such patients tend to have very unstable identities. They display their emotions in a very dramatic fashion, have poor boundaries, and sometimes have poor reality testing.

When dealing with such parents, there are specific attitudes and skills that may help clinicians manage these challenging visits. It is helpful to keep your personal expectations low and to pay attention to the process of the visit rather than the desired outcome. Do not try to control them, but instead work diligently to control your own irritation, maintain a professional manner, and empathize with their concerns and worries. It can help to view the difficult encounter as a worthy challenge, one you have trained many years for, rather than seeing it as something you want to avoid. Try to avoid or minimize helpless-hopless thinking. At times it can be helpful to promise yourself a reward for getting through the encounter without losing your cool.

It is critical that the provider maintain control over the visit. Breathe slowly and deeply, and use a firm but caring voice. Asking questions can help keep you to stay in control of the visit. Make simple requests of the parents and reinforce their compliance. You may also start and stop the encounter as you see fit, controlling who is present to maximize a cooperative alliance. Dr Stonehill may be wise to advise Leroy at times that Mr Floyd can be present as well. Given the challenges posed by Mrs Floyd, Dr Stonehill should maintain appropriate boundaries and try to provide pediatric services that are within his scope of practice. ⁵, ⁶
Dr Stonehill should be encouraged to speak with his colleagues and staff members to help deal with the feelings these encounters often generate. In most instances, an effective therapeutic relationship can be reestablished. If this cannot be accomplished and the relationship continues to be characterized by mistrust and miscommunication, Dr Stonehill may need to excuse Mrs Floyd and her son from his practice and refer them elsewhere. In this case, this would be an unfortunate outcome, because clearly Mrs Floyd needs a knowledgeable pediatrician who is kind, patient, and caring.

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REFERENCES

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Every pediatrician should experience a parent like Mrs Floyd during the formative stage of pediatric training. A healer’s anxiety, potential anger, and loss of confidence are not uncommon responses to the frustration and recognition of one’s therapeutic limitations. These experiences should lead to consultation with a clinician who has the wisdom, understanding, and practical suggestions found in the commentaries by Drs Jellinek and Wells.

Pediatric resident training, however, is not organized in a manner that encourages these learning experiences. Most clinical encounters are fleeting—caring for a patient in the emergency room or during a block inpatient rotation. Therapeutic relationships with patients and parents are not long-term. Although the requirement for continuity clinics has improved this situation modestly, few residents learn to respond effectively to a parent like Mrs Floyd. Often, the parent is shunted to a social worker who may have the knowledge and skills to approach the parent’s anger therapeutically. How many pediatric residents have observed the dialogue between a social worker and parent during this type of intervention?

As educators, we can begin to improve the situation by recognizing the “difficult parent” as an opportunity for learning. Many primary care pediatricians, both in academic centers and in the community, can mentor a resident through the experience. When the situation is more severe, as Dr Stonehill found with Mrs Floyd, further consultation should be encouraged. We do not hesitate to ask an allergist to assist in the care of a child with severe, persistent asthma. We should seize the same opportunity to consult with another developmental-behavioral pediatrician or mental health professional.

This Challenging Case is a reminder of the importance of practicing as a reflective clinician. Informative and intelligent thinking is not limited to a differential diagnosis or treatment plan. Both commentators emphasized the importance of insight into psychodynamic processes that may be critical to an understanding of Mrs Floyd and provide clues to a therapeutic strategy. Pediatricians (myself included) too often pass over the opportunity to become informed about a parent’s childhood. Dr Jellinek emphasized the importance of a parental childhood history in this case because “Quite possibly there have been other losses in her life, most likely in her childhood, that she could not accept. Was there a severe, chronic circumstance—a discordant divorce, mental illness, abuse, or alcoholism—that was overwhelming and that she could not face?” Significant childhood losses are usually followed by a grief period. Without experiencing grief, unresolved feelings about oneself and others persists and may adversely affect subsequent adult relationships, including those with physicians and other clinicians.

Dr Jellinek observed that “Mrs Floyd has not fully grieved the loss of her son’s potential. She has not reevaluated her hopes and expectations. She has not accepted the sad realities of an Asperger diagnosis at this level of severity.” This indicates a good starting point for a dialogue between Dr Stonehill and Mrs Floyd.

My experience has taught me to recognize the significance of trust as a critical element in any therapeutic relationship. It is something we assume to be present in pediatric practice in which most parents respect our knowledge and recognize our concern for their children. It seems that with many “difficult parents” there is mistrust, not only in the doctor-patient relationship but also as a pervasive part of their lives. Whether generated by childhood experience or conflictual adult relationships, it affects the way these parents relate to health professionals and staff. I do not imagine that I possess the power to change a core personality. However, knowledge that the negative feelings generated by a demanding, unappreciative parent often have their source in a pervasive and chronic mistrust of others helps me to understand the behavior. With understanding (most of the time) comes more patience and the strength to pursue the suggestions offered by Drs Jellinek and Wells.

SUGGESTED READING

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### The Difficult Parent: A Reflective Pediatrician's Response

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