Virtual Mentor

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Clinical Case Controlling Diabetes Commentary by Robert P. Hoffman, MD

Sharon Smith was diagnosed with type 1 diabetes at age 11. Under the watchful eye of her parents, Sharon was an active teenager, participating in high school sports and extracurricular activities. In college, she continued with soccer and diligently controlled her blood sugar, following the same insulin regimen she had begun in her mid-teens. After college, Sharon moved across the country to pursue graduate studies. To help pay her living expenses, she began working 4 days a week as a waitress. One night as her shift was ending she noticed that her hands were shaking as she was replacing glassware, and she later passed out. The restaurant staff, unaware that she was diabetic, called 911 for assistance.

Sharon was admitted to the hospital, and Dr Stone—an endocrinologist—was called. Dr Stone had seen Sharon quite a few times since her move to the city about 6 years earlier, usually after emergency episodes. When he first met Sharon, she was moderately overweight and had elevated cholesterol levels. Examining Sharon's medical records at that time, Dr Stone noted that these developments were recent. Since their initial clinical encounter, Dr Stone had encouraged Sharon to lose weight and had explained the possible complications for someone who had had type 1 diabetes for more than 5 years. Sharon claimed that she had tried to lose weight, but found it impossible to balance glycemic control with weight loss. Adding to her frustration were a bum ankle, intense graduate coursework, and her waitressing job, all of which prevented her from exercising as regularly as she had in college.

Dr Stone has attempted—numerous times—to modify Sharon's insulin regimen and provide her with a clearly laid-out dietary plan to help her lose weight and control her blood sugar. He believes some of Sharon's noncompliance might be due to depression or other psychological factors and referred her to a counselor who had worked successfully with many of his patients with diabetes. Sharon saw the counselor once but refused to continue, stating that she had neither the time nor the money to attend regular sessions. Despite Dr Stone's continued efforts, Sharon has been admitted to the hospital a number of times with recurrent diabetic ketoacidosis.

Sharon repeatedly tells Dr Stone that she understands the consequences of ignoring his advice, and she constantly expresses her annoyance with this disease, especially in relation to her living situation. Dr Stone is sympathetic to Sharon's plight—she is young, busy, and burdened with a disease that will be with her for the rest of her life. But he is frustrated by her lack of responsibility; she doesn't adhere to the diet, she sometimes cancels appointments at the last minute, and, he suspects, she has begun drinking alcohol. When he confronted Sharon about her behavior during her latest

hospital stay, she shrugged and responded, "C'mon, Dr Stone. It's not that bad. You always pull me through."

Commentary

Study after study has demonstrated that many patients—adults and adolescents, alike—with type 1 diabetes do not follow through with the numerous aspects of their diabetes care [1]. Sharon's failure to appropriately follow diabetes management recommendations may be due to a variety of problems including subclinical eating disorders, depression, fear of hypoglycemia, feelings of failure due to recurrent hospitalization, or dislike of injections and glucose monitoring. How Dr Stone reacts to Sharon's situation will be reflected by the terminology he uses when discussing his concerns and by who he thinks is in charge of managing Sharon's diabetes. According to the American Heritage Dictionary, to adhere means to "to carry out a plan, scheme, or operation without deviation" and to comply means "to act in accordance with another's command, request, rule, or wish." Thus, if Dr Stone believes the patient should follow his rules, and she does not, he will consider her to be noncompliant; if he believes she must help develop her own treatment plan, and she is unsuccessful, he will then view her as being nonadherent. This difference between compliance and adherence plays a critical role in answering several questions regarding Sharon's care.

Is Dr Stone obligated to continue to serve as Sharon's endocrinologist?

If Dr Stone uses the language of compliance to describe Sharon's actions, then he is not obligated to continue to care for her. Simply stated, she has not followed his prescribed medical plan and recommendations, and thus he is wasting his time caring for a patient who doesn't follow through. In this situation he is only obligated to take care of her in an emergency if he is the best available physician to do so. Once the crisis is over he can give her names of other health care professionals in the area who can care for her diabetes, as her health care coverage allows.

This course of action puts Dr Stone in a position of power over Sharon, and its ultimate purpose may be to feed Dr Stone's ego. He would do well to consider that he is most likely noncompliant in some area or areas of his own health care $[\underline{2}]$ and to remember the Golden Rule: "Do to others what you would have them do to you."

If, instead, Dr Stone uses the language of adherence, his obligation to Sharon is different. He will have to help her develop a treatment plan for controlling her diabetes that is compatible with her lifestyle. The goal of diabetes management should always be to train and encourage the person who has the condition to assume control and responsibility for his or her treatment [3]. In this situation Dr Stone must provide Sharon with the best possible evidence-based medical advice and the basis for this advice. This approach reduces his paternalism while allowing Sharon to make choices based on his recommendations.

In this scenario Dr Stone's decision to continue or discontinue his care of Sharon is based on whether he believes he is the best person available to help her manage her

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diabetes. If he feels that his frustrations with Sharon or her emotional dependence on him interferes with helping her to develop and follow an effective diabetes treatment plan, then he must tell her why this is the case and offer to assist her in finding a professional who will help her. This future care may or may not be under Dr Stone's supervision, depending on the availability of allied health care professionals such as diabetes nurse educators, dietitians, and psychologists.

What responsibilities does Sharon have to manage her diabetes?

Ultimate responsibility for Sharon's diabetes care clearly falls on her. She appears to be mentally competent; she is attending graduate school and holding a job. This is not a situation in which Dr Stone has the right, responsibility, or ability to carry out medical care independent of Sharon's wishes [4].

Sharon's obligations when she was under the pediatric care team would have been much different. The responsibility for managing her diabetes would legally have fallen to her parents until Sharon reached her eighteenth birthday. Prior to her turning 18 the physician would have been required by the state to report Sharon's parents' failure to assure that she got proper diabetes care. In part due to Sharon's minor status, the patient-physician relationship would have been much more paternalistic when Sharon was first diagnosed with diabetes, although one hopes that, even at age 11, there was an attempt to involve her in some of the decisions regarding her treatment plan. If this did not happen, particularly as Sharon became an older adolescent, her current nonadherence may be traced back to her overdependence on others to keep her safe. At the other end of the spectrum, adolescents given *excessive* autonomy by their parents also have poor metabolic control [5].

Unfortunately, patient transition from the more paternalistic pediatric care model to the more autonomous adult model is not always well handled, due to factors both within and beyond the control of the physician or patient. These include insurance company and hospital regulations that govern the age of patients allowed to be seen by pediatric and internal medicine subspecialists, decisions regarding employment, advanced education, and changes in location. Because of these factors many young adult patients with diabetes are in a medical "limbo" when it comes to getting their diabetes care. It was thus critical for those managing Sharon's diabetes during her adolescence to ensure that she had the skills to take over that responsibility independently by the time she left pediatric care and to assure that she was aware of the importance of regular close followup and where this could be obtained.

References

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