**Case Study: Whose Diabetes Is It Anyway? Diabetes Self-Management After a Stroke**

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**Presentation**

H.S. is a 55-year-old woman who has had type 1 diabetes since age 36 years. Except for retinal microaneurysms, she has no microvascular diabetes complications. She has statin-treated hyperlipidemia, mild peripheral vascular disease, and mild carotid artery stenosis. She has no history of hypertension. Her family history is positive for cardiovascular disease, including a father, uncle, and brother who died of myocardial infarctions in their 50s. She is a former smoker, having quit about 5 years ago. Her husband smokes two packs per day.

H.S. had a syncopal episode, fell, and lost consciousness in autumn 2003. She was found by her husband, who contacted paramedics. Blood glucose measured by the paramedics was 42 mg/dl. She was given glucose tablets. She complained of neck pain and so was transported to a hospital, where X-rays and a computed tomography scan of the neck revealed multiple cervical spine fractures that required surgical intervention. During surgery, she suffered a large, right-sided stroke.

After nearly 4 months of hospitalization and inpatient rehabilitation, she was able to return home. She has persistent motor deficits on her left side. She is able to walk with a cane but has no useful motor function in the left hand or arm. Her speech is accurate but slow, and her affect is somewhat flat. She reports that she sometimes forgets recent events and occasionally has difficulty with sequencing tasks. As a result of the stroke and her persistent deficits, she elected to retire from her job as a records department manager in a local government office. Her husband also left his job in order to provide full-time assistance to her.

H.S.’s diabetes management routine before her stroke consisted of two shots daily of mixed NPH and rapid-acting insulin. She checked her blood glucose levels twice daily and more often if her schedule was unusual or if she was going to be more active. Her dietary intake was very consistent from day to day, so she rarely adjusted her rapid-acting insulin dose and only occasionally took an extra dose of rapid-acting insulin for larger-than-usual lunches or for extra snacks. She had no history of severe hypoglycemia or of hypoglycemia unawareness.

While the benefits and risks of more intensive treatment to lower her glucose levels had been discussed on several occasions, she was satisfied with her self-management plan and did not wish to adopt a more aggressive one. Her hemoglobin A1C (A1C) at her routine diabetes health-care visit preceding her stroke was 7.5%, her blood pressure was 124/84 mmHg, and her weight was 147 lb. She is 5 feet, 5 inches tall.

An intensive insulin regimen of once-daily glargine insulin with lispro given before meals was implemented and refined over the course of H.S.’s hospitalization and inpatient rehabilitation. During that time, her husband gradually assumed responsibility for her daily diabetes care and become adept at implementing the intensive therapy regimen. After she returned home, her husband continued to perform H.S.’s daily diabetes care activities and continued the intensive insulin regimen. He monitored her blood glucose at least six times daily (including checking every night at about 3:00 a.m.) and diligently recorded the results. He prepared all meals and snacks and calculated pre-meal bolus insulin according to the carbohydrate content of the meal and her blood glucose level. He was in regular contact with the diabetes treatment team for advice regarding insulin dose adjustments.

H.S. was seen for an outpatient diabetes care visit ~ 6 months after the stroke. Her husband was present throughout this visit. H.S. expressed a preference to resume her prestroke diabetes treatment regimen of two injections per day with less frequent monitoring, citing the frequency of monitoring (and routine monitoring in the middle of the night) as being especially bothersome. Her husband, who continued to be responsible for preparing all meals, administering insulin doses, and monitoring and recording her blood glucose levels, stated that he preferred to continue the intensive insulin regimen.

On further discussion, the husband revealed that he was fearful of hypoglycemia, especially at night, and was thus reluctant to discontinue the overnight blood glucose checks. He also reported giving H.S. juice to drink whenever her blood glucose was < 80 mg/dl. Her A1C was 7.3%, blood pressure was 109/59 mmHg, and LDL cholesterol was 113 mg/dl.

**Questions**

1. Given H.S.’s preference to return to a simpler treatment regimen and the minimal improvement in her A1C thus far, is continuing the intensive insulin therapy warranted?
2. How can the treatment team address the disparities between the patient’s desire for a simpler regimen and her husband’s desire to continue intensive therapy?
3. What psychosocial support is needed for H.S. and for her husband to facilitate increasing H.S.’s independence related to her diabetes self-care?
Discussion
The benefits and risks of improving blood glucose levels have been demonstrated in both the Diabetes Control and Complications Trial (DCCT; type 1 diabetes) and the U.K. Prospective Diabetes Study (type 2 diabetes).1–5 Although these studies demonstrated the beneficial effects of glucose lowering on the appearance and progression of microvascular complications of diabetes, the impact of intensive insulin treatment on the appearance and progression of macrovascular disease is less clear. Similarly, whereas evidence of reduced morbidity and mortality with aggressive glucose control during acute illness (stroke or myocardial infarction for example) is growing,6–12 less is known about the effects of continued aggressive glucose control on long-term recovery and outcomes.

Any potential short- or long-term benefit from intensive therapy has to be weighed against the known risks of intensive therapy, the costs and burden to the patient and family (for example, might a return to a simpler regimen allow the husband to return to work?), and, most importantly, respect for the patient’s right to make an informed, reasoned choice regarding care.

The potential of intensive insulin therapy to slow progression of H.S.’s retinopathy, as well as to reduce her risks for neuropathy and renal disease, which would markedly increase her risk for cardiovascular disease, supports the argument to continue intensive treatment as a means to minimize future additional disability. While the current A1C (7.3%) is similar to the mean level attained by subjects in the intensive treatment arm of the DCCT11 (and therefore would be expected to result in clinical benefits similar to those achieved by the DCCT intensive treatment group), it represents only minimal improvement from the A1C achieved using H.S.’s prior regimen. Continuing intensive therapy would seem reasonable then only if further lowering of A1C could be safely achieved and, most importantly, if H.S. agreed to continue this course of treatment.

The current regimen was started at a time when H.S. was unable to actively participate in decisions regarding her care. She is now recovered to a point where her daily routine, at least in terms of meal schedule and caloric intake, physical activity (owing largely to ongoing physical therapy), and hours of waking and sleeping, are not very different from her routine prior to the stroke. She has expressed a desire to return to the prior diabetes care regimen. Her husband wants to continue the current regimen of frequent monitoring and a basal/bolus insulin regimen. When addressing these disparate treatment preferences, the treatment team has to consider whether H.S. is capable of making an informed decision regarding her treatment, the reasons both H.S. and her husband have for choosing a specific treatment approach, their understanding of the risks and benefits of the treatment plan, and whether their different preferences are adversely affecting their relationship.

Despite her impairments, there is no doubt that H.S. has the capacity for informed decision making,14 and her preference for a two-shot regimen is perfectly consistent with her prior decisions regarding her diabetes care. Prior to the stroke, her husband was wholly uninvolved with H.S.’s diabetes care and admittedly knew little about diabetes or about his wife’s diabetes treatment. In the few months after the stroke, he quickly developed an understanding of diabetes and its treatment and the skills needed for diabetes care. He believes that the intensive therapy regimen is in his wife’s best interest. He believes that the frequent blood glucose monitoring and delivery of insulin in a basal/bolus regimen decreases the likelihood for hypoglycemia. He does not know whether H.S.’s motor and cognitive deficits will affect her ability to recognize and appropriately respond to hypoglycemia.

H.S.’s flattened affect needs to be considered when assessing levels of distress, so attention needs to be paid to verbal as well as nonverbal cues, both in the presence and absence of her husband. When asked, H.S. did not report any significant personal or intramarital distress related to the intensive treatment regimen. But she did say that her husband’s persistence in checking nightly 3:00 a.m. blood glucose levels was disrupting her sleep.

H.S. and her husband have had sudden, unexpected, major changes in their lives. Beyond the obvious impairment in physical abilities and independence, there are also changes in the availability of financial and other health care resources now that both have stopped working. Furthermore, there are changes both for H.S. and her husband related to their social activities and relationships outside of the marriage. H.S. has expressed a desire to re-engage in her former social activities and would like to go out of the house more with friends and family. But her husband is concerned that others won’t know how to check her blood glucose or give insulin if she is out over a meal time. He is reluctant to leave her alone or to trust others with her diabetes and other care needs, even though both H.S. and her husband have family and friends who have expressed a willingness to provide help. Issues related to control and independence will likely increase as H.S.’s recovery continues.

The diabetes treatment team needs to regularly assess the physical and emotional impacts that these various psychosocial changes have on the patient, the caregiver, and their marital and social relationships. A more concrete recommendation is to help H.S. clearly define short- and long-term goals (for example, meeting friends for lunch every Wednesday), to work with H.S. and her husband to identify the resources needed and the physical and emotional barriers to attaining these goals, and to develop a plan to reach them. These are complex, yet important, issues that are easily overlooked in a diabetes care environment that is often “glucose centric.” They speak to the important role of mental and behavioral health care specialists in comprehensive diabetes care.

At the conclusion of the visit, H.S. agreed to continue the intensive therapy regimen for the time being and agreed to a slight increase in the pre-meal bolus doses to improve glucose control during the daytime. The treatment team used the record book to emphasize to her husband that there had been no episodes of low blood glucose occurring in the overnight hours, so it was reasonable to stop...
checking blood glucose every night at 3:00 a.m. unless the blood glucose at bedtime was low. He agreed to try.

The signs, symptoms, and treatment of low blood glucose were reviewed. H.S. was able to state what actions she would take in case of low blood glucose, and suggestions were made to place quick-acting carbohydrates within easy reach throughout the home. A prescription for glucagon was provided. The treatment team also discussed possible strategies for allowing H.S. greater flexibility in meal and insulin dosing to make it easier for her to go out socially.

H.S.’s atorvastatin dose was increased to 40 mg daily, and her husband was encouraged to stop smoking, with further information provided on how to get assistance in quitting. A follow-up visit was scheduled for 4 months, and both H.S. and her husband were encouraged to contact the treatment team in the interim if needed.

Follow-up
H.S. appeared to be doing well at the 4-month follow-up visit. She was accompanied by her husband and her sister-in-law. She asked that they both remain in the waiting room during her visit.

She demonstrated improvement and increased confidence with ambulating. She remained unable to use her left hand and arm. Her A1C was decreased to 6.5%, and she was pleased by this. She had not had any hypoglycemia requiring assistance. Her blood pressure was 110/60 mmHg, and her LDL cholesterol was 80 mg/dl. Her weight was stable. Her blood glucose monitoring records showed testing being done, on average, still six times per day with continued regular testing at about 3:00 a.m. She reported that her husband had not smoked cigarettes for the past month. She reported that she had gone out with friends more frequently in the interim and that they had helped check her blood glucose and given her shots. She expressed interest in returning to work in some capacity and getting out more but said her husband didn’t think she would be able to do that.

When asked if she would like the treatment team to help her discuss these issues with her husband, she declined and said she wanted a chance to discuss them directly with him first, but she would contact the treatment team if needed. A referral to social work to explore available resources was offered and declined.

At the conclusion of the visit, H.S. asked her husband and sister-in-law to join the discussion. He was congratulated on stopping smoking. No changes were made to the insulin regimen, but the treatment team restated that regular 3:00 a.m. monitoring could be discontinued, and steps for increasing flexibility in the treatment plan (to allow for greater independence by H.S.) were reviewed. A recommendation to increase the atorvastatin to 80 mg was made, but H.S. stated she did not want to take more medications. Instead, she spent time discussing dietary options with the nutrition specialist.

Clinical Pearls
- Diabetes treatment recommendations should represent a balance between known and potential benefits and risks and must also respect the wishes of the patient.
- Diabetes treatment goals should be regularly reevaluated and modified to best meet the patient’s physical and psychosocial needs.
- Patients’ and caregivers’ ability to recognize and treat hypoglycemia needs to be regularly reassessed.
- In cases such as this, ongoing psychosocial support and diabetes education is needed and should include the patient, caregiver, and others as designated by the patient.

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References

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