What's So Tough About Taking Insulin? Addressing the Problem of Psychological Insulin Resistance in Type 2 Diabetes

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Patients with type 2 diabetes are often reluctant to begin insulin and, in many cases, delay the start of insulin therapy for quite lengthy periods of time. Patients may refuse insulin outright ("Look, doc, there is just no way I could take the needle."), bargain with their health care providers for more time ("Please, I just need a few more months to see if I can drop this weight."), or even drop out of treatment altogether. Sadly, actions such as these can lead to chronically elevated blood glucose levels, possibly for considerable periods of time, raising the risk for long-term complications.

But what do we really know about such cases of "psychological insulin resistance" (PIR)? How often do they occur, why do patients harbor such powerful misgivings, and how can busy clinicians respond most effectively?

While clinical lore suggests that PIR is quite common, there has been little formal study in this area. In the United Kingdom Prospective Diabetes Study (UKPDS),[1] of those type 2 patients randomized to insulin therapy, 27% initially refused. Early reports from the international Diabetes Attitudes, Wishes, and Needs (DAWN) study[2] indicate that the majority (54.9%) of insulin-naive patients worry about the possibility of insulin therapy. Okazaki et al.[3] reported that 73% of type 2 patients beginning a diabetes education program where insulin was to be started were reluctant to do so at first. Finally, in a recent survey of insulin-naive type 2 patients,[4] 24.7% of respondents reported being not willing to take insulin if it was prescribed. Furthermore, the survey showed that Hispanic patients were much more frequently unwilling than non-Hispanic whites (55.6 vs. 21.5%). Qualitative data from Hunt et al.[5] also suggest that PIR may be common in the Hispanic population.

Overall, these data suggest that PIR may be relatively common across multiple ethnic groups and across nations. However, although patients may express significant reluctance in the abstract, it is not yet known how often this leads to outright refusal or bargaining when the patient is alone with his or her provider and an actual recommendation to begin insulin is made.

Why are so many insulin-naive patients averse to the possibility of insulin therapy? Six major factors are apparent.

First, insulin is often associated with *a perceived loss of control over one's life.* When asked to identify their reasons for insulin therapy reluctance, 61.4% of patients agreed that, "Once I start insulin, I can never stop," and 50.6% believed that insulin therapy would restrict their lives.[4] Recent data from the DAWN study point to similar concerns.[6] As one patient explained, "Taking insulin would mean no more spontaneous adventures for me. It would make it too hard to travel, or eat out, or even have a life!" In the days before glargine, lispro, and aspart insulins became available, it was certainly true that insulin therapy often required significant vigilance and changes to one's lifestyle, but in the vast majority of cases, this no longer needs to occur.

The second factor is *poor self-efficacy* about insulin therapy. Approximately 40–50% of patients do not feel confident that they could handle the demands of insulin therapy, such as determining the proper timing and dosages.[4,6] Without proper care and explanation, insulin therapy can at first seem much too complicated and overwhelming. And when patient do not have confidence in their ability to perform a particular self-care behavior, it is unlikely that they will follow recommendations to do so.[7]

A third factor is that as many as 50% of patients associate insulin therapy with *personal failure*.[4,6] In other words, insulin is viewed as a well-deserved punishment for one's own gluttony, sloth, or negligence in some other area of diabete self-care. As one patient described it, "If I have to take insulin, it means that I hav messed up, that I haven't done a good enough job taking care of my diabetes."

The fourth factor concerns *perceived disease severity.* For many patients, insulin therapy signifies that their diabetes is now suddenly more serious and more dangerous.[4,6] As first reported by Hunt et al.,[5] many patients are concerne that insulin therapy may cause further health problems. In some cases, such beliefs may be at least partially correct (e.g., a slightly increased hypoglycemia risk), while in other cases (e.g., "Insulin will cause me to go blind."), they may be quite wrong. Not surprisingly, if people are convinced that insulin will worsen their health, they may be very resistant to begin insulin therapy.

Of interest, Polonsky et al.[4] noted a sizeable ethnic split on this latter issue. While the majority of Hispanics (72.2%) felt that insulin therapy could cause further health problems, very few non-His-

panic whites (8.1%) believed this to be so.

A fifth factor concerns *injection-related anxiety*. Approximately 50% of patients report being fearful of injections.[6] Although this is often presumed to be the single, or single largest, contributor to PIR, we suspect that this may be overstated. True injection phobia is rare, even among insulin-using patients with diabetes.[8] Certainly, few people look forward to injections. But when patients report that they "could never take the needle," this may often represent a broader reluctance to consider insulin therapy, reflecting their many negative beliefs about insulin or lack of knowledge about its use (e.g., the relative painlessness of insulin injections) rather than simply a fear of needles per se.

A final factor contributing to PIR is the *perceived lack of positive gain*. Skovlund et al.[6] found that few insulin-naive patients anticipated positive benefits from insulin therapy. Less than 10% believed that insulin might help them achieve good glycemic control, improve their energy level, or improve their health. In total, given the widespread appraisal of insulin therapy as a negative and perhaps harmful intervention and the lack of recognition that it might have positive benefits, it is no wonder that PIR appears to be so commonplace.

What causes patients to develop such negative beliefs toward insulin? One contributor is likely to be patients' personal experiences. Consider the following story:

"My mother had diabetes, and it was no big deal to her for over 20 years. She rarely saw a doctor and never paid much attention to it, and it never really bothered her. But then her doctor finally convinced her to start insulin and—bam! Over the next year, she started having serious problems with her eyes, and then there were terrible pains in her legs. In fact, she eventually lost most of her left leg. No doubt about it, insulin was the culprit. And now you want me to start insulin? No way!"

In cases like these, it is likely to be the many years of self-care neglect that is the major source of harm, not insulin. Still, such stories are not uncommon, and it is understandable—given the chronology—that patients may come to confuse cause and effect.

Another contributor, and perhaps the major one, is the subtle and not-so-subtle messages that patients receive from their providers.[9] For example, it is common for insulin-naive patients to be threatened with insulin, to be told that if they don't work harder to manage diabetes, then there will be no choice but to start insulin, to "get the needle." Clinicians may inadvertently influence patients' beliefs about insulin through the use of such unfortunate terms as "oral agent failure."

And clinicians' own negative feelings about insulin therapy may also play a role. Many clinicians are, understandably, fearful of the extra time needed to start and manage insulin therapy, they may be loathe to handle the potentially unpleasant confrontations with patients who do not want to take insulin, and they may be concerned about the potential for severe hypoglycemia, excessive weight gain, or other adverse effects. Therefore, they may collude with their patients to delay the initiation of insulin (e.g., "Why don't you take a few more months and try to get more serious about exercise and weight loss. Maybe you can get those numbers down by the time we meet again."). As patients witness such actions and hear such messages repeatedly over the years, the lessons absorbed are *1*) insulin is a bad thing and should be avoided at all costs; *2*) if insulin therapy is necessary, it is because you have failed to take adequate care of yourself; and *3*) insulin therapy is how you will be punished for your lack of personal success.

Patients, therefore, should not be blamed for harboring such inaccurate views of insulin. In many cases, they may be merely drawing the best conclusions possible from what they have learned from their providers.

How should PIR be addressed? To date, there are no published intervention studies, but it seems evident that the most powerful solution is, of course, prevention. Type 2 diabetes is a progressive disease, and it is recognized that as many as one-third of type 2 patients are likely to require insulin at some point. Therefore, rather than threatening patients with insulin, patients should be forewarned early in treatment that the need for insulin is quite likely to arise at some point in the future—not because of anything they have done wrong, but because of the nature of the disease.

Long before insulin is actually prescribed, explain to patients that the eventual need for insulin is linked to the fact that they are currently healthy, not because they are sick. For example, "Diabetes gets tougher to handle as the years go by. The longer you live with it, the more likely it is that you will need powerful medications like insulin to control it. And because you are relatively young and healthy, you're probably going to live a long time. So it is fairly likely that you'll need insulin at some point, just because you're so darned healthy."

When clinicians are faced with PIR, there are eight possible intervention strategies to consider:

1. **Identify the patient's personal obstacles.** When patients profess an unwillingness to start insulin therapy there is a natural tendency to immediately respond with helpful comments (e.g., "Injections aren't so bad," "Taking insulin doesn't mean your diabetes is getting worse," or "Trust me, you're going to have so much more energy.") or, perhaps, to jump to one of the strategies described below. But few of these are likely to be beneficial unless the intervention matches the patient's perceived reasons for resisting insulin.

   Indeed, patients may be unable to appreciate any reassurances or additional information until their personal beliefs about insulin are recog-

nized and discussed. Consider a simple, respectful, open-ended question such as, "Could you tell some of the reasons why you feel so strongly about not taking insulin?" Alternatively, to prompt patients' thinking and to engender a more detailed conversation, administering a brief, self-report PIR questionnaire might be advantageous.[4,6]

2. **Restore the patient's sense of personal control.** When necessary, introduce insulin as a brief, temporary experiment only (e.g., "I'd like you to try insulin for just a month. At the end of the month, if you don't think it has been worthwhile, or if it still seems as awful as you're imagining it might be, I promise to help you stop."). Of course, patients always retain this choice whether it is offered or not, but by putting this forward as a viable alternative that is supported by their clinician, it serves as an important reminder that insulin does not mean they will lose control of their lives.
3. **Enhance self-efficacy as quickly as possible.** When insulin is first introduced, the process of insulin use should be demonstrated for patients while they are in the clinician's office, and they should be encouraged to practice before returning home. With the support and encouragement of a caring clinician, the hands-on discovery that injections are easily accomplished and that insulin therapy is not difficult to master can be an enormous boost to confidence. This is enhanced even further as patients first observe the surprisingly small size of insulin needles and realize firsthand that injections are all but painless.

   The number of recommended behavioral changes also should be minimized, at least at first. If reluctant patients are introduced to insulin with a dizzying array of additional self-care procedures (e.g., much more frequent self-monitoring of blood glucose and recommendations to make major changes in the timing and composition of meals), it should not be surprising if they become even more concerned that they will not be capable of managing the demands of insulin therapy successfully (and, thus, even more resistant to insulin therapy).

   Luckily, it is increasingly common for type 2 patients to be first introduced to insulin as combination therapy. In this manner, when a single shot of insulin (often nighttime glargine or NPH insulin) is typically added to the existing or somewhat modified regimen of oral agents, few additional self-care steps are needed, and there is little further disruption to the person's lifestyle.

   Clinicians need to follow-up quickly with initial insulin dose adjustments to ensure that patients will quickly see improvements in their glucose numbers following this new treatment. If a suboptimal dose is started and no changes are made in this dose until the next visit, the perceived efficacy of insulin may be undermined.
4. **Consider insulin pens.** Because pens are easier to operate and appear less forbidding than the traditional bottle and syringe, they may be more acceptable to insulin-naive patients struggling with PIR. To date, there is only anecdotal evidence to support this observation. Many providers have commented that PIR in their practices has dramatically lessened since they begin initiating insulin therapy with pens. Not uncommonly, the response from patients has been, "You mean that's all there is to it?!"
5. **Frame the insulin message properly.** When talking about the need for insulin, stay focused on glycemic outcomes, sharing hemoglobin A_{1c} (A1C) results with patients and explaining that the critical goal is to protect their health through the achievement of glycemic targets. Ideally, clinicians and patients should come to an agreement on specific A1C targets. When those targets are then not being met by a regimen of oral agents and lifestyle changes, insulin becomes a natural choice, providing patients with the additional tool they need to meet their goals.

   It should be stressed to patients that they have not "failed" with their diabetes, that they have done nothing wrong, and that insulin therapy does not indicate that their diabetes is getting worse. As mentioned earlier, it should be explained that diabetes is now understood to be a progressive disease—not that the disease is getting worse, but that more or stronger medications may be needed over time to achieve glycemic targets. And when such medications, including insulin, are needed, this is a function of the underlying disease, not the person's failure at proper diabete self-care. Removing patients' sense of personal guilt is critical.

   Finally, when patients worry abou untoward side effects, it may be useful to remind them that insulin is on of our most "natural" drugs; indeed, it is far more natural than any of the oral agents with which they may be familiar.
6. **Discuss the real risks of hypoglycemia.** Type 2 patients' worries about hypoglycemia can often be traced to the dramatic tales told by type 1 patients or to hypoglycemic episodes as portrayed in films. Patients should be told that while severe hypoglycemia (an episode where help from another is required) may occur frequently in type 1 diabetes, it is quite rare in type 2, even among patients on insulin. In the UKPDS, for example, the annual incidence of severe hypoglycemia in insulin-treated patients was < 3.0%.[10]

   Still, events do occur. Patients should be reassured that a modicum of vigilance on their part and on the part of their provider (e.g., through more frequent blood glucose monitoring and a careful review of results), as well as further diabetes

education (so that patients become more skilled regarding recognition and treatment of hypoglycemia), can reduce the risk of any potential problems even further.

7. **Tackle injection phobias.** In cases where patients are truly too fearful of needles to begin insulin therapy, clinicians may want to consider referral to a mental health provider familiar with cognitive behavioral therapy, especially the well-documented approach to phobias known as "systematic desensitization." Needle phobias can usually be resolved quite rapidly.[11]
8. **Pass along the good news.** Once patients' personal obstacles have been addressed, it may be worthwhile to review the positive benefits associated with insulin (to be more precise, with better glycemic control). Patients need to know that they may soon notice improvements in their mood, sleep, and energy level and that better glycemic control means that they are making a sizeable investment in the protection of their long-term health.

Summary

In insulin-nai ve patients with type 2 diabetes, PIR is not uncommon. It is likely that PIR contributes to unnecessarily long delays for initiating insulin and, consequently, to extended periods of hyperglycemia.

Patients' reasons for avoiding insulin extend far beyond a simple fear of needles and often involve deeply held beliefs about insulin and the nature of diabetes. It appears that clinicians' standard method for talking about insulin, in which insulin therapy is used to frighten patients toward taking better care, may be a major contributor to PIR.

The good news is that PIR can be overcome when patients' personal obstacles to insulin therapy are recognized and addressed. Most importantly, it seems likely that the majority of PIR cases could be prevented if clinicians began to introduce the possible need for insulin early in treatment, refrained from using insulin as a means for threatening or blaming patients, and helped patients see insulin as a possible friend rather than a foe.

REFERENCES

[1]United Kingdom Prospective Diabetes Study Group: Relative efficacy of randomly allocated diet, sulphonylurea, insulin, or metformin in patients with newly diagnosed non-insulin dependent diabetes followed for three years. *BMJ* 14:83–88, 1995

[2]Korytkowski M: When oral agents fail: practical barriers to starting insulin. *Int J Obes Relat Metab Disord* 26:S18–S24, 2002

[3]Okazaki K, Goto M, Yamamoto T, Tsujii S, Ishii H: Barriers and facilitators in relation to starting insulin therapy in type 2 diabetes (Abstract). *Diabetes* 48:A1319, 1999

[4]Polonsky WH, Fisher L, Dowe S, Edelman S: Why do patients resist insulin therapy? (Abstract) *Diabetes* 52:A417, 2003

[5]Hunt LM, Valenzuela MA, Pugh JA: NIDDM patients' fears and hopes about insulin therapy: the basis of patient reluctance. *Diabetes Care* 20:292–298, 1997

[6]Skovlund SE, van der Ven N, Pouwer F, Snoek F: Appraisal of insulin treatment in type 2 diabetes patients with and without previous experience of insulin therapy (Abstract). *Diabetes* 52: A419, 2003

[7]Bandura A: Self-efficacy: toward a unifying theory of behavioral change. *Psychol Rev* 84:191–215, 1977

[8]Zambanini A, Newson RB, Malsey M, Fehe MD: Injection related anxiety in insulin-treated diabetes. *Diabetes Res Clin Pract* 46:239–246, 1999

[9]Wallace TM, Matthews DR: Poor glycaemic control in type 2 diabetes: a conspiracy of disease, suboptimal therapy and attitude. *QJM* 93:369–374, 2000

[10]United Kingdom Prospective Diabetes Study Group: Intensive blood glucose control with sulphonylureas or insulin compared with conventional treatment and risk of complications in patients with type 2 diabetes. *Lancet* 352:837–854, 1998

[11]Zarate R, Agras WS: Psychosocial treatmer of phobia and panic disorders. *Psychiatry* 57:133–141, 1994

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