

# Barriers to Insulin Initiation

## The Translating Research Into Action for Diabetes Insulin Starts Project

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**OBJECTIVE**— Reasons for failing to initiate prescribed insulin (primary nonadherence) are poorly understood. We investigated barriers to insulin initiation following a new prescription.

**RESEARCH DESIGN AND METHODS**— We surveyed insulin-naïve patients with poorly controlled type 2 diabetes, already treated with two or more oral agents who were recently prescribed insulin. We compared responses for respondents prescribed, but never initiating, insulin ( $n = 69$ ) with those dispensed insulin ( $n = 100$ ).

**RESULTS**— Subjects failing to initiate prescribed insulin commonly reported misconceptions regarding insulin risk (35% believed that insulin causes blindness, renal failure, amputations, heart attacks, strokes, or early death), plans to instead work harder on behavioral goals, sense of personal failure, low self-efficacy, injection phobia, hypoglycemia concerns, negative impact on social life and job, inadequate health literacy, health care provider inadequately explaining risks/benefits, and limited insulin self-management training.

**CONCLUSIONS**— Primary adherence for insulin may be improved through better provider communication regarding risks, shared decision making, and insulin self-management training.

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Insulin is typically recommended for patients with type 2 diabetes if they have failed to achieve adequate glycemic control despite treatment with multiple oral agents at maximal dose (1), especially when  $\beta$ -cell function declines (2,3). Despite the known benefits of insulin, many patients fail to begin insulin treatment (4). In a previous study (5), we followed a cohort of patients with diabetes who were prescribed new glucose-lowering medications. We observed that 4.5% of insulin-naïve patients who were prescribed insulin never filled that pre-

scription (were primary nonadherent) and an additional 25.5% had zero refills (early-stage nonpersistence). Thus, one in three insulin-naïve patients who were prescribed insulin never became ongoing users.

A patient's reluctance to initiate insulin has been dubbed psychological insulin resistance (PIR) (6). Current understanding of PIR is based largely on surveys of insulin-naïve patients queried about their hypothetical willingness to initiate insulin (7,8). However, the reasons why patients fail to initiate therapy after actually agree-

ing to and receiving a first prescription for insulin have not been explored. In this study, we evaluate barriers and attitudes among insulin-naïve patients who had failed to initiate newly prescribed insulin therapy (i.e., primary nonadherent) versus those who did initiate insulin therapy (i.e., primary adherent).

### RESEARCH DESIGN AND METHODS

Subjects for this study of insulin adherence came from Kaiser Permanente Northern California (Kaiser) and Horizon Blue Cross Blue Shield of New Jersey and were participants in the Translating Research Into Action for Diabetes (TRIAD) Study (7), an ongoing study of quality of care and self-care for people with diabetes in managed-care settings across the U.S.

We identified poorly controlled, insulin-naïve and insulin-eligible type 2 diabetic patients receiving a new electronic prescription for insulin. Eligibility criteria included 1) newly prescribed insulin during August 2007 to February 2008, 2) Two or more diagnoses for type 2 diabetes 18 months prior to the new insulin prescription, 3) no insulin use in prior 2 years, 4) already taking one oral agent at maximum and a second oral agent at maximal/submaximal dose, 5) two consecutive A1Cs  $\geq 8\%$  2.5–12 months apart or last A1C  $\geq 9\%$ , and 6) two or more clinic visits in the previous 12 months. Patients aged  $>85$  years, with limited English proficiency, life-limiting malignancy, hospice care enrollment, significant cognitive deficits, psychiatric illness (excluding major depression), or visual impairment limiting insulin self-administration, were excluded.

We identified a random sample of eligible subjects who were primary adherent (at least one dispensing of insulin) and primary nonadherent (not dispensed the newly prescribed insulin within 60 days of the prescribing date) from pharmacy records. Computer-assisted telephone interviews and self-administered mailed surveys were used to collect insulin treatment, provider communication, self-management training, health literacy (8), and depressive symptoms (9). We used standard American Association for Public

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Opinion Research (AAPOR) algorithms for calculating response rates (10). The human subjects review boards in the TRIAD translational research centers involved with this study (Kaiser, the University of Medicine and Dentistry of New Jersey, and Indiana University) approved this study.

**RESULTS**— We mailed an invitation letter to 195 and 186 primary nonadherent and adherent subjects, respectively, following approval of their providers. Sixty-nine nonadherent and 100 adherent patients responded to the survey and are the basis for this study. The AAPOR response rate, which assumes that those who could not be contacted for eligibility confirmation had the same proportion of eligibility as those contacted, was 60% overall (50% in the nonadherent and 68% in adherent group). The cooperation rate (percent survey completion among eligible subjects we were able to reach) was 98% (100% in the nonadherent and 92% in adherent group). None of the patient characteristics differed significantly between adherent and nonadherent subjects. Nonadherent subjects had a mean age of 61 years and 35% were women, 49% were of a minority ethnic heritage, 37% had an income <\$40,000, 33% had no college education, and 48% were retired or unemployed. Adherent subjects had a mean age of 58 years and 47% were women, 54% were of minority ethnic heritage, 22% had an income <\$40,000, 31% had no college education, and 33% were retired or unemployed.

Among nonadherent patients, the most commonly cited reasons for failing to initiate insulin included the following reasons: The patient planned to change health behaviors instead of starting insulin (25%), injection phobia (13%), negative impact on work (9%), concerns about long-term medication use (9%), inconvenience (6%), and not believing insulin was needed (6%). Nonadherent patients believed that people who require insulin “have not taken care of themselves in the past” (47%) and that “taking insulin can cause...” blindness (20%), renal failure (32%), amputations (15%), heart attacks or strokes (19%), and early death (19%). In all, 35% of the insulin-nonadherent group reported that they believed insulin causes harm (at least one of the possible complications listed above).

Compared with adherent patients, nonadherent patients expressed signifi-

**Table 1—Comparisons of survey responses for primary nonadherent and adherent patients newly prescribed insulin\***

	Nonadherent	Adherent
Stated moderate/extreme concerns (versus not at all or a little concerned) regarding:		
The cost of insulin shots	12/51 (24)	22/82 (27)
How insulin shots might restrict your activities or “hold back” your lifestyle	20/54 (37)	20/82 (24)
The additional burden associated with home monitoring of blood sugar	15/59 (25)	19/82 (23)
Difficulty giving insulin due to things like poor eyesight, shakiness, or arthritis	23/55 (42)	24/81 (30)
Your ability to make dose adjustments†	22/54 (41)	10/82 (12)
How insulin shots may negatively impact your social life†	21/56 (38)	15/82 (18)
A negative impact on your job (if you work outside the home)†	15/45 (33)	6/72 (8)
The insulin shots being painful†	17/56 (30)	12/82 (15)
Possible side effects of giving yourself shots†	24/55 (44)	10/81 (12)
Insulin shots causing you to have low blood glucose†	22/51 (43)	13/81 (16)
Patient-provider interactions and communication		
Never or only sometimes (versus usually or always) felt confidence or trust in personal physician that manages diabetes	11/68 (16)	11/97 (11)
Moderately or extremely difficult (versus not at all difficult or a little difficult) to talk with doctor about concerns about diabetes medication or insulin	9/66 (14)	10/100 (10)
Risks and benefits were not very well or not well at all (versus somewhat well or very well) explained†	37/67 (55)	37/96 (39)
Inadequate health literacy: sometimes, often, or always (versus never or rarely); have problems learning about medical condition because of difficulty understanding written information (not including problems due to poor vision)†	35/69 (51)	30/99 (30)
How was the insulin self-management training provided		
Doctor trained†	1/66 (2)	13/77 (17)
Insulin self-management class†	5/66 (8)	31/77 (40)
Nurse trained†	4/66 (6)	33/77 (43)

Data are n/N (%). \*N takes into account missing responses. †Significant contrasts ( $P < 0.05$ ).

cantly more concern about their inability to adjust insulin dosage, the impact on social life and work, injection pain, and side effects, particularly hypoglycemia (Table 1). Significantly more nonadherent patients reported problems learning about their medical condition because of difficulty understanding written information (inadequate health literacy) and claimed providers failed to adequately explain insulin’s risk and benefits. Substantially fewer nonadherent patients reported receiving insulin self-management training from their doctor, nurse, health educator, or a class.

**CONCLUSIONS**— Among poorly controlled patients with type 2 diabetes newly prescribed insulin, the major predictors of insulin nonadherence included

plans to improve health behaviors in lieu of starting insulin, negative impact on social and work life, injection phobia, and concerns about side effects or hypoglycemia. Nonadherent patients often blamed themselves, believing prior poor self-management caused the current need for insulin and erroneously conceptualized insulin as itself the cause of future complications. These patient-level findings are consistent with previous studies of attitudes about insulin (11,12).

Not previously reported is our finding that nonadherent patients frequently felt their provider had not adequately explained the risks and benefits of insulin. The importance of provider communication is underscored by the association between insulin initiation and health literacy (13). Primary nonadherence

likely also reflects inadequate shared decision making or lack of self-management training. Interventions for PIR need to address both provider- and system-level factors (14–16).

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