Background

Anecdotally, patients with diabetes commonly decline insulin therapy. However, little data exists on the epidemiology of insulin decline. Information on patients declining insulin is not easily available. Medication decline occurs before any prescription is written and is not reflected in either administrative or structured electronic clinical data, but is primarily recorded in narrative notes.

Methods

We designed a natural language processing (NLP) tool for identification of documented insulin decline by patients based on the open-source Canary NLP platform. The NLP tool was validated against 1,501 manually reviewed provider notes. We used the validated NLP tool to analyze the incidence of insulin decline among patients with diabetes with HbA1c ≥ 7.0% treated in primary care practices affiliated with an academic medical center between 2000 and 2014 who were offered insulin therapy.

Results

The NLP tool achieved sensitivity of 100% and PPV of 95%. We used the NLP tool and identified 3,295 diabetes patients who were offered insulin therapy. 984 (29.9%) declined insulin therapy. 374 (11.4%) subsequently initiated insulin therapy after a mean of 790 days. Incidence of insulin decline was highest (34.2%) among patients with HbA1c ≥ 9.0%.

Conclusions

Insulin decline is common among patients with severe hyperglycemia and may lead to significant delays in treatment. Natural language processing of electronic medical record data provides an unprecedented opportunity to study epidemiology, risk factors and outcomes of insulin decline by patients.