Evaluating Patient Knowledge and Understanding of

HbA$_{1c}$ and Disease Duration in Adult Diabetics

By

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Abstract

Diabetes prevalence among adult Americans continues to rise on a yearly basis. Lifestyle, personal attitudes, knowledge, and choices profoundly affect the control of diabetes in individuals. HbA$_{1c}$ values and duration (in years) of the disease are two key benchmarks used in determining overall control of diabetes. In late 2012, we surveyed a sample of 21 adult, non-pregnant, diabetic subjects. Of those subjects, 61.9% of respondents did not know their HbA$_{1c}$ value and 28.6% did not know how long they had had abnormal blood sugar (within one year of accuracy). Other larger, studies have exhibited similar trends. Widespread lack of patient knowledge and understanding about key diabetes control benchmarks leads to reduced overall control of the disease. A credit card-sized wallet card to be carried by diabetics can help improve knowledge and control of diabetes. This card will contain: date of diagnosis, medications taken with dosages, and HbA$_{1c}$ logs over time (with dates for each HbA$_{1c}$ reading). The card will be reviewed and updated by providers in the diabetic’s care system including, but not limited to: primary care physicians, nurses, nurse practitioners, eye doctors, dentists, podiatrists, pharmacists, dieticians, endocrinologists, and physician assistants. The diabetes care card would provide an inexpensive, straightforward way to monitor HbA$_{1c}$ and disease duration in diabetics, and to improve knowledge and understanding in diabetic patients, thereby increasing control of the disease.
Introduction

Diabetes prevalence continues to grow across the United States and other developed countries. Based upon prevalence data from 1980-1998, it is projected that by 2050, the number of Americans diagnosed with diabetes will increase 165%, from 11 million in 2000 to 29 million in 2050 (Boyle, 2001). If diabetes is poorly controlled, it can affect lifespan, quality of life, lives of family and friends, and healthcare costs. There are two key benchmarks in determining control in diabetes: duration of the disease (in years) and Hemoglobin A$_1c$ (HbA$_1c$).

Duration of diabetes increases the risk of congestive heart failure death independent of coexisting risk factors (Fox, 2004). Furthermore, duration of diabetes is the strongest predictor for the development and progression of diabetic retinopathy, the most frequent cause of new blindness in adults aged 20-74 years (Fong, 2004).

HbA$_1c$ is a measure of glycosylated hemoglobin, showing a person’s average blood glucose level over a period of 2-3 months (American Diabetes Association, 2013). HbA$_1c$ is widely accepted as a tool to monitor control of blood glucose in diabetics, and is typically measured every three or six months. An HbA$_1c$ value of less than 5.7% is considered normal, 5.7%-6.4% is considered pre-diabetes, and an HbA$_1c$ value of 6.5% or greater is considered to be diabetes. The current goal for HbA$_1c$ in diabetics is between 6.5% and 7.0% (Medline Plus, 2013).

Because duration of diabetes (in years) and HbA$_1c$ are such important indicators of control and risk in diabetes, it is important for diabetics to know and remember these two key numbers. Our study was designed to survey diabetics during a routine eye examination to
ascertain the proportion of diabetics that actually know the duration of their diabetes (in years) and their HbA1c.
Methods

In order to evaluate patient knowledge of diabetes key benchmarks and numbers, a study was carried out in late 2012. The study was carried out by Matthew Bittel, O.D. and consisted of a short survey verbally administered to diabetic patients during a routine diabetic eye examination. The subjects were recruited if they made an appointment for a diabetic eye examination at either of two optometry clinics located in Pittsburgh, PA and Jefferson Hills, PA. Furthermore, subjects were limited by the following criteria:

1. They must be at least 18 years of age
2. They must not be pregnant
3. The subject must be able to answer the survey questions on their own, without help

Other than the above limitations, no racial, gender, age, or demographic factors limited subjects’ participation in the study. A brief synopsis of the study was explained to the potential subjects, and if they agreed to participate, a consent form was given, reviewed, and signed. Following the consent process, an oral survey was administered consisting of the following four questions (answer choices are noted in parentheses):

1. Are you diabetic? (yes, no, borderline)
2. Do you know how long you have had abnormal blood sugar within one year of accuracy? (yes, no)
3. Do you know your HbA$_{1c}$? (yes, no)
4. Is your blood sugar well-controlled? (yes, no)
Little to no clarification was given on questions posed by subjects. If subjects asked what HbA\textsubscript{1c} is, a brief, vague explanation was given: “HbA\textsubscript{1c} is an important measure of your blood sugar.” Following the 30-60 second survey, the regular eye examination commenced as usual.
Results

Twenty-one adult diabetic men and women were surveyed during the study. Subjects included were: Caucasian, Asian, and African American. Ages ranged from their twenties to nineties. Survey results were as follows (answer choices are in parentheses):

1. Are you diabetic? (yes, no, borderline)
   - No: 0 (0%)
   - Yes: 20 (95.2%)
   - Borderline: 1 (4.8%)

![Pie chart showing survey results](chart.png)
2. Do you know how long you have had abnormal blood sugar within one year of accuracy?

(yes, no)

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<td>No</td>
<td>6</td>
<td>(28.6%)</td>
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<td>Yes</td>
<td>15</td>
<td>(71.4%)</td>
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![Diagram](image1.png)

3. Do you know your HbA1c? (yes, no)

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<td>No</td>
<td>13</td>
<td>(61.9%)</td>
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<td>Yes</td>
<td>8</td>
<td>(38.1%)</td>
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![Diagram](image2.png)
4. Is your blood sugar well-controlled? (yes, no)

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Reviewing interactions between survey responses, the following trends were observed:

Of the 13 subjects who did not know their HbA$_{1c}$, 9 subjects contradictorily also responded that their blood sugar is well-controlled. Likewise, 3 of the 21 subjects surveyed (14.3%) stated that their blood sugar was well controlled, despite not knowing how long they were diabetic or what their HbA$_{1c}$ value was currently. Conversely, 5 out of 21 subjects surveyed (23.8%) did not know how long they were diabetic and also answered that they did not know what their HbA$_{1c}$ value was.
Discussion

Results show that 61.9% of diabetics surveyed did not know their HbA\textsubscript{1c}, one of the most important measures of control in diabetes. We hypothesize that this number is falsely low (i.e. it is likely larger in the US population). Reasons for this assumption include: the subjects were already seeking eye care, which shows that they, at least partially, care about their diabetes and overall health. Secondly, the clinical sites surveyed mainly serve middle class Americans, most of which hold a private or public health insurance plan.

In a 2005 study by Heisler, et al, 686 adult type II diabetics were surveyed, and 66% of these subjects did not know their HbA\textsubscript{1c}. Furthermore, this study showed that respondents who knew their HbA\textsubscript{1c} reported better diabetes care understanding and assessment of blood sugar (Heisler, 2005). A study by Harwell, et al found that 24% of subjects who reported having the HbA\textsubscript{1c} test actually remember the value (Harwell, 2002). From review of ours and similar studies, we can conclude that when surveyed, approximately 60-80% of adult diabetics in the US do not know their HbA\textsubscript{1c} value. These numbers are affected by demographics as well as the patient’s health insurance coverage, or lack thereof, causing disparities and regional variation. Considering the importance of HbA\textsubscript{1c} to diabetes control, this lack of understanding warrants extra attention by primary care physicians, nurses, nurse practitioners, eye doctors, dentists, podiatrists, endocrinologists, physician assistants, public health professionals, and politicians and lawmakers.

The study shows that 42.9% of subjects in our study did not know their HbA\textsubscript{1c} value, but reported that their blood sugar is well-controlled. It is difficult to understand why nearly half of
respondents think that their blood glucose is controlled, but do not know their HbA$_{1c}$ values. Although it is difficult to understand these subjects’ thought processes, we estimate the following sources of misunderstanding and/or bias:

1. The patients are afraid to tell their eye doctor (the survey administrator) that their diabetes is not under control.

2. The patient’s primary care physician is not conveying important numbers and benchmarks like HbA$_{1c}$.

3. The primary care physician is telling the patient that their disease is controlled or not, without mentioning or explaining HbA$_{1c}$ and other benchmarks.

4. The patient’s spouse or family member tracks their numbers, but the patient does not.

5. The patient’s HbA$_{1c}$ has not been tested recently.

6. The patient believes that their blood glucose is controlled, when it is actually not.

7. The patient has an overall poor knowledge of diabetes and key numbers and benchmarks.

Studies estimate that 50-80% of adult diabetics have significant diabetes knowledge skill deficits (Heisler, 2005). Our study showed that 28.6% of subjects did not know how long they have had abnormal blood sugar (within one year of accuracy). Duration of diabetes is a strong indicator for the progression of diabetic retinopathy which can cause vision loss and blindness (Boyle, 2001). Furthermore, diabetes duration increases the risk of congestive heart failure (Fox, 2004). Duration of diabetes is also a key piece of medical information when giving a medical history to a new provider, clinic or hospital.
Furthermore, 23.8% of respondents did not know how long they were diabetic, or what their HbA\textsubscript{1c} is, and 14.3% of respondents stated that their blood sugar was well controlled, despite not knowing how long they were diabetic or their HbA\textsubscript{1c}. This and similar studies grossly show widespread patient misunderstanding, misinterpretation, and lack of knowledge of diabetes numbers and benchmarks, the nature of the disease, and whether or not the disease is under control.

Interventions and programs addressing patient knowledge of diabetes and numbers and benchmarks are urgently needed as the prevalence of diabetes continues to grow with aging baby boomers and increasing obesity. Not only patients, but providers of diabetic care, including, but not limited to: primary care physicians, nurses, nurse practitioners, eye doctors, dentists, podiatrists, endocrinologists, physician assistants, public health professionals, and politicians and lawmakers can make a difference in diabetes knowledge and patient empowerment.
Intervention Strategy

Although patient knowledge of diabetes and its benchmarks like HbA$_{1c}$, date of diagnosis, and general information about the disease are extremely low, there are straightforward, relatively inexpensive interventions that can improve patient knowledge, leading to empowerment and better control of the disease. A credit card-sized laminated wallet card to be carried by diabetics can help improve knowledge and control of diabetes. The card will be carried by diabetics constantly to each of their provider visits. The card will contain an area for the provider to write in HbA$_{1c}$ values (next to the corresponding date), an area that will note date of diagnosis (in order to remember disease duration), and an area that notes current medications and dosing (with the corresponding date). Providers of diabetic care, including, but not limited to: primary care physicians, nurses, nurse practitioners, eye doctors, dentists, podiatrists, endocrinologists, and physician assistants will participate in the filling out and reviewing of these cards at diabetic visits, follow-ups, and blood work appointments. The cards will be reviewed at every visit, even if HbA$_{1c}$ is not measured and there are no changes in medications and/or treatment goals/regimens

Several states including, but not limited to: Wyoming, New York, California, and Texas already have public versions of similar cards. These cards include HbA$_{1c}$, blood sugar, blood pressure, weight, blood cholesterol level, and various other key indicators of diabetic control. Date of diabetes diagnosis and/or current medications and dosing are not present on these cards however. Furthermore, the cards are not standardized from state to state.
A successful diabetic care card program would include the following features:

1. Standardization from state to state
2. Widespread support from state provider coalitions and associations
3. Minimal printing and distribution costs

A main intervention goal to improve patient knowledge and understanding of diabetes general information and number benchmarks would be to establish a standardized personal diabetes control card from state to state. The card should include important diabetes information without including extraneous information. This would include:

1. Date of diagnosis
2. HbA1c
3. Medications and dosing (with dates for changes)
4. Dates of last and next visits and phone numbers for patient’s:
   a. Primary care physician
   b. Endocrinologist
   c. Podiatrist
   d. Eye doctor
   e. Dentist
   f. Dietician
   g. Pharmacist
   h. Blood chemistry lab
   i. Other provider(s)
5. Instructions for dealing with a diabetic emergency/crisis

If the patient carries this card at all times, they can refer back to it and review their key diabetes numbers and benchmarks on their own, and with each provider. Use of this card would directly improve patient knowledge of their diabetic status and numbers. Furthermore, patients will bring this card to provider visits, both routine and emergency (since it will be in their wallet). Providers will be able to review and discuss both data found at that particular appointment, as well as any numbers and findings from other providers that are listed on the card. This will allow the diabetic patient to ask any questions, or point out any significant information at their provider visits. The personal diabetes card will thus increase knowledge and understanding for the providers as well as the patients.

Once a standardized diabetic care card is designed, provider cooperation and participation is vital to the success of the program. Professional organizations and coalitions at the state level would need to adopt the diabetic care card program, and members would participate in the data updates and reviews at each patient visit. Patients can also choose a doctor based upon their participation in the card program. The diabetic care card program will not only improve knowledge, understanding, health, and quality of life for diabetic patients, but providers will also be motivated to use it from a clinical administration or practice management standpoint. The card will remind patient and providers alike of their recommended follow-up and testing schedules, so these appointments are scheduled and achieved in a timely fashion. This will increase business for providers, further motivating the providers to participate in the program. The time burden of updating the card is approximately one minute—enough time to put the date, the appropriate data, and provider
initials. This will most likely minimally affect provider and patient schedules and appointment times. Widespread support of providers is of course vital to the success of the diabetes care card program. State and local associations’ and coalitions’ endorsement is vital for the program benefitting both patients and providers.

Funding and costs are a concern of any new public health program. The diabetes care cards will be very inexpensive (less than 50 cents per card). Funding can be obtained from health insurance companies, which will save funds with healthier beneficiaries. Medicare and Medicaid as well as private health insurance companies may want to fund cards for their beneficiaries to foster healthier living and lower health costs from surgeries and/or emergency diabetic interventions and inpatient situations. The cards will likely provide a high return on investment (ROI) for health insurance companies. Funding cards for the uninsured can also be obtained from the endorsing coalitions and state provider associations, and well as public health associations, and public assistance programs. Eventually, an electronic version of the card may be adapted, as electronic medical records become more mainstream. A scanning card may be adapted in the future, integrating diabetic medical data into the “cloud” system of medical informatics. Although this will increase costs and distribution logistics initially, it will result in long-term standardization of diabetic health data.

Diabetes care cards will provide a cost-effective solution to the widespread lack of knowledge and understanding of diabetic patients regarding their diabetes numbers and benchmarks including HbA$_{1c}$ and disease duration. State to state standardization, support from provider associations and coalitions, as well as funding considerations are three key aspects to a successful diabetic care card program.
Conclusion

As indicated by this and similar studies, patient knowledge of key diabetic numbers and benchmarks, especially HbA1c and duration of the disease, is extremely low in the United States. Additionally, knowledge of the general nature of the disease among diabetics is extremely low. Concurrently, an aging baby boomer population and increased obesity prevalence add to the overall number of diabetics in the country. Diabetes continues to be one of the most costly chronic diseases in American health care, both monetarily, and more importantly, in terms of length and quality of life. There is a great and urgent demand for cost-effective interventions to not only treat current diabetics, but to help future diabetics gain life-long knowledge, control, and empowerment towards their diabetes.

The diabetic care card provides a very inexpensive, easy, and straightforward way to track HbA1c, disease duration, medications, and overall control of the disease. Furthermore, it is an easy means to spur conversation and habitual communication between diabetic patients and providers.

In order to make the diabetic care card feasible and efficacious, a few program requirements would ensure the success of the diabetic care card. These include, but are not limited to: state to state standardization of cards, widespread endorsement from state and local provider coalitions and associations, and maintaining minimal printing and distribution costs. Diabetic patients will carry this card in their wallet, with their medical cards, driver’s license, and credit cards, ensuring that the information will be at each provider visit.
Establishing patient knowledge and understanding is the first step towards empowerment and fostering lifelong, healthy choices in diabetes. It is the duty of diabetic health care providers and public health professionals to design and implement programs like the diabetic care card that will increase patient awareness and knowledge, reduce health care costs on a national level, and improve overall health and length and quality of life.


