

How information about the time requirements and legacy effects of treatments influence decision-making in patients with diabetes and hypertension

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ABSTRACT

Objective: When deciding about diabetes treatments, patients are typically uninformed about how much time is required before (time requirements), or for how long treatments change outcomes (legacy effects). However, patients may be motivated to adopt treatments with time-related treatment information. We explored whether this information alters a patients' likelihood of starting medications.

Research design and methods: We conducted semistructured interviews with 60 adults with type 2 diabetes for <10 years and hypertension on oral medications. We measured change in likelihood of starting medications after receiving time requirement (diabetes, 10 years; hypertension, 3 years) and legacy effect (diabetes, 10 additional years; hypertension, none) information. Responses were analyzed for themes about time-related treatment information.

Results: At baseline, 70% of participants reported being very likely to start a recommended medication. Nearly half (40%) were less likely to start a diabetes medication after being informed of time requirements; but after being informed of legacy effects, 32% reported being more likely. Fewer participants changed likelihoods of starting antihypertensives with time-related information. Many participants expressed that medications' benefits were important to them regardless of time-related information. Participants considered time requirements for diabetes medications too long and compared them to their life expectancy. Many participants were interested in legacy effects of diabetes medications because they looked forward to discontinuing medications, although some expressed doubt that benefits could persist after stopping medications.

Conclusions: While prolonged time requirements may dissuade patients from adopting treatments, the promise of legacy effects may motivate patients to commit to diabetes treatments.

In the management of type 2 diabetes, just like with preventive services and other chronic diseases, there is a trade-off between the upfront clinical intervention and its delayed benefits, which could be called a treatment's 'time requirements'.^{1 2} For

Key messages

- Informing patients about the time requirements for diabetes medications may dissuade them from starting medications.
- Informing patients about the duration of benefits from diabetes medications may encourage them to start taking medications.
- Providers should consider discussing the long-term benefits of diabetes medications with patients to improve medication adherence and uptake.

example, in the UK Prospective Diabetes Study (UKPDS), which randomized participants with newly diagnosed type 2 diabetes to intensive glycaemic control or standard control, it took 10 years to demonstrate that intensive glycaemic control significantly lowered microvascular complication rates;^{3 4} thus, patients with limited life expectancy are no longer routinely recommended to maintain intensive glycaemic control.⁵ In chronic disease management, the 'time requirements' concept has also been introduced into guidelines for common treatment decisions. In preventive care, guidelines recommend considering a patient's life expectancy before recommending breast and colon cancer screening, because the risks versus benefits of screening become less favorable for patients with limited life expectancy.⁶

Another potentially important time-related feature of interventions is how long the benefits from a clinical intervention persist, or its 'legacy effect'. For diabetes, hypertension, and hyperlipidemia, legacy effects have been demonstrated, even after clinical trial protocols used to maintain intensive control have been discontinued.⁷⁻¹⁴ Notably, intensive glycaemic control had persistent lower rates of microvascular complications for 10 years after patients in the two UKPDS arms had equalization of glycaemic levels for type 2 diabetes.¹⁵



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Despite the clinical importance of time requirements and legacy effects of treatments, few studies have examined how patient decision-making for chronic disease treatments, like diabetes, may be affected by time-related treatment information. Our aim was to understand how patients with diabetes and hypertension may change their likelihood of starting medications after being given time-related treatment information.

RESEARCH DESIGN AND METHODS

We conducted a mixed-methods study using semistructured in-person interviews with adult patients diagnosed with type 2 diabetes and hypertension who received primary care at an academic urban hospital-based clinic. Interviews were conducted in English using a semistructured guide, which included scaled-response questions and follow-up exploratory questions. This study was approved by the University of Chicago Institutional Review Board.

Participant recruitment

We prescreened patients seen between 1 August 2012 and 31 July 2013 using data from the Clinical Research Data Warehouse at the University of Chicago. We included patients who were between 40 and 70 years old with both type 2 diabetes and hypertension, with duration of diabetes <10 years, and who were taking oral medications for both conditions. We excluded patients who were on insulin, pregnant, had severe visual impairment, or deafness. We also excluded patients who may have had difficulty considering the future in their decisions due to mental disability (ie, a history of stroke or cognitive impairment) or limited life expectancy (ie, on dialysis, active cancer, liver failure). A research assistant telephoned eligible participants to confirm data, screen for cognitive impairment,¹⁶ and schedule interviews.

After in-person consent was obtained, participants were interviewed by one of two trained interviewers (PCF and AN). Interviewers recorded responses to scaled questions and digitally recorded interviews. We interviewed participants until we reached our a priori sample of 60 completed interviews. We used stratified purposeful sampling in order to obtain a distribution in race/ethnicity.¹⁷ Recruitment and interviews occurred between January and September 2014.

Measures

Our main outcomes were change in likelihood of starting an oral medication for diabetes and hypertension after being provided information about its (1) time requirements and (2) legacy effects.

Prior to informing participants about the medications' time requirements and legacy effects, participants were asked how likely they would be to start an additional medication if recommended by their doctor, using a response scale of 1 (not at all likely) to 10 (very likely). Patients were told that the short-term benefits of the medication were to

lower their sugars (or blood pressure) and the long-term benefits of lower blood sugars (or blood pressure) was a moderately lower risk of complications, like amputation, heart attack, stroke, kidney disease, blindness, and numbness (or heart disease, stroke, kidney disease, eye disease, and vascular disease). Patients were told that the medication would be taken once a day and would be easy to swallow and affordable. Patients were provided information on the potential side effects based on metformin and hydrochlorothiazide. For diabetes, they were advised that the medication could cause low blood sugar in a very small number of people and could cause a very small amount of weight gain. If asked, the interviewer was able to quantify moderately lower risk (12% relative risk), very small number (<3%) and weight gain (4 lbs). For hypertension, they were told that the medication could cause muscle cramps, aches, and irregular heartbeats in a very small number of people. If patients asked how much a moderately lower risk or very small number was, the interviewer quantified moderately lower risk as a 24% relative risk and very small number as 4%. As their likelihood of starting a medication may be associated with their self-efficacy¹⁸ and outcome expectancy for taking additional medications,^{19 20} participants were also asked, on a scale of 1–10, how confident they were that they could take the medication and how likely they believed they would obtain its benefits.

Then, to ascertain how information about time requirements and legacy effects impacts decision-making, the interviewer told participants how long they would need to take the additional medication in order to get its benefits and how long the benefits would persist after stopping the medicine. We used data about the time requirements and legacy effects of intensive control from the UKPDS. The UKPDS demonstrated a lower risk of complications after 10 years of intensive glycemic control and 3 years of intensive blood pressure control, and a legacy effect of 10 years with intensive glycemic control and no legacy effect with intensive blood pressure.^{3 4 15 21 22} We used the starting of a medication as a proxy for intensive control.

For example, for diabetes, the interviewer informed participants that it would take 10 years to get the long-term benefits of taking the additional medication and then asked if their likelihood of taking it would change. Then the interviewer informed participants that the long-term benefits of taking the medication would last an additional 10 years, even after they stopped taking it, and asked if their likelihood of starting it would change. A similar scenario was described for hypertension, except the time requirement was 3 years and there was no benefit of taking the medication after stopping it. To control for sequencing effects, participants were randomized to either receive information about diabetes or hypertension first. Interviewers also asked participants how certain they were that they would be alive in 10 or 20 years, on a scale of 1 (absolutely no chance) to 10 (absolute certainty).

Finally, participants were asked whether they were interested in learning about the time requirements of medications, and why. Participants reported their socio-demographics; electronic health records were reviewed for their most recent glycated hemoglobin and blood pressure values.

Data analysis

On scale-based responses, participant responses were categorized into high (≥ 7), medium,⁴⁻⁶ and low (≤ 3). Interviews were transcribed verbatim, and a modified template approach was used for qualitative analysis. We created a codebook with predefined codes and iteratively updated it to capture new information and identify themes.²³ Each transcript was reviewed and coded by two or more trained coders (PCF, AN, NL, CL, NS, or DG). Codes were compared and discrepancies discussed until agreement. Data were collected and managed using REDCap electronic data capture tools hosted at the University of Chicago.²⁴ We used SAS V.9.3 to conduct quantitative analyses and atlas.TI (V.7.5) to manage qualitative data.

RESULTS

Our participants were about 60 years old and two-thirds were female. About 20% reported a high school degree or less, and nearly half reported an annual household income of $\leq \$50\,000$ (40%). Participants had diabetes for about 4 years and had hypertension for about 10 years. The mean glycated hemoglobin was 7.0% (53 mmol/mol) and mean blood pressure was 134/76 mm Hg. See [table 1](#) for further description of the clinical characteristics.

We successfully randomized participants to either being asked about diabetes or hypertension first; 31/60 were initially asked about diabetes. Responses to time requirement and legacy effect information for diabetes and hypertension were not significantly associated with the question order. However, more participants who were asked about hypertension first were likely or very likely to start a medication if recommended by their physicians (27/29 vs 21/31, $p=0.03$).

The majority of participants were very certain (≥ 7 out of 10) that they would be alive in 10 years (87%) and 20 years (75%). Among the remaining participants, 13% were uncertain (5–6/10) that they would be alive in 10 years, 8% were very uncertain (1–3/10) that they would be alive in 20 years and 15% were uncertain (4–6/10) that they would be alive in 20 years.

In general, participants stated that they were very likely to start a medication if recommended by their physician. About 70% of participants reported that they were very likely (≥ 7) to start a medication (diabetes, 72%; hypertension, 68%). Participants were highly confident (≥ 7) they would take it (diabetes, 85%; hypertension, 92%) and get its benefits (diabetes, 88%; hypertension, 82%).

Table 1 Participant characteristics (N=60)

Age, years, mean (SD)	59.8 (6.2)
Female, n (%)	39 (65.0)
Race/ethnicity, n (%)	
Non-Hispanic black	35 (58.3)
Non-Hispanic white	19 (31.7)
Hispanic	4 (6.7)
Asian/Pacific Islander	2 (3.3)
Education, n (%)	
High school or less	10 (16.7)
Some college, associate degree, or technical programme	24 (40.0)
College degree or more	26 (43.3)
Income, n (%)	
$\leq \$50\,000$	24 (40.0)
$\$50\,000$ to $\$100\,000$	17 (28.3)
$> \$100\,000$	17 (28.3)
Missing	2 (3.3)
Diabetes duration, years, median (IQR)	4.0 (3.5)
Diabetes medication duration, years, median (IQR)	4.0 (3.0)
Hypertension duration, years, median (IQR)	9.0 (7.5)
Hypertension medication duration, years, median (IQR)	8.0 (7.8)
Glycated hemoglobin, per cent, mean (SD)	7.0 (1.2)
Systolic blood pressure, mm Hg, mean (SD)	133.9 (17.0)
Diastolic blood pressure, mm Hg, mean (SD)	75.6 (11.5)
Number of diabetes medication, mean (SD)	1.2 (0.5)
Number of hypertension medications, mean (SD)	2.2 (1.0)
Likelihood of starting an additional diabetes pill*	
Very likely (≥ 7)	43 (71.7)
Somewhat likely (4–6)	7 (11.7)
Not likely (≤ 3)	10 (16.7)
Likelihood of starting an additional hypertension pill*	
Very likely (≥ 7)	41 (68.3)
Somewhat likely (4–6)	7 (11.7)
Not likely (≤ 3)	12 (20.0)

*Response scale options ranged from 1='not likely' to 10='very likely'.

Time requirements information

Providing participants with information about the time requirements for diabetes and hypertension medications did not change most participants' likelihood of starting a medication (diabetes, 58%; hypertension, 75%; [table 2](#)). However, a large minority of participants (40%) were less likely to start a medication for diabetes after being told that it would take 10 years to decrease their risk of complications.

Participants expressed several views on the 10-year delay including that the time requirements did not matter because they wanted the benefits of the medication, regardless of how long it took to get them. For example, one participant said:

Any benefit is a good benefit...There's no risk to a delay. You're still going to get the benefits sooner or later.

Table 2 Change in likelihood of starting an additional medication after receiving time-related treatment information

	Diabetes N (%)	Hypertension N (%)
<i>Time requirement information: 'If your doctor told you that it would take ___ to get the long-term benefits, would your likelihood change?'</i>	'10 years'	'3 years'
Increase	1 (2)	7 (12)
Stay the same	35 (58)	45 (75)
Decrease	24 (40)	8 (13)
<i>Legacy effect information: 'If your doctor told you that you ____, would your likelihood change?'</i>	'Could stop taking this medication after 10 years and the benefits would last 10 more years'	'Had to continue taking this medication in order to get its benefits'
Increase	19 (32)	7 (12)
Stay the same	40 (67)	44 (73)
Decrease	1 (2)	9 (15)

Some participants considered the time requirements too long. For example, one participant commented:

It seems like it's a wasted time. That's a long gap, 1 to 10 years for something to work. I feel like I'm wasting my time and I just wouldn't be interested.

Participants also compared the time requirements to how long they expected to live, and in general, thought that they would be alive long enough to benefit from the additional diabetes medication:

...like I said, I plan on being around in 10 years so hopefully it will benefit.

Some participants also expressed that they thought medications should work faster than the 10-year time requirement.

I can't see how it would take that long...[to] take a pill and see the results.

For hypertension, after being told that it would take 3 years to decrease their risk of complications, only 13% were less likely to start an additional hypertension medication. Participants responded similarly to the time requirements for hypertension. They expressed a desire to benefit from medications regardless of the 3-year delay. One participant said:

Because either way I'd get the benefit now and then I'd get the benefit in the future.

Some participants said that the 3-year time requirement was too long to wait for benefits while others expressed that 3 years was not too long, as highlighted by the participants' comments below:

I've got to wait 3 years for it to give me the full benefit. That's quite a bit of a long time.

It took even longer to get it where it is now, so 3 years would be just like a drop in a bucket.

Legacy effect information

In general, after receiving information on legacy effects of the medications, the majority of participants did not change their likelihood of starting them (diabetes, 67%; hypertension, 73%). However, for diabetes, about one-third (32%) reported an increase in their likelihood.

Participants expressed that the 10-year legacy effects were appealing, mostly because they were very interested in the concept of discontinuing the new medication in the future. For example, participants said:

20 years is better than 10...It just struck me as being a win/win situation.

I don't like taking pills or nothing you know, and after 10 years I don't have to take those anymore.

Also participants stated that they wanted the benefits of medications and, if there was a legacy effect, that was helpful, but not necessary for their decision-making.

...the position that I take (is that) the benefits are there. If the benefits are going to stay there for an additional 10 years I'm all for that.

In comparison, few participants changed their likelihood of starting a hypertension medication after receiving information that there was no legacy effect (12%). The most common themes were that they wanted the benefits of the medication and that was enough reason to take it.

It still would serve a purpose in lowering the blood pressure.

Participants expressed doubt that legacy effects were even possible, as demonstrated by these quotes:

Because if it's just kind of a temporary blocking reaction and not stabilizing anything it raises doubts about the mechanism of how it's working.

I haven't taken a pill for 10 years, then I can't see taking a pill for 10 years and it's going to [grow on you]. Medication eventually comes out of the body...Right?

General interest in time requirement information

Nearly all participants were interested in hearing about delays between starting a new medication and its long-term benefits (95%). The most common themes included that they wanted as much information as possible and that this information would help them make decisions and plan for the future. For example, participants commented:

It would influence you as to whether or not you were really truly interested in the program and how it would affect you in the future.

It just makes you a little more aware and educated and it lets you know that there is a plan.

However, only one participant spontaneously mentioned that their doctor provided them with time requirement information routinely.

DISCUSSION

This study explored how information about the time requirements and legacy effects of diabetes and hypertension medications influence patient decision-making. We found that many patients reported that these types of time-related information affected their likelihood of starting a chronic medication. We also found that large time requirements for a treatment could be counterbalanced to some degree by information about its legacy effect, mostly because patients were interested in

stopping medications. Shorter time requirements and the lack of a legacy effect had smaller effects on a patient's likelihood of starting a medication.

How patients respond to information about a treatment's time requirements and legacy effects is linked to the concept of time preference, the degree to which people prefer immediate over future benefits.²⁵ Previous studies on the role of time preference in health behaviors have been inconsistent and conducted in healthy participants.^{26 27} These studies found that people who smoked were more likely to be present-oriented, but that people who had received the influenza vaccine—a potential indicator of a future-oriented time preference—were actually not more likely to be future-oriented.^{26 28 29}

Our study strongly suggests that many patients with diabetes and hypertension have a present-oriented time preference, since many patients thought 10 years was too long to benefit from diabetes medications. These patients may agree with the common-sense model,^{30 31} that diabetes and hypertension have acute symptoms that medications treat, and thus viewed medications more like 'on-off' switches. The limited literature on time preference in patients with chronic diseases suggests that patients with hypertension who have a more future-oriented time preference are more likely to adhere to treatments³⁰ and that expectations about how long a behavior is required (temporal expectations) may affect levels of persistence.³² Also, our results suggest that some patients may shift to a future-oriented time preference by being provided information about legacy effects. Thus, additional patient-provider discussions on the chronicity of diabetes and hypertension may allow patients to shift time preferences and lead to deeper patient engagement in adhering to a lifetime of improved lifestyle choices.

We found that we were able to explain the concepts of time requirements and legacy effects to patients; however, some patients still had difficulty accepting these concepts. Previous studies have found that the concept of time requirements for cancer screening at the end of life was difficult for elderly patients to comprehend.^{33 34} Though a previous study on preventive care and time horizons found that younger patients were most interested in a long time horizon and older patients with a short time horizon.³⁵ In our study of middle-aged adults, the majority of participants readily accepted the concepts of time requirements and legacy effects and on their own compared these new pieces of information to their life expectancy. Based on literature on health numeracy³⁶ and risk perception,^{37 38} it is likely that some patients are more time 'literate' and that better time literacy may correlate with better disease control.

Nearly all of our participants were interested in hearing information about time requirements; however, it is possible that information about time requirements may not enter clinical conversations. Previous studies have suggested that people, in general, may be inattentive to the duration of trials,³⁹ and so it is possible that

clinicians may be unaware of the time requirements of treatment. However, sharing information about time requirements may be an important strategy for prioritizing treatment decisions for patients and providers. For example, in patients with both diabetes and hypertension, since blood pressure control decreases the risk of complications after about 3 years, it would make sense to prioritize controlling high blood pressure prior to asymptomatic hyperglycemia.

Our results also suggest that considering the legacy effects of treatments may convince some patients to change treatments. Providing information about legacy effects would take additional time during clinic visits, but it could provide some patients with important long-term incentives to start diabetes medications. Our study also supports the importance of long-term post-trial follow-up studies, such that patients and providers can understand the full duration of treatment benefits.

Even though time requirement and legacy effect information influenced a large minority of our participants' decision-making, it is important to note that the majority was not influenced by these types of information. Owing to our small sample size, we were unable to elucidate which, if any, characteristics may be predictive of which patients who would be influenced by this information.

A major driver for participants interested in the legacy effect of diabetes was the ability to stop taking medications in the future, which speaks to the strong patient desire to not take medications, and perhaps may not have been strictly related to their interest in its legacy effect. The strong desire to stop chronic disease medications has been shown previously.⁴⁰

Several strengths and limitations exist. To our knowledge, this is the first study to examine how information about time requirements and legacy effects influences patient decision-making. However, we performed this study at a single academic urban primary care clinic, and our population was relatively well-educated; populations in other settings or with less education may find time-related treatment information challenging. Another limitation is that our participants may be more future-oriented than the general population, since they were willing to enrol in clinical research. On average, our participants had well-controlled diabetes and hypertension, which may have limited their willingness to start a new medication; however, these ceiling effects make our findings more notable. Also, we assumed that starting an additional medication would lower blood pressures and blood sugars successfully, even though additional medications may not translate into improved control in clinical practice. In addition, in our description of the legacy effect, we assumed that the addition of a diabetes medication would simulate the changes in blood sugar seen in the UKPDS trial, such that after the initial 10 years, the medication would no longer be necessary. This assumption does not account for the possibility that patients would need more medications over time to achieve the same level of glycemic control or that their glycosylated

hemoglobin values may increase over time. Finally, we controlled for important factors like costs and side effects, by using descriptions of metformin and hydrochlorothiazide, and did not discuss all factors that affect patients' decisions about medications. It is likely that information about time requirements and legacy effects would differently weight on patient's decisions in the setting of other medications or other information.

Information on the time requirements and legacy effects of interventions are available in clinical studies, but are not routinely discussed or disseminated for chronic diseases. We found that patients were interested in learning about time-related treatment information and many patients were influenced by these types of information. Future studies are needed to understand how to best use time-related treatment information to improve patient adherence for chronic diseases, like diabetes.

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