

Patients' Future Expectations for Diabetes and Hypertension Treatments: "Through the Diet... I Think This is Going to Go Away."

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BACKGROUND: Diabetes and hypertension are chronic conditions for which over 90 % of patients require medication regimens that must be intensified over time. However, delays in intensification are common, and may be partially due to unrealistic patient expectations.

OBJECTIVE: To explore whether patient expectations regarding their diabetes and hypertension are congruent with the natural history of these conditions.

DESIGN: Qualitative analysis of semi-structured interviews.

PARTICIPANTS: Sixty adults from an urban academic primary care clinic taking oral medications for both diabetes (duration <10 years) and hypertension (any duration)

MAIN MEASURES: (1) Expectations for their a) current diabetes and hypertension medications, b) need for additional medications, c) likelihood of cure (not requiring medications); (2) preferences for receiving information on expected duration of treatments

KEY RESULTS: The average patient age was 60 years, and 65 % were women. Nearly half (48 %) of participants expected to discontinue current diabetes medications in 6 years or less, whereas only one-fifth (22 %) expected to take medications for life. For blood pressure medications, one-third (37 %) expected to stop medicines in 6 years or less, and one-third expected to take medicines for life. The vast majority did not expect that they would need additional medications in the future (oral diabetes medications: 85 %; insulin: 87 %; hypertension medications: 93 %). A majority expected that their diabetes (65 %) and hypertension (58 %) would be cured. Most participants believed that intensifying lifestyle changes would allow them to discontinue medications, avoid additional medications, or cure their diabetes and hypertension. Nearly all participants (97 %) wanted to hear information on the expected duration of their diabetes and hypertension treatments from their healthcare provider.

CONCLUSIONS: Providers should educate patients on the natural history of diabetes and hypertension in order to manage patient expectations for current and future medications. Future research should assess whether education can increase the adoption of and adherence to medications, without diminishing enthusiasm for lifestyle changes.

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INTRODUCTION

Complications from diabetes and hypertension can be prevented by effective glycemic and blood pressure control.^{1,2} In order to attain effective control, over 90 % of patients with diabetes and hypertension will require medication,³⁻⁵ and over their lifetimes, most patients will require higher doses and more than one medication to maintain control.^{6,7} However, many patients experience delays in medication intensification.⁸⁻¹³

Delays in treatment initiation and intensification may be partially due to patient beliefs about their chronic diseases. Prior studies have found that patients hold inaccurate beliefs about diabetes and hypertension, which negatively impact decision-making.¹⁴⁻¹⁸ For example, some patients with hypertension believe that they only have hypertension when they experience symptoms, and stop taking medications when they are asymptomatic.^{14,15} Patients who believe they are not at risk for complications from diabetes and hypertension have been found to be less willing to intensify their medications when necessary.¹⁶ In other studies, patients who believe that insulin leads to diabetic complications are more likely to resist initiation of insulin therapy.^{17,18}

While many studies have described patient knowledge of diabetes and hypertension and its impact on treatment adherence,¹⁴⁻¹⁸ few studies have explored patient expectations for treating their conditions in the future. One study of African American patients with high blood pressure found that 38 % believed they would not need to take medication for life,¹⁹ and a study of low-income African American and Latino patients with diabetes found that almost one-third believed a doctor would cure them of diabetes.²⁰ These studies paint a general picture of unrealistic patient expectations and suggest that these expectations contribute to poor treatment compliance and poor outcomes; however, these studies do not provide a systematic understanding of beliefs about time-sensitive decisions that patients may face regarding their current and future medications.

Since patient expectations are an important driver of patient behavior,²¹ we used qualitative methods to understand patients' expectations for the future of their 1) current diabetes and hypertension medications, 2) need for additional treatments, and 3) possibility of remission (not needing medications) in the future.

METHODS

In this qualitative exploratory study, we conducted semi-structured interviews with individuals diagnosed with both diabetes and hypertension to assess their expectations. This is part of a larger study²² (The On Time Diabetes and Hypertension Study) focusing on patient decision-making in relation to information about the time requirements for diabetes and hypertension treatment. This study was approved by the University of Chicago Biological Sciences Division Institutional Review Board.

Setting

All interviews took place between January and September 2014 at a primary care clinic in an urban academic medical center. All interviews were conducted in private patient rooms within the clinic.

Participant Selection

The flow of participant selection is outlined in Supplementary Appendix Figure 1. As previously described,²² using the Clinical Research Data Warehouse maintained by the Center for Research Informatics at the University of Chicago, we identified 1158 eligible adults who had been seen in the primary care clinic between August 2012 and August 2013. We required participants to have had diabetes for less than 10 years. We intended to study individuals with type 2 diabetes, so we limited the population to those 40 years and older. To minimize issues with cognitive impairment and/or limited life expectancy, we limited the population to those less than 70 years of age. We required participants to have both diabetes and hypertension, because the larger study was among patients with both conditions. We required that patients were prescribed oral medications for both conditions and not prescribed insulin, because we wanted to minimize general preferences against taking chronic disease medications and insulin.

We reviewed the electronic medical record (EMR) for eligible subjects and excluded individuals who were currently pregnant, on dialysis, or had active cancer, liver failure, severe visual impairment, deafness, or cognitive impairment. We then contacted eligible individuals by phone to screen for cognitive impairment and to verify chart review data.²³ Eligible individuals were invited to participate in an hour-long in-person interview. Eligible individuals who declined to participate did not differ

significantly in sex, race/ethnicity, or age from those who consented. We used stratified purposeful sampling²⁴ to reach a minimum of 30 % white participants and to ensure racial/ethnic diversity in respondents. We recruited and interviewed individuals until we achieved the a priori sample size of 60 participants, at which point we expected to reach theme saturation.

Interview Guide

The interview guide (Supplementary Appendix) was created through an iterative process with the research team and contained scaled-response and open-response questions. For scaled-response questions (e.g., 1–10 scale), visual aids depicting response options were created and provided to participants. The interview guide was pilot-tested with non-patient volunteers by the internal research team. The interview was administered in English for all participants.

Interview Sessions

Two interviewers (AN and PF) obtained informed consent, then conducted and audio-recorded the interviews. Interviews ranged from 30 to 60 min. All interviews took place 1 h before scheduled appointments. In gratitude for their participation, participants received their choice of a parking pass or public transit voucher, as well as a \$20 mailed check.

Measures/Data Collected

We asked participants the following open-ended questions: 1) "How much longer do you think you'll take your current medicines?" 2) "Do you think that you'll have to take more medicines in the future?" 3) "Do you think your conditions can be cured?" and 4) "Before starting a new medicine for your diabetes and high blood pressure, would you like your doctor to tell you how long you'll be on the medication?" We did not define the term "cure" for the participants, leaving it open to their interpretation. Participants gave free responses, and interviewers probed for further explanations. Interviewers also asked participants to report when they had been diagnosed with hypertension, when they began taking medications for hypertension and diabetes, their current self-rated health status, smoking history, marital status, race, ethnicity, education, and income range. We used EMR data to document each participant's duration of diabetes, most recent A1C value and blood pressure reading, and current diabetes and hypertension medications.

Data Analysis

Study data were collected and managed using REDCap electronic data capture tools hosted at the University of Chicago.²⁵

Interviews were transcribed, and a modified template approach was used to qualitatively analyze participant responses.²⁶ The initial codebook was aligned with the interview guide and was amended throughout the coding process to capture new information and themes. Each interview transcript

was reviewed and coded by two or more trained coders (PF, AN, NL, NS, CL, DG), and codes were discussed and agreed upon by consensus. Codes were then compared across transcripts and grouped into high-order themes. Representative quotes were chosen to illustrate major themes. Responses to some questions such as “How much longer do you think you’ll need to take your current medications?” favored participant responses that could be categorized. We used the software ATLAS.ti (version 7.5) to manage the qualitative data and SAS (version 9.3) to conduct quantitative analysis.

RESULTS

Participant Characteristics

The average age of participants was 60 years, and 65 % were women. In line with our purposeful sampling design, 35 participants self-identified as non-Hispanic black (58 %), 19 (32 %) as non-Hispanic white, 4 (7 %) as Hispanic, and 2 (3 %) as Asian/Pacific Islander. The majority of participants reported at least some college education (83 %); however, 40 % reported an annual income of \$50,000 or less. The median duration of diabetes was 4 years (interquartile range [IQR] 3.5), and participants reported taking diabetes medications for a median of 4 years (IQR 3.0). The median duration of hypertension was 9 years (IQR 7.5), and participants reported taking hypertension medications for a median of 8 years (IQR 7.8). The average A1C value was 6.9 % (standard deviation [SD] 1.1 %) and blood pressure was 134/76 mmHg (SD 17/11 mmHg).

Expectations for Current Diabetes and Hypertension Medications

Nearly half of the participants (48 %; n = 29) expected to discontinue their diabetes medications in six or fewer years; about one-third (37 %; n = 22) expected to discontinue their hypertension medications in six or fewer years. These participants expressed plans to improve their lifestyle and control their glucose or blood pressure levels (Table 1). For diabetes, participants also mentioned that good social support, including support from their physician, would help them to discontinue their medications in the near future.

Nearly one-third of participants (30 %; n = 18) thought that they might be able to discontinue diabetes medicines someday, while slightly fewer participants (25 %; n = 15) thought that they might be able to discontinue hypertension medications someday. These participants also stated that they could stop taking medications if they changed their lifestyles or controlled their glucose or blood pressure levels, but expressed less confidence in their ability to make changes. More importantly, external factors affected their expectations regarding continuation of medications, specifically that their doctors would tell them if they could stop taking medications, that life stressors may prevent them from stopping medications, and that scientific advancements may allow them to stop taking medications.

About one-fifth of participants (22 %; n = 13) expected to take diabetes medications for the rest of their lives, and 37 % of participants (n = 22) expected to take their hypertension medications for the rest of their lives. These participants expressed low self-efficacy in the ability to change their lifestyles, and believed that their diseases

Table 1 Themes and Representative Quotes: “How much longer do you think you’ll need to take your current medicines? Why?” (N = 60)

Response category	Diabetes N (%)	Hypertension N (%)	Representative quotes
≤6 Years	29 (48)	22 (37)	
	I will change my lifestyle		“I lost a lot of weight in the last months so I was thinking maybe that’s enough to get me off the [high blood pressure] pills.” -#1307
	I will control my blood sugars/blood pressure		“About 3 years...I’ve been doing it right and I check it every day.” -#331
	I have good support		“I have a very good physician that’s helping and directing me.” -#716
It depends	18 (30)	15 (25)	
	If I can change my lifestyle		“Well, as long as I do good I figure I will be off of it, but if I don’t, I’m going to take it for the rest of my life.” -#619
	If I can control my blood sugars/blood pressure		“[Diabetes] can be controlled. I know as long as I get it under control I will be okay.” -#2025
	It depends on what my doctor says		“I heard that you can get off the pills...I would have to discuss that with the doctor to see when.” -#882
	Depends on stress levels		“Whenever all these crazy folks in my family quit stressing me out.” -#138
	Depends on scientific advancements		“I think I would probably say as soon as they find a cure.” -#453
Rest of life	13 (22)	22 (37)	
	Diabetes/hypertension is not curable		“I was told that type 2 is not curable.” -#920
	I am not able to change my lifestyle		“Everyone tells me if I get under 200 lbs I can stop taking [the high blood pressure medicine]. I’ve been trying for 10 years to get under 200 lbs.” -#624
	Not curable because of my family history		“My mother has been taking [high blood pressure pills] for a long time...my sister did the same thing, so I don’t think there [are] any changes for me.” -#841
		I am getting benefits from the medication	“Because my doctor told me about the benefits of lisinopril for kidney function.” -#920

were not curable in general, and pointed to their family histories of diabetes and hypertension as evidence that their own diseases were not curable.

Expectations for Future Treatment Intensification

About 85 % of participants ($n = 51$) expected that they would not need additional oral diabetes medications or insulin ($n = 52$) in the future. Similarly, 93 % of participants ($n = 56$) expected that they would not need additional hypertension medications in the future. These participants explained that improving their lifestyle and adopting healthier behaviors would prevent them from needing additional medications, and stated that the diseases were currently under good control (Table 2).

Fewer than three participants each were unsure whether they would need additional diabetes or hypertension medications in the future (oral diabetes medications: $n = 2$, insulin: $n = 1$, hypertension medications: $n = 1$). They expressed uncertainty as to their ability to improve their lifestyles and considered external factors like the possibility of scientific advancements and their doctors' opinions.

Some participants (oral diabetes medication: $n = 7$, insulin $n = 7$, hypertension medication: $n = 3$) believed that they would need additional diabetes or hypertension medications in the future. They stated that their current level of control was poor and that they doubted their ability to improve their lifestyles, and thus expected their diseases to worsen in the future.

Expectations for Being Cured of Diabetes and Hypertension

Nearly two-thirds of participants (65 %; $n = 39$) believed that their diabetes could be cured, compared to 58 % of participants ($n = 35$) who believed that their hypertension could be cured. These participants were confident in their ability to improve their lifestyles and also attributed their expectations to scientific advancements, good social and physician support, and stress reduction (Table 3).

Over one-third of participants (35 %; $n = 21$) believed that their diabetes could not be cured; 40 % of participants ($n = 24$) believed that their hypertension could not be cured. These participants emphasized that their conditions were chronic, and thus could be successfully managed or controlled, but not necessarily cured. In addition, they commented that their family histories suggested that they could not be cured, and that science may not find a cure in their lifetimes.

Preferences for Information About the Duration of New Medications for Diabetes and Hypertension

Nearly all participants (97 %; $n = 58$) stated that they would want their provider to tell them how long they might need to be on a new medication for diabetes or hypertension (Table 4). Participants reported that this information would be "good to know" and that it would help them "know what to expect" with regard to managing their condition. However, some participants doubted that their doctors would have that kind of knowledge.

Table 2 Themes and Representative Quotes: "Do you think you'll have to take more medicines in the future? Why?" ($N = 60$)

Response category	Diabetes N (%)	Hypertension N (%)	Representative quotes
No	Pills: 51 (85) Insulin: 52 (87) I will change my lifestyle	56 (93)	"I'm planning not to [need additional diabetes medications]. Because it's a goal for me to control my weight and what I eat." -#481 "Because I don't plan to take anymore. Well I'm not going to take anymore. This is it. I'm never taking more." -#836
It depends	My current medicines are working well Pills: 2 (3) Insulin: 1 (2) If I can change my lifestyle Depends on scientific advancements	1 (2)	"I just need to improve my health overall." -#631 "I read a lot of scientific literature like a newsletter on diabetes studies. As soon as there's something that can get me off the medication I will be first in line for it." -#728 "As long as I have a reasonable doctor we're okay." -#328 "And meditation, which may be more important than anything else in my opinion." -#728 "I'm one of the early adopters of a new drug that's had a drug dramatic effect for me." -#728
	It depends on my doctor	Depends on stress levels	
	Depends on current medicines		
Yes	Pills: 7 (12) Insulin: 7 (12) My diabetes is uncontrolled Because of my family history I am not able to change my lifestyle	3 (5) My blood pressure will get worse with age	"It's not been a good 6 months. The blood sugars and A1Cs, instead of going down...they're creeping." -#1648 "My brother did this. Now he's on insulin." -#624 "Yes, because they started me on 500 mg. They upped me to 1000 mg, so if I don't change my way I think yeah, I would have to take more." -#624

Table 3 Themes and Representative Quotes: "Do you think your conditions can be cured? Why?" (N=60)

Response Category	Diabetes N (%)	Hypertension N (%)	Representative quotes
Yes	39 (65)	35 (58)	
	I will change my lifestyle		"[My diabetes can be cured] through the diet... That's why I think this is going to go away." -#897
	Science is advancing		"In the future they might find something to cure diabetes." -#152
	I have a good doctor or support system		"A good doctor tells you what you're facing and he tells you good or bad what's going to happen." -#716
No	I've been cured before	I will lower my stress/control my emotions	"When I had that motorcycle accident and lost that weight, it was cured." -#331 "No stress. That's the cure right there, no stress, no headaches, that's all." -#518
	If diagnosed early		"If it's caught early it can be undone..." -#406
	21 (35)	24 (42)	
	Diabetes/hypertension can be managed, but not cured		"I don't think [high blood pressure] can be cured. It may get better, but it might not get cured." -#502
Diabetes/hypertension is a chronic disease		"I've never known anyone that had it cured." -#741	
Diabetes/hypertension will not be cured in my lifetime		"It would be nice to think it would be cured in my lifetime, but I don't believe it will." -#661	
Diabetes/hypertension is in my family		"Probably not because my mother, my brothers and sisters has it. I mean it's like genetic." -#841	
I'm getting older		"As I get older, you know, I know it takes longer and longer...to feel better, so the same thing with high blood pressure." -#481	

DISCUSSION

In this study of patients with diabetes for less than 10 years and with hypertension, the majority expected that they would be able to discontinue their diabetes and hypertension medications in about 5 years, nearly all expected not needing additional diabetes and hypertension medications, and the majority thought that their conditions could be cured. Participants' expectations were closely related to how certain they were that they could achieve significant lifestyle changes. The minority of participants who were less certain that they could stop medications in the future were more likely to mention the influence of external factors such as the opinions of their doctors, scientific advancements, life stressors, and family history. Participants also expressed a strong desire to know how long they would need to take new diabetes and hypertension medications in order to help them manage their expectations for these diseases.

Participant expectations for their diabetes and hypertension were very inconsistent with the natural history of diabetes and hypertension. Participants attributed their beliefs to expectations that they could achieve significant

lifestyle changes. However, multiple studies³⁻⁵ suggest that remission is rare and that the majority of patients with diabetes and hypertension need to intensify medications over time. An epidemiologic study of adults with type 2 diabetes found that less than 2 % achieved partial remission (defined as two or more consecutive normoglycemic A1C measurements over a period of at least 12 months) and less than 1 % achieved prolonged remission (two or more consecutive normoglycemic A1C measurements over a period of at least 5 years) of diabetes.⁴ Higher rates of remission were found in the Look AHEAD [Action for Health in Diabetes] trial, which compared an intensive lifestyle intervention to support and education (11.5 % at year 1 and 7.4 % at year 4 for the intervention arm, compared to 2.0 % at years 1 and 4 for the control arm).³ Similarly, for hypertension, less than 10 % of participants in the Framingham Heart Study discontinued their antihypertensive medications and were normotensive after 2 years.⁵ Thus, while remission of diabetes and hypertension is possible with lifestyle changes, a large discrepancy remains between our participants' expectations and the clinical evidence.

Table 4 Themes and Representative Quotes: "Before starting a new medication for your diabetes and hypertension, would you like your doctor to tell you how long you'll be on the medication? Why would you like to know that information?" (N=60)

Response category N (%)	Themes	Representative quotes
Yes 58 (97)	The more information the better	"It would tell me basically how serious my situation is, and I would ask questions about what do I have to do to change this and try to get all the information that I could." -#897
	It would help me with my decision-making	"If you told me one way or the other, then that would be something that I could try to figure out...and what I need to do to help fix the problem." -#418
	I would know what to expect with my diabetes and hypertension	"Well, that will put me more at ease, when I know how long I'm going to be taking this and what benefits I'll be expecting." -#331
No 2 (3)	I doubt a doctor would know that information	"Your doctor is not responsible for your health, you are." -#728
	I expect to take it forever anyway	"I don't think it would change anything; I would still take it." -#478

This discrepancy may be an important reason that many patients are resistant to the idea of treatment intensification. In the Translating Research Into Action for Diabetes (TRIAD) study, one-quarter of the subjects who chose not to initiate insulin reported that they instead planned to change their health behaviors.²⁷ While it is important to encourage individuals to improve their health behaviors, providers should engage patients in a realistic conversation regarding the magnitude of changes in diet, exercise, and weight needed to appreciably change the need for medication. Also, improving patient understanding of the rarity of remission may be an important strategy for reducing delays in treatment intensification.

A patient-provider conversation about patients' expectations for the future of their conditions may help providers manage these expectations. This conversation would involve eliciting patient understanding of their diabetes and/or hypertension, the course of treatment, likely outcomes, and role of self-management. Providers could then focus on correcting unreasonable expectations. The use of a "teach-back" technique, where patients repeat key points back to the provider, who in turn corrects the key points until consensus is reached, can help ensure understanding and retention.

One reason to believe that this strategy may be beneficial is that participants in our study overwhelmingly reported that they would want to hear about treatment durations for hypertension and diabetes from their providers. Prior research has found that patients respond positively to seeing medication regimens presented as a planned sequence of intensification, and they appreciate knowing what to expect in terms of their treatment.²⁸ Providers should consider initiating discussions regarding the importance of initiating, continuing, and intensifying therapy for individuals with hypertension and diabetes early in the disease course.^{17,27,29,30} Providing patients with information about the rationale for medication intensification may help them anticipate changes in their regimen, and thus be more receptive to them.²⁸ However, having such discussions may be time-consuming, since we also previously showed that among these participants, about 40 % were less likely to start a diabetes medication if they were informed of the medication's time requirements, and the estimated 10-year lag before the risk of complications is reduced.²² Thus, decision support tools may be needed to properly inform patients about the expected treatment duration and time requirements for diabetes and hypertension medications.

Limitations

This study has several limitations. First, it was a single-site exploratory study of patients with diabetes and hypertension on oral medications at an urban academic center. Thus, results may not be generalizable to patients taking insulin or who receive care in other settings. Second, we had a small sample size, making it difficult to look at subgroups, though our study was very large compared to most qualitative studies. Third, the participants tended to be healthy, with well-controlled diabetes and hypertension, so results may not be generalizable to individuals with poorly controlled diabetes and hypertension.

Fourth, because the interviews were conducted in person, there is the possibility of response bias, in that participants may have wanted to appear more masterful and optimistic about their expectations for their diseases. Fifth, we did not ask patients what information they had previously received about their diabetes and hypertension. To objectively ascertain this information would likely require corroborating data from providers, which was beyond the scope of this study.

CONCLUSIONS

In summary, we found that many participants with diabetes and hypertension were expecting to discontinue their current medications, most anticipated no future need to intensify medications, and many expected to be cured from these conditions. Our results highlight the need for health-care providers to deliver patient education about the natural history of diabetes and hypertension treatment. Beliefs and expectations about illness are mutable and are constantly reconstructed based on individual experiences and acquired knowledge. With education, individuals with diabetes and hypertension can learn that they may require additional medications as their diseases progress, enabling stronger efforts towards lifestyle change, timely treatment intensification, and reduced risk of complications. Future research should investigate whether educating patients on the natural history of diabetes and hypertension treatments can improve the adoption of and adherence to medications, without diminishing enthusiasm for lifestyle changes.

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Conflict of Interest: The authors declare that they have no conflict of interest.

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