

# “I TAKE WHAT I THINK WORKS FOR ME”: A QUALITATIVE STUDY TO EXPLORE PATIENT PERCEPTION OF DIABETES TREATMENT BENEFITS AND RISKS

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## ABSTRACT

### Background

Diabetes is impacting more and more people each year. A key aspect of disease management is patient adherence to prescribed treatments. Treatment adherence is influenced by many factors, including the understanding of a treatment's benefits and risks.

### Objective

This study sought to describe the experience of benefit and risk assessment for people with type 2 diabetes when making treatment decisions.

### Methods

This study utilized qualitative research methods. Individual interviews were conducted using a semi-structured interview guide. Both purposeful and theoretical sampling was used. A grounded theory approach was employed to facilitate data collection and analysis.

### Results

The 18 study participants were on varying treatment regimens for diabetes (diet therapy, oral medications, and insulin). Many people felt that they had not received enough information about the benefits and risks of treatment at the point of decision-making and later sought this information on their own. Participants did not seem to consciously assess treatment benefits and risks when treatments were prescribed or suggested, but rather continued to make decisions after the clinical encounter by means of experimentation or experience with treatments. In general, benefits and risks were conceptualized very broadly, and some people were not able to verbally articulate their perceptions of treatment benefits and risks.

### Conclusion

Patients' assessment of treatment benefits and risks is an ongoing, often unconscious process that requires continuous interaction with the health care system. Access to information and an opportunity to discuss treatment options with health care providers are important to people with diabetes when making treatment decisions.

**Keywords:** *Qualitative research, patient perspective, diabetes, benefit & risk assessment*

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The prevalence of diabetes in Canada has increased from 3.4% in 1994/95 to 4.5% in 2000/01, representing almost 1.1 million people 18 years or older.<sup>1</sup> The health care costs

associated with diabetes are staggering -- almost 5 billion dollars (CAD) in 1998<sup>2</sup>, with a large proportion of costs resulting from serious complications that could be prevented if diabetes

was better controlled. Given the major impact that diabetes has on the health of the public, researchers, health educators, and clinicians are trying to learn how to minimize the complications associated with diabetes. A key component of this effort concerns how actively people manage their diabetes and adhere to treatment recommendations.

Treatment for diabetes involves several options depending on the level of disease progression, with each treatment option offering potential benefits and risks. Benefit and risk assessment is the process of examining the pros (benefits) and cons (risks) of a treatment, and using this information to inform decision-making. The literature indicates that people generally want information regarding both treatment benefits and risks, and typically want more information about risks and side effects than they are currently given.<sup>3-7</sup> However, there is a dearth of literature regarding how patients understand diabetes treatments benefits and risks. This study sought to examine how people with type 2 diabetes define the benefits and risks of treatments, and whether this information is used to assist with the decision-making process.

## METHODS

The methodology for this study was qualitative and a grounded theory approach was utilized.<sup>8-11</sup> The primary research question for this study was: What are diabetic people's experiences of treatment benefit and risk assessment when making a treatment decision? The term 'treatment' was conceptualised broadly to encompass any clinician recommendation or action that the participants considered taking or doing for the management of diabetes, such as oral agents, lifestyle modification, or insulin. 'Benefits' and 'risks' were considered to be the positive and negative aspects, respectively, of each treatment that the participants had discussed with their physician (or other clinician), discovered on their own, or believed to be relevant to their health. The Research Ethics Board at St. Joseph's Healthcare Hamilton approved this study.

### Recruitment and Sampling

All participants volunteered to take part in this study. The inclusion criteria included: age (18

years or older) and diagnosis (a formal medical diagnosis of type 2 diabetes for at least 1 year). This study also sought participants using a range of treatment modalities (diet control, oral hypoglycaemic medication, insulin). People who were not able to speak English, had gestational diabetes, or who had a cognitive deficit (as evaluated by the interviewer when someone called to express interest in participating in the study) were excluded. Participants were recruited through advertisements in local diabetes newsletters and in local hospitals (including the diabetes clinic), and through a website request for participants at the local university.

At the onset of this study, purposeful and convenience sampling<sup>8</sup> were used to elicit a wide range of data. As the study progressed, more specific criteria were used for sampling (theoretical sampling) to target the search for people who could provide data to address any gaps in the emerging analytic picture. For example, approximately midway through the study it became evident that participants who were responding to the study were very similar in nature. These participants described themselves as successful in their attempts to manage diabetes. As a result, a more focused effort was made to seek out people that had encountered difficulties with their diabetes, or people who were still struggling with coming to terms with having diabetes. Data collection continued until no new information resulted from the interviews and primary themes were saturated.<sup>12</sup>

### Data Collection and Organization

All participants took part in a single, individual, in-depth interview. Interviews took place at a location determined by the participants, with reimbursement provided for any transportation costs. The principal investigator (KN) conducted all the interviews. A focus group was held near the end of the analysis process as a means of "member checking"<sup>13</sup> the interpretation of the data.

All interviews were conducted using a semi-structured interview guide that was modified throughout the data collection process to accommodate emerging themes. Interviews were audio taped and transcribed verbatim by a professional transcriber. Any personally identifying information was removed from the transcript and

participants were given a unique code number. Transcripts were organized using QSR NVivo.<sup>14</sup>

### Data Analysis

Data analysis began as soon as the interviews started, using the constant comparative approach in which data are repeatedly examined for examples of the categories that will comprise the emerging theory or model.<sup>11:15</sup> A thematic analysis of the data was conducted using open and axial coding techniques.<sup>9</sup> Analysis was completed primarily by the principal investigator (KN), with co-investigators providing input and feedback regarding the analysis process and emerging themes at regular intervals throughout the study. Participants attending the focus group concurred with the interpretation of their experiences and there was concordance between the focus group and the interviews.

## RESULTS

### Description of Participants

Eighteen participants took part in this study. The mean age of participants was 60.0 years (SD=13.3, median=55.0). Ten people (55.6%) were female, and four people (22.2%) had been diagnosed with diabetes within the last 2 years. Nine participants (50%) had completed high school or had some high school education; the rest had a university or college education. Of note, 3 people (17%) had doctoral degrees. On average, interviews lasted approximately one hour (Min:20 minutes, Max: 90 minutes).

The mean number of years with diabetes was 10.7 (SD=12.2, median=6.0). Fifteen participants (83%) received their primary diabetes care from a family physician, with the remaining 3 participants seeing a diabetes specialist at a clinic. Four other participants also regularly attended a diabetes clinic. Those patients attending a diabetes clinic also noted nurses and dietitians/nutritionists as providers of diabetes care.

### Overall Theme

#### ***“I take what I think works for me”***

The primary sentiment expressed by participants was: “I take what I think works for me” (Int17-125). It was evident that participants’ own perception of the value of a particular treatment was the prevailing factor that influenced treatment

decision-making. Underlying this were four factors that contributed to participants’ determination of what ‘worked for them’:

1. personal perception of benefits and risks of a treatment,
2. disease management and lifestyle impacts,
3. decision-making expectations and experiences,
4. treatment information sources and needs.

### Personal Perception of Benefits and Risks

Participants had varying degrees of understanding about the benefits and risks of treatment for diabetes. Although some people could not differentiate between the symptoms or other manifestations of their diabetes and adverse effects of treatments, most participants were knowledgeable about the benefits that diabetes treatments could provide.

### Treatment Benefits

The main benefits of their treatments that people mentioned included: feeling healthier, living longer, increased understanding of disease, improvement in their quality of life, more stable blood sugar levels, decreased likelihood of complications, and avoiding the appearance of further diabetic symptoms.

*“Well, it does lower my blood sugar. It makes me more aware. And I think going on medication was good for me, because when I was diet controlled I wasn’t always cognizant [of my diabetes]. But now I check my blood and say, ‘Oh yeah, that does make a difference.’ It clearly does do what it is supposed to do.” (Int17-141)*

It was apparent that people who were more recently diagnosed did not comprehend the potential benefits and risks of treatments to the same degree as those who had more experience with their disease. These participants used tentative language when describing treatment benefits.

*“Well, hopefully it will give me a better quality of life.” (Int11-48), and “Umm, obviously [my goal is] the avoidance of diabetic symptoms and probably a healthier lifestyle.” (Int13-44)*

There were also differences in participants' expectations for treatments depending on the type of treatment that participants were taking or doing. Lifestyle changes were associated with increased energy, feeling better about oneself, and improved general well being.

*“I think it's the fact that there was positive reinforcement early on. I started from a very low position [was very ill with diabetic symptoms]. The treatment very rapidly made me feel better; positive reinforcement. As luck would have it, I had been exercising for a couple of years before. As soon as I reduced the sugar, I actually began to get the benefit of that exercise; positive reinforcement.”*  
(Int3-90)

For those taking oral hypoglycaemics, there was an increased recognition of having a serious chronic illness and the importance of medication in controlling blood sugar levels and preventing complications. Older participants equated diabetes treatments with helping to maximize the number of years of good health they had.

### **Treatment Risks**

The treatment risks identified by participants were broader than simply physiological outcomes (e.g. hypoglycaemia), and encompassed any barrier the proposed treatment could impose. Medication cost and number of medications were perceived as risks when starting a treatment, as was the potential for no benefit to health. For some people, taking yet another medication was avoided as they believed they were already taking too many medications. The main risks or downsides associated with treatment recommendations also varied by treatment. Interestingly, most participants conceptualised the difficulty of diet restrictions and of trying to maintain a regular exercise schedule as treatment risks.

Past experience with adverse effects due to medication triggered participants to consciously assess whether the risks of a treatment were worth the potential benefits it could offer. For some participants, the risks associated with side effects from a treatment were greater than the potential benefits. In these cases, participants were apt to stop their medication.

*“I can live with it high [blood sugar levels] better than living with it on the pills, because on the pills I was not living happily. I hated having to keep checking it all the time. It went up and down so low and fast, and [then] high, that I never knew what to expect, or couldn't seem to depend on a certain reaction to something. And I was very frustrated on all those pills.”* (Int6-41)

Other people were willing to cope with the inconvenience of treatment side effects if they believed that the treatment was working. Most participants were willing to tolerate them for a short while in anticipation that they would dissipate once their bodies became accustomed to the medication.

*“When I found out later on what the side effects are I thought, ‘Oh well, that's better than having this up and down all the time [in blood sugar levels].’ But I think for me, any medication probably takes a long time for my body to get attuned to it, so I'll give it a good year before my body can get used to it.”*  
(Int8-54)

For more major side effects, participants often stopped their medication on their own and then called their physician for guidance. In general, however, it was only through deliberate probing during interviews that this pattern was revealed.

The participants taking insulin (n=5) talked about their initial discomfort with and resistance to being on insulin. Potential risks of insulin included discomfort of giving injections, hypoglycaemia, and the need for a routine to regularly administer insulin injections.

### **Disease Management and Lifestyle Impacts**

The majority of study participants used oral hypoglycaemic medication to manage their diabetes (n=11, 61.1%), followed by insulin (n=5, 27.8%) and a regulated diet (n=2, 11.1%). Interestingly, as people moved from less to more intensely biomedical treatments (e.g. from diet therapy to oral medications to insulin), there was a lessened expectation for the treatment they had previously been following to work well. Further,

more participants conceptualised themselves as using only *one* form of treatment even though they may have been using two or more treatments (e.g. oral hypoglycaemic medication plus insulin). As a result, many people on insulin or oral hypoglycaemic medication had to be prompted to discuss whether they were engaging in diet changes or exercise.

Two participants had initiated treatment with an alternative remedy and later had stopped it because of the lack of improvement in their blood sugar levels. Another four people were taking, or had tried, alternative medications for other conditions. Some participants articulated their dislike for prescribed medications, indicating that they preferred more natural remedies. In general, participants who tried alternative medications did so without consulting their physician, typically relying on the advice of a family member or friend, or on their own research.

People talked about different periods in their lives when their diabetes was better or worse controlled. In some cases, poor control was attributed to their own lack of self-management. In other cases, patients were aware that despite their adherence to treatment recommendations, their disease was progressing. A number of participants described not being ready to make changes when they were first diagnosed and found that they only began to maintain control of their diabetes after a “switch” went off for them:

*“I’m sure you will meet various people who have had weight problems all their lives. With me, there have been many times when I lost the weight, but it’s a mindset. You have to have this little switch go off in your head saying, ‘Okay, I have to do something about this.’ And no persuasion from outside is any good whatsoever. It’s gotta come from within. And you gotta get something to trigger it.” (Int3-98)*

Five participants (*Int5*, *Int6*, *Int10*, *Int12*, and *Int16*) had experienced complications that they attributed to diabetes. These complications included nerve damage in the feet (*Int6*, *Int10*), decreased kidney function (*Int12*), mini-stroke (*Int6*), and vision problems (*Int5*). One person (*Int16*) had had two toes amputated, triple bypass

surgery, a kidney transplant, and diabetic retinopathy. All of these participants felt that the seriousness of these complications reinforced the desire to effectively control their blood sugar levels. However, many participants acknowledged that it was difficult to make these changes without any direct symptoms associated with the damage that was occurring:

*“With diabetes, you have nothing [wrong with you] until something else, which is caused by the damage, hits you. I mean, even when I was told that my kidney function had dropped from 100% down to 80%, even then I didn’t pay too much attention. Because that’s another thing; that doesn’t hurt, doesn’t ache. And I wasn’t told that this was caused by the diabetes. I didn’t know there was a link between the two things until much later.” (Int16-56)*

For most participants in this study, integrating diabetes self-management behaviours into their lives, such as maintaining a healthy diet and weight through exercise and food choices, was seen as a challenging but necessary task, and even a personal responsibility. Participants acknowledged that they played a vital role in the management of their own diabetes, yet this did not always translate into adherent behaviour.

### **Decision - Making Expectations and Experiences**

Several participants expressed the view that treatment decision-making was a life-long process that required ongoing discussions and experimentation to find the optimal treatment. As such, benefit and risk assessment was also seen as an ongoing process.

*“I find I have a good relationship with my family practice guy in the sense [that] it is kind of a collaboration. I hear about something and I will discuss it with him, and we will try things. He said, ‘Try this first and then if it doesn’t work, come back.’ You never know - side effects, interactions; you have to be aware [of them] and you have to be willing to have this sharing with your doctor. That means you have to have an exceptional doctor.” (Int18-58)*

Participants identified a number of clinician characteristics that promoted an effective decision-making relationship. These included being knowledgeable, open to dialogue, listening attentively, able to recall the patient's medical history, taking time with a patient, providing referrals to specialists who were easy to access quickly, providing information, and explaining reasons for their treatment recommendations. Most people noted that their physicians independently made treatment decisions for them, which they found to be satisfactory:

*“I think, for the main part, I trust the doctor in what they (sic) are prescribing.” (Int14-111)...“I will just more or less accept the doctor's decision.” (Int114-113)*

Many participants mentioned wanting to have individualized care from their physician, where treatments and care were tailored to their own personal situations. There were three participants who indicated that they did not have a positive relationship with their physician. They were more likely to listen to what the physician said in a clinical encounter and then do something entirely different once they left the physician's office than other people in this study. Here, the interplay between benefit and risk assessment and relationships dynamics is evident.

### **Treatment Information Sources and Needs**

Participants cited having adequate information about a prescribed or recommended treatment as a key factor in their treatment benefit and risk assessment. A lack of knowledge or understanding about a particular treatment increased the likelihood that the treatment would not be taken. Typical information sources included physicians, pharmacists, nurses, and dieticians.

Many participants also independently sought information about diabetes and its associated treatments to fill knowledge gaps from sources such as: national diabetes association, local newsletters, the Internet, books, magazines, and newspapers. Participants also expressed the view that their information needs changed over time, and that it was only through experience that they discovered unanswered questions or information gaps.

*“I had to find these things out on my own. I was warned about an insulin reaction, that I would have to eat [to counteract hypoglycaemia] and what to do if I had one. I remember that was emphasized. [But] until I actually experienced one, I couldn't really tell what they were talking about.” (Int9-91)*

## **DISCUSSION**

A key theme identified in this research was participants' attempt to balance benefits and risks according to their own expectations and experiences. This concept of seeking balance has been documented in previous studies of people with type 2 diabetes,<sup>16,17</sup> but not in relation to treatment benefit and risk assessment. Balance for participants in this study implied taking into consideration a wide range of factors in an effort to maintain a “homeostatic balance”. This meant minimizing symptoms, minimizing side effects, and maximizing health to create balance in their overall lives. Not surprisingly, participants identified issues that they considered relevant to treatment risk-benefit analyses that lay outside the clinical realm (e.g. medication cost, influence on daily routine or family life, etc). This is similar to Kleinman's distinction between disease (biomedical focus) and illness (how people cope and live with a health problem).<sup>18</sup>

In this study, people with diabetes who were able to articulate what they considered to be benefits and risks of their treatment seemed more confident about their treatment decisions and self-reported higher levels of treatment adherence. In addition, people who had been more recently diagnosed with type 2 diabetes or had no other medical conditions did not seem to be as able to discuss their conceptions of benefit and risk. Experience with a disease can help people better assess what they would be willing to accept with regards to treatment.<sup>16,19</sup>

Decision-making was an *ongoing* process that involved daily choices about how and when to implement self-management strategies (e.g. food choices or exercise) and whether or not to adhere to therapeutics regimens. For most participants, discussing treatment benefits and

risks was not a common experience or a conscious process. Similar to other studies, many people felt that they had not received enough or any information about recommended treatments.<sup>20,21</sup> This lack of knowledge may have negatively affected their ability to talk about treatment beliefs. However, even for participants satisfied with the type and amount of information they had received or found, assessing treatment benefits and risks was typically not a conscious process. This implies that although people with diabetes make many decisions related to their diabetes care, they may not always be aware of how they decide what to do. For some people in this study, the belief that one should not take some or any prescribed medications is an example of how an underlying belief system influences the weighing of benefits and side effects associated with a particular treatment.

For many participants, treatments were only conceptualised in terms of medications, highlighting what patients with diabetes prioritise in terms of treatment. Other research has also suggested that patients with diabetes who are taking medication, sometimes feel that this lessens the necessity for control of lifestyle factors because their disease is already being treated.<sup>22</sup>

Participants' expectations and needs regarding their relationships with their health care professionals were congruent with the current literature, reinforcing that basic communication processes, such as active listening and information sharing, are essential to the development of successful relationships.<sup>23-25</sup> Of particular note is participants' mention of wanting personalized and individualized care from their physician. People with diabetes in this study did not want to be treated 'as a number'. They wanted their personal life situations factored into treatment recommendations. If this did not happen, some patients took steps towards individualizing their treatment regimens to suit their own unique situations (e.g. stopping medication). This reinforces the need for health care providers to take a proactive role in developing treatment regimens that include input from patients and regular assessment of how this is working.<sup>23,25-27</sup>

The findings of this study are concordant with prevalent social cognition models such as Self-Efficacy Theory and the Health Belief Model<sup>28,29</sup> as well as the transtheoretical Model of

Change (or Stages of Change Model).<sup>30</sup> These models suggest that change is an ongoing process that will result in both successes and failures; people must feel ready to successfully execute a change; and people must also believe in their ability to make a needed change. In this study, readiness to change (i.e. adherence to treatment recommendations) was linked to participants' perception of the value of the treatment, which was based on an individual's benefit and risk assessment, as well as their ability to successfully implement the change.

### **Implications for Clinical Practice**

In this study, although participants were able to list many benefits and risks of recommended treatments, this information was typically not consciously part of the decision-making process. Even with research questions framed in lay language, participants often needed encouragement (probe questions) to elucidate these factors. Therefore, for clinicians who want to better understand why their patients make the decisions they do and the benefits and risks that they have considered, time and care will be needed to allow people to articulate these for themselves. Within the context of a research interview, people felt comfortable talking about a variety of issues that may not emerge within in a clinical encounter. With many patients voicing concerns about the lack of time to raise issues with physicians, it is unlikely that patients may have the opportunity to discuss some of these deeper underlying issues.

It is therefore incumbent on physicians to ask questions that will elucidate the beliefs, values, and concerns of patients related to potential treatments for their diabetes:

1. What information would you like to know about this treatment?
2. What are you hoping this treatment will do for you?
3. What would you do if this treatment does not work in the way that you expect it to?
4. Are there any risks or barriers that you see with this treatment? What are some strategies that could be used to deal with them? Are you concerned about the costs associated with this treatment?
5. What do you hope these alternative medications you are suggesting will do for you?

6. Do you have any concerns about the overall number of medications that you are taking?
7. How will managing your diabetes fit into your life, including the way you manage other health concerns?

Regular assessment of the above issues by physicians will be necessary because the priorities of people with diabetes will shift and change over time. As well, patients will experience their own unique challenges and concerns, necessitating an individualized approach to diabetes care.

### Study Limitations

Although people using a wide range of treatment modalities were sought for this study, there were disproportionately more people using oral hypoglycaemic medication than diet therapy or insulin. As well, the distribution of participants across various treatments varied from that of the Canadian primary care setting, where 73%, 12%, and 15% of patients were on oral hypoglycaemics, insulin, or lifestyle changes, respectively.<sup>31</sup> Despite many commonalities across groups, the experiences, expectations, and needs of patients who are taking insulin, oral hypoglycaemic medication, or making diet changes likely differ, and this warrants further exploration.

Likewise, although five of the 18 participants had experienced complications as a result of their diabetes, only one had had several more serious complications. Previous literature has indicated that disease complications are often the catalyst for better self-management and treatment adherence.<sup>32;33</sup> It would be of interest to know whether treatment benefit and risk assessment also differs for people with more serious complications of diabetes, such as kidney failure, blindness or amputation. Recruiting patients directly from a hospital after an admission for a diabetes-related complication would help answer this question. As well, further research with those who have experienced a major vascular complication, such as myocardial infarction, would be useful to explore.

### CONCLUSIONS

People with diabetes are engaged in a cycle of dynamic decision-making, balancing potential and actual risks of treatments with their benefits to

gain a sense of control, balance, and mastery in their lives. By explicitly discussing with patients their perceptions of treatment benefits and risks, both patients and health care providers can come to a better understanding of what influences a particular person's treatment decision-making and adherence patterns.

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