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## Adult Patient Perspectives on Care for Type 1 and Type 2 Diabetes Across the Institute of Medicine's 6 Domains of Quality



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### Key Messages

- A comprehensive view on quality of diabetes care can be drawn from the Institute of Medicine's 6 quality domains.
- People with diabetes expect high-quality care to include all 6 domains with a stronger emphasis on safe, effective and patient-centred care.
- Future diabetes program evaluations should incorporate a comprehensive patient-informed view of what constitutes high-quality care.

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### ABSTRACT

**Objectives:** To gather patient perspectives on quality of care provided in diabetes clinics within the framework of the Institute of Medicine's 6 domains of quality.

**Methods:** A qualitative study including semi-structured interviews was conducted at 5 academic hospital sites. Transcripts were analyzed using a direct content approach for themes and subthemes with saturation of themes achieved. Purposive sampling was conducted at 5 diabetes clinics (n=47 interviews).

**Results:** The median age of participants was 50 years with a mean duration of diabetes of 14 years; 53% of participants were male, 57% had type 2 diabetes and 81% were using insulin. Patients ranked safety as the most important Institute of Medicine domain, followed by the domains effective, patient-centred, timely, equitable and efficient. Their expectations spanned the first 4 Institute of Medicine domains. They expressed a desire for a knowledgeable, caring, available and communicative team that assist with self-management and overall control of diabetes (effective, patient-centred and timely). They wanted to avoid diabetes complications, including hypoglycemia (safe and effective). They wanted to share in care planning and achieve personalized goals (patient-centred). Efficient and equitable care were not prioritized as highly, but many patients expressed concerns about the costs of medications and insulin supplies.

**Conclusion:** Patients' views of high-quality diabetes care include all 6 domains of quality with a stronger emphasis on safe, effective and patient-centred care. Future evaluation of diabetes programs should incorporate a comprehensive and patient-informed approach to consideration of what constitutes high-quality care.

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### R É S U M É

**Objectifs :** Recueillir les points de vue des patients sur la qualité des soins dispensés dans les cliniques du diabète en fonction des 6 dimensions de la qualité définies par l'Institute of Medicine.

**Méthodologie :** Une étude qualitative comprenant des entrevues semi-structurées a été réalisée dans 5 établissements hospitaliers universitaires. Les transcriptions ont été l'objet d'une analyse de contenu directe par thèmes et sous-thèmes jusqu'à saturation des thèmes. L'échantillonnage par choix raisonné a eu lieu dans 5 cliniques du diabète (n=47 entrevues).

#### Mots clés :

expérience des patients

qualité des soins

diabète

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**Résultats :** L'âge médian des participants et la durée moyenne du diabète étaient respectivement de 50 et 14 ans; 53 % des participants étaient des hommes, 57 % présentaient un diabète de type 2 et 81 % prenaient de l'insuline. Les patients ont estimé que l'innocuité constituait la dimension la plus importante parmi celles définies par l'Institute of Medicine. Venaient ensuite les dimensions efficacité, priorisation du patient, opportunité, équité et efficacité. Leurs attentes englobaient les 4 premières dimensions définies par l'Institute of Medicine. Les patients ont exprimé le souhait de pouvoir compter sur le soutien d'une équipe compétente, attentive, disponible et communicative dans le cadre de la prise en charge personnelle et de la maîtrise globale du diabète (efficacité, priorisation du patient et opportunité). Ils voulaient éviter les complications du diabète, l'hypoglycémie notamment (innocuité et efficacité). En outre, ils désiraient participer à la planification des soins et atteindre des objectifs personnalisés (priorisation du patient). L'efficacité et l'équité des soins n'ont pas été autant priorisées, mais de nombreux patients ont exprimé des préoccupations au sujet du coût des médicaments et du matériel d'injection d'insuline.

**Conclusion :** Les points de vue exprimés par les patients sur les soins de haute qualité à dispenser aux diabétiques englobent les 6 dimensions de la qualité et mettent davantage l'accent sur l'innocuité, l'efficacité et la priorisation des patients. L'évaluation ultérieure des programmes axés sur le diabète devrait aborder la caractérisation des soins de haute qualité dans le cadre d'une démarche intégrant une optique globale et branchée sur la réalité du patient.

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## Introduction

Diabetes is a chronic disease with potentially devastating complications, affecting 1 in 12 people worldwide (1). Previous efforts to evaluate the quality of diabetes care have focused primarily on biologic outcome parameters (reaching target values for blood sugar, blood pressure and cholesterol) and process indicators (screening for complications) (2, 3). A systematic review provided insufficient evidence that many widely used diabetes quality indicators predict better patient outcomes (4). One explanation is that these indicators neglect to take into account the patients' experience with chronic disease management and their level of participation in their diabetes care plan (5). Achieving improvements in the quality of care provided for patients with diabetes requires a focus not only on biologic outcomes but also on the contextual factors that contribute to the poor adherence and resistance cited by providers as primary barriers to achieving optimal biologic targets (3). For example, the Diabetes Attitudes Wishes and Needs Study showed that high diabetes-related distress scores were common and the availability of person-centred chronic illness care was perceived as low. Further, only 48.8% of respondents had participated in diabetes educational programs to help manage their diabetes (6).

In contrast to the usual focus on biologic outcome parameters and process measures, a more comprehensive view on quality can be drawn from the Institute of Medicine's (IOM's) 6 quality domains: safe, effective, patient-centred, timely, efficient and equitable (7) (Table 1). Increasingly, patients and their families are being engaged in discussions and decisions around policies and service delivery to improve quality of care provided for chronic diseases (8–10). Balanced scorecard methodology is an analysis technique designed to translate an organization's mission statement and overall business strategy into specific,

quantifiable goals and to monitor the organization's performance in terms of achieving these goals. Scorecard methodology has been used successfully in several health-care organizations (11). We proposed to design a balanced scorecard with specific diabetes quality objectives, measures and targets within each of the 6 IOM domains of quality.

As part of this larger project to identify a balanced set of quality indicators, we undertook a qualitative study of individuals living with diabetes. The overarching purpose was to have patient input into the development of our balanced scorecard for specialty diabetes care.

## Patients and Methods

### Recruitment process

Patients were recruited from the ambulatory diabetes clinics at 5 university-affiliated hospitals in Toronto, Ontario, Canada. Participating endocrinologists and diabetes educators (nurses and dietitians) identified patients who met the study inclusion criteria (type 1 or type 2 diabetes, age >18 years, English speaking and able to give informed consent). Demographics were determined to ensure that the patients interviewed represented a broad range of experiences living with diabetes. At the end of each week, the demographics of participants were shared among the research team to ensure that nonrepresented groups could be targeted in future interviews.

### Sample

Participants were recruited from 5 hospitals in Toronto by means of a maximum variation sampling method. We sought to include representative individuals living with type 1 and 2 diabetes with variety in age, duration of diabetes and burden of complications. We specifically targeted vulnerable populations, such as ethnic minorities, those with low incomes and women who had recently given birth or who were currently pregnant. The target was a sample ranging from 6 to 10 participants per hospital site, allowing for flexibility while seeking saturation on key themes (12).

### Interview structure

A semi-structured interview guide (Appendix 1) was used to facilitate the individual interviews. The interview guide starts with open-ended questions about patient experiences and expectations related to diabetes care and then poses more specific questions about patient priorities within the 6 IOM quality domains (7). At the end of the interview, participants were asked to rank the IOM domains in order of importance to their diabetes care. The interview guide was refined based on emergent findings of interest (12). The interviews were digitally audiotaped and transcribed.

**Table 1**  
Institute of Medicine quality domains framework (8)

Effective	Providing services based on scientific knowledge, to all who could benefit, and refraining from providing services to those not likely to benefit.
Safe	Avoiding injuries to patients from the care that is intended to help them.
Timely	Reducing waits and sometimes harmful delays for both those who receive and those who give care.
Equitable	Providing care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location or socioeconomic status.
Efficient	Avoiding waste, including waste of equipment, supplies, ideas and energy.
Patient-centred	Providing care that is respectful of and responsive to individual patient preferences, needs and values and ensuring that patient values guide all clinical decisions.

## Data analysis

Data were analyzed using a directed content analysis approach (13, 14), with the IOM's 6 quality domains as the a priori framework. Specifically, the analytical process involved 3 investigators (IJH, MM and LJ) and 4 research assistants independently reviewing transcripts, line by line, to identify sections of text that could serve as codes. There were 3 in-person meetings of the investigator team during which codes were organized by frequency into themes in the domain "patient experience expectations," as well as each IOM domain. Themes from the open-ended questions were cross-referenced to themes that emerged from responses to the more directed questions about the IOM domains. We used 2 methods to determine ranking of IOM domains. In the first method, the rank order was summed, with the lowest score representing the highest rank; in the second method, we tabulated the frequency with which each domain was ranked first.

## Ethical considerations

Ethical approval for the research was obtained from all 5 academic hospitals at the University of Toronto.

## Results

### Participant characteristics

Forty-eight participants were interviewed. The average interview lasted 37 minutes (range, 30 to 70 minutes). Demographics can be found in Table 2 and Table 3. All participants reported having

**Table 2**  
Demographics of interview participants

	N (%)
Male	25 (53)
Married or common law	28 (64)
Type 2	27 (57)
Taking insulin	38 (81)
Caucasian	30 (64)
Older adult (<30 years)	6 (19)
Elderly (>65 years)	14 (43)
Lesbian/gay/bisexual/transgendered	4 (16)
Recently pregnant	4 (12)
Born in Canada	29 (62)
Highest level of education	
High school	11 (25)
Postsecondary	24 (50)
Postgraduate	11 (25)
Estimated household income (CAD)	
<30,000	11 (25)
30–60,000	12 (27)
60–100,000	9 (20)
>100,000	12 (27)

**Table 3**  
Demographic details

Ethnicity/race	Count
White	30
Latin American	2
First Nations/Aboriginal	1
West Indian	7
South Asian	3
Asian	1
Middle Eastern	1
Filipino	1
Black	1
Other	1
Total	48

a family physician, but 42% reported never seeing their family physician specifically for diabetes care. Forty-six percent of participants reported seeing a speciality diabetes care team 4 or more times a year. The remaining 54% reported seeing a specialty team 2 or 3 times per year. Participants reported a range of complications including retinopathy (n=3), coronary heart disease (n=3), chronic kidney disease (n=3) and others such as neuropathy (n=1), mastopathy (n=1), Charcot foot (n=1) and diabetic ketoacidosis (n=1).

## Key Themes

### Experience and expectations of care

Before the IOM framework was introduced, patients were asked general questions about their experiences and expectations of care. Three major themes that represented 4 of the 6 IOM domains of quality emerged.

- 1) Having a knowledgeable, caring, available and communicative team that assist with self-management and overall control of diabetes (effective, patient-centred and timely)
- 2) Avoiding diabetes complications, including hypoglycemia (safe and effective).
- 3) Sharing in care planning and achieving personalized goals (patient-centred)

Efficient and equitable care were not commonly discussed in response to open-ended questions about experience and expectations. Table 4 lists the key themes derived from patients' experiences and expectations and how they overlap with the more specific responses obtained from the IOM framework questions and includes some representative quotes.

### Effective: Glucose control and support for living well with diabetes

The most frequently cited expectation was that good diabetes care involved controlling blood glucose levels. Participants understood the link between good glycemic control and avoidance of diabetes complications; avoidance of complications was a frequently emphasized expectation in the domains of expectations, effective and safe care. Participants emphasized the importance of providers being up to date on the latest evidence and technology. Specifically, they expect physicians to effectively communicate this knowledge to patients and provide rationales for the tests and treatments they recommend. Yet participants also expected the team to move beyond technical expertise and to provide more support for the psychologic aspects of living with diabetes.

However, participants also recognized the need for their own involvement in achieving these goals, reflecting on the importance of self-management of diabetes during the open-ended questions and in the domains of safe, effective and patient-centred care. Most participants expressed a general confidence in their ability to self-manage, which seemed to be in proportion to the adequacy of education and ongoing support provided by the diabetes team. Participants also recognized the important role they played in coming prepared to their appointments (having completed their blood tests and bringing in their self-management logs) and in the day-to-day management of their disease based on the lifestyle choices they made.

### Safe: Supporting patients to prevent hypoglycemia and other medication side effects

In addition to the expectation of avoiding diabetes complications, the safety concern most emphasized by patients was avoiding hypoglycemia. A minority expressed significant fear and lack of education on how to manage hypoglycemia. Most felt that hypoglycemia was something to monitor for and avoid, but because of adequate education and experience over time, they were not particularly concerned about experiencing hypoglycemia. Without

**Table 4**  
Key themes and Institute of Medicine quality domains represented with illustrative quotes

Themes	Safe	Effective	Timely	Patient-centred
Having a knowledgeable, caring, available and communicative team that assist with self-management and overall control of diabetes	<i>"Seeing [the] nurse... it's an educational thing... now I have a chart that I follow... never had that before. 'Cause nobody likes having a disease like that but at least now, I can deal, cope, and feel comfortable with it." (DS-01-003, 76-year-old male with type 2 diabetes for 7 years)</i>	<i>"They have taught me so much. In the last few years, I have learned more about my diabetes than I ever knew before. The team works together, and they help you learn..." (DS-02-006, 59-year-old female with type 1 diabetes for 50 years)</i> <i>"We could do more work in getting patients understanding. 'I want you to take your eye test once a year because...' 'I'm pushing a little straw because...' 'Checking to see if you have ingrown toenails because...'... I don't think we do that good of a job on effective from my perspective as a diabetic patient, because I don't know what care should be given to me, so I don't know if it's effective or not. I know what you do but is that based on effective research and evidence or is it just habit?" (DS-01-001, 56-year-old male with type 2 diabetes for 15 years)</i>	<i>"Well I... there's has been instances when I first was diagnosed with diabetes that I mean we were trying to work out the medications... it's a balancing thing, right? And sometimes things would go awry, a little bit awry and whenever I called the doctor it was immediate response. She called me, she even gave me her home phone number in case an emergency arose, so I've had no major issues." (DS-02-003, 65-year-old male with type 2 diabetes for 10 years)</i>	<i>"Especially with diabetes, it's not just a doctor telling you what to do. It's you taking charge of your body, and you doing what you're supposed to do. (DS-02-006, 59-year-old female with type 1 diabetes for 50 years)</i> <i>"It's more important to stop scaring us and just help us... There's probably something else going on that's preventing us from getting target blood glucose... I think it's more important to really get to know the person, figure out what's making them tick, what are they worried about, what are some of their barriers to good control. For me it was fear of low blood glucose. The fear of complications twenty years ago didn't outweigh the fear of dropping or fainting in front of my fellow classmates. (DS-05-005, 30-year-old female with type 1 diabetes for 13 years)</i> <i>"I really see the two sides of my diabetes care. There's the technical side, which is the pump therapy and the food charts and that cookie cutter type of care and then there's diving more into the psychological aspects of having diabetes and the more personal care... I would say that the technical is definitely emphasized over the personal... the psychological/personal care just needs to be more incorporated into the overall experience. (DS-02-001, 21-year-old female with type 1 diabetes for 14 years)</i>
Avoiding diabetes complications including hypoglycemia	<i>"There's not much the doctor can do on their own, other than educate you, and warn you about it, and ask you about the highs and lows you're experiencing... It's up to the patient to make sure they manage that properly, but the initial, when you first become insulin-dependent, that understanding is important, that education is important." (DS-03-009, 44-year-old male with type 1 diabetes for 18 years)</i>	<i>"When it comes to gangrene of the legs... the blindness, kidney failure, dialysis... the better you control your sugar levels now the less harm you're going to get down the road. (DS-04-003, 40-year-old male with type 2 diabetes for 12 years)</i>		
Sharing in care planning and achieving personalized goals		<i>"The team... have been very good at keeping me at the centre of the care they've been recommending and trying to make it work for my lifestyle and... so it's not rigid care, it's very fluent and fluid... he's very good at figuring out what my goals are, how to get to shared goals." (DS-05-005, 30-year-old female with type 1 diabetes for 13 years)</i>		<i>"Here at Hospital-X definitely [the doctors] have an attitude that I'm capable of taking care of myself, which I really appreciate because not all doctors have that approach. I would say my needs are met when my input is considered equally as valuable, and I'm treated like I know what I'm doing." (DS 03-002, 28-year-old female with type 1 diabetes for 13 years)</i>

**Table 5**

Quotes supporting the equity theme of poor diabetes self-management because of financial constraints

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"I knew that when I go back to work there's going to be no benefits (because the patient was receiving disability benefits from the government). No benefits mean no strips, no medications, no nothing. So, what I was doing I was only taking half of my medications every month and storing half. ... I'm not the only one doing this. There's a lot of people out there doing that. Again, these people, the diabetic teachers, the specialists, the nurses, the dietitians, they all say that they understand it, but the truth is, they don't." (DS-04-003 40-year-old male with type 2 diabetes for 12 years)

"I did have a job for about five to seven years where I didn't have insurance coverage, I found challenging, that was a lot of money every year for those. One endocrinologist I saw wasn't very understanding of wanting to switch me to certain things, and I was like, I can't afford to use those particular ... whether it was test strips, actually, the insulin. ... ." (DS-03-007, 36-year-old female with type 1 diabetes for 25 years)

"Just being able to purchase things because I'm using the food bank for most of my food right now, for the family. So, it can be frustrating with regards to not having fresh produce and things and it was getting really stressful because I thought it was negatively affecting my diabetes. But they (the team) gave me a lot of ideas with regards to the use of the beans and use of some of the canned items to still meet my goals around eating healthier." (DS-03-003, 38-year-old female with type 2 diabetes for 4 years)

"But I do know people that don't have proper coverage, aren't aware of the coverage they can have, and are not treating themselves nearly effectively, their doctors don't know enough about what is going on." (DS-05-003, 55-year-old male with type 1 diabetes for 53 years)

"...when you can only afford so much, I buy strips, 100 strips and instead of using three strips a day, I use one every day and test my blood once a day, but that's not good enough. Once a day is not good enough. You should be doing it three to four times a day, but if you cannot afford it, your back is against the wall. .... The needles to prick your fingers and the needles to inject your insulin, you have to buy it, you don't get that for free. You know what I mean? As a diabetic, those needles should be covered, but they're not. ... Re-using your needle in yourself is not safe. But, when your back's against the wall due to financial costs, you have to do that." (DS-04-003, 40-year-old male with type 2 diabetes for 12 years)

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being prompted, patients mentioned that driving while at risk for hypoglycemia was an important source of anxiety. When further questioned, some patients indicated that they had never received counselling on preventing and managing hypoglycemia while driving, whereas others felt their physicians mentioned this frequently. Another theme that emerged in the domain of safety was side effects from medications (9 codes). In addition, patients equated a feeling of safety with a higher degree of diabetes self-efficacy; that is, the more confident they were in their ability to manage their blood sugar levels, the safer they felt.

#### *Timely: Rapid and convenient access to advice*

Timely and flexible access to care (including advice for blood sugar management and referrals) was emphasized by participants as a general expectation of high-quality care. Participants expected to be able to access advice for blood sugar management over the phone or by e-mail. When questioned about response time for phone calls or e-mails, most felt it was important to hear back as quickly as possible. When participants were asked specifically about an acceptable wait time to see a specialist when they were first diagnosed with diabetes, responses varied based on the type of diabetes. Patients with type 1 diabetes felt that they needed to be seen by someone from the team right away, whereas patients with type 2 diabetes mentioned a range from right away to 2 months. When participants were asked about wait time on the day of an appointment, most felt that waiting more than 20 minutes was unacceptable.

#### *Patient-centred: Sharing in care planning and achieving personalized goals*

This theme reflects how patients want to be involved in setting and achieving personalized goals and decision-making around their treatment plan. During the open-ended and patient-centred components of the interviews, patients frequently highlighted the importance of setting and achieving goals for diabetes and lifestyle management. Patients repeatedly expressed that being an active participant in the decision-making process regarding their care was important. Patients also expressed a desire for personalized recommendations in which individual circumstances are taken into account. Of particular note, there was a specific desire for more personalized, culturally sensitive advice about exercise and diet.

#### *Equitable: Recognizing barriers to self-management*

Equity issues related to physical ability, race, culture, sexual orientation, disability or distance from the clinic did not come up when equitable care was discussed with interview participants. However, study participants described the limitations of the current provincial health insurance in Ontario, Canada. The most frequent subtheme

that emerged in the domain of equitable care was suboptimal adherence to diabetes self-management activities (checking blood glucose, injecting insulin, taking medication) because of financial constraints. Many patients commented that without private health insurance (Table 5), they would not be able to manage their disease. Others mentioned an ongoing inability to pay for medications, supplies and healthy food. An oddity with the Ontario provincial drug coverage also came up frequently. Insulin, injection pens and test strips are covered, but the lancets for capillary blood glucose testing and pen tip needles are not covered, forcing many patients to reuse these supplies, an unsafe practice.

#### *Efficient: Perceived importance of teamwork and routine appointments*

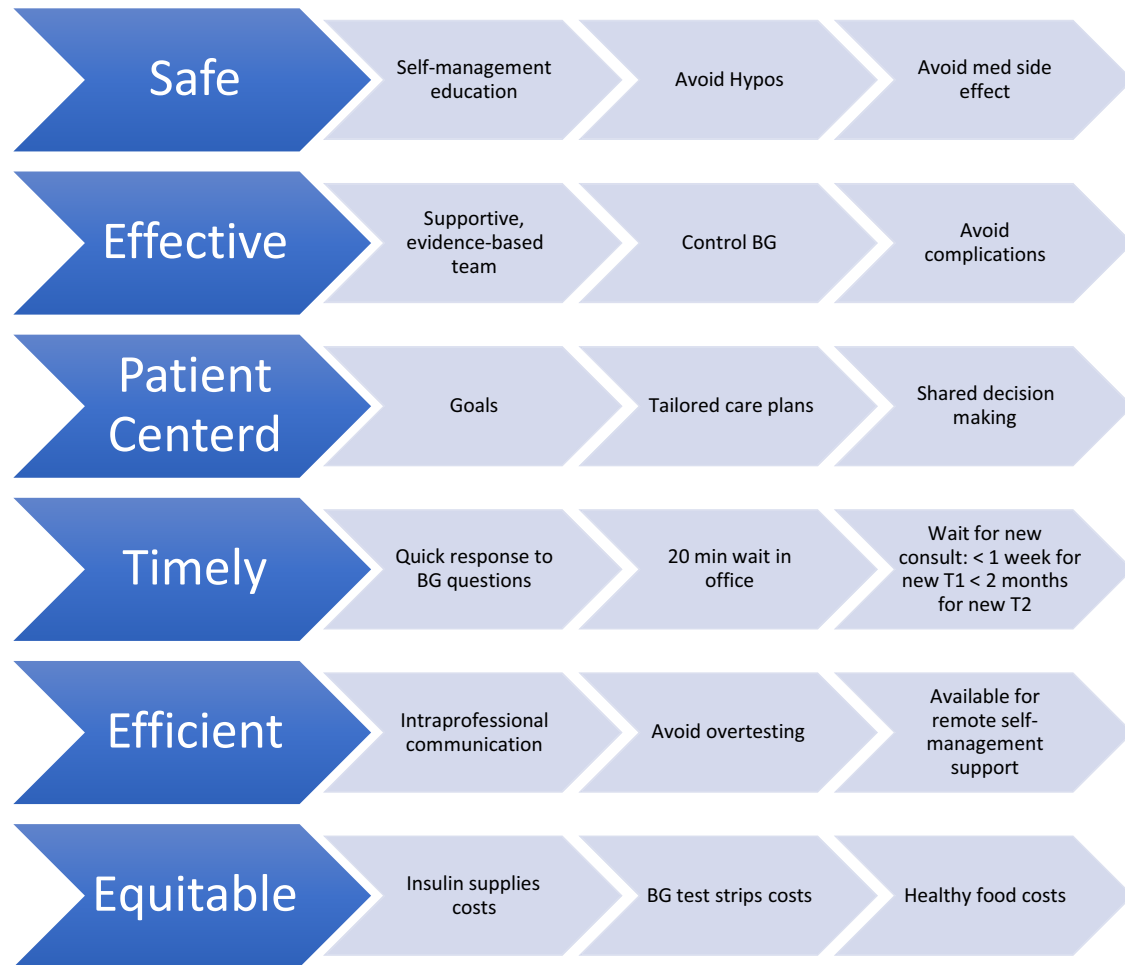
The majority of patients also felt that communication between diabetes care team members and primary and specialty care providers was well executed. A minority felt there was room for improvement of care coordination and interdisciplinary communication. Patients generally felt that the frequency of their appointments was appropriate to the degree of care required. Most patients interviewed felt that their diabetes care was quite efficient. A minority of patients interviewed felt that needing to see the specialist every 3 months when their diabetes was well controlled was excessive. A minority expressed frustration over repeated and duplicated blood tests.

#### *Ranking*

Based on the combination of 36 responses, patients value effective care most (rank sum 69). The domains of safe (rank sum 76), timely (rank sum 80) and patient-centred (rank sum 81) were ranked nearly equally, followed by equitable (rank sum 101) and efficient (rank sum 114). However, although the overall rank sum for effective was lowest, safe was most frequently ranked first (10), followed by patient-centred (9), then effective (8); timely, efficient and equitable were most unlikely to be ranked first with only 3 votes each. Combining both methods of assessing rank order leads to a final rank order of safe, effective, patient-centred, timely, efficient and equitable (Figure 1).

## **Discussion**

Understanding patients' perspectives as to what constitutes quality in health care is paramount, particularly in management of a chronic disease, such as diabetes, to ensure adequate self-management. Further, quality indicators are more reflective of



**Figure 1.** Institute of Medicine domains in rank order with key subthemes. *BG*, Blood glucose; *Hypos*, hypoglycemia; *med*, medication; *T1*, type 1 diabetes; *T2*, type 2 diabetes.

the broad definition of quality when patients' perspectives are considered in the development and selection (8). Using the IOM's 6 domains of quality framework, our study findings support the growing body of literature suggesting that a broader view of quality diabetes care includes patients' experiences and expectations (6, 15–17).

There was no consensus from the patients on which domain was most important in the delivery of high-quality diabetes care. However, there was a clear preference for care that encompasses elements of safety, effectiveness and patient-centredness. When the rank sum approach was used, the quality domain of effective was rated highest by our participants, and achieving good control of blood sugar through clear communication of evidence-based care is their top priority. Fortunately, technical quality (high adherence to process-of-care guidelines) is associated with improved patient experience in other studies (18). The ranking by our participants is in contrast to findings from a qualitative study in the Netherlands assessing stakeholders' (providers, insurers, policymakers and patient advocacy groups) perspectives on IOM quality domains for diabetes care, which showed that most stakeholders prioritized patient-centredness above the other domains. Secondary priority was assigned to safety, effectiveness and timeliness, whereas insurers also prioritized efficiency (9). Perhaps the reason patient-centred care was ranked lower in terms of importance in our study is that many participants defined effective care as involving patient-centred elements, such as empathic communication, support for the psychologic aspects of living with diabetes, and setting and achieving

shared goals. This broader view of effectiveness in diabetes care held by patients in our study illustrates the importance of working with patients to determine what constitutes high-quality care.

In keeping with our findings, effective communication and shared decision-making have been shown to improve adherence to provider recommendations (19), thereby resulting in more effective control of diabetes and avoidance of complications. The value of the expertise of the team (endocrinologist, nurse educator and dietitian) and their engagement with patients in efforts to promote self-management and enhance adherence emerged as a key theme, building on prior work showing that lack of continuity of care and limited access had a negative effect on patient experience (20), whereas empathic communication and shared decision-making positively contribute to productive interactions (21). Participants in our study also emphasized the important role that the specialty clinic can play in supporting the development of self-management skills. Our findings regarding the importance of self-management for achieving both glucose control (effectiveness) and avoiding hypoglycemia (safety) are similar to those of previous studies, which demonstrated that better understanding of the disease and self-management skills are associated with fewer adverse events (17, 22).

In Ontario, Canada, the provincial health insurance provides universal access to physician, dietitian and nurse services for those with diabetes; however, medications and diabetes supplies are only provided for those who are older than 65 years or who are receiving social assistance. In our study, patients who were unable to afford

medications and supplies admitted to poor medication adherence and self-management. This adds to the growing body of literature that links financial barriers and high out-of-pocket costs for patients with diabetes to less frequent diabetes care and increased vascular morbidity (23, 24). One study, from our jurisdiction, indicated that the association between lower socioeconomic status and diabetes morbidity and mortality rates disappeared in the population older than 65 years; this was postulated to be due to universal drug coverage for these older patients (25). A systematic review from 2007 established consistent links between medication nonadherence—not only due to costs and financial burden but also due to symptoms of depression—and heavy disease burden (26). Thus it is not surprising that studies have shown that a trusting patient-physician relationship may partially mitigate poor medication adherence caused by high out-of-pocket costs (27). Front-line providers, however, can only do so much to alleviate financial burdens for patients, so these collective findings need to inform policymakers in decision-making discussions related to universal coverage for pharmaceuticals.

A major strength of our study was our large and diverse sample of patients representative of the general population of Canada (28), with just under 40% identifying as being part of a visible minority. However, given that we are a specialty clinic, we purposely oversampled those with type 1 diabetes, which may increase the nonvisible minority population. Our study is the first qualitative report to use the IOM framework of 6 quality domains to assess patient expectations and experiences of chronic diabetes management. Our work demonstrates how qualitative interviews in which the IOM framework is used can help to establish patient priorities for quality of care. This framework could be applied to other chronic diseases or the experience of primary, specialty or long-term care. However, our study does have some limitations. Although it was conducted at multiple sites, they were all academic, specialty clinics located in a large urban centre, potentially limiting the transferability of our results. The frequency with which the patients saw specialists and the lack of primary care for diabetes suggest that our population was more complex and may not be representative of primary care populations. Priorities and expectations of patients who receive their diabetes care from primary care clinics or in a rural location may differ significantly from those found in this study. In addition, equity issues related to gender, sexual orientation and accessibility were not commonly raised, possibly reflecting a selection bias. Equity issues related to access to care and costs of diabetes medications and supplies may be very different in a different health insurance context. Finally, given that only English-speaking patients were represented in this sample, barriers specific to immigrants and non-English-speaking individuals could not be explored.

Measurement of quality in diabetes has been occurring for more than 2 decades (2). More recently, there has been a shift toward evaluation and benchmarking of patient experience data (6, 29). There is a growing push for patients to be actively involved in selecting quality indicators and determining priorities for quality improvement (30, 31). Our study adds to the literature by establishing the priorities for patients across each of the IOM domains of quality and provides clear direction for the selection of quality indicators for monitoring specialty diabetes care. (See Supplemental Material for what was provided to the Delphi Panel.) Future research will focus on how the 6 domains of quality can be operationalized into indicators for quality improvement purposes.

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## Author Disclosures

The authors have no relevant conflicts of interest to declare.

## Novelty Statement

- The Institute of Medicine definition of quality is broader than clinical effectiveness.
- Patients' views of high-quality diabetes care include all six domains of quality with a stronger emphasis on safe, effective and patient-centred care. Future evaluation of diabetes programs should incorporate a comprehensive and patient-informed approach to consideration of what constitutes high-quality care.

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## Appendix 1: Developing an Innovative Balanced Score Card for Diabetes Care – Qualitative Arm

### Interview Questions Stage 1

Thank you for taking the time to participate in this interview. Across the University of Toronto we are interviewing patients to understand their views on high quality care in diabetes. The information we gather will be used to help develop a list of measures on which the diabetes programs will be evaluated. We are planning to design a diabetes score card that will be used to monitor and benchmark key measures for quality diabetes care.

We will start by asking you a series of open-ended questions about your experiences with the care you have received and finish by having you rank certain broad categories in terms of the importance to you.

1. Tell me about your care that you have received for your diabetes here at [insert hospital]
 

Prompt(s)

  - Tell me about your most recent care experience
  - Describe a care experience when your care needs were met or were not met.
2. What are your expectations around your care for diabetes at [insert hospital]?
 

Prompt(s)

  - What do you think should happen around your care at [insert hospital]?
3. Can you describe a time in your experience living with diabetes (not necessarily at this hospital) where you received high quality or low quality care?
 

Prompts:

  - How did you know it was a quality experience?
  - What would be ‘measures of success’ of a quality experience?
4. There are six dimensions (aspects?) of quality in health care. Let’s discuss what quality diabetes care means to you in each of these domains: (You may choose to show patients appendix H if you think this will be helpful)
  - 4a. The first is SAFETY- making sure you feel safe while managing your diabetes. Is there an area of your diabetes care that you feel at risk or a potential for harm?
 

Prompt: how confident do you feel in managing low blood sugars? Do you feel safe managing your diabetes when you get sick (flu, gastroenteritis, diarrhea, fever)? Do you have concerns about the side effects of your diabetes medications or interactions with other medications, over-the-counter therapies or alternative therapies?
  - 4b. The second is TIMELY: getting the diabetes care you need in a timely manner with minimal wait times; how have wait times or delays affected your diabetes experience?
 

Prompt: how long do you think a person with diabetes should wait to see a diabetes health professional (GP, RN, RD, SW, Chiropractist, ophthalmology, nephrology). How long to you have to wait to see your diabetes care team for an urgent matter, how long is it reasonable to wait at the lab to have your blood drawn or in the waiting room for a specialist to see you on the day of your appointment?
  - 4c. The third is EFFECTIVE- care that has been shown to be effective in improving the short and long term health outcomes of patients with diabetes. How do you know if you have received effective care?
 

Prompt: For example, Are you familiar with certain exams the doctor should do at every visit or once a year (eye, feet, weight) and certain tests that should be ordered regularly. Are you familiar with the long-term benefits of the medications you are taking for your diabetes and its complications?
  - 4d. The fourth is EFFICIENT- care that does not waste and over use health care resources; What areas of your diabetes care do you think could be done more efficiently?
 

Prompt: Are there tests or procedures ordered by your diabetes team that you feel have been a waste of health care resources? Have you ever had your family doctor and the endocrinologist both request blood work within a month of each other? Have you had to repeat yourself to each member of your health care team? Have they not been aware of what other doctors have ordered or done?
  - 4e. The fifth is EQUITABLE- care that does not change based on social and financial considerations; have you encountered any barriers that prevented you from accessing the best care for your diabetes?
 

Prompt: Have financial constraints or any other barriers (distance, language, culture, etc. . .) ever kept you from filling prescriptions or following the advise of your health care team?
  - 4f. The last is PATIENT-CENTRED- care that is responsive to the patients’ individual values and involves them in their health care decisions; how do you see this relating to your diabetes experience?
 

Prompt: For example, has your provider ever asked you what is your biggest concern with respect to your diabetes? Has your provider ask you to set a goal for your own care. Has your provider taken your specific personal situation or circumstances into account?
5. Do you have any other suggestions for evaluating the quality of the care you receive here?
 

Prompts: or just improving the quality of the care you receive?

  - What is needed for you to experience quality care?
6. Is there anything we missed or that you feel would be important to talk about given the purpose of our study?

We have finished the interview. Thank you again for taking the time to participate and share your opinions with me today.