Title: Patients' perspectives on how to improve diabetes self-management
and medical care: a qualitative study

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Abstract:

Background: The experience of living with a chronic disease such as diabetes can provide valuable knowledge about medical care and self-management. Such knowledge may be of use to people seeking to improve diabetes self-management and to health professionals seeking to provide better patient-centered care.

Objective: To identify potential areas for improvement in diabetes care from the perspectives of people living with diabetes and their caregivers.

Methods: We interviewed 21 people living with diabetes (hereafter called expert patients) who were patient partners in a national Patient-Oriented Research network. Expert patients were men and women from various backgrounds, including Indigenous people and immigrants to Canada. They had significant lived experience of diabetes and were able to offer diverse patient and caregiver perspectives. Three authors independently analyzed videos using inductive framework analysis, identifying themes through discussion and consensus.

Results: From expert patients' perspective, people living with diabetes benefit from acknowledging and accepting the reality of diabetes, receiving support from their family and care team, and not letting diabetes control their lives. To improve diabetes care, health professionals should understand and acknowledge the impact of diabetes on patients and their families, and communicate with patients openly, respectfully, with empathy and cultural competency.

Conclusions: From the perspectives of expert patients, there are areas for improvements in diabetes care. These improvements are actionable individually by patients or health professionals and also collectively through collaboration between both groups. Improving the quality of care in diabetes is crucial for improving health outcomes in Canada.

Introduction

People caring for or living with a chronic disease are increasingly valued as experts based on their long-term experience with the condition and the health system. Expert patients provide a unique and meaningful perspective of care based on their disease-specific knowledge and experience of life with a chronic disease (1–3). Research on patient-to-patient education shows that patient perspectives are significantly relevant to diabetes self-management and may lead to improvements in clinical, lifestyle, and psychosocial outcomes (4–6). In other clinical contexts, such as rheumatoid arthritis, patients' expertise has helped health professionals improve patient-centered care (7). Although involving patients in their care is the standard of practice in diabetes (8), the experiences and perspectives of men and women of diverse backgrounds are often missing in studies examining the quality of care in diabetes. This is particularly true in Canada and similar industrialized countries, where the prevalence of diabetes among members of ethnocultural minorities is 2-5 times higher than in the general population (9,10). In this study, we draw on the perspectives of people living with diabetes to identify potential areas of improvement in diabetes self-management and health care.

Methods

Study design and study team

This was a qualitative narrative study. Our research team included researchers, clinicians and people living with different types of diabetes to encompass multiple perspectives (11).

Participants

People living with diabetes (hereafter called expert patients) were recruited during the annual meeting of Diabetes Action Canada, a national Patient-Oriented Research network that includes patients to bring expertise in diabetes care (12). Patient partners were identified through professional and personal networks, community-based organizations, and from respondents to a national survey (13). Prior to attending the annual Diabetes Action Canada meeting in May 2017 (Toronto, Canada), 23 expert patients received an email explaining the study, inviting them to participate and introducing each interviewer's training, background, and research interests. During the annual meeting, patients who voluntarily agreed to participate provided detailed consent regarding which ways they wished their interview to be used or not used (e.g., for analysis only, to show to other people with diabetes, to show to health professionals, etc.)

Data collection

A convenience sample of 21 expert patients (91% response rate) provided written consent and participated in 3-8 minute in-person video interviews conducted in English or French by one of three authors (RN, BB, HOW). Interviewers had clinical (BB) and research training (RN, HOW). We used any quiet place at the hotel setting to record the interviews. We used video so that segments could potentially be used in future learning modules for people with diabetes and health professionals. Interviews consisted of three questions: (a) What makes you feel healthy? (b) What knowledge, wisdom or advice do you want to share with other people like you living with diabetes about living well with diabetes? (c) What knowledge, wisdom or advice do you

want to share with health professionals who care for people living with diabetes like you or your loved one to help them provide better care? Since no interview's pretest was done, we gave expert patients the opportunity to see their initial recording and to record a new video if they wished to change their statements. Two expert patients chose to re-record sections of their interviews. Field notes were provided by all interviewers after data collection.

Analyses

Three authors (RN, SCD, HOW) conducted the analyses, using inductive framework analysis (14). All three independently reviewed the video recordings to become familiar with the content and identify initial codes. This process was influenced by the questions asked during the interview, and the goal of identifying segments that could be used in learning modules. They then came together to discuss why these segments were found to be meaningful, and to compare and group codes around similar themes and subthemes. These themes provided the initial analytical framework that was applied to all the video recordings. In subsequent rounds, analysts identified segments that were illustrative of each theme and synthesized findings in tables. They met repeatedly to compare, discuss and resolve any discrepancies found, and integrate their findings (15). Preliminary and final results were discussed with a committee of 9 expert patients, 8 of whom had participated in the study. Of these, three are co-authors (RP, AMM, PD). One of the researcher is living with diabetes (HOW).

Results

Expert patients' characteristics are provided in **Table 1**. Participants were 19-71 years old and had lived with the diabetes for 1-70 years. Five themes emerged from expert patients' perspectives to share with other people living with diabetes (**Table 2**).

Accepting that you have diabetes is an important step towards living well. Accepting the diagnosis or the disease is a key step towards living well with diabetes. Patients with all types of diabetes may need to work through denial, anger, or fear in order to accept the presence of the disease in their lives and move on to making positive lifestyle changes.

People with diabetes don't have to be defined or limited by diabetes. Expert patients emphasized that diabetes is a disease, not an identity or social role. Diabetes should not restrict people from pursuing their life goals. One expert patient noted that diabetes can serve as a 'wake-up call' that can push patients to accomplish more in their life than they might have without diabetes.

Diabetes is a constant, chronic condition with good and bad days. Living with diabetes can be compared to a rollercoaster. There are good and bad days and, "it's never going to be perfect." (P21, mother of a teen with type 1 diabetes). Therefore, it's important for patients to not be discouraged by bad days and aim for realistic self-management goals.

Self-management requires learning. People with diabetes need high quality evidence to guide their self-management. In addition to seeking knowledge from health professionals, expert patients recommended reading and attending conferences and education sessions when these

are available and feasible. Learning ‘tools and tricks’ from more experienced patients may also help ease the burden of self-management, especially when it comes to the challenge of implementing recommendations in one’s life.

Managing diabetes requires support, a good team, flexibility and taking responsibility.

Living well with diabetes is “hard work” (P7, woman with type 2 diabetes) that requires support. It’s beneficial for patients to work with an active team in order to find what works best for them in terms of treatment and self-management. Critical support often comes from family members through their actions (cooking, learning about diabetes, attending medical encounters with patients) and attitudes (patience, trust, understanding). Despite the importance of support, it is ultimately patients who are responsible for diabetes management to delay or decrease the chances of developing diabetes-related complications. Expert patients highlighted the importance of a healthy diet and regular physical activity. Some expert patients also noted the importance of taking responsibility for their medical care, especially during hospitalization, emergencies, or any situation involving health professionals outside their care team.

Nine themes emerged from expert patients’ discussion about how health professionals could provide better care to people with diabetes (**Table 3**).

Being diagnosed with diabetes can be frightening and this potential fear should be addressed by health professionals. Health professionals should be prepared to address patients’ negative emotions, especially fear, when they provide a diagnosis of diabetes. One expert patient also noted the insufficiency of giving newly diagnosed patients blood test meters but offering no education on how to use them from the start.

Diabetes puts a burden on patients and their families. The burden of diabetes and its management on other family members can include emotional, financial, logistical and physical impacts. For example, parents of children with diabetes and spouses of adults with diabetes may lose sleep to help manage their loved one’s blood glucose overnight.

Health professionals influence patients’ attitudes about their health and diabetes. Health professionals’ attitudes and communication significantly influence patients’ attitudes about how well, or how poorly they are doing. Health professionals should convey that they are there to help, and be honest with patients without being discouraging.

Health professionals can reinforce or alleviate the blame and shame that patients may feel. People with diabetes may feel blamed by health professionals for not being a ‘good diabetic’; for example, when their blood glucose levels are high. This can be discouraging for patients, and may damage motivation to improve. Patients may also blame themselves when things are not doing as well as they would like in their self-management. Health professionals can help by alleviating their negative perspective of themselves rather than reinforcing it.

Patients are people with lives beyond their diabetes. In expert patients’ experiences, health professionals often focus on the biomedical aspects of the disease without seeing the person in

front of them. Psychosocial challenges in patients' lives influence diabetes management and patients may not be able to prioritize diabetes management because of these challenges. Expert patients spoke warmly of health professionals who recognize life's challenges, suggesting that this helped them learn to trust those professionals.

It's important for health professionals to provide care that respects the social, cultural and historical contexts of patients. Each patient has a unique context of life. It is important to avoid stigma or labelling based on social status or personal characteristics, including implicit assumptions that some patients cannot understand or learn how to manage diabetes, that being overweight is the sole cause of diabetes, and the refusal to support patients in getting financial aid based on a prejudiced assumption that they would misuse the money. Indigenous expert patients, in particular, reported that a lack of respect toward Indigenous people is a barrier to good health. Health professionals need to be trained in trauma-informed care to better understand the impact of settler colonialism in Canada on Indigenous peoples' health outcomes. For example, a person who was often hungry as a child in a residential school may benefit from a different approach to meal planning.

Health professionals should ensure their knowledge about diabetes is up to date. Seeking and maintaining up-to-date academic, cultural and practical knowledge about diabetes is crucial to foster optimal health care, including when patients with diabetes are being treated for other health issues. This may be particularly relevant for health professionals who have less frequent contact with patients with diabetes, such as emergency department staff.

Patients need to be able to ask questions until they fully understand. Patients may struggle to understand medical jargon or highly technical terms. Patients appreciate health professionals who take time to explain the diagnosis and treatments in understandable ways, and make time to answer questions and ensure patients understanding.

Patients want to be part of decision making about their care. Expert patients valued health professionals who listen, explain available options (for example, regarding medication) and make patients feel heard. Lifestyle changes and self-management require sustained effort on the part of patients and that it's easier for patients to exert such effort when they've been truly involved in the decision-making process.

Interpretations

The goal of this study was to identify areas for improvement in diabetes care from the perspectives of a diverse group of expert patients. Our findings suggest avenues to improve diabetes care and management. For patients, expert patients noted the importance of accepting the realities of diabetes and tackling the challenges of self-management without limiting one's life because of diabetes. For health professionals, expert patients noted the importance of communicating with empathy and respect, seeking to understand patients' lives, emotions, and social contexts, and ensuring that one's diabetes-specific knowledge is up to date.

Our study aligns with previous work showing that people living with diabetes have valuable insights to offer their peers about living well with diabetes (16). Consistent with our findings, previous studies showed that patients have different challenges depending on personal characteristics (17). For example, key challenges faced by people recently diagnosed with diabetes were accepting the diagnosis and becoming motivated to change their lifestyle, while experienced patients were challenged by issues related to complications and medications (18). Our findings also align with research suggesting that for patients to maintain their desired level of diabetes self-management, they need the support of those around them (19,20) and need timely access to care and additional support as needed. Our results also demonstrate the importance of socio-cultural diversity when seeking evidence and ideas of 'what works' in diabetes self-management (21).

Our results support that expert patients can help provide relevant information that could be used in the healthcare system to support people with a chronic disease (22,23). Placing our findings in the context of the CanMEDS framework (24), we note that expert patients' recommendations for improvement centre primarily around the Communicator competency. Interventions designed to improve health professionals' skills in communication have been shown to have positive effects on patients' health outcomes that are comparable in effect size to the positive effects of aspirin or the negative effects of smoking (25). Communicating effectively may be particularly important in diabetes care since its management requires consistent effort by patients. Cultural competency in communication is important because of the prevalence of diabetes is higher among members of marginalized and underserved populations compared to members of the general population (26). As recommended in principles of patient-centered care, health professionals should avoid focusing solely on biological aspects, but also examine psychological and social factors that may affect their patients' health (27); for example, the impact of settler colonialism and the role of cultural norms and beliefs in the lives of patients (28,29). Finally, our findings support the need for health professionals who are more junior or who have less training in diabetes care to acknowledge the limits of their knowledge. People who live with diabetes may offer valuable opportunities for learning (3).

A limitation of our study is that we did not have a large enough sample to compare the views of patient partners by gender, diabetes type and ethnicity. We also did not triangulate the results with caregivers and/or healthcare providers to determine if these themes were consistent across groups. Also, people who shared their knowledge in our study were explicitly not representative of people with diabetes in Canada. Other people living with diabetes may have different views. Patient partner recruitment to Diabetes Action Canada includes explicit recruitment in communities of people whose views are often under-represented in research. Depending on how one sees these distinctions, this may be considered either strength or a limitation. Strengths of this study were that we identified translatable knowledge from a diverse group of expert patients and integrated patients' views throughout the research process. Patient partners in Diabetes Action Canada are deliberately selected for their expertise and ability to reflect on their own experience and place it in the context of that of others. Additionally, many are familiar and comfortable working as members of a research team, allowing them to better translate knowledge from patients for health professionals.

In conclusion, patients' expertise helped identify main areas for improvements in diabetes care that can be acted upon individually and collectively by patients and health professionals. Improving diabetes care and management is necessary to improve diabetes-related health outcomes, a major concern in Canada and around the world. Future work will evaluate whether sharing expert patients' perspectives; for example, in video learning modules, changes knowledge and attitudes of health professionals and people with diabetes.

DECLARATIONS

Ethics approval and consent to publish

This study was approved by the Laval University Research Ethics Committee (#2016-287).

Availability of Data and Materials

Data are not available for this study for privacy and confidentiality reasons.

Competing Interests

RN holds a fellowship grant from Diabetes Action Canada. Most authors are also members of Diabetes Action Canada, either as staff (OD), researchers (JD, MCT, JG, HOW), or patient partners (RP, AMM, PD). We also sought for the feedback of patients' collective circle regarding our results. All participants (Diabetes Action Canada patient partners) were informed that participation in this study was independent from their other participation in Diabetes Action Canada and that if they preferred not to participate, this would have no impact on their participation in Diabetes Action Canada. No compensation fees were offered to patient partners for their participation in video recording. However, all patient partners were offered compensation for their time attending the meeting and reimbursement of travel costs. Such compensation and reimbursement was in accordance with the network's compensation and reimbursement policy. This policy aims to appropriately recognize and value the expertise that patient partners bring to research within the network. Patient partners were also offered compensation for time spent reviewing and commenting on the findings of this study.

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Authors' Contributions

RN, JD, MCT and HOW contributed to the design of the study. RN, BB, and HOW contributed to data collection. RN, SCD, BB and HOW conducted data analysis and interpretation. RN and HOW drafted the first version of the article with early revision by BB, SCD, JD, MCT and OD. RP, AMM, PD, and JG critically revised the article and approved the final version for submission for publication. RN and HOW had full access to all the data in the study and had final

responsibility for the decision to submit for publication. HOW had overall responsibility for the research design and implementation, including data collection, analysis and writing up.

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Table 1: Demographics of participants

	Participants (n)
Gender	
Men	10
Women	11
Background	
Immigrants to Canada	2
Indigenous (First Nations, Métis, Inuit)	9
Francophone, non-immigrant	5
Anglophone, non-immigrant	5
Language	
French	7
English	12
Other*	1
Diabetes type	
Prediabetes	2
Type 1 diabetes	5
Type 2 diabetes	10
Caregiver** of person with type 1 diabetes	4

* n not mutually exclusive

** All caregivers were dealing with type 1 diabetes

Table 2: Expert patients' knowledge and wisdom for other patients

Theme	Sample quote(s)
Accepting that you have diabetes is an important step towards living well	<p>"The first piece of advice I will give is to really accept that it is possible to have diabetes" - P6 (woman with T2D)</p> <p>"When you are told about the disease, it is a time that you must mourn your illness. Until this is done, you will not accept your illness and you will not be ready to make changes in your life."- P1 (man with T2D)</p> <p>"Get over any anger or denial and live life." - P11 (man with T1D)</p>
People with diabetes don't have to be defined or limited by diabetes	<p>"I hate when people say, 'you are a diabetic.' I say no: I am [first name], I am a mom, I am a grandmother, I am a daughter, I am not 'a diabetic'." - P21 (woman with T2D)</p> <p>"I don't have to limit my life in any way because I have diabetes." - P11 (man with T1D)</p> <p>"We have the choice if we will control the diabetes or if we will allow the diabetes to control our life." - P5 (man with prediabetes)</p>
Diabetes is a constant, chronic condition with good days and bad days	<p>"The reality of diabetes is: it's 24 hours a day, every day." - P12 (woman and caregiver of husband with T1D)</p> <p>"It is never going to be perfect. Diabetes is like a constant rollercoaster [...] Really, it's a marathon not a sprint." - P20 (woman, mother of a teen with T1D)</p>
Self-management requires learning	<p>"Get information, attend conferences, read about diabetes." - P2 (man with T2D)</p> <p>"Try to understand how diabetes works and what to actually do to be able to manage anything related to diabetes [to avoid] the complications that are known to diabetes." - P6 (woman with T2D)</p> <p>"Listen to your dietician, listen to your doctor." - P21 (woman with T2D)</p>
Managing diabetes requires support, a good team, flexibility, and taking responsibility	<p>"I think it is very important to be part of a very active team with your nurse, your doctor, your partner-spouse, all working towards an end goal [...] If you don't think that you've got a good team as part of your treatment with diabetes, then continue looking until you are happy that you've got a team that you can work with." - P13 (man with T2D)</p> <p>"Patients should tell the doctor, this is how I see my life, and I want you to help me to live that life." - P4 (man with T2D)</p> <p>"There is not only one way to manage. There is more than one way to manage. And if you have to try all those ways, then you need to try all those</p>

	<p>ways.” - P8 (woman, mother of a teen with T1D)</p> <p>“It’s my responsibility to be in charge of my life. My body, my mind and my spirit [...] understanding that the past has taken place [...] What I am responsible [for] now is my journey now and moving forward.” - P5 (man with prediabetes)</p>
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Table 3: Expert patients' knowledge and wisdom for health professionals

Theme	Sample quote(s)
Being diagnosed with diabetes can be frightening and this potential fear should be addressed by health professionals	<p>"When I got the diagnosis ten years ago, I actually thought it was a death sentence." - P21 (woman with T2D)</p> <p>"Help the person to accept he/she has [diabetes], without fear, because often we are afraid when we are told [we have diabetes]." - P6 (woman with T2D)</p>
Diabetes puts a burden on patients and their families	<p>"I am a parent of a child who lives with diabetes. Check in on the parents because it is hard on the parents too." - P8 (woman, mother of a teen with T1D)</p> <p>"He was low at night, [I used to] give him his glucose and then I go and get my book [...] and read for ten minutes and then stop and check and see how are you doing now. And may be do another blood test" (Patient 12 – Woman and caregiver of husband with T1D)</p>
Health professionals influence patients' attitudes about their health and diabetes	<p>"Healthcare providers should stick with the reality: this is a disease that can be managed, [if] you work at it. [...] If you don't do the work, you are not going to see the results." - P12 (woman, wife of man with T1D)</p> <p>"Give a positive attitude towards diabetes and towards the management of it. It's not all bad. It's something that will make the patient live probably a better life than they would if they didn't have diabetes." - P19 (man with T1D)</p> <p>"Tell people when they do something right, what they are doing well." - P20 (woman, mother of a teen with T1D)</p> <p>"I feel healthy when my endocrinologist is happy with my results." - P13 (man with T2D)</p>
Health professionals can reinforce or alleviate the blame and shame that patients may feel	<p>"There is a lot of shame in diabetes. It's one of the only chronic illnesses where the people who live with it are constantly blamed for how their disease is managed." - P20 (woman, mother of a teen with T1D)</p> <p>"Sometimes, too, for people like me who are a little overweight, they will immediately put it on the fact that it is because you are overweight that you have diabetes." - P6 (woman with T2D)</p> <p>"I have the privilege of working with very amazing [health professionals...] all very understanding people [...] I used to criticize myself too much and say, Oh my number was bad this day and stuff like that and they will always correct me and say, you know what, it was an off day." - P9 (woman with T1D)</p>

Patients are people with lives beyond their diabetes	<p>“Go beyond the disease. Do not see the disease. Rather, recognize the person who is in front of you.” - P4 (man with T2D)</p> <p>“Speaking for everyone with diabetes, I will have to say, you really have to work to understand your patients. And that’s a much broader understanding than what the A1C is, what the blood sugar levels are this morning.” - P11 (man with T1D)</p> <p>“Learn about their life, learn about what they like to do in their free time, their career, if they have any free time, if they are working three jobs, and their personal leisure [...] By knowing that person, their background, their history, all about them, I think it will open a whole new appreciation for the physician as to where that person is coming from. And maybe why they may be having some issues.” - P18 (woman with T1D)</p> <p>“I had received some very tragic news, and my doctor ... I was missing appointments ... and I was just having a hard time ... and then finally he called me. I thought ‘Oh, he called me, I better get my butt in there.’ So I sat down and as soon as he got into the room I started crying so hard. And he looked at me and he goes, ‘Whoa, I don’t think this appointment is going to go the way I thought it was going to go.’ And I said, ‘No, probably not.’ And I said I haven’t been coming because I’m dealing with x and y, and he kind of sat still and then he goes, ‘Okay, can we just put your diabetes on a shelf for a little bit here?’ And I said ... ‘Thank you.’” (Patient 21 - Woman with T2D)</p>
It’s important for health professionals to provide care that respects the social, cultural and historical contexts of patients	<p>“As an Indigenous patient [...] I expect health professionals to speak to me as an equal, as a human being.” - P5 (man with prediabetes)</p> <p>“The overall thing I will say, being an Indigenous person, is not to label, not to make us feel like we are inferior, that we can’t learn how to do this, that we just have [...] our own way to do it.” - P8 (woman, mother of a teen with T1D)</p>
Health professionals should ensure their knowledge about diabetes is up to date	<p>“General practitioners know nothing about [diabetes]. And they don’t really like patients to tell them that they are [wrong...] My family doctor acknowledges that I know enough to teach doctors.” - P2 (man with T2D)</p>
Patients need to be able to ask questions until they fully understand	<p>“I expect health professionals to [...] explain things in the way that I understand and if I have questions that need clarification, that is my right to ask those questions and the responsibility of the health professional to explain things to the point that I understand the situation.” - P5 (man with prediabetes)</p>
Patients want to be part of decision making about their care	<p>“Often, in some treatments that they give you, you have options. As long as the doctor is open [...] For some doctors, it will be NO right away because they are used to giving [a specific medication].” - P1 (man with T2D)</p> <p>“[When prescribed medication is not well-tolerated] as patients, we can feel</p>

	<p>like guinea pigs.” - P6 (woman with T2D)</p> <p>“What health professionals have to consider when they talk with the patients is not to tell patients what they have to do. Many people are not willing to be told. But if there is a dialogue [...] that’s the direction that I want to see things as a patient.” - P5 (man with prediabetes)</p>
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