

# BMJ Open Patients' perspectives on how to improve diabetes care and self-management: qualitative study

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## ABSTRACT

**Objective** People living with diabetes need and deserve high-quality, individualised care. However, providing such care remains a challenge in many countries, including Canada. Patients' expertise, if acknowledged and adequately translated, could help foster patient-centred care. This study aimed to describe Expert Patients' knowledge, wisdom and advice to others with diabetes and to health professionals to improve diabetes self-management and care.

**Design and methods** We recruited a convenience sample of 21 men and women. Participants were people of diverse backgrounds who are Patient Partners in a national research network (hereafter Expert Patients). We interviewed and video-recorded their knowledge, wisdom and advice for health professionals and for others with diabetes. Three researchers independently analysed videos using inductive framework analysis, identifying themes through discussion and consensus. Expert Patients were involved in all aspects of study design, conduct, analysis and knowledge translation.

**Results** Acknowledging and accepting the reality of diabetes, receiving support from family and care teams and not letting diabetes control one's life are essential to live well with diabetes. 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.

**Conclusion** Expert Patients pointed to a number of areas of improvement in diabetes care that may be actionable individually by patients or health professionals, and also collectively through intergroup collaboration. Improving the quality of care in diabetes is crucial for improving health outcomes for people with diabetes.

## INTRODUCTION

People living with diabetes (hereafter called patients) need and deserve high-quality, individualised care.<sup>1 2</sup> Patients who bring knowledge, wisdom and insights from their experiences, hereafter called Expert Patients, can help encourage such care. In patient-to-patient diabetes education, Expert Patients

## Strengths and limitations of this study

- This study addressed patients' priorities and involved Expert Patients in all steps of the research.
- Expert Patients participating in this study were selected for their expertise gleaned from years of living with diabetes combined with an ability to reflect on their own experience and place it in context.
- Analysed using inductive framework analysis, Expert Patients' knowledge offers actionable recommendations for diabetes self-management and for care offered to people with diabetes.
- Although multiple and diverse, the perspectives of participants in this study may not be fully representative of the experiences or views of other people living with diabetes.

have shared knowledge particularly relevant to diabetes self-management and that may lead to improvements in other patients' clinical, lifestyle and psychosocial outcomes.<sup>3–5</sup> Expert Patients' knowledge can also be used to help clinicians better understand the subjective experience of service users in order to improve the quality of healthcare support.<sup>6–8</sup>

Patients' views and perspectives have helped identify domains for improvements in healthcare, including in diabetes in Canada.<sup>2</sup> Clinical practice guidelines in Canada suggest substantial room for improvement in providing patient-centred care to people living with diabetes. Among other recommendations, Diabetes Canada clinical guidelines (2018) highlight the need to tailor discussions about treatment and management to the needs and preferences of each patient.<sup>9</sup> To achieve this goal, health professionals could draw on Expert Patients' expertise regarding how to effectively accomplish this.

We developed this study building on findings from a recent patient-centred study



about what matters to diverse patients in Canada.<sup>10</sup> In Canada and similar industrialised countries where the prevalence of diabetes among members of ethnocultural minorities is two to five times higher than in the general population,<sup>11 12</sup> it is particularly important to consider a diverse group of patients in studies examining the quality of care. Therefore, this study aimed to identify potential areas of improvement in diabetes self-management and clinical care from the knowledge, wisdom and advice of a diverse group of people living with diabetes.

## METHODS

### Study design

In this qualitative descriptive study,<sup>13</sup> we used inductive framework analysis approach developed by Ritchie and Spencer and further operationalised by Gale and colleagues.<sup>14</sup> The Consolidated Criteria for Reporting Qualitative Research checklist for the present study is provided in the online supplementary appendix.

### Participants and patient involvement

Expert Patients for this study were Patient Partners previously identified and recruited through Diabetes Action Canada, a national Patient-Oriented Research network, through professional and personal networks, community-based organisations and from respondents to a national survey.<sup>11</sup> Patient Partners were all identified as being able to bring diverse points of view and meaningful expertise about living with diabetes and receiving care from health professionals.<sup>15</sup> They all have the ability to reflect on their own experiences and how these might or might not reflect the experiences of others with diabetes.

Prior to attending the annual Diabetes Action Canada meeting in May 2017 (Toronto, Canada), all eligible participants (n=23) received an email explaining the study objectives, inviting them to participate and introducing each interviewer's training, background, as well as the research and interview questions. Eligible participants were people (1) having diabetes or caring for someone affected by diabetes; (2) invited to the annual meeting in May 2017 (Toronto, Canada) and (3) who gave their informed consent to be video recorded. During the meeting, Expert Patients willing to participate in our study spent time interacting with interviewers (RN, BB and HW) and had the opportunity to ask any questions they had about the project, including the data collection process. Expert Patients were all proficient in French or English, either because one of these languages is their mother tongue, or because they speak and understand it well as an additional language.

### Research team

To ensure multiple perspectives in the design and conduct of the study,<sup>16</sup> our team included a diverse group of researchers (RN, SCD, OD, JD, M-CT, JMcG and HW), healthcare providers (BB and RP) and patients with various types of diabetes (AMMcC, RP, PD and HW). The

interviewers (RN, BB and HW) spoke both English and French. All coauthors were involved in each step of the research process, including the definition of the objective, the analysis and the discussion. We also discussed preliminary and final results with a committee of nine Expert Patients, eight of whom had participated in the study.

### Procedures

Each of the 21 participants provided written informed consent in English or French and participated in a brief (3–8 min) in-person video interview conducted in English or French by one of three interviewers (RN, BB and HW). In one case, a carer completed the form on behalf and in the presence of a blind participant. Interviewers had clinical (BB) and research training (RN and HW). We conducted interviews in quiet and isolated places at the hotel at which the meeting was taking place. We video-recorded interviews because our eventual goal is to translate patients' expertise into education video modules. During the interviews we asked three questions developed by our research team based on priorities defined by Expert Patients: (1) What makes you feel healthy? (2) What knowledge, wisdom or advice do you want to share with other people like you living with diabetes about living well with diabetes? (3) 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? For the second and third question, we prompted when needed, 'What should they do or not do, or say or not say to provide better care?' Interviews were intended to be short to collect Expert Patients' most important knowledge, wisdom and advice. Interviewees were welcome to go off-topic when answering the questions and to add any important information they wanted about their experience with diabetes. Thanks to Expert Patients' advance preparation and reflection about the questions, we were able to conduct interviews efficiently and to gather their perspectives in short times. We gave interviewees the opportunity to see their initial recording and to record a new video if they wished to change their statements; one patient re-recorded a short section of his interview to ensure he conveyed his idea in the way he preferred. We also invited participants to ask for their recording anytime during the study and stated it clearly in the consent form; no one did so. Field notes were compiled by all interviewers after data collection.

### Analyses

Three authors (RN, SCD and HW) conducted the analyses. We used semi-inductive analysis, with the structure of interview questions serving as the basic framework.<sup>14</sup> Specifically, we used inductive framework analysis to identify all segments meaningful to our questions. Two analysts independently reviewed the video recordings to become familiar with the perspectives provided by participants and identify initial codes using NVivo software V.11 (Victoria, Australia). NVivo software allows direct coding of short

**Table 1** Demographics of participants

	Categories	N*
Gender	Men	10
	Women	11
Age (years)	Range	19–71
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	Pre-diabetes	2
	Type 1 diabetes	5
	Type 2 diabetes	10
	Carer† of person with type 1 diabetes	4

\*Not mutually exclusive.

†All carers were dealing with type 1 diabetes.

videos. For this reason, we did not perform verbatim transcription. The analysts then came together to discuss why specific segments of the recordings were found to be meaningful. They compared and grouped codes around similar themes and subthemes. These themes provided the analytical framework that was applied to all the video recordings. Emerging concepts were discussed with three Expert Patients and coauthors (RP, AMM and PD). Transcripts were not returned to participants for comment. Instead, they were able to view their video segments using a secure electronic link. In subsequent rounds of analysis, analysts identified segments that were illustrative of each theme and charted findings in tables using Microsoft Excel, meeting repeatedly to compare, discuss and resolve any discrepancies found.<sup>17</sup> Finally, we analysed the key characteristics of the charted data to answer the three interview questions.<sup>14</sup> The same three coauthors (RP, AMM and PD), along with six other Expert Patients, reviewed final codes and quotes before we drafted the article.

## RESULTS

Overall, 21 Expert Patients (10 men and 11 women, 91% participation rate) agreed to participate. Expert Patients were a diverse group from several Canadian provinces and ethnocultural backgrounds, including Indigenous peoples and immigrants to Canada (table 1). Participants were 19–71 years old and had lived with different types of diabetes for 1–70 years.

## Expert patient's perspectives relevant to patients

Five themes emerged from Expert Patients' perspectives to share with other patients (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. In this study, this concern was raised exclusively by people diagnosed with type 2 diabetes as adults. None of the adults living with type 1 diabetes mentioned this aspect; however, all people with type 1 diabetes in our study were diagnosed during childhood.

### People with diabetes do not have to be defined or limited by diabetes

Expert Patients emphasised that diabetes is a disease or condition, not an identity or social role. Diabetes should not restrict people from pursuing their life goals. One Expert Patients 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 with a rollercoaster. There are good and bad days and 'it's never going to be perfect' (P21, Mother of child 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.

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

Living well with diabetes is 'hard work' (P7, woman with type two diabetes) that requires support. It's beneficial for patients to work with an active and interprofessional 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 and attending medical encounters with patients) and attitudes (patience, trust and understanding). Despite the importance of support, it is ultimately patients who are responsible for self-management. 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 hospitalisation, emergencies or any situation involving health professionals outside their care team.

**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.	'The first piece of advice I will give is to really accept that it is possible to have diabetes'. P6 (woman with T2D) '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) 'Get over any anger or denial and live life'. P11 (man with T1D)
People with diabetes do not have to be defined or limited by diabetes.	'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) 'I don't have to limit my life in any way because I have diabetes'. P11 (man with T1D) 'We have the choice if we will control the diabetes or if we will allow the diabetes to control our life'. P5 (man with pre-diabetes)
Diabetes is a constant, chronic condition with good days and bad days.	'The reality of diabetes is: it's 24 hours a day, every day'. P12 (woman and carer of husband with T1D) '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)
Self-management requires learning.	'Get information, attend conferences, read about diabetes'. P2 (man with T2D) '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) 'Listen to your dietician, listen to your doctor'. P21 (woman with T2D)
Managing diabetes requires support, a good team, flexibility and taking responsibility.	'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) '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) '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 ways'. P8 (woman, mother of a teen with T1D) '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 pre-diabetes)

T1D, type 1 diabetes; T2D, type 2 diabetes.

### Expert Patients' perspectives relevant to health professionals

Nine themes also emerged from Expert Patients' discussions about how health professionals could provide better care to patients (table 3).

#### Diabetes diagnosis can be frightening and 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 metres but offering no education on how to use them and telling them only to return in 3 months for follow-up. In interpreting this finding, an Expert Patient (PD) highlighted the related need for health professionals to support patients in managing diabetes-related and other stress in their life.

#### 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 should be prepared to discuss these issues with patients and families and to direct them to appropriate support and services, if available, and to consider advocating for such support and services if they are not available.

#### 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

Patients may feel blamed by health professionals for not being a 'good diabetic'; for example, when their blood glucose levels are higher than a specified range. This can be discouraging for patients and may damage motivation

**Table 3** Expert Patients' knowledge and wisdom for health professionals

Theme	Sample quotes
Being diagnosed with diabetes can be frightening, and this potential fear should be addressed by health professionals.	'When I got the diagnosis ten years ago, I actually thought it was a death sentence'. P21 (woman with T2D) '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)
Diabetes puts a burden on patients and their families.	'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) '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 maybe do another blood test'. P12 (woman, wife of man with T1D)
Health professionals influence patients' attitudes about their health and diabetes.	'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) '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) 'Tell people when they do something right, what they are doing well'. P20 (woman, mother of a teen with T1D) 'I feel healthy when my endocrinologist is happy with my results'. P13 (man with T2D)
Health professionals can reinforce or alleviate the blame and shame that patients may feel.	'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) '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) 'I have the privilege of working with very amazing [health professionals] all very understanding people(...)I used to criticise 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)
Patients are people with lives beyond their diabetes.	'Go beyond the disease. Do not see the disease. Rather, recognise the person who is in front of you'. P4 (man with T2D) '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) '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) '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"'. P21 (woman with T2D)
It is important for health professionals to provide care that respects the social, cultural and historical contexts of patients.	'As an Indigenous patient(...)I expect health professionals to speak to me as an equal, as a human being'. P5 (man with pre-diabetes) '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)
Health professionals should ensure their knowledge about diabetes is up to date.	'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)

Continued



Table 3 Continued

Theme	Sample quotes
Patients need to be able to ask questions until they fully understand.	'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 pre-diabetes)
Patients want to be part of decision making about their care.	'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) '(When prescribed medication is not well-tolerated)as patients, we can feel like guinea pigs'. P6 (woman with T2D) '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 pre-diabetes)

T1D, type 1 diabetes; T2D, type 2 diabetes.

to improve. Patients may also blame themselves when things are not going as well as they would like in their self-management. Health professionals can help by alleviating their negative self-perspectives rather than reinforcing them.

#### 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 factors in patients' lives influence diabetes management. Sometimes, patients may not be able to prioritise diabetes management because of other challenges in their lives. Expert Patients spoke with appreciation of health professionals who recognise the other factors in their lives, suggesting that this helped them learn to trust those professionals.

#### It is 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 and it is important to avoid stigma or labelling based on social status or personal characteristics. Harmful stigma and labelling include 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, consistently emphasised the need for respectful and culturally safe care. Lack of respect toward Indigenous peoples is a barrier to good health. Indigenous Expert Patients encouraged health professionals to seek training in trauma-informed care in order to better understand the impact of settler colonialism in Canada on Indigenous peoples' health outcomes, including diabetes, and to consider certain personal factors accordingly. For example, a person who was often hungry as a child in a residential school may require a specific 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 healthcare, 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 (eg, regarding medication) and make patients feel heard. Lifestyle changes and self-management require sustained effort on the part of patients and that it is easier for patients to exert such effort when they have been truly involved in the decision-making process.

## DISCUSSION

This study aimed to identify areas for improvement in diabetes self-management and care according to a diverse group of Expert Patients, recording with video to enable sharing Expert Patients' knowledge, wisdom and advice in future. Our findings suggest avenues to improve diabetes care and management. For other 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.

This study has four main strengths. First, it was designed to address patients' priorities for patient care, as recommended in patient-centred care.<sup>18</sup> In the same way that people with clinical experience develop expertise that can inform clinical practice, people with lived experience develop expertise that can inform practices of high-quality management and care of people with the condition. Second, we identified translatable knowledge from a diverse group of Expert Patients and integrated the views of other Expert Patients throughout the research process. Expert Patients meaningfully contributed to all aspects of this study, and the insights gained in the discussion with them were invaluable. The study's senior researcher (HW), who has lived with type 1 diabetes since childhood, used her dual perspective to bridge patients' perspectives and research knowledge. Third, participants were recognised for their diabetes expertise combined with their ability to reflect on their own lived experience and to place it in the context of that of others. Many were familiar and comfortable working as members of a research team, allowing them to better translate patient knowledge for health professionals. Fourth, we used open-ended questions to allow Expert Patients to choose what to emphasise.<sup>19</sup> This study also has some limitations. First, we did not seek a comprehensive understanding of observed concepts. Our approach did not allow us to unpack deeper questions or identify which mechanisms may explain our findings. We believed our approach was suitable for our overarching aims of capturing key opportunities for improving diabetes self-management and care in ways that would allow us to translate findings in new ways. Second, we drew on a convenience sample of Expert Patients, deliberately oversampling in groups that are often under-represented in this type of research. This can be considered both strength and limitation. The strength is that interviewees were people with expertise and experience reflecting on the types of questions posed. The limitation is that while their responses were well-informed, crystallised and reflected their expertise, it may or may not fully represent the experiences or views of the groups to which they belong. Third, we cannot rule out potential information bias because we did not pilot interview questions, nor social desirability bias because of prior relationships between some interviewees and interviewers. To minimise such biases, we organised interviews such that interviewees were allowed to ask questions and only 2 of the 21 interviews took place between people who already knew each other.

Our study aligns with previous work showing that Expert Patients have valuable insights to offer their peers about living well with diabetes.<sup>20</sup> Consistent with our findings, previous studies showed that patients have different challenges depending on personal characteristics.<sup>21</sup> For example, key challenges faced by people recently diagnosed with diabetes were accepting the diagnosis and

becoming motivated to change their lifestyle, while more experienced patients were challenged by issues related to complications and medications.<sup>22</sup> Our findings also align with research suggesting that for people to maintain their desired level of diabetes self-management, they need the support of those around them<sup>23 24</sup> and need timely access to care and additional support as needed, for example, financial aid. Our results also demonstrate the importance of sociocultural diversity when seeking evidence and ideas of 'what works' in diabetes self-management.<sup>25</sup> The consistency with prior work is not surprising, but is disappointing to patients and those striving to achieve the highest possible quality of diabetes care.<sup>9</sup> If previous research were achieving its intended impact in terms of health system improvement, we would expect different advice from people living with diabetes. Thus, we suggest that different approaches are likely required to translate what matters to people living with diabetes into improved diabetes care.

Our results support that Expert Patients can help provide relevant information that could be used in the healthcare system to support people living with a chronic disease.<sup>26 27</sup> Placing our findings in the context of the CanMEDS competency framework, a framework used to structure competency-based health professions education in Canada and elsewhere,<sup>28</sup> we note that Expert Patients' recommendations for improvement in clinical care centre primarily around the role of communicator. Interventions designed to improve health professionals' competencies within this role 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.<sup>29</sup> Communicating effectively may be particularly important in diabetes care since its management requires consistent effort by patients. Cultural competence in communication is particularly important because diabetes is more prevalent among members of marginalised and underserved populations compared with members of the general population.<sup>30</sup> As recommended in principles of patient-centred care, health professionals should avoid focusing solely on biological aspects, but also examine psychological and social factors that may affect their patients' health.<sup>18</sup> It is also recommended to avoid relying primarily on views of people in dominant sociodemographic groups.<sup>2</sup> Although Expert Patients from our diverse group shared many of the same concerns and expectations about diabetes care, Indigenous Expert Patients more often referred to the association between their history and culture and diabetes care. This may be explained by the impact of settler colonialism and related stigmatisation on Indigenous peoples' health and the role of cultural norms and beliefs in the lives of Indigenous patients and communities.<sup>31 32</sup> Although non-Indigenous participants included people of colour, none of them shared concerns about racial discrimination in care. This may reflect the fact that this concept was not explicitly included in our questions, or it may reflect participants' discomfort raising such issues in a video

interview. It is recommended to provide culturally safe care to every person living with diabetes.<sup>33</sup> Finally, our findings support the need for health professionals, particularly those who are more junior or who have less training in diabetes care, to acknowledge the limits of their knowledge. Patients may offer valuable opportunities for health professionals' learning.<sup>8</sup>

We did not triangulate results with health professionals to determine if these themes were consistent with professionals' experience or perspectives. It is plausible that professionals' perspectives align with our findings, as they are supported by recent clinical practice guidelines.<sup>10</sup> Although specialists may be more likely to care for people with type 1 diabetes and to implement processes of care, Shah and colleagues recommended that research should focus on ways to implement high-quality diabetes care regardless of specialty. They suggest that differentiating specialists and generalists provides little insight into improving quality of care because the difference between them is often small compared with the overall deficiency in quality.<sup>34</sup>

Although adults diagnosed with type 1 diabetes in childhood did not report diagnosis-related emotions in this study, adults with new-onset type 1 diabetes<sup>35</sup> and type 2 diabetes face emotional challenges.<sup>1</sup> Therefore, people with all types of diabetes may need to work through denial, anger or fear at different stages of living with the disease in order to accept the presence of the disease in their lives and to move on to making positive lifestyle changes.

Although we cited only broad reflections, some participants may be potentially identifiable from these quotes. The overarching goal of the project, dubbed 'Patients as Teachers', is to explore the potential of online learning modules in which the content is patient-led. For ethical reasons, all participants were aware that the study was video-based, consented to having their recordings used for analysis and eventually shared, and are offered the opportunity to withdraw their consent at each new stage of the overall project. We are collaborating with Expert Patients to translate our findings into learning video modules that may be used online to enhance diabetes and health professions education. Videos are a promising medium for education because learners often relate better to participants' experience when they can see the person.<sup>36</sup> We will further invite Expert Patients to share their views about whether and how videos modules should be disseminated.

## CONCLUSION

Expert Patients described areas for improvement in diabetes care that can be acted on 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 in video

learning modules changes knowledge and attitudes of health professionals and patients.

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**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 (MJD, M-CT, JMcG and HW) or Patient Partners (RP, AMMcC and PD). We also obtained feedback on our results from Diabetes Action Canada's Patient Partner Collective Circle. All participants (Diabetes Action Canada Patient Partners) were informed that participation in this study was independent of their other participation in Diabetes Action Canada and that, if they preferred not to participate, the decision would have no impact on their participation in Diabetes Action Canada. Patient Partners were not compensated for their participation in the video recording. However, all Patient Partners were offered compensation for their time attending the meeting and reimbursement of travel costs. Such compensation and reimbursement were in accordance with the network's compensation and reimbursement policy. This policy aims to appropriately recognise 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

**Patient and public involvement** Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

**Patient consent for publication** Not required.

**Ethics approval** This study was approved by the Laval University Research Ethics Committee (#2016-287). Expert Patients provided (or declined) line-by-line consent to a list of potential uses of the video interviews: for analysis only, for health professionals, for researchers, for the public, to show at conferences or in appendices to journal articles and all previously mentioned uses. Nineteen of the 21 participants consented to their videos being used to create educational modules for future research and medical education. Videos of personal narratives supporting the results in the present paper are archived and stored in a database on a secure server located on the campus of Laval University. Excel files and codes used to generate the analyses presented in the paper are archived in the same server. To protect participants' privacy, our Research Ethics Committee does not permit us to provide the link to the repository we have used.

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#### REFERENCES

- Jull J, Witteman HO, Ferne J, *et al*. Adult-Onset type 1 diabetes: a qualitative study of decision-making needs. *Can J Diabetes* 2016;40:164–9.
- Halperin IJ, Mukerji G, Maione M, *et al*. Adult patient perspectives on care for type 1 and type 2 diabetes across the Institute of medicine's 6 domains of quality. *Can J Diabetes* 2018;42:36–43.
- Jimison HB, Pavel M, Parker A, *et al*. The role of human computer interaction in consumer health applications: current state, challenges and the future. In: Patel VL, Kannampallil TG, Kaufman DR, *et al*, eds. *Cognitive informatics for biomedicine*. Springer International Publishing, 2015: 259–78.
- Kwan BM, Jortberg B, Warman MK, *et al*. Stakeholder engagement in diabetes self-management: patient preference for peer support and other insights. *Fam Pract* 2017;34:cmw127–63.
- Coppola A, Sasso L, Bagnasco A, *et al*. The role of patient education in the prevention and management of type 2 diabetes: an overview. *Endocrine* 2016;53:18–27.
- Karazivan P, Dumez V, Flora L, *et al*. The patient-as-partner approach in health care: a conceptual framework for a necessary transition. *Acad Med* 2015;90:437–41.
- O'Neill N, Mitchell G, Twycross A. The expert patient. *Evid Based Nurs* 2016;19:41–2.
- Snow R, Humphrey C, Sandall J. What happens when patients know more than their doctors? experiences of health interactions after diabetes patient education: a qualitative patient-led study. *BMJ Open* 2013;3:e003583.
- Ivers NM, Jiang M, Alloo J, *et al*. Diabetes Canada 2018 clinical practice guidelines: key messages for family physicians caring for patients living with type 2 diabetes. *Can Fam Physician* 2019;65:14–24.
- Dogba MJ, Dipankui MT, Chipenda Dansokho S, *et al*. Diabetes-Related complications: which research topics matter to diverse patients and caregivers? *Health Expect* 2018;21:549–59.
- Jacklin KM, Henderson RI, Green ME, *et al*. Health care experiences of Indigenous people living with type 2 diabetes in Canada. *Can Med Assoc J* 2017;189:E106–12.
- Public Health Agency of Canada. Chapter 4: Diabetes in Canada. In: *Facts and figures from a public health perspective – Type 2 diabetes – Canada.ca*, 2011. <https://www.canada.ca/en/public-health/services/chronic-diseases/reports-publications/diabetes/diabetes-canada-facts-figures-a-public-health-perspective/chapter-4.html>
- Creswell JW. *Qualitative inquiry and research design: choosing among five traditions*. CA, US, Thousand Oaks, 1998.
- Gale NK, Heath G, Cameron E, *et al*. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Med Res Methodol* 2013;13:117.
- SPOR Network, Diabetes Action Canada. Spor network. Available: <https://diabetesaction.ca/> [Accessed 14 May 2018].
- Bergold J, Thomas S. Participatory research methods: a methodological approach in motion. *Forum Qual Soc Res* 2012;13.
- Ryan GW BHR. Data management and analysis methods. In: Denzin NLY, ed. *Collecting and interpreting qualitative materials*. CA, Thousands Oaks: SAGE, 2000: 259–309.
- Frank L, Basch E, Selby JV, *et al*. The PCORI perspective on patient-centered outcomes research. *JAMA* 2014;312:1513–4.
- Shaffer VA, Zikmund-Fisher BJ. All stories are not alike: a purpose-, content-, and valence-based taxonomy of patient narratives in decision AIDS. *Med Decis Making* 2013;33:4–13.
- Kazemi S, Parvizy S, Atlasi R, *et al*. Evaluating the effectiveness of peer-based intervention in managing type I diabetes mellitus among children and adolescents: a systematic review. *Med J Islam Repub Iran* 2016;30:442.
- Spenceley SM, Williams BA. Self-Care from the perspective of people living with diabetes. *Can J Nurs Res* 2006;38:124–45.
- Gardsten C, Blomqvist K, Rask M, *et al*. Challenges in everyday life among recently diagnosed and more experienced adults with type 2 diabetes: a multistage focus group study. *J Clin Nurs* 2018;27:3666–78.
- Vallis M, Burns KK, Hollahan D, *et al*. Diabetes attitudes, wishes and needs second study (DAWN2): understanding diabetes-related psychosocial outcomes for Canadians with diabetes. *Can J Diabetes* 2016;40:234–41.
- Pierce JS, Aroian K, Caldwell C, *et al*. The ups and downs of parenting young children with type 1 diabetes: a Crowdsourcing study. *J Pediatr Psychol* 2017;42:846–60.
- Barton SS. Using narrative inquiry to elicit diabetes self-care experience in an Aboriginal population. *Can J Nurs Res* 2008;40:16–36.
- Fiddes PJ, Brooks PM, Komesaroff P. The patient is the teacher: ambulatory patient-centred student-based interprofessional education where the patient is the teacher who improves patient care outcomes. *Intern Med J* 2013;43:747–50.
- Feijoo-Cid M, Morriña D, Gómez-Ibáñez R, *et al*. Expert patient illness narratives as a teaching methodology: a mixed method study of student nurses satisfaction. *Nurse Educ Today* 2017;50:1–7.
- CanMEDS. pour les médecins - The Royal College of Physicians, 2015. Available: <http://www.royalcollege.ca/rcsite/documents/canmeds/framework-series-1-f.pdf>
- Kelley JM, Kraft-Todd G, Schapira L, *et al*. The influence of the patient-clinician relationship on healthcare outcomes: a systematic review and meta-analysis of randomized controlled trials. *PLoS One* 2014;9:e94207.
- American Diabetes Association. Statistics about diabetes. Available: <http://www.diabetes.org/diabetes-basics/statistics/?referrer=https://www.google.ca/> [Accessed 20 Jan 2020].
- Mosby I, Galloway T. "Hunger was never absent": How residential school diets shaped current patterns of diabetes among Indigenous peoples in Canada. *Can Med Assoc J* 2017;189:E1043–5.
- Howard HA. Canadian residential schools and urban Indigenous knowledge production about diabetes. *Med Anthropol* 2014;33:529–45.
- Canadian Ethnocultural Council. A community guide on diabetes in immigrants Ehtnic populations: sampled programs for early detection and management. public health agency of Canada, 2013. Available: [https://ethnocultural.ca/sites/ethnocultural.ca/files/Community%20Guide%20on%20Diabetes%20\(Eng\)%202013%20CEC.pdf](https://ethnocultural.ca/sites/ethnocultural.ca/files/Community%20Guide%20on%20Diabetes%20(Eng)%202013%20CEC.pdf)
- Shah BR, Hux JE, Laupacis A, *et al*. Deficiencies in the quality of diabetes care: comparing specialist with generalist care misses the point. *J Gen Intern Med* 2007;22:275–9.
- Thomas NJ, Lynam AL, Hill AV, *et al*. Type 1 diabetes defined by severe insulin deficiency occurs after 30 years of age and is commonly treated as type 2 diabetes. *Diabetologia* 2019;62:1167–72.
- Hurtubise L, Martin B, Gilliland A, *et al*. To play or not to play: Leveraging video in medical education. *J Grad Med Educ* 2013;5:13–18.