Original Research

Exploring the Lived Experience of Diabetes Through an Intersectional Lens: A Qualitative Study of Adults With Type 1 and Type 2 Diabetes

Zoey Jones PhD; Jennifer Akerman MPH; Virtue Bajurny MSW; André Gaudreau; Paula Rochon MD, PhD; Robin Mason PhD,

Key Messages

Lived experiences of diabetes can best be understood through an intersectional lens that considers peoples’ diverse socioeconomic locations and identities.

Those who experience discrimination may experience multiple marginalization, requiring greater attention to supporting their resilience.

Consideration of the varied needs of diverse individuals should be integrated into routine diabetes care.

ARTICLE INFO

Article history:
Received 30 November 2021
Received in revised form 23 April 2022
Accepted 8 June 2022

Keywords:
lived experience
gender
intersectionality
qualitative study
resilience
type 1 diabetes
type 2 diabetes

ABSTRACT

Background: Our aim in this study was to explore the lived experience of adults living with type 1 and type 2 diabetes through an intersectional sex- and gender-based analysis plus lens.

Methods: Qualitative interviews with 15 adults (9 women, 6 men) were conducted in February and March 2021. Interviews were recorded, transcribed and analyzed for semantic and latent themes noting differences in participants’ accounts of living with diabetes by gender, age, race and ethnicity, type of diabetes and other key demographics.

Results: Participants’ experiences differed substantively by gender, age and racialization. “Resilience” was identified as a central feature in participants’ lives. Factors that contributed to resilience included supportive relationships, a feeling of agency and social acceptance; confounding factors included unsupportive relationships, a lack of agency and experiences of stigma, discrimination and microaggressions.

Conclusions: Lived experiences of diabetes can best be understood through an intersectional lens that considers peoples’ diverse socioeconomic locations and identities. Those who experience discrimination, including women, older individuals and racialized people, may also experience the compounding effects of multiple marginalization, requiring greater investment in factors that contribute to their resilience. Considering the varied needs of diverse individuals should be integrated into routine diabetes care.

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Mots clés: expériences vécues  
genre  
intersectionnalité  
étude qualitative  
résilience  
diabète de type 1  
diabète de type 2

RÉSUMÉ

Introduction : L’objectif de la présente étude était d’explorer les expériences vécues des adultes diabétiques de type 1 ou de type 2 par une analyse fondée sur le sexe et le genre plus dans une perspective intersectionnelle.

Méthodes : Nous avons mené des entrevues qualitatives auprès de 15 adultes (9 femmes, 6 hommes) en février et en mars 2021. Les entrevues ont été enregistrées, transcrites et analysées pour dégager les thèmes sémantiques et latents qui mettaient en évidence les différences par genre, âge, race et ethncité, type de diabète et autres variables démographiques importantes dans les récits des participants qui vivent avec le diabète.

Résultats : Les expériences des participants différaient substantiellement selon le genre, l’âge et la racialisation. La « résilience » était considérée comme une caractéristique centrale de la vie des participants. Les facteurs qui contribuaient à la résilience étaient notamment les relations solidaires, le sentiment d’agentivité et l’acceptation sociale ; les facteurs confusionnels étaient notamment les relations non solidaires, l’absence d’agentivité et d’expériences de stigmatisation, de discrimination et de microagressions.

Conclusions : La perspective intersectionnelle permet de mieux comprendre les expériences vécues des adultes diabétiques puisqu’elle exige de prendre en considération les diverses identités et situations socioéconomiques des personnes. Celles qui subissent la discrimination, notamment les femmes, les personnes âgées et les personnes racialisées, peuvent aussi subir les effets cumulatifs de la marginalisation multiple ; de ce fait, elles doivent s’investir davantage dans les facteurs qui contribuent à leur résilience. Les besoins variés des divers individus devraient être pris en considération lors des soins courants en diabète.

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participants were selected from a group of volunteers based on maximum variation sampling focussing on several criteria: type of diabetes, and then gender, age, ethnicity and language spoken, to permit the greatest possible diversity of experience. Six men and 10 women were included in the final sample. Maximum variation was applied and included:

- All men who volunteered.
- The oldest and youngest woman for each type of diabetes (n=4).
- One woman from each of the different ethnicities represented in volunteer pool (n=4).
- One woman randomly selected from among English speakers and French speakers (n=2).

All participants were cisgender. One participant (a 63-year-old woman) withdrew before her interview, resulting in a total of 15 participants.

**Data collection**

The semistructured interview guide was developed and piloted with the team's patient partners. After modifications, 2 members of the research team conducted interviews in English (n=8) and French (n=7) using teleconferencing software. Open-ended questions focussed on the diabetes experience across 3 domains: personal (e.g. identity, day-to-day life), interpersonal (e.g. relationships) and institutional or systems-based (e.g. within the health-care system, workplace). After consenting to participation, interviews were recorded, and later transcribed. Participants were compensated $35 for their time. French interview transcripts were translated into English before analysis. Interviews were conducted in February and March 2021 and lasted between 30 and 90 minutes (see Interview Guide in Supplementary Material).

**Data analysis**

Anonymized transcripts were entered into a qualitative analysis software program, Dedoose (version 8), to organize coding. Pseudonyms were applied before coding and are used in this study. Data were separately coded for those with type 1 and type 2 diabetes as well as by gender, and later compared. Thus, transcripts from women with type 1 diabetes were coded and analyzed separately from those of men with type 1 diabetes; transcripts from women with type 2 diabetes were coded and analyzed separately from those of men with type 2 diabetes before any comparisons were made. Each participant's transcript was labelled with important identifiers (type of diabetes, language of interview, age, race/ethnicity, household income) to retain critical demographic information and allow for ongoing intersectional analysis.

Initial coding was completed using a constant comparative method to elicit general “buckets” or semantic themes (23) that “open up” meaning in the data (22). Initial coding was reviewed by the research team and a codebook developed. New codes were added as needed; the codebook was updated twice based on developments in the data. Data saturation was reached when no new codes emerged and repetition across transcripts was apparent. In the next phase of analysis, the semantic themes were analyzed for “underlying ideas, assumptions, and conceptualizations” (23, p 84), emphasis in original, or latent themes, that provide additional insight. This interpretive phase resulted in further revisions to the codebook. In the final step, the team immersed themselves in reviewing the codes and developed conceptual themes and an illustrative framework.

**Trustworthiness/rigour of analysis**

Several techniques were used to triangulate initial codes and ensure trustworthiness of code application. The codebooks were developed as a group after independent coding of data excerpts by team members. The codebook was applied to the full data set by Z.J. with oversight and auditing by J.A. and R.M. Discussions during the auditing process resulted in the refinement of a few codes.

**Results**

The 15 participants ranged from 21 to 73 years of age, with a mean age of 50.6 years (women, 44.4 years; men, 60 years). Nine cisgender women and 6 cisgender men participated. Nine participants had type 1 diabetes and 6 had type 2 diabetes. Those with type 1 diabetes ranged from 21 to 69 years of age, whereas those with type 2 diabetes were between 45 and 73 years of age. The majority of participants were Caucasian (n=10); 2 Caucasian participants also identified as Ashkenazi Jewish. One third of participants were racialized (n=5), specifically Indigenous, Arabic, biracial, Latinx and Indo-Caribbean. Several participants were Francophone residents of Québec and 7 chose to interview in French. The remaining participants resided in other parts of Canada.

Participants included health-care workers, teachers, information technology professionals, students, bartenders and retired individuals with household incomes ranging from $25,000 to over $100,000 annually (Table 1).

Whereas participants’ demographics offer important context into understanding peoples’ experiences, each person's account resists simple categorization by such demographics. For example, in this excerpt describing her work situation, Elizabeth, a 58-year-old, cisgender, racialized woman with type 2 diabetes referenced the intersecting influences of sex, gender and race in her life, as well as her status as a mother:

Maternity leave? The maximum with my three kids I ever had of mat leave was three months. Yeah, I had to come back because things were out of control and I did because of being a visible minority. I had to show, “Yeah. Okay. I'm good. I'm rooting for the team. I'm coming back. Leave my baby with my parents and come back to work.” But yeah, I think that women ... somehow, we're still perceived as the nurturers, that we are somehow

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superheroes and that we could do everything and we can’t complain.

While Elizabeth described the impossibility of separating her sex, gender and race, she went on to add that diabetes is also an inextricable part of her identity. Rachel, a 21-year-old, Caucasian, Jewish, bisexual woman with type 1 diabetes, observed how answering our demographic form inspired her to consider the complexity of her identity:

... when you were doing your demographics survey and you were asking me to list all these different things that make me me, one thing that I always list and is very high up there is diabetes. When I think about the things that impact my life and who I am, there’s definitely being a woman, being diabetic, being Jewish and being bi. That all goes together ...

As James, a 31-year-old Caucasian man with type 1 diabetes, briefly explained, “I see everything through the lens of being a man”; Philippe, an older Caucasian man with type 1 diabetes, echoed the sentiment saying, “There are two things ... I don’t know if it’s me or if it’s because I’m a man; I don’t know the difference between the two.” As participants made clear, their social location and other aspects of identity, intersect in myriad and complex ways not readily disentangled (Figure 1).

Despite differences in social location and substantive medical differences between type 1 and type 2 diabetes, our analysis revealed some common themes. In the first stage, the analysis resulted in 5 initial themes: medical issues and relationships; health-focused issues, including physical activity, the body and emotional states; the social world, including interpersonal/professional relationships; the person, which included self-care, clothing issues and sexuality; and the demanding requirements of living with diabetes, which included knowledge about the condition, and the day-to-day and, for some the moment-to-moment, awareness of diabetes.

Initial themes were further explored for conceptual meanings or latent themes, reorganized and subsequently named: personal life (including having or lacking agency); interpersonal relationships (both supportive and unsupportive and with family members, health-care providers and work colleagues); and systemic and social issues (including stigma, discrimination and social acceptance experienced through interactions with institutions, systems and the wider society). There is some overlap across these themes. What emerged at this phase of the analysis was the concept of resilience, which served as a thread through each of the identified themes. Underlying all themes were positive emotional states (e.g. pride, hope and optimism) and some that were less comfortable (fear, anxiety and vulnerability). Managing these emotions required effort and this influenced the resilience of those living with diabetes. Resilience, as used here, refers to an individual’s ability to, or the process of, overcoming and coping with stress, challenge and adversity. Resilience was the conceptual link and organizing framework for considering the influences of sex, gender and other intersections of identity on individuals’ experiences of living with diabetes (Figure 2).

**Personal life**

A significant aspect of participants’ diabetes experience related to feelings of having or lacking agency or self-determination. Feeling independent and able to influence their own health and well-being was characteristic of resilience and was often the byproduct of learning how to manage diabetes. Elizabeth, a 45-year-old, cisgender, Francophone woman with type 2 diabetes explained:

[Health-care professionals] have to teach us to stand on our own two feet, because we need that if we want to continue. Then we become ... we own it and all that. The anxiety will subside, we will get to know each other better, then it is also easier to follow the path of our care.

Access to diabetes-related knowledge, whether via the internet or personal connection, was important to most participants’ sense of agency. Some younger, Caucasian women with type 1 diabetes used Facebook groups and online communities to share gendered information related to, for example, clothing adaptations to accommodate insulin pumps (“Insulin pumps and CGM are not designed for females,” complained one young woman) and work-arounds to mitigate the cost of adhesives used to hold the continuous glucose monitors in place (eyelash glue was suggested as a cheap and safe alternative). However, Youssef, an Arabic man in his late 60s with type 2 diabetes, wished for social media—based avenues of information and community connection, suggesting that the types of groups favoured by young Caucasian women were not available (or visible) to him. Unlike either the younger Caucasian women or older men such as Youssef, older women with both type 1 and type 2 diabetes typically relied on face-to-face relationships within their local communities and their physicians for information and social connection.

Challenging participants’ feelings of resilience was the loss of, or fear of losing, independence or agency expressed by some participants, particularly those with type 1 diabetes. One young Caucasian woman shared her worries about who would manage her insulin during childbirth, whereas Marc, a Caucasian man in his late 60s with type 1 diabetes, explained:

The worry I have about diabetes is if I lose autonomy. COVID scared me because with COVID, there is no one in a hospital setting who would manage my insulin pump. I would have been unplugged or given different treatment because I would not
have been in the condition to manage this thing. ... So, I find that my fears are that if I lose autonomy, I will not be able to maintain the same type of control.

Although resilience was supported by personal agency, it was challenged by anxieties related to loss of autonomy. For those experiencing anxiety, maintaining a sense of well-being both challenged and required resilience.

For many of those with type 2 diabetes, agency was frequently associated with exerting control over their physical bodies through diet and exercise. At times, these accounts were celebratory as individuals spoke of pride in meeting their goals; in other instances, participants sounded discouraged and expressed self-recrimination for the state of their health. As Maria, a Latinx woman in her early 70s with type 2 diabetes, said: “I feel guilty because I am not disciplined to maintain my health.” Those with type 2 diabetes regularly described receiving blaming messages that held them responsible for their diabetes and/or issues related to the condition. Resilience was crucial to participants’ ability to resist the stigmatizing narrative; those with more supportive relationships were better able to do so.

Interpersonal relationships

Participants discussed supportive and challenging relationships that contributed to or acted to confound resilience. A small number of participants reported their family as their primary source of support, but more commonly participants reported support from both those within and those external to family. Examples of other critical relationships included those with health-care professionals, friends and others with diabetes. Thomas, an Indigenous man in his late 60s with type 2 diabetes, provided an example of how positive relationships support his well-being. He explained:

Indigenous people have the highest diabetes rate, so in a community at [reserve], there’s a lot of people that have diabetes ... I pass on the information of what I’ve learned through my experience and what I learned from others so that people in the community are aware of some of the implications of diabetes and what you need to do to take care of yourself.

Thomas’s resilience allows him to extend care to others in his community. However, unsupportive interpersonal relationships significantly challenged resilience. These included relationships with sexist and judgemental health-care providers; strangers ignorant about diabetes; and interactions with coworkers, friends and family that left participants feeling disrespected, challenged or ignored. Heather, a 33-year-old, Caucasian woman with type 1 diabetes, shared feeling frustrated and disrespected, at least in part because she is a woman:

My father-in-law ... they had a dog that got diabetes and they wanted to talk to me about it, and I just didn’t know how to be, like, “This is an entirely inappropriate conversation.” ... I think I just left the room. ... If the situations were reversed, I don’t think they would have asked a male the same thing, or a dude would have just been like, “well, I’m not a dog,” and it would have been funny, but if I say that, then it would have been ... that’s not funny, right?

Society and institutions

Often mimicking what was expressed through interpersonal relationships, participants reported supportive experiences at the societal level (such as social acceptance) and challenging experiences (such as social stigma and discrimination). Social acceptance was associated with having easily acquired accommodations at school or in the workplace, as well as positive conversations with
strangers or non-intimate persons. However, outside the diabetes communities, there were few such stories. Those most likely to feel socially accepted were Caucasian men of all ages. Phillippe, a Caucasian man in his late 60s with type 1 diabetes, freely shares that he has diabetes, “I would say that it can make for an interesting topic of conversation on occasion. People, for the most part, are very curious.” In contrast to Phillippe’s experience, Lisa, a Caucasian Ashkenazi Jewish woman in her 50s with type 1 diabetes, described multiple experiences of prejudice:

I’ve had to hide the fact many times that I’m Jewish because that’s been used against me. I’ve had to hide the fact that I have type 1 diabetes because that’s been used against me. You can’t hide how you look and that you are a woman, but I have experienced prejudice for all those three things.

Most of those who described experiencing stigma, discrimination and microaggressions were women with diabetes, marginalized by at least one other characteristic. Almost all women, irrespective of age, race and ethnicity or culture, reported at least one negative social interaction and most explicitly recognized how their identities impacted these experiences. Caucasian men almost exclusively reported positive or neutral social and institutional experiences in the present, although some acknowledged having experienced diabetes stigma in past decades. Racialized men reported discrimination due to race and ethnicity as well as immigrant status, but not due to having diabetes.

**Considering disclosure**

Participants’ personal, interpersonal and systemic experiences, as well as their identities and social locations, influenced their resilience. This was most evident during discussions of when and to whom they disclosed having diabetes. Those most comfortable in disclosing diabetes were younger people of all genders and race/ethnicities and older Caucasian men. Some young people used disclosure to combat diabetes-related stigma, as Rachel, a 21-year-old Caucasian, Ashkenazi Jewish woman with type 1 diabetes, explained: “I’ve found that really embracing it has really helped me because I’m proud of diabetes. It’s like a fun fact and I want people to know.” Alexis, a biracial young woman with type 1 diabetes, was less political or outspoken about disclosing. Instead, she described managing blood tests and injections in public spaces but only discloses having diabetes when asked.

Some older women of all racial and ethnic identities were more selective in disclosing, concealing diabetes-related equipment and managing blood tests and injections in private.

Elizabeth, a 45-year-old Francophone woman with type 2 diabetes explained, “I can talk about it to whomever asks, but I wouldn’t write it on the wall, so to speak.” Heather, a 33-year-old Caucasian woman with type 1 diabetes responded as follows to a question about whether she had experienced discrimination or stigma:

It’s why I don’t tell people. Especially as I get older … “You can’t eat that!” or, “Are you sure you should be eating that?” I’m like, “Are you sure should be commenting on that? I don’t comment on your [eating] habits, so you don’t have a right to say what I eat or should or should not … people just don’t understand and there’s a lot of shame.

Older Caucasian men felt significantly less vulnerable to diabetes-related stigma, making disclosure less of an issue. Marc, a 69-year-old Caucasian man with type 1 diabetes, explained that he disclosed his diabetes during job interviews, believing coworkers need to know “in case they saw me in a difficult condition. … I have always shared with all the staff and all my bosses.”

The story of disclosure changed for women and men of colour. Cynthia, a 58-year-old racialized woman with type 2 diabetes, described hiding diabetes at work:

Part of it is being a visible minority woman and working in a very White-dominated environment as a visible minority woman perceived as an anglophone or an allophone certainly in Québec. That’s a very particular environment. Couldn’t really complain or make a big fuss about challenges around the illness and the hypoglycemic attacks that I would often get because sometimes meetings are three or four hours and I can’t get food when I should have been able to do so because I didn’t want anyone to figure, “Okay. Here’s the brown girl causing some kind of a problem and slowing things down.” As a visible minority woman in this context, you always have to show that you were [performing well] at your job … You could lose your job at any minute. You could lose it, so I always felt in that high-risk group. I could lose my job, especially because [my boss] liked calling me the N word from time to time.

As a woman of colour who experiences discrimination, Cynthia recently and reluctantly disclosed having diabetes to her coworkers and long-time friends to explain her anxieties about COVID-19. When asked explicitly if he felt his age, race and ethnicity, immigrant status or gender impacted his experience of diabetes, Youssef, a 67-year-old Arab man with type 2 diabetes, initially said neither his race nor immigrant status impacted his experience, but later reported:

It gets more complicated when you have diabetes and you’re racialized, it gets too complicated to deal with. But in my case, it’s not really … I fought against discrimination, but as a person with an immigrant background, not as an immigrant with diabetes, because I didn’t tell anyone. I’m not telling anyone.

Youssef refrained from disclosing diabetes was a way to avoid compounding stigma he experiences as a racialized person and immigrant in Canada.

**Discussion**

An intersectional lens is a way of centering marginalized identities, social locations and the influences these have on an individual’s relationship to systems of power. Intersectionality applied to research aims to both see and redress inequities. As described by Abrams and colleagues:

Through intersectionality, we can illuminate and dissect the complexities of minds and bodies as sites of intersectional oppression and generate new knowledge and more holistic representations of marginalized experiences and the forces that create those experiences to facilitate greater understandings of health as well as more comprehensive solutions. (p 2)

Intentionally applying an intersectional lens to the lived experience of diabetes required that we, the research team members, reflect on our own understanding of identity-related factors; our positions of relative power or marginalization; and what we knew, or thought we knew, about living with diabetes. We were of different ages, and had different first languages and different religious, social and academic backgrounds. Some of us had the experience of living with diabetes (type 1 and type 2) or parenting a
child with diabetes (type 1); we all had some experience with diabetes-related research.

Still, we did not and could not represent the spectrum of identities and experiences attending differing social locations. We learned how individuals with very varied social identities, some invisible others less so, live with diabetes, a sometimes hidden or invisible disability. For example, there were significant differences between younger and older adults, racialized and nonracialized individuals and men and women, related to disclosure and comfort with disclosing their diabetes status. Disclosure and decisions about when and to whom one discloses having diabetes has been explored in a few recent studies (24–26). Disclosure decisions may vary by population. Among our participants were those who expressed significant anxiety related to decisions about disclosure and those for whom disclosure was less of an issue. The COVID-19 pandemic and its impact on individuals with diabetes was initially unknown and was a source of additional anxiety related to disclosure as well as uncertainty, and hence anxiety, about ongoing access to insulin and other medications, potential hospitalization, intubation and ventilation, managing diabetes in hospital and the resulting loss of “agency.”

As diabetes-related hypoglycemia for those with type 1 diabetes is a serious risk with a potentially lethal outcome, making the decision to not disclose diabetes status can be a dangerous one. However, disclosure has also been associated with resilience. Past research has suggested that disclosure can influence one’s thinking about the topic and this is associated with improved resilience. By contrast, suppressing disclosure requires ongoing emotional investment, which serves to undermine resilience (27). Therefore, encouraging and supporting appropriate decisions about disclosure can contribute to resilience and, thus, to health and well-being.

Resilience has been identified as an important characteristic for those managing a chronic health condition or physical challenge (28,29). However, resilience is a multilevel construct that has been challenging to define, sometimes referring to the process and sometimes the outcome of overcoming or coping with stress, challenge or adversity (30,31). Recent understanding has emphasized that resilience results from the interplay of multiple personal traits and the external environment (32,33), meaning resilience is variable and can be influenced by an individual’s age, gender, socioeconomic status and culture and life circumstances (34). As a chronic disease that requires considerable and ongoing self-management (e.g. 150 separate behaviours have been identified in managing type 1 diabetes) (35), life for those with diabetes has been described as including considerable stress, emotional strain, worry and anxiety (36–39).

Yet, we saw considerable differences in experience by gender, age and race/ethnicity—for example, the influence of age on older men’s perception that diabetes stigma has improved over time, suggesting that improved public awareness of diabetes is working to decrease expressed or felt stigma. Those without other experiences of marginalization (such as older Caucasian men with good incomes and younger Caucasian women and men) felt accepted and/or empowered as individuals with diabetes. However, somewhat older women reported decades of challenging and sexist treatment in their interpersonal and health-related encounters; this group did not perceive any lessening in their experiences of stigma over time. We learned of harassment based on gender, race and ethnicity and diabetes, as well as the complex calculations associated with disclosure as a racialized immigrant in Canada. The lived experience of diabetes occurs at the intersection of identities, relationships and the broader social system in which we all live.

In the context of health care, relationships among social position, stigma, diabetes as a visible or invisible disability, decisions about disclosure and resilience are highly relevant to care delivery and the provider/patient relationship. As a provider, acknowledging one’s own social location and its advantages, as well as its limitations, can engender humility, thereby inviting the patient to share their experience and expertise. Recognizing the complexity of identity and how identity influences the ways individuals live with and manage diabetes can open the door to more honest communication about disclosure, stigma and resilience while also allowing for tailored recommendations for additional guidance and support.

In conclusion, by applying an intersectional lens to the experiences of those living with diabetes, we become aware of significant differences based on identities, social location and other personal characteristics. Health-care providers who take the time to learn from their patients about the particulars of their experience may be better able to support their resilience, health and overall well-being.

Limitations

There are several limitations to this study. First, the participants in this study may have had more knowledge about diabetes and greater comfort in discussing their experiences due to their status as patient partners in Diabetes Action Canada. Being a patient partner was often important to participants’ resilience as they recounted the encouragement, knowledge-sharing, destigmatization, community-building and acceptance resulting from their association with Diabetes Action Canada. Accordingly, the experience of resilience may differ for people with diabetes without this connection.

Second, we included both English- and French-speaking participants, but the analysis was completed on English translations of the French interviews. This may have impacted some understanding due to subtleties in interpretation when analyzing peoples’ lived experiences in translation.

Finally, although there are more men than women with diabetes in the general population, our study participants included more women than men.

Supplementary Material

To access the supplementary material accompanying this article, visit the online version of the Canadian Journal of Diabetes at www.canadianjournalofdiabetes.com.

Acknowledgments

The work was supported by the Canadian Institutes of Health Research (CIHR Grant 2016–2021) Strategy for Patient-Oriented Research Network (SCA-145101: PI: Lewis, Diabetes Action Canada). The CIHR and Diabetes Action Canada played no role in determining the study design, planning for data collection or analysis, decision to publish or manuscript preparation.

Author Disclosures

Conflicts of interest: None.

Author Contributions

Z.J.: study design, data collection, data analysis and interpretation, drafting the article, final approval of the version to be published. J.A.: study design, data collection, data analysis and interpretation, final approval of the version to be published. V.B.: data analysis and interpretation, final approval of the version to be published.
published. A.G.: data analysis and interpretation, final approval of the version to be published. P.R.: data analysis and interpretation, final approval of the version to be published. R.M.: conception of the work, study design, data analysis and interpretation, critical revision of the article, final approval of the version to be published.

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