Can J Diabetes 44 (2020) 370–373

Contents lists available at ScienceDirect

Canadian Journal of Diabetes

journal homepage: www.canadianjournalofdiabetes.com

Special Article

Language Matters – A Diabetes Canada Consensus Statement

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ARTICLE INFO

Article history:
Accepted 21 May 2020

ABSTRACT

Language reflects and shapes our thoughts, feelings, behaviours and experiences and can have a profound impact on the lives of people with and at risk for diabetes. Inappropriate language has a negative impact on self-efficacy, well-being and confidence of people living with diabetes, can seriously undermine experiences with health-care providers and, more broadly, can contribute to diabetes stigma.

To date, Diabetes Canada has had no formal position to facilitate positive and affirming attitudes towards diabetes, which is reflected by the use of more appropriate language around diabetes. This consensus statement was developed by Diabetes Canada, by a working group comprised of health-care professionals and lived experience subject matter experts (LESME: patient partners) and validated by volunteers from Diabetes Canada's Professional Section and Diabetes Action Canada's Patient Circles. The principles outlined in this document will be valuable in three broad domains: 1) Diabetes Canada's internal and external communications, 2) increasing public awareness of diabetes and reduction of stigma around diabetes and 3) enhancing the health, wellness and self-efficacy of persons living with diabetes. A major strategy to effect change in this third domain will be to disseminate these concepts broadly among all current (and future) health-care professionals to help integrate positive and supportive attitudes in everyday clinical practice.

Background

Language reflects and shapes our thoughts, feelings, behaviours and experiences. For those living with diabetes – an umbrella term for a number of conditions characterized by elevated blood glucose levels, which can adversely affect health – language has a profound impact on health behaviours and health-care experiences (1,2). Managing diabetes is a 24/7 activity, and its daily work (monitoring blood glucose, exercise, monitoring diet, addressing and coping with blood glucose excursions, etc.) is done outside health-care settings. The language used when communicating with and about people with diabetes can encourage self-efficacy and confidence, improve self-management, and – at a broader societal level – decrease the stigma, stereotypes and prejudice associated with this condition (3). Alternatively, poor communication may perpetuate stereotypes and prejudice, stigmatize, shame or blame people with diabetes, ultimately having a negative effect on their physical and mental health outcomes (4,5).

This consensus statement aims to raise greater awareness of the language used when speaking with and about people with diabetes. We endeavour to promote and help guide the use of inclusive, equitable and value-based language in diabetes clinical practice, health care and research settings, policy development, and media communications. We hope that greater attention to the language used when speaking of diabetes will contribute to enhancing public understanding of diabetes and its complications, decreasing the stigma, and stereotypes and prejudices associated with it. Ultimately, it is our hope that this work will contribute to improving the mental, emotional and physical well being of the 11 million Canadians living with diabetes and prediabetes.

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https://doi.org/10.1016/j.jcjd.2020.05.008

Our work is inspired by guideline development and media campaigns in organizations from other jurisdictions, including Diabetes Australia (6), NHS England (7), the American Diabetes Association (8) and the International Diabetes Federation (9). These guidelines and associated or related campaigns (e.g. #LanguageMatters) highlight how language impacts diabetes care and management and provide recommended frameworks for communication. Our work also adds to the growing movement towards acknowledging the importance of language in health and health care by providing recommendations for the Canadian context.

Methods

To develop this framework, a steering committee was convened by Diabetes Canada, chaired by the co-chair of the professional section, and including Diabetes Canada staff, and several members of the professional section who also have lived experience of diabetes. The initial work of the steering committee was to perform an environmental scan and conduct a literature review. We assessed literature describing the impact of language on equity, inclusivity, people living with illness, the emotional health and self-management practices of people living with diabetes, and stigma. In parallel, we sought validation for this work with a broader group of LESMEs (including indigenous organizations) through partnership with Diabetes Action Canada. Broader input from health professionals and people living with diabetes was acquired in several ways. To hear from health-care professionals, we conducted workshops with multidisciplinary groups of health-care providers working in diabetes care and management to hear their perspective on the role language plays in their interactions with people with diabetes, self-management behaviours, and stigma and stereotyping. To ensure this work represents the experiences of people living with diabetes, our team consulted with Patient Partners from Diabetes Action Canada, a patient-oriented research national network whose Patient Partners include a wide diversity of people living with diabetes across the country. Three Patient Partners from Diabetes Action Canada sat on our steering committee and led meetings with other Patient Partners ("patient circle meetings") to discuss issues raised. The purpose of these meetings was to help us better understand how language impacts the lived experience of diabetes care and management, and to ensure that our final framework reflects the views of those living with diabetes. The consensus statement was thus developed as a partnership between Diabetes Canada, academics, clinicians and LESMEs.

Scope of this Initial Consensus Statement

Given the diversity of the Canadian population, we recognize that no single framework can speak to the needs of everyone in Canada. Therefore, our intention is for this document to be a first step in raising awareness of the importance of language used when talking with and about people living with diabetes, and we plan (and encourage others) to develop further recommendations as they pertain to specific groups, including those of African/Caribbean/Black, South Asian and Chinese descent, those living with low income and newcomers to Canada. Further work addressing the unique needs of Indigenous people living with diabetes in Canada will be Indigenous led, developed, owned and implemented.

Why it matters: Accuracy

Diabetes is not a single condition; it is an umbrella term for a collection of conditions with similar symptoms, but very different causes, progressions and prognoses. There are three main types of diabetes: type 1 diabetes (T1D), an autoimmune condition that cannot be prevented and in which the pancreas is unable to produce insulin; type 2 diabetes (T2D) which is caused by a complex interplay of genetic, environmental and behavioural factors where the pancreas can make insulin but not a sufficient amount for the body's needs; and gestational diabetes (GDM), a temporary condition some women experience in pregnancy that usually goes away after birth. There are other rarer causes of diabetes: e.g. monogenic diabetes, or diabetes which develops as a result of pancreatic diseases or surgery. Prediabetes is a term used to describe minor elevations of blood glucose levels, but not high enough to classify them as living with T2D. People with a history of GDM or prediabetes are at risk for developing T2D.

When speaking about people with diabetes, it may be important to be type-specific. Talking in generalities contributes to confusion about and a lack of public understanding of diabetes. It may also perpetuate and overextend inaccurate ideas that contribute to issues of safety. For example, advocating for sugary drink consumption is helpful in reducing the risk of developing T2D, but it is often discussed as helping prevent "diabetes." For the public, this idea can be misunderstood and overgeneralized such that they believe that no one with diabetes should consume sugary drinks. For people with T1D, however, sugary drinks can help when experiencing low blood sugar. In this document, we purposefully use the term "diabetes" when discussing aspects of these conditions that are common across all, and we are type-specific when we address unique factors relevant to a particular type.

Why it matters: Power

Language can perpetuate or challenge the power imbalance between health-care professionals and people with diabetes, and between people with diabetes and the health-care system. Overreliance on medical terminology may intimidate and create a power differential between health-care professionals and people living with diabetes. It can also discourage people with diabetes from actively participating in developing a care plan because they assume they are not knowledgeable enough or that "doctor knows best." Conversely, those confident in their knowledge may disengage from health-care professionals who do not show respect for their knowledge.

Why it matters: Labelling

It is important to use person-first language. The term "diabetic" (used as a noun) overextends the salience of living with diabetes on one's life and defines the person as their health condition. Diabetes is but one aspect of a person's lived experience. Similarly, the term "patient" can contribute to this dynamic as it disregards the fact that being a patient is only a small part of their life experience. Individuals have other roles and activities outside of doctors' offices that take precedence and contribute equally, if not more, to their sense of identity. However, it is important to note that this is not the case for all individuals living with diabetes. Some, particularly those with T1D, self-identify as "diabetic" because they feel diabetes plays such a significant role in their life that it permeates their life course and daily decisions. If there is ambiguity around this term, ask the individual for their preference.

Medical terminology influences how people with diabetes feel about their condition, and how family, friends and the general public view people with diabetes. The terms used by health-care professionals often label people as "sick," "ill" or "suffering," when individuals may not feel that way. These terms are overly negative and position people with diabetes as passive, helpless, powerless victims when there is no intrinsic reason that this diagnosis will impede the ability of people with diabetes to live fulfilling and meaningful lives.

Labels such as "noncompliant," "nonadherent" and "poorly controlled" are especially problematic. Labelling people with diabetes this way suggests that they are uncooperative and may leave them feeling as though their health-care providers do not recognize the effort they are putting in to manage their diabetes. These terms deny patients a sense of agency and discount the ways in which they might be balancing the risks and benefits of different behaviours and choices. For example, someone may choose to let their blood glucose levels run higher than the clinically recommended range to better avoid hypoglycemia. These terms also fail to acknowledge the impact of social determinants of health. For example, people with higher incomes are more easily able to purchase food to follow a particular eating plan.

The opposite terms, “compliant,” “adherent” and “well-controlled,” are also problematic in that they imply that acceptance of patients’ actions and decisions is contingent on the extent to which these align with health-care professionals’ priorities. In other words, they imply conditional approval that may be withdrawn.

All forms of diabetes can be unpredictable, challenging and demanding to manage. Life events, relationships and financial constraints can all impact on people’s capacity to cope with the challenges of diabetes. Despite best efforts, many people with diabetes experience blood glucose levels that fall outside targeted ranges. Given the chronic and progressive nature of diabetes, balancing glucose levels can become harder over time. Terms such as “noncompliant” and “nonadherent” do not take these factors into account.

Ultimately, use of these terms may prevent opportunities to explore a patient’s values, life circumstances, skills and constraints, thus limiting opportunities to codevelop ways of improving their health. This collaboration should include consideration of their beliefs, priorities and lifestyle considerations.

Why it matters: Shame, blame, stigma and stereotyping

Stigmatizing language is often used in talking about diabetes. Due mainly to its association with overweight, obesity and “lifestyle factors,” such as diet and physical inactivity, this is especially true of T2D. Misperceptions hold that T2D can be easily prevented, so those who develop the condition are erroneously seen to have “brought it on themselves.” In fact, some people with T1D report concern that they will be mistakenly identified as T2D due to the stigma associated with this disease.

Additionally, language contributes to perpetuating harmful stereotypes, prejudices and biases. The terms “overweight” and “obese” carry negative social connotations, and their use can signal disapproval or moral judgment. This contributes to weight bias in the health-care profession and in the public, contributing to negative attitudes towards those of a certain size or weight, as well as discrimination, for example, in the labour force.

The lack of empathy and compassion conveyed in these views contribute to people with diabetes feeling demoralized, defeated and blaming themselves for any adverse health outcomes they experience. They also contribute to a culture of shaming that stigmatizes those living with diabetes in the eyes of the public. Ultimately, these messages can have a negative consequence on a person’s health and mental wellness, and it may leave them concerned about discussing their condition with friends or family, advancing their care (for example, adding insulin to the use of oral medications for those living with T2D), requesting needed accommodations at work or seeking out professional support for fear of being judged.

Why it matters: Framing

Language constructs meaning and impacts one’s lived experience of diabetes and self-identity. Language that focuses on “curing,” “fixing” or “battling” diabetes frames those living with the condition as fundamentally flawed. Particularly for those with T1D, who are often diagnosed at young ages, this adds a layer of complexity that encourages people to be unhappy with their bodies and their health, overidentify with the negative aspects of diabetes and understand themselves to be abnormal. People living with diabetes may have valid feelings that call for such descriptions, but these descriptors should not be imposed on people with diabetes. When discussing diabetes, aim to frame discussions in ways that focus on people’s strengths and empowering messages.

Framing diabetes as a “disease” may also be harmful due to the negative connotations associated with it. Diabetes is a chronic condition that is not contagious, which the term “disease,” as it is popularly understood, implies. Using “condition” may be less likely to cause misunderstanding.

What kind of language is needed?

People living with diabetes deserve to be spoken with and about in ways that are respectful, inclusive and value based.

We recommend that the language used….	
Is accessible and understandable	To decrease the risk of people misunderstanding their condition and/or treatment plans, the language used in health-care settings, and in online educational tools and resources, needs to be accessible and easily understood. This also helps people with diabetes to be active participants in decisions about their health management decisions.
Frames thoughts, ideas and suggested directions in ways that are motivating and encouraging	Language does not simply reflect reality; it creates it. Make an effort to use language that is motivating, encouraging and acknowledges the efforts people with diabetes are making to manage their health. Acknowledge the realities of challenges in people’s lives and, when people are able to participate in such discussions, focus on the opportunities for positive changes that are available, both now and in the future, to improve self-management behaviours and health outcomes.
Is empathetic and compassionate	To support the emotional wellbeing, enhanced feelings of self-efficacy, and increase self-management practices of people living with diabetes, work to understand their perspective.
Is realistic and avoids judging, shaming and/or placing blame	Avoid the use of language that implies moral judgement of another’s behaviour or perspective. Avoid language that implies a person with diabetes is wholly responsible for having their condition or experiencing complications, as this is inaccurate and may be harmful. While people with diabetes who have the resources to do so may be able to enact recommendations and decrease their risk, an individual could do everything according to evidence-based self-management guidelines and yet still experience an undesired outcome.
Is type sensitive	Some statements apply to all types of diabetes, while other statements are specific to one or more types of diabetes. Communicating about decreasing one’s risk of developing diabetes is insensitive to people with type 1 diabetes, which cannot currently be prevented. Similarly, speaking about children with diabetes in a way that assumes all children have type 1 diabetes is insensitive to children with type 2 diabetes and their families. Lack of type sensitivity contributes to public misunderstandings and stigma. Be specific about types of diabetes in all communications to help shape social norms and expectations.
Aligns with the preferences of the person with diabetes	Different people with diabetes have different preferences. What helps one person may not help the next. In individual interactions, be sensitive to individual preferences.

In addition, the following practical tips can enhance language and communication further:

- Check in with yourself and those with/to whom you are speaking: Language is cultural and, therefore, the meanings associated with words and phrases change with time and between groups. Pay attention to shifts in language use and meaning to monitor your own underlying assumptions, and how the words being used may be perceived by people with diabetes and larger audiences.
- Language is more than words: Language reflects attitude, and may be harmful regardless of the intention of the speaker. Conversely, using the right words is not a substitute for having empathy, compassion and helpful attitudes. Also, be aware of your body language and tone. Try to present yourself in a way that is open and receptive.
- Be consistent and use the same language you would talking with people with diabetes when referring to them in writing or with colleagues.
- Speak to the whole person: Ask questions about someone's life in general, as opposed to about their "diabetes control." Focusing squarely on "diabetes control" leaves little space for understanding their life circumstances and perspectives, all of which must be considered in order to develop an effective diabetes management plan.

Avoid	Use Instead
Referring to "diabetes" generally when your statement is only accurate for specific type(s)	Type 1 diabetes, type 2 diabetes, gestational diabetes, prediabetes
Focusing appointments on glycated hemoglobin (A1C) results	People living with diabetes are greater than their A1C. Focusing on A1C can elicit feelings of failure. Treat discussions as a check-in and not an evaluation. Use A1C as an opportunity to ask about both successes and struggles, and offer suggestions/support.
Diabetic, patient, suffering	Person living with diabetes, has diabetes
Disease	Condition
Overweight, obese	Person living with overweight/obesity
Compliant, noncompliant, adherent, nonadherent	Collaborative goal-setting and decision-making terms that acknowledge the realities of people's lives; e.g. "Demands of diabetes exceed current capacity" (10).
Prevent, prevention	Reducing risk of…
Blood test	Monitoring, self-monitoring, checking
Should, should not, can't, must, must not, have to	Here are some options…, you could try…, consider these options…, you could consider…, other choices to consider…
Control	Manage, self-manage, influence, discuss how diabetes impacts the individual's life overall
Poorly controlled, poor control, good control, well controlled	Glucose levels that are: stable, within the target range
Failed, failing	Has not, was not able to, this time didn't, lacked capacity or support to…

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Next Steps / Conclusions

The importance of language and its impacts will be emphasized internally throughout Diabetes Canada, including the board, staff, professional and other volunteers, through accompanying educational material and workshops. It will impact on fundraising, advocacy, policy, position statements, clinical practice guidelines and educational materials for the public and health-care professionals. It should impact the language used by speakers invited to present at Diabetes Canada fundraisers and conferences. Extending the impact of #languagematters beyond Diabetes Canada is essential if we are to have the greatest impact on the lives of persons living with or at risk for diabetes— be that policy makers, the media or through changes to the curricula in schools and institutes responsible for training health-care providers.

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