

Majority of teens to young adults with type 1 diabetes feel socially stigmatized

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Michael Wright, patient co-author; Dr. Kaberi Dasgupta, clinician-scientist in the Metabolic Disorders and Complications Program at Research Institute of the McGill University Health Centre; Debbie Chan, Research Assistant, RI-MUHC. Credit: MUHC

Michael Wright was your average high school student, juggling the responsibilities of school and friends while taking the first steps towards finding his first real job. Being diagnosed, suddenly, with type 1 diabetes was a shock. Suddenly, Michael found himself struggling with the sudden requirements that accompany treatment, from the intense monitoring of dietary habits to administering insulin—either through injections or via a cell phone-sized pump attached to the body. And, in addition to the daily struggle of staying on top of his new diagnosis, he felt stigmatized.

A team at the Research Institute of the McGill University Health Centre (RI-MUHC) report that teen and young adult (aged 14-24 years) type 1 diabetes sufferers often experience stigma, which leads them to neglect treatment and tread dangerously close to suffering medical emergencies. Michael was one of two patient partners engaged to participate in a study that is the first of its to estimate the stigma prevalence in this age group related to type 1 diabetes, which can lead to elevated HbA1c levels and severe hypoglycemia. Their findings are published in *The Journal of Medical Internet Research*.

"A lot of things that tend to be automatic in our bodies suddenly have to be managed, which is super stressful. Then you superimpose on this the fact that you are a young person worrying about your career, your romantic life, education, autonomy from your parents—all this stuff happening and then you get hit with this and it ticks you off," says study senior author Dr. Kaberi Dasgupta, who is a clinician-scientist in the Metabolic Disorders and Complications Program at the RI-MUHC and internal medicine specialist at the MUHC. "They are always kind of dancing with death—constantly treading that fine line."

Type 1 diabetes affects under 10 per cent of diabetes sufferers worldwide but accounts for 95 per cent of diabetes that starts in childhood and adolescence. It requires intensive and complex round-the-

clock self-care and when vigilance dips, the risk of medical emergency is real—be it loss of consciousness and death related to low sugars or dehydration and [medical emergencies](#) related to very high blood sugars. In the longer term, blindness, renal injuries, amputation, heart disease, and strokes are all a real possibility in the absence of careful management. These constant demands mean youth with type 1 diabetes can feel stressed out while struggling with their predicament, burdened by issues with self-esteem, body image, social role definition, and peer-related issues. Two-thirds of study participants experienced stigma, with a higher proportion rate found among females compared to males.

"When I was diagnosed at 16, my friends were supportive but they could not understand—it was a shock to them as much as it was a shock to me," Michael remembers. "I didn't expect them to understand and I didn't feel like I belonged as much anymore. And that is a common theme we discovered: a lack of social support leaving people feeling alone."

Three hundred and eighty participants between the ages of 14 to 24 were specifically recruited via social media with the help of Diabetes Canada and diabetes clinics and organizations across the country. This has led to the creation of a [Virtual Patient Network \(VPN\)](#) where this type 1 age group can communicate with one another to offer a variety of health and practical tips. This ranges from managing blood sugar levels in relation to physical activity to the must-have items for a weekend camping excursion.

"The patient partners thought of the questions and helped us develop and formulate our questionnaire, and they helped interpret and analyze the data," says Dr. Dasgupta, whose team is at the Centre for Outcomes of Evaluative Research (CORE) of the Research Institute. "The creation of the peer-to-peer network has provided those coping with stigma a platform toward the research agenda of helping to reduce stigma and live

with type 1 diabetes."

"Canada is facing a diabetes epidemic—one in three Canadians lives with diabetes or pre-diabetes and young people in their twenties have a 50 per cent chance of developing the disease in their lifetime," said Dr. Jan Hux, president of Diabetes Canada.

"Despite the fact that type 1 diabetes is not the fault of the person affected by it—is not related to any behaviour patterns or choices—young people diagnosed with it experience a distressing level of stigma. Research and programs that raise public awareness and support around type 1 [diabetes](#) and foster resiliency in those affected by it are urgently needed. Diabetes Canada is pleased to have supported this first of its kind research in Canada."

More information: Anne-Sophie Brazeau et al, Stigma and Its Association With Glycemic Control and Hypoglycemia in Adolescents and Young Adults With Type 1 Diabetes: Cross-Sectional Study, *Journal of Medical Internet Research* (2018). [DOI: 10.2196/jmir.9432](https://doi.org/10.2196/jmir.9432)

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