COMMENTARY

Impact of Living with Stigma in Persons with Type 1 Diabetes: A Patient–Physician Perspective

Mohammed Najeeb Ashraf · Alice Y. Y. Cheng

ABSTRACT

Type 1 diabetes mellitus (T1D) is an autoimmune disorder characterized by a complete deficiency in insulin due to the destruction of pancreatic beta cells. Globally, T1D accounts for nearly 5–10% of the total diabetes cases. Living with this life-long condition has a significant emotional, psychological, physical, mental, and social impact. Despite extensive research characterizing the underlying physiology of T1D, additional work is needed to address the psychosocial aspects associated with the condition and its effect on the quality of life (QoL) of people living with T1D. One area that warrants further exploration is the stigma-related stereotypes and prejudice of people living with T1D experience in real-life settings. Despite the acknowledgment of stigma for conditions such as obesity, mental illness, and epilepsy, its association with T1D and ensuing psychological distress remains relatively under-investigated. Health-related stigma is a huge barrier to seeking appropriate, timely support for enhanced healthcare management and engagement in such patients. Here, we provide the perspectives of an adult with over 33 years of living with T1D and an expert endocrinologist who details their experience of T1D-related stigma. The self-reported factors explored by the person living with T1D include (but are not limited to) blame, mockery of the condition/person, diabetes-related shame, exclusion, rejection, negative judgments, fear, stereotyping, and discrimination. The lived experience supported by the clinical insights of the endocrinologist highlights the urgent need to decipher the severity, extent, nature, determinants, and consequences of stigma faced by a person living with T1D. Raising societal awareness, increasing education for caregivers, access to counseling for people living with diabetes, and engaging in shared decision-making remain the path forward.

Mohammed Najeeb Ashraf: Patient Author.

M. N. Ashraf (✉)
Patient Author, SciVoc Consulting Inc., Toronto, Canada
e-mail: najeeb.ashraf@scivoc.com

A. Y. Y. Cheng
Trillium Health Partners & Unity Health Toronto, Toronto, Canada

A. Y. Y. Cheng
University of Toronto, Toronto, Canada

Key Summary Points

People with long-term type 1 diabetes have managed/been managing several stigmatic experiences related to the condition that lead to a substantial mental and physical toll on their well-being and quality of life.

People with type 1 diabetes facing higher levels of perceived stigma have been known to display significantly greater levels of distress, anxiety, mood swings, blood glucose levels, and trauma-related events than those without it, thereby adding to the psychosocial burden of such people.

Understanding the extent and nature of the impact of diabetes-associated stigma on people with type 1 diabetes is crucial for developing necessary interventions and mechanisms to address this impending issue, which remains largely under-investigated.

Our patient–physician perspective article aims to bring out the experiences of the patient living with type 1 diabetes for the past 33 years and his experiences of tackling the condition by himself and with support from others. His perspective, combined with that of the endocrinologist, helps highlight the importance of engaging patients in decision-making while trying to find answers to tackling the stigma associated with the condition.

Bringing patient and physician perspectives to acknowledge and manage the stigma associated with diabetes could serve as the future way forward toward establishing a robust ecosystem fostering healthy dialogue and partnership between patients and physicians to jointly tackle the demon of stigma associated with the condition.

BACKGROUND

Type 1 diabetes is an autoimmune disorder with increasing global prevalence [1]. The use of novel technology, glucose sensors, and insulin pumps has allowed enhanced glycemic control. Despite this, the association of such tools with complications in diabetes needs further exploration [2]. The experience of people living with type 1 diabetes mellitus (T1D) with perceived stigma and the associated emotional and psychosocial distress could impact their mental health and health-related quality of life (QoL) [3–6]. Stigma is defined as the negative aspects of a person's characteristics that differ from the norms associated with their culture, and stigmatization is a condemnatory response that is based on stigma perceptions [5]. Several components constitute stigmatization, including distinguishing and labeling, linking labels to negative stereotypes, in-group/out-group comparisons ('us vs. them'), status loss, and discrimination, as outlined per the prominent stigma theorists Link and Phelan [7]. A meta-analysis of 12,777 participants in 19 studies showed a high pooled correlation between diabetes-related stigma and psychological distress ($r = 0.50$, 95% CI [0.43–0.57]) [8]. The psychosocial impact of stigmatization in people with T1D can significantly harm the social identity of the person affected [9]. In this article, we will share the lived experience with T1D of one of the authors and the perspective of an endocrinologist.

This article is based on previously conducted studies and does not contain any new data or information on human participants or animals performed by any authors.

BEYOND THE DISTRESS—A T1D LIVED EXPERIENCE

In my 33 years living with T1D, I injected insulin four times daily until the last 10 years when I shifted to an insulin pump. At the time when I was taking injections and even during days of using an insulin pump, I recall countless occasions of stigmatic responses by society and people who were unaware of what diabetes is,

what it entails, and what it means to have diabetes. Walking with the insulin pump glued to my pocket, I would often invite a stare with curious and amusing questions such as, "Is this a pager?" As a child, I used to be reclusive and feel ashamed about my condition; however, as I grew up and learned more about my condition, I understood the considerable gap in knowledge, education, and society's awareness about T1D. It is unsurprising since a significantly higher proportion of people with T1D have reported diabetes-associated stigma compared to type 2 diabetes (T2D) (76 vs. 52%, respectively; $P < 0.0001$) [5]. My experiences of living with T1D were congruent with the stigmatic forms of fear, shame, unhappiness, flaws in myself, and burden on family and loved ones. I want to emphasize a few that took a toll on my mental state and confidence in the past and how I dealt with such negative feelings and emotions due to diabetes stigma.

TYPES AND CONSEQUENCES OF T1D-ASSOCIATED STIGMA

Stigma related to T1D refers to negative experiences including (but not limited to) blame, mockery of the condition/person, diabetes-related shame, exclusion, rejection, negative judgments, fear, stereotyping, self-reported depression, and isolation. The top three that I frequently encountered include the following:

Guilt and Shame

I always felt something was wrong with me based on how my colleagues, society, and peers questioned, mocked, smirked, and started treating me starting from my diagnosis of T1D. As a child, it profoundly impacted my confidence and social standing since it made me feel guilty about something I could not control. If I had been physically active and not eaten much sugar, would I still be healthy and not get diabetes? I sometimes felt ashamed and angry, trying to hurt myself for being in this unhappy situation. During my formative years, I started

hiding my T1D diagnosis from my friends, family, and peers.

Social Fear, Isolation, and Embarrassment

Closely related to mental health, the feelings of guilt transformed into social fear. I was frightened of how people would perceive my condition and pass a callous remark that would affect me. Not only did this make me moody, but the anticipation of this negative feeling made me avoid social gatherings for fear of being judged by strangers who do not know what I am dealing with. It is better to avoid meeting people than live in fear of being labeled as having diabetes as "my problem." I realized it was accessible for people without understanding T1D to judge and pass unwelcome comments. I intentionally delayed insulin dosing and blood glucose monitoring for fear of being judged when in the company of others. This, consequently, led me to choose unhealthy food at delayed times to "fit in" with society and cultural norms. There were occasions when I had to inject myself in front of people, and some got worried and offended, thinking I was taking drugs, an emotion that patients with T1D strongly advocate [4]. Undoubtedly, this impacted my HbA1c significantly, being high most of the times due to undue stress and fear. This, eventually, made me feel isolated, which is common among those living with T1D [3, 5, 6].

Physical Impact

During my formative years, I had the challenge of trying to understand multiple aspects of diabetes management. It took a toll on my physical health. I was often tired due to high blood glucose, worsened by the fear and guilt I was hiding. The most common remark I encountered, even in professional settings, was as insensitive and callous such as, "You seem not to have slept last night; you look so worn out as if you just stepped out of bed; go and get a bath, you never look fresh," and more. Being tired also impacted my mood and behavior, affecting my participation in social events. I used to feel enervated most of the time,

fighting hard to keep up with my energy, and I always felt something was wrong with me and that I might not keep up eventually with all the burden associated with managing T1D.

Mental Health Impact

I spent significant time thinking about people, society, judgments, reactions, blame, and prejudices, which affected my mental health and capacity to endure. These negative emotions weighed heavily on my mental health at various stages in my life, requiring me to seek professional support. I recognized the feeling of depression (without a clinical diagnosis), checked with my treating physician, located a treatment facility, and finally shared my thoughts with the mental health practitioner. This dialogue was the only way to let me share my inner fears and demons, which I felt my family would not understand—causing me to be quiet, secluded, and withdrawn. Today, after having experienced depression a few times during my 33 years of living with T1D, I understand the importance of dealing with this menace as quickly as possible for better health. Having lived through all of this, today, I am privileged to understand and advocate for people with diabetes (type 1 or type 2).

PHYSICIAN PERSPECTIVE

As a physician, one of the most important, yet often missed, things we must do is listen. Listen to the person we are serving and inquire about their lived experience. Then, and only then, can we develop a greater understanding of the whole person and what we can do to best help them. During my training, this was not emphasized. We spent much time learning facts and knowledge devoid of human experience. So, the concept of "diabetes stigma" was not apparent to me. It made no sense to me. Diabetes is a medical condition related to insulin and its actions. Why would anyone be stigmatized for that? But when I started to listen to people living with diabetes and paying attention to the noise of society, I realized that diabetes stigma is very real and pervasive. It affects those living with diabetes and is perpetuated by society, media, health care professionals, and even by people living with diabetes on each other. In my opinion, one of the root causes is misinformation. There is a lack of understanding about the different types of diabetes and how one develops diabetes. It is not from overeating sugar or being "careless" with their lifestyle. Genetics and other biological factors that have yet to be understood play huge roles, and these are not things under one's control. This experience has taught me that when diagnosing diabetes and communicating this for the first time to someone, we must tell them and their families that it is not their fault. The blaming and shaming around a diabetes diagnosis is not rooted in science and can adversely impact the health of the individual with diabetes, as exemplified above. We must stop doing that. Also, as a society, there is a misplaced sense of pity for those living with type 1 diabetes ("oh poor thing") and contempt for those living with T2D ("If only they took better care of themselves"). The treatments are perceived negatively, such as the notion that using insulin is "bad" or "severe" and something for which we should pity someone. Again, these notions are false but pervasive, and we, as healthcare professionals, need to reflect on whether we are perpetuating some of these in the language we use when speaking to patients. Then there is also the interesting phenomenon of diabetes stigma perpetrated by people living with diabetes on each other. Those living with T1D may not want to be categorized together with those living with T2D because they do not want to be seen as having the kind of diabetes that could have been avoided—which, again, is rooted in stigma.

After one has been diagnosed with diabetes, there is an expectation that they will be engaged with the healthcare system chronically to implement the multitude of interventions that have been shown to reduce complications of diabetes. However, it is well established that the achievement of guideline-directed targets and the use of guideline-directed therapies is lacking worldwide [10]. Although many human and system factors explain this gap, diabetes stigma and the role of healthcare professionals

in perpetuating this must be recognized. People living with diabetes may be stigmatized by their diabetes team at visits for not doing everything they were "told" to do at the last visit. There may be a need for more empathy to recognize the day-to-day burden of managing a chronic disease. Therefore, the team inadvertently blames and shames the person for not trying hard enough or not caring enough. This will only serve to alienate, and some people will stop engaging with healthcare altogether. In addition, I have seen how the stigma of diabetes has prevented some people from using technologies to help reduce the burden of diabetes, like wearable technology, for fear of making their invisible disease visible. This, of course, can then impact their future health and QoL.

FUTURE FORWARD—RECOMMENDATIONS

The following are recommendations for society, governing bodies, community, and healthcare professionals that may help reduce the stigma associated with T1D. These include:

- Increased public education, awareness, and knowledge sharing on type 1 and type 2 diabetes. Social media campaigns, fundraising events, and more could assist with this initiative.
- Patient advocacy groups can assist newly diagnosed individuals in addressing diabetes stigma by sharing best practices to tackle such challenges. It is critical to have informed communication about daily living experiences with diabetes.
- Development of national policies and social programs to address diabetes stigma.
- Patient engagement opportunities to share and bring forth real-life experiences could help guide well-crafted research that could impact patient health.
- Extensive patient–physician dialogue facilitates healthy and mutual healthcare management decisions.
- Patient counseling programs to assist anyone dealing with diabetes-associated stigma. For this purpose, there is a need to educate and train nurses, counselors, and psychologists to work together toward solving this.
- Healthcare professionals must familiarize themselves with the Language Matters documents, initially spearheaded by Diabetes Australia [11], which impact the language used when speaking to people with diabetes and in medical communication.
- Media partners should also utilize Language Matters recommendations when writing or depicting diabetes to the public to stop perpetuating the stigma.
- Further research is needed to measure the frequency of diabetes-related shame, how it impacts daily living conditions, and how to minimize negative emotions.

Everyone should commit to stopping diabetes stigma by endorsing the pledge on the Diabetes Stigma website [12] and sharing it widely (#EndDiabetesStigma).

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