GUEST EDITORIAL

Type 1 Diabetes: Our Voice Must Be Heard

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UNDER THE SHADOW

Seemingly just an eight-letter word, ‘diabetes’ actually encapsulates multiple heterogeneous disease states, comorbid conditions, complications, and outcomes[1]. Because of the sheer number of persons living with type 2 diabetes mellitus (T2DM), this syndrome takes centerstage in most discourse on the disease. This shift in focus has become more accentuated in recent years, as attention shifts to the cardiometabolic and barometabolic aspects of T2DM. T2DM also fits neatly in the narrative of noncommunicable disease (NCD) that dominates modern global health policy[2]. In an ecosystem where funds and facilities are always limited, type 1 diabetes mellitus (T1DM) often tends to get sidelined[3].

CHALLENGES AND CONCERNS

Persons living with T1DM represent a significant proportion of all persons with diabetes[4]. However, this is nowhere near to the magnitude of T2DM. Person with T1DM are more often children, adolescents, or young adults. They may not have the clout and capability required to ensure effective awareness and advocacy for their cause. They are dependent upon insulin for survival, and their financial vulnerability and logistic challenges keep them engaged in basic survival. This prevents them, in many countries, from creating effective patient advocacy organizations. Even if these are formed, changes in life circumstances (moving school, college, place of work and/or city, country) create high levels of attrition in community leaders. Such factors limit the ability of the T1DM community to advocate for themselves.

LANGUAGE MATTERS: THE WAY WE SPEAK SHAPES THE WAY WE ARE HEARD

The words used to describe type 1 diabetes (T1D) shape how we, as a community, are seen and treated. Too often, language is used as a barrier—casting blame, reinforcing stereotypes, and dismissing our struggles. Being labeled as “patients” rather than “people living with type 1 diabetes” reduces us to our condition rather than recognizing us as individuals. The misconception that we must “control” our diabetes, as though it is a personal failing when we struggle, only fuels stigma. We need the world to hear our voices clearly: language must evolve to reflect our lived realities[5]. We are not defined by numbers, but by our resilience, strength, and the right to be treated with dignity. This messaging must be clear in general advertisements, public policy agendas, and day-to-day verbatim – it always begins with language.

EDUCATION IS NOT A PRIVILEGE—IT IS A RIGHT

For too long, T1D education has been treated as secondary to access—seen as an “extra” rather than a necessity. But access without education is just another form of inequity. People with T1D do not just need insulin; we need the knowledge and tools to use it safely, to navigate our blood sugars, and to live without fear of misinformation or medical illiteracy[6]. The world must understand that education is what empowers us to survive and thrive. We call for structured, accessible, and culturally relevant education programs that are designed with—and for—our community. Without education, our voices are silenced by confusion and unnecessary struggle. Hear us: we demand the right to informed, independent, and empowered living.

DIABETES STIGMA: SPEAKING OUT

Stigma is one of the loudest forces working against people with T1D—yet it thrives in silence. It exists in workplaces where we are questioned for taking breaks to manage our blood sugars. It exists in schools where children are penalized for needing insulin[7]. It exists in relationships, where a chronic condition is seen as a burden rather than a reality. This silence must be broken. Our voices must be heard in every room where we are judged unfairly, in every conversation where we are misunderstood, and in every space where we are made to feel less than. We do not need pity—we need understanding. The more our voices rise, the more we can erase the misconceptions that hold us back.

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SPECIFIC NEEDS AND NECESSITIES

Persons living with T1D have distinct challenges and concerns as well. Some relate to the pathophysiology of the disease: there is a need to screen for, diagnose, and manage comorbid conditions such as celiac disease and hypothyroidism.

Other challenges according to the phase of life: attention to pediatric, adolescent, reproductive, and geriatric health is required for persons in specific age groups. A few facets of T1D and T2D advocacy do overlap. The need for economical, easily available and accessible insulin, glucose monitoring devices, and ancillary supplies is equipollent for all types of diabetes. With newer developments in T2D and obesity management, the focus on insulin has reduced in T2D care. This is unfortunate, as insulin remains a life-saving drug for those who need it.

Apart from insulin, we must advocate use of technology like continuous glucose monitor and insulin pumps in people living with diabetes to improve their quality of life. Technology has entered every aspect of our lives to make it better, Hybrid close loop pumps as a hope and relief for many. Some government organizations and non-profit organizations are also providing basic models of insulin pumps to the less privileged group of T1D. However, making technology available for everyone is still a distant dream.

THE PROFESSIONAL MANDATE

Health care professionals, especially diabetes care professionals, have a mandate to work for better health. This work is limited not only to the clinic or hospital, but extends to society as a whole. Endocrinologists and diabetologists are expected to speak up for the T1DM community, voicing their needs and preferences. In practice, however, most professionals handle other diseases apart from T1DM. The multiplicity of responsibilities, which may create hurdles in prioritization of T1DM.

Another related to this is the status of the primary care provider for T1DM. Depending on country, region and health care system, the pediatrician, pediatric endocrinologist, adult endocrinologist, or adult diabetologist may provide care to the bulk of people living with T1DM. The same professional may manage children and adults in some ecosystems, while there may be dedicated age-specific providers in others. These issues interfere with focused, concerted efforts at T1DM advocacy.

TEAMWORK: ARTICULATE AND AMPLIFY

In such situations, what is the solution? Teamwork. All stakeholders must work together to speak for the rights of persons living with T1DM. Children, adolescents, and adults; family members as well as physicians and paramedical personnel: all must shoulder the responsibility of advocacy. Pharmaceutical manufacturers, advocates of other endocrine disease care, and societal leaders must be involved. This is necessary to amplify our voice, and make it heard.

There are organizations which have taken the lead to do so. In India, the Changing Diabetes in Children (CDiC) program has spearheaded such efforts. Involving health care professionals at 30 sites in 20 states, CDiC has created an awareness movement around T1DM[8]. This has been supplemented by enthusiastic person-lead organizations, such as Blue Circle. These national activities find partners across the world; the International Diabetes Federation (IDF) and International Society for Pediatric and Adolescent Diabetes (ISPAD) are actively involved in T1DM advocacy.

At the global level, Global Alliance for Patient Access (GAfPA) and International Alliance of Patients Organization (IAPO) work to build partnerships and advocate for person-centered policies. Their expertise and experience can be leveraged for T1D advocacy. At the national stage, the Indian Association of Patient Group (IAPG), an umbrella organization of patient advocates, welcomes active participation of persons living with T1D.

These concerted efforts are gaining traction, as professional organizations increasingly involve persons living with diabetes in co-planning and co-designing educational events. This collaboration facilitates better understanding of each other's viewpoints, thus promoting better care.

FROM POLICY TO ACTION: WE ARE NOT AN AFTERTHOUGHT

Too often, T1D is left out of health care policies, pushed aside in funding discussions, and ignored in research priorities. The argument is always the same: "Type 2 diabetes is a bigger issue". But we refuse to be invisible. We refuse to have our needs dismissed because we are fewer in number. We demand that our health is valued, that policies are not written without us, and that resources are distributed equitably. Every government, every health care system, and every institution that claims to care about diabetes must prove it by making T1D a priority—not an afterthought.

OUR VOICE MUST BE HEARD

There is a concern that because persons living with T1D are less in number, their voice will not be heard. This is untrue. Rare and orphan diseases have been able to attract attention, and ensure action, because of effective advocacy. Within India, a stellar example is the work done by the Thalassemia Association of India for hemophilia, sickle cell anemia, and thalassemia awareness.

This society has brought together three seemingly diseases, under one umbrella, and created strength through unity. A similar approach should be followed for T1DM: every friend is important, every foot soldier necessary.

T1D ADVOCACY IS STRONGER TOGETHER: OUR VOICES WILL NOT BE SILENCED

Advocacy is not just about raising awareness—it is about demanding action. We do not accept the idea that because we are fewer in number, we must fight alone. The diabetes community, the rare disease community, the chronic illness community—together, we are a force that cannot be ignored. We must work across movements, industries, and policies to make sure that no one living with T1D is left behind.

Our voices are loud, our demands are clear, and our movement is growing. The world must listen: We are here. We matter. And we will not be silenced.

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