Mexico adds its voice to the Advocacy Agenda of People Living with NCDs

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As part of the NCD Alliance's 'Our Vision, Our Voice' initiative, dozens of community conversations were convened around the world, with a number of conversations taking place in Mexico City during August. Their purpose: compiling first-hand accounts to include in the Advocacy Agenda [1] of people living with NCDs to be presented at the upcoming NCDA Forum in Sharjah (United Arab Emirates) next December. Analía Lorenzo attended one of them and reflects on the experience.

The main recommendations and challenges that arose during the community conversation on obesity, diabetes and kidney disease included a call for a more human response to chronic diseases on the part of the health system; the proposal to ask nutritionists to give training to improve food at schools; the need for greater access to healthy food; and the call for greater protection and inclusion in the workplace, both for people living with NCDs and for organ donors, who are essential if transplants are necessary.

Diverse experiences forming a single agenda

The first surprise was the high level of involvement of the group of patients living with diabetes from the Hospital General de México and the Venados kidney association. These two organisations hosted the conversation held in the beautiful gardens of the old Mexican manor house belonging to the InterAmerican Heart Foundation in Mexico. There were over 30 participants, who began to share their experiences of living with a disease, not only on a personal level (such as how it had changed their lives) but also in terms of access to diagnosis and medical treatment within the healthcare system.

In all, 27 people (20 women and seven men) living with an NCD, four healthcare professionals and one friend met to share their thoughts and contribute to the Global Advocacy Agenda that the NCDA is establishing. The majority were people living with diabetes and various comorbidities, and there were six participants with kidney disease, four of whom had received a transplant.

"I didn't look after myself because it didn't hurt"

"I didn't look after myself because it didn't hurt", is how Paula, aged 60, introduced herself at the start of the community conversation on obesity, diabetes and kidney disease which took place in Mexico City. *"I had a urinary tract infection and so I went to the doctor, but until that point I didn't realise that I had diabetes. When I sought help, they suggested that I attend meetings, and that made me cross. How were meetings going to cure me? But I went, and I learnt a lot. I learnt how to eat properly and to accept that I have to live with diabetes, although I'm still not used to eating fat-free foods.*" Paula's experience is not unusual; in spite of how serious diabetes can be, about half of all sufferers have no idea.

During the conversation, a number of issues were discussed, including risk factors such as unhealthy diets. What we eat has a lot to do with the majority of NCDs. Also, food, diet and nutrition, including overweight and obesity, are linked to high blood pressure, high blood cholesterol and insulin resistance. These conditions are not only NCD risk factors; they are also the main cause of preventable forms of such diseases. Malnutrition, as well as overweight and obesity, place people at risk of developing an NCD.

> *"We have to take full advantage of all opportunities to modify our behaviour",* said Ema, who has had two kidney transplants.

The discussion led to problems and proposals. *"We need nutritionists in schools to teach pupils, parents and teachers. The subject should also be on the school curriculum"*, said the participants. Doctor María Eugenia Vargas, an endocrinologist who advises people living with NCDs, supported the idea of education as a key tool to put a stop to the epidemic of obesity, diabetes and other NCDs: *"Educated people are healthy people"*, she stated.

Nevertheless, there continue to be many barriers to accessing a healthy diet, ranging from modern "sedentary and hectic lives", as defined during the meeting – to the price and availability of healthy food in communities.

Breaking down discrimination in all areas of life

The issue of discrimination came up at the event. The women and men present agreed that obesity, diabetes and transplants lead to acts of discrimination at school, in the workplace, in the healthcare system and at all ages. *“It’s better not to tell anybody you’re ill or have had a transplant”,* the majority advised with resignation.

> Elsewhere, the need for social protection that guarantees confidentiality about the state of health of people in different areas of their life was raised, along with the inclusion in legislation of articles that prevent discrimination on an institutional level.

Other requests made during the discussion were aimed at broader policies providing economic protection for those people living with NCDs, but also for those close to them and their carers. *“My cousin was my donor. There are very few organ donors, and the culture of organ donation needs to be promoted, although donors need to be given certain guarantees. My cousin was not paid a full wage during our recovery”.*

A more human response from the healthcare sector for early diagnosis

With regard to healthcare, although people acknowledged positive and negative experiences with the healthcare system, the overall majority tended to agree with the fact that the medical sector needs to provide a more human response, and primary healthcare professionals and doctors need to be made aware of the importance of early detection and follow-up of NCDs.

One of the specific requests was to ask doctors to *“stop blaming the disease for everything. You go for an appointment and you’re told ‘it’s diabetes’. I know it’s diabetes, but I need to be told what’s happening and why it hurts*”, said one of the participants. *“All healthcare departments need to be given courses on providing a human response, including pharmaceutical laboratories, which could end up taking over and managing healthcare in a country”,* added the participants.

The conversation was obviously limited in time, but it included a wealth of subjects, contributions and proposals. One of the women had no doubt about motivating the other participants: *“We can be seeds for change, and make our voices heard”,* she said. And there is no doubt about the fact that these conversations are a powerful tool for raising awareness about chronic diseases from a human point of view. Through them, the irrefutable voice of those who, on a daily basis, face one of the most challenging epidemics of the century can be heard.

We are looking forward to hearing what arose during consultations in other countries, and to our views and voices based on our lived experiences helping to shape the advocacy agenda of people living with NCDs.

About the author

Analía Lorenzo ***[2]*** *has a Degree in Communication Sciences from the Universidad Nacional de Córdoba, Argentina. She has been a photojournalist for more than 20 years. She currently lives in Mexico City, where she has been specialising in health, gender and human rights issues. Her work as a journalist and for NGOs has enabled her to cover humanitarian crises (mainly in Latin America, although she has also studied African contexts) and design* *communication strategies based on international analysis.*

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