Through the eyes of a person with diabetes

People with diabetes in India face a number of challenges in understanding their diabetes and manage their self-care. A little education, though, goes a long way toward empowering a person.

Baby Naz doesn’t have time for illness to slow her down. A 48-year-old housewife in the Indian state of Bihar, Baby Naz has a husband and five adult or college-age children to support. All seven live together in a little third-floor apartment. For Baby Naz, shopping, cooking, cleaning make up only the beginning of a long list of daily responsibilities.

So when Baby Naz began feeling lethargic two years ago, she did what many women in her village of Mainpura do: she visited the local ayurvedic doctor. He diagnosed her diabetes and sent her home with an ayurvedic regimen. Bitter gourds, cinnamon powder, fenugreek seeds – these are the diabetic medicines of ayurveda, along with advice to avoid sugary foods.

For two months, she followed the doctor’s instruction. By then, she was feeling better. Figuring she was cured, Baby Naz dropped the regimen, stopped seeing her doctor, and went on with her life.

Then, last June, she felt weak again. This time, her husband took her to the nearest public hospital.

Public-private partnership

It just so happened that Baby Naz arrived at New Gardiener Road Hospital on a Wednesday. On that day, each week, a Novo Nordisk Education Foundation (NNEF) team helps to staff the hospital’s Community Diabetes Centre. New Gardiener Road Hospital is home to one of 42 centres in Bihar where, under an agreement with the state, NNEF provides diabetes screening and counselling.

The Community Diabetes Centre stems from an innovative public-private partnership – the first of its kind for management of chronic illness in India – known as the Changing Diabetes® Barometer. The Community Diabetes Centre is a specialised centre for treatment and counselling developed together with state governments. At the centre, NNEF promotes diabetes awareness and conducts screenings. Steno Diabetes Center trains healthcare professionals at the centre. Government hospitals provide a home for the centre and collect and mine data to support the development of a strategic plan to contain India’s diabetes pandemic.

This approach makes sense in India, where the public healthcare system is overwhelmed and underfunded.

1 Novo Nordisk Education Foundation (NNEF) is a non-profit organisation established by Novo Nordisk India in 1998.
2 Steno Diabetes Center is a world leading institution within diabetes care and prevention owned by Novo Nordisk A/S.
According to DAWN2™, the largest ever global study to explore the attitudes, wishes and needs of people with diabetes, their family members and the healthcare professionals who care for them across 17 countries, less than one third of healthcare professionals in India believe their healthcare system is well organised to manage chronic conditions⁴.

“There are so many programmes under the health department: maternal and child care, vaccinations, prevention of communicable and waterborne disease outbreaks,” says Dr. Neelam J. Patel, chief district health officer of the Ahmedabad District in the state of Gujarat. “Because of their burden, there is not that much attention given to non-communicable diseases. The willingness is there, but there is no time.”

Money is scarce, too. Health spending accounts for 1.3% of India’s gross domestic product – less than a fourth of the world average⁵.

Turn of events
At the New Gardener Road, NNEF counselors test the blood sugar of people with diabetes and teach them the basics about diet, exercise, and diabetes care and self-management. It sounds so elementary, but that’s the state of need in India. Even among healthcare professionals who treat diabetes, one out of four at the primary care level has no postgraduate training in diabetes care⁴. They don’t know what they don’t know – and DAWN2™ data back that up. Only 66% of people with diabetes who receive care in India said that someone on their healthcare team had measured their long-term blood sugar control level within the last 12 months.

NNEF counselors screened Baby Naz for fasting and postglucose blood sugar. In both cases, her numbers indicated uncontrolled diabetes. Baby Naz received counselling on her condition, educational materials, a report card, and an identification card that enables her to free professional services at the Community Diabetes Centre. She was referred to Dr. Manoj Kumar Sinha, a consultant at the centre, for follow-up.

Days like this could be a lifesaving turn of events for people like Baby Naz, whose family scratches out a living on her husband’s modest income as a tailor. Private healthcare services in India are expensive, and many public hospitals don’t have the expertise or the medicines to help people with diabetes stay healthy.

In those cases, people often are referred to hospitals far from home – a journey that, for many, is either unaffordable or impractical. For them, their diabetes only gets worse.

Getting sicker wasn’t what Baby Naz envisioned for herself or her family. Always active in her children’s lives, she ensured that they received a good education and a chance for success. Now, diabetes threatened to change all that – and Baby Naz became deeply depressed about her situation. She knew others with diabetes who weren’t getting better. Would she become one of them?

Her fears are common in India, where 52% of patients in DAWN2™ reported being “highly distressed” about their diabetes. Information can wash away fear, and DAWN2™ suggests a vast need in India for simple education about how to manage diabetes and recognise signs of complications. Across populations studied in DAWN2™, people in India with diabetes are less likely than the mean to monitor their blood sugar or get a foot examination⁶.

Look at her now
The good news is that Baby Naz took the counselling she got at the Community Diabetes Centre to heart. Today, her diabetes is under control. Moreover, the words she uses to describe her diabetes suggest that she understands her disease and how to manage it: blood sugar, exercise, food/diet, self-care, control, progress, healthy, and peace of mind. This is a woman who feels empowered.

She’s not without her challenges. Though her visits to the centre are free, it’s not always easy for Baby Naz to pay for her medications on her family’s tight income. She also admits that, sometimes, diet and exercise can be difficult. Still, she stays adherent because she knows the importance of doing so.

Baby Naz talks a lot about her care and encourages her friends with diabetes to use the centre. Comforted by a wide support network, she praises the NNEF screening team for “taking so much care it feels as if my own sons are helping me.”

India needs to create an environment for people with diabetes to be in control like Baby Naz. A healthy society is a win for everyone.

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³ For more information, visit http://www.dawnstudy.com/dawn2/dawn2.asp
Diabetes in India: a paradox

DAWN2™ is the largest ever global study to explore the attitudes, wishes and needs of people with diabetes, their family members and the healthcare professionals who care for them across 17 countries. Paradoxically, India ranks at or near the top – and bottom – in several categories. When it comes to family support, for instance, India was ranked best (97%) and 3rd when it comes to quality of life. But 59% of people with diabetes said their diabetes interfered with their ability to live a normal life, relegating India to 14th place in the survey. When it comes to participation in educational programmes, India ranks last.

1st of 17 countries
How supportive have your family been in helping you. (% reporting ‘somewhat’ or ‘very’ supportive)

82% 97%

3rd of 17 countries
% reporting ‘poor’/’very poor’ quality of life

13% 11%

14th of 17 countries
‘My diabetes medication routine interferes with my ability to live a normal life’ (% who ‘mainly’ or ‘fully’ agree)

38% 59%

17th of 17 countries
% participating in any diabetes educational programmes/activities

59% 23%

For more information, visit: [http://www.dawnstudy.com/dawn2/dawn2.asp](http://www.dawnstudy.com/dawn2/dawn2.asp)