

## Living on the outside: The impact of diabetes-related stigma



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"Who will marry my daughter who has diabetes?" asks Ram Anuj, a native of Ganga Jamuni village, Bagraich district in India. Ram Anuj's 14 years old daughter Munni (name changed) has type 1 diabetes and needs daily insulin injections.

The family members stopped sending Munni to school when other children made fun of Munni when she took her insulin. In a village-setting, giving insulin injections to Munni, is a public knowledge. Munni often gets scorned for being a burden on the family. Munni's family doesn't have enough money to take adequate care of her and provide the treatment she needs.

Stigma-related to diabetes, is particularly more pronounced for girls. Stigma in response to illness is not a new issue in some parts of the world. Stigma has long been associated with mental illness, physical disability, leprosy, cancer and tuberculosis. However, diabetes-related stigma is particularly severe as diabetes is a life-threatening chronic condition. Stigma is particularly complex as it operates at many different levels and has both social and psychological aspects. Diabetes-related stigma at the workplace or in the community and self-stigma has adverse impact on the mental health and feeling of wellness of people with diabetes.

Primary definitions of stigma usually refer to Irving Goffman (1963) whose text provides seminal critique: "Stigma can be seen as an attribute that discredits the individual, denying full social acceptance, and where notions of social inclusion and exclusion are firmly brought to the fore."

There are many factors surrounding stigma including denial, shame, blame, fear, rejection and discrimination. For any child or adolescent living with diabetes, learning to cope with it is often a daunting task.

Dealing with a chronic illness such as diabetes may cause emotional and behavioral challenges, at times, leading to depression. The need for high-quality counseling sessions, for the people with diabetes and their family members, is paramount at the diabetes care and treatment centres, which may eventually help combat stigma. It may also help them to adjust to the lifestyle changes needed to stay healthy.

"Counseling and emphasizing that diabetes is not a disease but a metabolic condition and every person with diabetes should be referred to as a 'person with diabetes' and not a 'diabetic patient' will go a long way in reducing the diabetes-related stigma" stresses Dr Sharad Pendsey, a noted expert on diabetes, who runs a charitable trust - Diabetes Research Education And Management Trust (DREAM Trust, [www.dreamtrust.org](http://www.dreamtrust.org)) in New Delhi. This trust provides free insulin, syringes, blood glucose monitoring strips and complete healthcare to the poor children with Type-1 diabetes. "Our centre has an education wing where diabetes educators regularly conduct educational classes, one to one counseling with patient and the family members. We have counselors at our centre and we have noticed a

remarkable change in reducing diabetes related stigma" shares Dr Pendsey.

In addition, lack of skilled healthcare staff, apart from the treating diabetes physician, exacerbates the situation. There are not enough nurse educators, diabetes counselors, nutritionists, podiatrists (foot experts) and other health educators to help raise awareness and understanding of unique care and treatment needs of people with diabetes in society. This not only fuels the diabetes-related stigma but also reduces the quality of healthcare for people with diabetes. The treating physician is usually single-handedly dealing with all the different responsibilities of being a counselor, educator, doctor, nutritionist, podiatrist, to name a few. "The patients' inability/ unwillingness to pay for this additional support also hinders the treatment" says Dr Surendra Khanna, a Physician at Diabetes Centre in Kanpur.

According to International Diabetes Federation (IDF, [www.idf.org](http://www.idf.org)), over 250 million people live with diabetes around the world. In addition, more than 200 children are diagnosed with type 1 diabetes every day, requiring them to take multiple daily insulin shots and monitor the glucose levels in their blood. Currently, over 500,000 children under the age of 15 live with diabetes. With such an enormous number of people with diabetes requiring attention, it is clearly vital to make the treatment, care and support services for people with diabetes made available in public sector hospitals without any further delay.

"Diabetes-related stigma can block access to existing diabetes-care services. If people with diabetes are felt to not be well anymore, then many mainstream systems do not want to spend their scarce resources on them, when they are fighting to have enough antibiotics and IV fluids to combat infections and diarrhoea, still the leading causes of death in children in the developing world. There are not enough specialists in many regions who are knowledgeable of diabetes to take care of all the children," said Mr Phil Riley, Campaign Director, World Diabetes Day Campaign ([www.worlddiabetesday.org](http://www.worlddiabetesday.org)).

On this year's World Diabetes Day (14 November), let's hope that governments and other stakeholders will commit themselves to invest resources in mobilizing communities in a radical scale-up of awareness programmes, health education initiatives and treatment literacy efforts

directed towards not only those living with diabetes but also their family members and people in the community. To reduce the diabetes-related stigma, and to create an enabling environment where people living with diabetes can live a normal healthy life, it is crucial to spread the message that often with appropriate lifestyle modifications type 2 diabetes is preventable, and that proper, affordable and accessible treatment, care and support programmes for people living with both type 1 and type 2 diabetes exist.

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