

## Review Article

# Guidelines for ethno-centric psychosocial management of diabetes mellitus in India: The north east consensus group statement

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### ABSTRACT

Recently published guidelines on Psychosocial Management of Diabetes in India provide evidence-based recommendations for the whole nation. However, they do not fully address the myriad socio-cultural issues prevalent in the North Eastern states. The eight North Eastern states of India house 45 million people, belonging to 220 ethnic groups who speak an equal number of dialects, and follow distinctly unique cultures, which impact health-related behavior. Such diversity is difficult to cover in any national guideline. This lacuna makes it necessary to have a document, which addresses the specific needs and requirements of diabetes care professionals in the North-east of India. This consensus statement aims to highlight evidence- and experience-based strategies for psychosocial management of diabetes, based upon the unique ethnographic constitution of this part of the country. It is based upon the results of a daylong focused group discussion, held at Sonapur, Assam, on 9<sup>th</sup> February 2013, involving key opinion leaders from most North-eastern states, including all geographical divisions of Assam. Recommendations are classified into three domains: General, psychological, and socio-cultural, and graded by the weight they should have in clinical practice. Eighteen recommendations of varying strength are made, to help professionals identify the psycho-socio-cultural determinants of diabetes, and to explore the role of psycho-socio-cultural interventions in devising support strategies for people with diabetes and their families. They also aid in developing core skills needed for effective diabetes management. These recommendations provide practical guidelines to fulfill unmet needs in diabetes management in the North-east and help achieve a qualitative improvement in diabetes care. The guidelines may also be useful for diabetes care professionals working with other indigenous groups across the world.

**Key words:** Diabetes, ethno-centric, north-east, psycho-social

## INTRODUCTION

As the underdeveloped agrarian India of yesteryears is giving way to a modern rapidly developing techno-smart

India, type 2 diabetes mellitus is becoming a major health concern. The North Eastern states are no exception to this disturbing trend. A purely pharmacological approach to successfully contain the scourge of diabetes may be considered insufficient at best! Factors beyond the pale of pharmacology, which include psychological, social, and emotional challenges faced by people with diabetes, must be given due consideration.

It has been acknowledged recently that management of chronic disease in general and diabetes mellitus in particular is futile if the psychosocial factors are not given due weightage. To this end, the recently published national

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guideline on “Psychosocial Management of Diabetes in India”<sup>[1]</sup> is a commendable and timely step, to say the least! This is an improvement over the other guidelines suggested by national and international stakeholders. However, there is too much of generalization, and poor ‘cross-cultural’ applicability is an inadvertent limitation of the currently available guidelines. No wonder, they contribute little to the local understanding of diabetes.

India is a vast country with diverse psychosocial environment. The linguistic, social, cultural, economic, and ethnic heterogeneity of the North East India’s population, and the unique presentations of the diabetes epidemic in the North East India justify the development of guidelines for psychosocial management, sensitive to such needs and limitations cogent to the North East India, and based on the region’s socio-cultural strengths and resources.

## PSYCHO-SOCIO-CULTURAL LANDSCAPE OF THE NORTH EAST INDIA

The North East India is an ethnographer’s paradise, where mind boggling diversity in society, culture, language, religion, literacy, dress, and economy can be seen amongst its over 220 tribes and ethnic groups, who live in 8 states: Arunachal Pradesh, Assam, Manipur, Meghalaya, Mizoram, Nagaland, Sikkim, and Tripura. Assam includes four distinct areas: Lower Assam, Upper Assam, Hill Districts, and Barak Valley. Each state is home to multiple ethnic groups and tribes with rich cultural heritage. Many unique factors affect diabetes management, by modifying availability, access to, affordability of, and acceptance of modern health care.

### Geography

Patients often face difficulty in access to health care. Although road density is claimed to be fairly high in Mizoram and Manipur (43.97 and 42.95 m/km<sup>2</sup>, respectively), placing them at position 2 and 3 amongst all Indian states, most of other states are not as fortunate. For example, Sikkim has an abysmally low road density (8.74 m/km<sup>2</sup>), making it a challenge to access diabetes care facilities.<sup>[2]</sup> It is also notable that road density may not always translate to good connectivity.

Electrification is poor in Assam (37.1%) as compared to India (67.3%). The other North-eastern states fare much better, but fall significantly short of the optimal requirement. Naturally, it may be difficult to maintain cold chain in remote parts of the region, thus making insulin or incretin use a challenge. This should be factored in

while choosing appropriate therapy for diabetes. Insulated pens, for example, can be used to deliver insulin, or novel methods of insulin storage can be popularized. Extreme climatic conditions are a challenge for health care providers as well. Mawsynram in Meghalaya has the world record for maximum rainfall. Arunachal Pradesh and Sikkim experience severe Himalayan winters, which leaves many areas snow-bound, and makes it difficult to follow lifestyle modification and access medical care or drugs.

### Human development index

North-East India (excluding Assam) scores 0.573 on the Human Development Index, thus achieving 6<sup>th</sup> rank amongst all Indian states, comfortably above the all India average of 0.467. Assam ranks 16<sup>th</sup> amongst all states, with a score of 0.444. This makes it relatively easier to propagate psychosocial aspects of diabetes care, as communities, on the whole, accept and appreciate “softer” markers of human development, such as quality of life.

### Economic factors

Sikkim is the only north-eastern state with a per capita gross domestic product greater than the national average (US \$1,469 vs. \$1,219). All other states have lower GDPs, though Arunachal Pradesh, Meghalaya, and Nagaland are almost at the national mean (US \$1, 126, 1,025, and 1,015, respectively).<sup>[2]</sup> This means that financial factors will play major role in determining diabetes care and cannot be ignored.

### Literacy

Literacy of almost all NE states is higher than that of the national average. Aizawl has a nearly 100% literacy rate (98.80% as per 2011 census). However, there do exist pockets of high illiteracy.<sup>[2]</sup> There is a lack of educational material related to diabetes in local languages. Media exposure is extensive in Manipur and Tripura, both of which have a higher percentage of people exposed to media than the all-India average. Manipur in fact ranks 2<sup>nd</sup> amongst all states in this respect. Meghalaya and Arunachal Pradesh have poor exposure to media, limiting its use as a vehicle for dissemination of diabetes awareness. Similarly, television ownership is above 50% only in Mizoram.

### Gender

Gender discrimination, mercifully, is less obvious in the North East of India. Many tribes of Meghalaya, including the Khasis, Garos, and Jaintias, live in a matriarchal society. Even here, however, the impact of diabetes on female care providers in family is greater, as women shoulder the burden of supporting people with diabetes.

## MEDICAL CARE

The North East India has a low doctor: Population ratio. Mizoram is the only state, which has achieved the required number of doctors.

Since the demography of north east India is predominantly rural, even with a lower rate of prevalence, rural population in India can be expected to constitute a larger proportion of the diabetes population. The urban: Rural gradient in diabetes prevalence is especially steep in Nagaland. Affirmative action is required on the part of diabetes care professionals to ensure that no section of society is discriminated against, as far as diabetes care is concerned.

### Traditional and alternative medicine

The region has a wide range of alternative healthcare systems, which are patronized by the general population. A considerable number of patients still utilize the indigenous forms of medicine. Each tribe has its own medical system, and the rich ethno botany of the region is just being uncovered. Plants used to manage diabetes include touch-me-not and passion fruit in Meghalaya, 'bhadailata' in Assam, turmeric in Manipur, and neem, fenugreek, and jamun across the region. 'Puinam' plant is used in Mizoram for management of hypertension.

## COMMUNITY STRUCTURE

Opinion building organizations, religious leaders, and community groups are strongly placed in the North East. Examples include Naga Mothers Association (Nagaland) and Meira Peibi (Manipur). These can be used to modulate public opinion and praxis in favor of modern diabetes case.

## METHODOLOGY

The recommendations, specific to the North Eastern states, have been developed as an add-on to the national Indian guidelines for psychosocial management of diabetes in India.<sup>[1]</sup> The target is all diabetes care professionals in the region, but it is hoped that this document will serve as an inspiration for all indigenous communities across the world. The current recommendation has been developed partly in accordance to the American Association of Clinical Endocrinologist (AACE) Protocol for clinical practice guideline production.<sup>[3]</sup> Recommendations are assigned a grade for strength, but evidence level ratings (on the basis of the quality of supporting evidence) have not been mentioned because of lack of publications in this area. The guidelines have been written by a core group of 15 authors, during a focused group meeting held at Sonapur, Assam,

on 9 February 2013, and reviewed by a committee of six multidisciplinary experts from India. It has been refereed by a South Asian panel of six reviewers from the neighboring countries of Myanmar, Nepal, and Bangladesh, all of which have conterminous borders with North East India, and by an international panel of four reviewers.

The recommendations try to transcribe the subjectivity of a complex psycho-socio-cultural scenario into the objectivity demanded by modern evidence-based medicine. As mentioned in the national guidelines, individual patient circumstances and psychosocial environments differ. The ultimate clinical management should be based on what is in the best interest of the individual patient, and what is appropriate for the local scenario, involving shared decision making by patient and clinician. In the absence of local evidence, health care professionals should follow "logical empiricism" while deciding appropriate psycho-socio-cultural interventions.<sup>[4]</sup>

## RECOMMENDATIONS ON PSYCHOSOCIAL ASSESSMENT AND MANAGEMENT

The guidelines mentioned in this communication follow the arrangement of the national Indian guidelines. This work highlights unique North Eastern psychosocial recommendations, while remaining a part of the larger, national, picture, to present a flavor of the guiding principles of psychosocial management. Only fresh recommendations are presented and have been broadly narrated in three clinical domains:

1. General assessment and intervention
2. Psychological assessment and management
3. Socio-cultural assessment and management

### General

The social fabric of the North East is very strong and can be utilized to help improve diabetes awareness and diabetes care. Peer support and community support can be generated for better outcomes in diabetes management. A beginning should be made at healthcare profession and at community levels.

### *Improving awareness/skills of healthcare professionals*

#### Recommendation 1

Healthcare professionals must ensure linguistic and cultural competence to as great a degree as possible (Grade A).

#### Recommendation 2

Physicians should be trained in patient empowerment, psychology of diabetes, co-existence with traditional medicine, health economics, qualitative research, and medical writing (Grade B).

### *Improving awareness among persons with diabetes*

#### **Recommendation 3**

There is a need to create interactive educational modules for North East India, in local language, using pictorial designs (Grade A). Pictorial visual aids are necessary for some areas such as interiors of Nagaland, as Nagamese is only a (spoken) dialect, not a formal (written) language with proper alphabet.

#### **Recommendation 4**

Services of 'lay' diabetes educators picked up from amongst various supportive areas of the existing health care delivery system such as anganwadi workers, auxiliary nurse and midwife, pharmacist, phlebotomist, malaria workers etc., can be put into meaningful services through empowerment and encouragement. Additionally or 'peer' support from well-motivated and intelligent diabetic patients can be utilized to improve diabetes care. Such measures should help overcome the acute shortage of diabetic counselor and educators prevailing in the region (Grade A).

### *Community-oriented approach*

#### **Recommendation 5**

Given the huge respect shown to their individual commune amongst all ethnic population of the North East India, the community should be targeted as a unit, to dissipate education on healthy nutrition, physical activity, and lifestyle through multiple approaches (Grade A).

#### **Recommendation 6**

Improving community awareness about diabetes should be done through community leaders, religious organizations, youth groups, and non-governmental organizations such as weekly sermons by churches, discourses by Moulvis after 'Namaz,' street dramas in Manipur, discussions in 'Namghars,' small music festivals in Nagaland and Mizoram etc., (Grade A).

#### **Recommendation 7**

School children should be sensitized to the importance of preventing diabetes and other non-communicable diseases, through health education, included in school curricula (Grade B).

#### **Recommendation 8**

Community support must be garnered for people with diabetes, as part of normal praxis, by involving village headmen, gamboras in Assam, pastors, and village councils (Grade A). The Mizo code of ethics or dharma focuses on "Tlawmngaihna," which means that it is the obligation of all members of society to be hospitable, kind, unselfish, and helpful to others. Tlawmngaihna is that moral force, which finds expression in self-sacrifice

for the service of others, and can be invoked to encourage community support for people with diabetes.

#### **Recommendation 9**

Physicians should increase noise level regarding diabetes in the community, and unite to curb misleading advertisements and propaganda by alternative therapy practitioners, regarding cure for diabetes, must be curbed (Grade A).

### *Optimization of access to medical care*

#### **Recommendation 10**

Therapy should be tailored to the unique geographical characteristics and seasons, e.g., availability of monitoring facilities, drug supplies, and frequency of follow-up visits (Grade A).

### **Psychological assessment and management**

The North-eastern Consensus suggests the use of simple, less time-consuming instruments for psychological assessment. The easiest tools for use in primary care settings [and diabetes clinics] are the Whooley questions and the WHO-5. The two Whooley questions<sup>[5]</sup> are:

"During the last month, have you often been bothered by feeling down, depressed, or hopeless?"

"During the last month, have you often been bothered by little interest or pleasure in doing things?"

#### **Recommendation 11**

The Whooley questions and the WHO-5 are appropriate tools for psychological screening. Screening and management should preferably be done by diabetes care professionals (Grade A).

#### **Recommendation 12**

To be reliable, validated translations of these tools must be available for health care professionals (Grade A).

### *Coping and counseling therapy*

#### **Recommendation 13**

It is recommended that people with diabetes, their healthcare professionals, and family members should receive coping skills training.

### *High-risk behavior counseling*

Diabetes is frequently associated with human immunodeficiency virus (HIV) infection.

#### **Recommendation 14**

Physicians should be trained to evaluate for HIV in diabetes and for diabetes in HIV. They should be trained to provide related counseling (Grade A).



### Social assessment and management

In north-east India, diverse social, cultural, as well as religious economic, psychological, regional, educational, and familial factors impact the clinical progression, treatment, and outcome of any disease management. Thus, one needs to lay emphasis on working on the environment (eco-sensitivity) and medical anthropology for better management of diabetes. Physicians must not overlook the concept of ethno pharmacy, which largely refers to variability of perceptions of patients from different social background (ethnicity) to the same therapeutic agent.<sup>[6]</sup> Diabetes care professionals must also be aware of the ethno botany of the area they practice in, as some plants used for the management of diabetes may cause hypoglycemia.

The influence of social background or ethnic group on the incidence and management of diabetes is observed nationally as well as in the North-East. Fibrocalculous diabetes mellitus, for example, is more common among the Bodo tribe, but is not observed in other ethnic groups inhabiting the areas in and around Bongaigaon, Assam.

#### Recommendation 15

Physicians must be sensitive to socio-cultural environment of patients while choosing therapeutic options to promote greater adherence to therapy and improve outcome (Grade B).

#### Custom/Religion

Different religions including Christianity, Hinduism, Buddhism, Islam and traditional religions are followed in the North East. This information is necessary for health care providers, who may wish to use religious sayings to motivate patients to follow better healthcare-related practices. The Galos of Arunachal feel that disease is caused by malevolent spirits called Uyos, who have to be worshipped with help of village priests or Nyibos. Instead of trying to displace such age-old customs, modern diabetes care professionals should learn to co-exist with them. Burha-cha (god of healing) is worshipped in Tripura and can be invoked to help increase the efficiency of modern diabetes care.

Folk music and song are integral part of North-eastern culture. For example, Shumang Lila and Phampak Lila of Manipur can be harnessed to improve diabetes awareness by requesting composers and organizers to include health promotional messages. Indigenous outdoor sports such as mukna, mukna Kangjei (Khong Kangjei), sagol Kangjei (Polo), yubi lakpi (Coconut Rugby), oo-Laobi, hiyang-Tannaba, arambai Hunba should be encouraged as a means of physical activity.

Festivals and feasts, like the 'Losar' in Sikkim and Arunachal Pradesh, 'Losoong' in Sikkim, 'Choskar' in Arunachal, 'Bihu' in Assam, and Durga Puja and Christmas and Eid across the region, can be utilized as platforms for dissemination of diabetes care-related messages. At the same time, diabetes therapy has to be modified during these festivals to manage the swings between feasting and fasting that inevitably occurs.

#### Recommendation 16

Indigenous forms of folk dance, music, and theater must be utilized to promote healthy practices related to diabetes (Grade B).

#### Recommendation 17

Indigenous sports should be promoted as a means of socially acceptable physical activity (Grade B).

#### Recommendation 18

Diabetes therapy should be tailored to specific needs during periods of fasting and feasting (Grade B).

## CONCLUSION

North east India has a linguistically, culturally, and socio-economically heterogeneous population. It is a developing area, and its physically challenging terrain severely restricts the availability of resources for diabetes care. At the same time, its strong socio-cultural ethos can be utilized to manage diabetes more efficiently at the individual, family, and community level. Given these challenges and strengths, this consensus statement has framed suggestions for psychosocial management of diabetes, sensitive to, and appropriate for, the north eastern Indian context. We hope that this will help people with diabetes, both within and beyond the North East India.

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