## LEPROSY TERMINOLOGY IN NEPAL

Editor,

The recent International Leprosy Congress was a great opportunity for many of us to renew acquaintance and to update our knowledge and thinking about leprosy in the fight for 'a world without the problems associated with the disease – both medical and social' (Dr Yo Yuasa).

What to tell people just diagnosed with early leprosy about their condition was a subject discussed at the Congress. 'We must tell them they have leprosy – we must tell the truth!' was the strong opinion of a European working in Africa. Certainly we should 'tell the truth', but we must be very aware of what 'truth' we are telling. Dr Noordeen mentioned that in some languages there may be several words for leprosy. That is certainly the case in Nepal. The translation task would be simple if the words for 'leprosy' used in the different languages each held the same constellation of meanings and cultural implications. However, this is not the case. Languages must be examined carefully before a word choice is made. A word should be used with full knowledge of what is actually being said.

Nepali holds three main words which can be translated by the English word 'leprosy'. These are 'Kustha Rog', 'Maha Rog' and 'Kor'. There are similar words in Indian and Asian languages.

'Kustha Rog' is a word meaning literally 'the disease of rotting flesh'. 'Kustha' is an ancient term: 'According to Vagbhata (600 AD) the name ''Kustha' was derived from ''Kushnate' which means 'eating away' in Sanskrit, and was mentioned in the Sushruta Samhita, written in India in about 600 BC'. The term 'Kustha Rog' therefore holds the concepts of disability and deformity, ulcerated hands and feet, 'having no hands and feet', incurability, a curse from the gods and implies the need for social separation.

'Maha Rog' is an old Nepali term which used to be used in official documents – the law previously made provision for compulsory isolation, with food, clothing and shelter provided.

'Kor' is best rendered by the English 'leper' and contains the expectation of being a social outcast', of begging, of deformity; some go as far as to say that those who are 'Kori' (one with 'Kor') have a duty to commit suicide. The three words are to some extent used interchangeably by the general public in Nepal, with the term 'Kor' frequently used as a term of abuse.

In Nepal, the word 'Kustha Rog' is used to translate 'leprosy'. It was introduced to the National Legal Code in the 1970s and is now used in official government documents to refer to 'leprosy'. During my research, it became clear that the term 'Kustha Rog' in Nepali has almost no commonality of meaning with what medical scientists mean by the term 'leprosy'.

From a scientific biomedical perspective, particularly in reference to early cases, the word 'leprosy' is used to mean a manifestation of skin and nerve signs and symptoms which may be a single particular kind of skin patch or nerve enlargement. Definitely no disability, deformity or social isolation is meant. When we tell a new patient that they have 'leprosy' (rendered in Nepali) we are unfortunately actually saying, 'You have 'Kustha Rog', with its association of physical deformity and broader socio—cultural implications.

There can be life-and-death consequences from using these terms in Nepali. While undertaking research I heard of patients who had attempted suicide in reaction to their diagnosis. A teenage girl hanged herself upon diagnosis and admission to the leprosy hospital. Another woman confided that she had been 'on her way to jump in the river' when she was encountered on the trail by the leprosy staff. By all means let us 'tell the truth', but let us be clear which 'truth' we are telling.

There is much more to share on this issue, but I will leave it there for now and ask if others have experiences and insights about telling the 'truth' to patients.

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## Reference

<sup>&</sup>lt;sup>1</sup> Thangaraj RH, Yawalkar SJ. Leprosy for medical practitioners and paramedical workers, 2nd revised edition. Ciba-Geigy Limited, Basle, Switzerland, 1987: p14