

# **CEREBRAL PALSY IN NEPAL — A CULTURAL EXPLORATION OF COSMOLOGY AND DISABILITY**

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## **Introduction**

The need for cross-cultural studies of disability has often been stated but seldom acted upon. It was nearly thirty years ago that Edgerton, in a highly influential paper, made the intellectual case for increased study of disability within and between societies, both developing and developed (Edgerton, 1970). Despite this call, the social science literature on physical disabilities suffers a curious omission in the relative lack of attention paid to a cross-cultural perspective. Thus Scheer and Groce (1988:23) write that the "definition and social consequences of physical impairment in various cultural settings remain an open field for anthropological investigation. The diverse range of social responses for physical disabilities is not well appreciated or understood by social scientists, policy makers, nor disabled people themselves".

Of the few ethnographic studies that have been conducted among disabled people in developing countries, much of the information is anecdotal in nature. The lack of observation and thoughtful inquiry by social scientists is partly a reflection of the ethnocentric belief of researchers that people with disabilities are singular and unique cases in human social groups, to be mentioned only in passing. Social scientists too often assume that disability automatically causes an individual to become marginal to his or her social group. However, this dearth of studies has not been just because of indifference: there are substantial methodological problems to overcome too and even highly experienced/researchers undertaking field studies for many years have raised questions about validity in studying disability in another culture (Miles 1992).

There are, as far as we know, only a handful of critical attempts at formulating a model linking sociocultural variables with perceptions of disability and the actual status of the disabled in nonwestern societies

(Hanks and Hanks 1948, Miles 1992, Edgerton 1970, Manion and Bersani 1987), in multicultural societies (Westbrook et al, 1993; Mallory et al. 1993), and among ethnic minorities in Western societies (Edgerton 1970, Atkin 1991; Burghart 1988, Ahmad 1993).

The present study was conducted in the spirit that even studies with problematic methodologies or with limited exposure to another culture can enhance understanding if their findings are treated with caution and circumspection. More importantly, studies in other cultures can give insights into our own culture and can lead to questioning and development of taken-for-granted academic understandings. As a short-term, tentative exploration (indeed envisaged as a feasibility study rather than a research project in its own right) it would be implausible to conceive of it as a fully-fledged cross-cultural study. Instead it has provided insights and facilitated the formulation of tentative conceptual frameworks which can then be refined (or replaced) before being rigorously empirically tested.

### **Medical Pluralism in Nepal**

One of the central premises in formulating this study is that health care systems are symbolic systems, built out of meanings, values, behaviours, norms, and perceptions that are constructed, deconstructed and reconstructed within communities. There is a complex and sometimes contradictory relationship concerning disability between the health care system and cultural values and beliefs within the community it serves. This mediation includes beliefs about causation, experience of symptoms, patterns of decisions concerning treatment alternatives, actual therapeutic practices, and evaluations of therapeutic outcomes (Kleinman 1986).

A majority of the literature on medical pluralism in the developing world has focussed on the sometimes strange marriage of different indigenous modes of healing with biomedical systems. Medical pluralism refers to the parallel existence of a number of different healing modes. Unlike Britain, Nepal does not have a powerful and highly organised profession; whilst individual doctors have a high status and income, they have as a group to compete with other indigenous forms of medicine which also have official recognition. In general, they have been less protected by the state from market forces than in countries like Britain.

Nepal has an ethnically and culturally diverse population with a wide range of religious beliefs, including Hindu, Muslim, Buddhist and folk religions. It also has diverse medical and health-belief systems, including Sanskrit-based ayurvedic medicine, Tibetan medicine, homeopathy, acupuncture, unani (Greco-Arabic medicine), various types of spiritual and herbal healers (Dhamis, Jhankris, tantric Buddhist healers, local folk practitioners, traditional midwives), as well as Western allopathic medicine (Durkin-Longley, 1984; Streefland, 1985).

### **Disability in Nepal**

While illness and perceptions of illness in Nepal have received some ethnographic attention (Stone 1976 and 1988, McHugh 1993, Acharya 1994), there has been very limited research on either the prevalence of or understanding and cultural beliefs about disability. Kleinman notes in general that non-sacred aspects of 'illness' have received little ethnographic attention anywhere, and that there has indeed been a tendency to focus on ritual activities (1980:147). There is a small amount of literature concerning pluralism (in both provision and beliefs) and the uses of cultural knowledge in health care (Macfarlane 1981, Durkin-Longley 1984, Adams 1988, Parker 1988, Subedi 1989 and 1992, Dhungel 1994; Pigg 1995) but because disability of any kind is not included under academic categories of 'disease' or 'illness', it has been neglected.

Furthermore, there are a large number of inconsistencies in the sources on disability and its prevalence in Nepal. For instance, the estimates of the proportion of disabled people in the total population of Nepal ranges from less than one percent, to three percent (His Majesty's Government, 1993). Other small-scale studies estimate the prevalence to be as high as 13 per cent (BPEP/DANIDA, 1995; ICS/DANIDA, 1995). There are estimated to be over 60,000 children in Nepal who have cerebral palsy (based on data for other developing countries with similar demographic and socio-economic profiles). It is estimated that less than a thousand of these receive any type of biomedical therapeutic assistance, such as physiotherapy or speech or occupational therapy; less than 200 receive schooling, either in 'special' schools or in mainstream schools. There are no reported cases of young people with cerebral palsy living past the age of twenty years.

There have been very few ethnographic studies of disability in Nepal and none, that we are aware of, specifically about cerebral palsy or similar conditions. On the basis of a year's fieldwork in 1976 and 1977 in rural settings near Kathmandu Peters concluded that learning disabilities are recognised, labelled and stigmatised (Peters, 1980). Richardson, during a two-month study tour of rural areas north and west of Kathmandu, estimated that around one per cent of the population had physical disabilities. His data collection methods were highly impressionistic and so his estimate needs to be treated with caution, but he made the interesting observation that high levels of physical impairment and disability were often coupled with low levels of handicap (Richardson, 1983).

Two other studies are relevant, although they do not directly address issues of disability. Streefland, in an exploration of the interface between western and traditional medical system, points out that ideas, beliefs and practices which are characteristic of a specific medical system are often

deeply embedded within the culture of an ethnic or religious group (Streefland 1985). Pigg, after undertaking fieldwork from 1985 to 1988, concluded that modernisation and development have profoundly affected people's perception of medical realms and healing (Pigg 1995).

### **The Study**

The study aimed to explore the cultural beliefs and actions concerning cerebral palsy and similar conditions of parents and families of children with cerebral palsy; medical, healing and other professionals working with the children and; where possible, the children themselves.

Fieldwork was undertaken in Nepal between October and December 1997 by Dr. Rebecca Saul who has previously undertaken two and a half years of applied and cultural anthropological fieldwork in Nepal. Data was collected in two locations: Kathmandu (for four weeks: 30 interviews undertaken) and Janakpur, (for two weeks: 0 interviews).

The research population in Kathmandu was comprised primarily of staff, parents and children at the Self-help Group for Cerebral Palsy (SGCP) school and rehabilitation centre; families who are part of the outreach programme run by the SGCP; and staff of other organisations who work in the disability sector.

Several of the teachers at the SGCP school are themselves parents of children attending the school, and the field methodology included observing, interviewing, and discussions with these mother/teachers. Using the SGCP as a base also permitted access to families from outside Kathmandu when they brought their children to the rehabilitation centre for diagnosis, therapy, or annual check-ups. There was also ample opportunity to have discussions with the Nepali staff at the centre.

The SGCP runs an outreach programme both to follow up families who have visited the centre, and to establish contacts with families who are referred to them either by medical institutions and social services in Kathmandu, or by concerned neighbours and family members. These home visits enabled Rebecca to visit several of the families again on her own after an initial introduction by the home visit staff.

As in Kathmandu, the school for disabled children in Janakpur (SMKK) became the main means by which contact was made with children with cerebral palsy and their families. The school in Janakpur is supported by funds from the local Hindu temple, although children of all faiths attend. The school is built on temple land and is staffed by three teachers, a gardener (who also brings disabled children to school on his bicycle), and a carer/cook/housekeeper. Between eight and fifteen children with various disabilities, including cerebral palsy, attend the school at any one time. As

well as play and learning sessions, the children also make candles and chalk to sell in local bazaars in order to purchase equipment for the school.

A main aim in this exploratory study was the testing of our methodological approach which included mobility mapping, ranking, ethno-histories and biographies of disability, art, and story-telling, as well as participant observation, focus group discussions, and unstructured and semi-structured interviews. We were particularly keen to develop ways of involving the children themselves in the research by conversational interviews and role playing.

Some important ethical issues arose from cultural and religious differences. For example, one major question which must not be asked of adults who do not have a disabled child (e.g. school teachers, physicians, carers etc) is: "How would you feel/cope if you had a disabled child?" The reason for this is the fatalistic Hindu belief in self-fulfilling prophecies. Discussions of disability are also sensitive for another reason, discussed more fully below, the belief in 'karmic disability'.

### Findings

**Rural-Cosmopolitan Continuum:** Nepal is an extremely heterogeneous society in terms of religion, demography and social geography, and is also in the throes of rapid, but uneven, development. Thus it has a wide range of cultural beliefs and cosmologies. Based on our, as yet, tentative understandings of the cosmologies of different people and groups within Nepali society, we suggest that conceptualisations of disability (among other things) can be placed on a continuum (developed from Redfield 1947, Mahale 1983, Bell 1992, and Beggs, Haines, & Hurlbert 1996), ranging from 'rural', through 'urban', and on to 'cosmopolitan'. This is not an exclusively geographic model in the sense of rural dwellers having a rural ideology, and urban dwellers having an urban ideology (Streefland 1985). For example, there are a large number of people living in urban centres in Nepal who continue to adhere to a rural cosmology and there are many Nepalis with cosmopolitan world-views who live in rural areas. Rather, it implies that the way that people understand and deal with disability are influenced by income, education, mobility, exposure to outside ideas and technologies, as well as other factors such as caste and ethnicity.

Broadly, a rural cosmology can be seen as one firmly based in traditional values, often strongly influenced by beliefs in ghosts, spirits and witchcraft. An urban cosmology will often be influenced by systematic belief systems based on the written word, often associated with ayurvedic medicine<sup>2</sup> and Hindu, Muslim or Buddhist teachings. People with cosmopolitan

cosmologies have been exposed to modernity in all its facets and will be informed about western biomedical teachings, such as germ theory, and will have a detailed awareness of mother and child vaccinations; information concerning maternal nutrition; and therapies such as physiotherapy, occupational therapy and speech therapy. They will also be aware of different types of medical services outside of Nepal and the Indian subcontinent in places such as Brunei, and Hong Kong where the Brigade of Gurkhas had been based<sup>3</sup>.

In using this framework we do not assume that a cosmopolitan cosmology is the same as a 'western' (biomedical) cosmology. It will generally be characterised by some degree of adherence to Hindu religious beliefs and practices, including ayurveda and astrology (indeed, cosmopolitans in Kathmandu, for example, often have strong beliefs in astrological influences). In addition, there are also other dimensions to understanding: some aspects of an individual's or family's beliefs may be embedded in traditional folk understandings, while others may have their origins in cosmopolitan experiences and encounters. Thus the boundaries between cosmologies are blurred and individuals often simultaneously hold several different (and sometimes contradictory) beliefs from all three points on the continuum.

**The Causes of Childhood Disability:** Perceptions about the causes of childhood disability vary greatly but there are a number of general and fairly widespread beliefs about pre-natal and post-natal causes. Pre-natal causes include:

1. parental sins in a previous life
2. the child's sins in a previous life
3. the results of accident, poor food, or unsuccessful attempts at abortion through the use of large amounts of 'medicine' by the mother during pregnancy
4. a 'self-fulfilling prophesy' where thoughts about or visions of disability entered the mother's mind during pregnancy
5. contamination through the mother coming into contact frequently or continuously with a disabled child during her pregnancy
6. mother's ill health during pregnancy, which may or may not have supernatural causes
7. astrological mischance via an inauspicious alignment of stars and planets at the time when the child was conceived and born, as well as when the parents were conceived and born.

We can look at these perceived causes within the rural - cosmopolitan framework. Explanations one, two, and six (and, to a lesser extent,

explanations four and five) are consistent with a rural cosmology: they find their meaning in often highly specific regional, ethnic and cultural understandings. Explanations three, four, five, six and seven are commensurate with urban cosmology and can be seen as a composite of, or perhaps even a transition between, rural and cosmopolitan cosmologies. Causes three and six are cosmopolitan in orientation: they are grounded in biomedical understandings, as well as a more literate knowledge of Hindu teachings. To a lesser extent, cosmopolitans sometimes subscribe to explanation seven.

Post-natal causes include:

1. childhood illness
2. possession or a curse
3. the child being contaminated or 'infected' by contact with an already disabled child: *rog sātne*, literally to trade or exchange disease - an explanation not uncommon among South Asians in England (Shah, 1992).

Childhood illnesses are the most common explanation given by those who adhere to a cosmopolitan cosmology; the rural folk explanation is more likely to be that the child or mother was possessed or cursed or else that the child was contaminated. Contamination or childhood illness are more likely explanations for people with an urban cosmology.

During the course of collecting disability biographies, parents mentioned all of the above explanations for their children's disability, as well as a few idiosyncratic or highly individual reasons. Sometimes both pre-natal and post-natal explanations are combined, as can be seen from the following examples:

I was pregnant in the village and was ill for six months during the pregnancy. I did not eat much and maybe this was a cause. Also, my father-in-law give me *goributi* [herbal medicine] and I think that it was bad for me. *Rai*<sup>4</sup> mother, Kathmandu.

Our son was normal at birth and we did not see any abnormality until he was several months old. He became ill and was admitted to Kanti Hospital. It was there that we believe he was switched for a disabled baby. Maybe, though, because our son was ill with pneumonia and was weak and defenceless he was attacked by a ghost in the hospital [this latter explanation is supported by the grandmother]. *Brahmin* mother and father, *Bhaktapur*<sup>5</sup>.

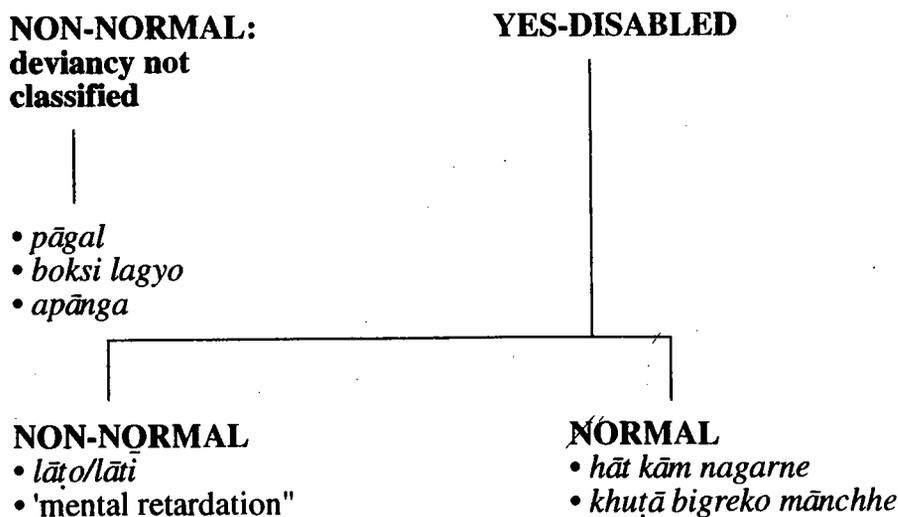
My son got encephalitis when he was two years old. That is why he has CP. There are no other explanations. *Newar<sup>6</sup> mother, Kathmandu.*

This is the hand of God; it is God's will that Sunu has CP. *Muslim uncle, Janakpur.*

### Understanding Disability: Deviance and Normality

The complexity in explanations of the *causes* of disability is mirrored - and even amplified - in relation to beliefs and understandings of its *nature*. As well as differences in cosmologies on the rural cosmopolitan continuum, there are varying perceptions of different manifestations of disability. One key issue is that of 'deviance' from the norm. People may perceive some but not other disabilities as 'normal' within their own society. An important element of this discourse concerns the categories of 'non-normal' and 'yes-disabled' suggested by Devereux (1963) and developed by Sachs (1995). 'Non-normal' refers to deviance not yet categorised, whereas 'yes-disabled' refers to a specifically recognisable deviance which fits into an indigenous category. Devereux and Sachs conceptualise these statuses as mutually exclusive but this does not adequately reflect the range of rich and complex folk conceptualisations among the Nepalese. In order to make a start it is necessary to create a new category which encompasses both the non-normal and yes-disabled categories (see Figure One).

**Figure One: Non-Normal, Normal and Yes-Disabled**



*Non-normal, deviancy not classified.* People who exhibit forms of bizarre behaviour such as extremely poor personal hygiene, lack of normal modesty and verbal ranting are often referred to as *pāgal* literally 'crazy'. Alternatively, a person exhibiting similar behaviour but of a more disturbing or violent nature may be considered to be possessed by a witch: *boksi lāgyo*. In these, as yet undetermined, states it is still possible that the deviation from normality may be temporary (see Stone: 1986 for a discussion of indeterminate status in relation to a sudden onset of non normal behaviour classified as *man bigryo* - literally broken mind).

*Yes-disabled and non-normal.* The category *lāto/lāī* in Nepal, meaning literally deaf and dumb males and females respectively, is often applied to people with a wide range and variety of disabilities, including communication difficulties (such as deafness and speech impediments) and learning disabilities. *lāto/lāī* are generic terms covering specific permanent conditions which are seen as both disabling and deviating from normality in terms of either demeanour, behaviour or speech.

*Yes-disabled but normal.* People who, for example, have suffered from polio or who are crippled or have had limbs amputated, are placed in this category. Unlike the previous two categories of *pāgal* and *lāto/lāī* it is the disabilities (physical rather than mental), rather than the people, which are named and this is a reflection of their 'yes-disabled but normal' status. People who have a crippled leg are described as *khuṭā bigreko manchhe* (man with a broken leg); if someone has a crippled arm, the disability will be described as *hāt kām nagarne* (arm which doesn't do work), etc. Even though their *bodies* do not meet normative standards, their behaviour, demeanour and speech fall within normative limits and they therefore retain their 'normal' status.

These three examples are all consistent with rural Nepali cosmologies but there are other, different conceptualisations from the urban and cosmopolitan cosmologies (see Figure Two). For example, a cosmopolitan is unlikely to characterise a person as *pāgal* or *boksi lāgyo*. A cosmopolitan term for non-normal behaviour presumed to be beyond the person's control is *apānga* a catch-all term for an as-yet undiagnosed or unrecognisable condition that can be explained within a western biomedical framework.

*lāto/lāī* are terms for non-normal and yes-disabled statuses which are commonly used within rural and urban cosmologies, and to a lesser extent by cosmopolitans. But cosmopolitans will use the term *susta mansthiti* (or its western equivalent 'mental retardation') in situations where to western eyes a person unambiguously has severe learning disabilities, and this term is increasingly being used by urbanites too. The cosmopolitan 'yes-disabled but normal' category is more straightforward in that a western biomedical

term (or its shorthand version) would normally be used: e.g. cosmopolitans virtually universally refer to cerebral palsy as 'CP'.

People with learning disabilities, but no physical disabilities are normally referred to as 'MR' mentally retarded - by biomedical practitioners, and mental retardation is called *susta mansthiti* by other cosmopolitans. These diagnoses are also 'tacked on' to describe learning disabilities which accompany physical disabilities. Cerebral palsy is called *mastiska pancha ghāt* (brain paralysis) by cosmopolitan lay persons, but is generally referred to as CP by educated urbanites and professionals who work with such children.

Perhaps specific terminology for different types of disability is not necessary for those with a rural cosmology, because it serves no purpose in terms of diagnosis, referral, treatment or therapy. There are no real options for biomedical treatment either in rural areas, or among those whose lack of education or money are effective barriers to accessing services if they do exist locally. Terminology becomes more specific progressively from rural to cosmopolitan as it becomes more necessary in order to identify and gain access to specialised ayurvedic and biomedical health care resources.

**Figure Two: Cultural Categories of Disability**

	Rural	Urban	Cosmopolitan
<b>Non-normal:</b> deviancy not yet classified	Paagal (crazy) Boksi lagyo (witch-possessed)		Upanga (catch-all term for non-specified disability - with a western emphasis)
<b>Non-normal and</b>	Laato/laati (‘deaf/dumb’ - but generic meaning)		Specific to impairment: (often with biomedical label)
<b>yes-disabled</b>		Susta mansthiti "Mental retardation"	
<b>Yes-disabled but normal</b>	Specific to impairment - descriptive of impairment (e.g. hat kam nagarné, khuta bigreko manchhe		Specific to impairment: often with biomedical label (e.g. CP)

Figure Three identifies those conditions classified in each of the normality/disability categories for each cosmology. All cosmologies treat the 'non-normal: deviancy-not yet classified' category in the same way. It includes undiagnosed debilitating mental illness and socially unacceptable odd behaviour. There are some subtle differences between the three

cosmologies in relation to the 'non-normal and yes-disabled' category: all include learning disabilities, and these may be accompanied by physical disabilities, but they treat communication difficulties differently. Within a rural cosmology, communication disabilities are unequivocally within the 'non-normal/yes-disabled' category but this is not the case in a cosmopolitan cosmology (so long as there are no associated learning disabilities). The situation is less clear-cut in the urban cosmology where the extent of the communication difficulty and the presence of any associated physical disability are relevant issues. A similar situation arises in the classification of the 'yes-disabled: not perceived as non-normal' category, as can be seen from the final row in Figure Three.

Other commentators have noted the particular attention paid to communication difficulties in Nepal. They were explored in some detail in Peters' 1980 study. He undertook research among the Tamang, the largest ethnic group in Nepal, living in two sites: a small market town and a village, both about eight kilometres from Kathmandu. He found that categorisation of people as *lāto/lāṭi* was 'based partially on insufficiency of intelligence and behavioural adaptation, but primarily on speech incompetence' (Peters 1980:352). Individuals with less severe speech impediments were called *adhā-lāto/adhā-lāṭi* (literally 'half dumb' - i.e. mildly yes-disabled and non-normal). He argues that competence in communications is important in the ritual life of the rural Tamang where clarity in enunciating mantras is essential in performing the rites necessary to fulfil the householder's role.

Peters and Sharma also state that the belief that *lāto/lāṭi* is caused by 'bad karma' - consequences of bad actions by parents or patrilineal kin in previous lives - is widespread. Other mental disorders with supernatural causes, on the other hand are attributed to witchcraft, spirit possession or soul loss and are, in principle, amenable to cure by traditional ritualistic means (see also Stone 1988 for a discussion of indigenous Nepalese classifications of curable and non-curable conditions).

The placing of people within the above three normality / disability classifications is a result of mediation between various actors. Most children with cerebral palsy go through several classificatory stages, beginning with either 'normal' or 'non-normal', and ending up as either 'yes-disabled and non-normal' or 'yes-disabled but normal', depending on the sociocultural, economic and educational characteristics of the child's family, the diagnosis, and the severity of the disability. Because there is no folk term for cerebral palsy in Nepal children with undiagnosed cerebral palsy are either termed *lāto/lāṭi*, *boksi lagyo* or *apānga* depending on the biography and severity of the disability. The following case study illustrates this negotiation and movement between conceptual categories of disability.

We took Sunu to many hospitals and doctors in Nepal and India. Even after they told us in Patna [India] that he had CP, we continued to talk to western physios and doctors who visited Janakpur. Our friends and neighbours advised us that, with such cases, a hole should be dug and the child placed in it, with his arms resting outside the hole and supporting his body. They said that his body and legs would then straighten until his feet touched the bottom of the hole. This would cure him if it was done for one to three hours every day. The doctors told us to ignore this advice, which we did. Besides, we think that he has been attacked by a ghost. We paid much money to Hindu sadhus [ascetics] and Muslim holy men who said that they could cure Sunu, but they were just charlatans. Our neighbours and distant relatives sometimes ask us if Sunu is getting better, or if we have found a cure, but now we know he has CP so it will be very difficult for him to get better. We need to wait until the big western doctors find a powerful medicine to help Sunu. But he is getting weaker, worse, and maybe it will be too late for Sunu. Muslim *grandfather*, Janakpur.

**Figure Three: Conditions Classified in Cultural Categories**

	Rural	Urban	Cosmopolitan
<b>Non-normal:</b> deviancy not yet classified	Undiagnosed debilitating illness Mental illness Socially unacceptable odd behaviour		
<b>Non-normal and yes-disabled</b>	Learning or communication difficulty: can be accompanied by physical disability	Learning difficulty: can be accompanied by physical disability; Physical disability along with communication difficulty	Downs Syndrome; Some cerebral palsy; Diagnosed learning difficulties: can be accompanied by physical disability
<b>Yes-disabled but normal</b>	Physical disability with no learning disability or communication problems	Physical disability with no learning disability or communication problems; Mild communication disabilities	Physical disability with no learning disability; Some cerebral palsy; Communication disabilities

While some community and family members (and also some traditional practitioners) believe that the boy has been attacked by a ghost (*bhūt*) - a potentially curable, 'non-normal', condition - others believe instead that he is *lāo* - an incurable, 'yes-disabled and non-normal', condition. The close family, based on a biomedical diagnosis, have accepted that Sunu has cerebral palsy, but are unsure of whether this 'yes-disabled' condition is curable or not. Sachs writes: "among Turkish migrant families it seems that when someone is seen as non-normal, there is still the possibility of correcting this state into a normal state but when the person is classified as yes-disabled, it is a permanent state and there is nothing else to do" (Sachs, 1995:212). This, as the above case illustrates, is not always true in the Nepali context.

**Pluralism Revisited:** Sunu's case study exemplifies the different beliefs that can be held simultaneously by different family members or even by the same person. Very little has been written about plurality of beliefs about the *causes of disability*, although Stone (1988) writes movingly of a family's pluralistic attempt to explain a teenage son's sudden severe mental disorder. There is, however, a considerable literature about plurality of beliefs and practices related to *illness and healing* in Nepal (Stone 1976, Macfarlane 1981, Oswald 1983, Adams 1988, Parker 1988, Subedi 1989 and 1992).

Parents often access a number of different practitioners and healing systems in dealing with their disabled child. Anthropologists have described how traditional healers, unlike Western-trained physicians, share conceptions of illness and curing with their patients (Adams 1988). Patients may consult traditional healers because they understand afflictions that biomedical practitioners deny are real, such as possession. Also, biomedical services can be geographically or financially inaccessible to patients forcing them to rely on traditional healers when they might otherwise seek biomedical solutions. Finally, people may describe an illness-specific pattern of therapy to the outside investigator, but follow a multiple-use pattern (pluralistic) as they try anything that may provide relief (Durkin-Longley, 1984). Parents often turn to a number of different practitioners in an attempt to make their child better. Because of the presence of interpenetrating belief systems, Nepal offers numerous opportunities for individuals to construct varied, unique, and highly individual explanations for and responses to disability. McHugh writes that at times of adversity, people in Nepal often

... turn to sources of social and psychological support available in a given cultural context ... The cultural

diversity of the Nepalese context allows members of particular groups a familiarity with other peoples whose world views may be similar but are nevertheless not identical to their own. Thus, they are aware of alternatives that exist at the periphery of their own cultural situations (1993:208).

Because many of the interviewed families were contacted through the biomedical system, family members were often reticent in discussing the alternative healing modes which they accessed. It was usually during a follow-up visit, unaccompanied by professionals, that people would reveal multiple use patterns in dealing with their child's illness and/or disability. The following cases illustrate this:

When Prasad became ill [at the age of two years] I despaired. I called every Buddhist, Hindu and Muslim holy man I could find. Some of them were very good, and could even tell me where my house was and what it looked like before they visited. I did this for two years, spending so much money, and going every day to Pashupatinath temple and other holy places to perform *pūjā* [religious offerings]. When Prasad was five I took him to the CP centre, and now I know that this was just his fate, and that no one is to blame, and that Prasad will never be cured [here she is crying]. *Newar mother, Kathmandu.*

For many months after I noticed that Santi was ill I called a *dhāmi* [indigenous healer] to come and expel the evil spirits who had attacked her. But this did no good, so we took Santi to Brunei, where the medical doctors told us she had CP. *Rai mother (her husband is an ex-Gurkha soldier).*

### **Conclusions**

This has been a small-scale exploratory study and any conclusions drawn from it need to be treated with caution. We make no claims that the families interviewed are representative of families of children with cerebral palsy in Nepal as a whole. Similarly we do not believe that the empirical findings have exhausted the possible - or even the most important - perceived causes or cultural classifications of cerebral palsy in Nepal.

Any strength of an exploratory study such as this lies in its ability to illuminate an under-researched area and to encourage the development of concepts of more general significance. We believe that the

rural-cosmopolitan continuum enables some of the complexities of pluralistic beliefs in developing countries to be unpacked. Even within an indigenous setting there are complex and sometimes contradictory relationships between different belief systems, as well as between the health care system and cultural values and beliefs within the community it serves. People can be reticent to discuss their beliefs concerning illness, disease and disability, and their own cultural categories and definitions, because they are not the same as the dominant medical perspective - or the perspective that the researcher is assumed to have.

We also hope that this paper has illustrated to those involved in both policy and practice the need to recognise that disabled categories and identities (as well as the causes behind them and the interventions sought for them) are culturally constructed. In one's own cultural context indigenous categories are, by definition, acceptable because they are outgrowths of the dominant cosmology and are widely held. The relationship between 'non-normal' and 'yes-disabled' sheds some light on the subtleties of labelling different statuses.

We believe that the conceptual frameworks that we developed to contextualise and to try to help explain our findings are of some heuristic value. While both frameworks need further conceptual refinement based on further research, it is our intention that they be a contribution to the oft-heralded but as yet nascent field of cross-cultural disability studies.

### Notes

1. Information provided by Professor Batuk Rajbhandari, Director of the Nepal Cerebral Palsy Self-Help Group: the longevity data is from the Kathmandu Valley, not the whole of Nepal, but it is unlikely that there is higher life expectancy in the rest of Nepal.
2. Ayurvedic medicine has a complex and rigorous theoretical base and is rooted in the religious teachings and world view expressed in the Vedic scriptures of the Indian Sub-Continent.
3. Although it is an independent sovereign state, Nepal has close links with the UK and has a unique connection with the British armed forces through the Brigade of Gurkhas, which has Nepalese and British officers and Nepalese other ranks.
4. Rai is the name of an ethnic group indigenous to East Nepal. They have their own indigenous religious belief system, but nowadays often adhere to Hinduism, especially if they live as an ethnic minority in areas of high Hindu concentration such as Kathmandu
5. Kanti Hospital and Bhaktapur are both in the Kathmandu Valley
6. The Newar are an ethnic group, centred in the Kathmandu Valley area, who adhere to both Hinduism and/or Buddhism.

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### References

- Acharya, B. 1994. "Nature, Cure and Indigenous Healing Practices in Nepal: A Medical Anthropological Perspective." In M. Allen (Ed.), *The Anthropology of Nepal: People, Problems and Processes*. Kathmandu: Mandala Book Point.
- Adams, V. 1988. "Modes of Production and Medicine: An examination of the theory in light of Sherpa medical Traditionalism." *Social Science Medicine* 27(5), 505-513.
- Ahmad, W., ed. 1993. *'Race' and Health in Contemporary Britain*. Buckingham: Oxford University Press.
- Beggs, J., Haines, V., and Hurlbert, J. 1996. Revisiting the rural-urban contrast - personal networks in nonmetropolitan and metropolitan settings. *Rural Sociology* 61(2), 306-325.
- Bell, M. 1992. The fruit of difference: the rural-urban continuum as a system of identity. *Rural Sociology* 57(1), 65- 82.
- BPEP/DANIDA. 1995. *Disabled People of Nepal*. Kathmandu: DANIDA.
- Burghart, R. 1998. "The Use of Cultural Knowledge in the Provision of Health Care Services among Ethnic Minorities in Britain: The Case of Residents and Citizens of South Asian Origins." In S. Allen and M. Macey (eds), *Race and Social Policy*. Swindon, ESRC: 72-88.
- Devereux, G. 1963. Primitive psychiatric diagnosis: a general theory of the diagnostic process. In I. Galdstone (Ed.), *Man's Image in Medicine and Anthropology*. New York: Institute of Social and Historical Medicine, New York Academy of Medicine.
- Dhungel, B. 1994. The Qualitative Community Judgement: The Role of Intermediate Health Practitioners in Nepal's Family Health Services. in M. Allen (Ed.), *Anthropology of Nepal: Peoples, Problems and Processes*. Kathmandu: Mandala Book Point.
- Durkin-Longley, M. 1984. Multiple therapeutic use in urban Nepal. *Social Science and Medicine* 19(8), 867-872.
- Edgerton, R. 1970. Mental retardation in non-Western societies: towards a cross-cultural perspective on incompetence. In H. C. Haywood (Ed.), *Social-Cultural Aspects of Mental Retardation: Proceedings of the Peabody-NIMH Conference*. New York: Appleton-Century-Crofts.

- Hanks, J. and L. Hanks. 1948. "The Physically Handicapped in Certain non-Western Societies." *Journal of Social Issues*, 4:4, 11-19.
- His Majesty's Government. 1993. *Population Census 1991*. Kathmandu: Central Bureau of Statistics.
- ICS/DANIDA. 1995. *Disability Survey of Kanchanpur District, Kathmandu*. Kathmandu: DANIDA.
- Kleinman, A. 1980. *Patients and Healers in the Context of Culture: An Exploration of the Borderland between Anthropology, Medicine, and Psychiatry*. Berkeley: University California Press.
- Kleinman, A. 1986. "Goodbye to All That: An Editor-in-Chief Takes his Leave." *Culture, Medicine and Psychiatry*, 10:2, 95-96.
- Kleinman, A. Ed. 1978. *Culture and Healing in Asian Societies: Anthropological, Psychiatric, and Public Health Studies*. Boston: G.K. hall.
- Macfarlane, A. 1981. Death, Disease, and Curing in a Himalayan Village. In C. von Furer-Haimendorf (Ed.) *Asian Highland Societies in Anthropological Perspective*. Delhi: Sterling Publishers Pvt.
- Mahale, P. 1983. Relevance of folk-urban continuum in studies of complex societies. *Man in India* 63(2), 197-205.
- Manion, M. L., & Bersani, H. A. 1987. Mental retardation as a Western sociological construct: a cross-cultural analysis. *Disability, Handicap and Society* 2(3), 231-245.
- McHugh, E. 1993. Culture and the transformation of suffering among the Gurungs of Nepal. In C. Ramble & M. Brauen (Ed.), *The Anthropology of Tibet and the Himalayas*. Zurich: Ethnological Museum of Zurich.
- Miles, M. 1992. Concepts of mental retardation in Pakistan: towards cross-cultural and historical perspectives. *Disability, Handicap and Society* 7(3), 235-255.
- Oswald, I. 1983. Are traditional healers the solution to the failures of primary health care in rural Nepal? *Social Science and Medicine* 17, 255-257.
- Parker, B. 1988. Ritual coordination of medical pluralism in highland Nepal: implications for policy. *Social Science and Medicine* 27(9), 919-925.
- Peters, L. 1980. Concepts of mental deficiency among the Tamang of Nepal. *American Journal of Mental Deficiency* 84(4), 352-356.
- Pigg, S. 1995. The social symbolism of healing in Nepal. *Ethnology* 34(1), 17-36.
- Redfield, R. 1947. The folk society. *American Journal of Sociology* 52, 293-308.

- Richardson, S. 1983. Physical impairment, disability and handicap in rural Nepal. *Developmental Medicine and Child Neurology* 25, 717-726.
- Sachs, L. 1995. Disability and migration: a case story. In S. Reynolds Whyte & B. Ingstead (Eds.), *Disability and Culture* (pp. 210-225). Los Angeles: University of California Press.
- Scheer, J. and N. Groce. 1988. "Impairment as a Human Construct: Cross-cultural and Historical Perspectives on Variation." *Journal of Social Issues*, 44:1, 23-37.
- Shah, R. 1992. *The Silent Minority: Children with Disabilities in Asian Families*. London: National Children's Bureau.
- Stone, L. 1976. Concepts of Illness and Curing in a Central Nepal Village. In *Contributions to Nepalese Studies* 3, 55-88.
- Stone, L. 1986. Primary health care for whom? Village perspectives from Nepal. *Social Science and Medicine* 22(3), 293-302.
- Stone, L. 1988. *Illness Beliefs and Feeding the Dead in Hindu Nepal: an Ethnographic Analysis*. Lewiston, NY: Edwin Mellon Press.
- Streefland, P. 1985. The frontier of modern western medicine in Nepal. *Social Science and Medicine* 20(11), 1151-1159.
- Subedi, J. 1989. Modern health services and health care behavior: a survey in Kathmandu, Nepal. *Journal of Health and Social Behavior*-30, 412-420.
- Subedi, J. 1992. Primary health care and medical pluralism exemplified in Nepal: a proposal for maximizing health care benefit. *Sociological Focus* 25(4), 321-328.