

## **Palliative care services in Nepal**

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The modern specialist palliative care services have developed on the back of hospice movement according to Christian values although the semantics of the word Hospice can be debated and history of hospices dated back to the early part of the last millennium. The greatest landmark development in palliative care started with the opening of St. Christopher Hospice in London by Dame Cicely Saunders in 1967 who worked tirelessly with terminally ill cancer patients<sup>1</sup>. No wonder that the lay people consider palliative care to be synonymous with hospice care.

The Nepalese people are predominantly influenced by Hindu and Buddhist philosophies. The nation has many ethnic groups who are deeply rooted in ancient traditions and beliefs. It is widely known that the attitudes towards death and suffering vary greatly across Nepal. Many communities have well established customs for dealing with death and funeral rites<sup>2</sup>. A sort of common good fund known as *guthi* which deals with many social events including death are important sources of support in some communities. Hard anthropological data regarding these issues nationally are not available. The concepts of *karma* and reincarnation as well as the observance of 'pollution' (*untouchability, jutho*) have given different values to the suffering of an individual. Hence, one needs to look at the definition of modern palliative medicine to ascertain the relevance of this specialty in Nepal.

The WHO defined palliative care in 2002 as: 'an approach that improves the quality of life of patients and their families facing the problem associated with life threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual<sup>3</sup>. This was simplified succinctly by the National Institute for Clinical Excellence (NICE), United Kingdom in 2004 as follows: 'palliative care is the active holistic care of patients with advanced progressive illness'. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments<sup>4</sup>. The latter sentence is probably intended to imply diseases like HIV/Aids and many congenital incurable conditions.

This definition is far from any religious or cultural bind and hence has an universal appeal. The key is 'holistic care' which indicates the vast scope of palliative care. This exceeds the realm of medical science and transcends to the art of living and dying with chronic disease and disability. The twelve principles of good death propagated by Richard Smith<sup>5</sup> can be taken as the gold standard by any individual or community. However, the logistics of achieving these desirable principles must vary between individuals and communities. Consideration of the epidemiology of death and chronic illnesses become important in this context.

About 56 million people die every year. 44 million, i.e. about 79 per cent, die in the developing world<sup>6</sup>. Mortality rate is known to be inversely related to socioeconomic status in a community. Chronic diseases and ageing account for about 60 percent of deaths in the developed and 40 per cent in the developing world. Acute illnesses, such as infectious diseases, accidents, pregnancy and acute cardiovascular conditions are the predominant causes of death in developing countries. It is estimated that the developing world is having to deal with two thirds of the worlds health problems by a mere 5 per cent of the resources whereas the developed world with its global share of 33 percent uses 95 per cent of the world resources<sup>7</sup>.

Nepal is one of the poorest countries in the world with a population of nearly 27million, (2006 estimate). The average life expectancy at birth ranges from 74.4 years in Kathmandu to 37 years in Mugu. 86 per cent of its population live in rural areas where access to trained medical manpower is rare. Over half of its population survive on less than one US dollar per day. The World Bank report of health and socioeconomic condition of Nepal makes a very grim reading<sup>8</sup>. In spite of unacceptably high prevalence of death across all ages, the population growth rate is 2.7 per cent. Paradoxically, there are no organised services for tackling this high numbers of deaths. None of the planning documents acknowledge any need for the care of the dying patients and support at end of life situations. None can deny the need for this service in a humane society.

In Nepal, the burden of care of the slowly dying rests upon the family as there is no social or state support for these individuals. Tempered with hard realities of living and having to provide for the family, poor Nepalese individuals in remote places postpone the cremation until late in the day when they return home after working all day. Many have no time to mourn for the dead<sup>9</sup>. In certain communities, a mandatory 13 days of mourning after cremating the body of the parent and the enforced 'pollution' (*jutho*) gives an opportunity for a son (or wife) to grieve for the deceased. In reality, whether this period of bereavement allows one to come to terms with the grief is questionable. The anxiety about the expenses incurred during the last rites, the remainder of the rites to follow, the subsistence of the family and the problem of debt at exorbitant interest rates are all matters of great concern

Absence of paediatric palliative care service is another glaring deficiency considering Nepal has one of the highest infant and under five mortality rates in the world. The infant mortality rate in the hills and urban areas are about 85.6 and 60.4 per 1000 live births which are relatively better compared to rural and Terai areas (100.2 and 104.3) respectively. The worst is in the remote mountains where it is 132.3 per 1000 live births<sup>10</sup>. The under five mortality rate is about one and half times higher than the infant mortality rates and shows similar regional variations. These figures reflect the severe economic deprivation and lack of health services for the population out with urban areas. The Long Tern Health Plan of the Government of Nepal does not mention palliative care<sup>11</sup>.

In service terms, palliative care starts from the diagnosis of an incurable disease and ends with the help and support for the bereaved after the death of the patient. It aims to improve the quality of the life that is remaining. Medical care, although essential, is only one aspect of palliative care. It is important to differentiate specialist palliative care from routine palliative care, the latter being essential for all. Many patients do not need specialist palliative care but those who do are usually suffering from one or more complicated symptoms such as extreme pain, breathlessness, nausea, seizures, fear, depression and facing break down of even the most intimate and caring relationships. It is estimated that about 60% of patients diagnosed to have advanced incurable illnesses require specialist care. Palliative care service also includes support to the carers, family and partners, not only the patient.

Specialist Palliative Care is necessarily a team work. The core members of the team are usually the physician, nurse, priest, volunteer and the carer. But the contributions from an occupational therapist, dietician and nutritionist, a physiotherapist, speech and language therapist, stoma therapist, clinical psychologist and a clinical pharmacist can be invaluable. The use of complementary and alternative medicine is gaining world wide acceptance.

The modern specialist palliative care services are expensive. Even the most developed economies in the world have been unable to meet with the demands of this service for their suffering population. Doyle<sup>12</sup> describes how difficult it was to get this specialty recognised as a subspecialty of General Medicine in 1987 and how the services have developed in the UK since then. It is estimated that only about 45 per cent of those who need this specialist service are getting it in the UK. The hospice movement in the UK gets about 20 per cent support from the NHS and is largely run by voluntary organisations<sup>13</sup>. On a background of dire poverty and paucity of health services nationally, it is indeed a daunting task to plan for a specialist, modern palliative care service in Nepal.

INCTR has been active in this field in Nepal since 2002<sup>14</sup>. Most of the services are confined to patients in Kathmandu and are very limited. It is necessary to have a broad perspective in order to develop this essential service nationally. The different cultural traditions regarding death, terminal rites and rituals, socioeconomic conditions and complementary medical practices, all become very relevant in this context. There are several successful palliative care services in many developing nations as enumerated by Stjernsward and Clark<sup>6</sup> which can guide us to design an appropriate model for Nepal. A three pronged strategy is suggested which will help to evolve this service over a few years in Nepal.

Incurability is still seen as an embarrassing failure of the medical profession. Hippocratic tradition prevented doctors from treating incurable patients because it was not for the doctors to challenge nature and the Gods<sup>15</sup>. Unfortunately, vestiges of this practice still remain. Most doctors get their thrill in making the diagnosis and recommending treatment. Many doctors offer platitudes and withdraw hastily from the inevitable death of their patients. It is also true however, that many doctors who are aware of the need for palliative care for their patients lack the expertise within themselves to provide this support. Those who are specialists in this field find the speciality most fulfilling and humbling experience. It

is amazing to see the transformation in a patient sunk to the depths of despair surfacing with a smile and become prepared to face the inevitable in a calm and collected manner.

One of the medical colleges in Nepal should take the lead in establishing an academic unit for specialist palliative care and become a focal point for training medical students and doctors. This academic unit should conduct and/or commission anthropological research in the modalities of dying, family and community support and funeral arrangements across the many ethnic groups in Nepal. Service oriented research will greatly help to appropriately deliver specialist palliative care in a local community. Other NGOs and voluntary organisations like INCTR could relate to this institution.

A national Association of Palliative Care, with membership in as many villages as possible, needs to be established in the voluntary sector. Its governing council or board, made up of religious and social leaders, the representatives of socio-religious organisations and *guthis*, needs to lobby to promulgate relevant legislature. Subsidised or free opiate availability for pain relief in terminally ill and cancer patients, financial support for the terminally ill, state help with funeral expenses are examples of these legislations. This council must influence the government to incorporate palliative care in its long term health plan.

A national public health programme for palliative care in Nepal can be developed in conjunction with any of the current vertical programmes. Palliative care programmes are successfully incorporated along with tackling HIV/Aides control programme in Uganda, South Africa and other countries<sup>7</sup>. HIV/Aides are devastating public health concern in Nepal also<sup>16</sup>. Many of these patients need palliative care.

Besides incorporating the concepts of good communication i.e. giving full and correct information to the patients, the health education programmes should advise and inform the possibilities of pain relief, avoidance of pressure sores, nutritious diet, and the availability of spiritual and psychological support for the terminally ill. It is the education and communication that are the primary requisites at this time. Even if a little of these concepts of help and support could be made available at every health institution, ranging from a sub health post to a tertiary hospital, the needy and suffering humanity in Nepal will get substantial succour. The inclusion of principles of palliative care

into the curriculum of training manuals of all health workers could be made mandatory. The teaching of social studies in schools could include information on good death and how palliative care helps to achieve this.

The variety of existing *guthis*, religious organisations, voluntary organisations and many NGOs have to be encouraged by the government to include support for the terminally ill in their sphere of activities. Nepalese rural world is full of traditional healers e.g. *Dhamis, Jhankris, Guvajus, Suneni, Lamas* etc. These are very useful assets and have been an integral part of Nepalese society at times of distress and need for support. The system of Ayurveda has been well accepted in the country. All of these can be given education and orientation in modern palliative care. This can enhance their usual traditional support to the community.

Complex ethical issues at the end of life will always remain and be debated<sup>16, 17, 18</sup> but these must not be influenced by the ability of a person to pay. There is a great potential for the proponents of euthanasia and physician assisted suicide to push ahead in an atmosphere of doom and gloom. The health care planners and providers in Nepal need to be aware of this possibility. Nepalese society, like any civilised human society, must try to provide for a painless and dignified death for its members. The present situation clearly is not acceptable.

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