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Medicare

End the pain

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Tough narcotic rules had meant that even patients with terminal illness had no alternative but to endure pain. But palliative care is now getting a new lease of life in Kerala.

Even when narcotic regulations are relaxed, unless physicians realise the need for pain relief and palliative care and get themselves trained in the subject, the movement cannot go forward.

Photo: S. Mahinsha

care and concern in treatment: **Dr. Babu Raj with Rajan, a cancer patient.**

An estimated two million cancer patients in India live their days in excruciating, needless pain. In a country which is one of the largest producers of raw morphine in the world, this easy and low-cost pain relief medication reaches less than one per cent of the needy patients. Not just cancer patients, many with burns, spinal injuries, paraplegia or motor neuron diseases also can benefit from palliative care. But in a health system which has never considered pain and palliative care as an integral part of mainstream medicine, even the physicians themselves might not come forward to demand pain relief for their patients.

But Kerala seems to have succeeded where the rest of India has failed. Its experiments in palliative care since 1993, with active involvement of local

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communities, have been so successful that today 80 per cent of all palliative care services in the country are delivered in Kerala.

Spreading wings

The Neighbourhood Network in Palliative Care (NNPC), an initiative that began in Kozhikode in Kerala in a small way in 1996, has now established about 60 palliative care units spread across six northern districts of Kerala, serving a 11-million population. The southern districts are also now in the process of establishing similar networks, with the help of Pallium India, an NGO. Together, the State now has about 75 centres which dispense oral morphine to patients and provide home care services.

In its first guide on planning palliative care services for people with end-stage diseases, released on October 6, the World Palliative Care Day, the WHO has identified Uganda and Kerala as having the most effective low-cost public health models of palliative care.

Stringent narcotic regulations (Narcotic Drugs and Psychotropic Substances Act of 1985) has been one of the major barriers in the way of getting oral morphine to people suffering in pain. As M.R. Rajagopal, a former professor of Anaesthesiology and the chairman of the Task Force on Palliative Care and Rehabilitation under the National Cancer Control Programme puts it, these laws resulted in a whole generation of physicians getting trained without exposure to proper evaluation or management of pain and the appropriate use of opioid drugs.

Even though various studies have proved that the use of oral morphine can be managed very well so as not to create addiction, many doctors still fear that opioids can lead to dependency and hence there has been little demand from their side to popularise palliative medicine. "It is sad how medicine has lost its humane face. It is easy for us doctors to focus only on the disease and to turn our back on the patient to say that nothing more can be done for him," Dr. Rajagopal says.

Dr. Rajagopal, who has pioneered palliative medicine in the country, now heads Pallium India and is engaged in delivering palliative care services, including training in palliative medicine to doctors and nurses in the periphery.

"Pain relief has been a major focus for palliative care-related work in India. But pain is often only the tip of the iceberg. Even morphine cannot erase a dying patient's agony about his family's fate. More than drugs, care and compassion are the essentials of palliative care," he says.

In his clinic, Priya, a 32-year-old, spoke about her long battle with the crippling pain of rheumatoid arthritis and disc prolapse. There were days when she could not even move from the bed and had to give up her job. Dr. Rajagopal put her on morphine at 75 mg, four times a day, which changed her condition dramatically. The dosage has now been brought down to 15 mg. Priya says that for the first time in months, she feels that surge of hope in her heart...

In 1998, the Government of India asked all State governments to amend and simplify its narcotic rules so that oral morphine can be made available to patients through recognised medical institutions which have at least one doctor trained in palliative medicine. Nine years later, 15 Indian States are yet to follow this directive. Even in those States where rules were amended, the supply of opioid drugs has been irregular.

There are other barriers too. Palliative medicine, because it has not been part of mainstream medicine, still does not figure in the curriculum of medical students in India. Of the 340-odd medical colleges in the country, there are only five that offer some amount of training to physicians in palliative care. Add it to the fact that India, where most cancers are detected at an advanced stage and where few have the access to treatment, is yet to formulate a national palliative care policy. Even an impoverished country like Uganda has one.

What began as an NGO initiative in a small way at Kozhikode in 1993 has today become the NNPC, which takes care of over 3,000 patients and their families and trains thousands of volunteers.

Volunteer-driven

Volunteers today have taken over the responsibility of advocacy, fund-raising and planning and organising care services. Most of the funds of NNPC are raised from the local community through small donations. Every one, right from school children, vendors and labourers contribute to the funds. In Kozhikode, for example, a box has been kept in the main bus stand where the crew of every bus that comes in donates whatever they can.

Over the years, the NNPC has linked successfully with local self-government bodies, the public health care system, the *anganwadis* and other self-help groups so that it can identify and deliver the health care requirements in each region.

Why did palliative care services take off in Kerala while it failed to in other States?

One of the foremost factors would be the need for physician education and advocacy. Even when narcotic regulations are relaxed, unless physicians realise the need for pain relief and palliative care and get themselves trained in the subject, the movement cannot go forward. But the crucial ingredient was the will and commitment of a few individuals who mobilised the community to care for its dying. This is also one reason why Dr. Rajagopal believes that despite the beauty of NNPC, it is not easy to replicate it elsewhere. "Individuals and NGOs have certain limitations. Networking with the government machinery is required so that pain and palliative care gets woven into the fabric of routine health care," he feels.

Bringing change

The stench of stale fish and sewage was overwhelming as we walked through the narrow pathways separating the fishermen's houses in the Erikkaravila colony along the Poovar coast, near Thiruvananthapuram. Daami (45) lay on a rubber mat spread on a bare cot, inside one of the houses. Tears trickled down his emaciated cheeks as he spotted the ever-smiling Valarmathi, a local volunteer, and the palliative care team from Pallium India at the doorway. And the relief on his wife's face was palpable.

Daami barely resembles the robust fisherman that he used to be. He suffered a stroke while at sea. One side of his body has been paralysed and he is likely to be bed-ridden for the rest of his life. After prolonged treatment at the medical college, the doctors had sent him home because clinically, there was little they could do to improve his condition.

A month later, when Valarmathi saw him, his arms and limbs had become

stiff. He was in terrible pain and could not speak. Bed sores had begun to develop on his back. Hygiene was poor because he was defecating on the bed.

After the team from Pallium India included Daami in their weekly home-care schedule, things have been much better. Analgesics have taken care of his pain; the nurses in the team have trained the family on wound care so that his bed sores do not worsen; exercises have been keeping his arms and limbs supple.

Valarmathi visits regularly to ensure that the doctor's instructions are being followed and also to keep up Daami's spirits. Daami, as well as the family, looks forward to these visits because the strain of constant care and social exclusion were beginning to tell on them. "Palliative care is not only for the patient, the family too needs emotional support and counselling. A bed-ridden patient soon becomes a burden for the family and will be relegated to some corner in the back of the house. If it were not for the constant monitoring and support given by volunteers, the level of care delivered would naturally go down," says Dr. Babu Raj of Pallium India.

* * *

At Karumkulam, Michael, another volunteer, was waiting to accompany the team to the house of Rajan, a 58-year-old suffering from cancer inside the cheek.

Though he underwent radiotherapy, the disease is so advanced that only symptomatic management is possible. A manual labourer, he has tears in his eyes when he speaks of the love and care that Dr. Rajagopal has given him. Whenever he went to the pain clinic, it was the doctor who would buy him lunch. Then one day, he hesitantly told the doctor about his family's situation. His only son, 22-years-old, who had been a student of civil engineering, had to quit his studies after his father's illness. When the boy tried to commit suicide, Pallium India decided to step in with a rehabilitation package for the family.

The cow that was tethered near the house is Pallium India's gift to the family. "We do not offer monetary assistance. Our aim is to give the family a sustainable livelihood so that even when Rajan is no more, they need not depend on others," says Vijayakumaran Nair, who opted to be a volunteer with Pallium India, after working for 28 years in a nationalised bank.

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