The Atlantic

HEALTH

India's Movement to Help People Die Better

Volunteers are taking the care of their terminally ill neighbors into their own hands.

By Jeremy Laurance

Camilla Perkins / Mosaic

MARCH 1, 2017

SHARE

Thirty years ago a young anesthetist, newly appointed as head of department at Calicut Medical College Hospital in the Indian state of Kerala, encountered a case that would change his life.

More From Mosaic

Mosaic Science

- The Little Yellow Box Making Surgery Safer in Developing Countries
- Kangaroo care—why keeping baby close is better for everyone
- Virtually Painless—How VR Is Making Surgery Safer

A college professor aged 42 with cancer of the tongue had been referred to him by an oncologist. The man was in severe pain, and the anesthetist, M.R. Rajagopal, asked if he could help. He injected the mandibular nerve in the jaw in a procedure known as a nerve block, and told the patient to return in 24 hours. Next day, the pain had almost completely gone and Dr. Raj, as he is known, was pleased with his work.

“He asked me when he should come back. I told him there was no need to come back, unless the pain returned. I thought he would be happy I had cured the pain. Instead, he went home and killed himself that night.”

It turned out that the oncologist had avoided explaining to the college professor that his cancer was terminal. Instead he had said he was referring him for further treatment.

“It was only when I told him there was no need to come back that he realized his cancer was incurable. He went home and told his family it was all over.”

Dr. Raj reaches for a glass of water. We are sitting in his simple home in Trivandrum, the leafy state capital, where he now lives with his wife, Chandrika, a pathologist. In front of us, a plate of yellow jackfruit gleams in the low afternoon light. A fan whirrs above.

That experience caused Dr. Raj to examine his own practice. In addition to putting people to sleep for surgery, an anesthetist’s job is to tackle pain. So what was he missing, he wondered.

“In those days pain was all over the hospital. It was everywhere. We pretended not to see it, but it was there. Injections of morphine were used sparingly, after surgery and for patients injured in accidents. It was never used in cancer pain.”

(Camilla Perkins / Mosaic)

Medical staff coped with the suffering the same way they cope everywhere. “No one teaches you, but you learn to see only the disease, not the human being who has it. Maybe if there is nothing you can do it is easier to turn your back.”

Dr. Raj had had two earlier traumatic experiences involving the dying. Aged 18, in his first year in medical school, he had lived close to a man who had terminal cancer of the sweat glands. “I would hear him screaming in the night. He had nodules all over his scalp. The family knew I was a medical student and asked if I could do anything. I didn’t know how—I was helpless. I am ashamed that I never visited him after that. I did not want to go there and feel helpless again.”

RECOMMENDED READING

Why Are Americans Still—Still!—Wearing Cloth Masks?

YASMIN TAYAG

Did Pfizer Peak Too Soon?

BRENDAN BORRELL

We're Already Barreling Toward the Next Pandemic
ED YONG

Later, he was looking after a patient with a gangrenous toe who was in excruciating pain. "I asked my head of department if I could try a nerve block. He refused—it was not part of routine care and there was a shortage of anesthetists. I had to tell the man there was nothing I could do. I still remember the look of hopelessness on his face."

When he became head of department at Calicut, there was no one to tell him what he could and couldn't do. That is how he came to treat the college professor. But his patient's suicide showed him that treating the pain was not enough.

"I realized that thinking about nerve blocks was too narrow. Pain is just the visible part of the iceberg of suffering. What is ignored is the part below the surface—feelings of hopelessness and despair, worries about money, about children. That is what palliative care is about. That man gave up his life to help me understand it."

* * *

We all wish for a pain-free, dignified death. Too few of us achieve it. Worldwide, the last year of life is marked by widespread unnecessary suffering. At least 40 million people need palliative care each year, but only around half that number receive it, according to the Worldwide Hospice Palliative Care Alliance.

India comes near the bottom of the global league in access to end-of-life care—ranked 67 out of 80 countries in 2015—but Kerala is an exception. This small green and fertile state in the south-west has just 3 percent of India's population but provides two-thirds of the country's palliative-care services. These have developed over the last 20 years, driven by the local community and supported by a unique system of volunteers. Some claim it is Kerala's strong ethos of community involvement that is the secret behind its palliative care provision, which would be difficult to replicate elsewhere.

Dr. Raj, one of the drivers of the movement, disagrees. “Yes, of course the strength of the community is important. But is Kerala the only part of the world where there are compassionate people? Is Kerala the only place where people who may have gained material success then want to do something meaningful with their lives?”

> “In the hospital, we were working in a sea of suffering. But in the clinic, you could see people smiling, talking, finding comfort.”

Now a youthful 69, he recognized early on that tackling pain and supporting the dying could not be achieved by medical staff alone. The need was too great. It would depend on harnessing the commitment of volunteers.

In 1993, after he had attended a course run by an English nurse, Gilly Burn, he and his colleague Suresh Kumar established the Pain and Palliative Care Society in Calicut, a town in the north of Kerala, together with an activist friend, Ashok Kumar, who ran a printing business and provided a vital layman's perspective.

"Six of us put in 250 rupees each, worth about £10 then," says Dr. Raj. "We found two volunteers, young women with children at school, to register patients and sit and talk to them. Then I would come after work to see them."

The project took off after Burn, who ran a trust, Cancer Relief India, donated 100,000 rupees (£4,000 in the mid-1990s), enabling them to appoint their first doctor. Calicut hospital provided two nurses.

"It very quickly got attention. In the hospital, we were working in a sea of suffering. But in the clinic, you could see people smiling, talking, finding comfort."

Within a year, it was being copied—by a medic whom Dr. Raj met on a train and by a former student who wanted to open a clinic in his own town. The ball was rolling.

There was a limitation, however. It was exposed early on when a young man came begging for help for his mother, who was in severe pain. She lived in a remote spot where there was no road and could not be moved. When Kumar told the man that the doctors could not prescribe without seeing the patient, he broke down in tears. Kumar weakened and told the man someone would come. It was their first home visit. Gradually demand increased. Then someone donated a vehicle.

The doctors, working in their spare time, could not meet the demand alone. The organization of the clinics and the home visits depended on volunteers. But the volunteers also provided the link between their communities and the service—they knew who was sick and where to get help. Over time, they became more and more involved. Some assisted with nursing tasks, following brief training, but most provided social care—advice, support, a shoulder to cry on.

By 2000, there were 30 palliative care groups in northern Kerala, run by volunteers and supported by mobile medical teams. Today, though there are no official figures, Dr. Raj estimates there are 300 voluntary groups across the state, providing care to patients in their own homes, identifying those in need, and helping to direct limited medical resources to where they can do the most good. Kerala is now a World Health Organization demonstration site for palliative care and plays host to a stream of international visitors wishing to learn how it was done.

The strength of the groups is that they have grown organically, rooted in their communities, by popular demand, and thus have strong local support. They are largely funded by local donations, some as little as 10 rupees (12 pence) a month.

They supplement the work of the 167 institutions licensed to dispense morphine and the 900 government–funded panchayats, or village councils, each of which employs a nurse who provides palliative care—though they may visit patients only once a month.

* * *

Thirty kilometers outside Trivandrum, in the district of Uzhamalakkal, the white van carrying the community team turns off the road and bounces along a rutted track to a group of houses half-hidden in the rubber trees. The team of doctor, nurse and volunteers enter a house where Surendran, a former rubber tapper aged 50, is lying on a bed naked to the waist, his lower body covered by a striped cloth. His chest rattles, his stick-like arms are drawn up to his face and his breath comes in painful rasps. He is in the terminal stages of lung cancer, and for the last week has been unable to swallow—food, liquid or morphine tablets. A Josco Jewellers calendar hangs on the bare cement walls, under a strip light, and a blanket covers the window. Mini, his wife, stands at the foot of the bed.

Dr. Raj lays a hand on Surendran's arm and gently explains that, as he can not swallow, to treat his pain the morphine will have to be administered rectally. The nurse will teach Mini how to do it. Dr. Raj asks if he has any questions. "Can I get out of this?" Surendran says. Before Dr. Raj can answer, Mini intervenes: "Yes of course you can. You will get better."

Dr. Raj suspects she knows the truth, but decides against trying to broach it with her at that point, worried about the reaction it might provoke. Just as a wrong dose of a drug can harm, so can an ill-chosen word, he says later. A reflective man, with kind eyes and neat moustache, he comes ever ready to lay a soothing hand on a fevered brow. Wearing a blue open-necked shirt and sandals, his gentle demeanor and soft voice put patients at their ease while he gently probes for their stories before quietly instructing his team, who hang on his words.

"We help people live at home and die at home. Most want that," he says. But Surendran's condition is extreme, and his suffering severe, so Dr. Raj urges Mini to bring him to the city, where there are a few hospice-style beds. She says she can not leave her 17-year-old daughter alone, so Dr. Raj suggests bringing her too. While neighbors are often supportive, in this case they stopped visiting when they heard Surendran had cancer. Mini says she will consider it. The volunteers will help arrange transport.

The group that requested the home visit, called Sangamam (meaning "confluence"), was started four years ago by Dileep, 43, the manager of a paint shop, whose wife died of cancer. It is one of 11 that have sprung up in the Trivandrum area in the last decade. They are supported by Pallium

India—the organisation Dr. Raj founded in 2006 after he retired from the government medical service and moved to the city—which provided the mobile medical team.

Sangamam is one of the most successful groups, with 12 active volunteers and another 50 whose help can be drawn upon. It is funded by donations from the local community. In this case, friends have been generous enough to allow Dileep to hire a nurse and buy some land, where he hopes to construct a clinic. The local panchayat gives 50,000 rupees a year for drugs. "Because they are convinced we are doing good work," Dileep says.

Guided by the Sangamam volunteers, the Pallium India team sees two more cases this Tuesday morning in January. One, a woman of 55, who had her tongue removed a month previously because of cancer, has developed severe pains in her neck, which prevent her sleeping. Wearing a pink sari, she breaks down in tears as it emerges from Dr. Raj's careful questioning that she has argued with her son in a dispute over land, and he has left. Sobha, a volunteer, has learned from neighbors that the son is planning to get married but has not told his mother. She undertakes to contact him to try to negotiate a reconciliation. Palliative care, in this conception, is about tackling emotional pain, as well as the physical kind.

* * *

What Kerala has recognized, though the rest of the world has been slow to do so, is that the scale of the need for palliative care cannot be met by professionals alone. In the U.K., the hospice movement provides the gold standard for end-of-life care. Yet just 4 percent of deaths occur in hospices. Most people—over three-quarters in some surveys—say they would prefer to die at home, but less than a quarter do so.

Julia Riley, consultant at the Royal Marsden Hospital, London, and visiting professor at the Institute of Global Health Innovation, Imperial College, says: “Hospices do terrific things—but there are not enough of them. We have got to get the service out into the community—it can be done at home. Only 10 percent of people who are terminally ill need specialist palliative care. The rest need only generic care.

“Palliative care is so cheap. We can do so much, relative to other areas of medicine, for so little. Giving people a dignified death is so important—both for them and for their families.”

In the U.K., the number of deaths is rising as the postwar baby boomers age, says Max Watson, consultant in palliative care at the Northern Ireland Hospice and visiting professor at the University of Ulster. “To continue in the way we are—relying on hospices and specialist care—isn’t an option,” he says. “It is really important to democratize specialist knowledge. We need to engage carers, voluntary groups, nursing homes and patients themselves so they can be empowered to provide good-quality end-of-life care. Most of those helping are over 60 themselves. They are a fantastic resource we are not using properly.”

In the U.S., hospice care is more widespread—45 percent of Americans at the end of their lives in 2010 received hospice care, more than half of them at home. These are among the highest rates in the world, according to Atul Gawande in his book *Being Mortal*. However, spending on the U.S. health system is widely acknowledged to be out of control, substantially outstripping the costs of comparable systems in Europe.

The Kerala model is thus drawing attention from around the world. The estimated 300 voluntary groups are often described as a network. This suggests, wrongly, that there is some overarching organization that links them all. In truth they are a series of networks that have grown organically,