Palliative Care Home Visits in Rural India

By: Stephanie Carmichael, Allison Smith

Note: All photos were taken and are shared with permission of the persons pictured.

It is a pleasant morning in late February as we bump along a rural road in Uttar Pradesh, India. We are joining a palliative care home visit to a man with late-stage oral cancer. When we arrive, we find there is little to do medically. The palliative care nurse, Sr. Rajani, checks his nasogastric feeding tube and finds no clogs or nasal breakdown (**Figure 1**). The family has learned to diligently maintain the tube while creating their own feeding formula: a slurry of diluted rice, lentils, curd and egg.

The patient presented to Kachhwa Christian Hospital (KCH) two years prior with a serious case of oral cancer. He was suffering incredible pain, with his jawbone visible through a weeping, open tumor, and malnutrition had left him in poor condition. Now he is back at home receiving pain management, nasogastric feeds, and caregiver support from medical staff. Weight gain, symptom management, and simple physical therapy techniques have significantly improved his independence and quality of life.

Figure 2

Figure 1

Our next visit is to a woman with metastatic breast cancer in a neighboring village. Soon after we park, relatives and curious bystanders arrive. The patient lies on a cot in a covered breezeway, finding relief from the sun (Figure 2). She is suffering from nausea, dizziness, and pain.

The atmosphere soon feels crowded, and then hostile. There are complicated layers of distrust for medical personnel (who are not local healers). A crooked path of information exists where the patient's husband has withheld his wife's diagnosis and prognosis from her and most of the family. Community members with social authority insert themselves next to the woman, trying to stand between her and Sr. Rajani. More family members press in; neighbors soon appear on their roofs to get a glimpse.

"Why aren't you helping her? Why isn't she getting better? What are you doing for her?"

The team is peppered with questions, but still, they stay with her. Sr. Rajani answers questions while asking a few of her own to determine how best to navigate the conversation. When the staff gets as much positive interaction as they can, we head to the truck and back onto the rutted road. Knowing how difficult it is to get a medical team into rural communities, this stunted interaction is heartbreaking. I'm sure my (Allison) frustration shows on my face as I ask "*will you keep visiting a patient in a family like that?*"

"*They all start like this*," Sr. Rajani answers off-handedly.

KCH's Community Health and Development Director echoes her, "*There is a lot of misunderstanding about disease, both its causes and cures. And there is little framework to understand palliative care medicine and what we can do. We connect patients to government services, order and update medications, manage symptoms and provide wound care. But we have to start with the same question: 'Do you understand what is happening to you?'*"

We heard this refrain at every hospital we visited. "*Our patient population doesn't understand palliative care medicine… People don't know about the relief and dignity palliative care can bring*," Landour Christian Hospital Deputy Medical Superintendent says.

She continues, "*Our program is completely accessible to anyone. But it is equally bypassable, so we must do a lot of educating. Each case is different, requiring unique conversations and care. Palliative care can be integrated with curative and restorative medicine as part of the continuum of care. And it provides a golden opportunity that few other programs can.* ***It values the patient in any condition and allows for honesty****. It can set family members free from lying about a diagnosis. If a relative wants to hide a diagnosis from the patient, we can work one-on-one with both of them. It all starts with communication. Open dialogue can help with the ups and downs of a terminal disease*."

No matter how the patients we visited feel about their treatment teams, they are in rarified space. The World Health Organization estimates that 56.8 million people need palliative care annually.[1] Worldwide, only 14 percent receive the palliative care they need, and this number dwindles to 1% in India, and much lower in rural northern India where the patients we visited live.[2]

I (Stephanie) am a registered dietitian in Philadelphia caring for people with amyotrophic lateral sclerosis. In my practice at home, I often have an uphill walk to educate people about palliative care, but my patients and caregivers are overwhelmingly literate and can access information. My protocols are the best of what modern technology and research can give us. In contrast, these nurses have chosen to practice where more than 75 percent of the population is below the poverty line, and malnutrition is so high that an egg a day is a rarely reached protein goal. We have different challenges, resources and practices.

At the same time, we are practicing the same type of medicine. In rural India, where resources are scarce, we witnessed the essentials of palliative care practice: compassionate experts providing medical care, understanding and advocacy in fragile seasons of life.

After our visit, we learned more about the woman with breast cancer in the breezeway. She had been diagnosed with cancer at a larger hospital more than a year before. At that point, the cancer was treatable, and her prognosis had a 5+ year survival rate. Then came the tragic advice from a community member with high status: she shouldn't receive cancer treatment or even be told her diagnosis; her daughters would have a hard time getting married if people knew their mother had cancer, and she was considered not emotionally strong enough to handle the information.

In the following months, her cancer metastasized and her pain worsened. More family members slowly learned her diagnosis/prognosis but demanded she remain ignorant. The palliative team continued to delicately approach her care within the cultural context to give her the best medical care and build trust with her family.

As it turned out, the team didn't have much time. The woman passed away just four weeks after we met her. The team was able to provide her significant relief by administering morphine– a noteworthy step considering India has only a small percentage of the morphine needed for health-related suffering.

It was sad news, but everyone who crowded the breezeway saw palliative care in action. They saw a medical team help a patient get relief from her pain, dignity in her care, and clarity in her confusion. And seeing that care might be a catalyst for the next person to understand what palliative care medicine can provide.

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