Home-Based Palliative Care Program Relieves Chronic Pain in Kerala, India: Success Realized Through Patient, Family Narratives

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ABSTRACT

An estimated 1.5 billion people across the globe live with chronic pain, and an estimated 61 million people worldwide experience unrelieved serious health-related suffering (SHS) worldwide. Therefore, one can estimate that 10 million people with unrelieved SHS live in India, which is home to one-sixth of the global population. The overall prevalence of chronic pain in India was estimated at 13% in 2014. Cancer is the major source of unrelieved pain in India and more than 1 million people develop cancer every year, and an estimated 80% of those patients are believed to live with significant pain.

Pain, a subjective experience for every person, is influenced by many factors including genetic characteristics, general health status, comorbidities, the brain’s processing system, the emotional and cognitive context in which pain occurs, and cultural and social factors. As defined by the World Health Organization, palliative care is intended to prevent and relieve “suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”

In India, palliative care is accessible to fewer than 1% of the people who need it. In its absence, treatment is disease-focused with little regard for SHS. The magnitude of this need is best illustrated by reported opioid consumption across countries. Global mean morphine consumption in 2013 was 6.27 mg/capita; per capita consumption in India was 0.11 mg, ranking 113 of 139 countries. Morphine equivalent (ME) rates in the highest-use countries such as Canada (723 mg/capita ME), the US (718 mg/capita ME), Australia (454 mg/capita ME), UK (241 mg/capita ME), France (213 mg/capita ME), and Italy (204 mg/capita ME) demonstrate the global misdistribution of opioids. These high ME rates include the therapeutic use and the misuse/abuse of opioids in those countries.

In contrast to high-resource countries, in low-resource countries, morphine consumption is a surrogate measure of access to palliative care. The state of Kerala in southwest India, with a land mass of 1% and a population of 3% of India, has managed to make robust community involvement, and palliative care services are being delivered by an informal network of health care professionals and volunteers with significant input from the government. Pallium India, a charitable trust formed in 2003 in Trivandrum, Kerala, provides palliative care to underserved populations in and around Trivandrum with inpatient and outpatient care, home visits, and advocacy, and works with local institutions in 16 of India’s 29 states to promote palliative care.

During the 2015-2016 University of Iowa Winterim Program (a 3-4 week intensive study-abroad program at Pallium India with courses led by University of Iowa faculty), students learned about the biological, psychological, and sociologic aspects of disease; how to care for and treat patients with terminal and chronic illness; drug restrictions on pain medication and opioid use in India; and the differences between the health care systems in the US and India. For many of these health science preprofessional students, this was their first exposure to palliative care.

Students also shadowed clinical teams during home visits. The use of empathic listening to treat and assess patients sharply differed from our own experiences as patients in health care in the US. We depict the pain stories of six patients treated by Pallium India with the goal of understanding the importance of palliative care and empathic listening for patients with SHS.

PROJECT DESCRIPTION

The project was conducted with sensitivity and respect for patients and families. Patients and patient families granted permission to participate in the project and to be photographed. The institutional review boards from the University of Iowa and Pallium India reviewed the project and found it did not require full review because it was a photojournalism project.

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Six home care patients were chosen by the palliative care team for their willingness to talk to visitors and to tell their stories. Basic demographic information was obtained including age, sex, family, occupation, education, and underlying illness. Each patient was asked the following: Can you describe your current pain level? How long have you been treated by palliative care? What was your pain like before and after interventions from palliative care? How does your pain affect your life? Pallium India health care workers translated all questions into Malayalam, answers were translated back into English, and narratives were written from their answers. All direct quotes depicted in the patient pain stories represent rough translations from Malayalam to English. The pain stories are based on translated patient testimonials and observations during home visits. The stories cannot speak completely for patients and simply represent observations during these experiences. All patient names were changed to protect confidentiality.

**PAIN NARRATIVES**

**Ambuja**

I have nobody, no kids or family. My husband, an alcoholic, sold all of my property for alcohol and left me with nothing. Pallium India has given me so much relief; not only have they alleviated my pain, but now they seem like family. My pain used to be an 8 on a 0-10 pain scale. After palliative care by Pallium India, it is now a zero. I am finally able to laugh and smile. I owe a lot of this to the pain relief that Pallium India has given me.

Ambuja’s husband abandoned her when she was very young, and her dreams of starting a family were crushed. She found work as a maid and worked long hours. Just when she thought she was finally getting back on her feet, she sustained a painful cervical fracture after falling in a deep canal while performing household chores. At age 71, Ambuja became bedridden and her pain was excruciating. She described feeling as if millions of needles were pricking her neck and electric shocks were radiating from her neck to her arm. And her pain was not only physical. Ambuja lost all of her independence, relying on her sister for help with simple toileting and eating needs. Her pain and losses led to a downward spiral into depression. When Pallium India heard of Ambuja’s situation, they offered to provide free palliative care and pain medications in her home. After receiving physical therapy and pain treatment from Pallium India, Ambuja was able to sit, walk with support, and attend to her own toileting.

**Akshay**

I feel like I have made a 100% recovery because of Pallium India. Before, I was completely bedridden. Now, I am able to move my hands and legs, and flexing and extending my muscles is easier. Most of all, Pallium India brings care to my home. Because of this, I do not have to take an ambulance to the hospital, which would be very expensive and extremely painful. After Pallium India’s arrival, I feel wanted and cared for.

Akshay is a devoted husband and father of two sons. After being trained as a taxi driver in Mumbai, he moved back to his home state of Kerala where he worked as a paid driver for 20 years. During this time, he started a family and enjoyed life raising his two sons. After sustaining a fall and injuring his head and neck, he became partially incapacitated. His condition deteriorated over time, and 4 years ago he became completely bedridden. Being paralyzed from the neck down at the age of 65 caused emotional turmoil for the formerly energetic Akshay. Driving his taxi, playing with his sons, and spending time with his friends and family brought meaning to his life. When Pallium India heard of Akshay’s case, they initiated physiotherapy to help him regain muscle movement and taught the exercises and skin management techniques to his wife. The physician treating Akshay explained that because palliative care was started early, pressure sores and depression had been avoided. After many months of physiotherapy, Akshay gained partial movement in his legs and hands.

**Ankita’s daughter**

Pallium India provides free pain care, free pain medication, and teaches me how to care for my mother. We work as manual laborers and cannot afford much, so free health care is a major weight off of our shoulders.

Ankita, age 60 years, has a seizure disorder and lives with her extended family. Before Pallium India intervened, she was experiencing long postictal states after having severe convulsions. During our visit, she lay curled on her bed, moaning and whimpering. In their best efforts to alleviate her pain, the family laid her on a tarp on a wooden cot that was cushioned with blankets.
After entering the room, the physician gently put a hand on Ankita’s arm and quietly told her that he would perform a quick health assessment. When speaking to the family, the physician mentioned that simple techniques such as physiotherapy and use of an air bed to prevent pressure sores could have decreased her pain dramatically. He noted that these omissions were not the family’s fault, but perhaps a pitfall of a health care system that focused only on disease instead of treating and caring for the whole person.

The physician quietly talked to the family about the next course of treatment. He prescribed pain medications while nurses cleaned Ankita’s wounds and addressed her pressure sores.

Bhavana’s daughter

We are very grateful for the care for my ailing mother. We work as manual laborers and cannot afford a lot. Pallium India has provided my mother with catheter changes, has taken care of her wounds, has given pain medications, and has given transportation for care, all free of charge.

Bhavana, age 86 years, had diabetes and hypertension. When we visited her, she was very weak and minimally responsive. It was clear that she had stopped eating; her breathing was very labored. Periodically, she would bend over her bed; eyes still closed, and vomit a dark liquid. Bhavana’s family insisted that she was fine the day before but suddenly took a turn for the worse. Before providing any medicine, the Pallium physician took Bhavana’s hand and gently rubbed it, offering warmth and comfort. He then gave her medicine to stop the stomach bleeding. He sat the family down to discuss Bhavana’s impending death. The family, although saddened, nodded their heads in understanding as the situation was explained.

Ekta’s daughter

My husband is very attached to my mother. Although she is unconscious, he can read her every facial expression. Before Pallium India, her expression was full of pain. Now my husband says she is happy and at peace. We are grateful to Pallium India. They change her catheter; tend to her painful bed sores; teach us how to take care of her; and, most of all, provide emotional support. The doctors and nurses don’t talk down to me but communicate to me on a level that I can understand.

Ekta had been a hard-working and energetic laborer who harvested rubber and managed household chores. The once-vibrant Ekta now slept for most of the day, only waking occasionally during the night with confusion. The family took care of her to the best of their ability, frequently moving her, cleaning her wounds, and emptying her catheter bag. When we visited Ekta she was in an unconscious state, mumbling occasionally as the physician examined her pressure sores, which were tunneled deep into her skin. Some were bleeding; others were dark black, indicating necrotic tissue. Although Ekta appeared unconscious, the Pallium physician acknowledged her presence, asking how she was doing, rubbing her arm, and providing notice before moving her. Her daughter expressed appreciation to the Pallium team for treating her mother with respect and compassion. Although the Pallium team addressed Ekta’s physical pain, the family had the most appreciation for Pallium’s support for the family’s grief.

Harsha

I feel as if I am a burden to my family and have no purpose on earth. I have struggled so much and am constantly in pain. After Pallium India, I feel like I have gained some of my independence back.

Harsha, age 76 years, has been under the care of Pallium for 2 years. When we entered her home, she greeted us with a warm, genuine, and dazzling smile, fussing over offering seats for her visitors and offering orange juice. After listening to the Pallium physician speak to her, we learned that Harsha had heart problems, pressure sores, and urinary incontinence, which repeatedly led to painful and uncomfortable infections. Harsha never stopped smiling during the visit. Her smile faltered, however, when she talked about her struggles with depression and said that she felt she was a “burden to my family and had no purpose on this earth.” Harsha had been very active, tending to the farm and looking after her household. Her health problems prevented her from doing the jobs that gave purpose and meaning to her life. Throughout the home visit, the physician simply listened to Harsha while the nurse held her hand. When asked to describe the ways in which Pallium India has helped this family, they expressed deep gratitude, stating that Harsha has gained a sense of autonomy. They report that her condition has greatly improved, and she can bathe herself, use her walker, and do small activities independently.
DISCUSSION

It should be noted that Pallium India health care workers translated all narratives from Malayalam to English, and the accuracy of direct quotes from the patients and details from the patient pain stories could not be verified. These narratives are, in a sense, cocreated among the patients, translators, and international visitors. A patient originates a story, but his or her words are translated; in the sections that are not direct quotes, an international visitor is crafting the story. Although the utmost effort was made to depict pain stories with objectivity, some unavoidable inherent biases on the part of the translator and transcriber may have influenced pain story content. Time constraints also were an issue because the Pallium team had to treat many patients during home visits, question-asking time was limited, and answers may have been rushed.

Another limitation is more systemic in nature: Because 80% of health care expenses in India are self-pay and home health care visits are not typically offered, the free home visits offered by Pallium India could have placed patients and their families in the emotional position of expressing gratitude and not feeling comfortable mentioning possible care shortcomings.

CONCLUSION

Narrative is “a representation of an event or a series of events.”18 Pain narratives told in the social context of home visits provide powerful evidence for health care teams and illustrate the importance of palliative care. From an international visitor’s perspective, the palliative care team’s empathetic listening was striking in its impact and contrast to the disease-focused health care practices in both high- and low-income settings. Early exposure to global and local palliative care for health profession students allows for proactive engagement in close and empathic listening and builds skills on gathering evidence to match the data found in disease-focused textbooks.

Disclosure Statement

The author(s) have no conflicts of interest to disclose.

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References


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