

## Palliative Care in India: A Hidden Necessity

By: Sarah Luke

What is Palliative Care (PC)? According to the World Health Organization, PC is the alleviation of pain and suffering to ensure the quality of life for persons with chronic and life-limiting diseases; this is accomplished through the holistic care of patients and taking into account their physical, psychosocial, emotional, and spiritual needs<sup>1</sup>. Here in the United States long term and end of life care, such as hospice care, are familiar to most of us. But in India only 1% of the nearly 1.4 billion people has access to PC<sup>2</sup>. This means the majority of people with chronic or terminal diseases risk undue pain and suffering until death, which could otherwise be alleviated by high quality, accessible PC. Because PC is not well established in the Indian hospital system, it is mainly non-governmental organizations (NGOs) scattered across the country who have developed unique programs to make PC accessible and equitable. This is unique, as the Indian Constitution guarantees citizens a right to health, and yet fulfilling this important service remains largely in the hands of NGOs.

I wanted to better understand how NGOs providing PC operate, so I spoke to representatives from three NGOs located in geographically distinct areas of India (see figure 1): CanSupport, the Pain Relief and Palliative Care Society (PRPCS), and the Swami Vivekananda Youth Movement (SVYM). There were several commonalities among the NGOs regarding PC best practices that I will discuss in this article. Firstly, each emphasized the importance of a multidisciplinary approach, to support the unique holistic needs of patients. Secondly, they stressed it was essential to care for caregivers and families to ensure patient needs are being met. And thirdly, all respondents felt that lack of awareness has resulted in the neglect of palliative care in the Indian healthcare system.

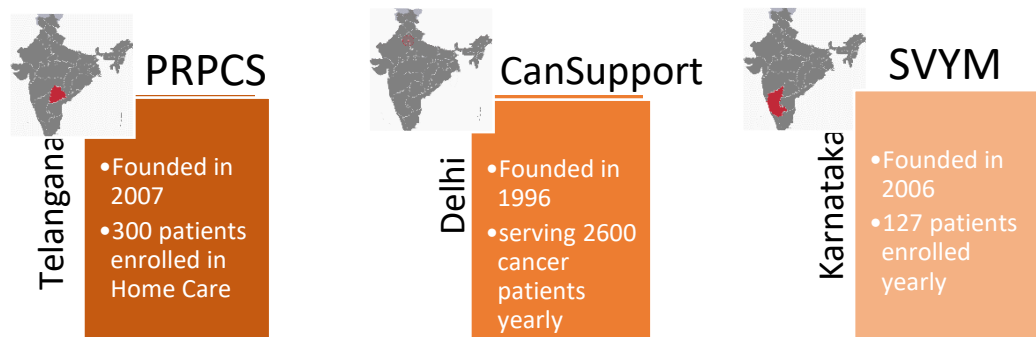


Figure 1

By किलसो (Filpro) - File:India dark grey.svg, CC BY-SA 4.0, <https://commons.wikimedia.org/w/index.php?curid=50825456>

### A Multidisciplinary Approach to Palliative Care

To be effective, PC must take into consideration a variety of healthcare needs. Persons with any incurable advanced chronic disease not only have physical issues, but also often have psychosocial needs that must be addressed. Thus, counseling becomes a vital part of PC. This was emphasized by a respondent from PRPCS in the South Indian state of Telangana who reminded me that “*less than 25% of palliative care is medical. The rest of the care is non-medical.*” They continued that because of the complexity of end-of-life illness there needs to be,

*“ a multidisciplinary expertise to provide holistic care, like counseling, preparing them for the eventuality, supporting the family, supporting social needs, and dealing with social issues, spiritual care. All this cannot be done by a doctor alone.”*

Recreational activities are also an important part of the PC model as a needed break for patients living with the day-to-day stresses of chronic disease. Homecare services are a defining component of many PC NGOs in which teams consisting of a doctor, nurse, and counselor visit and care for patients in the comfort of their own homes.

### **PRPCS: Recreation for hospice patients**



Source: PRPCS Annual Report FY2018-19

### **Caring for the Caregivers**

It is a defining characteristic of PC NGOs to prioritize caring for the caregiver because they realize that a supported caregiver is critical to providing the patient with quality PC as family members of patients often become the inevitable primary care providers for their ill loved ones. The PRPCS respondent again explained,

*“Family members are seeing their loved ones suffer and their condition deteriorate. It has a big psychological impact on the family and caregivers. They need support to deal with their own emotions and their grief. They are dealing with this day in and day out.”*

The NGOs I spoke with have developed strategies to alleviate some of the burden from families and caregivers. They empower caregivers to care for patients by educating them about the disease and forms of symptom management. Counseling and therapy services allow caregivers to process their emotions especially when they are preparing for the death of their loved one. After a patient expires, bereavement counseling is provided for families.

There is also a significant financial toll on patients and their families as most patients are bedridden and are in the end stages of life. The three NGOs I interviewed provide all services free of cost because they focus on marginalized sectors of the Indian population who come from very poor economic backgrounds. Thus, when one family member is rendered bedridden, especially if they are the breadwinner of the home, they lose their earning potential and livelihood. According to a PRPCS care provider, *“when cancer strikes, even the average middle-class family becomes so poor that they don’t have food to eat”*. Therefore, things like food assistance become a critical part of PC.

The long-term financial toll and the time-consuming role of caregiving mean that a whole family may be affected by the situation and certain forms of social rehabilitation are necessary. For example, a PRPCS representative points out that,

*“the first casualty is children, they stop studying because their priorities are so different. And the foremost thing we always want to do is to send children back to school. Otherwise, one future generation is lost because of one person having cancer in the family.”*

Another form of social rehabilitation is to teach members of the family, especially women, certain economical skills so they can have a source of income even after the death of the patient. NGOs also help families navigate government schemes that could provide the family with much-needed financial support. Quality PC makes life easier for the patient AND the family.

### **Lack of Awareness**

PC in India is a historically overlooked branch of medicine for one main reason: a lack of awareness. PC, as a specialty, never existed until very recently, and medical schools did not teach healthcare providers about pain management which may help explain why healthcare providers still largely lack awareness about PC. A representative from PRPCS states that *“doctors seem reluctant to refer patients to PC, even though the patient clearly needs it.”* Because of the lack of awareness among health professionals, policymakers do not know about this disparity, and it becomes difficult to implement policy. There is also a lack of awareness within the public and a stigma associated with diseases like cancer and the use of pain medication. A CanSupport care provider explained that,

*“Most people feel that if you're referred to PC that there is no hope. People are looking for a cure, especially cancer patients, everybody wants to be cured and wants to get better. People don't want to be referred to PC because they think that means the end is coming. And doctors will not involve the PC department early in the disease. So, when they refer the patient late, that means that there is no hope left and there is nothing that can be done.”*

A doctor from SVYM shares their experience with the stigma around PC and pain medication by the public and by healthcare professionals:

*“to accept this death in our regular medical medicine is quite difficult because that is like a failure for the practitioner. And there are a lot of myths in and around PC because of the use of morphine. People think that morphine is addictive and is the end drug to be given when the patient is in the end stage of life. I know doctors who will not prescribe it.”*

### **The Way Forward**

CanSupport, PRPCS, and SVYM express that partnership with the government is the most important way to integrate PC into the healthcare system to make it universally available. All have partnered with one or more government hospitals in their areas to ensure that patients are referred to PC provided by the NGOs. The NGOs are involved in training government hospital staff about proper PC, working to establish their models of PC in hospitals.

Although PC is becoming known in cities, about 70% of India's population lives in rural areas where PC is largely unknown. It is very difficult for NGOs to reach the thousands of villages surrounding the cities due to resource and staffing limitations. All three NGOs articulate the critical need for more integration with government systems which have the infrastructure to reach remote areas.

A care provider from SVYM sums up this sentiment,

*“We want to make palliative care a government-owned specialty. This can only be accomplished by collaborating with primary healthcare centers and communicating with them the importance of palliative care”*

PRPCS, CanSupport, and SVYM exemplify the importance of government partnerships to make PC a mainstream practice. CanSupport is pioneering palliative care clinics in government hospitals and all government hospitals in the Delhi area refer cancer patients to CanSupport. Similarly, SVYM partners with the Mysore Medical College, a government hospital, and runs their inpatient,

### **PRPCS: Hospice patient getting his last shave**



Source: PRPCS Annual Report FY2018-19

outpatient, and homecare based on their model. They are also knowledge partners of another government hospital, the Hassan Institute for Medical Sciences in which they are introducing a homebased care unit. PRPCS partnered with the government of Telangana advising them to establish a district-based PC program and have successfully integrated PC into the mainstream healthcare system. At the present, all 33 districts of Telangana have established PC programs with at least one inpatient facility, a home care service, and accessible oral morphine for those who need it.

Advocacy is critical to ensure that quality PC is made available to all people, especially as instances of chronic illnesses increase. An employee from PRPCS stresses that,

*“People who require palliation are a highly vulnerable and voiceless population. If you really want to help them, we have to make their voice heard.”*

Bringing this issue to the forefront and raising awareness is the most powerful tool to ensure that all people suffering from a chronic illness or who are at the end of life are alleviated of pain and suffering and are ensured a dignified death.

### **COVID-19 Impacts**

While the work of providing PC can already seem overwhelming, especially with meager infrastructure, dealing with COVID-19 added an extra layer of complexity to these operations. NGOs continued to provide essential PC services under the challenging circumstances presented by the COVID-19 pandemic and the country's lockdown. A care provider from CanSupport states that during the first wave *“all the hospitals were closed, and our patients were in need. We knew that we could not abandon our patients.”* To safeguard staff, they limited homecare visits to patients who were most in need and continued to supply patients with morphine, provide essential procedures, such as wound dressing and urinary catheter changes. COVID-positive patients would be cared for by phone and video consultation and pain medication was left at the doorsteps of homes.

Source: CanSupport Newsletter April 2021 – June 2021

For PRPCS the initial wave was very tough. A majority of their staff became infected, but thankfully they all recovered and were vaccinated. Despite this initial disruption in operations, staff continued to provide care leaning on telephone and video consultations. PRPCS opened a facility to care for elderly COVID-19 patients who could not be cared for in hospitals due to lack of space and closures.

SVYM shifted its focus from PC and became highly involved in COVID care, especially during the first wave. The home-based care model was adapted so that COVID-19 positive patients could be visited in their homes and cared for. SVYM provided oxygen concentrators and managed patients at home until their symptoms concluded, or until a bed in an ICU became available.

Humanity will always need palliative care, and the status of a global pandemic will not change that. These NGOs continued to provide care amidst these challenging circumstances and did not abandon their patients. The COVID-19 pandemic highlights how necessary healthcare providing NGOs such as these three are. For these NGOs to reach even more people in need, government support is essential to provide for the necessary infrastructure and to make PC mainstream in the healthcare system.

**SVYM : Palliative Care patient having a dressing changed on a deep wound on her ankle. The palliative care team visited her twice every week serving her with medical care during lockdown.**



Source: SVYM Comprehensive Covid-19 Report

**SVYM: Serving the community with essential healthcare services during lockdown.**



Source: SVYM Comprehensive Covid-19 Report

**CanSupport: home care teams continued visiting their home care patients throughout the second wave.**



Source: CanSupport Newsletter April 2021 – June 2021

## Acknowledgments

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Pain Relief and Palliative Care Society: [PAIN RELIEF AND PALLIATIVE CARE SOCIETY, HYDERABAD \(palliativecarepartners.in\)](http://PAIN RELIEF AND PALLIATIVE CARE SOCIETY, HYDERABAD (palliativecarepartners.in))

CanSupport: [CanSupport - Leaders in Home Based Palliative Care](http://CanSupport - Leaders in Home Based Palliative Care)

SVYM: [SVYM: : Home](http://SVYM: : Home)