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“Our Duty and Our Right”: Perspectives on Advancing Palliative Care in the Indian States of Kerala and Uttarakhand

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“Our Duty and Our Right”:  
Perspectives on Advancing Palliative Care in the Indian States of Kerala and Uttarakhand

By

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*Dedication*

श्रीमती कलावती पटेल की याद में

This thesis is in memory of Srimati Kalawati Patel,  
a spirited and beloved friend, mother and teacher,  
may she rest in peace,

and to people in India and around the world  
who are working hard to make palliative care a reality.

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# Literature Review on Palliative Care and Pain Treatment in India

## Introduction

Over the past three decades, the problem of untreated suffering at the end of life and during serious, chronic illness has risen in the consciousness of health care givers, global health institutions and human rights advocates globally. In India, such untreated pain and suffering has formed the impetus for sustained civil society efforts to improve palliative care provision throughout the country and to make morphine—a strong opioid analgesic—accessible for people with severe pain.

The World Health Organization (WHO) defines palliative care as “an approach that improves the quality of life of patients and their families facing the problem[s] associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” (2002). The WHO estimates that 40 million people worldwide need palliative care each year, yet only 14% of people dying with severe pain currently receive it (2016a). While the availability of palliative care in India is even more limited, innovative models have come from India, particularly from the southern state of Kerala (S. Kumar 2013).



Figure 1: Map of India, including States and Territories ([http://d-maps.com/carte.php?num\\_car=24868&lang=en](http://d-maps.com/carte.php?num_car=24868&lang=en)). See Kerala at India’s southern tip.

The goal of this literature review is to provide background in which to ground my research on palliative care in the Indian states of Kerala and Uttarakhand. Specifically, my research will seek to understand the barriers, strategies, strengths, weaknesses, and opportunities facing palliative care and pain treatment efforts in these two states.

India is a country of tremendous geographic, linguistic, social and economic diversity. This diversity manifests in many ways, including in state-level health and health care disparities that include palliative care (McDermott et al. 2008). After a successful national campaign to change morphine regulations, palliative care advocates in India appear focused on making state by state progress (M. R. Rajagopal 2015a; Vallath et al. 2016). Therefore, empirical study of inter-state variation in palliative care capacities and barriers is likely to be valuable and timely for advocacy. This literature review aims to provide a foundation—in palliative care’s meaning and history, in the Indian health care system, and in existing studies of Indian palliative care. This foundation will support my original research.

Few robust, empirical studies and systematic reviews of palliative care outcomes in India exist (Gielen, Bhatnagar, and Chaturvedi 2015; Singh and Harding 2015). Still, the founding of the peer-reviewed Indian Journal of Palliative Care (IJPC) in 1994, as well as collaboration between Indian palliative care doctors and international researchers have facilitated research and publishing on palliative care in India (M. Rajagopal, Joranson, and Gilson 2001; Wright, George, and Mingins 2004; M. R. Rajagopal, Karim, and Booth 2017). Furthermore, some young Indian clinician-researchers are taking interest in the field of palliative care (M. Gupta et al. 2016; Sunilkumar, Boston, and Rajagopal 2015).

Beyond empirical studies, a number of key “essays, commentaries and viewpoints on emerging themes” in Indian palliative care exist (S K Chaturvedi 2008, 612; Jan Stjernswärd 2005; S. Kumar 2013). Also, at least one non-academic empirical study on pain treatment and palliative care—conducted by Human Rights Watch—has proven important for advocacy in India (2009b). While not based in academic research, the insights and tensions within these pieces are valuable windows into Indian palliative care, and can spark ideas for meaningful research going forward. Therefore, I have cited some of these essays and viewpoints in this paper, identifying when I am drawing from a perspective piece versus an empirical study.

This literature review will culminate in a survey of evidence on some key themes:

- 1) challenges, dilemmas or barriers to palliative care in India
- 2) strengths and weaknesses of palliative care in India
- 3) opportunities to advance and strengthen palliative care in India.

The above themes are adapted from the Strengths, Weaknesses, Opportunities and Threats (SWOT) framework for strategic planning (Daemmrich 2016). Developed and refined since the 1960s, the SWOT framework has become a cornerstone of strategic planning in many fields, from business and non-profit management to health care (2016). The framework holds that in order to improve a system, its members must reflect on the strengths and weaknesses internal to the system, as well as the opportunities and threats facing the system from the outside. Taken together, this evaluation provides essential background for strategic planning and decision-making. Some health care researchers have used SWOT analysis to evaluate palliative care capacity and plan for improvement in Europe and Latin America (Tomasovic 2005; Pastrana, Centeno, and De Lima 2015). However, such an analysis has not been attempted in



India. Before investigating the literature for SWOT-related themes in Indian palliative care, however, some background on palliative care and the Indian health care system is essential.

*The first section of this literature review will discuss the definition and history of palliative care, with special attention to India.* Palliative care has certain defining principles, many of which developed from the work of Dr. Cicely Saunders in 1960s. These principles have informed the present WHO definition of palliative care, which resonates with diverse models from around the world. However, the meaning of each element of the WHO definition—from “life-threatening illness,” to “psychosocial and spiritual” problems, to “family”—can vary greatly across socioeconomic and cultural contexts. Therefore, this chapter will describe some of the models of palliative care developed in India, and the findings of some empirical studies and commentaries on the meaning of palliative care’s different domains in India.

*The second section will focus on the need for palliative care in India.* Numerous arguments regarding the need for palliative care around the world and specifically in India have been made. This section will review issues of low morphine availability and consumption; the rise of chronic non-communicable disease in India; empirical evidence of the needs and suffering of Indian patients who reach existing palliative and tertiary care settings; and human rights-based arguments for palliative care and pain treatment. This section addresses the “why” of my thesis.

*The third section will discuss the structure of the Indian health care system.* Palliative care providers operate within and alongside the existing government and private health care system in India. This system’s resources, capacities and shortcomings deeply affect palliative care patients, families and providers. A primer in Indian health care will provide essential background for understanding the fourth and final section: evidence about the challenges, strengths, weaknesses and opportunities of palliative care in India.

## **Section 1:**

### **Defining Palliative Care: History, Concepts and Indian Models**

Across cultures and contexts, human beings have developed varied practices for tending to the needs of people who are seriously ill and dying. Indeed, in India, “home-based spiritual and religious care of the dying” has a long-standing history (S K Chaturvedi 2008). Since the 1960s, movements to organize and improve care for people with terminal illness have gained momentum globally. These movements have together generated the concept of the modern Hospice—a place for residential, holistic, evidence-based care for people with terminal illness. The ideas of Hospice eventually gave birth to modern palliative care, whose basic goal is to improve quality of life for seriously ill patients and their families by controlling burdensome symptoms and providing holistic support. As palliative care has spread globally, it has taken distinctive forms to meet the needs of diverse populations.

#### **History of Palliative Care**

The birth of present-day palliative care has been widely attributed to the work of Dame Cicely Saunders in England in the 1960s (Clark 2016). Saunders—who trained as a social worker, nurse, and eventually a doctor—wished to care for patients dying from cancer. She set out to found a modern Hospice facility that would alleviate the suffering of patients dying from cancer while researching and disseminating good practices in end-of-life care. Christian faith was a central driver for Dr. Saunders’s work. However, the eventual guiding values of the movement Saunders and her collaborators founded were ecumenical (Saunders 2000).

Saunders and her colleagues researched the care needs of people with terminal cancer in a manner that was vital to establishing palliative care as a distinct field of medicine. Hospice historian David Clark has described how public attention to cancer grew in Britain in the 1950s, but the medical system was more focused on seeking cures than on attending to the distress of patients (Clark 2007, 431). However, studies by health care providers and social scientists at the time began to generate evidence about the social and clinical care needs of people dying from cancer (2007, 431). Saunders and her supporters contributed to this momentum when they founded St. Christopher’s Hospice in 1967 in London. The Hospice became a center of groundbreaking research on end-of-life care. In particular, the studies at St. Christopher’s on pain relief techniques were particularly important in defining the field of palliative care.

#### **The Significance and Interpretation of Pain**

Saunders and her collaborators observed that unrelieved pain was a serious problem facing many people with advanced cancer (Clark 2007, 432). She conducted tape-recorded interviews with hundreds of patients to understand the factors contributing to their pain (Saunders 2000, 9). From this process of listening to patients, Saunders developed a concept that is foundational in palliative care to this day: “total pain.”

Total pain conceptualizes patients' pain as having many domains, including and beyond the physical. Saunders writes, "physical, emotional and social pain and the spiritual need for security, meaning, and self-worth" all affect a patient's pain experience (2000, 9). This holistic understanding of pain offered a framework for caregivers to understand and treat a patient's suffering. This diagram by Dr. Robert Twycross, a St. Christopher's research fellow, demonstrates how different domains may contribute to total pain (2005):

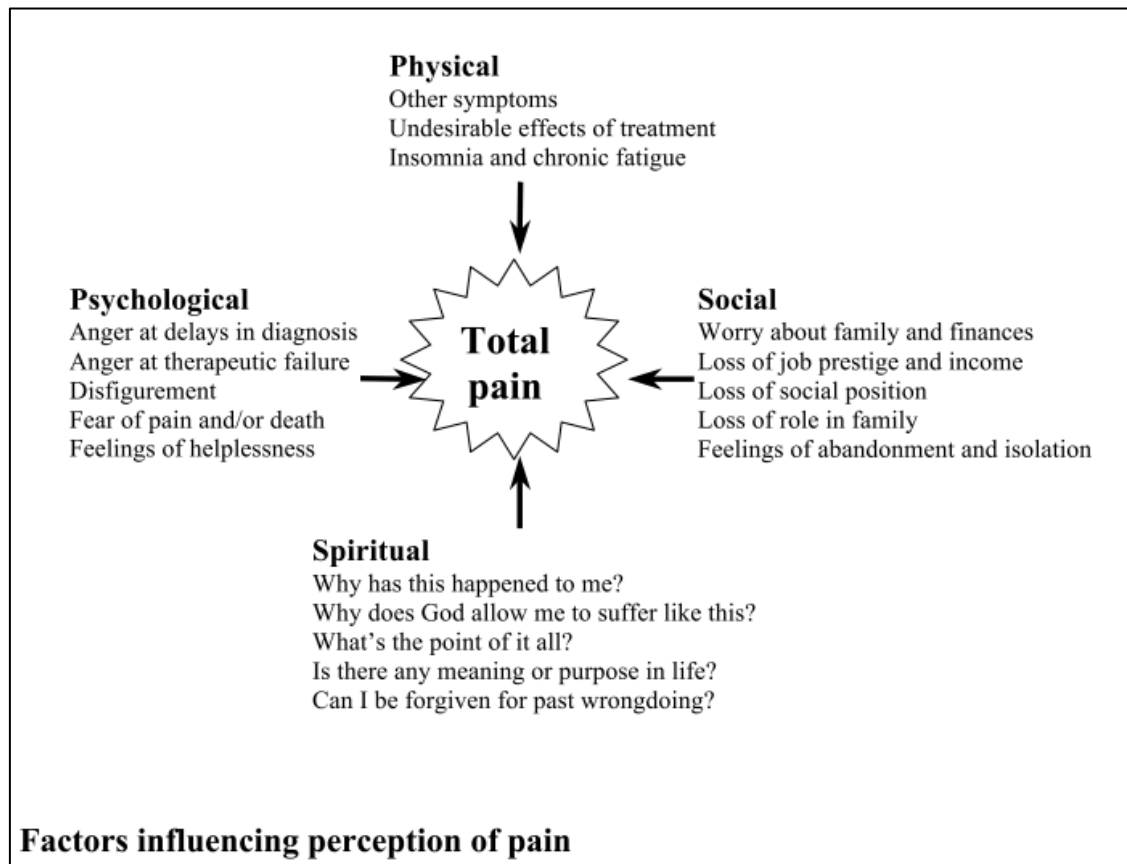


Figure 2: Total Pain: Factors influencing the perception of pain come from physical, social, psychological and spiritual domains (Twycross 2005, 22).

Research at St. Christopher's hospice also contributed to understanding of pain treatment, particularly the role of morphine in analgesia. In one of the Hospice's first studies, Twycross studied existing analgesic cocktails and identified morphine as the key therapeutic component (Clark 2007, 432). He continued to study and then teach about the safety and efficacy of oral morphine for alleviating pain in advanced cancer, and eventually for breathlessness in advanced chest and neurodegenerative diseases (Twycross 2005). Dr. Saunders also developed and taught the practice of administering analgesics on a schedule to prevent the needless re-emergence of pain (Clark 1999, 731).

## **International Collaboration**

Since its origins, palliative care has been formulated through collaboration and correspondence between practitioners and advocates worldwide (Clark 2016). In a retrospective essay, Cicely Saunders noted that the palliative care movement has “shown it can flourish in different cultures, each initiative with its own characteristics, but with the common aim that people should be helped not only to die peacefully, but to live until they die with their needs and their potential met as fully as possible” (2000, 11).

From the 1970s onward, international conferences on end-of-life care took place (Clark 2007, 434), and these began in India in the 1990s (Chaturvedi and Chandra 1998). Over time, palliative care providers from different countries and regions developed professional associations—from the United States and India, to Latin America, Asia-Pacific and Africa—as well as international associations with global membership. These groups have facilitated sharing of information and advocacy resources (2007, 434). They also have undertaken studies of regional barriers to palliative care (Pastrana, Centeno, and De Lima 2015).

## **Evaluating Palliative Care**

In the twenty-first century, clinical researchers, particularly in the United States, have studied the efficacy of palliative care interventions in terms of patient-reported outcomes. Historian David Clark has argued that these studies have helped palliative care become defined and recognized as a medical discipline (Clark 2016). For example, Temel et al. conducted a seminal study of outcomes for patients with metastatic non-small-cell lung cancer randomized to receive regular oncologic care alone or with early palliative care (2010). In the study, palliative care was defined as meeting and having access to a team of trained palliative care physicians and nurses focused on “management of symptoms, psychosocial support, and assistance with decision making” (2010, 734). The study found that patients receiving palliative care reported significantly better mood and had more documentation of their care preferences. Patients also had both significantly longer survival (on average 3 months) and less aggressive care at the end of their life. This study has been widely cited by the palliative care community, and shows the tremendous promise of palliative care. At the same time, it focused on one model of palliative care and one specific patient group in a high-resource setting.

In India—a setting of diverse palliative care models and limited health care resources—a 2015 systematic review found four studies reporting outcomes of palliative care interventions (Singh and Harding 2015). These few studies also show promising findings, which I will discuss later in this section.

A number of studies have attempted to compare palliative care activity internationally. For example, the International Observatory on End-of-Life Care developed a detailed methodology for categorization of countries (or states within a country) into four groups: “no known hospice-palliative care activity,” “capacity building activity,” “localized hospice-palliative care provision,” and “services...reaching a measure of integration with mainstream service providers” (Wright et al. 2008; McDermott et al. 2008). These categories do not assume that palliative care services are structured a certain way, but rather express the degree of coverage and mainstreaming of

palliative care. In contrast, another study of palliative care capacity, conducted by the Economist Intelligence Unit, is their “quality of death” index (2010; 2015). This index, which was not peer-reviewed, uses a variety of quantitative and qualitative indicators to rank countries around the world numerically based on overall “quality of death.” The Economist Intelligence Unit’s reports have been cited by advocates of palliative care in India as evidence of the need for more palliative care (M. R. Rajagopal 2016). At the same time, Zaman et al. warns that this kind of study may contain an underlying assumption of “one future” for palliative care globally (2017). In Zaman et al.’s view, the Economist’s studies suggest that the highly medical and resource-intensive model of palliative care predominating in Western Europe, the United States, and some other wealthy countries is the model toward which all should be progressing. Zaman et al. argues that palliative care providers should be open to innovation from all parts of the world and to the idea that there are “multiple futures” for palliative care. This seems very consistent with the ethos of “openness” propounded within palliative care itself (Saunders 2000, 8).

### **Involvement of the World Health Organization in Advancing and Defining Palliative Care**

The early research on end-of-life care at St. Christopher’s Hospice and other institutions eventually spurred the World Health Organization’s (WHO) decision to take up cancer pain as a global health problem. In the 1980s, the international non-governmental organization acknowledged that an estimated 5.5 million people with cancer were dying each year without adequate pain relief. They began to develop user-friendly guidelines for pain treatment (World Health Organization 1986). They also laid out three key domains for improvement of global pain treatment: 1) education of health care providers, 2) public policy improvement, and 3) efforts to increase the availability of essential drugs, specifically morphine (J. Stjernswärd, Colleau, and Ventafridda 1996). Initially, this effort was focused on treating cancer-related pain, with an intention to extend into a holistic palliative care approach over time (1996).

The WHO facilitated international communication and idea sharing in pain treatment through a growing network of collaborating centers and demonstration projects (J. Stjernswärd, Colleau, and Ventafridda 1996, 70). Collaborating centers developed expertise in different domains like policy, research and training, while demonstration projects created models for palliative care delivery in a range of countries and in low-resource settings. Kerala, India is home to both an early demonstration project and present-day collaborating centers (Ajithakumari, Kumar, and Rajagopal 1997; S. Kumar 2013).

### **The WHO Definition of Palliative Care**

Through its global activities, the WHO has developed and updated its own definition of palliative care. The first definition in 1990 focused on pain relief for cancer patients not responsive to curative treatment. However, the present definition from 2002 reflects an evolution in thought over time, and is cited around the world (M. R. Rajagopal et al. 2017). The 2002 definition is more expansive: it does not limit palliative care to a

specific diagnosis, and it includes the patient's family, psychosocial needs and spiritual needs as foci of care. The WHO now defines palliative care as “an approach that improves the quality of life of patients and their families facing the problem[s] associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” (World Health Organization 2002).

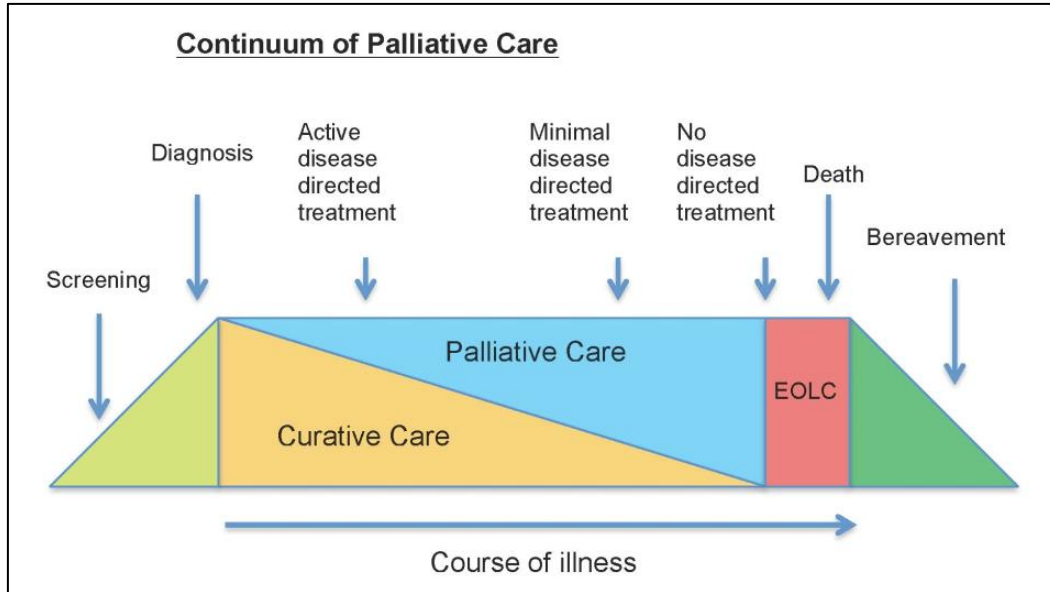
The definition enumerates specific aspects of palliative care, including “a support system” for patients to live as actively as possible until death, and for families’ bereavement; “a team approach” to address needs holistically; and applicability of palliative care “early in the course of illness, in conjunction with other therapies that are intended to prolong life.” The definition notes that palliative care intends “neither to hasten or postpone death,” but that it “will enhance quality of life, and may positively influence the course of illness.”

This definition indicates much about palliative care. First, it describes the goal of palliative care as “improved quality of life,” involving the assessment and holistic treatment of suffering. With such a broad mandate, it is no wonder that palliative caregiving requires a multi-disciplinary team. The definition also specifies that palliative care aims not to prolong life but to help patients achieve comfort and function—the ability to do daily tasks and things they love in their remaining lifespan.

The definition also describes the beneficiaries of palliative care as “patients and their families.” This means that care for the patient extends to include family, guiding them through caring for their ill family member and providing bereavement support after a loved one's death.

Furthermore, the definition also selects “life-threatening illness” as the indication for palliative care, moving away from a disease-specific definition and allowing for a context-dependent evaluation of which conditions are “life-threatening.” For example, in India, some palliative care programs serve people with quadriplegia and paraplegia, whose lives are indeed threatened by their condition in a setting without accessible rehabilitation medicine programs (M. R. Rajagopal et al. 2017).

Importantly, the WHO definition also affirms that curative, disease-directed treatment may continue alongside palliative care, as this globally popular illustration depicts:



**Figure 3: Continuum of Palliative Care (Indian Association of Palliative Care 2014).** EOLC = End of Life Care.

This concurrence with curative treatment means that palliative care both includes and goes beyond the concept of hospice, which focuses on care at the end of life.

### **Defining Palliative Care Across Cultures and Contexts**

The WHO definition of palliative care appears relevant across cultures. Empirical studies have investigated variation and consistency in the core elements of palliative care that are valued across cultures and ethnicities. For example, in 2010, a Canadian research team systematically reviewed qualitative studies of how hospice and palliative care is conceptualized by cultural minorities within pluralistic societies—including studies focused on South Asians, African Americans, Latinos, Jews and others engaged in palliative care in the US, UK, Canada and Australia (Bosma, Apland, and Kazanjian 2010). The main finding was a striking unity among concepts of hospice and palliative care between these diverse groups. These concepts included (1) “pain and symptom management,” (2) “tending to unfinished business,” (3) “spiritual and religious care,” (4) “support to family, friends and professional care providers” and (5) “quality of life and care choices,” informed by the patient and their families’ preferences and goals (Bosma, Apland, and Kazanjian 2010, 512–17).

While core concepts may be shared, empirical studies have also demonstrated that the meaning of “quality of life,” “spiritual and religious care” and a good death vary between and within cultures (Venkatasalu, Seymour, and Arthur 2014). Therefore, the WHO has sought to advance a definition and model of palliative care that is adaptable to different circumstances around the world (Jan Stjernswärd, Foley, and Ferris 2007).

### **Defining Palliative Care as a Public Health Issue**

Given the population-level need for supportive care in advanced illness and dying, the WHO has advocated defining palliative care as a global public health issue. Stjernswärd et al. of the WHO have written that a public health strategy “offers the best approach for translating new knowledge and skills into evidence-based, cost-effective [palliative care] interventions that can reach everyone in the population” (2007, 486). Sustainable, population-level coverage is the goal of this public health approach (Sepúlveda et al. 2002, 91).

Both Sepulveda and Stjernswärd et al. from the WHO argue that the public health approach requires commitment from governments to incorporate palliative care into all levels of their existing health system—from primary to tertiary care. Stjernswärd et al. add that programs are more likely to succeed when “owned by the community [and] society through collective and social action” (2007, 486). This public health model of palliative care implementation was recently endorsed by the World Health Assembly (2014), and is in progress in Kerala, India and a few other settings globally (Jan Stjernswärd, Foley, and Ferris 2007).

The public health model has two distinctive pillars, 1) government enactment of policies to make palliative care available at all levels of care—from primary care clinics to specialty hospitals; and 2) community mobilization to provide and help people access care. While this model has contributed to agenda-setting and progress in some countries, including India, moving beyond localized palliative care projects to integration with government health policies has been limited globally (Sepúlveda et al. 2002, 91). Furthermore, the issue of community involvement in palliative care—as endorsed by the public health model—has been debated in India. We will examine this debate in upcoming sections.

### **Defining Palliative Care as a Medical Specialty and Profession**

Care of people with life-threatening illness has become increasingly professionalized through research activities and the establishment of professional degrees and associations for palliative care.

While the WHO definition does not emphasize professional caregiving, this definition of palliative care published recently in the *New England Journal of Medicine* does:

“Palliative care is interdisciplinary care (medicine, nursing, social work, chaplaincy, and other specialties when appropriate) that focuses on improving quality of life for persons of any age who are living with any serious illness and their families. By treating pain, other symptoms, and psychological and spiritual distress, by using advanced communication techniques to establish goals of care and help match treatments to those individualized goals, and by providing sophisticated care coordination, palliative care provides an added layer of support to patients, their loved ones, and treating clinicians. Ideally, palliative care is initiated at the time of diagnosis and is provided concordantly with all other disease-directed or curative treatments” (Kelley and Morrison 2015, 747).

While resonating with the WHO’s definition and Cicely Saunders’ early principles, this definition of palliative care refers to “disciplines,” “specialties,” “advanced



communication techniques” and “clinicians”—all indications of the need for special training to provide palliative care. In a similar vein, Khosla, Patel and Sharma of the Regional Cancer Center in Chandigarh, India began their definition of palliative care as “a health care specialty” (2012).

A large body of palliative care expertise has been developed since the 1960s, and there is some tension between considering palliative care primarily as a medical profession or a community task. This debate is alive in India, where the most pressing question is how to extend quality palliative care to a vast population in need (H. Gupta 2004b; Stjernsward 2005; M. R. Rajagopal 2015a). As we will explore more deeply in Section II, the growing burden of non-communicable diseases such as cancer and stroke, and the aging of India’s population have increased the need for palliative care services. Furthermore, access to pain relieving medications is limited, and some states lack even a single center for palliative care services (McDermott et al. 2008; S. Kumar 2013, 218). Nevertheless, India is home to innovative and diverse models of palliative care. In order to further define palliative care, we will now examine some of these models.

### **Models of Palliative Care in India**

Descriptions of care models are a central part of the literature on Indian palliative care. A recent systematic review of palliative care evidence from South Asia found that most publications were descriptions of models of care in India (Singh and Harding 2015). Since the late 1980s and 1990s, many programs—run mainly by private not-for-profit organizations—have developed across the country, in Kerala, Maharashtra, Delhi, Karnataka, Assam and more (McDermott et al. 2008). We will begin with Kerala, whose distinctive model has been recommended by the WHO for implementation in other developing countries (World Health Organization 2016b).

#### ***The Kerala Model: Community Participation and Public Health Integration***

About two-thirds of India’s palliative care services are delivered in the southern state of Kerala, which is home to only 3% of the country’s population (S. Kumar 2013, 218). Commentators have attributed the success of palliative care in Kerala to the state’s high literacy rate (nearly 94%, whereas India’s average is 74%) and the presence of ambitious leaders in palliative care (M. R. Rajagopal 2016). Together, doctors, nurses and lay volunteers in Kerala developed a model of long-term and palliative care emphasizing active participation of the community in providing home-based care. The premise of the system is that the care of people with chronic and serious illness is a community responsibility, because needed care goes beyond what medical personnel can provide, especially where medical resources are scarce (Paleri and Numpeli 2005).

In 1993, two anesthesiologists and a layperson founded the Pain and Palliative Care Society (PPCS), which began to operate a pain and palliative care clinic out of the government medical college in Calicut, Kerala. This team included Dr. M.R. Rajagopal, now considered the “father of palliative care in India.” PPCS was designated from its early stages as a WHO Demonstration Project for palliative care in low-resource settings. From PPCS’s spark, other non-profit palliative care services caught on throughout northern Kerala.

Eventually, PPCS founders realized that outpatient activities in which volunteers had only limited, prescribed roles were inadequate “in terms of coverage and... other dimensions of total care” for patients (S. K. Kumar 2007, 624). According to Paleri and Numpeli, PPCS founders noticed that new centers led by community volunteers rather than doctors were more successful in reaching many patients and raising local funds to support the services (2005). While medical personnel initially resisted, the leadership of volunteers freed health professionals to focus on the medical needs of the patient. Therefore, an emphasis on training thousands of laypeople in basic principles and skills of palliative care began (2005).

To this day, trained volunteers are founding and leading the day-to-day operations in a network of non-profit programs throughout Kerala (Paleri and Numpeli 2005). These volunteers identify patients in need of care (anyone who is seriously chronically ill, frail and bedridden), provide counseling, transportation and other social support to patients and families, raise local funds to sustain free services, and invite specialized medical personnel as needed to provide the medical aspects of palliative care.

As Kumar, a PPCS founder, has noted, “a good percentage of families are financially broken by the cost of prolonged treatment by the time the patient registers with the palliative care unit” (S. Kumar 2013, 219). Because the philosophy of palliative care includes the total, psychosocial care of the patient and family, community-based teams in Kerala seek to support those devastated by the cost of prior medical treatment. Kumar (2013, 219) has written that they support needy patients and families with:

- Regular food rations to prevent hunger;
- Financial support for education of children in illness-affected households to prevent school drop-out;
- Free transportation to the hospital when needed, which can otherwise be prohibitively costly;
- Vocational rehabilitation and training of some patients and/or family members for income-generation;
- Direct financial support to poor patients in emergencies;
- And linkage of patients with community institutions and government schemes that can provide more help, including financial support for curative care.

These are considered important aspects of palliative care in the Kerala model, given the effect of poverty on quality of life.

From the 1990s until 2008, nearly all palliative care programs in Kerala were not-for-profit volunteer-led initiatives providing free services using locally available resources. Proponents of this model emphasize that it aligns with principles of “Health for All” expressed in the World Health Organization’s Alma-Ata declaration (S. K. Kumar 2007, 624) and of Gandhian self-reliance (Stjernswärd 2005). The WHO’s Stjernswärd has also stated that the “community approach is the only realistic model for achieving significant coverage of care for two thirds of the world’s terminally ill”—those in low-and-middle income countries (2005). In fact, the public health approach to palliative care advocated by the WHO suggests that the foundation of care should be a community-owned approach like Kerala’s (Stjernswärd 2007). In this model, palliative care specialists have an important role, but one which is relatively smaller than the role of the community.



**Figure 4: Public Health Framework of “Palliative Care for All” (J Stjernswärd 2007, 53).**

Ms. Harmala Gupta, a cancer survivor and founder of a home-based palliative care service for cancer patients in Delhi, has articulated a critique of the community-led Kerala model. She has questioned the quality of volunteer-led palliative care services (2004b), and expressed concern for patient confidentiality and safety in this model (2005). Indeed, she wonders if services led by volunteers rather than a professional multi-disciplinary team can fulfill the definition of palliative care (2004b, 601).

Stjernswärd of the WHO has responded by emphasizing the values of equity and coverage, which are strong in the Kerala model and the WHO public health approach to palliative care (2005). He argues that “quality” is not very meaningful without sufficient coverage of people who are bed-bound and seriously ill. Stjernswärd expressed doubt that multi-disciplinary specialist palliative care—reliant on human resources with extensive training—is a realistic model to reach all in need. Yet, as in the diagram above, he writes that “both approaches are needed, and one should not exclude the other” (2005).

Empirical studies of service quality and patient satisfaction in Kerala, and of unmet need throughout India, are needed to inform this debate. Unfortunately, there is a dearth of evidence on palliative care outcomes in Kerala. The one relevant study identified by Singh and Harding had major methodological limitations, such as convenience sampling and unclear data collection methods in a small, quantitative study of patients in community-led home care (Santha 2011). However, a robust study from the neighboring state of Tamil Nadu found that physical quality of life and perceived psychological support were significantly higher among a random sample of the elderly in 46 villages with “community-managed palliative care,” in comparison to a sample from 47 control villages (Dongre et al. 2012).

### ***Further Developments in the Kerala Model***

In 2008, the Government of Kerala created a policy to increase palliative care coverage in all of Kerala. The policy centers on provision of home care services by trained community nurses connected to primary health centers at the village level (Government of Kerala 2008). The policy also involves training of health care professionals and volunteers in palliative care principles. In a situation unique in India, the public sector now accounts for the majority of home care services delivered in Kerala. According to Kerala palliative care pioneer Dr. Suresh Kumar, the government’s involvement was sought to provide coverage and sustainability of services that NGOs were not able to achieve (2013, 219).

From 2008 to present, government capacity for palliative care has grown dramatically, but has not been evaluated much empirically. One proxy measure for palliative care coverage and quality is per capita medical morphine consumption. A quantitative study found that per capita morphine consumption in Kerala reached 1.56 mg/capita in 2015, with 48% of morphine provided by government palliative care entities. 1.56 mg/capita is much higher than the national figure of 0.11 mg/capita, indicating relatively more robust delivery of pain treatment in Kerala (M. R. Rajagopal, Karim, and Booth 2017). At the same time, this is lower than the global mean consumption level of 6.27 mg/capita, and much lower than the estimated need (2017, 3). Therefore, despite the many positive aspects of Kerala’s palliative care progress, some barriers remain to full coverage and access to pain relief.

The Kerala model of palliative care—both in community participation and government support—is very much aligned with the public health model promoted by the WHO. Indeed, the achievements in Kerala have shaped the WHO model and provided organizational and training practices they now endorse for global implementation (World Health Organization 2016b). Still, other models of palliative care also have an important place in palliative care in India today.

### ***Professional Home Care and Hospice Models***

Beyond Kerala, many of India’s palliative care programs are home-visiting services provided by multi-disciplinary teams (McDermott et al. 2008). This home care model in India is very similar to models dominant in Western countries, and involves a team with specialized palliative care training including a nurse and doctor (Kishore S. Rao 2006; Rajvanshi, Sharma, and Mohan 2015; Dhiliwal and Muckaden 2015). Some

programs, such as CanSupport in Delhi and Bangalore Hospice Trust include a trained counselor in their home care teams to provide psychological assessment and support of the patient and family (Kishore S. Rao 2006; Banerjee 2009). The vehicle driver is also considered an essential member of the home care team (H. Gupta 2004a; Iyengar 2017). While volunteers play various supporting roles in these programs, the team leaders are palliative care professionals.

Professional-led home care programs may receive referrals from affiliated hospitals, or by direct outreach of patients and families. This referral method contrasts with the Kerala model, wherein community volunteers or government community health workers often provide the initial contact between patients, families, and trained palliative care teams. Another contrast with the Kerala model is that some prominent home care programs focus exclusively on patients with cancer (Kishore S. Rao 2006; Rajvanshi, Sharma, and Mohan 2015; Dhiliwal and Muckaden 2015), though their model could be used to care for patients with other conditions.

Still, there are similarities between the community and professional-led models. Both kinds of home care programs in India are broadly charitable and donor-funded (Kishore S. Rao 2006; Rajvanshi, Sharma, and Mohan 2015). For example, the Rotary Club supports the Bangalore Hospice Trust, and locally collected donations fund many palliative care NGOs in Kerala. This allows programs to provide care and medicines for free. Furthermore, community and professional-led programs both emphasize teaching family members caregiving techniques, such as administering medicines, preventing bedsores, and caring for nasogastric tubes and tracheostomies (Dhiliwal and Muckaden 2015; Rajvanshi, Sharma, and Mohan 2015). Some also offer extensive training to their staff and to visitors wanting to replicate their programs elsewhere in India (Kishore S. Rao 2006; Rajvanshi, Sharma, and Mohan 2015). Lastly, some home care programs have relationships with inpatient hospice facilities to allow for round-the-clock care of patients with symptoms that are uncontrollable at home (Kishore S. Rao 2006). However, there are very few residential hospices in India (McDermott et al. 2008). Based on commentary articles, the hospices that do exist appear to be innovative and tailored to the cultural environment in which they have been built (Burn 2001, 161; Kishore S. Rao 2006).

There are few empirical studies of the outcomes of multi-disciplinary, specialized home care programs in India, but the available evidence is encouraging. For example, Dhiliwal and Muckaden found that pain and symptom burden among cancer patients significantly decreased between the first and second visit of a palliative home care program in Mumbai (2015).

### ***Hospital-based Palliative Care Services***

Some of the first palliative care programs in India were outpatient clinics of tertiary hospitals, medical colleges and cancer centers (Ajithakumari, Kumar, and Rajagopal 1997). These clinics can be important referral resources for clinicians who are otherwise unfamiliar or uncomfortable with managing severe pain and other symptoms, as well as for patients and families who feel their needs are not being met in the mainstream system (Lebaron et al. 2014).

The formation of small consulting teams of palliative care nurses and physicians within hospitals is also being considered as a model for improving pain treatment and

introducing palliative care throughout India and parts of Africa.<sup>1</sup> Additionally, the Government of India has nominally incorporated palliative care as a pillar of its cancer control strategy, so designated cancer centers across the country are expected to offer palliative care services (Ministry of Health and Family Welfare 2008).

Few hospital-based programs in India have been studied empirically. One prospective observational study of patients receiving palliative care in a teaching hospital's oncology clinic found significant improvements in quality of life and reductions in pain (Bisht et al. 2010). However, the design of the palliative care intervention was not clearly described in the article.

Given the limited empirical study of these care models, assessing their strengths and weaknesses through a case study could be helpful. It may also lend new voices to existing debates over the roles that different models should have in Indian palliative care going forward. The question of whether palliative care ought to be a professional or community-led service remains salient within Indian and global palliative care.

## **Conclusion**

This section has examined some of the history, core elements and definitional tensions in palliative care, particularly as manifested in India. While debates continue, what is clear is the vast need for palliative care. The next section will describe empirical evidence of this need, focusing on India. I will also touch on rights-based arguments for pain and palliative care provision. This is the “why” of palliative care, and of this thesis.

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<sup>1</sup> <http://treatthepain.org/pain%20free%20hospitals.html>, Accessed August 15, 2017.

## **Section 2:**

### **What arguments have been made regarding the need for pain treatment and palliative care in India?**

The need for palliative care has gained increasing recognition around the world since the 1970s (Clark 2016). The WHO estimates that 40 million people worldwide are in need of palliative care each year, and only 14% of those in need of end-of-life care currently receive it (World Health Organization 2016a).

Advancing understanding of the need for palliative care has occurred through many synergistic efforts, including research, public awareness-raising, and transnational collaboration between palliative care providers, policy analysts and human rights advocates (S. Kumar 2013; Clark 2016; Vallath et al. 2016). These efforts have generated diverse evidence—from clinical research to human rights investigations—that all illuminate the need for palliative care.

This section will review key evidence of palliative care need. I will focus on India, where this evidence includes epidemiologic patterns of rising non-communicable disease burden; research on physical and psychosocial suffering of patients with advanced diseases; data on the persistent lack of morphine accessibility; and efforts to establish a right to pain treatment and palliative care based on international human rights agreements and the Indian Constitution. As the reader will see, there are vast numbers of people in India who need palliative care in order to live and die without needless suffering; however, only 1-4% of those are estimated to be receiving palliative care (M. R. Rajagopal 2015a; Human Rights Watch 2009b).

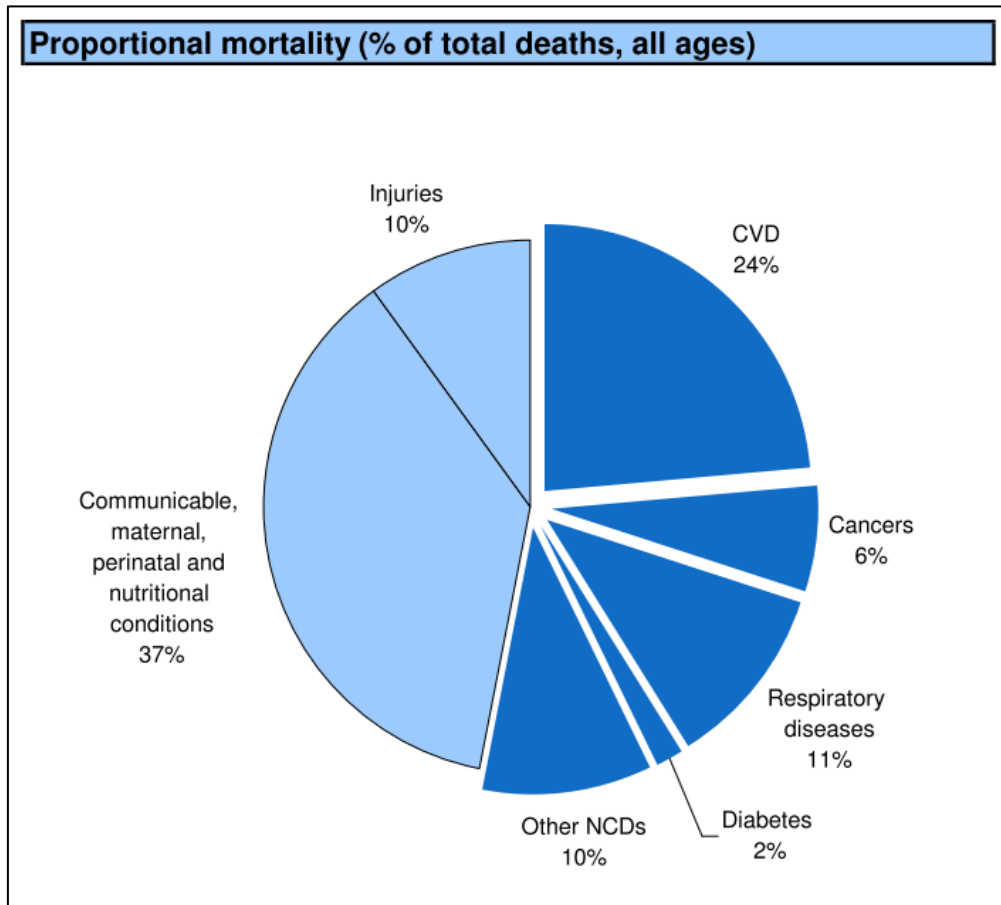
#### **Evidence from Epidemiology and the Burden of Disease**

Like many developing countries, India is experiencing an epidemiologic shift in which chronic, non-communicable diseases (NCDs) such as cardiovascular disease and cancer are becoming major causes of death and disability (Mallath et al. 2014; World Health Organization 2014). Tobacco use, pollutant exposure, diets high in sugar, and increasingly sedentary lifestyles are all noted risk factors in this transition. The growth of the elderly population in India is also a reflection of a decreased communicable disease burden, and it evidences the need for forms of long-term supportive and palliative care for the elderly (National Sample Survey Office 2006). India's population of older adults is expected to reach 140 million by 2021 (S. Kumar 2013).

The distribution of the older adult population in India varies by state. States with more robust social determinants of health often have more adults living into old age. In addition, older adults in urban areas appear to have relatively more illness than those in rural India (National Sample Survey Office 2006, 15). However, the need for supportive care in rural areas is likely high due to urban migration of young people, which can deplete direct family support for the aging, sick and bed-bound in villages (The Economist Intelligence Unit 2010, 9).

## The Double Burden of Disease

In addition to the rise of non-communicable diseases, infectious diseases continue to be prominent causes of death and life years lost in India. This co-occurrence of communicable and non-communicable disease prevalence creates what public health practitioners have called a “double burden” of disease in India and many low and middle-income countries, presenting a health policy and resource challenge (Mallath et al. 2014, 4). Below is a chart representing the leading causes of mortality in India as of 2010, which illustrates this double burden.



**Figure 5: Mortality Distribution for India, 2010 (World Health Organization 2011).** Dark blue pieces represent non-communicable diseases, while light blue pieces represent other causes of death. CVD = cardiovascular disease, NCDs = non-communicable diseases.

While infectious diseases continue to cause too many deaths, particularly among the poor, non-communicable diseases and injuries now account for an estimated 53% of all deaths in India, and 44% of disability-adjusted life years (Balarajan, Selvaraj, and Subramanian 2011). As an example, the burden of life-limiting cardiovascular disease is rising in India (World Health Organization 2011). Indeed, high blood pressure affected over 30% of men and women as of 2008. In a remote area of central India, stroke was found to be the leading cause of death, which was generally preceded by months of disability and need for supportive care (Kalkonde et al. 2015).



Furthermore, India faces rising incidence of cancer (Broom, Doron, and Tovey 2009; Mallath et al. 2014). The WHO's GLOBOCAN Project determined that just over a million new cancer cases were diagnosed in India in 2012, and cases are projected to rise to 1.7 million by 2035 (Mallath et al. 2014, 1). Because measuring disease incidence depends on diagnosis in a medical facility, these numbers underestimate the true cancer burden. The cancer burden is also significant among children. A study based on a national sample of verbal autopsies<sup>2</sup> estimated a pediatric cancer mortality rate of 37 per million, which exceeds prior estimates even of incidence (S. Gupta et al. 2016).<sup>3</sup>

For both adults and children, rates of cancer vary significantly by region, and this may be due to disparities in socioeconomic status, access to trained medical practitioners and diagnostic facilities, and variation in risk exposures (Mallath et al. 2014, 3–4; Pramesh et al. 2014, e224). Additionally, India has a disproportionate number of people affected by head and neck cancers due to oral tobacco use, and of cervical cancer due to lack of access to vaccines and routine gynecologic care (Ministry of Health and Family Welfare 2008). Complications from these cancers can be particularly distressing and challenging to manage as they progress, requiring palliative care (de Souza and Lobo 1994).

Palliative care is most often associated with chronic, non-communicable diseases like cancer. However, people with serious injuries or advanced, chronic infectious diseases like HIV/AIDS often have a high symptom burden and require palliative care (J Stjernswärd 2007; Jain and Phutke 2017). In India, incidence of HIV/AIDS has fallen remarkably since the early 2000s, but as of 2015, an estimated 2.1 million people in India were living with HIV/AIDS.<sup>4</sup>

### *Advanced Disease at Diagnosis*

Another vital argument for palliative care in India is the severity of non-communicable diseases when they manifest. For example, the vast majority of people with cancer in India are diagnosed in advanced stages, and an estimated 68% of people diagnosed with cancer in India die within five years (Mallath et al. 2014). Approximately 85% of people with advanced cancer report experiencing pain, so palliative care is particularly needed in a context of greater advanced illness (Kelley and Morrison 2015). Also, Dr. M.R. Rajagopal has suggested that palliative care in India can play an important role in mitigating physical and financial suffering due to futile medical treatment (2016, 26). With the majority of medical care in India provided in the largely unregulated private sector, patients with advanced illness may receive invasive, costly treatments that ultimately do not benefit them. This issue will be explored more in Section III of this paper.

To better understand the need for palliative care and other improvements in India's health care system, we must examine the root causes of late-stage diagnosis of

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<sup>2</sup> Verbal autopsy is a technique for assessing cause of death that relies on caregiver and family recall rather than vital records.

<sup>3</sup> The rate in the United States is approximately 17 per million, according to the American Cancer Society (cancer.org/cancer/cancer-in-children/key-statistics.html, Accessed August 8, 2017).

<sup>4</sup> <http://naco.gov.in/hiv-facts-figures>, Accessed August 8, 2017.

illness in India. The WHO acknowledges that low-and-middle income countries have the most people suffering from chronic, progressive illnesses, and yet “quite often there is little accessibility to prompt and effective treatment for these diseases” (2002, 91). In India, as in many low-and-middle income countries, lack of preventive care and disease screening within a robust, affordable, accessible primary health care system is a root cause of chronic disease burden (Sepúlveda et al. 2002, 91). Tobacco cessation, hypertension and diabetes management, vaccination and cervical and breast cancer screening are all forms of preventive care that could decrease the burden of chronic serious illness requiring palliative care.

The relationship between preventive, curative and palliative care can be particularly fraught in places with low access and quality of curative care. For example, the WHO has sometimes framed palliative care as a realistic alternative to curative treatment in low-resource settings. Taking advanced illness presentation as a pre-condition, the WHO has stated that “the development of palliative care through effective, low cost approaches is usually the only feasible alternative to respond to the urgent needs of the sick and improve their quality of life” (Sepúlveda et al. 2002, 91). The urgent needs of the sick certainly motivate palliative care practitioners in India and worldwide—and effective, low-cost models of care exist thanks to their efforts (M. Rajagopal, Joranson, and Gilson 2001; Joranson, Rajagopal, and Gilson 2002; Krakauer and Rajagopal 2016; S. Kumar and Rajagopal 1996). However, global health equity leaders such as Dr. Paul Farmer and Dr. Yogesh Jain have cautioned that lack of accessible curative treatment should not be followed by a disproportionate emphasis on either disease prevention or palliation (Farmer 1999; Jain and Phutke 2017). All three must go hand in hand.

Farmer and Jain have argued—and their organizations, Partners in Health and *Jan Swasthya Sahayog* have demonstrated—that the provision of quality, accessible, curative health care services is feasible in low-resource settings (Farmer 1999; JSS Bilaspur 2017). Furthermore, India has innovative ideas and capacity to improve their health system alongside the palliative care that is so needed (Pramesh et al. 2014, e229-31). Based on past and recent writings, I believe that Farmer and Jain would argue for both curative and palliative care as essential to protect the dignity and human rights of people with serious illness (Farmer 2005; Felicia M. Knaul et al. 2015; Jain and Phutke 2017). The intersection between poverty, curative care and palliative care seems to be an ethical and practical challenge likely to emerge in empirical research on palliative care in India.

## **Evidence of Symptom Burden**

We know that pain and other troubling symptoms are common in advanced stages of non-communicable diseases and some chronic infectious diseases (Kelley and Morrison 2015). Evidence on the consequences of persistent pain and symptom burden is growing. For example, international studies on pain have indicated that people with chronic, intractable pain report poor quality of life, and are four times more likely to suffer from depression and anxiety (Gureje et al. 1998; Brennan, Carr, and Cousins 2007). Chronic physical pain may also distort the personalities of people who suffer, thereby disrupting family relationships (Amon and Lohman 2011). Indeed, the problems associated with pain go beyond the suffering patient. Caregivers of patients with

persistent pain have been found to experience sleep deprivation, inability to work and care for children and other family members, and diminished participation in social and community life (Human Rights Watch 2009a, 6). Furthermore, studies of the relationship between overall symptom burden and quality of life have found, unsurprisingly, that lower symptom burden is associated with better quality of life (Desheids et al. 2014; Astrup et al. 2017).

Research documenting the nature and severity of physical symptoms of patients with serious illness has provided vital evidence of the need for palliative care around the world (Saunders 2000; Clark 2007; Kelley and Morrison 2015; Jackson, Widera, and Smith 2017). A number of observational studies conducted by Indian palliative care providers have done just this (S. Kumar and Rajagopal 1996; Muckaden et al. 2005; Santha 2011; Lal et al. 2012; M. Gupta et al. 2016). For example, a report based on observation of over 2,000 patients in an inpatient hospice in Bombay described how head and neck and cervical cancers—both disproportionately prevalent in India—produce especially difficult complications and symptoms to manage<sup>5</sup> (de Souza and Lobo 1994). Another study identified a high prevalence of pain, insomnia and loss of appetite as common problems among new palliative care patients based at a cancer hospital in New Delhi (Lal et al. 2012). The authors note that the prevalence of these symptoms is striking because it means they were not being adequately managed in the existing cancer care system (2012, 295). Making a similar point, a study of cancer patients in an Intensive Care Unit (ICU) in Uttarakhand found that 70% reported moderate-to-severe symptomatic distress on a validated scale (M. Gupta et al. 2016). Such studies are building an important foundation in their respective settings for increased symptom management, which is at the heart of palliative care.

While these studies have focused on patients with cancer, international studies have also shown the burden of symptoms in other advanced, serious illnesses such as AIDS and chronic-obstructive pulmonary disease. The graph below from a review article by Kelley and Morrison depict these symptoms, which include pain in 70% of patients treated for AIDS, 75% treated for congestive heart failure, and 85% of patients treated for cancer (Kelley and Morrison 2015).

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<sup>5</sup> These include lockjaw and dysphagia in head and neck cancers, and bleeding and the formation of painful fistulae leading to persistent incontinence in cervical cancer (de Souza and Lobo 1994).

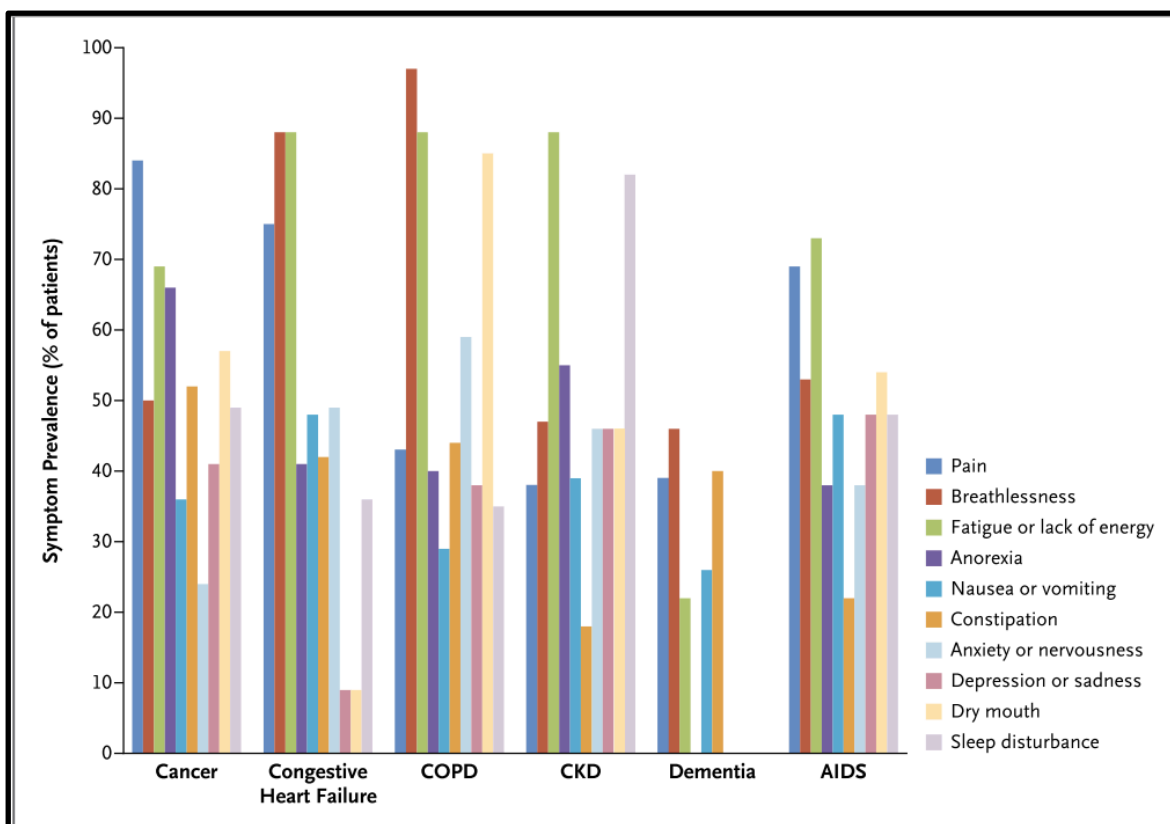


Figure 6: Symptoms experienced by patients with different diagnoses at the end of life (Kelley and Morrison 2015).

Taken together, these studies provide evidence of symptom burden in serious illness, including in Indian health care settings.

### Evidence of Psychosocial Burden of Serious Illness

Studies of palliative care in India also offer insights into the distinctive psychosocial, economic and spiritual problems of patients enduring serious illness in India. The holistic aims of palliative care make these domains especially important to understand. Evidence of distress in these areas is a call for palliative care.

#### *Psychosocial Distress*

Empirical studies of psychosocial problems of seriously ill people in India have provided some localized insights. Elsner et al. conducted in-depth interviews with 37 terminally ill patients receiving home care in Kerala, and found that certain fears were common among patients. These included becoming bedridden, becoming a burden on others, being abandoned, and dying (2012). Consistent with fears of abandonment, Muckaden et al. found that abandonment by husbands was a major problem affecting some women in palliative care for incurable cervical cancer in Mumbai (2005). They also found that some psychosocial distress was rooted in physical symptoms. For example,

symptoms of incontinence and sexual difficulty in women with cervical cancer led to feelings of “embarrassment” and “helplessness” for many patients (2005).

Indicating serious challenges to quality of life, both Elsner et al. and Muckaden et al. identified the wish to die or to commit suicide as psychosocial problems. Elsner et al. spoke to multiple patients who had attempted suicide or currently wished to die. Some of the stated reasons were being a burden on their family, and feeling helpless or useless. In comparison, a survey of geriatric cancer patients in Lucknow, India, found that 18 of 20 patients (90%) would like to undergo a procedure to prolong their life for 2 months, even if no cure is possible. They note that those patients who did express “despair or desire to die early [were] in pain or depressed” (V. Gupta et al. 2007, 76). The seriousness of this psychosocial distress is further corroborated by a recent study, which found that one in five suicides in India was related to chronic illness, including cancer, AIDS and paralysis (M. R. Rajagopal 2016, 26). Taken together, these findings show the scope for palliative care and the urgent need for total care of patients.

### *Roles and Responsibilities*

Multiple studies of Indian palliative care patients’ fears have identified a major fear of the effect a parent’s illness and death will have on their children’s future (Muckaden et al. 2005; Elsner et al. 2012; Gielen, Bhatnagar, and Chaturvedi 2017). Respondents in Kerala particularly worried about the education of their children and the marriage of their daughters—the completion of these being major life tasks of a parent (2012). At the hospice in Mumbai, women with cervical cancer feared for the safety of their children and grandchildren (2005). Muckaden et al. describe one case of a woman caring for her grandchildren who declined admission to hospice until the team promised to protect and rehabilitate them (2005). In both studies, fears about children’s future were intimately linked with financial concerns, debt and poverty. In fact, Elsner et al. found that financial concerns were woven through all the domains of psychosocial suffering among patients they interviewed (2012, 1189).

### *Economic Distress*

Elsner et al. and Muckaden et al.’s qualitative findings that poverty and financial stress are important problems for people with serious illness in India has been supported by multiple other quantitative and mixed-method studies. In 1996, Kumar and Rajagopal found that the majority (54%) of their palliative care patients in northern Kerala were not able to afford basic analgesic medicines on the market, and that paying for prolonged hospital care was a hardship or out of reach for 89% (1996, 294). A more recent study found palliative care patients and caregivers reported decreased ability to work and earn, and increased sale of assets or money borrowing (Emanuel et al. 2010). About one third of Emanuel’s respondents even reported “feeling pressure to take a job hazardous to their health or resorting to illegal activity” in order to address financial insecurity (2010). In a survey of older cancer patients in Lucknow, India, the vast majority of patients expressed equivalent fear of financial problems and of physical pain (V. Gupta et al. 2007).

Transportation over long distances was also found to be financially challenging for patients and families, but often necessary to reach medical care in urban centers (S.

Kumar and Rajagopal 1996). This continues to be the case in India, where nearly 70% of the population lives in rural areas, but urban centers are home to most medical facilities and trained personnel (Census of India 2011).

Based on these studies, financial distress is a clear cause of suffering for many palliative care patients in India. Outside of India, a study of financial strain in cancer found that patients with limited financial reserves had significantly worse pain, symptom burden and quality of life than those with a year or more of financial cushion (Lathan et al. 2017). Taken together, these findings evidence the need for palliative care to attend to financial suffering as a part of total pain. From the models of palliative care described in section one, it is clear that many existing palliative care programs in India seek to address this problem. A study of the barriers and strengths of palliative care in India, as I am proposing, could further illuminate the intersection of poverty and palliative care.

### **Spiritual Distress**

Another domain of psychosocial suffering that palliative care aims to address is spiritual distress. A recent study of 300 patients attending a cancer pain clinic in Delhi found that 83% of patients reported persistent thoughts about why their illness happened to them (Gielen, Bhatnagar, and Chaturvedi 2017). They also found a strong prevalence of “existential explanations of suffering that directly or indirectly put the blame for the illness on the patient.” These included the belief in 75% of patients that the illness was related to *karma*, the concept that one’s prior actions come to fruition in later suffering or wellbeing.

While this and the Elsner et al. study both found a burden of spiritual distress, they also learned that religion and spirituality were important coping mechanisms and sources of strength for a large majority of patients (Gielen, Bhatnagar, and Chaturvedi 2017; Elsner et al. 2012). Prevalent sources of coping reported in both studies included “a belief in God or a higher power who somehow supports them,” and experiencing peace while connecting with God through “prayer, chanting or *puja*” (2017). However, Elsner et al. found that God could have varying roles—even multiple roles—in patients’ minds, from causer or tormentor to savior or protector from illness (2012, 1187). While spiritual needs and resources are likely to vary between individuals and places in a country as diverse as India, the presence of similar findings across multiple studies from different regions is notable.

Looking farther afield, a qualitative study of end-of-life preferences of older South Asians living in East London found that the physical place of dying mattered less to participants than the ability to perform cultural and religious practices at the end of life (Venkatasalu, Seymour, and Arthur 2014). Most participants described religious rituals at the time of death as very important to them, including prayer, taking water by mouth, or facing Mecca. The participants (n=55) came from a variety of South Asian countries and had emigrated abroad, limiting the generalizability of the findings to patients in India. However, the participants came from diverse religious backgrounds (12 Muslim, 3 Sikh, 12 Hindu, 5 Christian, 1 mixed and 1 non-religious), which gives strength to the finding of common themes.

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<sup>6</sup> *Puja* is a form of Hindu worship of God, involving prayer and other rituals.

These studies together provide evidence of spiritual suffering, but also openness to drawing strength from religious beliefs and practices. It seems that there is a broad scope for religious care within palliative care in India, and that my case studies may find themes in this area. In addition to these important psychosocial issues, access to a key tool for physical pain relief is in short supply in India.

### Lack of Morphine Accessibility

Lack of access to morphine is a serious impediment to palliative care (M. Rajagopal, Joranson, and Gilson 2001). Morphine is considered an essential medicine by the World Health Organization, and is indispensable for the treatment of severe pain and for comfort care at the end of life (WHO Access to Controlled Medications Programme 2011; Longo, Blinderman, and Billings 2015). Furthermore, the 185 countries that are party to the United Nations Single Convention on Narcotic Drugs are required to make strong opioids available for medical and scientific use in their countries (United Nations Conference for the Adoption of a Single Convention on Narcotic Drugs 1972).

Despite these norms, 74% of people dying with pain from cancer and AIDS are located in low-and-middle income countries, yet these countries consumed only 7% of medical opioids in 2013 (American Cancer Society 2016). India alone is estimated to account for 23.8% of untreated deaths in pain globally (2016), and their per capita consumption of medical morphine is extremely low, as shown below.

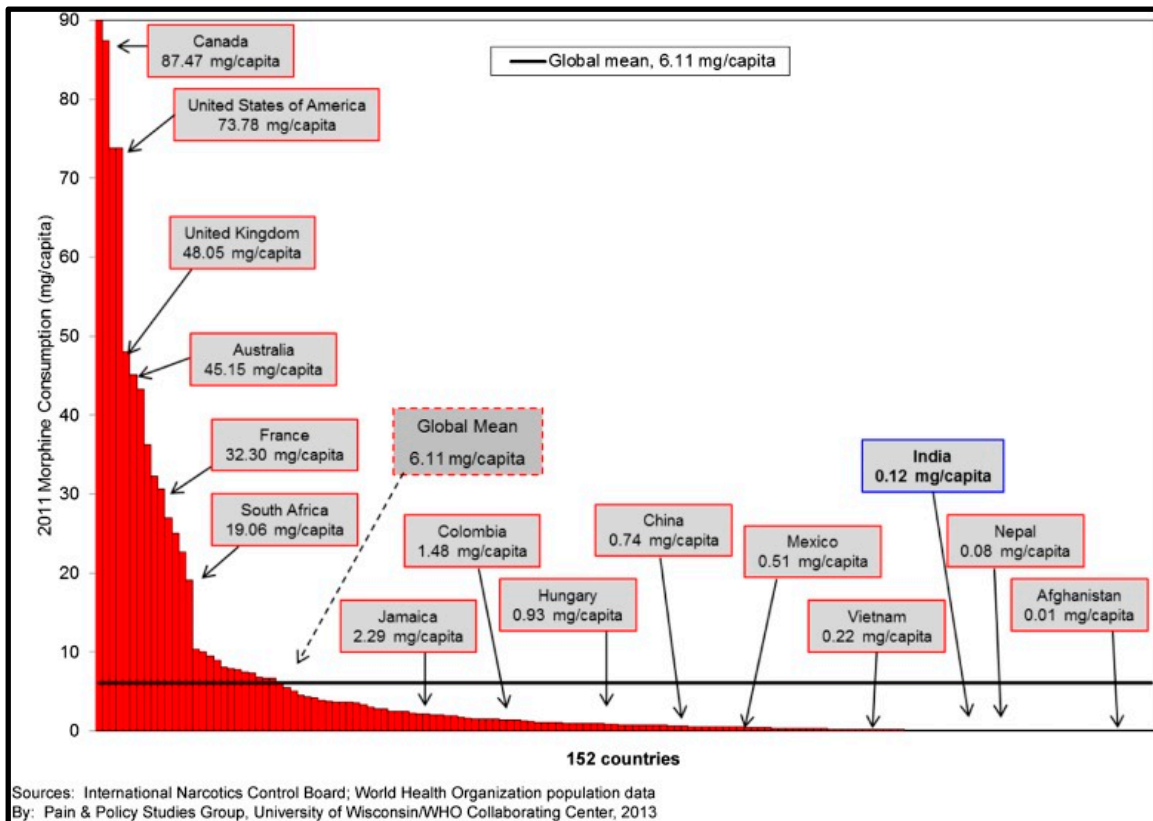


Figure 7: Global Comparison of Medical Morphine Consumption (mg/capita), using 2011 data from the International Narcotics Control Board (LeBaron et al. 2014).

In India, a drug law enacted in the 1980s introduced complex licensing procedures for strong opioids that essentially removed them from medical use (Joranson, Rajagopal, and Gilson 2002; The Lawyers Collective 2014). While morphine continued to be produced in India for export, Indian physicians could not provide it to their own patients for pain relief. A generation of doctors and nurses did not learn to use morphine. These disparities and policy barriers spurred advocacy for opioid access by palliative care providers and civil society in India, which succeeded over time in transforming state rules—and eventually the national law—to simplify licensing procedures (Human Rights Watch 2011; Vallath et al. 2016).

Even in the state of Kerala, where government and civil society support for palliative care is the strongest in India, morphine consumption per capita in 2015 was 1.56 mg, just one quarter of the global average (M. R. Rajagopal, Karim, and Booth 2017, 3). But 1.56 mg is thirteen times higher than India's national average. Pallium India, a palliative care training and advocacy organization based in southern Kerala, is pursuing a mission of facilitating palliative care and access to pain relief throughout India.

The stark inaccessibility of morphine for pain treatment in India and most low- and-middle income countries emphasizes the need for palliative care. Palliative care and human rights advocates have stressed this point, as we will now explore.

### **Rights-based Arguments**

Since the adoption of the Universal Declaration of Human Rights in 1948, human rights have served as a foundation for advocacy for freedoms and entitlements that protect human dignity. These include the domains of public health and health care access (Mann 1996a; Mann 1996b; Farmer 2005). Palliative care advocates in India and globally have found human rights and other rights-based approaches to be essential in their advocacy for palliative care (Lohman and Amon 2015; Vallath et al. 2016). For example, notifications to the Indian government regarding their responsibility to make morphine accessible have gained traction when grounded in human rights treaty obligations (Human Rights Watch 2009b).

Since the 1990s, physicians have been making arguments for a human right to pain treatment and palliative care (Brennan 2007). However, the efforts of Human Rights Watch, and the statements of United Nations Special Rapporteurs<sup>7</sup> on Health and on Torture, have increased the rigor and impact of human rights-based arguments for palliative care and morphine accessibility (Nowak and Grover 2008; Human Rights Watch 2009a; Lohman et al. 2010; Amon and Lohman 2011).

Specifically, Human Rights Watch and the Special Rapporteur for Health have laid out a right to palliative care under the International Covenant on Economic, Social and Cultural Rights (ICESCR)—to which India is a party. Article 12 of the ICESCR affirms that all member states must “recognize the right of everyone to the enjoyment of

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<sup>7</sup> The United Nations defines Special Rapporteurs as “independent experts appointed by the UN Human Rights Council to examine and report back on a country situation or a specific human rights theme” (<https://www.ohchr.org/EN/Issues/Health/Pages/SRRrightHealthIndex.aspx>, Accessed August 15, 2017).



the highest attainable standard of physical and mental health” (ICESCR States Parties 1966). In defining this right, the Covenant explicitly requires that member states create “conditions which would assure to all [people] medical service and medical attention in the event of sickness” (1966). In more direct reference to palliative care, the Committee overseeing implementation of the Covenant interpreted Article 12 to include “attention and care for chronically and terminally ill persons, sparing them avoidable pain and enabling them to die with dignity” (UN Committee on Economic Social and Cultural Rights 2000, 8). Furthermore, the Covenant obliges member states to make drugs on the WHO Essential Medicines List both available and accessible in their health systems (2000). These arguments have underpinned a call for improved access to palliative care services and to morphine, a WHO essential medicine.

Human Rights Watch and the UN Special Rapporteur on Torture have also argued for a right to pain treatment within Article 5 of the Universal Declaration of Human Rights, which prohibits cruel, inhuman and degrading treatment (Amon and Lohman 2011; Nowak and Grover 2008). They argue that governments who are aware of the inaccessibility of pain treatment and fail to remedy it “raise questions as to whether they have adequately discharged this obligation” to protect their people from cruel and degrading treatment (2008).

Indian palliative care physicians and advocates have also developed and used rights-based arguments for palliative care (Bollini, Venkateswaran, and Sureshkumar 2004; M. R. Rajagopal 2016; Shrivastava, Shrivastava, and Ramasamy 2016). As a palliative care team based in Kerala, India wrote in a description of their work from the early 2000s: “Being free from excruciating pain and dying in peace and dignity are basic human rights that should be assured to all people with incurable diseases” (Bollini, Venkateswaran, and Sureshkumar 2004, p.141). Furthermore, many states in India have their own human rights bodies. For example, in Uttarakhand, a member of the state’s Human Rights Commission recently filed a case with the state’s health system leadership questioning why the government has no palliative care policy (Dhaundiya 2016). Human rights arguments may therefore have an important role in advancing palliative care at the state level in India.

Indian palliative care advocates have also supported litigation in local courts and the Supreme Court of India to press the government to amend restrictive drug control laws (Vallath et al. 2016). These efforts have been based in part on the Constitution of India’s statement that all citizens have an “equal right to life” (K. Sujatha Rao 2017, ix). Specifically, various constitutional articles require that the government strive to ensure “assistance in ‘cases of unemployment, old age, sickness and disablement, and in other cases of undeserved want,’” indicating that citizens have a right to aid from the government which directly flows from their health status (2017, ix). These legal efforts in India have culminated in successful policy changes, removing *de jure* barriers to morphine access in many states and at the national level (2016).

## **Narrative and Storytelling**

A review of the evidence for need of palliative care would be incomplete without a mention of patient narratives. Attending to patients’ narratives was a distinctive feature of Cicely Saunders’ work on “total pain,” and remains important today (Saunders 2000).

Indeed, documentation of patient experiences are yet another source of evidence on the need for palliative care in India. For example, in their investigations of pain treatment barriers in India and elsewhere, Human Rights Watch has interviewed patients and included their narratives in public reports (Human Rights Watch 2009b). They quote numerous patients in India, including this man with a painful leg tumor, describing his suffering before he reached palliative care: “my leg would burn like a chili on your tongue. The pain was so severe I felt like dying. I was very scared. I felt that it would be better to die than to have to bear this pain” (2009b). Stories such as this patient’s are also central to a forthcoming documentary on palliative care in India, called “Hippocratic,” which features Dr. M.R. Rajagopal. In these ways, patient stories have an important role in advocacy and awareness raising.

## **Conclusion**

Now that we have developed some understanding of the multi-dimensional suffering affecting people with serious and terminal illness in parts of India, I wish to turn our focus to the medical system. Within the challenges of late-stage diagnoses and financial stress due to health care costs, the health care system in India shows its influence. Therefore, to understand the challenges faced by patients and palliative care programs aiming to support them, a basic understanding of the health care system in India is needed.

### Section 3:

#### Background on the Health System in India

The health care system in India has a vast array of public and private players, with striking regional variation in quality, availability and outcomes. As Mohanan et al. have noted, India is home to premier public medical colleges and innovative, high-quality private systems for advanced eye care and heart surgery (2016). At the same time, many Indians, especially people living in rural areas and in poverty, experience “unacceptably low-quality primary and hospital care” (2016, 1753).

India’s constitution grants the leading role in health care planning, funding and governance to the states. Therefore, state-by-state variation in the social determinants of health, as well as funding and governing capacity, all contribute to these variations in health services and outcomes.

All over the world, patients, families, and palliative care are affected by the dominant medical systems, so having a basic knowledge of India’s health system is essential. To build context for our understanding of palliative care in India, this section will describe India’s health sector and significant health inequities. I will draw on empirical public health research, as well as reflections by health sector leaders such as former health secretary, K. Sujatha Rao. Her recent book explores the evolution, shortfalls and successes of Indian health care since Independence, delivering both a personal and scholarly perspective (2017).

#### A Note on Health Disparities

In India, as in other countries, striking disparities exist in health outcomes and health care utilization amongst the population. Many of these disparities are based on the social determinants of health—poverty, education, water and sanitation, nutrition and social inequity around gender and caste<sup>8</sup> (Balarajan, Selvaraj, and Subramanian 2011, 2).

Caste, gender and wealth are among the chief contributors to socioeconomic status and to health outcomes in India (Balarajan, Selvaraj, and Subramanian 2011). In the domain of gender, for example, death rates from diarrheal disease and pneumonia are twice as high in girls (S. Gupta et al. 2016, 407). Also, the National Sample Survey in 2014 showed that both rural and urban females were less likely than males to be treated in private health facilities (Jana and Basu 2017, 4). These findings indicate that male lives are disproportionately valued, as males receive more curative and costly treatment. Similar disparities in health outcomes and access to care have been noted based on caste and wealth (Balarajan, Selvaraj, and Subramanian 2011).

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<sup>8</sup> Caste is a complex reality in India (Ambedkar 1916). It is an institution of social inequality and inequity in which groups of people within Hindu society are accorded different occupational roles and social standing. It is a persisting source of identity, discrimination and, more recently, affirmative action in India.

Mann has argued that such social disparities are critical to understanding and effectively addressing the health status of populations (Mann 1996a; Mann 1996b). It is likely that each of these disparities touch palliative care in some way, though a PubMed search for “palliative care,” “India,” and “gender” or “caste” in August 2017 showed that existing studies have not focused on these particular disparities.

Furthermore, socioeconomic conditions and health indicators vary markedly between and within Indian states (Patel et al. 2015; K. Sujatha Rao 2017). For example, there is an 18-year gap in average life expectancy between states, from 56 years in Madhya Pradesh to 74 years in Kerala (Balarajan, Selvaraj, and Subramanian 2011, 2).

The central and state governments in India have attempted to guide health policy to mitigate these disparities. Their approaches range from population-based public health interventions for clean water and sanitation; individual preventive care activities such as childhood immunization; and finally, health care services for illness treatment (Hammer, Aiyar, and Samji 2007, 4050). The remainder of this section will focus on the last domain, health care services, as this will prepare us best to understand palliative care’s current and potential role.

## **Systems of Medical Care in India**

Multiple systems of diagnosis and treatment coexist in India (M. Rao et al. 2011, 2). Allopathic medicine (a term for Western medicine) accounts for most health services provided in India, with nearly 90% of the population seeking these services (Patel et al. 2015, 2427). At the same time, multiple systems of Indian medicine have coexisted for centuries.

Systems of medicine in India that were practiced before allopathic medicine and continue to be sought include Ayurveda, Unani, Yoga, Siddha, and Homeopathy, among others. Ayurveda is an ancient Indian system of medicine that aims to restore balance between fundamental bodily elements, called humors or *doshas*. Ayurveda has its own textual tradition and a distinctive set of medicines derived from plants. Unani, a system deriving from Arabic, Persian and Greek influence, was introduced to India in the medieval period and also promotes balance of humors. Yoga is a spiritual and physical practice involving postures and breathing exercises to support health and prevent disease. Siddha is a healing system in Tamil-speaking regions employing certain medicinal substances meant to prolong life. And Homeopathy, which originated in Germany and involves administration of dilutions of disease-inducing substances in order to provoke cure, is practiced widely throughout India (M. Rao et al. 2011, 2). These systems have received public support by the Government of India, which created a Department of Indian Systems of Medicine and Homeopathy in 1995 to study these systems and provide accessible services (M. Rao et al. 2011, 2). There have also been efforts to professionalize health care providers in these fields (2011).

Multiple studies have found that people commonly seek and use both traditional and allopathic remedies for illness (Broom, Doron, and Tovey 2009, 698–99). However, as mentioned previously, 90% of the population in both rural and urban areas seeks some allopathic care (Patel et al. 2015, 2427). Furthermore, Broom et al. found that marginalized groups such as women and the poor may disproportionately use traditional

and home remedies due to lower priority of their care within the household, or to lack of access to allopathic care (2009, 704–5).

## **History of Health Services in India**

Allopathic medicine was introduced to India during the British Colonial period, at a time when its therapeutic efficacy was modest. Its history in India is intertwined with missionary presence and colonial governance, including public health and quarantine measures (Pati and Harrison 2009). During the colonial period, the establishment of public health efforts, allopathic medical education, and health care infrastructure varied significantly across India.

At Independence, the Government of India appointed a committee to study the health status of its people and make recommendations for health system development. The Bhore Committee's report in 1946 laid out an ambitious "vision and plan for providing universal coverage to the population through a government led health service" (1946; Balarajan, Selvaraj, and Subramanian 2011). Since this time, India's health care and other policy has occurred through "Five Year Plans," created by the central policy planning apparatus of the federal government. While the Bhore Committee's and subsequent plans have articulated the need for universal health care, multiple forces have prevented this reality, which we will soon discuss.

In India, state governments, rather than the central government, have the constitutional role of implementing health care services (Vallath et al. 2016, 522). While the central government formulates many policies, the states are constitutionally empowered to implement and run health programs, and to allocate funds as they see fit.<sup>9</sup> The central and state governments jointly fund public sector health care throughout the country, with the states bearing a greater share (National Health Systems Resource Centre (NHSRC) 2016).

Following the Bhore Committee report, states began to create a tiered system of government-run curative health services. Primary health centers and sub-centers at the village level were to refer patients to block-level community hospitals and then to a district-level tertiary care center as needed (Palat and Venkateswaran 2012, 212–13). These tiers were meant to provide integrated preventive and curative services with sufficient coverage in rural areas, where the vast majority of Indians live.

Over time, health care planners have also sought to respond to specific burdensome diseases—from HIV/AIDS, to polio, to cancer. For example, a National Cancer Control Programme was initiated in 1975, and it has designated specific hospitals as regional cancer centers, providing them with boluses of funding (Varghese, n.d.). The policy underlying this program was revised to emphasize screening and prevention, but this continues to be lacking, as evidenced by the presentation of late-stage and preventable cancers.

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<sup>9</sup> Some notes on governance: India has 29 states and 7 union territories (UTs). The states were organized based on linguistic and cultural boundaries, and are further subdivided into districts and blocks. Each state and two of the UTs have their own elected assemblies and governments, while the remaining UTs are governed by the center. In rural areas, elected village councils called Panchayati Raj Institutions (PRIs) provide local governance. PRIs are overseen by the state governments.

The mandate that states control health services delivery has some benefits for India's health care system. For example, this allows states to tailor public health interventions to their needs (S. Kumar 2013; K. Sujatha Rao 2017, 317; Parthasarathi and Sinha 2016). When the central government developed an initiative to strengthen the public health system in 2005,<sup>10</sup> Kerala decided to focus on "issues related to old age and non-communicable diseases, while Bihar, Madhya Pradesh and other backward states focused on building up their broken-down rural health system" (K. Sujatha Rao 2017, 317). Furthermore, state-level innovation and testing of new models for health care may inspire others to adopt them. For example, Tamil Nadu has built a public health system that sets an example for other states to follow (Parthasarathi and Sinha 2016). At the same time, state-level inequalities in resources, governing capacity and commitment to public sector health care lead to vast disparities in quality of health services between states.

### **Causes of Poor Performance in the Government Health Care Sector**

Today, the ideals of a universal health care system are far from being realized in India, as in many parts of the world. Despite the creation of a government-funded system, about 70% of health services in India are currently provided in the private sector, with the wealthy and poor both preferring to seek private care despite high out-of-pocket costs (Jana and Basu 2017). The causes of this situation are varied and essential to explore.

A range of empirical studies, reviews and commentaries lend insight into the causes of poor quality in India's public health system (Hammer, Aiyar, and Samji 2007; Patel et al. 2015; K. Sujatha Rao 2017; Mohanan, Hay, and Mor 2016). The most widely cited cause of poor quality public health care services is underfunding (Jana and Basu 2017; K. Sujatha Rao 2017; Patel et al. 2015).

#### ***Funding of public health care***

India's per capita public health spending is among the lowest in the world (Patel et al. 2015, 2428). Government funding of the health sector rose from under 1% to just above 1% of India's GDP in the 2000s, and has remained near that level (Ministry of Health and Family Welfare 2009). State-wise disparities in resources contribute to this problem, as states provide the majority of public health care spending. The table below shows the share of central and state health expenditure in comparison to other sources, including private entities.

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<sup>10</sup> The National Rural Health Mission (NRHM), which I will discuss later.

	Expenditure (rupees)	Percentage of total
<b>Public funds</b>		
Central government	111 552 195	8.34%
State government	183 444 520	12.21%
Local bodies	12 292 886	0.92%
Total public funds	307 289 601	21.47%
<b>Private funds</b>		
Households	951 538 903	71.13%
Social insurance funds	15 073 973	1.13%
Firms	76 643 295	5.73%
Non-governmental organisations	7 217 434	0.54%
Total private funds	1 050 473 605	78.53%
Overall total expenditure	1 357 763 206	100%

Figure 8: “Health Sector Expenditure by the Public and Private Sectors in India, 2010-11” (Pramesh et al. 2014).

Impoverished states with large populations, such as Uttar Pradesh, Bihar, Madhya Pradesh and Rajasthan face greater limitations in public sector health spending than wealthier states. In addition to financing, governing capacity and commitment to the health sector varies from state to state.

### ***Human Resources***

A recent review of evidence on human resources for health in India found that overall lack of qualified health care providers—as well as disproportionate emphasis on training and employing doctors over other cadres of health workers—has hindered public health care delivery (M. Rao et al. 2011). An absolute lack of qualified nurses, dentists and doctors limits the capacity of the health care system to reach all in need (2011). Furthermore, nurses and allied care workers are more willing to serve in rural areas, but for historical reasons there are fewer nurses than doctors in India (2011). This has contributed to urban-rural health disparities, as many physicians do not wish to work in rural areas after their training (2011).

Recently, a new cadre of community health workers has been successfully introduced at the village level throughout the country under the National Rural Health Mission (NRHM) (2011). Still, empirical studies have found that these workers—called Accredited Social Health Activists (ASHAs)—are overburdened by the range of tasks and vertical programs they must carry out (Scott and Shanker 2010; Mohapatra, Nandakumar, and Dharmaraj 2017).

## ***Influence of Interests Opposing Government-led Health Services***

Former central government health official K. Sujatha Rao has argued that influence of international donor agencies such as the World Bank on health policy agendas has contributed to the incomplete realization of a robust public health care system (K. Sujatha Rao 2017). She notes that donor agencies, despite relatively low contributions to overall spending, exercise “enormous influence on setting the agenda and shaping policy” in India (2017, 116). Rao and others have noted that these donors have particularly promoted vertical disease eradication agendas and policies favoring privatization of the health sector (2017, 116; The World Bank Group 2016). Rao argues that these agendas have undermined efforts to put primary health care and the social determinants of health first.

## ***Governance***

At the same time, governance and management problems within the public health sector have hindered performance. For example, health systems researchers have identified corruption as a significant obstacle to quality public health services in India (Hammer, Aiyar, and Samji 2007). They cite a stratified random sample survey of over 5000 people in rural and urban India, which found that respondents perceived health care as the most corrupt public sector, beyond police, education and others (Thampi 2002). The most recent, tragic example of mismanagement comes from Gorakhpur, Uttar Pradesh, where at least 30 children died at the government medical college due to an oxygen stock-out when the hospital administrators did not pay overdue bills (Jadid 2017). Additionally, absenteeism is common among public health sector staff, particularly at the primary health center level (Hammer, Aiyar, and Samji 2007; K. Sujatha Rao 2017).

Overall, the low quality of many public health services has driven demand for private care (M. Rao et al. 2011; Balarajan, Selvaraj, and Subramanian 2011; Pramesh et al. 2014, e224; K. Sujatha Rao 2017, xvii). The central government has sought to improve public health services in recent years, particularly through a program that has also played a role in palliative care provision: the National Health Mission.

## **The National Health Mission: An Effort to Strengthen Public Health Care**

To address some of the root causes of poor public health care services, the Government of India in the 2000s formulated a program to support health system strengthening. The program was initially called the “National Rural Health Mission,” and focused on improving rural health infrastructure, as well as integrating leadership for multiple, vertical disease control programs. In 2014, the National Urban Health Mission was also initiated, and these programs are collectively known as the National Health Mission (NHM).

Under the NHM, each state must develop implementation plans for their public health sector, which the central government then partially funds. A number of disease-specific vertical schemes now come under the NHM’s purview, including a National Programme for Prevention and Control of Non-Communicable Disease (National Rural Health Mission 2010). States may also seek funding for palliative care initiatives within



their NRHM proposals. This requires proactivity by the state, and Kerala has done this (S. Kumar 2013, 220–21; M. R. Rajagopal 2015a).

The question of whether the NHM is fulfilling its missions has been explored in a number of studies (Dhingra, Dutta, and Hota 2005; Working Group 2011; Jana and Basu 2017). There is some evidence of increased use of public sector health facilities following National Rural Health Mission implementation in 2005 (Jana and Basu 2017). Nevertheless, “private facilities continue to dominate” among health care service providers in India (2017, 7).

### **Growth of Private Sector**

The private, for-profit sector now provides a large majority of medical care in India. Some reasons for the sector’s growth include the attraction of human resources, who experience higher salaries and better working conditions (M. Rao et al. 2011). Furthermore, private health care is in demand for the perceived higher quality of services (Das and Hammer 2007, 3). There is some evidence to back this perception. For example, a robust empirical study based on unannounced visits with 305 medical practitioners in rural and urban India found that practitioners in private clinics adhered to current clinical guidelines more frequently than those in public clinics (Das et al. 2012). However, quality in both sectors was found to be low, with frequent prescribing of unnecessary medicines, particularly in the private sector.

While demand for private health care services is high, patients and families face the risk of impoverishment and even mistreatment in the private system. These risks are understood by health economists as “market failures” (Bhat 1996; Hammer, Aiyar, and Samji 2007; K. Sujatha Rao 2017). A market failure is a specific way in which a private market fails to protect consumers because of an inherent misalignment of interests. These are characteristic of private health care generally, while having specific manifestations in India that affect all patients, including those with serious illnesses and at the end of life.

#### ***Market Failure 1: The Burden of Out-of-Pocket Costs***

The rise of private, for-profit health care in India has exposed the public to risk of financial hardship from health expenditure (Krishna 2004; Hammer, Aiyar, and Samji 2007; Selvaraj and Karan 2009). Entry into the clinics and wards of the private system is based on ability to pay. This places a high burden on the poor, who have increasingly reported an inability to afford health care (Balarajan, Selvaraj, and Subramanian 2011, 6). Furthermore, costs in the private sector have grown at a rate 100% faster than the public sector, and overall costs are higher for care of chronic, non-communicable diseases than infectious diseases (2011, 7).

As with all market failures, government intervention can mitigate them. Indeed, K. Sujatha Rao links the government’s behavior directly to financial risk in the private sector: “Low public spending [on health]”, she writes, “means that the burden of financing is borne by individual households, resulting in their impoverishment and a denial of care on the grounds of affordability” (2017, xiii). The central government and some state governments have taken measures to mitigate out-of-pocket costs. These include instituting insurance schemes, some of which are supported by the World Bank

(The World Bank Group 2016). As of 2010, government insurance schemes covered about 20% of India's population, including many low-income and informally employed people (La Forgia and Nagpal 2012). However, low coverage caps and a focus on tertiary care at the exclusion of outpatient care and drugs have limited financial protection from these schemes (2012). Some public health advocates have argued that these schemes effectively transfer limited government funds to the largely unregulated private, tertiary care sector at the expense of public and primary care (K. Sujatha Rao 2017, 92–93). Still, health services researchers have argued that health insurance could be an important tool for mitigating financial strain (Hammer, p. 4051). With limited insurance and acceptable government health care options, households in India bore 71% of health care costs in 2010-2011 (Pramesh et al. 2014). Lack of insurance also limits funding options for palliative care programs (Khosla, Patel, and Sharma 2012, 154).

### ***Market Failure 2: Information Asymmetry***

The next important drawback or “market failure” of the private, for-profit system is asymmetry of knowledge between the patient and health care provider (Hammer, Aiyar, and Samji 2007; K. Sujatha Rao 2017). As Rao writes: “asymmetrical information endows providers with power and authority over the patients who have incomplete information about what ails them” (2017). This means that patients have little ability to gauge the correctness of the care they are provided. In an environment where the government is not monitoring quality, Rao continues, “providers often take advantage of such moments of vulnerability by ordering a battery of tests, unnecessary surgeries, or prescribing high-cost medicines” (2017). These findings have been confirmed by empirical studies of health care quality based on standardized patients in Delhi and other regions of India (Das and Hammer 2007; Das et al. 2012). Additionally, private practitioners have been found to prescribe more drugs than public ones, suggesting the possibility of irrational prescribing (M. Rao et al. 2011, 8). Improper practices can inflate the cost of health care and may endanger patients.

Furthermore, many providers of private medical care are not formally trained and licensed, particularly in rural areas (R. Kumar et al. 2007; M. Rao et al. 2011). For example, a review of evidence on delivery of cancer care in India noted that nearly 92% of rural patients with cancer “first present... to private practitioners, most of whom (79%) were not qualified in allopathic medicine” (Pramesh et al. 2014, e225). Patients may not be aware that a provider is unqualified due to information asymmetry, and then experience delay or denial of appropriate diagnosis and treatment. While the government has passed some laws to regulate the private health care sector, these have not been thoroughly implemented (Bhat 1996; K. Sujatha Rao 2017).

### ***A Note on Public Health***

Finally, another limitation of the private sector is that interests within the sector may not be most aligned with public health goals (Reddy 2015). For example, in a context of rising chronic, non-communicable illness, the for-profit health care sector has a motivation to provide more costly care (eg. advanced procedures and medicines), rather than cheaper and much needed prevention and screening.

## **Palliative Care and the Private Sector**

The rise of the private sector in Indian health care has some salient links to palliative care. First, many people who need palliative care have undergone or are pursuing treatments at costly private hospitals, putting them and their families at risk of catastrophic financial loss (Hammer, p. 4051). Because this loss may be among the most significant causes of suffering and poor quality of life for their patients, palliative care providers in India must grapple with how to address this in their activities (S. Kumar and Rajagopal 1996; S. Kumar 2013). Also, with the bulk of medical interactions in India occurring in the private sector, private hospitals and clinics appear to be important sites for advancing palliative care. At the same time, focusing palliative care initiatives in private sector facilities will have the same pitfalls of inequity and inaccessibility.

## **Cross-Cutting Issues in Health Care Quality and Accessibility**

Some key limitations within the private sector are also present in the public sector due to common root causes. These include limitations produced by human resources and geography. As we will see, these issues also affect palliative care, so an overview is warranted.

### ***Human Resources***

The size and quality of the trained health care workforce is another core quality issue India's health system faces (M. Rao et al. 2011). The bar chart on the following page (Figure 9) depicts the number of health workers per 10,000 people in India in 2005. The chart identifies two issues I mentioned earlier: first, the public sector has disproportionately focused on physician education, reflected in the physician-heavy distribution of health care professionals (2011, 5). Also, unqualified medical practitioners are more common than qualified ones (2011, 5). Furthermore, the availability of trained human resources for health varies greatly between states. The map below (Figure 10) depicts the disparities in concentration of medical graduates by state.

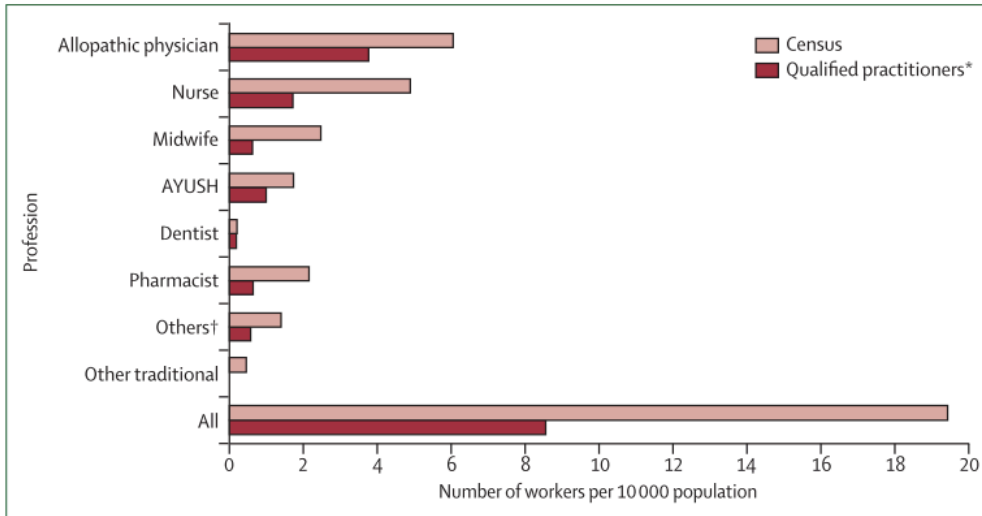


Figure 9: “Number of Health Workers per 10,000 population in India in 2005” (M. Rao et al. 2011, 5). “AYUSH” = ayurveda, yoga and naturopathy, unani, siddha and homeopathy. “Others” include dietician, nutritionist, optician, dental assistant, physiotherapist, etc.

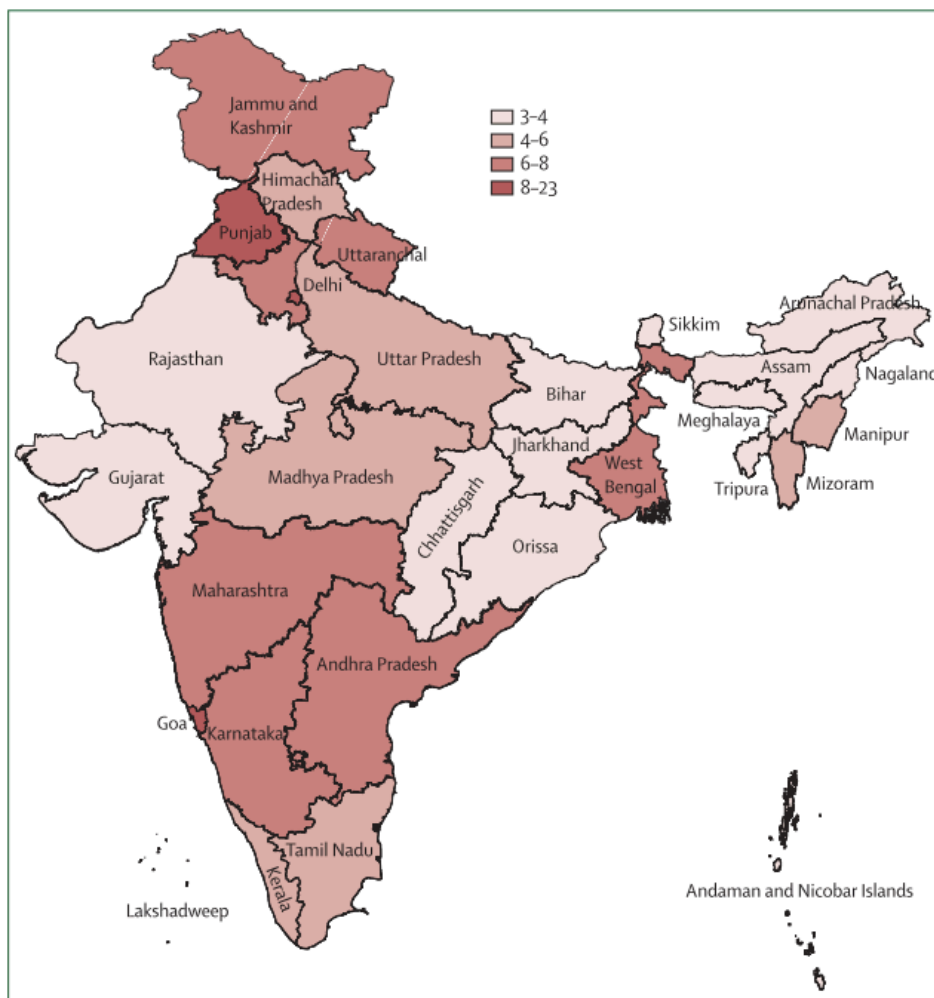


Figure 10: “Number of Doctors per 10,000 population in India in 2005” (Rao et al. 2011).

Lack of trained human resources for health care places family members in a pivotal role of delivering care. Both at home and in hospitals, families commonly provide food, obtain medicines and attend to nursing tasks like maintaining the patient's hygiene and caring for wounds. This central role for family has also been reported in hospice and palliative care settings (de Souza and Lobo 1994; Chellappan et al. 2013)

### ***Geography***

Another crosscutting challenge manifest in both the public and private sectors is geography. About 70% of Indians live in rural areas. However, rural India has approximately four times fewer qualified medical personnel—from nurses and doctors, to laboratory technicians and pharmacists—than urban India (M. Rao et al. 2011, 4). Vacancies in the public health system go unfilled much more often in rural areas, and more rural private practitioners are untrained (M. Rao et al. 2011). This greatly impacts access to quality health care.

### **Health Care Improvement**

Certain ideas for improving health care in India have been popular at the central level. These chiefly include decentralization of policy planning, promotion of community participation, and partnership with the private sector to increase access to services<sup>11</sup> (Balarajan, Selvaraj, and Subramanian 2011, 2). The former strategies have been formulated through engagement with public health advocates, and the latter with leaders in private sector health care (K. Sujatha Rao 2017). These ideas are present in the 1983 National Health Policy and the 2005 National Rural Health Mission, which is being implemented to this day.

### ***Decentralization***

Decentralization of resources and decision-making power for health was a core value of the NHM. However, Rao notes that most states continue to conduct central planning of health delivery, and have been reluctant to give control to districts and blocks (K. Sujatha Rao 2017, 310). A few states have gone on to promote decentralized planning of health services, including the states of Kerala (Elamon, Franke, and Ekbal 2004) and Tamil Nadu (Parthasarathi and Sinha 2016). Interestingly, the World Bank has recently contributed to capacity building for decentralized health services efforts, including in Kerala (The World Bank Group 2016). This is relevant to palliative care, which is run in a decentralized manner in Kerala (S. Kumar 2013).

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<sup>11</sup> A range of other approaches to health care improvement has been proposed. These include training informal practitioners to provide evidence-based care (which has been attempted in West Bengal and some other states with mixed results), and strengthening monitoring of quality in the public and private sectors through computerization of medical records and formalization of patient grievance and feedback mechanisms. (M. Rao et al. 2011; K. Sujatha Rao 2017).

## ***Public-Private Partnership (PPP)***

Some health policy planners have supported public-private partnership as a way to unburden the public system from directly providing services. PPP may include insurance schemes or contracting for care. Public health scholars and advocates have critiqued PPP for transferring public funds to private businesses without adequate regulation and quality oversight (K. Sujatha Rao 2017). However, Rao presents a nuanced view of public-private partnership, warning that advocates of government-led health services should not throw the baby out with the bathwater (2017). She refers particularly to the promise of partnership with private not-for-profit health care providers in India. These organizations often serve marginalized and remote populations in innovative ways, though they are a very small part of overall medical service provision in India (National Health Systems Resource Centre (NHSRC) 2016).

PPP is relevant to palliative care, because almost all palliative care efforts in India operate in the private not-for-profit sector (McDermott et al. 2008). In fact, Kerala may be an important case study of the potential for PPP in palliative care. Though community-run, private non-profit organizations initiated palliative care, local and state governments now “play a major role in running palliative care services” in the state (S. Kumar 2013, 218). This potential for PPP matters, for as Kumar has noted, palliative care programs ultimately need some manner of collaboration with government to ensure coverage and longevity (2013).

## **New Cadres of Health Care Providers, and Competency-based Education**

A couple of last proposals for improvement that I want to mention include the creation of new categories of health care providers, and the training of existing providers to provide evidence-based care. Initiatives to create new rural primary care providers and public health administrators with a shorter period of training have helped fill extensive public health care vacancies in Assam, Chattisgarh and West Bengal, for example (M. Rao et al. 2011). Additionally, training of informal providers has shown promise, and incorporation of key competencies into medical and nursing training can better align workforce capacity with population health needs.

I mention these approaches because they are relevant to palliative care, as well. As we are about to learn, palliative care has a number of strengths and weaknesses in India, and efforts such as those above—the creation of brief training programs for palliative care capacity-building; and attempts to incorporate palliative care competency into medical and nursing education—have been used to advance palliative care.

## **Conclusion**

Now that we have some context regarding the health care system in India, we are ready to focus in on palliative care.

## Section 4:

### **Strengths, Weaknesses, Barriers and Opportunities facing Palliative Care in India**

We have already explored palliative care's definition, as well as India's models, debates, and need for palliative care. Next, we developed some understanding of the health care system in India, and some of its key challenges that affect palliative care. All of this background provides the perspective we will need to assess the small but valuable literature that has evaluated palliative care in India for its strengths and weaknesses, as well as those studies and essays that reveal barriers to palliative care and potential opportunities for it to grow. Building on the rest of the literature review, this section will help to identify gaps in understanding and directions for my research.

I have chosen the domains of strengths, weaknesses, barriers and opportunities to align with a common framework for strategic planning in health, called SWOT (strengths, weaknesses, opportunities and threats) analysis (Daemmrigh 2016). I have changed the name of the "threat" domain to better mirror the language used in articles. Understanding these domains can help clarify the paths towards improvement of health services and organizations.

### **What can both empirical studies and commentaries tell us about the strengths and weaknesses of palliative care in India?**

According to a recent systematic review, few studies of palliative care outcomes in India exist in the peer-reviewed literature (Singh and Harding 2015). As of February 2014, four studies had reported outcomes from palliative care program evaluations. These studies, as I described in Section I, focused on a single intervention at a single site. They give promising but localized evidence of pain treatment and palliative care effectiveness in India. Rarely, studies have collected data over multiple programs or regions, helping discern a picture of larger trends in Indian palliative care (M. Rajagopal et al. 2014; M. R. Rajagopal, Karim, and Booth 2017).

At the same time, authors of numerous reflective essays and review articles describe strengths and weaknesses of palliative care in India. These narrative sources are worth exploring, as their claims suggest themes that may arise in my qualitative study.

### **Strengths**

Some clear strengths of palliative care emerge from examining both empirical literature and commentaries by leaders and friends of palliative care in India over time. These include 1) a simplified national drug law, 2) the presence of an "alliance" of effective advocates for palliative care in India, 3) the existence of innovative models for palliative care, and 4) efforts to improve palliative care.

#### ***A simplified national drug law***

Drug availability is a pillar of the WHO's public health framework for palliative care, and the amendment of a national drug control law in 2014 was welcomed as a major victory for palliative care in India (Pallium India 2014; Human Rights Watch 2014). Until 2014, the law governing opioid stocking and distribution in India was the Narcotic Drugs and Psychotropic Substances (NDPS) Act of 1985.

This Act set the standard that opioids were to be regulated by both the Department of Health and the Department of Revenue—an approach that had its roots in the British colonial period when opium was a cash crop (Joranson, Rajagopal, and Gilson 2002). The NDPS Act instated a mandatory minimum sentence of 10 years imprisonment for violations involving narcotic drugs (Human Rights Watch 2009b).

At the same time, complicated licensing rules varied from state to state. Clinics that wanted to order morphine had to obtain separate licenses from the state-level departments of Health and Excise<sup>12</sup> for morphine possession, storage, and transport, as well as for import and export if traveling across state lines (Joranson, Rajagopal, and Gilson 2002, p. 154-5). This complexity made incidental violations more likely to happen. Furthermore, state-level rules increased the amount of work for advocates, because they required distinct efforts in each state (Joranson, Rajagopal, and Gilson 2002).

Even for the most persistent organizations, the NDPS and state-level regulations essentially blocked the use of morphine throughout India—consumption dropped by 97% in the years following the Act (The Lawyers Collective, 2014). Due to low and unpredictable demand, the single manufacturer of morphine powder in the country—the Opium and Alkaloid Factory—repeatedly ran out of stock to sell during the 1990s (M. Rajagopal, Joranson, and Gilson 2001, p. 143). Through persistent advocacy (which I will describe as the next strength of palliative care in India), palliative care providers and their allies focused on amending the NDPS Act.

Eventually, in 2014, the amended act passed Parliament, creating a simplified, uniform rule for the country and taking back regulatory power from the states. As long as clinics, hospitals or medical non-profits maintained their official status as registered medical institutions (RMI), they could engage in “possession, transport, purchase, sale, distribution” of opioids for legitimate medical purposes (The Lawyers Collective, 2014). This victory occurred through the effort of many groups working together.

### ***Advocacy and Coalition Building***

Since the late 1980s in India, pioneering Indian palliative care physicians and their allies have formed a transnational network aiming to advance pain relief and palliative care in India (Lohman and Amon 2015; M. R. Rajagopal 2015a; Vallath et al. 2016). The presence of this effective team of advocates appears to be a true strength of palliative care efforts in India. Thankfully, a recent article in the *Journal of Pain and Symptom Management*, co-authored by many of these advocates, describes how they collaborated to achieve Amendment of the NDPS Act in particular (2016). The article presents their work as a model for global advocacy to re-orient drug control laws towards humanitarian rather than punitive ends (2016, 530). Vallath et al. characterize their group of health professionals, lawyers, policy analysts, media, government officials, human rights advocates and laypeople as an “informal civil society movement” and an “Alliance” (2016).

### ***The Work of the Alliance***

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<sup>12</sup> The name for revenue departments at the state level.



From the beginning, palliative care in India has developed through the collaborative efforts of Indian and foreign believers in palliative care. From early on, for example, the WHO sent experts such as Dr. Twycross and Nurse Gilly Burn to teach about palliative care and support nascent programs in India (Burn 1990; J. Stjernswärd, Colleau, and Ventafridda 1996).

Early practitioners of palliative care in India witnessed the suffering of patients during morphine stock-outs, and decided this was unacceptable (M. Rajagopal, Joranson, and Gilson 2001; Joranson, Rajagopal, and Gilson 2002). The first hurdle they overcame, Vallath et al. note, was “recognizing the multilayered complexities of the prior policy framework and understanding their adverse impact on field practices to chart an appropriate and viable path for reform” (Vallath et al. 2016, 518).

In this effort, palliative care providers in India received support from policy experts at Pain and Policy Studies Group (PPSG) at University of Wisconsin, another WHO Collaborating Center. The PPSG helped analyze India’s national and state-level drug policies to understand the barriers described above (Joranson, Rajagopal, and Gilson 2002; M. R. Rajagopal and Joranson 2007). Vallath et al. describe this as a critical early partnership (2016). Together, PPSG and Kerala palliative care leaders not only built a critical understanding of legal barriers to pain relief in India, they also formed early transnational relationships that helped fuel effective advocacy and policy change for many years (Vallath et al. 2016).

This coalition of domestic and foreign physicians and policy analysts reached out to national and state officials, holding workshops on the need for opioids in palliative care and the striking lack of access in India (Joranson, Rajagopal, and Gilson 2002). This led to fourteen states simplifying rules by 2012 (Palat and Venkateswaran 2012, 215).

At the same time, a collaborative and diverse civil society within India—made up of doctors, lawyers and more—was emerging. Vallath et al. note that the existence of the Indian Association of Palliative Care (IAPC) helped in this regard. Both national conferences and the IAPC’s peer-reviewed journal provided a “platform for regular discussions on opioid availability, touching on the legal, policy, medical and human angles” (Vallath et al. 2016, 521). Unsatisfied with progress at the state level, this alliance lobbied for simplification of the NDPS Act (Vallath et al. 2016). Palliative care activists lobbied various committees of Parliament, the Department of Revenue, and the governing political party at the time (The Lawyers Collective 2014).

Eventually, the Indian alliance introduced public interest litigation at the Supreme Court of India. Petitioners in the case included a cancer survivor, a family member of a cancer patient, and the Indian Association of Palliative Care (IAPC). The case framed opioid access as a human right, and drew upon the right to life and dignity guaranteed by the constitution of India (M. R. Rajagopal 2015b, p. 59). The court subsequently sent questions to the Ministry of Health and Family Welfare, which drew officials into meetings on pain relief and palliative care (M. R. Rajagopal 2015b, p. 59). Additionally, in the late 2000s, Human Rights Watch joined this push for opioid medication, strengthening the alliance’s case (Human Rights Watch 2009b).

This collective advocacy led to the amendment of the NDPS Act in 2014. The amendment simplified the licensing procedures in alignment with policy recommendations by the alliance. Furthermore, transnational advocacy led three states to adopt policies for palliative care (Government of Kerala 2008). However, some of these policies remain unfunded and unimplemented, with Kerala as the exception. Taken together, these activities and policy victories evidence the strength of political engagement and advocacy among palliative care providers in India and their allies.

### *The Dynamics of the Alliance*

While Vallath et al.'s article is a rich portrayal of the alliance's strategies and accomplishments, it does not explicate the dynamics and consensus-building methods that helped this collaboration succeed. Observations such as Nurse Gilly Burn's can give a small window into the possible strengths in leadership. She describes briefly Dr. Rajagopal, one of the founders of Kerala's palliative care efforts: "With his excellent team-building skills, he formed a truly multi-disciplinary team, including untrained volunteers and medical students" (2001, 160). Still, a deeper understanding of the dynamics and leadership approaches that helped advocacy efforts succeed could be valuable for advancing palliative care throughout India and globally.

### *Advocacy Continues*

Advocates acknowledge that much more progress is needed to ensure access to palliative care for all who need it in India (Vallath et al. 2016). Thankfully, advocacy appears to remain a strength. Vallath et al. note, "the alliance continues to be an informal network of members connected together through the common purpose of improving access to opioid pain medications for the needy" (2016, 521). Additionally, Pallium India, a Kerala-based organization founded in 2003, is providing mentorship and funding to fledgling palliative care programs throughout the country. Pallium aims to support local palliative care pioneers in sparking advocacy in their own states. And there is evidence of activism in states beyond Kerala. For example, Dr. Mayank Gupta of Uttarakhand notified the Indian Journal of Palliative Care (IJPC) about a June 2016 advocacy workshop with key state health officials to promote morphine accessibility and a state palliative care policy (M. Gupta 2016).

### **Existence of Innovative Models of Palliative Care in India**

According to a recent review article synthesizing literature on palliative care outcomes in India, the majority of published articles focus on describing novel models of care (Singh and Harding 2015). This reflects a strength of palliative care in India: the emergence of diverse, innovative efforts for palliative care provision. Some of these models, such as the Kerala model of palliative care and training, have even become the basis for WHO materials on palliative care (World Health Organization 2016b).

These models show some evidence of meeting core needs of patients and their families. For example, Kumar described how financial relief and support of children are built into the Kerala model (2013). Furthermore, these models often incorporate education, because of the need for more qualified providers of palliative care. For example, awareness trainings for the public—which progress in a step-wise manner if people wish to become trained volunteers—are central to the Kerala model (Kumar 2013). Furthermore, inter-professional courses for physicians, nurses, and social workers are now present in India at multiple centers throughout India.<sup>13</sup> These clinical and educational efforts reflect the vibrancy and strength of existing models. However, all states do not share this strength.

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<sup>13</sup> <http://palliumindia.org/courses/>, Accessed August 15, 2017.

## **Efforts to improve palliative care quality**

There is evidence in the literature of recent efforts to measure and improve the quality of palliative care programs in India. In 2006, a working group of members from across the country was organized by Pallium India to develop a tool for assessing “minimum standards for palliative care” in India (M. Rajagopal et al. 2014). This working group of doctors, nurses and “non-professional palliative care activists” developed consensus on “essential” and “desirable” components of palliative care. These components lie in multiple domains, including structure and process of care, training of personnel, drug availability, and inclusion of all domains of palliative care: physical, psychosocial and spiritual. This audit tool is available for free download online, meaning that any palliative care program in the country can audit and compare their program to a consensus standard of quality. At the same time, there have been calls for attention to quality of palliative care programs in India, without much clear follow-up activity (Selman and Harding 2010).

An initial study using this minimum standards audit tool is a valuable source, as it aggregates data from 49 palliative care entities across India (M. Rajagopal et al. 2014). The authors note that their results must be interpreted with caution, as institutions with poorer results may have chosen not to respond, and may not have even been included in the sampling frame. Nevertheless, the study provides the largest sample available, and it offers one estimate of how prevalent essential and desirable practices are. It also provides a sense of what domains may be weaker.

### ***Stronger on basic human resources and morphine availability, weaker on psychosocial care***

The audit survey found that programs scored highest on measures related to personnel and pain treatment. These measures included having a “trained physician with at least 10 days of supervised clinical training [in palliative care]” (mean of 3.96 on a 0-4 scale), a “trained nurse with at least 10 days supervised clinical training [in palliative care]” (3.92), “sufficient access to morphine and palliative drugs free of charge for poor patients” (3.94), “an uninterrupted supply of oral morphine” (3.92), “a system for documentation of step 3 opioid use including names of patients and identification number, quantity dispensed each time and balance of stock after each transaction” (3.92), and “assessment and documentation of pain with at least the body chart and pain scale, and assessment and documentation of other symptoms” (3.67) (M. Rajagopal et al. 2014). Based on these findings, the 49 programs studied appear to have surmounted some human resource and drug access barriers. While these programs reported good access to strong opioids, the authors recommend caution in interpreting these results. They state this finding is “in no way representative of the country as a whole” (2014). However, it is promising that the respondents in this network did have good access.

## **Weaknesses**

Fewer studies give a sense of the weaknesses of current palliative care efforts. However, the audit study suggests that psychosocial aspects of care may be weaker in 49 palliative care programs throughout the country. The elements for which programs self-scored relatively lower included “assessment and documentation of psychosocial and spiritual issues including family

tree” (3.57), “regular team meetings” (3.47), and “team members trained to deliver psychosocial and spiritual support” (3.37) (2014). These findings suggest that issues of team communication and the psychosocial and spiritual elements of palliative care could be weaknesses.

This finding is supported by a qualitative study, which suggests that spiritual care may be a neglected domain of palliative care efforts in Kerala. This study, which explored the meaning of spiritual care in Indian palliative care, quoted Dr. Suresh Kumar of Kerala, who stated:

“When you work in a multireligious community as we do, as a policy we have, from the very beginning, decided that when it comes to spiritual care or spiritual support, we won’t mix religion with spiritual care. For example, we have decided that we won’t employ, or we won’t seek help from say, a Hindu priest, Muslim priest, or Christian priest...and also we believe that when it comes to the realm of spirituality one can only act as an active observer and guide the patient to disclose his or her own spiritual dimension or spiritual problems. There have been a lot of occasions where the patients particularly request some sort of religious help, in which case we are happy to direct them to a religious person or bring a religious person to the patient’s place. But generally, we see spirituality as something beyond religious practice... There is a risk that we are taking an extreme position and avoiding the religious perspective altogether... In a way, I think this probably is still one of our weak areas, I must say... [W]e are missing the clergy during the training and during work with the patients” (Wright, George, and Mingins 2004, 225).

This interview expresses that spiritual care in alignment with patient wishes may be a weakness of palliative care in Kerala. I did not find sources to elucidate this issue in other places.

### **Factors Affecting Strengths and Weaknesses**

The national survey audit found that certain strengths and weaknesses might be more characteristic of certain types of palliative care programs (2014). For example, hospital-based programs in the study reported lower levels of psychosocial assessment and community involvement. On the other hand, hospitals uniformly reported rigorous documentation systems for step 3 opioid dispensing, while some community-based providers did not. The national survey audit also suggests that strengths and weaknesses may be shaped by the size of a palliative care program. In the audit, larger programs with more than 750 patients per year “had better systems in place for documentation of pain and other symptoms,” as well as better availability of funds, professional development for staff, and participation in research (2014, 5). In contrast, smaller programs reported “greater community support” than large programs and scored higher for “conflict resolution,” “debriefing” and ongoing audits of their own work (2014, 5). In other words, while larger programs may have greater capacity in training and research, smaller programs may have strengths in community relations, interpersonal dynamics and self-improvement efforts. The type of service may therefore be important to consider when interviewing diverse palliative care providers on the strengths and weaknesses they perceive.

## **What can both empirical studies and commentaries tell us about the Barriers to Palliative Care and Pain Treatment in India?**

Over the past two and a half decades, palliative care pioneers in India and their global allies have analyzed the structural barriers to making quality pain treatment and palliative care available (Burn 1990; de Souza and Lobo 1994; S. Kumar and Rajagopal 1996; Burn 2001; Joranson, Rajagopal, and Gilson 2002; M. R. Rajagopal 2016). Indeed, in my literature search, I found that authors more frequently discussed barriers than strengths, weaknesses or opportunities. This analysis has allowed palliative care pioneers to overcome many barriers, and to see new mountains before them (M. R. Rajagopal 2015a; Lohman and Amon 2015).

Having a grasp on what has already been written about existing barriers provides an important foundation for exploring them in a new study. Many accounts of barriers, while not research-based, are the results of direct observation and practice in palliative care, which can supplement our understanding from the few empirical studies available.

Among the barriers most discussed are 1) persisting inaccessibility of pain treatment, 2) limited education of health professionals, 3) lack of funded policies for palliative care, 4) limited evidence for palliative care in India, 5) state-wise variation in commitment to palliative care, 6) cost and geographic inaccessibility of medical treatment, 7) the role of traditional medicine at the end-of-life, and 8) “collusion” between providers and physicians to conceal diagnoses of serious illness. These barriers have root causes that range from structural issues of policy and resources, to interpersonal and cultural challenges.<sup>14</sup>

### ***Inaccessibility of Pain Treatment***

Limitations in access to morphine and in pain treatment delivery have been cited numerous times as key barriers to palliative care in India and other low-and-middle income countries (M. R. Rajagopal and Joranson 2007; M. Rajagopal, Joranson, and Gilson 2001; Vallath et al. 2016; S K Chaturvedi 2008; Palat and Venkateswaran 2012; Human Rights Watch 2011). In terms of empirical research, two studies—a quantitative study of morphine consumption patterns in Kerala, and a rich ethnographic study of barriers to pain treatment in an Indian cancer hospital—offer particularly helpful evidence of how morphine accessibility remains a serious barrier to pain relief and palliative care in India, often with multiple underlying root causes (LeBaron et al. 2014; M. R. Rajagopal, Karim, and Booth 2017).

The recent study from Kerala—the state with the best pain and palliative care coverage in the nation—found that per capita morphine consumption rose significantly between 2012 and 2015, but remained only ¼ of the global average (M. R. Rajagopal, Karim, and Booth 2017). This reflects unmet need for pain treatment, despite high levels of home care coverage in the state. Furthermore, there were large variations in morphine consumption between districts, indicating that barriers may exist within a state, despite uniform state laws or policies.

The qualitative study by LeBaron et al. can help us understand potential barriers in more detail. LeBaron conducted ethnographic fieldwork and interviews, primarily with nurses, in a 300-bedded government cancer hospital in a large south Indian city (2014). While the hospital was the only place with a fairly reliable supply of oral morphine in the state, the hospital still faced challenges in delivering pain treatment. LeBaron et al.’s work indicates that barriers to

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<sup>14</sup> The structural barriers are important targets of advocacy (Lohman and Amon 2015), but I have included cultural barriers that dominate in the literature reviewed.

pain treatment are multi-factorial, and include at least 1) nurse and physician-level factors, 2) fragile systems of obtaining morphine, 3) bureaucratic hurdles that caused morphine stock-outs, and 4) geography. Each of these is worth examining.

#### *Nurse and Physician-level Factors as Causes of Inaccessibility*

LeBaron et al. found that nurse and physicians' roles, attitudes towards pain, and comfort with providing analgesia could be barriers to pain treatment. One of LeBaron et al.'s core findings was that nurses did not regularly perform proactive patient assessment, and that family caregivers, rather than nurses, were expected to take on the role of "patient advocate" regarding symptoms including pain (2014).

LeBaron et al. identified nurse-to-patient ratios that sometimes exceeded 1 to 60 as a structural impediment to providing individualized care and symptom assessment. At the same time, they did not observe differences in pain care between the general ward nurses and nurses in intensive care, where the ratio was 1 nurse to 4 or 5 patients, indicating that proactive nursing assessment and advocacy for patients may not entirely depend on staffing challenges (2014, 518).

Furthermore, they found that when nurses did try to advocate for a patient to receive pain treatment, doctors were very reluctant to prescribe morphine. In fact, the vast majority of morphine was prescribed by the hospital's dedicated palliative care service. Some empirical studies and commentaries have cited lack of training and fear of causing addiction or respiratory depression as factors in physician discomfort with morphine prescribing, even in advanced illness (M. R. Rajagopal and Venkateswaran 2004; M. R. Rajagopal and Joranson 2007; McDermott et al. 2008).

From these deeper barriers, LeBaron et al. argue, a lack of *opportunities* for nurses to witness effective pain treatment on their wards reinforced "a prevalent attitude that cancer pain was inevitable and largely unmanageable," and a sense of "helplessness when confronted with difficult pain situations" (2014, 518).

#### *Fragile Systems as Causes of Inaccessibility*

LeBaron et al. also found that morphine availability in the hospital "hinged on one (nonmedical) individual," an administrator, "who had taken it up as her personal responsibility to ensure that the hospital had an adequate supply of morphine" (2014, 518). This administrator made extensive efforts to arrange for the hospital to order and pay for regular morphine shipments.

The reliance on a single person's initiative rather than a routine institutional procedure is not surprising, as Indian hospitals emerge from decades in which licensing barriers to morphine were so steep that it was almost impossible to obtain (M. R. Rajagopal 2015a, 58). This shows, on one hand, the power of an individual to make a great impact. However, the lack of an institutionalized method of stocking morphine made the system vulnerable to other barriers, such as government bureaucratic hurdles.

#### *State Government Bureaucracy as a Cause of Inaccessibility*

The barrier that most struck LeBaron et al. was a delay that reliably occurred in dispensing the morphine supply once it reached the hospital (2014). Before a shipment could be

opened, the state required that a Drug Inspector come and make a report for the Drug Controller's office. Obtaining this inspection took days or even weeks of repeated calling by the devoted administrator.

A recent statement by Dr. Rajagopal reinforces the salience of such state-level bureaucratic barriers (2016). He writes that though the national drug law was simplified in 2014, "previous experience tells us that unnecessary procedural hurdles are likely to be raised by the state government departments during the phase of implementation" (2016, 29). LeBaron et al. noted that "bureaucratic delays in dispensing morphine, even after it was procured and physically available in the hospital" caused a few periods of supply gap which were extremely distressing for patients and for the palliative care team (2014, 519). This delay was particularly difficult when combined with the issue of geographic barriers.

### *Geography as a Cause of Inaccessibility*

LeBaron et al. found that the typical patient of the hospital was "financially destitute, illiterate, suffering from metastatic disease, and had traveled hundreds of kilometers to seek care" (2016, 519). Even if patients went home following treatment, the lack of morphine availability in rural health outposts caused hardship. Subsequent journeys to the city for monthly morphine refills were required, and this was costly for patients' families (2016, 519). The problems of geographical unevenness and urban bias in healthcare delivery discussed in Section 3 are evident here, too.

LeBaron et al.'s findings are from the period before the 2014 NPDS Amendment Act, which reclaimed control of drug policy from the states and streamlined the process of procuring morphine. Still, individual states need to comply with the amended law in order to overcome the bureaucratic hurdles mentioned by LeBaron et al. (M. R. Rajagopal 2016). To date, no studies have reported on how many states have complied. The barriers LeBaron et al. identified are likely to remain salient.

Furthermore, as LeBaron et al. note, "even when morphine is available, training and education are essential elements in improving cancer pain management" (2016, 520). Dr. Rajagopal has made a similar point in a recent commentary (M. R. Rajagopal 2016). These observations on the need for education bring us to another key barrier facing palliative care and pain treatment in India.

### *Limited education and awareness of health professionals*

In a recent commentary, Dr. Rajagopal of Kerala affirms that palliative care education and awareness is a key barrier to true access to pain relief. He writes, "even if the NDPS Amendment Act is implemented both in letter and principle, access to pain relief still depends on the medical community. As doctors and nurses are unfamiliar with modern principles of the pharmacologic management of pain, and as the current and past medical and nursing curricula do not include palliative care, translating the legal change to clinical practice will require a major shift in the attitude, knowledge and skills of medical professionals" (2016, 29).

A number of empirical studies support this argument. For example, multiple survey studies have found that awareness of palliative care and confidence in key practices are low among Indian medical trainees, physicians and nurses in their samples (V. Gupta et al. 2007; Bharadwaj et al. 2007b; Bharadwaj et al. 2007a; Mohanti et al. 2001; Sadhu, Salins, and Kamath 2010; Prem et al. 2012). The authors of these studies have argued that knowledge limitations and

discomfort—with pain management and discussions of end-of-life care—support the need for dedicated curricula on these topics (Mohanti et al. 2001; Bharadwaj et al. 2007a; Bharadwaj et al. 2007b), including in the field of pediatrics (Latha et al. 2014).

A commonly noted barrier in this area is that the Medical Council of India (MCI)—the body that until recently oversaw medical education—has yet to include palliative care in the national requirements for undergraduate level medical education (Pallium India 2016). This has remained a hurdle despite persistent advocacy.

At the graduate level, however, advocacy has been fruitful. In 2010, the MCI accepted “palliative medicine” as an official medical sub-specialty. This paved the way for the first M.D. level programs in palliative medicine, which began in 2012 (M. R. Rajagopal 2015a, p. 60). Still, a specialty track will not generate the widespread awareness and skills in palliative care that incorporation into undergraduate curricula would provide.

LeBaron et al. found that the presence of palliative care specialists was important, but not enough to provide pain relief in the hospital they studied: “With rare exception,” they write, “morphine (oral and intravenous) was prescribed exclusively by two or three physicians in the palliative care outpatient clinic...Consequently, despite some form of morphine being mostly available in the hospital, the benefits did not reach most patients on the general wards—many of whom suffered in pain without referrals to the palliative care department” (2014).

In addition to physician education, nursing education in pain and palliative care skills will be vital to improving access to pain relief (LeBaron et al. 2014; Prem et al. 2012). Indeed, integrating palliative care into nursing education is a recommendation of the draft national policy created in 2012 (M. R. Rajagopal 2015a, p. 60).

There is some evidence of allied health professional and medical colleges independently seeking to incorporate palliative care into their curricula (Veqar 2016; Bharadwaj et al. 2007a). However, these efforts are localized at the moment. More training in palliative care communication skills is also important to address another challenge cited in the literature: the frequent concealment of serious diagnosis.

### ***Concealment of Serious Diagnoses from Affected Patients***

Extensive involvement of family in patient care is often a critical support for people with serious illness and their medical team in India (Datta et al. 2016). However, a more fraught side of this involvement is the practice of not disclosing serious diagnoses directly to patients (V. Gupta et al. 2007; Santosh K. Chaturvedi et al. 2014). An interview-based study of caregivers and geriatric cancer patients in Lucknow provides some evidence of this challenge (V. Gupta et al. 2007). While 76% of family caregivers preferred that the diagnosis not be disclosed to the patient, 80% of patients wished to be directly informed. Furthermore, 82% of physicians in the study reported that their practice was generally to disclose to the family rather than the patient. Similarly, Muckaden et al. found that family members of two thirds of women in their program diagnosed with cervical cancer initially concealed the diagnosis (2005). While studies have found that families wish to protect their loved one through this practice, it presents a particular challenge for palliative care, in which discussion of prognosis and end-of-life wishes is a central endeavor (de Souza and Lobo 1994; Santosh K. Chaturvedi et al. 2014).

### ***National Policy for Palliative Care***



A structural barrier that impedes palliative care coverage in India is the lack of a funded national policy for palliative care (M. R. Rajagopal 2015a). While the Government of India and palliative care experts went through an extensive policy drafting process, the policy was ultimately not adopted (Directorate General of Health Services 2012; 2015a). Supportive government policy is one of the WHO pillars of palliative care advancement, and the lack of this on a national level is an important remaining barrier.

### ***Cost and Inaccessibility of Medical Treatment in General***

Medical treatment is too often inaccessible for patients, due to a combination of cost and distance. We have already discussed the effects of out-of-pocket medical costs on families of people with serious illness (Pramesh et al. 2014). These can present a financial challenge to palliative care programs, which are charged with holistically mitigating suffering (S. Kumar and Rajagopal 1996). Furthermore, distance limits the ability of rural dwellers to come to palliative care centers in urban areas. De Souza et al. writes that the distance presents a difficult decision when patients wish to return home to die, potentially sacrificing their symptom control for the ability to be at home surrounded by family (1994). These issues of distance and cost likely still challenge palliative care providers, particularly outside of Kerala where resources for palliative care are fewer.

### ***The Intersection of Traditional Medicine and Palliative Care***

The presence of diverse, traditional sources of medical authority has been framed by some prominent palliative care leaders in India as a barrier to effective palliative care (de Souza and Lobo 1994; S. Kumar and Rajagopal 1996). In a study of 156 patients attending a pain and palliative care clinic in New Delhi, 17% of patients reported pursuing therapies such as Ayurveda and homeopathy alongside allopathic treatment (Lal et al. 2012). Kumar and Rajagopal describe how “even after a detailed discussion of the prognosis [in a palliative care setting], the patient is given the option of a cure by several other systems of medicine. Not uncommonly, the patient hops from one system to another” without finding an effective treatment (S. Kumar and Rajagopal 1996, 298). Furthermore, they note that traditional treatments can be costly, and some practitioners prohibited the consumption of analgesics (S. Kumar and Rajagopal 1996, 298), or prescribed difficult diets that caused nutritional problems for the patient (de Souza and Lobo 1994).

Despite these reported challenges, the editor of the Indian Journal of Palliative Care has recently called for more evidence on the role of traditional healing practices in Indian palliative care (Salins 2017). Indeed, Indian systems of health promotion and spiritual practice, such as yoga and meditation, have spread to palliative care settings outside India. The benefits of yoga in people with cancer in the United States and Western European countries have been studied extensively (Cramer et al. 2017). The Journal’s editor expresses hope that if more traditional approaches are studied for their efficacy in Indian palliative care contexts, then “this will broaden our horizons from a pure Western reductionist biomedicine to an integrated more culturally acceptable Indian system of medicine in chronic and life-limiting illness management” (Salins 2017). Given this dual potential for traditional medical systems to be a barrier or opportunity, the relationship between these systems and contemporary palliative care may arise in my interviews.

### *Limited Evidence to Guide Practice*

Finally, Khosla, Patel and Sharma argue that the limited evidence base for palliative care within India is currently a barrier to delivery of effective palliative care (2012, 153–54). Practitioners in India have noted that models of palliative care found in the West cannot be directly copied, and must consider local resources and be adapted to the needs and preferences of patients and families in India (Zaman et al. 2017). More research could illuminate the efficacy of emerging models in India, and guide best practices in challenging areas.

### **What can both empirical studies and commentaries tell us about the Opportunities for Advancing Palliative Care in India?**

A number of opportunities exist to strengthen palliative care efforts. These include resources outside of palliative care on which efforts can build, including: 1) the strength of family support; 2) the desire of health care professionals to learn about palliative care; 3) the spiritual resources of patients and families; and 4) community participation.

#### *The strength of family support*

Families often have a leading role in caring for and managing the medical care of sick members (Santosh K Chaturvedi, Loisel, and Chandra 2009). This involvement of family is a resource on which palliative care in India has built, and can build further (Lebaron et al. 2014, 520). For example, a number of programs have incorporated training of family members in caregiving skills (de Souza and Lobo 1994; Chellappan et al. 2013). In Tamil Nadu, a palliative home care program provided family caregivers a color-labeled box of oral and subcutaneous medicines for acute symptom management, along with a lesson in how to use it (2013, E47). The vast majority of caregivers used the box, and felt that the lesson was useful to them. Approaches such as these could strengthen the home-based provision of palliative care.

Furthermore, training family caregivers could help palliative care programs fulfill their mission of financially rehabilitating patients' families. There is some evidence from a small pilot study in Kerala that family caregivers are interested in training in order to become employed in caregiving in the future (Emanuel et al. 2010). This would also contribute to the growing need for a long-term care workforce in India. In Bangalore, for example, a hospice has trained young women from their community in providing home-based long-term care (Kishore S. Rao 2006, 82).

#### *Desire of Health Professionals to Learn*

Beyond the potential of families to learn, there is also evidence that medical trainees and professionals want more training in communication skills, pain management and end-of-life care (Latha et al. 2014). There is also evidence of dissatisfaction among medical providers with the current system that lacks robust palliative care. For example, a survey conducted in Lucknow found that 98% of general practitioners and oncologists were not satisfied with the current system for dealing with geriatric cancer cases (V. Gupta et al. 2007). The disenchantment and desire for learning among health professionals appears to be a ripe opportunity for palliative care.

### ***Community Participation***

While there are debates over the role that trained volunteers should have in palliative care in India, Kerala and areas of Tamil Nadu have offered examples of how leadership by community volunteers helps palliative care's coverage and ability to holistically support patients at home (Jan Stjernsward 2005; Dongre et al. 2012). Many organizations in states beyond Kerala and Tamil Nadu have not yet attempted this approach.

### ***Spiritual Resources***

Finally, studies of the psychosocial needs of patients in India have identified spiritual and religious practices as a source of comfort and strength for many patients (Elsner et al. 2012; Gielen, Bhatnagar, and Chaturvedi 2017). Palliative care programs may be able to build on patients' strengths and coping ability by facilitating these practices.

### **Conclusion**

Varying types of evidence exist for the barriers, strengths, weaknesses and opportunities facing palliative care in India. Barriers—such as lack of morphine access and limited knowledge of palliative care and pain management among health professionals—have been well characterized in some empirical studies and numerous review articles and commentaries. My search also found that strengths—such as advocacy and leadership in palliative care—have been better characterized than weaknesses. Furthermore, opportunities have been articulated in more essays and review articles than empirical studies.

Overall, there is a dearth of empirical research on these aspects of palliative care, which could contribute meaningfully to strategic planning (Pastrana, Centeno, and De Lima 2015). Furthermore, most of the available research has been conducted in areas of relatively more palliative care activity, like Kerala, Karnataka, Tamil Nadu and Maharashtra. Furthermore, the effect of the amendment of the national drug law in 2014, which ought to facilitate pain treatment, has not yet been studied.

## Conclusion

As this literature review demonstrates, few empirical studies of the barriers to palliative care and pain treatment in India exist (Lebaron et al. 2014). Furthermore, most of the available commentaries on barriers and strategies for palliative care are from a physician's perspective (de Souza and Lobo 1994; S. Kumar and Rajagopal 1996; S. Kumar 2013). Therefore, empirical research on barriers to palliative care that incorporates diverse perspectives could help fill a gap in understanding.

A qualitative study focused on specific states appears to be the most useful approach to exploring the strengths, weaknesses, opportunities and threats to palliative care. Because health care delivery is a state issue in India, states must take action in order for opioid availability and palliative care coverage to improve (M. R. Rajagopal 2016). States have been relevant units of progress in Indian palliative care, with Kerala as a positive outlier (Joranson, Rajagopal, and Gilson 2002; Bollini, Venkateswaran, and Sureshkumar 2004; Vallath et al. 2016). Furthermore, a comparative case study could illuminate if existing barriers in one state resemble or differ from those that have already been overcome in another.

As shown in this literature review, the preponderance of descriptive and empirical papers on palliative care come from Kerala (Singh and Harding 2015). Therefore, focusing on at least one state other than Kerala would contribute to knowledge of the diverse contexts, challenges and potentially successful models in India. At the same time, the approach of qualitatively assessing strengths, weaknesses, opportunities and barriers may also discover new perspectives on palliative care in Kerala. This is particularly true given the limited evidence following the Kerala government's palliative care policy in 2008 (M. R. Rajagopal, Karim, and Booth 2017). Furthermore, while Kerala has rightfully drawn praise, advocates and practitioners in Kerala likely continue to see room for improvement (Elamon, Franke, and Ekbal 2004, 684).

Ultimately, the strength of a qualitative case study approach lies in its ability to hear and integrate diverse viewpoints. Zaman et al. argue that India faces a "plurality of past and present local problems and issues relating to end of life care, as well as the plural possibilities of how they might be overcome" (Zaman et al. 2017). In order to identify diverse possibilities for overcoming difficulties, one must first seek out a granular understanding of those difficulties in different states and programs. As organizations such as Pallium India endeavor to advance palliative care across a vast, diverse country, I hope that in-depth study of these variations will provide useful grist for considered action.

## **“Our Duty and Our Right”: Perspectives on Advancing Palliative Care in the Indian States of Kerala and Uttarakhand**

“When you develop a palliative care service, you are saying that the basic attitude...that ‘there is nothing else that can be done’ is wrong. There are a lot of things that you can do.”

-- Palliative Care Doctor, Kerala

### **Introduction**

In the global health community, palliative care and pain treatment are gaining increasing recognition as essential health services, specifically for the relief of serious health-related suffering (Felicia Marie Knaul et al. 2017). Suffering due to lack of palliative care during life-threatening illness and the end of life disproportionately affects people in low and middle-income countries (LMICs). In India, an LMIC of 1.3 billion people, the vast majority of the population does not have access to palliative care or morphine, an essential medicine for relief of severe pain and breathlessness. However, since the 1990s, palliative care efforts have taken root in a number of Indian states and major cities. These have been notably robust in the southern state of Kerala<sup>15</sup>, where a social movement for care of people with serious illness has flourished.

Palliative care providers in the state of Kerala have created an internationally recognized community-based model of palliative care, in which the government has played an increasing role since 2008 (S. K. Kumar 2007; S. Kumar 2013). In contrast, other Indian states have not yet built the same level of political action, community awareness, and care coverage. Yet palliative care pioneers in numerous states are participating in efforts to establish and strengthen services (McDermott et al. 2008; M. Gupta 2016). Furthermore, leading palliative care organizations in Kerala are supporting and mentoring efforts in other states and countries.<sup>16</sup>

According to India’s constitution, states have the primary power to create health care policy and to implement services. For this reason, health system transformation requires action at the state level. Health resources and outcomes vary dramatically from state to state, affected by socioeconomic and governance conditions (Balarajan, Selvaraj, and Subramanian 2011). This state-level variation affects palliative care. For example, in 2014, the national law controlling opioids, called the Narcotic Drugs and Psychotropic Substances (NDPS) Act, was amended at the central level to improve opioid accessibility in registered medical institutions (RMIs). However, implementation of the amendment is not uniform across India (M. R. Rajagopal 2016; Vallath et al. 2016). State-level barriers to this implementation, and to advancing palliative care services in general, remain incompletely understood.

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<sup>15</sup> While Kerala is home to just 3% of India’s population, it is home to more palliative care services than the rest of India combined (M. R. Rajagopal 2015a).

<sup>16</sup> These organizations include Pallium India, Trivandrum (<http://palliumindia.org/about/about-pallium-india/>, Accessed November 29, 2017) and the Institute of Palliative Medicine (IPM), Calicut, (<http://www.instituteofpalliativemedicine.org/whatwedo.php#whatwedonational>, Accessed November 29, 2017).

A goal of this research paper is to provide a synthesis of varied key informant perspectives on the important barriers and strategies for palliative care in India. Some leading physician-advocates in Indian palliative care have written very thoughtful commentaries, guided by extensive personal experience, on the barriers their states have faced and overcome in advancing palliative care (M. R. Rajagopal and Palat 2002; S. Kumar 2006; M. R. Rajagopal 2016). Seeking out the voices of nurses, community volunteers, dentists, social workers, and government officials in addition to physician-advocates can build upon already acknowledged challenges and strategies, and may also define new priority areas.

A second goal of this research paper is to inform advocacy in and collaboration between states with both robust and emergent palliative care activities. To fulfill this goal, a comparison between a state with a relatively robust system--Kerala--and another state with a more nascent palliative care movement--Uttarakhand--is warranted. Briefly, Uttarakhand was selected because of its location in a different region of India and because its measures of health system functioning are closer to the Indian average than Kerala's. Finally, the state has ongoing palliative care activities, which made it possible to study. Comparing state-by-state is meaningful because India's states are extremely diverse, have primary control over health care, and have been important units of progress in palliative care policy and services. Comparison is therefore vital to determining how palliative care can be strengthened in such a heterogeneous country.

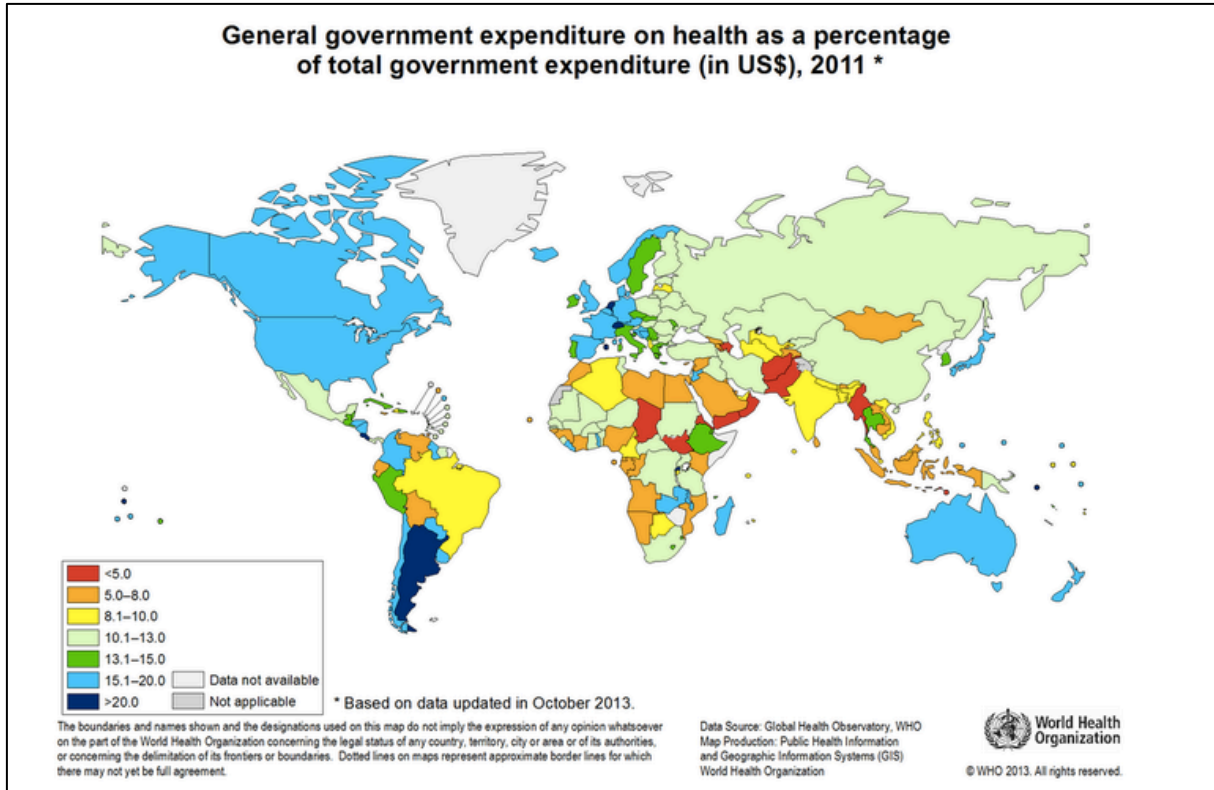
In light of these aims, the *research questions* for this study were:

- 1) How do palliative care providers in the states of Kerala and Uttarakhand perceive the barriers to and strategies for their work?
- 2) How do these perspectives overlap and contrast between the two states?

Before providing the findings, we must first review some background about the Indian health system and the two states in this study.

### **Background on India's Health System, and the States of Kerala and Uttarakhand**

Palliative care efforts in India exist in the context of India's health care and governance systems. While India is home to about 16% of the world's population, it accounts for only 1% of global expenditure on health (La Forgia and Nagpal 2012, 17). Furthermore, as the map below shows, government prioritization of health expenditure is relatively lower in India than in all major countries except Brazil and Indonesia. Because of low government spending on health services, private sector services have risen to meet public demand (Jana and Basu 2017). However, few Indians have health insurance, and much of India's population relies on the government for their health care or bears large out-of-pocket costs (Patel et al. 2015).



**Figure 11: General Government Expenditure on Health as a Percentage of Total Government Expenditure, 2011 (World Health Organization Global Health Observatory, [http://www.who.int/health-accounts/expenditures\\_maps/en/](http://www.who.int/health-accounts/expenditures_maps/en/)).**

In 2008, the central government of India increased the funding available to states for their health services by creating the National Rural Health Mission (NRHM), now called the National Health Mission (NHM). However, states must take the initiative to request these funds for specific health priority areas. As we will see, state governments' initiative in health services and funding also affects palliative care.

***Kerala***

Kerala has a particularly strong track record on health and human development. A small, coastal state in southwest India, it has the highest literacy rate, the greatest life expectancy, and the lowest infant mortality rate in the country. Table 1 below shows these data and compares India's average health and social indicators with Kerala's and Uttarakhand's.

	India (average)	Uttarakhand	Kerala
Literacy (%) <sup>*</sup>	74	80	94
Female Literacy (%) <sup>*</sup>	65	70	92
Life Expectancy (years) <sup>#</sup>	68	72	75
Institutional Deliveries (%) <sup>#</sup>	79	69	100
Infant Mortality Rate <sup>#</sup> (per 1000 live births)	40	32	12

<sup>\*</sup> Census of India, 2011 (<http://pib.nic.in/newsite/PrintRelease.aspx?relid=103446>),

<sup>#</sup> Nagaich 2017 (<http://niti.gov.in/state-statistics>).

Kerala has a distinctive system of government that supports local investment in health and other sectors. In 1996, political mobilization led the state to decentralize governance and policy planning. In the decentralized model, 35 to 40% of state funds are given to local bodies called *panchayats* or Local Self-Government Institutions (LSGIs) to spend as they choose within certain requirements (Elamon, Franke, and Ekbal 2004).

The state of Kerala also has the strongest history of palliative care. Beginning in the early 1990s, a vibrant network of non-profit palliative care organizations emerged through the joint leadership of medical professionals and community volunteers (S. Kumar and Rajagopal 1996; Bollini, Venkateswaran, and Sureshkumar 2004). In 2008, Kerala's state government took the unprecedented step of creating a palliative care policy. This policy built on Kerala's decentralized governance model. Early on, the state prioritized training the public and members of the LSGIs about palliative care and the new policy. Next, the policy required all LSGIs to allot funds and develop home-based palliative care units (Government of Kerala 2008). These units consist of a trained community health nurse who makes home visits to bedridden people in the LSGI's area with consultation and supervision by a local government doctor.

Kerala's government also requested funds for palliative care from the central government through the National Rural Health Mission (NRHM). These funds now support palliative care services in Kerala's government hospitals at the *taluk* and community levels,<sup>17</sup> which are located in rural areas. The degree of Kerala's government involvement in palliative care is unique within India, and lights a path for other states to emulate and adapt to their own contexts.

Because of Kerala's dynamic palliative care leadership and progress, most studies and commentaries on palliative care in India have focused on Kerala. However, only one study has explored Kerala's palliative care outcomes since the 2008 state policy (M. R. Rajagopal, Karim, and Booth 2017). While that study provides valuable quantitative data on morphine consumption by district, it does not assess qualitative issues such as challenges encountered and strategies for improving implementation. This leaves a gap in data for strategic planning in Kerala, which this paper hopes to help address.

<sup>17</sup> Government health services in Indian states are organized in a tiered referral system. Primary health centers and sub-centers at the village level refer patients to block-level community health centers, and then up to sub-district or *taluk* hospitals, and finally to district-level tertiary care centers (Palat and Venkateswaran 2012, 212–13).



## *Uttarakhand*

Uttarakhand, a state in the Himalayan region of north India, has health and social indicators more typical of the rest of India. As with each state, however, it has distinctive history, culture and geography. In 2000, Uttarakhand separated from India's most populous state of Uttar Pradesh. Since then, Uttarakhand has been home to just less than 1% of the country's total population. Uttarakhand's terrain is mainly mountainous and forested, though its capitol city, Dehradun, is located on the plains. Uttarakhand's literacy and life expectancy rates lie between Kerala's and the national average, and the state has a relatively low institutional delivery rate and near-average infant mortality rate, reflecting relatively average health system functioning.

Similar to many Indian states, Uttarakhand's palliative care services are not presently incorporated into government health services. One non-profit organization has provided home-based palliative care services in the plains cities of Rishikesh, Haridwar and Dehradun since 2007. A couple major hospitals on the plains also have budding efforts to provide pain and palliative care services to inpatients and outpatients, and some academic institutions, including a dental college, teach palliative care lessons in their curricula and conduct sensitization and training programs in palliative care for doctors and nurses.

Though the number of institutions may seem small, Uttarakhand has a critical mass of people from different sectors (non-government, academic, and government) who care about palliative care and are working together to advance it. Their collaboration, including with the state Human Rights Commission and with experts from outside Uttarakhand, led to a key meeting with government health officials in February 2016 (M. Gupta 2016). This meeting spurred subsequent progress toward eventually adopting the centrally amended opioid regulations and obtaining funding from the central government for palliative care in November 2017. With this funding, government doctors in Uttarakhand will begin to receive palliative care training in January 2018. However, a state policy for palliative care is still pending as of December 2017. In addition, some palliative care providers in Uttarakhand are connected to mentorship programs, including from a leading NGO in Kerala and a regional palliative care association. Such domestic and international mentoring relationships have potential relevance for many states in India, but their role in perceived barriers and strategies has not been formally studied. This study provides the first systematic exploration of the challenges and strategies expressed by the palliative care community in Uttarakhand.

## **The Study**

### *Methodology*

In June and July 2017, the author conducted a qualitative study in Kerala and Uttarakhand with key informants in the field of palliative care. The purpose of the study was to identify barriers to and strategies for advancing palliative care in each state, as well as the strengths and limitations of existing efforts. The author conducted 31 individual and small-group interviews with a total of 40 respondents. Interviews were

semi-structured and included open-ended questions and probes that were iteratively revised to explore emergent themes.

### *Recruitment*

Interviewees were initially recruited by purposive sampling. With the help of the partner organization, Pallium India, the author contacted leaders and health professionals in a range of roles in the field of palliative care in Kerala and Uttarakhand. Subsequently, the author recruited participants through snowball sampling. This involved asking each interviewee for additional individuals with whom to speak to better understand the barriers and strategies for palliative care in their state. This strategy was used until a broad range of palliative care providers were interviewed and thematic saturation was reached.

### *Data Collection and Analysis*

The author interviewed all respondents using a semi-structured questionnaire. Questions included: “What barriers have you faced in your work on palliative care in your state?” and “What has helped to overcome those challenges?” or “How do you think these barriers can be overcome?” Areas of strength and weakness in existing palliative care efforts, as well as opportunities and threats to these efforts, were also explored.

After each interview, the author wrote a memo about key points and potential themes emerging from the interview. The author incorporated these ideas into subsequent versions of the questionnaire. In this way, preliminary theories from earlier interviews were tested and, in some cases, elaborated more fully in later interviews. Memoing and altering subsequent questionnaires to pursue theories are common components of qualitative methodologies (Charmaz 2006; Steinhauser and Barroso 2009).

Interview recordings in English were transcribed by a confidential transcription service (Rev.com). The author transcribed the English portions of interviews containing Malayalam, and a research assistant transcribed and translated the Hindi interviews. Finally, the author checked all transcripts for accuracy by comparing the transcripts to the original recordings in English and Hindi.

Thematic Analysis guided the transcript coding and data analysis process (Steinhauser and Barroso 2009; Marks and Yardley 2004). To develop the initial codebook, the author selected eight transcripts—four from Uttarakhand and four from Kerala—in a purposive manner, to include a range of interviewee identities and to optimize for interview length and quality. The author then coded the 8 transcripts, using techniques including: (1) deductive coding of interview segments about barriers and strategies for palliative care, and (2) open coding to allow for the addition of inductive codes not originally part of the deductive schema. Two different de-identified interview transcripts (one from Kerala, one from Uttarakhand) were shared with two committee members for collaborative development of the initial codebook. Using the codebook from the first 8 interviews, the author coded the remaining interviews, continuing to modify

the codebook to include emergent codes and to consolidate themes.<sup>18</sup>

### ***Participants***

Interview participants were physicians (30%), community volunteers (22.5%), nurses (15%), palliative care pioneers (12.5%), administrators (10%), dentists (10%), social workers (7.5%), spiritual care workers (5%), health department officials (5%), and a human rights commission member (2.5%). Table 2 below shows respondent characteristics by state, role and sector. Respondents with multiple roles (e.g. physician and pioneer) were counted in each relevant category. Roles were defined on the basis of respondents' current activities relating to palliative care. The role "palliative care pioneer" was defined as a provider of palliative care who has led engagement with the state government on behalf of palliative care; "community volunteer" was defined as a layperson who volunteers in palliative care settings; and "administrator" was defined as someone who manages the logistics and/or fundraising for palliative care programs. In the results section, quoted respondents are labeled with a single role to preserve anonymity.

Respondents were affiliated with multiple sectors, including the non-governmental organization (NGO) sector (77.5%), academic or teaching sector (50%), government sector (17.5%), and the private for-profit sector (15%). These categories sometimes overlapped, and so some respondents were counted in multiple sectors. The vast majority of respondents worked or volunteered directly in palliative care settings, including home care, inpatient, clinic, and residential hospice settings.

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<sup>18</sup> In the future, the author will perform member checking by sharing the themes/codes with key informants from each state in India. Their feedback may lead to interpretive changes, and will help establish validity and usefulness of the findings.

<b>Table 2: Participant and Interview Characteristics</b>			
	<b>Kerala</b>	<b>Uttarakhand</b>	<b>Total</b>
<b>Number of participants</b>	19	21	40
<b>Number of interviews</b>	16	15	31
<i>English</i>	14	12	26
<i>Hindi</i>	0	3	3
<i>Malayalam with English interpreter</i>	2	0	2
Participants per interview (mean, median, range)	1.19, 1, 1-3	1.4, 1, 1-4	1.29, 1, 1-4
Length of interview (mean, range in min.)	58, 21-103	58, 20-119	58, 20-119
<b>Number of Participants by Role</b>			
Palliative Care Pioneer	2	3	5
Doctor	7	5	12
Palliative Care	5	3	8
Oncology (Medical & Surgical)	0	3	3
Pediatrics	2	0	2
Community Volunteer	5	4	9
Nurse	2	4	6
Administrator	2	2	4
Dentist	0	4	4
Social Worker	3	0	3
Spiritual Care Worker	1	1	2
Health Official	1	1	2
Human Rights Commission Member	0	1	1
<b>Number of Participants by Sector</b>			
Private, non-profit (NGO)	17	14	31
Academic	9	11	20
Government	5	2	7
Private, for-profit	0	6	6

### ***Limitations***

This study has several limitations. First, interviewer bias and social desirability bias may affect the findings of interviews. In an effort to limit bias, the core questionnaire was developed with the input of multiple advisors, including from UC Berkeley and Pallium India. Furthermore, language was a limitation. In India, numerous official and local languages are spoken. Students may be educated in the medium of any official language, including English, depending on their school and level of education. All

respondents understood and could speak some English, but their fluency varied. In addition, the author is conversant in Hindi, but she is neither fluent in Malayalam (spoken in Kerala), nor a native speaker of Hindi (spoken in Uttarakhand). These language disparities increased the possibility of misunderstandings. To mitigate this risk, a native Malayalam speaker interpreted during some interviews in Kerala, and a native Hindi speaker translated the Hindi interviews into English before verification by the author. In addition, the author asked clarifying questions as needed during interviews.

Next, a number of limitations relate to the sampling methods. Respondents from only two states were sampled, limiting the ability to infer differences between groups that could be more generalizable within India. Furthermore, respondents were predominately sampled from urban and peri-urban areas, limiting the geographic scope of the findings. Purposive and snowball sampling methods make use of social networks, which limit access to unconnected members of a population. This may explain another limitation of the study, which is the relatively low level of public sector workers interviewed. Finally, the study did not include other stakeholders such as patients and caregivers, who likely have distinct perspectives on barriers and strategies for palliative care.

To address these limitations, the author recruited respondents from a deliberately wide range of roles in palliative care. In addition, several respondents from each state had lived or worked in rural areas. They provided some insight into rural challenges and strategies. Finally, in the analysis phase, it became clear that many themes repeatedly arose across respondents' states and roles. The conclusions and recommendations of this paper are based on these significant patterns. These findings provide insights into palliative care activities in parts of Kerala and Uttarakhand, but are limited in their generalizability to other contexts.

## Results

Interview participants in Kerala and Uttarakhand highlighted a broad range of barriers they have faced in their work to advance palliative care. They also discussed numerous strategies, many of which they have already used successfully. Their insights fell into four overarching categories, which structure the rest of this paper. These four categories are:

- (1) Palliative care awareness and education among **health professionals**,
- (2) Provision of health and palliative care **services**,
- (3) Capacity and involvement of **the public** in palliative care, and
- (4) The **state government's role** in palliative care and opioid regulation.

Each of these domains contains a variety of barriers and strategies that are intertwined with one another. The domains themselves do not have an order of importance, though certain themes within each domain were more emphasized than others.

## **Section 1: Palliative Care Awareness and Education among Health Professionals**

The vast majority of respondents discussed the need for greater palliative care awareness and education among health professionals in their states, as well as more human resources for palliative care.

### ***Challenges & Barriers related to Health Professionals***

Respondents identified key challenges in this domain, including the lack of awareness and training about palliative care among health professionals; overall lack of human resources for health; and knowledge differentials between respondents and colleagues. The issue of career stability in palliative care also arose.

First, the vast majority of respondents reported a lack of sufficient awareness about palliative care among health professionals. This lack of awareness was a crosscutting issue mentioned by doctors, nurses, dentists and social workers in both states. It was mainly attributed to a lack of training opportunities and requirements. As a nurse from Uttarakhand said, “While studying nursing or becoming a doctor, no course teaches about palliative care. We did not even [really] know what it was when we started working here.”

Many respondents raised the problem that palliative care and pain treatment is not included in the nationally mandated undergraduate curriculum for their professions, including medicine, nursing, and dentistry. In medicine, for example, a central regulatory body called the Medical Council of India (MCI) accredits all colleges and mandates that certain specialties must be taught to medical undergraduates. Palliative care is not presently a required subject. In both Kerala and Uttarakhand, respondents emphasized that this must change in order for awareness and human resources for palliative care to grow.

Some respondents in both states reported that lack of health professional awareness and education in palliative care manifested in poor pain treatment practices. For example, a doctor in Uttarakhand noted:

If you have a simple [analgesic like] an NSAID, tramadol, paracetamol,... ibuprofen, or diclofenac sodium... their usage remains suboptimal... I can see the deficiency in the prescription of individuals. [Also,] the knowledge [of how to combine analgesics] does not exist, because in [the] medical curriculum, these things were not taught... At least in India, this teaching [and] practical training is not imparted... to treat pain adequately.

Additionally, many respondents, particularly doctors, said that lack of correct education manifested in misconceptions about opioids, such as morphine. As a doctor in Uttarakhand put it:

In my [MBBS] training, [the] bottom line I got is, “you don’t write morphine, otherwise people get addicted to it... If you start prescribing morphine, there is something wrong with you”...Even now, if I talk to [another] doctor, “Oh morphine? Don’t your patients get addicted? How do you manage that once they get addicted?” That stigma is there.

Some respondents also found that these misconceptions were exacerbated by the present opioid addiction epidemic in the United States.<sup>19</sup>

Furthermore, some respondents noted that they want to improve their own knowledge and skills in palliative care, but cited limited learning opportunities as a barrier for themselves and others. A nurse in Uttarakhand described her initial experience in palliative care:

When I started, I was not trained [yet] and went straight to meet patients... It was difficult, because... I did not know there was so much death and dying in this work... It is important to have training to prepare yourself for this... We should have an orientation when we join [explaining] that these situations will arise and how to handle them...

This nurse continued to describe why such preparation is particularly needed in palliative care settings:

In a hospital, ... patients change on a daily basis and relationships are not maintained, [but] it is totally different in home care and palliative care... So beforehand we should have trainings on how to maintain the relationship with the family [and] deal with the psychological and spiritual aspects.

Similarly, in Kerala, a nurse also discussed limited access to training for spiritual care, and a community volunteer wished for more training on how to communicate with families. These wishes may also reflect a need for additional personnel specializing in psychosocial and spiritual care, which some respondents, particularly in Uttarakhand, reported.

In addition, many respondents, particularly in Uttarakhand, described an absolute shortage of health care personnel as a barrier to palliative care. In Uttarakhand, respondents discussed this shortage, particularly in remote, mountainous areas, as a barrier to palliative care. A doctor noted:

The biggest barrier in Uttarakhand you will face--in any medical field--is the geography. Dehradun, Rishikesh, Haridwar, these are big cities, but if you go to the real Uttarakhand, the major [area is] in the mountains. The road connectivity is poor. Plus, we also don't have [a high] enough number of doctors attending to the patients there.

In this way, human resources and geography were interrelated barriers in Uttarakhand. A lack of human resources was also felt to limit the overall capacity of some palliative care institutions and teams in both states. In Kerala, a doctor and nurse described how the sheer number of patients that government medical staff must see in a day limits their attention to patients' comfort and chronic needs. This will be discussed further in the coming section on health services.

Next, a variety of respondents in both states, including nurses, doctors and social workers, described facing knowledge differentials between themselves and other team members. These knowledge disparities were an especially significant challenge when a supervising doctor's knowledge was limited. In this vein, a nurse from a private institution in Kerala shared a distressing experience:

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<sup>19</sup> The opioid addiction epidemic in the United States has a variety of distinctive drivers, including misleading pharmaceutical marketing to physicians, overprescribing of opioids, and abundant supply of illicitly made and trafficked opioids (Ryan, Girion, and Glover 2016; Quinones 2015).

After the [palliative care] training, I knew morphine can relieve pain. My religious Sister was dying, and she had *severe* pain. Then I phoned my Medical Superintendent and asked—I was a nursing in-charge, so I could ask—“morphine is available, can we give?” And then his answer was, “I don’t believe in mercy killing.” It put me off, and I saw my Sister dying in pain. He has the power to say that to me.

While this was an especially distressing example, a variety of respondents described awareness of palliative care among their supervisors as a critical help or hindrance of their efforts. In a positive example, a nurse from Uttarakhand described:

Our [Medical] Director is very concerned with palliative care—for example, how will a patient with a colostomy care for himself at home? ... Sir is very concerned about these issues, and he... encourages us a lot in this work.

Similarly, dentists at an academic institution in Uttarakhand described their Dean as a key supporter whose endorsement made their work in palliative care possible. In contrast, one junior doctor in a government hospital in Kerala often felt hindered by his Head of Department, who did not have palliative care experience.

Finally, a variety of respondents, including doctors and nurses in both states, mentioned that palliative care presently does not offer a secure career path. They related this insecurity to the newness of the field, problems of formal degree recognition, and limited pay. Some respondents felt that these factors hindered a broad entry of health professionals into the field.

### ***Strategies for Awareness and Education of Health Professionals***

Respondents discussed numerous strategies for overcoming these challenges, including incorporating palliative care into health professional curricula; engaging positive gatekeepers at academic institutions; offering NGO-led sensitization and training activities; and increasing continuing education opportunities. These strategies were felt to be important for overcoming the barriers described above. Additionally, some respondents noted that under the Amended Narcotic Drugs and Psychotropic Substances (NDPS) Act, doctors are required to have completed a palliative care course before their institution can obtain a license to stock and dispense opioids. This was another reason cited for the importance of training.

As a strategy to improve health professional knowledge of palliative care, some doctors in Kerala and Uttarakhand described incorporating palliative care into the curricula of specific medical colleges or institutions. As one palliative care doctor from Uttarakhand said:

Palliative care has not been included in the undergraduate [medical] curriculum in India as a whole. But a lot of palliative care physicians are doing it unofficially in their own institution. So we thought, why don’t we start it [and] sensitize 150 undergraduate students who are going to be doctors in a year... The only [issue] was that the timings are very much specified within the MCI curriculum... So, we requested to our principal to include [two lectures] in [the] anesthesia [time frame]... one for basics of palliative care [and] the philosophy of palliative care, [and one for] basics of symptom management, in which we focus mainly on pain.

While efforts at specific universities were important, many respondents emphasized that a national mandate to teach palliative care in undergraduate health professional courses is



ultimately needed to improve awareness. A palliative care doctor from Kerala explained the barriers to achieving this mandate, and a new strategy to compensate:

Unfortunately, our [efforts directed at] the Medical Council came at a time when the Medical Council itself was facing... major allegations of corruption, [and a decision to] hand its power over to different commissions... So it is not a good time [to propose reforms, and] we are now trying to see what else we can do... Kerala University of Health Sciences has agreed for the integration of palliative care into undergraduate medical education. It is not going to be a separate subject, which would need the Medical Council's involvement, but in any subject...a little bit of palliative care is brought in.

Some respondents in Uttarakhand and Kerala found this approach of going institution by institution to incorporate palliative care into undergraduate medical curricula to be important. Dentists and nurses also noted that palliative care was not included in their undergraduate curricula and should be incorporated locally and nationally.

With respect to knowledge differentials within teams, one nurse from Kerala offered a strategy for dealing with situations in which her palliative care knowledge exceeded that of her colleagues and supervisors. She emphasized the importance of building rapport with colleagues, and of demonstrating her skills over time, so that others could then call on her for help if they faced difficulty in keeping a patient comfortable or caring for their tracheostomy, for example. At the same time, this nurse felt that wider training of health professionals was needed to improve palliative care in her government medical institution.

Some respondents mentioned another strategy for improving palliative care education: engaging positive gatekeepers in academic institutions. Respondents in both states described how leaders and decision-makers in various institutions could either help or hinder the advancement of palliative care efforts. In this way, they played the role of “gatekeeper” within specific institutions and bureaucracies. In a positive example, a doctor from Uttarakhand described how he was able to change his own institution:

Over the years I became senior. I hold a position myself. If I say something, people are listening. Another [factor] is, I worked through the Dean of the medical school [and] a council of all the faculty members. I convinced them, and ...they said, “yes, this is important.”

Such engagement of gatekeepers in institutions mattered to respondents across sectors, from government, to academia, to NGOs. Gatekeepers were essential both for training health professionals and for provision of services (to be discussed in the next section).

Respondents also noted that NGOs have a vital role in providing palliative care training and sensitization activities. Exemplifying this strategy, NGOs in both Kerala and Uttarakhand offer diploma courses in palliative care, though Kerala has a greater number of established training centers and local teaching faculty. In Uttarakhand, an NGO collaborates with a dental college to conduct a regular palliative care sensitization course using the Indian Association of Palliative Care (IAPC)'s curriculum. A doctor reflected on the significance of the course:

The number of candidates we are getting for our IAPC courses is increasing. So that means that the healthcare professionals want to learn what palliative care is. And indirectly, we are building up a strong healthcare force, which will be trained in palliative care in Uttarakhand.

In Kerala, a health official also commented on how important NGOs were for training their government workforce:

[A leading palliative care NGO in South Kerala] has got a training center. So, if we can send [more of] our doctors and staff nurses for training in that center, training is one important part where [the government and NGOs] can cooperate. Similarly, a health official in Uttarakhand stated that local palliative care NGOs and academic institutions could be important partners for training a government workforce.

In addition to the strategies above, respondents suggested a variety of approaches to engage practicing health professionals in learning about palliative care. These included creating Continuing Medical Education (CME) programs, doing outreach to local professional organizations and nursing colleges, and offering on-the-job training.

Some respondents in Uttarakhand described setting up CME conferences on palliative care in their hospitals as a strategy to increase awareness and referrals. In addition, a doctor and dentists in Uttarakhand reported giving lectures at local nursing and dental colleges to sensitize students. These respondents said that the talks emphasized the importance of the contributions nurses and dentists can make in palliative care. A nurse described how this affected her own awareness:

When I was a first year, [people from the NGO] came to our college to explain what [palliative care] is. I was already interested in cancer [because of experience in my family], and this sparked my interest.

Furthermore, some respondents discussed on-the-job training strategies. A doctor in Kerala described how nurses at a cancer center in Kerala rotated on and off the palliative care service in a staggered manner, so that nurses with more experience could orient and train the new arrivals.

Within the realm of continuing education, some respondents emphasized that some competence in certain palliative care skills is universally needed. For example, a doctor in Kerala described:

The argument I have been putting forward [is] that if you are a doctor, you should know how to treat pain. We are not asking you to become a palliative care doctor, but [when] a patient comes to you... with pain, or nausea, or vomiting, you should know how to treat it, irrespective of whether the patient is incurably ill, curably ill, young or old... Also, you should know how to talk to [a] patient and family if you are a clinician... [and] you should know how to handle a fungating wound. So we have been pushing [palliative care skills] as basic clinical skills of a health care professional.

Dentists and doctors in Uttarakhand echoed the belief that all physicians and dentists should be sensitized about palliative care and comfortable supporting patients with serious and terminal illnesses.

Finally, in addition to strategies for sensitizing health professionals to palliative care concepts, some trained palliative care providers emphasized the need for more opportunities to learn and develop specialized skills. As a palliative care doctor from Uttarakhand put it:

Even after so many years, I want to get further trained... because I know that with my knowledge, I am not doing justice to all the patients I am seeing... I would love to get trained in non-cancer palliative care... and I would like to get trained in an institution [with] a dedicated facility for management of psychosocial issues... who can teach me how to deal with the psychiatric issues in palliative care. [Also,] we have very few nurses who are trained in palliative care, so I ...would like myself to be trained in...nursing issues... I would like to have a hands-on experience [in these areas, and also in] pediatric palliative care.

Both doctors and nurses in Uttarakhand saw opportunities for such specialized training outside of their state (e.g., in Kerala), and also in working alongside palliative care physicians from abroad who come to volunteer. A nurse from Uttarakhand suggested that volunteering visits like these should include a strong focus on building the clinical skills of local staff. Among respondents who wished for more training as a strategy to advance palliative care, the greatest wishes were for training in communication skills, as well as palliative care of children and of special groups like people with psychiatric illness and HIV/AIDS.

Finally, some respondents described strategies to improve career stability in palliative care. These included building awareness of palliative care in the broader health professional community, providing sufficient pay to palliative care professionals, and advocating to have a range of degrees in palliative care officially recognized by health professional regulatory councils.

## Section 2: Provision of Health and Palliative Care Services

Next, the vast majority of respondents emphasized challenges and strategies in the realm of service delivery. This theme included both the overall health care system and palliative care services specifically.

### *Challenges & Barriers in the Provision of Health and Palliative Care Services*

Challenges that respondents emphasized included lack of access to quality, affordable health care for patients and families; lack of essential opioid availability; and lack of orientation towards chronic care in the current medical system. Specifically within palliative care services, key challenges identified were the challenges of funding and maintaining NGO services; of being asked to perform services beyond the scope of palliative care; and of communication with patients and families.

First, many respondents, particularly in Uttarakhand, mentioned that patients suffer from lack of access to medical care, and from poverty caused or worsened by medical expenses.<sup>20</sup> Numerous respondents described how medical care and expenses become a source of suffering that palliative care programs then must address. A palliative care administrator in Uttarakhand expressed this challenge through a patient's story:

[The] poor little [boy]... had a huge tumor in his thigh. The doctor didn't know it was cancer...and he calmly took half of it out... Within six months, it was back, and that boy suffered. These people are suffering from the medical profession. They're suffering because they're too poor to go to [capable doctors], and they're too poor to reach an oncologist, until it's much too late. And too poor means, they've sold everything they own. If they owned fields, they've sold their fields. They've sold their house. They've sold their furniture. They've sold their jewelry. They've sold everything... and then they start to borrow... That's their side of it, which also gives a huge onus to us, because we've got to provide for this. With our more wealthy patients, we can write a prescription. We can give the emotional [and] spiritual support. But for these people, we've got to give everything, because they have nothing.

In this way, many respondents felt that palliative care services have to address pain caused by structural problems of quality and cost in the broader health care system.

Secondly, respondents often discussed problems of opioid availability in the health system. While respondents in Kerala felt that this barrier had been overcome in important ways, opioid access was still an important issue. As previously discussed, some respondents cited physician misconceptions about opioids as a key barrier. Another

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<sup>20</sup> For context, the vast majority of Indians pay for health care fully out of pocket, as over 80% lack health insurance (National Sample Survey Office 2015, 20). Furthermore, the average medical expenditure *per hospitalization* in India nearly meets the median annual income in the case of cardiovascular disease, and exceeds it in the case of cancer (Phelps and Crabtree 2013; National Sample Survey Office 2015). While Gallup estimated in a 2013 study that the median annual income in India was US\$616, the National Sample Survey Office reported that average expenditure per hospitalization in 2014 was US\$872 for cancer and US\$487 for cardiovascular disease. (These values were calculated from ₹56712 and ₹31647 respectively, using ₹65 per US Dollar as the exchange rate.)

challenge mentioned in both Kerala and Uttarakhand was the need for a wider range of opioid formulations. A doctor in Uttarakhand stated:

Currently, it's only the oral morphine and injectable which are available [in our hospital]. But...a lot of patients are unable to swallow. If there could be a sublingual tablet or maybe [a] rectal suppository, that would work better.

A few respondents in Kerala mentioned similar needs, and added that substitution options for morphine, such as methadone, are needed. In both states, respondents noted that fentanyl patches are available, but unaffordable for most patients.

Beyond the need for more opioid formulations and education of health professionals, the challenges around morphine were quite different between the two states. In Uttarakhand, the chief challenges reported were the limited supply and burdensome licensing processes to obtain morphine. At the time of this study's data collection, the state government had not yet adopted the Amended NDPS Act. Furthermore, a government health official in Uttarakhand acknowledged that morphine was not presently available in government medical facilities.

In contrast, a distinctive challenge reported in Kerala focused on collaboration between NGOs and the government for opioid provision. Some doctors and community volunteers mentioned that the government had funding to procure morphine and other drugs, yet NGOs were still using their own limited funds to purchase these for patients. These respondents believed that collaboration between the sectors to provide morphine and other drugs could be improved. This will be discussed further in the section on the government's role in palliative care. In addition, a government sector nurse noted that her hospital, among others, did not presently have a morphine license due to lack of a doctor with the needed training.

Thirdly, some respondents described a lack of capacity in the current health system to care for people with chronic illness. They felt this was a challenge for palliative care to take on. As one pediatrician at a government hospital in Kerala put it:

Our average [daily outpatient (OP) census] is 450 to 500. Among them, probably there will be ten or twenty children with chronic diseases. How can you find time to sit alone with [them], discuss all these matters, and rehabilitate? It's not possible. So when a child with cerebral palsy is brought to a doctor in the OP, his primary focus will be on [the acute issue like] aspiration pneumonia or maybe fever... We are not bothered about the other conditions because of the overcrowding and the time factor.

In this way, time pressure in the present health care system supports an orientation toward acute care, leaving patients with chronic needs behind.

Specifically within palliative care services, respondents also described several challenges. The first was the challenge of maintaining and funding NGOs. A variety of respondents including administrators, doctors and social workers expressed that the longevity of individual NGOs is uncertain, and that maintaining sufficient staffing and funding is a constant effort. A frequently mentioned challenge in this domain was finding or developing infrastructure for providing palliative care.

Secondly, some respondents discussed a challenge that arose when palliative care teams were asked to perform services beyond the scope of palliative care or of their training. As a palliative care doctor in Kerala put it:

Palliative care has a big role, and I think it is now expanding beyond our imagination... There is a big demand from the community [to see] more types of

patients who require long-term care, [such as] psychiatric patients. But the problem is that it is beyond our expertise.

Another doctor from Kerala also perceived that as community awareness of palliative care has spread, demand for services has increased and sometimes exceeded the expertise of providers.

The last theme in this domain focused on communication with families. Some respondents expressed that when families wish to hide serious diagnoses from patients, this challenges the team's communication skills and moral compass. A dentist from Uttarakhand noted:

Most of the time, the family thinks the patient is very weak, so even when we go, they say, "We have not told him he is suffering from cancer, so even you don't disclose it."

Respondents who discussed this issue expressed that the patient needs to know their diagnosis in order to voice their wishes and exercise autonomy, but that communication of diagnoses is very sensitive.

### ***Strategies for the Provision of Health and Palliative Care Services***

Strategies for overcoming these challenges to service provision were varied. First, having community volunteers and social workers assess and meet patients' basic needs was seen as a strategy to reduce suffering from poverty and medical expenditure. Second, engaging the state government in palliative care was viewed as essential to increasing access to opioids and palliative care services.

Within the specific domain of palliative care services, participants shared rich perspectives on strategies such as starting home and hospital-based palliative care services; employing social workers to improve communication with families; working with organizations from other states and sectors; and obtaining funding for services. A key theme running through all of these is collaboration.

First, palliative care pioneers in Kerala described how engaging with state government officials was ultimately critical for expanding access to morphine in Kerala. This strategy in both states will be discussed further in the section on the government's role in palliative care and morphine regulation. Secondly, many respondents emphasized that community volunteers or social workers were needed to address the material and psychosocial needs of patients. The role of community volunteers will be discussed more in the following section. These two strategies exemplify how the challenges and strategies for palliative care intertwine across themes.

In terms of palliative care services, respondents raised a wide range of strategies for starting home care services and for improving pain treatment and palliative care in hospitals. In Uttarakhand, nurses and doctors at a cancer hospital described establishing a free palliative care service, which provides ward-by-ward consultation and a setting for group therapy and teaching of caregiving skills, such as tracheostomy, colostomy and lymphedema care. This hospital was also establishing a relationship with an NGO in Kerala to train their house staff in evidence-based pain assessment and treatment.

In Kerala, community volunteers described how they initiated their own home care services by contacting other palliative care NGOs to learn from their practices. A key strategy mentioned by a variety of respondents was for newer, smaller palliative care

units to rely on a larger NGO for their medical personnel until the smaller unit could grow and hire their own medical team.

Furthermore, respondents offered several strategies for improving communication with patients and families. First, doctors, dentists, and community volunteers all voiced a desire for more training in communication skills. Next, a variety of respondents felt that the involvement of social workers was valuable for improving communication. In Uttarakhand, where social workers are currently not involved in palliative care and many medical fields, a doctor noted:

A medical social worker is very important for the palliative care team... The cultural and emotional depth to which they can go is not something taught in the medical curriculum. We would love to have medical social workers.

In Kerala, where social workers are key team members in some NGOs but not all settings, the social workers themselves described what they bring to their teams. They noted that social workers are professionally trained in assessing psychosocial distress and responding therapeutically. A social worker shared an example of how his involvement helped make a difference in patient care:

[A patient in our inpatient unit did not have] adequate pain relief, [and] I started to have a conversation with him... to explore more about his emotional issues... I acknowledged the fact that he is in trouble, he is in pain, and he slowly started speaking to me... He was concerned about one thing. He wanted to see... his new house that is being built... he worked for almost 20 years abroad, and with that money finally he made a house, but he couldn't see it.... The family [had been] thinking that it's not the right time to do the housewarming [as] he was almost dying... I just communicated with the family, [and] they fixed the housewarming for the next day itself... He attended the function, and [when] he came [back] here, you could see the relief on him... on the next day, he passed away.

Social workers described a number of similar situations when their strong communication skills helped them meaningfully intervene and alleviate suffering.

Additionally, a strategy of collaboration was vital when providers felt stretched beyond their expertise by patients' needs. For example, social workers from an NGO in Kerala described how collaborating remotely with a psychiatrist helped them provide better care for their patients with co-occurring mental illnesses. Furthermore, some respondents in Uttarakhand and Kerala spoke about the importance of collaborating with experts from other Indian states or other countries to strengthen palliative care services. For example, a doctor in Uttarakhand described how collaborating with an NGO in Kerala was helping his institution establish palliative care services:

They are supporting partly the salary of a doctor and a nurse, and... they provided six weeks of intensive training. Not only that, they are providing ongoing advocacy in terms of any problem that we have, [and sending experts to] help us with our doubts.

This respondent noted that the international credentials and credibility of the NGO were helpful in getting the respondent's hospital to welcome the collaboration.

Finally, a variety of respondents from both states discussed fundraising strategies to support palliative care services. Community volunteers reported raising funds by calling on family and social networks. In addition, NGO administrators described efforts to fundraise by holding public events like benefit concerts, and pursuing donations from charitable foundations and corporations through their required corporate social responsibility (CSR) programs. Furthermore, a doctor in Uttarakhand described palliative

care organizations outside of their state, such as Pallium India in Kerala and the Asia Pacific Hospice Network, as key sources of funding and mentoring of new palliative care programs. Finally, in Kerala, a variety of respondents described the central government's National Health Mission (NHM) and the state's allocations to LSGIs as key sources of funding for public palliative care services. Government sources of funding will be discussed further in a later section.



### Section 3: Capacity and Involvement of the Public in Palliative Care

Many participants identified public capacity and involvement in palliative care, either in caring for family members or broader communities, as an area with important challenges and strategies.

#### *Barriers & Challenges in Capacity and Involvement of the Public*

Respondents described the challenges to public involvement in palliative care as including low public awareness of palliative care; limited capacity for caregiving at home as families become more nuclear; and limitations in NGO capacity and approach to training the public.

First, many respondents in Uttarakhand, and some in Kerala, described low public awareness of palliative care as a challenge to advancing palliative care in their state. This challenge included lack of awareness of the term “palliative care” and its meaning, as well as what services are available. Dentists, nurses, doctors, and community volunteers were among those who described this barrier. A dentist from Uttarakhand noted her personal experience:

[My father had cancer, and he] went to radiotherapy as well as chemotherapy, but after that, again, there was a recurrence... So after that, [the doctor] just wrote, “the patient [is] advised for palliative care.” That’s it. Now [that] you have given this prescription to the patient, what will the patient do? What will the family members do, when they don’t know about palliative care?

In addition, some respondents observed that families’ capacity to care for sick members at home is lessening as family structure changes in India. A few respondents described a transformation from a traditional “joint” family with multiple generations living together, to a “nuclear” family, in which only one couple with children live together, perhaps with the male spouse’s parents. Those who described this transformation mentioned that having fewer household members decreased the capacity to care for chronically ill members at home. A physician in Uttarakhand put it this way:

This transition has taken place in India, from being a joint family to a nuclear family... But at the same time, the support systems within the society... to enable nuclear families to live did not come up. [So, we need] hospice homes, nursing homes, or good support systems within the society to sustain a new culture of being [a] nuclear family.

On the other hand, two respondents from Uttarakhand--a community volunteer and a human rights commission member--made the point that the high cultural value of family and elders in their state is a strength that can facilitate palliative care.

Also in this theme of caregiving capacity, two doctors from Uttarakhand and a nurse from Kerala observed that a lack of female presence in a household increases the suffering of women with serious illness.<sup>21</sup> Some respondents said that males are uncomfortable providing bodily care to female family members, and that the presence of

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<sup>21</sup> The number of families facing a lack of female members is likely to increase in parts of India because of son preference and prenatal sex-selection practices, leading to a low ratio of female to male children in many areas. An increase in families with both parents working may also affect home-based caregiving.

a female caregiver is very beneficial for the ailing woman. The nurse from Kerala spoke from her own experience with her mother, which inspired her to start palliative care at her hospital:

How I came into this palliative care is, my mother was sick, and there was nobody to take care [of her]. My sister-in-law, who was staying at home... she died. So, practically there was no one to take care of my mother when she was not able to take care of herself... So I was going and taking care as a nurse. [And] the confidence I have--because I am a nurse--to take care of my mother was really, really comforting for my brothers.

Finally, while the need for greater public awareness of palliative care was a strong theme, a challenge that arose in Uttarakhand was that NGO capacity to engage volunteers and promote public awareness was limited. An NGO administrator from Uttarakhand noted:

There are certain families that I feel we've done a lot more for than other families, just from lack of time and lack of resources. The volunteers, the local community, could do so much more, but they've *got* to be taught, and they've got to be reached.

This administrator said that the human resources at the NGO were generally too limited to conduct mass outreach, but that their capacity increased during the winter months when foreign medical volunteers are also present at the NGO.

### ***Strategies for Capacity Building and Involvement of the Public in Palliative Care***

Strategies for increasing public awareness, capacity and participation in palliative care were among the most commonly mentioned strategies in interviews. These approaches included engaging and educating the public and volunteers; celebrating and rallying around World Palliative Care Day; engaging youth and families through schools-based awareness programs; and having the government conduct awareness programming for palliative care. A key aim of these strategies was to engage community volunteers in providing palliative care. The most prominent role that respondents described for community volunteers was assessing and meeting patients' basic needs, including food, transportation, clothing, and educational expenses for children.

Many respondents stated that efforts to increase public awareness and participation in palliative care were essential in their state. This assertion linked with a diverse set of strategies, including public events and trainings. Social workers and community volunteers in Kerala, and health professionals in both states, often led these public awareness activities. A palliative care pioneer with extensive experience in training the public asserted that the underlying approach of these trainings matters. He stated:

People sometimes talk about recruiting volunteers, [but] this is more about capacity building. You train people, whoever is available, and you tell them, "this skill may be useful to you in your future... Anyhow you will be making a visit if your family member or colleague becomes seriously ill... Why don't you make [the visit] a little more meaningful...for you and for that person. So we will train you. And if you have time to spend with us, spend it with us. But that's not a condition." So ... this is a process whereby the local community gains some skills and knowledge and confidence, and then some of them may decide to volunteer.

While volunteer activity is most widespread in Kerala, many respondents believed that extensive, direct community participation is also possible in other states, including Uttarakhand. As a doctor from Uttarakhand stated:

I don't think that the people at other places are any *less* than what they are in Kerala. You just have to reach out to them with an open heart--with an equalness, [which expresses that] "as much as I am important, so are you in this care system." ...We have a good number of volunteers, [and people in Uttarakhand] who have beautiful hearts and want to serve. So, it's just...that we have to reach out in that manner.

Other commonly mentioned strategies for raising public awareness and participation in both states included celebrating World Palliative Care Day or other significant days with public rallies; and conducting awareness programs for school children in order to promote civic engagement and palliative care awareness among children and parents. A wide range of respondents including social workers, dentists, doctors, palliative care pioneers, a human rights commission member, and community volunteers discussed these strategies. In Kerala, volunteers and social workers reported organizing these events. In Uttarakhand, respondents said that health professionals, as well as foreign and local volunteers, had leading roles.

A final strategy for promoting public awareness of palliative care was engaging the government in public awareness campaigns. A nurse in Uttarakhand recommended this strategy, and a health official confirmed that when the state of Uttarakhand becomes involved in palliative care in the future, it would use its Information, Education and Communication (IEC) programming to promote awareness. He explained:

We are hopeful, once the palliative programs also launch, we will definitely be able to make people aware... We have a centralized helpline, and obviously banners, posters, newspapers, print [and] electronic media. We use it quite frequently to generate awareness in people. IEC is not a problematic area for us.

Once community members become volunteers, many respondents expressed belief that they can provide patients with social support that harmonizes with efforts of medical teams. For example, a doctor from Kerala described a system characteristic of numerous NGOs in the state:

Once we register or accept a patient [in our] palliative care unit, there is a local network [of] neighbors or people living next door... One of them will be sent a note that this particular patient is registered [and] could you please inquire about his suffering and socioeconomic background... whether they have food, whether they have other facilities at home, and what are the [socioeconomic] factors ... adding to his pain? Those factors are really well taken up by the society.

In addition, respondents in Kerala noted that trained volunteers in both NGO and government systems have a key role in first identifying neighbors in need of palliative care.

In both Kerala and Uttarakhand, community volunteers described how they work to assess and provide for basic needs of patients and their families.<sup>22</sup> This role is often

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<sup>22</sup> Interestingly, the code for "having volunteers engaged" was strongly related to the code for "meeting basic needs of patients and families." They appeared adjacent to one another 53 times in the coded interviews. The next most related code to "having volunteers engaged" was "challenges of manpower," which was adjacent 27 times.

meant to overcome socioeconomic suffering, which can be caused by catastrophic medical expenditure as described earlier. A community volunteer from Kerala described the work that she and her fellow volunteers do in their small town:

I go with the team and most of the time I will sit with the patient and listen to their sorrows, their concerns. And there are some patients here who do not even have proper food in their home. So if we are planning to go... I will take a packet of food from my home and give that... I will do a small, small help however I can do... For one patient, I gave 1000 rupees for him to start [raising] poultry at home.

These small-scale support activities are strikingly similar to those undertaken by some community volunteers in Uttarakhand. For example, one volunteer described driving to a remote area to provide clothing and money to a young boy with cancer and his impoverished family. She had met them at a cancer screening camp where she volunteers in her town, and remained in touch with them by phone. Another volunteer described how she used her social network to help a patient's child:

Recently, there was a child here [whose] father had cancer, [and] they had removed his name from [his school's] admission list, because they could not pay the fees. So... we found a school that was willing to teach him without taking any fees up until his 12th [grade]... I also felt that, even if they did not agree to waive the tuition, I will [pay]... We are connected to many individuals, and when you have these connections, you can do a lot.

Interviews with volunteers in Uttarakhand showed a commitment and desire to directly help patients, and a hope that such activities would become more widespread.

Exemplifying how community volunteers can also provide more organized and resource intensive support, a volunteer from Kerala described the social support activities of the small palliative care organization she helps run:

We built a home for [one patient]. And [the organization is] supporting many children with educational support and many patients with a monthly food kit... Also, if a patient needs to be taken to the hospital...we will provide our vehicle for traveling.... Even at every call, if the patient calls for an emergency, the team will reach there very soon.

In this way, the voluntary activities of neighbors form a social safety net in numerous communities across Kerala. These activities by volunteers, as well as psychosocial assessments and care by social workers, emerged as important strategies for holistically supporting patients and families.

Finally, respondents who discussed the limitations in families' capacity to care for ill family members recommended various strategies to address this. Primarily, respondents thought that palliative care services themselves would help. For example, two doctors in Uttarakhand said that inpatient hospice and respite care services would help families with limited capacity to give care at home. Additionally, some respondents emphasized the importance of nurses, especially female nurses, in providing care to women in their homes. Lastly, a doctor in Kerala emphasized the importance of public training aimed at capacity building, so that families and neighbors have a higher level of knowledge and comfort about caring for an ill, bed-bound person at home.

## **Section 4: State Government's Role in Palliative Care and Opioid Regulation**

Finally, the vast majority of respondents discussed challenges and strategies relating to the state government's role in palliative care and opioid regulation.

### ***Challenges & Barriers regarding the State Government's Role***

Key challenges that respondents described included barriers to engaging with health officials; and limited baseline capacity and functioning of government health services.

First, in both Kerala and Uttarakhand, respondents reported that government health officials were initially difficult to access and convince about palliative care. Respondents mainly attributed this difficulty to other demands on officials' time and to fear of opioids. A doctor in Kerala described his early interactions with health officials in the 1990s, saying "the officials, however willing they are, are always hard pressed for time. They are overloaded with work. So even if they have good intentions, it is usually a bit difficult to get someone's attention." Corroborating this challenge, a health official in Uttarakhand noted that competing demands on time were a problem for both health officials and care providers in the government system. A doctor in Uttarakhand described how this affected early attempts to meet with officials: "[Another palliative care doctor] and myself... would wait for three hours, and then the official concerned would meet for only five minutes."

When officials were reached, their perception of opioids was a challenge to address. A doctor in Kerala recalled that in the 1990s, "People were afraid... Naturally, people think of their own children or their grandchildren. They don't want them to get addicted, so it's generally well-intentioned antagonism." A health official in Uttarakhand also identified attitudes toward opioids within the government as a potential barrier. While these barriers of officials' accessibility and fear have been largely overcome in Kerala, the work to overcome them is still ongoing in Uttarakhand.

The second major theme that respondents described as a challenge was the baseline functioning of the public health system. In Uttarakhand, respondents including doctors, palliative care pioneers, and a health official characterized weaknesses of the existing government health infrastructure as a potential problem for palliative care. As a government health official put it:

The primary challenge and the most difficult one is human resources... Because of the difficult geographical conditions, hiring of HR... and posting them in remote areas--it's very difficult. People are not ready to serve in those remote areas... Then, there's space constraint, also, because the existing facilities that we have, they don't have space.

This official also mentioned that, while village-level government health workers may be in a good position to help provide community-based care, they are often overburdened by their numerous responsibilities under different health programs.

In Kerala, where the public health system is more robust at baseline, a variety of respondents described how the current government palliative care services are promising. However, many respondents noted that the government services in their present form do not meet the full definition of palliative care, since a lone community health nurse, rather than a multi-disciplinary team, generally provides care. Furthermore, some respondents

linked the quality of the government services to monitoring and motivation. A pediatrician spoke to both these points:

The *panchayat* palliative care units — they don't have a monitoring system... Some of the *panchayats* are doing very good work. It all depends upon the persons concerned. If the workers are innately interested in palliative care and they have that aptitude, those units are running well. But some units, you know, they don't offer good quality palliative care.

At the same time, respondents in Kerala felt very optimistic about the government's involvement in palliative care and that the system mainly needed fine-tuning. As a doctor put it: "beautiful is the only word to describe what happens in Kerala, where at least a nurse goes to the bedridden patients' home once a month—that's phenomenal."

A final challenge identified by respondents in Kerala relates to the funding of government palliative care, and its effect on the distribution of services. A doctor from Kerala explained how funding has limited government palliative care mainly to rural areas and sub-district hospitals, rather than urban tertiary care centers:

The [state] policy had envisaged palliative care exactly as the 2014 World Health Assembly recommendation announced:... at primary, secondary, and tertiary levels. But because the money came from National Rural Health Mission, it had to be spent in the primary health centers and *taluk* hospitals. Not at the big hospitals, not at the tertiary hospitals. So that is still going on after ... 9 years... It wasn't a genetic abnormality [in the policy], it was an anomaly developed in early infancy.

Because of this funding approach, urban and tertiary government hospitals often lack palliative care services, while smaller hospitals and village-level programs have funding.

### ***Strategies for Engaging the State Government in Palliative Care and Opioid Provision***

Respondents in both states described a diverse set of strategies for engaging with the state government. These included efforts to educate officials and convince them of the value of palliative care; use of legal action through the state Human Rights Commission; and strategies for NGOs and the government to collaborate on service provision.

Efforts to educate and convince officials of the value of palliative care took a variety of forms. In Kerala, a distinctive strategy for sensitizing politicians and officials included pre-emptive mass training. As a palliative care doctor described:

I had...trained a huge number of people from a couple of political parties... And during the [state palliative care] policy discussion... the Health Minister, she was actually one of my trainees a long time back... So when we started talking about palliative care, she understood.

Also contributing to this positive foundation for advocacy, some respondents emphasized that developing good personal relationships with government officials was important for the non-government sector. A doctor and pioneer in Kerala described how this was critical for progress in the 1990s:

The advocacy...eventually boils down to a good relationship. [A] mutual friend, unbeknown to me, told [the official] how genuine our work was, how good our intention was, so the *next* time I saw him, he was a different man, and he took it as his mission. He was the one who immediately rang up the manufacturing unit... and asked them, "can you make morphine tablets? I'll give you the permission." They said yes, and in a minute, a giant step had been taken.

Additionally, like this doctor, a doctor in Uttarakhand described the importance of having personal contacts to help in obtaining meetings with officials. Furthermore, some respondents noted that demonstrating safe and effective work for palliative care served as an example for government officials of what can be accomplished.

In both states, organizing special meetings with government officials was a critical strategy for advancing the government's role in palliative care and in simplifying opioid regulations. These meetings convened state officials, local palliative and health care providers, and outside experts who provided credibility to local advocacy efforts. The presence of these experts mattered in both states. As a doctor from Kerala described of early meetings in the 1990s:

The major thing that reassured them was David Joranson [of the Pain and Policy Studies Group of the University of Wisconsin]. Somebody coming like that, with all that commitment and sincerity, and explaining why this was safe, I think was a major factor.

Similarly, a doctor in Uttarakhand described how the presence of experts from Kerala and Delhi at a 2016 meeting with state officials was important for their efforts. He noted:

The government was receptive because [Doctor 1] was there from AIIMS, New Delhi... our highest tertiary care center, [and because Doctor 2] was there, with [his affiliation with the World Health Organization]. With [these two, and an official from the central government], the government was willing to listen to what we had to say.

Another distinctive strategy for spurring the government to take meaningful action on palliative care was taking legal action through the state's Human Rights Commission. Palliative care pioneers in Uttarakhand described this as a vital step for their advocacy. A member of the state commission explained how, on the basis of her personal experience with cancer, she raised the issue *suo moto*.<sup>23</sup> The Human Rights Commission member sent a letter to the state health services requesting that they explain and remedy the lack of morphine and a palliative care policy in the state. As a palliative care pioneer in Uttarakhand described:

In [our palliative care Whatsapp messaging group], once we posted, "See, [other states in India] have a policy for palliative care, and we should also have [one] in Uttarakhand." And [the human rights commission member] read it, and she said, "Who is stopping it? Why don't we have [it]?" I said, "who's *listening*? No one is listening to us." ... So, through the human rights [commission], she just filed a case! ... Then, we went [back], and [the officials said], "Oh! They are the people. The case has been filed. Ask them to sit. Let us work."

Finally, many respondents from the non-government sector in both Kerala and Uttarakhand recognized the government as a key present or future collaborator. Working with the government was seen as a strategy for improving availability of strong opioids and sustainability of services in both states. For example, in Uttarakhand, many respondents described how the state is very mountainous and forested, with small villages scattered in hard-to-reach areas. A doctor noted, "someone up in the hills has no access to morphine ... So, morphine needs to be made available in all the districts at [the government's] district hospitals." Another doctor in Uttarakhand emphasized:

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<sup>23</sup> *Suo moto* means that the Commission raised the issue on its own, rather than in response to a complainant's request.

If we want to reach each and every patient who is in need, something has to be done from the side of government... palliative care should be a part of the primary health care system, [and] provided in every district hospital, or for that matter, [every] primary and community health center.

A doctor in Kerala also observed the importance of government palliative care for service accessibility. He said, “being a government facility, there may be barriers, but there are opportunities, too, because...people...need not pay *anything* as [an] outpatient fee to see me... And the morphine is free for poor patients here.” In these ways, collaborating with the government to provide services in remote areas and to the poor was deemed an important strategy for increasing palliative care access. To make these services more widely accessible, some respondents in Kerala emphasized that the government should extend funding for palliative care services to its tertiary hospitals.

In Kerala, respondents also emphasized strategies for coordinating between NGOs and the government in order to provide holistic services. As one palliative care doctor in Kerala recommended:

One [way to collaborate is for] the NGO [to focus] more on... emotional support... social support, and things that are not done [by the government]... [Also,] there are few local self-government home care units that can actually offer a specialist service like, for example, lymphedema care. If it is not there, then the [NGO] group can [do it].

In addition to this kind of task sharing, this respondent also observed that the local self-governments could innovate and expand the range of services offered by their palliative care units. Furthermore, some community volunteers and doctors in Kerala felt that the government should provide more direct funding to palliative care NGOs, particularly for purchasing medications. A doctor from Kerala gave an example of how this could work:

The government sector [runs] non-communicable disease clinics in government hospitals, [and] they distribute medicines for hypertension, diabetes and dyslipidemia free of cost, [so] this NGO doesn't have to pay from its core fund for these medicines. Definitely, the [NGO] can provide care at home, but they can direct the family member to go to this government institution... to get medicine... So, working hand-in-hand... the system will be beautiful.

A community volunteer in Kerala also noted that they sometimes collaborate with local community health workers called Accredited Social Health Activists (ASHAs). The ASHAs help them identify patients in need of palliative care in the area where they work. While village-level government health workers juggle many responsibilities, respondents in both states viewed collaborating with them as a good strategy.



## Summary of Results and Key Figures

Overall, the findings of this research united around four categories of barriers and strategies for palliative care. Figure 2 below summarizes the content of these four categories, and how the strategies are interconnected and rooted in an ethic of collaboration.



Figure 12: Summary of Barrier and Strategy Theme Findings

In addition, the findings of this research indicate that Kerala and Uttarakhand have a variety of shared challenges and strategies, while others are distinctive to each state. Figure 3 below depicts the barriers and strategies which are shared, and those which are state-specific. While some common challenges have been overcome in meaningful ways in Kerala, they are still shared with Uttarakhand in terms of the overall experience of working to advance palliative care.

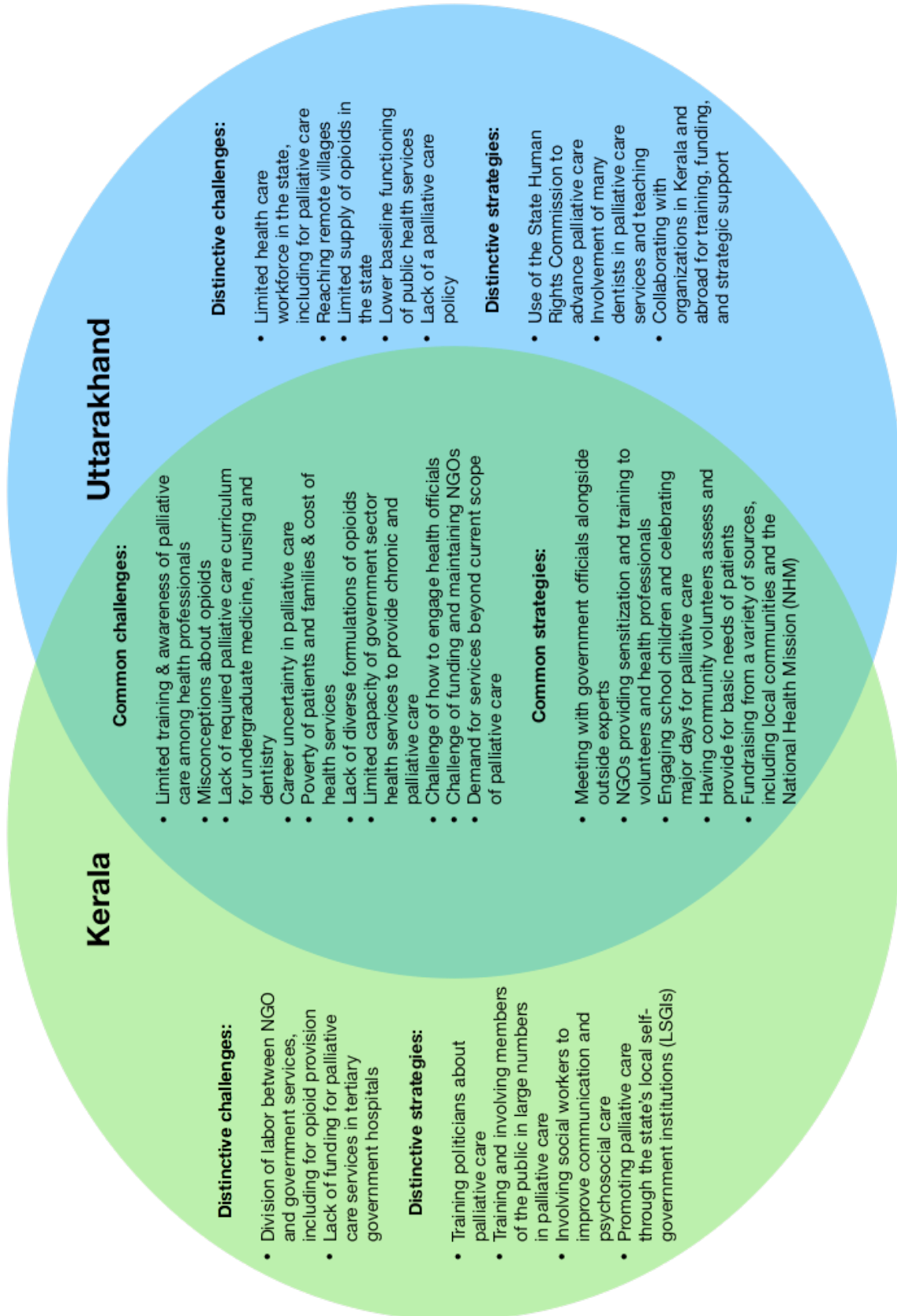


Figure 13: Shared and State-Specific Challenges and Strategies in Kerala and Uttarakhand

## Discussion

This research identified key barriers and strategies for advancing palliative care perceived by palliative care providers in two Indian states. Respondents across states expressed broad consensus on four domains encompassing these barriers and strategies, including (1) awareness and education among health professionals, (2) provision of health and palliative care services, (3) capacity and involvement of the public, and (4) the government's role in palliative care and opioid regulation. These domains were interconnected. For example, respondents expressed that challenges in one domain (such as health service delivery) could be addressed by strategies from another (such as public participation). Overall, respondents emphasized these domains about equally.

While an overarching consensus on the four domains occurred across states, some key differences appeared. In Uttarakhand, the lower baseline capacity of the public health system was reflected in the barriers respondents perceived, including in problems of health care access for patients and the potential for government-led palliative care in remote areas. At the same time, respondents were hopeful for increasing collaboration with their government, and with other local, domestic, and international medical institutions. These groups were deliberately networking to strengthen the capacity, infrastructure and training opportunities for palliative care in their state. Furthermore, respondents in Uttarakhand reported that a shortage of human resources in existing palliative care organizations limited their capacity to conduct public trainings and engage volunteers, yet many recognized the potential value of volunteer involvement.

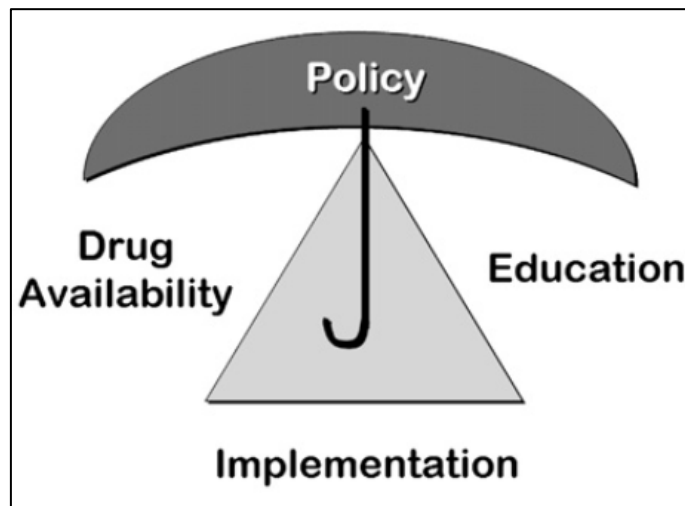
In Kerala, some distinctive themes emerged within the government's role and the public's role in palliative care. Respondents described that key barriers facing other states like Uttarakhand, such as opioid availability and palliative care policy development, had been significantly addressed in Kerala through early advocacy and mass training strategies aimed at the government. At the same time, respondents in Kerala wanted to improve NGO and government collaboration on palliative care provision. They expressed that government services could be made more comprehensive by NGO involvement and local government innovation. They also suggested that government funding for medicines and supplies could provide vital support and sustainability to NGOs, who have driven grassroots palliative care innovation. In addition, barriers to public involvement in palliative care were largely overcome in Kerala by public awareness campaigns and mass training, which other states could adapt for their settings.

Respondents from Uttarakhand reported using a number of strategies that have also been used in Kerala, such as conducting expert meetings with health officials, and leading public sensitization programs on World Palliative Care Day. However, Uttarakhand offered some distinctive strategies, including use of the state Human Rights Commission to engage the government, and use of a WhatsApp (secure, mobile text messaging) group for networking palliative care supporters. Respondents found the Human Rights Commission's involvement to be essential for spurring state health officials to listen and take action.

Some respondents in each state reported hearing people question whether the Kerala model of palliative care is applicable and feasible for other parts of India, given the extreme diversity of states' socioeconomic, political, and geographic conditions. Based on the results of this study, there are important overlaps between Kerala and the

very different state of Uttarakhand, both in challenges faced and strategies used. This overlap, depicted previously in Figure 3, suggests that mentorship between states can provide important and relevant guidance. Furthermore, volunteers in Uttarakhand described directly supporting some vulnerable patients and families and finding great satisfaction and meaning in the voluntary work. Their comments reveal the seeds of possibility for a social movement for palliative care in Uttarakhand, which has been a key approach to advancing palliative care in Kerala.

An argument for the validity of this study’s findings is that they resonate with the World Health Organization (WHO)’s public health model or “comprehensive” model of palliative care (Jan Stjernswärd, Foley, and Ferris 2007; World Health Organization 2016b). This model describes four components--palliative care policy, drug availability, education, and implementation--that must be addressed in order “to integrate palliative care into a society and change the experience of patients and families” (2007, 487). These elements are shown in the Figure 4 below.



**Figure 14: Public Health Model of Palliative Care, World Health Organization (Jan Stjernswärd, Foley, and Ferris 2007).**

The WHO model’s *policy* and *drug availability* components overlap strongly with this study’s findings on the government’s role in palliative care and opioid regulation. Furthermore, the *education* component resonates with findings on awareness and education among health professionals and the public. Lastly, the *implementation* component overlaps with findings on service provision and involvement of volunteers.

Additionally, a number of empirical studies and expert commentaries from various states support this study’s findings. For example, studies from multiple states found that patients and families in palliative care reported financial suffering, including fears for the future of children and their education, as major causes of suffering (Muckaden et al. 2005; V. Gupta et al. 2007; Elsner et al. 2012). Moreover, financial suffering has been associated with worse physical symptom burden and quality of life (Lathan et al. 2017). These studies are consistent with the challenges that respondents in this study expressed regarding poverty and medical expenditure. In addition, communication challenges with families and patients, particularly difficulties around

disclosing serious diagnoses, are well-documented (V. Gupta et al. 2007; S K Chaturvedi 2008).

In addition, survey-based studies have found that awareness of pain management and palliative care among medical and nursing trainees in India is low, and that the students surveyed desire further training (Mohanti et al. 2001; V. Gupta et al. 2007; Bharadwaj et al. 2007b; Bharadwaj et al. 2007a; Sadhu, Salins, and Kamath 2010; Prem et al. 2012). Numerous expert commentaries also echo the need for greater health professional awareness, and the lack of orientation toward chronic care in the health care system. For example, public health doctors from an NGO in rural Chhattisgarh state wrote in the *Indian Journal of Medical Ethics*:

“Large gaps exist in health worker training so that the vast majority of health professionals have little or no knowledge of the principles of palliative care. It seems that if a disease is incurable, physicians lose interest; they feel that they have nothing to offer other than to bear witness to suffering. The health system should be sensitized to consider that it is their moral duty to walk with the patient as they traverse the journey of illness, some patients cross the bridge to cure, others do not[,] but the system must accompany the patients, it cannot abandon them in [their] time of need” (Jain and Phutke 2017).

This perspective resembles those of respondents in this study.

Furthermore, review articles and a recent WHO manual entitled “Planning and implementing palliative care services: a guide for programme managers” also support a number of the strategies respondents discussed. For example, Indian palliative care pioneers and international collaborators, who spurred reforms in the NDPS Act, emphasized the importance of two strategies that also arose in Kerala and Uttarakhand: a collaborative approach with officials and civil society experts, and the use of legal mechanisms to press the government into action (Vallath et al. 2016).

The WHO manual also resonates with many of respondents’ strategies. For example, similarly to respondents in Uttarakhand and Kerala who voiced that palliative care skills should be a part of the core skills of health professionals, the WHO guide states that “specialist palliative care is one component of palliative care service delivery, but all health-care providers should be trained in pain management and the needs of patients with life-threatening illnesses” (World Health Organization 2016b, 47). Other strategies promoted by the WHO that arise in this study include “defining the government-civil society interface in establishment and delivery of care,” and “ensuring support for carers and families” (2016). The guide also touches on some strategies that were rarely mentioned in this study, including “establishing monitoring of palliative care need and access” (2016). While this study is not a how-to guide, it offers an analysis of the key challenges and strategies that matter to providers of palliative care in specific states of India. This level of context and detail can complement a generalized resource like the WHO guide.

## Conclusion and Recommendations

Within the four domains that arose from interviews, respondents and the author identified some key recommendations.

In the first domain, respondents reported a pressing need for education of health professionals about palliative care and pain management. They said that palliative care should be incorporated into the undergraduate medical curriculum regulated by the Medical Council of India (MCI). However, given the current barriers in the MCI, other professions including dentistry, nursing and social work may be more amenable to national-level curricular transformation at present. Action in these areas could improve the human resources for palliative care dramatically. Furthermore, in Kerala and Uttarakhand, the inclusion of more dentists and social workers, respectively, in palliative care education and service networks could strengthen human resources. At the same time, ensuring that doctors have undergraduate and continuing medical education opportunities is essential, because they are often gatekeepers for opioid access and for care throughout the health care system. Respondents also desired more training in palliative care, particularly in communication skills, nursing skills, and care of special populations like children and people with HIV/AIDS and mental illness. Curricula and collaborations to meet these training needs are important.

In the second domain, respondents recommended a number of strategies for starting home care services and improving pain treatment practices in hospitals. In both Kerala and Uttarakhand, the integration of palliative care into more hospitals in both private and public sectors appears to be a major frontier. In Uttarakhand, expanding services to rural areas is another frontier that many respondents felt should be prioritized. Additionally, some respondents in both states highlighted the need for more residential long-term care facilities and hospices in their health system.<sup>24</sup> NGO-affiliated palliative care providers and community volunteers in both states, including from the Rotary Club in Uttarakhand, expressed plans to develop such programs and should continue in this direction.

In the third domain, building public awareness and direct involvement in palliative care was accomplished in Kerala through diverse methods of public communication and mass training. Respondents in Uttarakhand reported that such coordinated efforts were beyond their present capacity. However, when possible, public awareness activities, and empowerment of volunteers to give direct help to patients and families, should be a priority. As a doctor and experienced trainer from Kerala recommended, training the public without expecting or requiring them to volunteer, and instead framing the training as something likely to be directly useful to them, has yielded greater public capacity and awareness. While the leadership of community volunteers in Indian palliative care has been somewhat contested (H. Gupta 2005; Jan Stjernswärd 2005), this study finds that volunteers express that their main role is to serve as a safety net for patients and families, and to meet their basic needs in the face of financial and social suffering. This kind of role is complementary to that of a medical team, and seems

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<sup>24</sup> These respondents noted that these facilities are needed for a variety of reasons: to provide care for people who are in severe poverty, have been abandoned by their relatives and neighbors, need better symptom control than can be managed at home, or whose relatives need respite from providing care.

to be an essential strategy for addressing suffering, particularly for the most socially isolated patients and families.

In the last domain, non-government actors should engage government officials through a variety of strategies. In particular, efforts to train groups of politicians, and to use state Human Rights Commissions to put governments on alert, are innovative strategies that other states can adopt. Finally, governments at both state and central levels may be critical partners for alleviating patients' financial suffering. Palliative care programs presently seek to address this suffering through a safety net of NGOs, community volunteers, and limited government schemes. These strategies remain vital. However, the government must also take action to protect people from sickness and catastrophic costs through investment in government health services--from preventing cervical cancer through immunizations and screening, to providing facilities for affordable diagnosis and treatment of diseases--as well as health insurance and other protective schemes.

Overarching all of these domains is a recommendation to collaborate. Respondents in both states emphasized the importance of forming genuine, positive relationships with gatekeepers and colleagues across institutions, sectors and geographies. Respondents reported that these relationships and efforts to humbly collaborate helped respondents stave off weariness and isolation, and were critical for achieving successes in each of the four domains.

In order to better understand how well these recommendations apply to other states in India, more research is needed. Future research should examine the barriers and strategies for palliative care in other, under-studied states, particularly large, populous states in North, Central and Eastern India. In addition, other states with palliative care policies, including Karnataka and Maharashtra, should be studied to assess specific challenges and strategies in the government domain. These may guide pioneers throughout India as they take the critical step of engaging their health officials. Finally, further research on the effectiveness of different models of palliative care throughout India is warranted. The ideal system of palliative care may not look the same for each Indian state, perhaps due to geography, sociocultural values, and existing institutions and resources. Such variation is an active question of interest in Indian and global palliative care (Zaman et al. 2017). Taken together, research on palliative care models and outcomes, as well as on barriers and strategies, can support strategic planning for palliative care in India. It is my hope that the challenges, strategies and recommendations presented here will be helpful to palliative care pioneers in Uttarakhand, Kerala, and beyond.

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