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# The Universality of Palliative Care Philosophy: A Case Study from India\*

Joris Gielen<sup>a</sup>

**Abstract:** The modern hospice movement, which is the origin of what is now known as palliative care, derived strong inspiration from Christianity. Given this original Christian inspiration, the global spread of palliative care even to countries where Christianity is only a minority religion may look surprising. In line with the theory of the “secularization of hospice,” it could be argued that palliative care has spread globally because its underlying philosophy has become secular, allowing it to become universal. However, given the continuing importance of religion in many areas of palliative care, we could wonder how secular contemporary palliative care really is. This article argues that the universality of palliative care philosophy resides in its susceptibility to contextualization. Palliative care has become a global success story because people all over the world committed to palliative care’s principles and ideas have contextualized these and developed models of palliative care delivery and even philosophy that are adapted to the local socio-economic and cultural-religious contexts. This article analyzes palliative care in India to illustrate this point, describing contextualized models of palliative care delivery and showing that palliative care physicians and nurses in India draw inspiration from their local context and religiosity.

**Keywords:** Palliative care; secularization; religion; India; Christianity; Hinduism

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\* Research article

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## *La universalidad de la filosofía de los cuidados paliativos: un estudio de caso de la India*

**Resumen:** el movimiento moderno hospitalario, que es el origen de lo que ahora se conoce como cuidados paliativos, obtuvo una fuerte inspiración del cristianismo. Dada esta inspiración cristiana original, la propagación global de los cuidados paliativos incluso a países donde el cristianismo es sólo una religión minoritaria puede parecer sorprendente. En consonancia con la teoría de la “secularización de la hospitalización”, se podría argumentar que los cuidados paliativos se han extendido globalmente puesto que su filosofía subyacente se ha vuelto secular, lo que le permite convertirse en universal. Sin embargo, dada la importancia continua de la religión en muchas áreas de los cuidados paliativos, podríamos preguntarnos cuán seculares son realmente los cuidados paliativos contemporáneos. Este artículo argumenta que la universalidad de la filosofía de cuidados paliativos reside en su susceptibilidad a la contextualización. Los cuidados paliativos se han convertido en una historia de éxito mundial, ya que personas de todo el mundo comprometidas con los principios e ideas de los cuidados paliativos los han contextualizado y han desarrollado modelos de prestación de cuidados paliativos e incluso una filosofía que se adapta al contexto socioeconómico y cultural-religioso local. Este artículo analiza los cuidados paliativos en la India para ilustrar este punto a través de modelos contextualizados de prestación de cuidados paliativos, y muestra que los médicos y enfermeras de cuidados paliativos en la India se inspiran en su contexto local y religiosidad.

**Palabras clave:** cuidados paliativos; secularización; religión; India; cristianismo; hinduismo

## *A universalidade da filosofia dos cuidados paliativos: estudo de caso da Índia*

**Resumo:** O movimento moderno hospitalar, que é a origem do que agora é conhecido como “cuidados paliativos”, derivou de uma forte inspiração do cristianismo. Tendo em vista essa inspiração cristã original, a propagação global dos cuidados paliativos, inclusive a países onde o cristianismo é somente uma religião minoritária, pode parecer surpreendente. Em consonância com a teoria da secularização da hospitalização, poderia argumentar-se que os cuidados paliativos vêm se estendendo globalmente, visto que sua filosofia subjacente vem se tornando secular, o que lhe permite converter-se em universal. Contudo, considerando a importância contínua da religião em muitas áreas dos cuidados paliativos, poderíamos perguntar-nos quão seculares são realmente os cuidados paliativos contemporâneos. Neste artigo, argumenta-se que a universalidade da filosofia de cuidados paliativos reside em sua suscetibilidade à contextualização. Os cuidados paliativos vêm se tornando uma história de sucesso mundial, já que pessoas de todo o mundo comprometidas com os princípios e as ideias dos cuidados paliativos os têm contextualizado e têm desenvolvido modelos de prestação de cuidados paliativos e inclusive uma filosofia que é adaptada ao contexto socioeconômico e cultural-religioso local. No texto, são analisados os cuidados paliativos na Índia para ilustrar esse ponto por meio de modelos contextualizados de prestação de cuidados paliativos e é mostrado que os médicos e os enfermeiros de cuidados paliativos na Índia se inspiram em seu contexto local e em sua religiosidade.

**Palavras-chave:** cuidados paliativos; secularização; religião; Índia; cristianismo; hinduísmo

## The Christian Inspiration that Led to Palliative Care

When patients suffer from a protracted or life-threatening disease, they are often in need of more than just curative care. Such patients, especially those beyond cure, may require an approach that addresses all their problems, many of which are not just physical. In this context, palliative care steps in. Palliative care aims at relieving all symptoms that accompany a serious disease in order to allow the patient and his or her relatives to live a life that is as meaningful, active, and joyful as possible. The goals and means of palliative care have been very accurately described in the World Health Organization's well-known definition of palliative care. According to the World Health Organization (WHO),

[p]alliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial, and spiritual (1).

Palliative care has its roots in the hospice movement, which began to take shape in the first two decades after World War II. Cicely Saunders (1918-2005) played a pivotal role in the origination of that movement. Its first culmination was the opening of Saint-Christopher's hospice in the summer of 1967 in London. That event is generally seen as the formal beginning of the modern hospice movement (2). The word 'modern' is not without significance, as the concept of 'hospice' was not altogether new. The idea of providing holistic care to terminal patients was indeed novel because, at that time, death was considered a medical failure, and not much attention was paid to the alleviation of pain and suffering of dying patients, though hospices had been existing in Europe since Mediaeval times.

Hospices had been places where members of Christian religious congregations cared for travelers and the ill as part of their religious vocation. In that sense, there was an intimate connection between hospice and the Christian religion. In many

ways, modern nursing care —and from there palliative care— can be seen as a development out of these mediaeval hospices. This becomes particularly clear when we consider that Florence Nightingale (1820-1910) and others who set out the first benchmarks of modern nursing in the nineteenth century did not entirely sever the ties between religion and nursing. Although Florence Nightingale contributed to transforming nursing into a lay profession, her Christian religious inspiration was never far away (3).

In the second half of the twentieth century, at least in the vision of the founders of the modern hospice movement, the ties between nursing and religion were renewed. Cicely Saunders, a nurse herself before becoming a physician, made religion an integral part of palliative care. Cicely Saunders was convinced that religion was not only important to the dying patients and their family members but also to the members of the palliative care team. She even pondered whether, ideally, professional palliative caregivers should not be members of a specifically dedicated religious congregation with its own rule and discipline (4). The close connection between Cicely Saunders' own Christian inspiration and the provision of good medical care to terminally ill patients becomes very clear in a letter that she sent to a certain Bruce Reed on March 14, 1960. She wrote:

During the course of our discussion you asked me more than once what I thought I was really aiming at. You were not certain whether my vision was a spiritual or medical one. Whether my interest in the medical side —the control of pain and so on, and my desire to spread the knowledge of how to do that— was really more important to me than my desire that every patient in our Home and in many similar Homes elsewhere in England should come to know the Lord ... [but] in this work the medical and spiritual are inextricably mingled. I long to bring patients to know the Lord and to do something towards helping many of them to hear of him before they die, but I also long to raise standards of terminal care throughout the country from a medical point of view at least, even where I can do nothing about the spiritual part of the work (4 p356).

Expressing this kind of idea was not particularly problematic in the UK in the early 1960s. Christianity was by far the dominant world view in British society, and, for most people, deriving inspiration from Christianity or attempting to spread a Christian message without proselytizing may not have seemed objectionable. At that time, Cicely Saunders could hardly have imagined how society would change in the coming five decades and how the UK would evolve into a truly multireligious society. Neither could she have envisioned the extent to which palliative care would spread over the world because by the end of the century, palliative care had become a global movement.

In 2013, an influential study on the levels of palliative care development across the world identified palliative care services in 136 of 234 countries (5). The authors did find wide-ranging differences among countries regarding coverage and types of palliative-care activities. Countries such as the UK, the USA, Australia, and Belgium were defined as countries “where hospice-palliative care services are at a stage of advanced integration with mainstream service provision.” This implied that health professionals were well aware of palliative care in these countries, a variety of palliative care services existed, and palliative care influenced policymaking. Countries such as China, Denmark, Israel, and the Netherlands had reached a level of integration that was characterized as slightly more “preliminary.” Countries such as Croatia, Cyprus, Turkey, Nepal, and India were characterized by “generalized palliative care provision.” These countries saw developing palliative activity across their territory, expanding local support and funding, as well as hospice organizations that provided some level of training. Countries where the development of palliative care activity was more “patchy” and enjoyed less support were characterized as countries with “isolated palliative care provision.” Countries such as Greece, Russia, Brazil, and Mexico fell into this group. Other countries, such as Honduras, Bolivia, and the Democratic Republic of Congo, were still in the phase of “capacity building activity,” where concrete steps had been initiated towards the development of palliative care services and policy. Although no hospice-palliative care activity was

detected in many countries, the study illustrates the global range of palliative care. Outside the UK, palliative care has spread to other European countries, North and South America, Australia and New Zealand, and even Africa and Asia.

The global development of palliative care is intriguing because it illustrates that palliative care is flourishing in contexts that markedly differ from the context in which Cicely Saunders began reflecting upon the care needs of terminally ill patients. She started her reflections in a predominantly Christian European context of the 1960s. From there, palliative care has spread to countries with radically different socio-cultural and religious constellations, such as the multireligious Indian context of the 21<sup>st</sup> century. It sounds plausible to assume that the worldwide expansion of palliative care would not have been possible if the underlying philosophy had remained strongly intertwined with its original Christian inspiration. It seems unlikely, for instance, that specifically Christian motivations would have appealed very much to Hindu physicians and nurses in India.

A possible explanation for the global expansion of palliative care may be found in the theory of the “secularization of hospice.” Several scholars have argued that simultaneously with its global expansion, palliative care has gradually moved away from the original Christian inspiration and has become more secular (3-4,6). Following this theory, we could argue that the original palliative care philosophy, which was steeped in Christianity, has become universal through a process of secularization in which it was separated from its original Christian foundations.

According to Ann Bradshaw (3), this “secularization of hospice” can be perceived in the four areas that constitute contemporary palliative care: the medical, the psychosocial, the educational and research, and the spiritual. Bradshaw argues that there is an increased focus on medical treatment of pain and symptoms in palliative care, including anxiety and depression, at the expense of attention to other approaches. Psychosocial issues tend to be addressed through learned techniques or counseling rather than theologically inspired love. The growing attention to palliative care education and

research and the perceived need to evaluate the services and programs led to decreased attention to aspects that are not easily measured, such as feelings and emotions. Attempts to interpret spirituality in palliative care broadly as a “search for meaning” so that it can be distinguished from religion markedly differ from the Christian spiritual care that Cicely Saunders originally had in mind. All these evolutions can be seen as signs of a move away from the original Christian inspiration of palliative care.

In this way, palliative care could be said to have become more of an effective technique that has no actual link with Christianity and can be applied to the care of the seriously ill in very diverse religious and cultural environments. This would indeed explain how palliative care can thrive in the 21<sup>st</sup>-century Western context where the influence of Christianity is often perceived as waning, in addition to other contexts, such as India, where Christianity has never been more than a minority religion. Yet, we can wonder how absolute this “secularization of hospice” has been. Religious influences may indeed have become less clearly noticeable over the past sixty years of palliative care development. This does not necessarily mean, however, that religion no longer plays an important, albeit less visible, role in global palliative care. Even if palliative care has become more of a technique devoid of its original Christian inspiration, religion could still be important in particular aspects of care both in the west and elsewhere.

In palliative care, not only the patients and their relatives but also the members of the palliative care team are confronted with the finiteness of health and life. This triggers existential questions, such as: “What is the purpose of this suffering?” and “Will there be life after death?” Religions have traditionally provided answers to these questions, and to many in palliative care, these religious answers may still matter (7-9). This is especially true at the end of a patient’s life when difficult decisions have to be taken regarding treatment options that may impact the quality and duration of life. People involved in these decisions may start wondering whether they are making the ‘right’ decision and are doing the ‘right thing.’ Also here, religion may

play a role and make caregivers consider a particular treatment decision at the end of life, either morally good or morally bad (10-13).

This is not to say that tendencies in palliative care philosophy towards secularization are a mirage. Healthcare professionals do not need to be religiously minded in order to have a meaningful and satisfying career in palliative care, but the secularization of palliative care philosophy can only partially explain the global expansion of palliative care. In the following sections, I will argue that what led to the global expansion of palliative care was not primarily secularization but the creative application of palliative care philosophy and ideas to local contexts by people who devoted themselves to developing palliative care within these contexts. The argument, in a nutshell, is that, rather than secularization, contextualization has enabled palliative care philosophy to become universal. Secularization may indeed have made it possible for palliative care philosophy to detach itself from its original Christian inspiration, but its global expansion has been made possible through processes of creative contextualization. The universality of palliative care philosophy, then, resides in its susceptibility to contextualization.

To illustrate this point, I will describe how palliative care principles and philosophy have been adapted or contextualized to India’s socio-economic and cultural-religious context. In the next section, I will analyze the variety of palliative care programs that have been developed in India in an attempt to meet the palliative care needs of the local population. In the section after that, I will briefly present empirical data that show that palliative care physicians and nurses in India derive inspiration to work in palliative care from their context and local religions.

## Palliative Care Programs in India

Since the 1980s, in different parts of India, palliative care programs have been developed. The programs were a reaction to the great unmet needs of patients. Diseases such as cancer can lead to severe pain and symptoms such as nausea, vomiting, and delirium that are sometimes hard to manage. Approximately one million people are diagnosed



with cancer in India each year. As such, this is not a very high number when we compare this in proportion to developed countries, yet the number of cancer cases is rising.

Moreover, when we have a look at the mortality burden, the picture becomes more dramatic. With an estimated six hundred to seven hundred thousand deaths, the cancer mortality burden of India rivals that of developed countries when we take into consideration that India has a relatively young population. Also, just 30% of Indian cancer patients survive five years or more after diagnosis. In North America and Western Europe, this is 60%. These findings indicate that treatment outcomes in India tend to be poor, and cancers are often detected in later stages (14). Late-stage cancer generally implies more severe symptoms and, thus, a higher need for palliative care. The inception of palliative care in India can be seen as a response to urgent needs for pain and symptom management.

A first major achievement of the palliative care movement in India materialized in Mumbai in 1986 with the foundation of Shanti Avedna Sadan, a hospice for cancer patients (15-16), that would later on open branches in New Delhi and Goa. Also in 1986, pain clinics were established at the Regional Cancer Center in Trivandrum, Kerala's capital, and Kidwai Memorial Institute of Oncology, a tertiary hospital in Karnataka's capital, Bengaluru (17). These events marked the beginning of the development of various palliative care programs and models in different parts of India. Over the years, the outcome was a very diverse landscape of palliative care programs that can be grouped as "home care," "outpatient clinics," and "inpatient provision" (18). In order to give an idea of the variety of services that exist in India, it may suffice to mention some compelling examples, without any claim of being exhaustive or denying the importance of other programs. In what follows, I will pay particular but not exclusive attention to examples from the Delhi region, as the empirical data that are presented were collected there.

A milestone for palliative care provision in India in general, and home care in particular, was the foundation of an NGO called the Pain and Palliative Care Society in 1993 in Calicut, another major city in Kerala. The originality of this project lies in its attempt to develop a palliative care model that

is attuned to the Indian context with its limited resources for palliative care. This goal was achieved by entrusting the care of patients primarily to relatives who get support and care training from an outpatient clinic. Inpatient care and home visits by a professional team are limited to those patients whose pain and symptoms can impossibly be controlled without professional assistance (19-20).

The pioneering work of the Pain and Palliative Care Society gradually expanded over the state and led to the foundation of the Neighborhood Networks in Palliative Care in 2001. This program successfully tried to more actively involve the local community in palliative care provision, as it was believed that this was the only way to improve the quality and reach of palliative care in that region of India. Under this program, volunteers from the local community are taught basic palliative care skills to respond to the needs of chronically and terminally ill patients with the assistance of a professional team. The activities undertaken by groups working under the program go beyond care for physical wellbeing; they address issues such as patients' financial problems, social and spiritual concerns and raising funds (21-23).

While community-based palliative care programs were budding in Kerala, different models of home care were being developed elsewhere in India. In 1997, CanSupport began its operations in the New Delhi region. This program caters to the palliative care needs of cancer patients through home care teams. Most patients are referred to the service by hospitals and pain clinics, including the pain clinic of the Dr. B.R. Ambedkar Institute Rotary Cancer Hospital at the All India Institute of Medical Sciences (AIIMS), a tertiary hospital in New Delhi. But, patients also come to know about CanSupport through word of mouth, *e.g.*, from family members of patients who have benefited from the program. The teams consist of a physician, nurse, and counselor and operate from field centers spread out over the national capital region (24). An essential difference between CanSupport and programs in Kerala is that the role of CanSupport's professional multidisciplinary teams is substantial, and reliance on volunteers is limited.

As illustrated by the example of CanSupport and the Neighborhood Networks in Palliative Care, home care programs often function in conjunction with outpatient pain clinics. Such clinics are often connected to government hospitals that provide space in buildings and some staff support. In the clinics, patients are assessed by a professional palliative care team. The team manages complex cases by diagnosing and prescribing pain medication, and, if necessary, the team refers them to other professionals for interventions such as physiotherapy, interventional pain management, or psychiatric assessment. The team can also empower relatives and other informal caregivers by educating them on the patient's care needs. Outpatient pain clinics, such as the clinic above of the Regional Cancer Center in Trivandrum and the one at AIIMS, are very important for providing palliative care in the Indian context, where there are insufficient home care teams and inpatient programs to alleviate all needs (25).

Inpatient models of palliative care include the hospices of Shanti Avedna Sadan that were mentioned above. These institutions and other hospices in India, such as Karunashraya in Bengaluru, resemble hospices that can also be found in Western countries. In a hospice, dedicated palliative care professionals, supported by some volunteers, provide high-quality care to the terminally ill, who come to the hospice in the last weeks or days of their life and usually stay there until their death. A pain and palliative care unit, like the one that has been founded in the Dr. B.R. Ambedkar Institute Rotary Cancer Hospital, is also an inpatient facility, but it functions differently. It is a hospital unit where patients usually only stay until their pain and symptoms have been satisfactorily controlled to go home. The patients will receive care through the pain clinic or from a home care team from then onward. Patients with high care needs may be advised to go to a hospice at the very end of their life.

The extensive development of palliative care in home care and inpatient and outpatient facilities has benefited from education and research.

The Indian Association for Palliative Care has coordinated educational and research efforts since its inception in 1994. The association publishes a journal: the *Indian Journal of Palliative Care*, an open-access journal available online for free (<http://www.jpalliativecare.com/>). The association also organizes an international conference each year. The first conference was held in Varanasi in 1994 (17). These conferences provide a unique opportunity for palliative care professionals and volunteers to update and refresh the knowledge that they gained in earlier palliative care training.

People who are interested in education and training in palliative care can pursue various courses. The Indian Association of Palliative Care has been particularly successful with its Certificate Course in Essentials of Palliative Care, open to physicians and nurses. It consists of fifteen hours of contact sessions, followed by ten days of clinical observation in a palliative care program. The course is offered multiple times a year in medical and palliative care centers all over India. There are other courses, as well. For instance, Pallium India, a national charitable trust based in Trivandrum that focuses on pain relief and palliative care, offers courses of six weeks and one month for physicians, nurses, and persons with other qualifications in Trivandrum, Hyderabad, and Jaipur. Several palliative care programs, including CanSupport, are also offering training to their new volunteers, physicians, nurses, counselors, and existing staff (24). Although attention to palliative care in most medical curricula has remained very limited, the Medical Council of India recognized Palliative Medicine as a specialty and sanctioned an MD course in Palliative Medicine in 2011. This postgraduate medical degree offers physicians the opportunity to train for three years in palliative care (26).

These remarkable achievements should unfortunately not make us oblivious of the fact that much work remains to be done before India can be categorized as a country “where hospice-palliative care services are at a stage of advanced integration with mainstream service provision” (5).



Palliative care in India has significant limitations. A first limitation of palliative care in India is its emphasis on cancer patients. This focus is certainly understandable given the particular needs for pain management among this group of patients. It also has to be added that recent research and presentations at the annual conference of the Indian Association of Palliative Care indicate that there is a willingness to include other patients with palliative care needs, *e.g.*, those with HIV/AIDS, and several programs are already catering to the needs of non-cancer patients. A second limitation is harder to overcome: the limited geographical coverage of palliative care. This is a huge problem. At present, palliative care services are functioning in just over half of the Indian states. Except for the South-Indian state of Kerala, the services are concentrated in large cities, and people living in rural areas do not have access to palliative care unless they are willing to travel long distances (16,18,20).

On an Indian scale, problems related to coverage cannot be entirely overcome without substantial financial investment. Organizations providing palliative care in India rely on various funding sources, but, generally, the charges made to patients for palliative care are limited. This is because the organizations that provide palliative care services are inclusive and do not want to exclude patients with less financial means. If the money for the services does not come from the patients, it must come from elsewhere. Through donations and charity, some organizations have been able to do substantial work in palliative care. But, this kind of funding is unlikely to ever be enough to alleviate all palliative care needs in India. Other options for funding are then private investors and the government. Although these two players are not absent in palliative care in India, their contribution is not very substantial compared to the needs. This may not change soon. From the perspective of private investors, the lack of interest in palliative care is understandable. Compared to invasive medical procedures aimed at cure, there is not much money to make in palliative care. The latter is also true for healthcare professionals who try to make a living

in palliative care in India. Given the limitations in funding, salaries do not tend to be grand. This brings us to the next issue: Why do people with healthcare degrees want to work in palliative care in India?

## Reasons to Work in Palliative Care

The job that people do to earn an income is a crucial part of their lives. The importance of the job in individuals' lives is illustrated by findings that point at the detrimental effects of joblessness on health outcomes. Studies have shown that unemployment is associated with poorer physical and mental health (27-29) and an even higher risk of mortality (27,30,31). This does not mean, however, that people are able or even willing to take on any job for which they may be qualified. Palliative care physicians and nurses in particular need a good amount of idealism, for working in palliative care is often a difficult job. Caring for palliative patients can be emotionally burdensome (32). The particular context of a developing country like India poses additional challenges to professional palliative care providers, given the very limited financial resources (16). At times, people who choose palliative care as a job in India have to be satisfied with lower wages than in other medical settings. For the members of home-care teams, traveling many hours a day on bad roads replete with potholes in a sometimes hot and humid climate can be physically tiring. These particular difficulties lead to the question of why Indian physicians and nurses start working in palliative care and why they continue working there.

Earlier, we saw that Cicely Saunders was driven to care for the dying by her Christian faith. What would motivate Indian physicians and nurses who may be Christian, Hindu, Muslim, or belong to another religion? An answer to this question may be gleaned from data that were collected among 27 physicians and nurses working in palliative care programs in New Delhi. These data were collected through an interview study based on Grounded Theory methodology. It assessed the influence of religion on the participants' attitudes to treatment decisions at the end of life. In the interviews, the

respondents spoke about how they came to work in palliative care and why they devoted their lives to the care of the terminally ill. This study's methodology and research design have been described elsewhere (10-11,33). In order to protect the anonymity of the participants, their names have been replaced by fictional names in the paragraphs below.

What struck in the interviews was that initially, the respondents did not join palliative care for any intrinsic reasons. In fact, the nurses and physicians hardly knew anything about palliative care before they started working in it. Most respondents started working in palliative care almost accidentally. Many interviewed physicians learned about palliative care when they started a specialization in anesthesiology. Others came to know about palliative care after responding to a vacancy in a palliative care program. Dhanya (a nurse), Dr. Arpita, and Dr. Alka were participants whose first encounter with palliative care was a call for applications to a vacancy in a palliative care program.

When I joined, I did not know anything of palliative care. That time, I was just searching for a job. (Dhanya)

There was a vacancy here [in palliative home care]. [...] I wanted to do this practice, because I did not want to do invasive works. So, I asked for this. [...] To be honest, I did not know about palliative care before this. (Dr. Arpita)

I was just going through the newspaper, and there was an ad for a walk-in interview. I just walked in as I was residing nearby. I got selected. After joining, I got interested in palliative care. (Dr. Alka)

Dr. Alka testified that the first confrontation with palliative care was indeed a chance encounter. But, the immersion in palliative care turned out to be a very positive and rewarding experience, and she became really interested to know more about palliative care practice. For Dr. Alka and the other participants, their work in palliative care was a source of professional gratification and personal satisfaction. Professional gratification resulted from the realization that physicians and nurses had most opportunities to be a good doctor or nurse in palliative care. The fact that palliative

care patients are in a very advanced stage of their disease did not prevent the interviewees from having this opinion. The interviewees were aware that in other healthcare settings, such patients are often considered hopeless cases for whom nothing can be done anymore, but they felt that as physicians and nurses, they still had "something to offer" to the patients and their relatives, even though they could not fully restore the patients' health. The interviewees particularly liked this aspect of their job. Dr. Alka testified how caring for patients whom other doctors have abandoned gave her much satisfaction.

Actually it's a very satisfying job, very nice. We take care of the people for whom the doors of other hospitals are no more open. They are no longer welcome there. They often have been told: "Don't come to the hospital. Now we have done everything." Taking care of those people who have really been abandoned by all other hospitals is very satisfying. [...] Here still you care for four, five, six months. [...] Still you have something to do, something to offer. (Dr. Alka)

Dr. Bhupesh described a similar experience of how it used to be customary for patients for whom cure was no longer possible to be left on their own devices. He felt happy that as a member of a palliative care team, he could help to increase the quality of life of terminally ill patients, which he called "adding life."

I'm enjoying the job. When I was a fresh graduate from medical college, palliative care patients were just left to themselves. The Family was told: "Take him home and look after him there. He's going to die now. So what? Let him die." And the agony the patient used to go through was terrible. Patients often longed for death because of pain and suffering. Dying was not with grace. Patients felt that life is a curse, which actually it is not. You see, I believe that in the worst of worst of circumstances one should do the best one can do. In the first place our view is that we don't add years to the lives, but we do add life. (Dr. Bhupesh)

An important way through which the physicians and nurses felt that they could help the patients was by reducing pain and suffering. According to the interviewees, even if they could not

restore their health, they could still relieve their pain and suffering. In the participants' view, relieving pain and suffering is an integral part of being a healthcare provider. Dr. Sandeep argued that looking after the patient's health and pain are equally essential. Particularly at the end of life, when cure is no longer possible, the focus shifts to pain treatment in order to make a peaceful death possible.

It is a fact that all doctors want to make the patient's health alright. But that should also be the case with pain. Because on the one hand we have to look after the patient's health, but on the other hand we also have to see to it that the last moments of his life are peaceful. (Dr. Sandeep)

Because pain treatment is so essential, Dr. Rahul even called the reduction of suffering a physician's duty.

It is the duty of us doctors regardless of our specialty to reduce the patient's sufferings as much as we can. That is a part of the basic expectation from any doctor. (Dr. Rahul)

Within the specific context of palliative care, the physicians and nurses did not consider physical pain and discomfort the only area they could do something for the patient. As palliative care physicians and nurses, they also paid particular attention to the patient's feelings and emotions. Shiji (a nurse) and Dr. Ashok contrasted this palliative care practice of paying attention to emotional needs with other healthcare settings where these needs are generally neglected. Shiji testified that understanding the patients' feelings enabled the team to provide emotional support.

In the hospital, it's all just routine duty. But in palliative care, we come to know the feelings of the patient and his family. Emotionally, we can help them so much. (Shiji)

Dr. Ashok emphasized the necessity of listening to the patients so that the team becomes aware of their emotional needs.

And you listen to them [*i.e.*, the patients]. That is most important. Most of the doctors and nurses don't do that. But here we do that. (Dr. Ashok)

The physicians and nurses felt that their efforts paid off. Over and over again, they observed that their patients somehow benefitted from their care. They then felt very satisfied with their work. Satendra (a nurse) expressed how satisfied he feels when a patient's pain improves and the patient is more relaxed.

I feel satisfied when a patient who had been in very severe pain at the time of admission gets pain relief after some time and becomes active. I feel glad when that person is happy. Then I compare how the patient was when he came in the [palliative care] ward and how he is now. What is the difference? (Satendra)

Gloria (also a nurse) had this feeling of satisfaction when she noticed that her efforts to empower the family caregivers through instructions on patient care paid off, and the patient improved.

To me, it seems that I have done something for the patient. I have dressed his wounds. I have taught his family members how to put on a bandage. When I go there the next time, I will notice that the wound is better and clean. So I will feel satisfaction and think: "I have taught them something." Because the family members now know how to put a bandage. I feel happy. (Gloria)

The positive feelings of the physicians and nurses regarding their work were further strengthened by clear signs of appreciation of the patients and their family members. The physicians and nurses felt that the patients and their relatives highly value their work. Dr. Arpita and Dr. Paravathy talked about signs of appreciation that they had experienced.

[The patients and their relatives] give us feedback, and I didn't get that before actually. Even in their letters and all— they send us letters— or even verbally they give us feedback. They really appreciate the efforts. (Dr. Arpita)

When you see how thankful patients are! Like, I can tell you: in the past week we went to a patient's house. Just compare the state in which we had seen her the first time and the state in which we found her four days later. In four days, there had been so much change in hygiene and in the way she was. You should have seen how thankful and grateful she was. (Dr. Paravathy)

The appreciation of patients and their relatives and the feeling that they had done something significant for them gave the nurses and physicians a strong feeling of personal satisfaction. Gloria and Shalini (another nurse) testified:

I get so much satisfaction. The patients are very sick and dying. In the evening [after my duty] I have the feeling that I did something for the patient. (Gloria)

After helping the patient, I feel mental satisfaction and I feel proud. (Shalini)

Such feelings of satisfaction helped the nurses and physicians to go on with their job, even though it would not make them rich, as Dr. Ashok laconically remarked.

[Palliative care] is a very important thing. But I think it is, you know, quite underestimated as a branch. There is not much monetary gain in this field. But the rate of satisfaction is quite high when you serve the people, when you hear them and when you serve them. It's quite satisfying. [...] As a human person, it is very satisfying when you work in palliative care. (Dr. Ashok)

From all this, it seems that the initial motivation and constant drive to work in palliative care was not specifically religious in nature. For the physicians and nurses, the first introduction into palliative care had been fortuitous, and professional gratification and personal satisfaction were sufficient reasons to continue working in palliative care. At first sight, this seems to lend credence to the theory of the "secularization of hospice." Nevertheless, several participants also gave a religious interpretation of their work. This religious interpretation further strengthened their appreciation for their job in palliative care. The interviewees, who were either Christian or Hindu, connected their job with God in a double way that could be described as ascent and descent. On the one hand, participants interpreted their work as an opportunity to ascend to or make contact with God. On the other hand, they saw their work as a way in which God descended or, we could say, extended His helping hand to suffering human beings.

We can speak of an ascent to God because the interviewees testified that their work brought them closer to God. Dr. Bhupesh stated:

After joining [the palliative home-care team] I am closer to God. I have never felt so close to God. This plus point is within me. (Dr. Bhupesh)

Hindu and Christian interviewees saw their work as an opportunity to connect with God because they interpreted it as a service to God. Through their care for the patients, they served God. Shalini, a Hindu nurse, linked her job with her devotion to Kṛṣṇa, a form of the Hindu God Viṣṇu.

My view is that whatever work I do, I do for Him [*i.e.*, God or Kṛṣṇa]. It is a service to Him. I take care of the patient. And somehow I think that I am serving Kṛṣṇa. (Shalini)

Shalini then explained that her care reached God because the patient is a "form of God." Since the patient is a form of God, serving a patient means serving God.

Indirectly it [*i.e.*, care for the patient] is going to Him. I do my duty for Him. [The patient] too is a form of God. (Shalini)

This statement has to be understood within the context of the Hindu belief that within every living being, there is a divine spark called the *ātman*. This *ātman* is believed not to be fundamentally different from the divine Absolute or God. In that sense, a patient could indeed be seen as a form of God, or God could be said to dwell in the patient, as Dr. Shweta argued.

When patients are suffering [...] then we have to think that God is residing in all. Like the *ātman* is residing in all. And so one has to serve them. (Dr. Shweta)

The idea that the divine is present in every living being could create a feeling of connectedness and solidarity because the same divine spark that is present in one person is also present in every other person. In that way, all human beings are connected. Because of this connection, it should be obvious for people to help each other (34). The quotes above show that some Hindu interviewees indeed used this idea to give meaning to their work in palliative care.

Christian interviewees, too, testified that their work brought them closer to God. Catherine, a Christian nurse, even saw her work in palliative care as a worthy substitute for individual prayer. Her work was a way to communicate with God, just like prayer. She felt that in palliative care, she was doing something that God wanted her to do. Thus, in her view, doing God's will is a kind of prayer.

I may not get much time for my personal prayer. But I am doing God's will through my care for our patients and by doing everything that is connected with that. I may not sit and pray for a long period. I do not have time. But even now I feel that what I am doing I'm doing for Him. (Catherine)

This view fits in well with the Christian belief that through dying on the cross, Jesus Christ showed that God shares in every human suffering. Therefore, Christians believe that whatever someone does to the poor and the needy is a service to God (Bible Mt 25.40). God is believed to love all human beings, but He feels a particular affection for those in need. Betty, a Christian nurse, expressed this idea in the following way while talking about her patients.

God feels a special love for them. God loves them in a special way [because] they're in the last stage [of their disease]. (Betty)

In this view, caring for palliative care patients thus means expressing the love that God feels for them. This aspect is related to the second way in which the interviewees connected their job with God: divine descent. Interviewees believed that through their work, they could make their patients feel God's grace. Hindu and Christian interviewees testified that the good things they did for their patients resulted from God acting through them. The physicians and nurses were, so to say, instruments of God's grace. Dhanya, a Hindu nurse, related the empathy that she shows in her palliative care practice to God's grace.

That [empathy for the patient] also is a grace of God. Because maybe God only sent you there. (Dhanya, nurse)

Dr. Bhupesh said that he believed that all his team's achievements are an expression of the grace of God.

Whenever we achieve something as a team, we feel that our intervention is God's grace. So we always tell patients: "We do the best we can do. [But] put yourself into God's hands. He is the Savior." (Dr. Bhupesh)

In this statement, Dr. Bhupesh argued that God acts through the physicians and the nurses. Without His support, they would not be able to accomplish anything. The physicians and nurses expressed the belief that God had given them the material means and emotional strength to provide palliative care. Dr. Bhupesh continued by thanking God for this.

I thank God that we can do this for our patients. Thanks for the facilities; for the vehicle; for the medicines. (Dr. Bhupesh)

Catherine, a Christian nurse, expressed a similar belief that she could function successfully in palliative care, which she described as her "mission," because God's grace supported her.

I am able to work and care for these patients, because God's grace is working in me. That's why I'm able to do that work. [...] He gives me strength and guidance so I could continue this mission. (Catherine)

Thus, religion did help respondents to give meaning to their efforts in palliative care. It is also interesting to note that Hindu beliefs, more in particular the idea of *ātman*, were integrated into interviewees' evaluation of their work in palliative care. This shows that palliative care has indeed become a truly global movement, and palliative care physicians and nurses also take recourse to non-Christian religious ideas to support palliative care philosophy and ideals.

## Conclusion

The roots of palliative care can be traced back to Christian inspiration. Gradually, the emphasis on that Christian inspiration has waned, and, in some respects, palliative care and its underlying philosophy seem to have become secular. However, secularization on its own may not have been sufficient to



make palliative care philosophy universal. Religion continues to be an important factor in palliative care. The universality of palliative care philosophy and ideals resides in its adjustability to local contexts with their own unique socio-economic and cultural-religious setup. As the example from India has shown, the global expansion of palliative care is possible through the creativity of local persons committed to palliative care who contextualize that general philosophy. Very practically, this is observed in palliative care programs in India that have been developed in response to local palliative care needs and considering the local socio-cultural and economic realities. This is also observed in how Indian palliative care nurses and physicians search for inspiration for their work within their local context. In the contemporary global context of palliative care, the inspiration may not always be Christian. As the interview data from India show, the inspiration may sometimes be secular, but, equally often, the inspiration may still be religious, albeit with a local flavor.

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