History of Palliative and Hospice Care, Kathryn Wehrmeyer, MS4

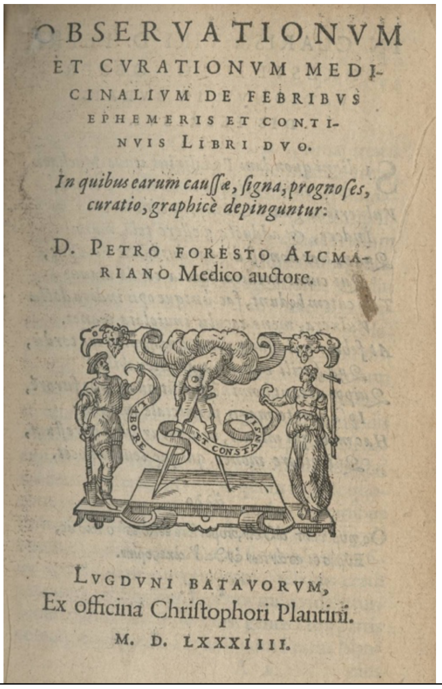
Palliative care is a burgeoning multidisciplinary field of medicine which emphasizes medical treatment and symptom management of those living with severe illness. The Latin root of palliative, *pallium*, means to cloak or provide covering. Hospice's Latin root, *hospes*, means to host. The number of palliative care and hospice fellowship programs for medical doctors has mushroomed to 156 training locations as of 2021 (American…) and a 138% increase in palliative care teams across hospitals since the early 2000s (Bhatnagar 95).

Prior to the advent of modern medicine, treatments for chronic diseases were limited. This lack of tangible cures and limited physiological understanding meant that death from common chronic disease involved incredibly prolonged suffering. During the sixteenth and seventeenth centuries the primary causes of this type of extended, painful death were cancer, consumption, and dropsy (Stolberg 16). Since the physical exam at this time was limited to palpation and visual inspection, breast and gynecological cancers were the most diagnosed and addressed.

The field of palliative medicine is typically attributed as developing from an offshoot of the 1960's United Kingdom hospice movement driven by the work of Dame Cicely Saunders and her work at St. Christopher's Hospice in London, England (Duffin 380). However, the origins of palliative medicine reach back far before the 20th century. In Korea, the concept of a specific place for the extremely sick and dying, called a Dongseodaebiwon dates to the early 11th century (Kim 1). The first western written text currently known to include the concept of palliative care was *Chirurgia* written in 1363 by Guy de Chauliac. In this text de Chauliac notes three times when radical, curative medical intervention should be withheld and palliative care interventions should be started: diagnosis of leprosy, working with uncooperative patients and when curative treatment would do greater harm than good (Stolberg 20).

Surgeons such as de Chauliac at were at the forefront of writing on palliative care during the early modern period. Surgical intervention was painful and dangerous, if surgeon unable to operate or if the patient was unwilling to undergo surgery, the need for palliative care was all but guaranteed. Hippocrates in 460 BC warned about treating breast cancer aggressively, and this fears of worsening a patient's illness were still forefront of palliative care writing at the time (Littres 572). Galen in 200 AD emphasized the alleviating effects of pharmacology, suggesting opium, Sulphur, castor oil and salves could help (Sprengel 37).

Dutch Physician Pieter van Foreest provided descriptive accounts of palliative treatments in 16th century in *Observationes* published in 1601. In the 30-page account he recommends treating breast cancer using salves and laxatives, not unlike the recommendations of Galen almost 1400 years prior. He also advised against woman to take physician-prescribed topical medications to ulcerate cancer, instead recommending laxatives and bloodletting as to not further provoke the cancer (Stolberg 29). There were further mentions of palliative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In quibus earum cauſſæ, ſigna, prognoſes,
curatio, graphicè depinguntur:

D. PETRO FORESTO ALCMARIANO Medico auctore.

LVGDVNI BATAVORVM,
Ex officina Chriſtophori Plantini.
M. D. LXXXIIII.

Figure 1. Original title page of Pieter van Foreest's Observations, the Latin inscription "Labore et constansia" translates roughly to "by Labor and Constancy" (Foreest 1)

treatment in medical texts throughout the 17th century spanning across the European continent from Rome to Hamburg. The term palliation was inscribed into a leading European medical dictionary, the *Lexicon Medium Graceco-Latinum,* in the late 1650s.

> *"Palliatio, palliativa cura, it is called by the doctors, when, in the case of desperate and incurable illnesses and with a fatal infaust prognosis, certain remedies are administered which soothe the pain or other burdensome symptoms, as in the case of cancerous ulcers, cancerous fistulas etc."* (James)

A treatise on palliative care and theory*, De Cura Pallitiva*, by Elias Küchler was published in 1692. This text discussed the chronic diseases associated with old age and no radical cure. According to Küchler were three types of palliative treatment. The first type was concealment, or compensating for physical deficiencies due to disease, for example prosthetic limbs, and belts for abdominal hernias. The second type was alleviation, specifically the management of pain with the use of medications like hemlock, henbane, and opium. The third and final type of palliative care was causal treatment, meaning the slowing of illness that would not be able to fully eliminate, for example china bark, camphor and gentian, helped improve breathing in patients with dropsy or tuberculosis (Stolberg 25).

In the late 19th century Europe and North America, people began to live longer. The increase if lifespans was thanks in part to improved infection control, public hygiene, medical innovations. As the 19th century progressed both the cause and location of death changed from occurring almost entirely in a person's home to transitioning to some extent to the hospital or other religious or medical institutions (Milligan 4, Institute 1). Madame Jeanne Garnier and her L'Association des Dames du Calvaire in Lyon, France in 1842 is commonly attributed as being the first hospice. However, some historians view this group as more of a nursing home for elderly women rather than a home for the dying. They postulate that the first hospital which had provided care specifically to the actively dying was Hundertsuppe in Nuremberg which was founded in 1780 (Stolberg 155). Regardless of which hospital holds the moniker of the world's first hospice it is key to note the influence and leadership of women within these institutions inspired in further generations.

The influence of Madame Garnier and her hospital in Lyonne provided a template for the development more hospitals for the dying. Sister Mary Augustine (known as Mary Aikenhead prior to taking religious orders) created a new order of nuns called the Irish Sisters of Charity in the early 1800s. Three of her nuns trained at Notre Dame de la Pitié Hospital in Paris, and with this knowledge the order founded Our Lady's Hospice in Harold's Cross, Dublin in 1834. The goal of this hospice was to care for "hopeless cases" as well as patients with very little time left to live. The therapeutic care provided at this hospice and other large hospices around Europe at this time is very unclear. Documents from this period do not clearly state the therapeutics or treatments provided in hospices to dying patients (Stolberg 168). The order expanded their reach, founding hospices in Australia, England and Scotland. Notably, the order sent nuns to East End Hospital in 1900 which led to the founding of St. Joseph's Hospice in 1905 (Milligan 6).


Figure 2. Jeanne Garnier


Figure 3. Mother Mary Augustine

Figure 4. Our Lady's Hospice in Harold's Cross

As the number of institutions dedicated to caring for the dying continued to grow throughout Europe the fear and stigma surrounding them also grew. With the industrial revolution, the population of western Europe doubled in size during both the 18th and 19th centuries. The intentions of hospices as founded by the Sisters of Charity and similar groups was certainly noble, however the bleak reality of dying as a patient in these hospices was incredibly grim and isolating for the patient. Urbanization during the industrial revolution meant there was a new part of the population who were geographically separated from their families with no one to care for them as they became sick (Stolberg 170). Due to the rising number of patients, space became a primary issue, patients at all stages of dying and with all types of conditions were placed crowded onto beds next to each other. As the world at large continued to industrialize the process of death too began to shift to being far more isolated and depersonalized experience.

Writings from clergymen visiting these institutions emphasize the patient's fear of an anonymous death. German preacher Johann Georg Lampe stressed in 1789 the patient's wishes to die at home stating, "regardless of all medical help and all care, (patients) miss their attentive spouse, their compassionate child or comforting friend, people who undoubtedly refresh them in their suffering more than all medication and all nurses." (Lampe). Almost a century after Lampe, German professor and physician August Stohr emphasized a similar sentiment, emphasizing the anonymity of death within a hospice:

> *"The unfortunate person wants something more besides the bed on which to stretch out his emaciated limbs, more than the food and care the law allows him with arithmetic precision: He wants a word of sympathy and comfort, to be understood somewhat as a person, which will help him forget the thought that he figures as a mere number in the large works of this 'city of suffering' operating with a cold regularity, a number that one day will be erased from the board above his head."*

With the progression medicine in the 20th century the average life expectancy increased drastically. The classic chronic disease tuberculosis decreased dramatically, while cancer and cardiovascular disease increased and continue to remain the top two causes of death into modern day (Stolberg 174). While medicine was advancing by leaps and bounds in terms of treatments, the process of death and dying continued to be relegated to the religious and social institutions of the 19th century (Younger).

Establishments specifically created for cancer patients arose in the early 20th century. In New York, Rose Hawthrorne and a group of organized women founded the Servants of Relief of Incurable Cancer in 1897. Hawthorn was inspired like Madame Garnier by the death of her own child to pursue the care of the sick and dying. The success led to the establishment of six more hospices located throughout the United States. In 1911, Douglas Macmillan established group named The Society for the Prevention of Relief of Cancer in England, which is now known as the Macmillan Cancer Support. After watching his father suffer and die from cancer, he wanted to ensure symptom relief and medical support were provided to dying cancer patients. Starting in 1975, this group funded the training for over 3000 hospice nurses (Milligan 6).

Cicley Saunders trained as a nurse and then social worker at St. Thomas Hospital in London, England. Her work with a terminally ill patient named David Tasma inspired her to improve the conditions and services provided at the end of life (Milligan 6). She furthered her training by beginning medical school at the age of 33 at St. Tomas's Hospital. Her initial research of patient narratives at St. Mary's Hospital in Paddington, England during the late 1950s led her to develop a concept known as "total pain" which encompassed the physical, social, and spiritual dimensions of a dying patient's distress (Clarke 433). There were three key aspects to Dr. Saunders hospice care: research, education, and superb patient care emphasizing treating all forms of pain (Hoffman 28). Her clinical practice emphasized the use of morphine as a pain management tool (Saunders 791). Saunders also emphasized the use of the "Brompton Cocktail" which combined cocaine, alcohol, and morphine with the potential addition of chlorpromazine or prochlorperazine to improve both pain and nausea and vomiting (Stolberg 181, Clark 432). During this time she trained at the aforementioned St. Joseph's hospital which was founded by the Irish Sisters of Charity.

Dr. Robert Twycross worked as a research fellow with Dr. Saunders at St Christopher's Hospice. Their collaborative research discredited the use of the traditional Brompton cocktail and emphasized the use of simpler methods of morphine administration and addition of supplementary analgesics and adjuvants (Clark 432). Dr. Colin Murray Parkes was a psychiatrist also working at St Christopher's. His research on pain in cancer patients showed that most cancer patients died with unrelieved pain regardless of death being managed in the home or in the hospital. Furthermore, his work confirmed that patients with severe pain who entered hospice immediately had far better pain management than those pain patients who were not referred (Clark 433).

Dr. Saunders traveled to the United States in 1963 where she presented her research and sowed the seeds for specialized care for dying at Yale University in 1963. All her research, training and personal experiences were distilled into the founding to St. Christopher's Hospice in London which opened its doors in 1967 (Milligan 6). The same year she published a handbook for end-of-life care titled *The Management of Terminal Illness* (Solberg 181). St. Christopher's and the accompanying handbook provided a template for other institutions across the globe to develop their own hospice programs (Solberg 182). Her contributions to the field of hospice and palliative care as well as the contributions St. Christopher's provided to the people of the United Kingdom led to her appointment as a Dame Commander of the British Empire.

While Dame Saunders was developing her ideas on hospice care in the United Kingdom, the Swiss-born psychiatrist Dr. Elisabeth Kubler-Ross was researching the end-of-life care Billing's Hospital in Chicago, IL. Through extensive interviews with terminally ill patients she developed the concept of the five stages of grief: denial, anger, bargaining, depression, acceptance (Kubler-Ross). Her book *On Death and Dying* published in 1969 raised awareness on the topics of end-of-life care and dying within the United States (Milligan 6). In 1972 she testified at the first national hearing on death with dignity, the US Senate Special Committee on Aging. She argued that treatment for a dying patient should be based on the patient's preference rather than that of the doctor (Hoffman 29).

> *"We isolate both the dying and the old, and it serves a purpose. They are reminders of our own mortality. We should not institutionalize people. We can give families more help with home care and visiting nurses, giving the families and the patients the spiritual, emotional, and financial help to facilitate the final care at home (Dr. Elizabeth Kubler-Ross, US Senate Special Committee on Aging, 1974).*

Nursing professionals in America, in particular the leadership at Yale School of Nursing, were particularly interested in Dame Saunder's work, inviting her to present at Yale in 1963 (Conner 2). In 1974, Florence Wald then Dean of Yale University School of Nursing took a sabbatical to work at St. Christopher's from 1968-1969. This experience inspired her to create first modern hospice in the United States named Connecticut Hospice in Brandford Connecticut, with two pediatricians and a chaplain (Hoffman 28). This initial hospice was home-based, and volunteer led since Medicare did not yet recognize hospice care there was no way for the hospice to seek reimbursement. The hospice functioned as a non-profit model, with patients treated regardless of ability to pay.

The development of hospice in America is notably different from that of the United Kingdom. In the UK, as we have discussed above the hospice movement occurred primarily in hospital settings or with hospital affiliation (Stolberg 184). The development of hospice in the home environment rather than the inpatient environment has multiple reasons including the American population's general distrust of medicine, a sense of American individualism and independence, and non-profit hospices lacking financial and structural resources due to their non-profit status. Volunteers have contributed greatly to the development of hospice in the United States and continue to play a vital role as around 400,000 people still volunteer in hospices around the United States (Connor 2).

As the hospice movement progressed the social connotations of a free-standing hospice as a place completely relegated for death and dying intensified. Furthermore, concerns arose that patients placed in stand-alone hospices might not receive adequate diagnostic and therapeutic care due to the lack of trained medical professionals (Stolberg 183). Dr. Balfour Mount, a surgical oncologist at McGill University in Montreal, Canada, coined the modern usage of palliative care to separate and distinguish away for hospice medicine. The hope was that the new term would remove some of the negative connotations with word hospice in French culture of Montreal's Quebecois community (Hospice). Palliative care now meant the diagnosis of serious illness and concurrently with curative or life-prolonging treatment.

Dr. Balfour and colleagues from McGill's Royal Victoria Hospital traveled to St. Christopher's in London with the hopes of understanding how to apply the fundamentals of St. Christopher's hospice care in a hospital unit (Stolberg 184). The first official palliative care unit in North American opened in 1975 with an emphasis on interdisciplinary approaches to severe illness which addresses the biopsychosocial needs of patients as well as their families (Milligan 2). The palliative care treatment team not only included a doctor and nurse, but also relied heavily on the social and spiritual support provided by chaplains and social workers. The palliative care unit created by Balfour prioritized improving symptom management with strict opioid regimens, allowing clear communication of grave illness to patients rather than concealing them, and providing personal hands-on contact with patients (Stolberg 182).

Throughout the 1970s the field of hospice care continued to grow with consecutive national symposiums on Hospice Care starting in 1975. In 1978 the National Hospice Organization (NHO) was founded, and its first national conference was held the same year. The NHO changed its name to the National Hospice and Palliative Care Organization in 1999 to emphasize the relationship between traditional hospice care and the newly developing field of palliative care (Connor 2).

The success of early hospices in the United States encouraged the federal government to develop an interest in funding hospice care. A development project was led by the Health Care Finance Administration to study how hospice care reimbursement affected 26 hospices located throughout the US (Connor 3). The conclusions from this study led the United States Department of Health, Education, and Welfare to say that hospice care "provided more humane care for Americans dying of terminal illness while possibly reducing costs. As such, it is the proper subject of federal support" (Neigh). The development study also provided hospice leaders with a framework on how to organize hospice care and develop national standards of care (Connor 3). Senators Frank Church and Frank E. Moss introduced initial legislation to Congress to provide federal funds for hospice programs but failed during the initial attempt. In 1982 Congress approved funding of the Medicare Hospice Benefit (MHB) clause (Hoffman 28).

By 1990, the World Health Organization (WHO) recognized palliative care as a distinct medical specialty. With all the progress made in the latter half of the 20th century, a 1997 report from The Institute of Medicine titled Approaching Death: Improving Care at the End of Life noted major discrepancies between the goals of what the American public wanted from end-of-life care in comparison to what they were actually experiencing (Loscalzo). With tremendous support from multiple philanthropic foundations, notably the Robert Wood Johnson Foundation and the Open Society Institute, efforts were made to promote palliative care. Efforts in the way of clinical demonstration projects, reviews of palliative and end-of-life care content of core textbooks, consumer awareness through Last Acts and the Bill Moyer's Series, "On Our Own Terms", and funding of palliative care faculty scholars were all completed.

The Clinical Practice Guidelines for Quality Palliative Care were released in 2004, these guidelines expanded palliative care's definition to include patients diagnosed with life-limiting illnesses such as heart disease and cancer along with those that were actively dying. By 2006, The American Board of Medical Specialties and the Accreditation Council for Graduate Medical Education (ACGME) recognized hospice and palliative care as its own specialty. Ten specialties co-sponsored the ABMS certification examination, and over 3,000 members now belong to the American Academy of Hospice and Palliative Medicine (Loscalzo).

Internationally, other countries have been slower to develop their palliative care and hospice programs. Hospice and palliative medicine have an inequitable history and present distribution, most development has occurred in wealthy western nations (Bahtagnar 95). In Europe the progress of hospice development was markedly slower on mainland Europe in comparison to the UK. In Soviet Russia and eastern bloc countries palliative care only began to develop after the Soviet downfall of the 1990s after which there was an enormous increase in the services and research being conducted notably in Poland and Russia (Clark 436). The first international meeting on palliative care development was held only in 2003 (Clark, Graham 636).

Korea and Japan notably have a stronger history of hospice development than other Asian nations thanks in part to Catholic missionaries founding hospices in the regions in 1965 and 1973 respectively (Clark 435). China's first hospice opened in 1988 and led to fast advancement of programs in large cities throughout the 90's due to the support of the Chinese Communist Party (Ning 199). Island Hospice Service was founded in Zimbabwe in 1979 and was considered the first hospice founded within a developing nation. Progress has continued on the African continent with the creation of influential hospice programs in Kenya, South Africa and Zimbabwe, however the vast need for end-of-life services in this region remains a major issue for the international palliative care community (KAINGROUP).

In 2010 the New England Journal of Medicine published a study by Dr. Jennifer Temel and colleagues that showed that people with lung cancer who received early palliative care in addition to standard oncologic care experienced less depression and increased quality of life and survived 2.7 months longer than those receiving standard oncologic care (Temel). This seminal research study has confirmed the importance of palliative care within the medical community and led to further acceptance. As the next stages of hospice and palliative care progress it is important to look back on the foundations of this movement. Religious institutions and key female trailblazers have led the study of palliative and hospice medicine to address the reality of death head on with compassion and understanding.

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Further Resources:

An excellent oral history of the palliative medicine in the United States by Dr. Marion Pohlen Primomo: https://www.youtube.com/watch?v=ZzLP_XKjJpc&ab_channel=GECMedEdVids