The Development of Palliative Care in the U.S.

Based on an interview with Dr. Sean Morrison in Dublin in June 2016

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Introduction

What is palliative care?

'Palliative care focuses on achieving the best possible quality of life for patients and their family caregivers, based on patient and family needs and goals and independent prognosis. Interdisciplinary palliative care teams assess and treat symptoms, support decision making and help match treatments to informed patient and family goals, mobilise practical aid for patients and their family caregivers, identify community resources to ensure a safe and secure living environment and promote collaborative and seamless models of care across a range of care settings (i.e., hospital, home and nursing home).'[1]

The emergence of palliative care in the U.S.

The development of palliative care in the U.S. over the last 50 years represents an intertwined evolution of medical and academic leadership and advocacy, research-led strategic thinking supported by philanthropy, federal legislation and policy, and public awareness campaigns. These strands of development generated evolving models of palliative care, legislation, standards, funding models, systems of professional education, and professional networks, as well as the infrastructure of hospice and hospital provision.

Palliative care as a discipline began in earnest in the early 1970s, effectively as a social movement led by the medical professionals who had visited the U.K. and wanted to emulate the developments they had seen there. Prior to that, Glaser and Strauss (1965; 1968) had examined patterns of death and dying in the U.S., concluding that there was considerable scope for improvement in the care of the dying in America, particularly in the area of psychological and social care. Subsequently, they developed education and training for medical and nursing staff; pioneered the planning and review of psychological, social, and organisational aspects of end-of-life care; planned for phases of dying occurring outside of the hospital or institution of care; and encouraged staff to discuss aspects of death, dying, loss, and care that might be perceived to be outside of their professional responsibilities or boundaries (Rosenberg, 2007).

In 1969 *On Death and Dying* was published (Kubler–Ross, 1969). This work described the emotional and psychological reactions to death and was based on the transcripts of over 500 interviews with people nearing the end of life. This work was seen as providing a voice for the dying that was heard in America by healthcare providers and planners; and as ultimately shaping palliative and end-of-life care services in the years that followed.

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[1] Meier, D.E Increased Access to Palliative Care and hospice services: Opportunities to Improve Value in Health Care, 2016, p1

An early leader in the field of palliative care was Florence Wald, the Dean of the Yale School of Nursing who in 1963 invited U.K. palliative care pioneer Cicely Saunders to give a series of lectures on hospice care. This visit led to the formation of the first U.S. hospice in Branford, Connecticut, which began serving patients at home in 1973.[2]

In 1978, **t**he National Hospice Organization (NHO) was formed following a series of national meetings. The first large national NHO conference was held in Washington DC that year, and the first Standards of a Hospice Program of Care were published by NHO in 1979.

Over the following decades, there emerged the medical leadership, the philanthropic investment, the growth of the hospice movement, the shifts in and development of thinking about end of life care among medical profession and the public, and the construction of the legislative and funding frameworks for palliative care.

Legislation, policy, and federal funding programmes

The first major policy and funding development was the establishment in 1982 of the Medicare hospice benefit, when palliative care was encapsulated within organised medicine. This positioned palliative care and the emerging hospice program as an alternative to curative or life prolonging treatments and was enacted to improve care of the dying. The regulations underpinning the Medicare hospice benefit programme required a person to have a diagnosis of six months or less to live, certified by two physicians, and also required that the person opt out of curative or life prolonging treatments available under the mainstream Medicare provisions.

The Medicare hospice benefit was made permanent by Congress in 1986, and federal funding increased over the following years. Legislative and funding changes were made over the following years up to and including the Affordable Care Act in 2010 including provision for population groups such as veterans and children.

Building the medical and academic leadership of palliative care

Around the mid-1990s questions began to be raised by leaders in academic medicine as to why a person had to be dying in order to access high quality care; this questioning coincided with other events. The assisted suicide movement prompted people in organized medicine to ask why people were opting to prematurely end their life rather than making other choices; also at this time, the 26 million-dollar study funded by the Robert Wood Johnson Foundation (RWJF) highlighted the huge gaps for seriously ill people being treated in American hospitals. George Soros's Open Society Institute (OSI) and RWJF invested several hundred million in building the field of palliative care. Soros invested in leaders within academic medicine including the first cohort of the project on Death in America Faculty Scholars; RWJF invested in programmatic development, public education and, to a certain extent, in policy. Huge successes happened between 1995 and 2005.

OSI's support helped put palliative medicine leaders in every major medical school in the United States. RWJF fostered the development of innovative programs in palliative care in a number of different institutions and established the Centre of Advanced Palliative Care at Mount Sinai with the idea of providing technical assistance to hospitals and health systems to develop palliative care programmes so that nobody would have to reinvent the wheel. One of the significant initiatives by OSI was bringing together academic leaders from the academic centres on a regular basis for the

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[2] Connor, S. R. (2007). Development of Hospice and Palliative Care in the United States. *Omega*, 56(1) 89-99.

purpose of building professional collaboration, a movement that grew from 500 participants in the 1990s to 3000 members of the professional organisation today.

The 1990s, then, was a period of intensive development in the field of palliative care, led by medical/academic leaders in the field. By 1997, the growing movement focused national attention on quality of life at the end of life as well as the need for increased public awareness and physician education. The hospice philosophy and concept of care were central to models for palliative and end-of-life care.

A framework of new organizations provided strong medical advocacy for the concept of end-of-life care, working on the development of standards, professional development, and placing a strong emphasis on informing and educating the public.

In 1999, the National Hospice Organisation (NHO) changed its name to the National Hospice and Palliative Care Organization (NHPCO), reflecting the melding of traditional hospice care with palliative care in the U.S.[3]

A key development in building the palliative care field was the recognition of palliative care as a medical sub-speciality. In the shortest time in the history of such developments, the American Board of Medical Specialities (ABMS) approved hospice and palliative medicine as a medical sub-speciality in 2006.[4] In 2008 the Centers for Medicare and Medical Services also recognized the speciality, and this recognition enabled payments for services. ABMS reported that 1271 physicians received sub speciality certification in 2008.[5]

Building the knowledge infrastructure: a collaboration of philanthropy and medical academic leaders

A grant by the Kellogg Foundation to the Joint Commission on Accreditation of Hospitals in 1980 to investigate the status of hospice and to develop standards for hospice accreditation was one of the first of what was to be a massive field- building investment in end-of-life care by philanthropic foundations over the following years.

From the mid-1990s**,** major grantmakers provided large grants for research, program initiatives, public forums, and conferences to transform the culture of dying and improve care at the end of life. The George Soros Foundation (OSI) and the Robert Wood Johnson Foundation (RWJF) invested several hundred million in building the field of palliative care; RWJF funded innovative programs in several institutions. RWJ funded innovative programmes in several institutions to provide technical assistance to hospitals and health systems and avoid re-inventing the wheel.

In 2002, Rallying Points, an initiative of RWJF's Last Acts campaign, began a three-year initiative to improve care and caring near the end of life. In 2004, RWJF then made a grant to National Hospice and Palliative Care Organization to advance public understanding and awareness of end-of-life care, and NHPCO's Caring Connections was created, facilitating the NHPCO's Caring Connections consumer engagement initiative with an additional $4.9 million grant.

The research strategy was multi-faceted and strategic, focusing on making the business case for palliative care, building the quality case, and translating the research evidence into technical systems

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[3] Connor, S. R. (2007). "Development of Hospice and Palliative Care in the United States." *Omega*, 56(1) 89-99.

[4] Patrizi, P, Thompson, E and Spector, A. "Improving Care at the End of Life: How the Robert Wood Johnson Foundation and its Grantees Built the Field," *RWJF Retrospective Series*, 2011, p5.

[5] Ibid.

and materials for use in all hospitals. The Center to Advance Palliative Care (CAPC) was established in 1999 as a national program office of the Robert Wood Johnson Foundation to provide technical assistance to hospitals, health systems, hospices, and other health care organizations to develop palliative care. CAPC has been supported by a consortium of foundations and individual philanthropists since 2006 and it now functions as a leading resource for palliative care.

Both the quality case and business case needed to be built. Starting with hospitals was pragmatic because that is where the business case was. Research data was used to show that palliative care was not only less expensive but also improved the quality of care. This business case was an important component of the move of palliative care into mainstream hospitals. A further strand of the research strategy was to bring research into the American Academy of Hospice and Palliative Medicine, so it became part of the mainstream culture.

The National Palliative Care Research Center was set up with funding from the Emily Davie and Joseph S. Kornfeld Foundation, directed by Sean Morrison. The center opened in 2006 funded by private sector philanthropy, with an initial budget of a million dollars a year. The goal was to create a community of researchers in the U.S. and ultimately increase NIH funding of palliative care research.

A key strategy was to engage people straight from fellowships and provide protected time for two years. A technical assistance program was developed, providing ten hours of consultant time for early stage investigators; capacity building was also done through workshops, skill building, interactive video, and seminars.

The second strategy was to target experienced investigators to go after large grants. The program targeted investigators who were bidding for large research grants in order to help them so that they had strong pilot data on methods that would allow them to compete. Pilot exploratory awards are given to people throughout the U.S. for two years to carry out pilot research, develop methods, and do other activities. An annual budget of 3.5 million dollars of philanthropic funding is currently expended on these continuing projects, with the aim is to bring palliative care to scale like other fields.

The next strategy was to build a community of investigators through yearly research retreats. These are highly structured to facilitate dialogue and the engagement of less and more experienced people. This approach has facilitated national collaborations across different institutions around the country and internationally.

Building standards for palliative care

Work on standards for hospice and palliative care services began in the 1980s and has been ongoing since then, driven by the medical/academic community, philanthropically funded research, and federal government accreditation processes.

One of the earliest initiatives arose from a grant by the Kellogg Foundation to the Joint Commission on Accreditation of Hospitals (JCAHO) to investigate and develop standards for hospice accreditation. From the mid-80s to 1990, JCAHO accredited mostly hospital-based hospice programs. The Office of Inspector General, the Health Care Financing Administration, the National Quality Forum, the Centers for Medicare and Medical Services were among the agencies providing guidance and standards for hospice care. In 2009, the Accreditation Council for Graduate Medical Education, a private, non-profit organization responsible for the accreditation of post-MD medical training programs in the U.S. added hospice and palliative medicine to its list of accredited programs.

Key recent developments have addressed standards for particular groups or settings. For example, in 2003, a *Clinical Guide to Supportive and Palliative Care for HIV/AIDS* was released. In 2005, the American Heart Association and the American College of Cardiology released guidelines for the treatment of heart failure that included recommendations for provision of hospice care education early in the course of an illness. The NHPCO *Standards of Practice for Pediatric Palliative Care and Hospice* was given the American Academy of Pediatrics' Affirmation of Value in 2010, and in 2009 *Quality Guidelines for Hospice and End of Life Care in Correctional Settings* was published.

Building public awareness

While there were huge successes in many aspects of palliative care development from the mid-90s to mid-2000s, what was not successful was the language around transforming the culture of death and dying in the United States. One of the important shifts in why palliative care took off in the U.S. in the mid- 2000s was when a national consensus project began around clearly defining what palliative care was and defined it as not care for the dying, and when the words *dying* and *end- of-life-care* were removed from palliative medicine. End-of-life care was not what patients and families or policymakers wanted to hear.

Public awareness and public education were seen by philanthropists and field leaders as a critical factor in shaping the acceptance of palliative care, and there was huge philanthropic investment in this aspect of field building. Large scale public awareness television campaigns and series across the U.S. were used to promote the palliative care concept from the late 1990s and through the 2000s, led by organisations such as the National Hospice Foundation, the Duke Institute on Care at the end of Life, and the NHPCO. In 2005, the first national conference on access to hospice and palliative care was hosted by NHPCO in St. Louis.

In 2007, the Alliance for Care at the End of Life, a 501(c)4 organization was created to provide the hospice community with a more comprehensive, strategic voice on Capitol Hill and in the same year, the Worldwide Palliative Care Alliance was formed to address global care needs at the end-of-life.

The public awareness campaigns run by NHPCO continued throughout the following years. One of the most recent *LIVE—Without Pain*, a new public awareness campaign from NHPCO's Caring Connections was introduced in 2012 to dispel myths about pain and empower consumers.

Where is the U.S. palliative care field now?

The goal of mainstreaming has been achieved, and now it is a matter of sustaining the hospitals. The business case has been made and the Affordable Care Act is in place to develop palliative care delivery in the community, and to evaluate programs and disseminate them as with hospital programmes.