Perspective Open Access

# Is Palliative Care reaching its Full Potential?

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### **Abstract**

Palliative care is underutilized. A number of philosophical, political, and financial barriers exist. A shift in paradyne/world view is encouraged. The results are the potential for increased satisfaction and cost savings.

Keywords: Palliative Care; Potential; AIDS; Death

## Perspective

Has Palliative Care fallen into a "hospice light" mode when it was conceived to be a way of moving "the gold standard of care further upstream"?

Historically, Dr. Balfour Mount was one of the first to use the term in the 1970's after a visit to St. Christopher's hospice in England [1]. In the 1990's the Inspector General of the United States began looking at homecare fraud and took note of lengthy stays in hospice. This was at the time of the AIDS epidemic a blooming and young men were dying; hospice agencies had stepped in to provide care (prior to retrovirus medications and Ryan White funds) these individuals were either uninsured or had lost their insurance when they lost their employment. AIDS meant almost certain death. When medications became available many AIDS patients remained on hospice significantly beyond the "six months" benefit period. At that time, the medical community became aware that the holistic care that hospice was providing could benefit others with chronic life limiting illnesses. However, the required six months prognosis would render many seriously ill chronic disease patients from being eligible because of a combination of absence of the required six months prognosis and unwillingness of people to stop all treatment.

Another historical contributor was landmark cases involving an individual or their designated representative to make the decision to remove or not initiate life prolonging measures when doing so would serve to prolong suffering or when such treatments were deemed futile and elf Determination Act unlikely to change the eventual outcome of death. I refer to Karen Ann. No 101-508Quinlan, Nancy Cruzan, and Terri Schiavo specifically. This prompted National discourse as well pub Las documentaries by Bill Moyers "On Our Own Terms" and "&Thou Shalt Honor... along with efforts to build community-based coalitions Rallying Points sponsored by the Robert Wood Johnson foundation and the Missoula Project led by Ira Byock are two examples of such coalitions. And the Support Study that looked at care at end of life. One of the focuses that emerged from the initiatives was an emphasis on creating Advance Directives which received support via the federal government in the form of "The Patient Self Determination Act of 1990" (pub. L. 101-508) which provided some guidance and direction toward education/information in the construction/completion of Advance Directives as applied to facilities receiving Medicare payment.

In 1995 a large study of End of Life Care in the United States the SUPPORT study and subsequent follow up studies in 2003, 2014 conclude that communication regarding preferences and prognosis with patients and their loved ones is a barrier to satisfactory car those with serious illness and probable life limiting outcome [2]. Communication of prognosis and probable outcome as well as the risk benefits of treatment vs. limited or no treatment is a delicate matter requiring skill, training and possibly a broad world view of patient

autonomy and informed consent. It was determined that the needed skills were not included in either physician or nursing education.

The Medicare Hospice Benefit was legislated in the early 1980's when cancer was the leading diagnosis for patient being admitted. However, because the criteria requires a six months or less prognosis and the foregoing of treatments consider to be life prolonging many individuals with not cancer diagnosis end stage diseases such as COPD, CHF, ESRD, ESLD are either difficult to prognosticate or are unwilling to stop treatments that provide comfort and quality of life. This occurs against a backdrop of high dollar expenditures for the average Medicare recipient who often occurs in the last two years of their life, with intubation and ICU care and death occurring in a hospital setting vs. home.

Medicine responded with the creation of Education for Physicians in End of Life Care (EPEC) which has now been changed to education in Palliative and End of Life Care [3]. These were/are CME seminar taught courses. The faculty was mostly hospice trained physicians and today many of trainer are leaders in Palliative care have helped to create hospital-based fellowships in Palliative Care Medicine. Nursing followed the Physician model creating the End of Life Nursing Consortium in the 1990's [4]. Nursing actually made an attempt to take it a step further by creating modules for the Deans of Nursing schools in hopes of encouraging them to integrate this knowledge and practice into their nursing curriculum.

However, these efforts have still not produced the probable needed cultural and medical-political change that would bring about widespread practice of Palliative care principles across relevant disciplines and the full continuum of health care service. Integration of palliative care their does not seem to be evidence of the encouragement or requirement for Hospitalist's to become fluent in the nuances of navigating, integrating and supporting patients and loved ones through the care options, benefits, burdens especially where these conversations are complicated by cultural, spiritual, ethnic and/or financial challenges. These conversations tend not to be expedient and can make providers uncomfortable if they lack they have not developed the knowledge, skills and world view to facilitate the decision making process.

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Palliative medicine practice has the potential to not only increase patient, loved ones, and provider satisfaction in also has the potential to lower health care costs [5]. The challenge lies in convincing health care savings is on par with increasing streams of revenue from aggressive curative/life prolonging focused care.

So, you may be asking yourself with these sorts of efforts what is keeping Palliative Care from reaching its potential. I define this potential as providing care for patients and families who are facing the challenges of illness with the potential of those illnesses having a life limiting life ending result. These are often chronically ill folks who's chronic illnesses are no longer stalely managed as evidenced by relapses, increased frequencies of hospitalization with longer stays and often ICU care requiring ventilator support, repeated shorten toleration of dialysis and failure of multiple lines of chemotherapy and radiation.

Palliative cares roots in hospice lead many to conclude that you consult Palliative Care when end of life seem imminent or obvious, "there is nothing more we can do for you" and the plan is referral to hospice. This often occurs in the absence of Advance Care Planning early in the illness/treatment process. The desire "not to take away hope" has the potential to produce false hope which may lead to erosion of trust with patients and loved one's experiencing feelings of abandonment when the decision is made "stop treatment and "go home and get your affairs in order".

What does my twenty plus years of practicing in palliative and hospice settings lead me to conclude? Palliative care has the potential to increase patient, loved ones, and practitioner satisfaction with the process and outcome for those patients who are facing the challenges of life limiting illness which has a high probability of ending in their death. Furthermore, this can be accomplished in the presence of cost savings with the potential to significantly contribute to the overall reduction of the ever-ending rise in health care costs.

Palliative care has been underutilized for the following reasons:

- Equating hospice with Palliative care Vs. seeing Palliative care as a continuum from Diagnosis to death
- Incorporation of the basic principles and philosophies of Palliative care in basic medical/nursing/social work education with a drill down on the application those principles and practice throughout education and training to include required refresher from renewal of licensures and certifications.
- A National effort to transparently address issues related to territory, service integration, streams of revenue Vs. cost savings
- Allowing for Advanced Care planning being reimbursable by insurers and government health care.
- Establishment of a National standard for Advance Care Planning that includes a National Physicians Orders for Life Sustaining Treatment (POLST, MOLST and the VA's LSTO)

I ask that all of you who read article to give these ideas some thought and if you are in a position to facilitate change or desire to change your world view and practice you do so with gusto.

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