

Why Doesn't Anyone Talk About Death?

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As the old saying goes, there are only two things in life which are certain, death and taxes. However, some people have smart accountants that work many hours to insure that person owes no money to the government at the end of the year. There are also people in the world who simply choose not to pay taxes and perhaps get away with that act for several years. However, it makes little difference how well a person takes care of themselves or even if they receive the best healthcare in the world, the day will come that they will die. There is only one way possible to skirt death and that deals directly with the timing when Jesus Christ returns to earth, but in the grand scheme of things that will only affect a minority of the population (1Thessal 4:15-17 New Century Version). Therefore, from the day everyone is born, with each passing day, they step a little closer to the day when one and all will die. The only true questions which remain a mystery about a person's death is how and when. Some people live long and relatively healthy lives which may last until their 90's or perhaps for a few, into their 100's. Sad to say there is the other end to that spectrum in which some babies are born dead or possibly only live a few hours or days. With death being the only certainty life has to offer, why is the American public so afraid to discuss their final wishes? Who, what, when and where would they like to have services or their final resting place? What if they become terminally ill and the dying process becomes long, and drawn out? Where will they stay, who will care for them, what if their disease process happens to be extraordinarily painful? If the family decides to care for their loved one, will they possess the skills and knowledge needed as the disease progresses? Caring for a dying family member is exhausting both mentally and physically (Empeno, Raming, Irwin, Nelesen, & Lloyd,

2011). Who will be there to ensure the family does not become the patient in need of care themselves?

There are so many questions and so many needed skills when caring for a terminally ill family member. Many families take on this burden of love without any professional support or prior training. However, for those willing to make the call, willing to face up to their own insufficiencies, there is one agency, one angel of mercy, just waiting to be invited. That one agency has been in the business of caring for the terminally ill and their families for forty years. The agency is located from coast to coast and simply goes by the name of Hospice.

Hospice in the United States was initiated in 1974 and was inspired by the palliative care method implemented in the United Kingdom by Dame Cicely Saunders (Reeves, 2008). It was looked upon as a new process in treating terminally ill patients whom had ran out of curative options. Consequently, the focus of treatment was turned to palliative care. Death in terminally ill patients often becomes a drawn out painful, arduous process. As with many medical conditions there are specialists who study and educate themselves almost entirely in their respective fields. However, death is not a condition that the medical field prepares itself. When the curative approach is completely exhausted, hospice steps in and takes over the show. Even though hospice is considered the gold standard for end of life care in terminally ill patients, current research indicates, it is one of the most misunderstood and underutilized programs in the medical field (DuPreez et al., 2008).

There are a plethora of reasons why anyone or anything can be misunderstood. This gives rise to the question; if something is misunderstood does that mean it will also

be underutilized? There is no simple answer to that unpretentious question but it is filled with the opportunity to explain. There are also some potential barriers which might prevent a terminally ill person from using hospice. The first barrier might be simply having the knowledge of hospice and what is their mission. Perhaps they have the knowledge of hospice but have fallen victim to the myths that surrounds that organization. Also, does hospice have a facility within that person's geographical realm? If a patient does not have private insurance or believe they must pay for services themselves could of itself be a large barrier. Simply having knowledge of or understanding of any situation or organization is the first step to overcoming barriers and myths.

Hospice was initiated as an all-volunteer agency from its humble beginnings and was funded through nonprofit community organizations which relied upon charitable contributions (Carlson, Morrison, & Bradley, 2008). Through the Tax Equity and Fiscal Responsibility Act in 1982, Medicare was authorized to reimburse Hospice for services rendered to qualified individuals (Carlson et al., 2008). Since that time other avenues of payment have become available, which includes private insurance, Medicaid, self-pay, and charitable care ("NHPOC's facts and figures," 2013). However, current circumstances dictated by Medicare conditions of Participation require volunteers to provide a minimum of 5% of total patient care hours ("NHPOC's facts and figures," 2013). In 2012 volunteer efforts maintained 5.4% or an estimated 19 million hours of direct, general, and clinical care support ("NHPOC's facts and figures," 2013). It is obvious by the number of hours spent that a portion of the general public is highly dedicated to the hospice mission.

Knowing it was an all-volunteer, publicly funded organization, one can only imagine the facilities and equipment which was available to that initial staff back in 1974. In fact there were only 45 Medicare certified hospices in 1983 (Carlson et al., 2008). Certainly by the mere number of operational facilities it is easy to understand a low patient census. Nevertheless, this was not to be the dictating situation for many years. During the 1990's more than 2000 Medicare certified agencies sprung up throughout the United States (Carlson et al., 2008). As a testament to the need of services rendered by this organization, there are now more than 5500 hospices located throughout all 50 states, Puerto Rico, Guam and the U.S. Virgin Islands ("NHPOC's facts and figures," 2013). Although these facilities operate under the same mission statement and share the same philosophy they are operated by different organizations. The majority or 57.4% of hospices remain as the original and operate as a freestanding, independent, non-for-profit agency ("NHPOC's facts and figures, 2013). The remaining hospices are owned and operated by hospital systems, home health agencies and nursing homes ("NHPOC's facts and figures," 2013).

Hospice does staff and maintain some inpatient facilities. In fact, 27.4% of the patients hospice cared for in 2012 were in one of those inpatient facilities ("NHPOC's facts and figures," 2013). However, hospice prefers to see itself as "a philosophy of care for terminally ill patients and their families" rather than a location (Rogers, 2009, p. 6). They do not refer to their terminally ill patients as dying with a disease but rather living with a condition that has no cure (Reeves, 2008). Their care is delivered by a team approach with a group of multifaceted health care professionals. This team consists of nursing, home health aides, social workers, Chaplin's and volunteers who may fulfill an

abundance of needs (Rogers, 2009). This team approach is considered the model for compassionate, medical care, pain management, with emotional and spiritual support for both the patient and their families ("NHPOC's facts and figures," 2013)

In the year 2000, hospice staff and facilities cared for 700,000 admissions ("NHPOC's facts and figures," 2013). By 2012 the number of hospice admissions grew to 1.5 to 1.6 million ("NHPOC's facts and figures," 2013). Of these admissions there were 1,113,000 deaths while under hospice care in 2012 ("NHPOC's facts and figures," 2013). This may sound like a tremendous number of people dying during that time frame but it is estimated that a mere 5% of patients who could qualify for hospice care are actually referred or choose that avenue (Reeves, 2008). With a percentage as low as 5%, many people could be left wondering what is wrong with this program and the people who operate it. There are many reasons, explanations and hypothesis as to why so few terminally ill patients turn to hospice in their final days, but none of them point toward a flawed system or staff.

To clarify this low percentage of referrals, the first measure is to determine who is eligible to receive hospice care. The answer is actually quite simple; anyone with a terminal illness who has been certified by two physicians to have a life expectancy of six months or less, regardless of age, sex, religion or race is entitled to hospice care ("NHPOC's facts and figures," 2013). This minimal criterion makes it all but impossible for a terminally ill patient not to qualify for care. With such strong values, a stellar reputation, and a focus upon caring not curing, why do an estimated 95% of terminally ill patients not receive a referral or choose not to act on that referral? A recent study indicated that some patients are being dissuaded by the medical community from using

hospice if their particular disease process is known to need high cost palliative care (Huskamp, Buntin, Wang, & Newhouse, 2010). Also, some hospice and home health organizations are avoiding taking on patients that do not have caregivers in their homes or that need high levels of in home care (Huskamp et al., 2010). Then there are some physicians who do not refer patients because they think if the patient does not die within six months they could be charged with malpractice (Huskamp et al., 2010). There are indications from this same study that evidence has surfaced implying that some hospices simply will not admit patients with high cost needs or they tell the patient up front they will not provide for those needs (Huskamp et al., 2010). The study also uncovered that some physicians are not referring these patients with high cost needs for fear of the strain placed on hospices budget (Huskamp et al., 2010). The bottom line is money. It appears that patients are either not receiving the proper referral or are being denied admission if they are thought to be a high cost patient. What about those receiving the referral but are choosing not to invoke their right to hospice care?

There are simply those people who hear the name hospice and their thoughts go to death and dying. They think of a loved one lying in bed that perhaps has not eaten or drank in days, they are in their final fight and the grim reaper is winning. With the many myths that surround hospice, some family members and perspective patients have a preconceived negative connotation of hospice. Some people believe that hospice is only for patients with terminal cancer. Although cancer is the number one diagnosis of hospice patients, with 36.9% of patients enrolled in 2012 having this diagnosis, that still leaves a vast number unaccounted ("NHPOC's facts and figures," 2013). The next four diagnoses and the representative percentages to round out the top five terminal diseases that patients

are admitted for are: debility unspecified 14.2%, dementia, 12.8% heart disease 11.2%, and lung disease 8.2% (Rogers, 2009). Another myth which may defer patients and family is that hospice “dopes people up” which makes them sleep all the time (Rogers, 2009). Although it is true that hospice uses medications to control pain, nausea, restlessness, anxiousness, and other symptoms brought about by the disease process, medication dosing and administration is tightly regulated by an expert team. To quote a 30 year veteran hospice nurse referring to people in the dying process, “people go out of this world in the same manner in which they came in (Irwin et al., 2008, p. 843).” That statement merely means that when people are dying they become as babies once again. They sleep most of the time, only waking for short periods to eat and they sometimes become incontinent of bowel and bladder. With this statement in mind it is completely expected for people in their final days to spend most of it sleeping. There is also a myth that hospice care actually accelerates the dying process (Rogers, 2009). In reality, it is not unusual for a patient’s health status to improve once they begin receiving hospice care (Reeves, 2008). In fact, it is not uncommon for a patient’s health to improve to the point they are discharged from hospice as chronically ill not terminally ill (Reeves, 2008). This is not to imply that hospice is actually curing people, eventually they will return to hospice care, but for the time being their prognosis has improved to the point they have more than six months to live.

If the myths are simply not a valid point in preventing a larger portion of patients from receiving hospice care then perhaps it can be attributed to their geographical location. Maybe a large portion of those who decline hospice care do so because the nearest hospice facility is located too far away. That could be a valid point except it has



already been established that hospice operates 5500 facilities within its territory. From those facilities, 88% of the population served lives within 30 minutes driving time and 98% lives within 60 minutes driving time (Carlson, Bradley, Qingling, & Morrison, 2010). This does leave an estimated six million people more than 60 minutes away from the nearest hospice facility but 90% of hospice care is accomplished by staff making home visits (Carlson et al., 2010). It is still conceivable that those living in rural areas could have difficulty receiving timely care simply due to their location. Consequently, hospice has come up with a means for people to have nearly instantaneous access. This relatively new system is based upon telehealth which has been in use by the Veterans Hospital Administration home health agency and civilian home health agencies for some time. In the hospice environment this new system is referred to as telehospice (Whitten, Holtz, Meyer, & Nazione, 2009). Telehospice involves the use of videophones which enable patients and providers to see and hear each other while conducting minor patient assessments (Whitten et al., 2009). Although this system has been shown to increase patient safety and satisfaction while reducing patient anxiety, cost as well as travel time, it has been met with some resistance at the staff level (Whitten et al., 2009).

If geographical location cannot logically be blamed for the low percentage of hospice enrollment, perchance is money or the lack there of to blame? America is in a time of economic uncertainty. Many people have either lost their job, looking for work or are working in a position which pays much less than they are accustomed. Often times lower paying positions also come with fewer paid benefits such as health insurance. This situation leaves many Americans with the belief or reality that they cannot afford needed healthcare. Hospice seemingly is no exception to this rule or at least that is how it could

be perceived. The fact is that in 2012, 83.7% of hospice care was funded through Medicare ("NHPOC's facts and figures," 2013). Of the remaining 16.3%, private insurance covered 7.6%, Medicaid paid 5.5%, charity covered 1.2% and a mere 0.9% was paid for out of individual funding ("NHPOC's facts and figures," 2013). The simple fact that some people think they have to pay for their own care is often enough to halt their pursuit.

That thought was evidenced in a recent study concerning why African Americans are known to use hospice services at a much lower rate than white Americans. It noted that African Americans who did not have health insurance believed they would not qualify for hospice care (Washington, Bickel-Swenson, & Stephens, 2008). That same study revealed some other beliefs which prevented African Americans from pursuing care. Among them was the belief that the only way to have a "good death" was if they possessed good health insurance (Washington et al., 2008). Some even believed that if by chance they did receive care, it would be substandard simply because they did not have insurance (Washington et al., 2008).

African Americans are not the only minority group which uses hospice services less than white Americans. In fact, recent data indicates that all minorities use hospice less than white Americans. By ethnicity 93.1% of hospice patients in 2012 were non-Hispanic or Latino origin while a mere 6.9% were Hispanic or Latino in origin ("NHPOC's facts and figures," 2013). When comparing 2012 hospice admissions by race, 81.5% were white, 6.7% multiracial or other race, African American 8.6%, Asian, Hawaiian or Pacific Islander 2.8% and American Indian or Alaskan Native 0.3%.

Looking for indications as to why some of these minority groups are known to use hospice at a much lower rate, a survey was recently conducted on 331 Latinos. The results indicated that only 29% knew about or had knowledge of the types of services offered by hospice (Selsky et al., 2012). That is somewhat ironic due to the fact that cancer is the number one reason patients are referred to hospice and cancer is the second leading cause of death among Latinos (Selsky et al., 2012). However, Latinos are known to be more secretive when faced with a potential terminal illness and they are notorious for seeking life sustaining intensive treatments in the last six months of life more often than white or black Americans (Selsky et al., 2012). Yet another recent study conducted on older Korean Americans indicated that a meager 28% of the representative group had any knowledge of hospice or its mission (Jang, Chiriboga, Allen, Kwak, & Haley, 2010). The prominent inhibitory reason among these minority groups was not money or insurance as previously noted with African Americans but rather a generalized lack of knowledge concerning the existence of hospice.

As previously indicated Medicare pays for the vast majority of hospice care. Once Medicare certifies a patient's eligibility and they are admitted into hospice care, hospice becomes that person's primary insurance carrier (Reeves, 2008). What this means to the patient is once hospice becomes the primary carrier, there is no further cost to the patient or the family for services, supplies, medications or anything else used in their care (Reeves, 2008). Hospice receives a daily per diem rate from Medicare for every day that patient is enrolled in their care which is intended to pay for the medical needs of that patient (Huskamp et al., 2010). The Medicare per diem rate for routine home care is \$98.96 per day, but for those patients who live in a rural area the daily rate is paid at a

lower amount (Huskamp et al., 2010). This seems to be somewhat unjust when considering the higher cost for hospice staff to travel in these remote areas.

Taking a look into the average length of stay for hospice patients will further exemplify the underutilization of their services. As previously noted hospice cared for 1.5 to 1.6 million admissions in 2012 ("NHPOC's facts and figures," 2013). Bearing in mind that a patient qualifies for hospice once their diagnosis becomes terminal and they have six months or less to live could lead a person to believe that the majority of patients would desire help with their symptom control as the earliest possible time. However, the average length of stay in 2012 was 71.8 days ("NHPOC's facts and figures," 2013). That means the average terminally ill patient, that accepted hospice care waited 102 days longer than required by criteria before they or their families had any professional help in dealing with the struggles of a dying family member. What a tremendous burden the average person places upon themselves and family members needlessly. To further illustrate this point, 35.5% hospice patients died or were discharged within seven days of admission, and 49.5% of the patients died or were discharged within 14 days of admission ("NHPOC's facts and figures," 2013). At the far end of the gamut, 11.5% of patients remained in hospice care for more than 180 days. For those types of situations, patients can be certified under Medicare for an additional 90 days (Rogers, 2009).

If elected early enough in the disease progression, hospice has also been shown to provide health benefits to both the patient and the caregiver (Rogers, 2009). Most patients want to maintain their independence as long as possible, but with terminal disease processes this can often be a challenge. Physical inactivity in the terminal patient can lead to increased pain, bowel and bladder dysfunction, fatigue, under nutrition,

depression and a host of other problems (Javier & Montagnini, 2011). Hospice helps to overcome the problems of physical dormancy through palliative rehabilitation (Javier & Montagnini, 2011). In fact, in a recent study of 200 terminal cancer patients, palliative rehab significantly increased both motor and cognitive functions in many of these patients (Huskamp et al., 2010). This is a significant benefit considering that 80-90% of patients with terminal cancer develop some type of severe mental deficiency before death (Irwin et al., 2008).

With 80% of the care for hospice patients typically being delivered by family members, they too can fall victim to physical and mental disabilities (Empeno et al., 2011). The social workers on the hospice team are the experts in this field. Not only are the social workers specialists at counseling family members through this difficult time, they orchestrate respite care giving the caregivers time to rest, run errands or simply to spend some time alone (Oliver, Wittenberg-Lyles, Washington, & Sehrawat, 2009). Also, after the death of a patient, social workers offer bereavement counseling to family members for one year (Yeolekar, Meheta, & Yeolekar, 2008).

The fore mentioned information indicates many positive attributes of hospice but also the underutilization according to the average patient. But, bear in mind that some diagnoses and patient race or ethnicities are well below these numbers and hospice is used at a much lower rate. Also, for every misunderstanding or myth listed there are multiple others which have not been listed or have not been brought to light. Although the misunderstandings or underutilization has been well established the problem remains. What can be accomplished to promote and understand what and how this organization operates? How can hospice become viewed in the positive light that it so richly deserves?

This is obviously a problem that yearns for intervention at the national, state and local level. Education is of key importance. The general public must be made aware of the existence of hospice and those that are cognizant must be educated as to its mission and methods. Fortunately there are organizations in place with the capability to fulfill this undertaking.

At the nationwide level is the National Hospice and Palliative Care Organization (NHPCO). The NHPCO was founded in 1978 and was originally named the National Hospice Organization ([www.nhpco.org](http://www.nhpco.org)). It has become the largest nonprofit membership organization representing hospice and palliative care programs in the United States ([www.nhpco.org](http://www.nhpco.org)). Not only does the NHPCO set the standards of care for hospice, it develops and promotes public and professional educational programs and materials to enhance understanding of hospice ([www.nhpco.org](http://www.nhpco.org)). The NHPCO also monitors Congressional and regulatory activities as well as work with other organizations that have a vested interest in end of life care ([www.nhpco.org](http://www.nhpco.org)).

Founded in 1992 by the NHPCO, the National Hospice Foundation (NHF) was tasked with the primary goal of fundraising to support the mission of the NHPCO ([www.nationalhospicefoundation.org](http://www.nationalhospicefoundation.org)). However, it was also tasked with educating America's public on end of life care and in so doing expand the understanding of the quality of care offered by hospice ([www.nationalhospicefoundation.org](http://www.nationalhospicefoundation.org)). They have attempted to accomplish this portion of their task by implementing traveling photo exhibitions, Home Box Office (HBO) documentaries, reaching out to physicians with educational videos, conducting national polls and various other educational programs ([www.nationalhospicefoundation.org](http://www.nationalhospicefoundation.org)). Their website is an absolute gold mine of

educational materials for both the professional and those interested in palliative or hospice care for themselves or their loved ones. It also contains web links to other sites such as [www.caringinfo.org](http://www.caringinfo.org) which contains do it yourself advance directives as well as other educational material directed at those caring for a terminally ill family member or who is grieving the death of a loved one.

Another national level hospice oriented organization is actually a coalition between the NHPCO and the Department of Veterans Affairs, (VA) it is appropriately named We Honor Veterans (WHV) ([www.wehonorveterans.org](http://www.wehonorveterans.org)). WHV was launched in 2010 and is designed to be a national awareness campaign aimed at encouraging partnerships between community hospices, state hospice organizations and VA facilities ([www.wehonorveterans.org](http://www.wehonorveterans.org)). In the United States 25% of those who die each year or 680,000 people are veterans ([www.wehonorveterans.org](http://www.wehonorveterans.org)). WHV was developed to help insure that veterans who die with terminal disease process do not go through that experience without the comforting care of hospice. Within WHV, Hospice-Veteran Partnerships or HVP's are formed to provide leadership, technical assistance and program development recommendations to improve veterans' access to hospice care ([www.wehonorveterans.org](http://www.wehonorveterans.org)).

On the Illinois state level is the Illinois Hospice and Palliative Care Organization (IHPO) which was founded in 1980 ([www.il-hpco.org](http://www.il-hpco.org)). This association is geared toward promoting and enhancing end of life care through education, advocacy, and technical assistance at the state level ([www.il-hpco.org](http://www.il-hpco.org)). Their mission is to expand access to hospice care and educate the public on end of life care ([www.il-hpco.org](http://www.il-hpco.org)). Their website contains educational materials as well as locations of hospice facilities throughout the

state. Listed for the veterans are the locations of VA facilities throughout the state along with locations in bordering states. The IHPO is also a member of the HVP.

Although there are many supporters and advocates on the local level such as Franklin-Williamson Bi-County Health Department, hospitals or local medical clinics, the bulk of formal hospice promotion and education falls on the shoulders of Hospice of Southern Illinois. However, they are equipped, prepared, and willing to speak or present on hospices behalf in the local area. Hospice of Southern Illinois was founded in 1981 as Belleville Hospice and originally provided hospice services to terminally ill patients' in the Saint Louis Metro-East communities ([www.hospice.org](http://www.hospice.org)). Their service area continued to grow over the years but in 1988 they merged with Hospice Care Incorporated of Carbondale Illinois and today their coverage area also includes 27 counties in Southern Illinois ([www.hospice.org](http://www.hospice.org)). The bulk of their care is delivered in the patients home, long term care facility or acute care facilities. Nevertheless, in 2010 they accepted the first inpatient in their new Relais Bonne Eau Hospice residence which is located in Edwardsville Illinois ([www.hospice.org](http://www.hospice.org)).

Although there may seem to be an overabundance of opportunities, materials, websites and agencies just waiting to educate the general public and consequently bolster the number of hospice patients the overall statistics tell the bottom line. To change the mindset or behaviors of the American public at the national, state or even local level would be a colossal undertaking and well beyond the scope of this intervention. Rome was not built in a day and a house is built one board at a time by driving one nail at a time. Therefore, it is the goal of this intervention to educate and persuade the future and currently terminally ill veterans and their families in the local area to seek and accept



hospice care. The ultimate goal would be achieved if not a single terminally ill veteran or a member of their family suffered needlessly without the comforting care of hospice. The best possible scenario would be for the veteran to accept care when they are initially diagnosed as terminally ill with six months or less to live. This goal could only be achieved with 100% education and complete understanding concerning the existence and mission of hospice. By grasping this understanding, veterans would accept their own mortality and realize hospice holds their best chance for a peaceful death.

This intervention will begin with a power point presentation aimed at educating the nurse managers at the Marion VA. The presentation will cover basic hospice history, statistics on the utilization of hospice services and the availability of internet based resources. The alliance formed between the VA at the national level and the NHPCO to form WHV and its mission will also be covered. Providing the managers “buy in” to the importance of informing the veteran population of the services available to them and their families, a suggestion for the dissemination of the educational material will be offered. The initial goal for this intervention is to build some interest in curtailing the tragedy that is happening among our local veterans and their families. The success of this intervention is dependent upon spreading the seed of despair among caring nurses. Nurses have an intrinsic need to help people who are in desolation and do not know where or to whom to turn. By arming the managers and successively their staff with this information gives them yet another opportunity to serve those in desperation.

This intervention took place on April 4, 2014 at the Marion VA main campus, annex building five conference room. The meeting was teleconferenced, consequently reaching many more managers than originally thought possible. Although this was spread

to a much wider audience there is no record of whom or how many were in attendance at the other locations, therefore all data and facts are limited to the conference room audience. There were a total of ten Registered Nurses (RN), nine of which were nurse managers and one being a nurse educator. The managers were from a wide array of service specialties which includes but is not limited to; surgery, community living center/hospice care long term care facility, medical/surgical, mental health, emergency department and intensive care unit. All of the audience was female by gender, nine were Caucasian, non-Hispanic, and one was African American. Their educational background ranged from Bachelors of Science in Nursing (BSN) to Masters of Science in Nursing (MSN). Although all were RN's their experience level in nursing ranged from seven years to 25 plus years. Their ages ranged from 30 to 61 and their longevity at the VA ranged from three to twenty years. Although the teleconference did reach a much wider audience, it did prove to be a minor distraction initially as the camera was not properly adjusted. This problem was quickly rectified and did not create another disturbance. The only other distraction was the work which one manager brought with her that kept her mentally and physically occupied for a portion of the presentation.

In summary, from its humble beginnings as an all-volunteer agency in 1974 hospice has continually grown to encompass 5500 agencies owned and operated in a variety of manners. Discussion has been made concerning the myths, misunderstandings and underutilization of this agency for a plethora of reasons among a variety of races or ethnicities. However, the most prevalent and widely accepted reason for these misgivings is simply a lack of knowledge of hospice and its mission. In an attempt to rectify this situation, national, state and local agencies have made concentrated efforts to educate the

American public. In an attempt to ensure no terminally ill veteran dies without the benefit of hospice care, the VA in coalition with the NHPCO have put forth joint efforts focused in this area under the title of WE Honor Veterans. By discovering this organization through conversation and subsequent research, it gave birth to a reasonably obtainable intervention on a local level.

From its conception, the intervention was approached with all the veracity due a critical medical interference. All of the reasonably obtainable, pertinent data and studies were dissected to ensure its relevance for the intended audience. Efforts were made to arm the audience with take home materials in hopes of adding water to the seed which was sown during the presentation. Although all of these great strides were made in an effort to educate and supply the managers with a spark which might turn into a flame, there is the possibility nothing will ever come from those efforts. Perhaps they will only see this as an opportunity merely to help complete a school requirement rather than another tool in their kit to aid a suffering veteran. The complete success or failure of this intervention rides squarely on the shoulders of those managers. If their new found knowledge is left in the conference room, there is little hope for any success. However, if any of them choose to arm themselves and subsequently their staff with this information there is the possibility for a good outcome.

If this intervention were to obtain its absolute best possible outcome it will fall miserably short of the needed results. Although studies have recognized the underutilization of hospice by the American public more is needed in direct relation to United States veterans. Little is known about veteran's healthcare if they do not receive care from the VA. Consequently, there is even less known about how many terminally ill

veterans are dying without hospice care. There is also a need for further study concerning the proper dissemination of education and how to extinguish the flames of myths or misunderstandings. No matter what is done to spread the acceptance and use of hospice, there is no more likelihood of complete success than in entirely repairing the structure of the American healthcare industry itself. However, this must not be used as an excuse because there are many terminally ill veterans dying in misery, without dignity every day.

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Appendix A

Handouts & Pamphlets

Facing the Future Together

We Honor Veterans Campaign Fact Sheet

We Honor Veterans, Serving Those Who Served Us

Hospice Eligibility Quick Reference Guide



Appendix B

Presentation Outline

Dying With Dignity

Hope for Every Veteran

History of Hospice

Implemented in the United States in 1974

Initially an all-volunteer agency

Tax Equity and Fiscal Responsibility Act of 1982

45 Medicare certified hospice agencies in 1983

During the 1990's more than 2000 new agencies originated

In 2012 1.5 to 1.6 million patients received hospice care

One of the most misunderstood and underutilized medical agencies in the United States

What is Hospice Care?

Considered the Gold Standard of care for people facing life limiting illness

Expert medical care, pain management, emotional and spiritual care tailored to each

Specific patient and their family

Focuses on caring not curing

Does not see their patients as dying with a terminal disease but rather living with a disease which has no cure

Services available to any patient with a terminal illness deemed to have six months or

less to live without regard to age, religion or race

#### Essence of Hospice Team Care

“As sickness progresses toward death, measures to minimize suffering should be intensified. Dying patients require palliative care of an intensity that rivals even that of curative efforts even though aggressive curative techniques are no longer indicated, professionals and families are still called on to use intensive measures with extreme responsibility, extraordinary sensitivity and heroic compassion.”

#### Agency Types

Free standing non-profit, independent Hospice 57.4%

Part of a hospital system 20.5%

Part of a home health agency 16.9%

Part of a nursing home 5.2%

#### Where is Care Delivered

Patients place of residence 66% which includes private residence 41.5%, nursing home

17.2%, and residential facility 7.3%

Hospice inpatient facility 27.4%

Acute care hospital 6.6%

#### Patients by Age & Gender

Women 56.4%

Men 43.6%

Less than 24 years of age 0.4%

25-34 years of age 0.4%

35-64 years of age 15.7%

65-74 years of age 16.3%

75-84 years of age 27.7%

85+ years of age 40.5%

#### Patients by Race & Ethnicity

Non-Hispanic or Latino origin 93.1%

Hispanic or Latino origin 6.9%

White/Caucasian 81.5%

Multiracial or other race 6.7%

Black/African American 8.6%

Asian, Hawaiian, other Pacific Islander 2.8%

American Indian or Alaskan Native 0.3%

#### Patient by Diagnosis

Cancer 36.9%

Debility unspecified 14.2%

Dementia 12.8%

Heart disease 11.2%

Lung disease 8.2%

Other 5.2%

Stroke or Coma 4.3%

Kidney disease (ESRD) 2.7%

Liver disease 2.1%

Non-ALS motor neuron 1.6%

Amyotrophic Lateral Sclerosis 0.4%

HIV/AIDS 0.2%

### Length of Stay

The median length of service-18.7days

35.5% died or discharged within 7 days

49.5% died or discharged within 14 days

11.5% remained under hospice care more than 180 days

### Methods of Payment

Medicare hospice benefit 89.0%

Managed care or private insurance 7.6%

Medicaid hospice benefit 5.5%

Uncompensated or charity care 1.2%

Self-Pay 0.9%

Other payment source 1.2%

### Team Approach

Physicians

Nurses

Social Workers

Chaplin's

Aides

Volunteers

Services Provided to Patients and Families

Manages pain and symptoms

Assists with emotional, psychosocial and spiritual aspects of dying

Provides medications, medical supplies and equipment

Educates the family on patient care

Physical/Occupational therapy

Provides short term respite care for caregiver

Bereavement care and counseling for family/friends

Health Promotion

Physical dormancy leads to increased pain, bowel or bladder dysfunction; fatigue, under nutrition, depression etc.

90% of cancer patients develop some form of severe mental deficiency before death

80% of patient care is delivered by family members

Increased survival periods

## Myths

Hospice is a place

Hospice is only for people with cancer

Hospice “dopes people up” so they sleep all the time

Hospice starves patients

Hospice hastens death

## Reasons Patients Do Not Seek Hospice Care

Hospice is “Saying yes to death”

Negative connotation

Lack of education/knowledge

Some minorities prefer life sustaining treatment

They cannot afford the care

Hospice is only for people with insurance

Physicians do not make a referral

## National Hospice & Palliative Care Organization (NHPCO)

Founded in 1978

Largest nonprofit membership organization representing hospice & palliative care

programs in the United States

Sets the Standards of Care for hospice

Develops and promotes public & professional education programs

Monitors Congressional & regulatory activities

[www.nhpco.org](http://www.nhpco.org)

National Hospice Foundation

Founded in 1992 by the NHPCO

Primary mission is fundraising to support the mission of NHPCO

Also tasked with educating Americas public on end of life care

Accomplished through traveling photo exhibitions, HBO documentaries, educational videos & conducting national polls

[www.nationalhospicefoundation.org](http://www.nationalhospicefoundation.org)

We Honor Veterans (WHV)

National level hospice oriented organization

Coalition between the NHPCO & Department of Veterans Affairs (VA)

Launched in 2010

Designed to be a national awareness campaign to encourage partnerships between state/community level hospice organizations and VA facilities

Developed to help ensure veterans dying with a terminal disease do not go through that arduous process without the comforting aid of hospice

Staff and volunteer training modules to help them better relate to veteran needs

Ensure that every veteran is able to receive hospice care at the time and place of need

Hospice-Veteran Partnerships (HVP)

[www.wehonorveterans.org](http://www.wehonorveterans.org)

WHV Home Page

Why Have Hospice-Veteran Partnerships? (HVP)

25% of the yearly deaths in the United States or approximately 680,000 people who die each year is veterans

Only 1/3 of the U.S. veterans receive their healthcare from the VA

ANY VETERAN qualifies for hospice care through the VA without regard to whether ornot

they receive or have received benefits from the VA

Veterans often have unique experiences from their military service that present unique challenges in end of life care

Specific Standards of Practice for veteran population

Veteran-to-veteran volunteer programs

The ratio of VA facilities to hospice organizations is about 1:32. Geographically this enables veteran's better access to care

From whom do Veterans Receive Hospice Care?

The veteran can choose from which organization to receive their care

In Southern Illinois the veteran chooses whether to receive care from VA Home Health, VNA Tip or Hospice of Southern Illinois

WHV: What Is In It For Us?



Increased confidence in making referrals to community providers

Enhanced ability to identify providers that have Veteran-specific skills and knowledge

Heightened satisfaction in being able to honor Veterans' preferences to go home

“How people die remains in the memories of those who live on”

Dame Cicely Saunders

Questions? Comments?

Thank You!

## Appendix C

<p style="text-align: center;"><b>HOSPICE PRESENTATION SURVEY</b></p> <p style="text-align: center;">For each item identified below, circle the number to the right that best fits your judgment of its quality. Use the rating scale to select the quality number.</p>	<b>Scale</b>				
	<b>P o o r</b>	<b>Good</b>			<b>E x c e l l e n t</b>
Overall how would you rate the presentation	1	2	3	4	5
Usefulness of the information provided	1	2	3	4	5
Handouts provided during the presentation	1	2	3	4	5
Relevance of the presentation topic	1	2	3	4	5
Did the presentation cover the subject with enough detail	1	2	3	4	5
Do you feel more competent to discuss this subject with a patient	1	2	3	4	5
How likely are you to use this information	1	2	3	4	5