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The Golden Room: an innovative choice for end of life care (or) Changing the culture to allow for more end of life care options

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Abstract

The Golden Room is an innovative, new concept for a place for end-of-life transition within the last three to ten days of life. This center can be freestanding or designed as a section in an acute care institution or nursing home for those patients who are no longer benefiting from aggressive or life prolonging medical or surgical care. Transfers into the *Golden Rooms* or hospice are to facilitating a peaceful, dignified end of life passing within the scope of receiving ethical, compassionate care in a serene, aesthetic environment. To utilize more end-of-life care options we must continue to address socio-cultural issues about death in our society.

Introduction

The vast majorities of nurses, physicians and everyday Americans say that they would like to avoid high-intensity care at the end of life (EOL), but these wishes are frequently overridden by family and/or health care providers themselves. Two years ago, an Institute of Medicine committee convened and concluded that major changes in the American health care system regarding EOL are needed [1]. This is where we are now in our history, a professed need for change, and what this article is about.

End of life care as a formal concept was most recently introduced in contemporary times by Dr. Cicely Saunders in England in the 1960s. Dr. Saunders came to the American east coast in the 1970s where I first met and heard her present at the University of Pennsylvania in Philadelphia. She called her idea "hospice" from the 17th century French term *hospice*, meaning rest house for travelers, and the 13th century Latin *hospitium* meaning guest house of hospitality. Today, 40 years later, this concept is finally becoming known, but in many parts of the nation it is still controversial.

During the early days of the 20th century most Americans died at home. During the wain of the century through very recent times most terminal elders die in a hospital, and many of these in intensive care areas. Thus, in the past 100 years there has been a dramatic shuffle of concepts about how and where we should die. In little over a 100 years our culture has gone full circle in processing the what's and wherefores of death. From natural death accepted as a carryover from the agrarian way of rural life through the decades of denial of death via encouraging invasive and heroic EOL care in acute care institutions, we have finally come full circle to viewing death as an important part of the full life cycle. However, we still need to flush out how to better accept the inevitability of death and at the same time create more ethical, caring environments with staff who recognize and accept EOL care attitudes to allow for peaceful EOL transitions.

Changing the culture-recognizing and accepting futile care

An increase in the elderly population with chronic diseases mean that more people are dying in acute hospital settings. While palliative care principles have resulted in quality care for the dying, many patients die in an acute care and still receive aggressive/resuscitative care. One study explored nurses' 'recognition of' and 'responsiveness to' dying patients to better understand the nurses' influence on end-of-life care. Findings were that nurses generally took a passive role in recognizing dying until a medical officer's declaration of the fact. Nurses demonstrated varying degrees of discomfort, indicating that they were underprepared for this role [2].

When patients are terminally ill, acknowledgement of dying is essential in providing appropriate care. It should not be assumed that all nurses are adequately prepared to provide dying care. Further work is necessary to investigate how the attitudes of nurses towards caring for dying patients in the acute hospital setting may impact care of the dying patient [2].

We all know of anecdotes of long suffering end of life scenarios. These frequently happen because either the patient/family or the physician/caregivers cannot face the fact that the loved one or patient is dying. The following poem was sent to me by a mother whose son is the primary caregiver for his wife. A year ago, her son's 45 year old wife was diagnosed with Hepatic Encephalopathy and Renal Failure.

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An uneasy truth, a poem by J. Doe

She will die? She is dying?

Who will tell you this if and when there is foreknowledge?

You don't want to know. But you do want to know.

You strongly suspect it, but are unsure that you want it confirmed.

You wonder what you could have done better.

Or what you should have done less.

You don't want to see her in hospital, but you can't maintain adequate care at home.

There is a stark reality to seeing her in hospital.

Because you suspect she will not be coming home again.

Because you don't want her to come home in such pain and so very sick.

Because you can't bear to consider the chores, the mess, the pain you can't fix at home.

Because you feel guilty you think that, and it seems selfish.

Because you know she is dying but no one will say

So you are paralyzed with uncertainty, guilt and dwindling resources.

Seeing her you must dredge up distant optimism for her

But your eyes know that it is false bravado.

D's mother who wrote this poem says her sons journey with K has shattered his view of this world, and he and K both deserve honesty. To drag this on is cruel. She goes on to say, "We are all still trying to understand why no doctor has undertaken a frank and honest conversation with D and K about her 'chances' of surviving with or without being on transplant list. My son and his wife totally rely on the 'word of doctors' and plod along in agony thinking it will be fixed if only she can make it on to the liver/kidney transplant list…but even then, what are her actual survival chances until organs are available? What level of deterioration must happen and doesn't that diminish her chances of surviving a transplant even if one becomes available" [3].

Since K was diagnosed with Hepatic Encephalopathy and Renal Failure, she has been on every other day dialysis and periodic blood transfusions ever since. When lucid enough, K attends rehab programs for alcoholism. Since K's downhill medical spiral, the couple has spent all their money and exist on Medicade and public assistance. D lost his job and spends full time caring for K and has experienced his own health severely deteriorating. All they seek now is someone with authority to talk to D and explain the situation, what is K's prognosis. K has mentally deteriorated to the extent that she cannot comprehend questions or verbal discussion. So, the mother asks again, "Will K improve? Is the past year of suffering and loss going to turn around, or is K terminal? Who will step up to the plate and talk to them? Her weight has gone from 375 to 95 pounds, she is already a shadow of a person. She cannot eat and finds feeding tubes unbearable. When is enough, enough? When will some doctor finally talk to them" [3]? When will our culture accept different levels of care giving and realize that people suffer during heroic caregiving when it is in reality futile care?

Delivering bad news to patients is difficult for many physicians. So many have been schooled in curing techniques that it seems onerous to have to admit defeat and give a terminal prognosis. Breaking bad news to patient is so difficult for so many that one group of researchers performed a systematic review of qualitative studies (a meta-synthesis) that focused on the experiences and points of view of oncologists about this very topic, breaking bad news to patients. The researchers identified 40 articles (>600 oncologists) from 12 countries and assessed their quality according to the Critical Appraisal Skills Program (CASP). The two primary themes that emerged were: essential aspects of the communication, including the process of dealing with emotions and the family, systemic and institutional factors, and cultural factors.

The conclusions and recommendations were that breaking bad news is a balancing act that requires oncologists to adapt continually to different factors: their individual relationships with the patient, the patient's family, the institutional and systemic environment, and the cultural milieu. Caregivers must personalize, adapt and advance from the ways they are currently trained in communication skills [4], In another study on intensive care in EOL seniors, researchers found that most measures of care intensity fell outside published benchmarks, signifying overly aggressive care. Intensity of late-life care among cancer affected seniors varies significantly by principal healthcare provider with the most intensive care shown were among those receiving combined care from Primary Care Providers (PCPs) and oncology specialists [5].

In India, the practice of intensive care includes withholding and withdrawal of care in EOL patients, when appropriate, and the goals of care change to comfort and palliation. One group of researchers surveyed the attitudes, training, and skills of intensive care residents in relation to end-of-life (EOL) care. They found that internal medicine residents have more experience in caring for dying patients and conducting EOL discussions. Even though majority of participants reported that they are comfortable with the concept of EOL care, this was not always reflected in actual hospital practice in the hospital. Based on their findings, these researchers recommended further training in skills around EOL care [6].

Another group conducted a cross-sectional survey in 9 health-care institutions located in 4 geographical regions in North and Central America, investigating attitudes toward end-of-life practices in health-care providers. The main outcome measured the correlation between the respondents' present code status and their preference for cardiopulmonary resuscitation (CPR) in case of terminal illness. The surprising finding is that most respondents (58.3%; n=500) desired "definitely full code" [7].

There are many journals and web sites to guide and support EOL discussion and cultural advancement. A few include: American Academy of Hospice and Palliative Medicine (http://aahpm.org), National Hospice and Palliative Care Organization (http://www.nhpco.org), Hospice and Palliative Nurses Association (http://hpna.advancingexpertcare.org). These and many others work tirelessly to advance both the culture and the care.

Populations statistics

The elderly population is growing. In 2014 (the latest year for which data is available) there were 46.2 million people 65 years or older. This figure represents 14.5% of the U.S. population, about one in every seven Americans. By 2060, projections are for about 98 million older persons, more than twice the number in 2014. People 65+ represent 14.5% of the population in the year 2014 but are expected to grow to be 21.7% of the population by 2040 [8]. With the oldest of these 78 million boomers turning 85 in 2031, the government tab could be staggering. In 2021, Medicare alone is expected to cost taxpayers $1.1 trillion, up from $586 billion in 2012.

One fact that we all must recognize is that of these figures, 100% of these people will eventually come to the end of their days; every one of them will die. It is the how, when, where, and why of EOL that is our health care challenge. How can we as a culture advance and offer the best possible end of life care to millions of souls?

March toward the future

Many large American cities are already addressing the needs of their growing elderly populations. Over [age 55 year old] retirement communities are rapidly proliferating, generally in the most distant suburbs of big cities. These communities of varying sizes often hold hundreds of free standing homes habituated by self-care seniors. They house the seniors, and their wants and needs in terms of meeting facilities, gyms, pools, sports courts, etc.

The newest variations in senior residences are the step-up, all needs level communities. The new designs and rapid creation are the whole package: tiered independent cottages, the assisted living building concomitantly housing memory care units, then the skilled nursing facility deeper into the complex, with the final stop, the hospice or terminal care center.

The *Golden Room*

Both nurses and physicians are the lead caregivers so it is natural that they have great interest in this field. To that effect, it was about a decade ago that myself and another professional colleague conceived of a new term and concept for the evolution of hospice into an expanded fullness. We termed this new housing and way of caring for EOL people *The Golden Room* [9-13]. This room or group of rooms is akin to hospice and is for any EOL individual with a terminal prognosis from a long-term disease or an acute, unexpected illness or event.

From Dr. Saunders first offering the idea of hospice, the growth and acceptance of the hospice concept has exponentially expanded during the past 50 years, however, still many people debate the idea and look for other solutions for themselves or their terminal family members. Might there be other options? The *Golden Room*, a specific place, introduces the next level in the evolution of palliative and hospice care. It requires a shift in consciousness and attitude toward death so that dying is accepted as a sacred process deserving of compassion, dignity and beautiful surroundings. Specially trained caregivers in this environment help people awaken their consciousness to overcome their fear of death. The *Golden Room*, is a dedicated place for those within a week or two of dying. The care in this setting is sensitive to immediate mental, emotional, and spiritual needs as well as physical comfort care without tests or treatments that extend life.

How *Golden Room* care can supplement to hospice care

Hospice admits during the last 6 months of life. *Golden Room* care specializes in the last 3 - 10 days of life as the body is imminently closing down. As such, the care is very sensitive mentally and emotionally to the immediate needs of the dying and their family in as well as physical comfort care, pain medication and complimentary modalities to relax and release. There are no tests, treatments, or life extending medications that are used in traditional care that suggests recovery. Natural process can occur. Transfers into *Golden Rooms* can occur easily from intensive care settings in acute care hospitals, nursing homes, clinics, and personal homes directly into free standing or inpatient *Golden Room* settings.

When one explores the need or desire for yet another care facility, there are a number of facts to consider. One for example, is that approximately 90% of the UK population spend some time in hospital in their final year of life, and more than half of the population die in hospital. The statistics are the same in the USA. A UK study explored the experiences of general nurses when providing end-of-life care to patients in the acute hospital setting. Six themes emerged from the literature: lack of education and knowledge, lack of time with patients, barriers arising in the culture of the health-care setting, communication barriers, symptom management, and nurses' personal issues. The themes cause concern about the quality of EOL care provided in acute care settings. The literature appears to be consistent in the view that terminally ill patients are best cared for in specialized care settings, such as palliative care units and hospices. However, increasing demands on health services will result in greater numbers of dying patients being admitted to the acute hospital settings [14]. The question posed then is, perhaps there is room for more options? It is proposed that *Golden Room* staff have additional training to learn best how to help their clients/patients reach resolution of conflicts. Living in the moment of life offers us the choice of embracing each moment or shrinking from it. Because of staff preparation of knowing how to begin the conversations about end of life and relaxing into enjoying this present moment, caregivers can help guide and participate with the terminal process with the natural cycle of life right up until the last breath. We can change both our experience and the experience of those we help.

We know that nursing homes have provided wonderful long term care option for many, but at EOL, most of them are not fully prepared. Therapeutic options for nursing home residents focus on functional improvement, while inadequate hospital admissions in the dying phase are frequent [15].

Although end of life comes to all of us, it is rare that this major life event is fully appreciated or understood by the majority of people. The body is specially designed so its systems shut down through a sequential slowing down and eventually stopping with the hearts last beat. What we want to remember is that this shutting down is a normal, natural process. Once we better understand this natural process the fear of what is happening is greatly reduced and we are able to better receive comfort, compassion and care as the body performs its final task of closing down. The better we understand this natural progression, the less upsetting and alarming it is as we experience death our self or support a loved one's dying process [9-13].

Is there a return on investment for *Golden Rooms*?

All Health Care facilities have an increasing focus on improving the patient's experience. It is known that a 1% decrease in patient satisfaction results in a 6% increase in complaints and a 5% increase in risk management episodes. Institutions with patient satisfaction in the top quartile are more profitable.

Financial incentive has precipitated a closer look at the entire patient experience with hospitals and providers focusing on very detail. Hospital reimbursement is now directly influenced by patient satisfaction scores. With the Hospital Value-Based Purchasing

Program (VBP) in 2012, patient satisfaction has become a top priority. Plus the Inpatient Prospective Payment System (IPPS) is now being tied to hospital scores on the Hospital Consumer Assessment of Health Providers and Systems (HCAHPS) survey. In the majority of surveys patient dissatisfaction was identified as communication. In fact, many of the questions explicitly focus on communication.

One UK study discovered the emerging themes of diagnosis and awareness of dying in which there is no substitute for experience. Significant resource is needed to engage staff, residents and relatives/carers with the idea of advance care planning. Advance care planning can reduce the distress from and number of inappropriate hospital admissions, but requires determination and consistent application of the approach [16]. Specially trained *Golden Room* nurses, comfortable with their own mortality, are specially trained to be supportive to both the dying and their families through their words, their actions and their presence. Working from a place of love and understanding, these nurses use their head, their heart and their hands to give compassionate care and understanding so that both the dying and their family can move through this transition time with dignity and grace AND can look back on it with a sense of wellbeing, having felt the support and gentle caring. As people and families realize the extra warmth, caring, compassion and dignity found in *Golden Rooms*, they will desire and seek out hospitals and institutions that offer this service. The efficiency of investing in *Golden Rooms* will be apparent.

We are all going to die

Death can be a painful reality. Even so it is the least understood body process because of three important facts. First, there is an emotional response to death on the part of the dying person and their family and/or loved ones. Second, each person and their family have a spiritual meaning attached to death and the dying process. Finally, death is the ultimate unknown and can only be entered alone. The simplest definition of death is a moment in time at the end of physical life which is preceded by a dying process.

The dying process

The dying process is a personal journey that usually begins well before physical death of the body. No one knows for sure the date and time of their death. Some have "feelings" that death is near but no one really knows. As one ages and the body slowing down becomes more noticeable, there is a tendency to progressively think more and more about death. The body slowing down or taking a longer time to heal is evidence of the beginning of the dying process though most people would disagree as this fact is hard to accept. Most people do not share these thoughts with each other or their family. When disease is part of the dying process, consciously or unconsciously, most people consider their imminent death and have some manner of preparation including watchful waiting. Even not preparing is a preparation!

Quest for prototypes

What is needed now are prototype *Golden Rooms*. Who among you know an institution you can convert to a *Golden Room* facility? Might your community hospital want to commit a section with a few beds to *Golden Room* status? Perhaps a nursing home in your area could agree to convert some of their beds to a *Golden Rooms*? Rather than rush the terminal nursing home patient to the acute care hospital would it not be better to simply move them down the hall to the wing dedicated to EOL care? Now is the time for all of us to consider the possibilities of the enormous numbers of upcoming elderly and the fact that all of us will face the inevitable death one day. The question is where, when, and how do we want to die?

Summary

In the final days of life all systems of the body are systematically shutting down. None are exempted. This process is natural, exquisite in its grand design, and experienced by everyone. Once we understand the process, death can begin to take its rightful place in physical life. It is one of the most important major events in every one's life second only to physical birth. Without death life, itself would have no conclusion, no culmination. To live forever would become a dread disease. But, death, itself, is not a disease to be treated and fought rather death is a normal natural process we can respond to with love, compassion, comfort measures and dignity. What is needed are new, widely accepted *Golden Room* centers where compassionate, ethical, loving care will be provided in fully funded environmentally, aesthetic rooms.

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