

# Psychological affects of end-of-life care

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As people approach the end of their lives, they with their families and their caregivers, face many tasks and decisions. They may be psychological, spiritual, or medical in nature, but all end-of-life choices and medical decisions have complex psychological components, ramifications, and consequences that have a significant impact on the suffering patients and their caregivers.

Hospice is a special healthcare option for patients and families faced with a terminal illness. At Hospice there's a multidisciplinary team of physicians, nurses social workers, bereavement counselors and volunteers that work together to address the physical, social, emotional and spiritual needs of each patient and family members ("Hospice"). The main focus of Hospice is to address the issues that are most important to the patients' needs or wants at the end of his/her life. The term "Hospice" comes from medieval times when it referred to a place of shelter and rest for weary or ill travelers on a long journey (Hospice).

The name was first applied to specialized care for dying patients by Physician Dame Cicely Saunders, who began her work with the terminally ill in 1948 and eventually went on to create the first modern hospice—St. Christopher's Hospice—in a residential suburb of London (National). Her lecture, given to medical students, nurses, social workers, and chaplains about the concept of holistic hospice care, included photos of terminally ill cancer patients and their families, showing the dramatic differences before and after the symptom control care. This later resulted in the development of hospice care as you know it today (National).

Caregiving is associated with physical, psychological, and financial burdens. Hospice nurses perform many traditional nursing duties such as observing, assessing, and recording symptoms. They still work closely with physicians, administering medications and providing emotional support, although psychologists do not have much of a presence in the hospice movement. Medications that hospice nurses administer and the symptoms they record are not intended to aid a patient in his or her recovery, but rather to make his or her remaining days as comfortable as possible (“Hospice”). Being a nurse of any kind is very difficult, but dealing every day with a dying patient requires an extraordinary temperament, one that symbolizes great caring and patience (“Career”).

It can be especially trying on nurses to attend patients who are as young as or younger than the nurse themselves are. Palliative care highlights the total well-being of the patient as well as that of loved ones and caregivers. The caregiver is there to listen, support, encourage, comfort and help the patient. Their goal is to prevent, treat, or eliminate discomfort whenever and, however it appears, never about giving up hope (“Career”). Every caregiver may be required to provide a variety of care tasks including physical, emotional, and practical.

Research shows that families find personal care to be the most physically and emotionally challenging aspect of caregiving. Emotional care involves listening, talking, reading, or playing music (Collins). Providing the kind and loving companionship that patient may need during the end-of-life process. Handling insurance and other legal matters, taking care of financial concerns such as paying bills, coordinating visits with loved ones, friends and hospice

staff is all a part of practical care (Collins). Along with discussing and ensuring that all of the patients' wishes are carried out if also the healthcare power of attorney ("What"). In 2009; 66 million Americans (3 in 10 U. S. Households) reported at least one person providing unpaid care as a family caregiver (Collins). Under Medicare, hospice is primarily a program of care delivered in a person's home by a Medicare - approved hospice.

Reasonable and necessary medical and support services for the management of a terminal illness are furnished under a plan-of-care established by the beneficiary's attending physician and the hospice team (Berry13). Hospice care is available under Medicare only if: the patient is approved for Medicare Part A, the patient's doctor and the hospice medical director certify that the patient is terminally ill with six months or less to live if the disease runs its expected course, the patient signs a statement choosing hospice care instead of standard Medicare benefits for the terminal illness, or the patient receives care from a Medicare-approved hospice program ("Hospice").

Hospice care can be provided by an agency or organization that is primarily engaged in furnishing services to terminally ill individuals and their families. To receive Medicare payment, the agency or organization must be approved by Medicare to provide hospice services (Berry15). Approval for hospice is required even if the agency or organization is already approved by Medicare to provide other kinds of health services. Medicare pays the hospice directly at specified rates depending on the type of care given each day. The hospice can charge five percent of the reasonable cost, up to a maximum of five

dollars, for each prescription for outpatient drugs or biological for pain relief and symptom management related to the terminal illness (Collins).

When Medicare beneficiaries choose hospice care, they give up the right to standard Medicare benefits only for treatment of the terminal illness. If the patient, who must have Part A in order to use the Medicare hospice benefit, also has Medicare Part B, he or she can use all appropriate Medicare Part A and Part B benefits for the treatment of health problems unrelated to the terminal illness. When standard benefits are used, the patient is responsible for Medicare's deductible and coinsurance amounts (Berry 14). All services required for treatment of the terminal illness must be provided by or through the hospice.

If not through the hospice then Medicare will not pay for treatment for the terminal illness which is not for symptom management and pain control. If you receive care given by another healthcare provider that was not arranged by the patients' hospice or if the patient is receiving duplicate care Medicare will no longer fund in the patients' healthcare (Berry14). When a patient is expected to live six months or less is when hospice is referred. Although many hospice patients have cancer as their primary diagnosis, hospice provides care to patients of all ages who are dealing with any potentially life-limiting illness, including Alzheimer's, congestive heartfailure, chronic obstructive pulmonary disease (COPD), dementia, and emphysema.

Once the patient has been diagnosed and chooses hospice care, this can generally take place at home or as in-patient care. Hospice neither prolongs life nor hastens death, but controls pain and discomfort allowing a person to live as fully and comfortably as possible during life's final journey ("

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Career"). Pain control is one of the central goals of hospice care. Every person facing a serious illness hopes for as little pain as possible. Fortunately, with advances in modern medicine, physical suffering can now be almost entirely managed, and in some cases eliminated. From the legal standpoint, the federal guidelines regulating hospice require the hospice to make every reasonable effort to assure that the patient's pain is controlled (Berry3).

Most state laws governing hospice also make pain control a primary and required component of hospice care. The hospice Interdisciplinary Team and the hospice Registered Nurse case manager are focused on making sure the patient is comfortable. The Attending Physician who orders all medications should be focused on the same goal, and in many cases does see to it that the patient is kept comfortable. Unfortunately, for varying reasons, some physicians may not order the needed medications to adequately control the patient's pain (Berry4). In these cases, the hospice staff must intervene to protect the patient and make sure the patient gets what is needed to control pain.

The hospice Medical Director, being a physician, has the authority to give medical orders and can intervene to provide the patient with the needed medications. In fact, the hospice Medical Director is required by law to make sure the patient's medical needs are met; these needs include medication for pain (Berry4). When dealing with patients and families in hospice care, the psychological and social needs of both patients and family members must be met in order to improve the quality of life throughout the dying process.

Many caregivers and loved ones feel overwhelmed by the fact that end-of-life may be near for someone they love; you have to have realization that the

patient is not going to get any better despite your best care. It may bring feelings of frustration, anger, sadness, grief and loss to the family of the patient ("What"). Ignoring feelings of depression, anxiety, confusion or delirium can be harmful... Expressing can be freeing. 48 children and spousal caregivers of hospice patients and 36 controls were evaluated shortly before deaths of their loved ones and again at 2, 7, and 13 months after their deaths. All subjects were administered the Hamilton Rating Scale for depression, symptom innovatory and the Texas Revised instrument of Grief (Dutton 30).

Caring for a loved one who is nearing death can be important time of growth for caregivers. Experience can bring a deep sense of joy and satisfaction in having helped to make a loved one's last days happier, and more peaceful. Studies indicate that the majority of patients would like their spiritual issues addressed. Spirituality has to do with respecting the inherent value and dignity of all patients. It is very important for the patients' beliefs to be known to healthcare workers so the patient is not disrespected in any way by the healthcare worker (Karnes<sup>2</sup>). Patients tend to become more spiritually connected during end-of-life care because they are nearing the end of their journey.

Families are impacted emotionally and spiritually and will be grieving the loss of their loved one whereas their journey is beginning (Karnes<sup>6</sup>). When a loved one dies, mourning is an essential step in the healing process for those suffering the pain and confusion of loss (Karnes<sup>8</sup>). Counselors work with clients to validate the experience of grief, find the strength and coping skills, and eventually regain a sense of hope (Karnes<sup>7</sup>). While grief is very

personal, there are many common experiences that accompany the death of a loved one.

Talking with a counselor helps clients learn more about the natural process of grief and identify areas of strength and support, as well as areas of potential growth (Collins). Grief support group sessions provide the opportunity for people to meet others who are experiencing similar losses. Grief that accompanies the death of a loved one often comes in waves-and sometimes those waves arrive in the days and weeks that follow. At other times, it may be months-or even years- before the reality of the loss sinks in (Karnes11).

Family members may also be grieving over the fact that financial issues may accompany them after their loved one passes. There is always help for any patient or family member in need. After learning more about Hospice and the care that they provide it's more of a " safe haven" and a place of comfort for you or your loved ones that are passing. Many others would personally choose hospice as their end-of-life care.