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Study on the Effect of End-of-Life Care

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Abstract

Most people probably heard of people who "lost their will to live" or "died when they were prepared." Such ideas are not only superstitions. Death involves an interaction of physiological, social, and psychological factors. Recently, more and more people do a research study on end-of life care. Besides, it has grown up to be a hot topic in China. This article is about end-of-life care and it is based on our country at a preliminary stage of the study of end-of-life care. So the article's theme is to introduce the changing context of death and the death progress of the old, end-of-life care, hospice care and some influential factors about these.

Key words: The old; End-of-life care; Study

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INTRODUCTION

On the whole, dying is associated primarily with the old. And now most deaths occur from chronic diseases, which make death predictable as a function of age. Death in old age has thus come to be viewed as a timely event and the completion of the life cycle. Others view death not only as a province of old people, but also as an unnatural event that is to be fought off as long as possible medically. In this sense, death has become medicalized and is distorted from a natural event into the end point of untreatable or inadequately treated disease or injury. As noted earlier, most older people don't fear being dead as much as the painful process of death. One of the most widely known and classic frameworks for understanding the dying process was put forward by Kubler-Ross. The concept of the death process highlights the importance of the ways in which end-of-life care was provided. Another trend, toward being more responsive to die patients and their families is the expansion of the hospice model of caring for the terminally ill.

1. THE CHANGING CONTEXT OF DEATH

The surroundings in which death occurs have changed with increased medical interventions. Death of old age has come to be viewed as a timely event and the completion of the life cycle. At the end of a prolonged illness, when medicine may provide care for but not cure the patient, death may seem to be more unnatural than if the person had been allowed to die earlier in the progression of the disease. Achieving a peaceful death is more difficult today because of the complexity of drawing a clear line between living and dying, which is a result of both technology and societal and professional ambivalence about whether to fight or accept death.

1.1 Attitudes Toward Death

More insulated from death than in the past, many Americans are uncomfortable about discussing it, especially about discussing the prospect of their own death. Such fear tends to make death a taboo topic in our society. Although in recent years death has become a more legitimate topic for scientific and social discussion, most people talk about it in a rational, intellectual level rather than discuss and prepare for their own deaths or those of loved ones (Cicirelli, 2006). Both acceptance and denial reflect the basic paradox surrounding death, in which we recognize its universality ,but cannot comprehend or imagine our own death. Death is one of the few events in life that are certain to occur, but for which we do not plan.

In general, people fear the inability to predict what the future might bring and the process of death, particularly a painful death (Cicirelli, 2006). More old patients tend to choose quality of life when they make their end-of-life decisions although this may vary both with the terminal illness and hopes and plans for the future. It is essential that health care providers take account of such cultural differences in order to ensure both a good life and a good health. Health professionals use the term of end-of-life because of their beliefs that the immortal soul carries on a journey of life after death (Crawely, 2001).

1.2 Variation by Age and Gender

Multiple factors, particularly age, previous experience with the death of loved ones, and gender influence socio-emotional responses to death. Younger women tend to express significantly greater fear than older women regarding the death of others and themselves. Midlife and oldest-old adults who have "unfinished business" and goals that they still want to accomplish appear to fear death more than the young-old. Regardless of age, a near-universal fear is the pain of dying, and concern over an afterlife--the possibility of either no afterlife or a threatening one (Cicirelli, 2006; Fortner, Neimeyer, & Rybarczyk, 2000).

Findings are mixed regarding fear of death among older adults compared with younger persons (Wilkinson & Lynn,2001).In general, the oldest-old think and talk more about death and appear to be less afraid of their own than are midlife and young-old adults. Aware of their limited survival, those who age 75 and over may desire more time beyond what is expected (Cicirelli, 2002, 2006). Having internalized society's views, the current cohort of elders may see their lives as having ever-decreasing social value, thereby lowering their own positive expectation of the future. If they have lived past the age they expected to, they may view themselves as living on "borrowed time." A number of factors may explain this apparent paradox of elders' lessened fear of death in the face of its proximity. On the other hand, having sustained contacts with younger family members and goals to be accomplished creates a greater desire to prolong life (Cicirelli, 2006).

Older adults facing death often turn inward to contemplation, reminiscence, reading or spiritual activities. They may review the awareness of one's life and death through life. Older adults usually can accept the inevitability of their own death, even though they tend to be concerned about the impact of their death on relatives.

Religion may interact with age and cohort to affect attitudes toward death. People who believe in religion have less fear of the unknown and view death as the doorway to a better stage of being. For instance, in all age groups, People who believe in religion may hold the strongest beliefs in an afterlife and may have less anxiety about dying. Religion can be either comfort or create anxiety about an afterlife, but in other cultures, it provides some individuals with one way to try to make sense of death. The age of the person who died is also a factor about how survivors react to death. Because the death of older people is often anticipated, it may be viewed as a "blessing" for someone whose "time has come" rather than as a tragic experience.

2. THE DYING PROCESS

The stages of dying, one of the most widely known and classic frameworks for understanding the dying process, was advanced by Kubler-Ross (1969, 1981). Each stage represents a form of coping with the process of death.

The five stages of grief are a widely known and debated the classic framework applied to both the dying and their survivors.

a) Shock and denial,
b) Bargaining, such as trying to make a deal with God,
c) Anger("why me?"), resentment, and guilt,
d) Depression and withdrawal from others,
e) Adjustment/acceptance.

Although Kubler-Ross cautioned that these stages were not invariant, immutable, or universal, she nevertheless implied that dying persons need to complete each stage before moving onto the next. Alternatively, some people remain at one of the earlier stages of denial or anger, while others move readily into acceptance (Weiss, 2001). She encouraged health care providers to help their patients advance through them to achieve the final stage. In fact, sequencing may not occur at all; rather, feelings of guilt, protest, anger, fearfulness and despair can intermesh with humor, hope, acceptance and gratitude, with the dying person moving back and forth between them. Her framework can be a helpful cognitive grid or guideline, not a fixed sequence that determines a "good death." Another contribution was her emphasis on dying as a time of growth and profound spirituality. Since the dying are "our best teachers," those who work with them can learn from them and emerge with fewer anxiety about their own death. In all instances, cross-cultural variations in how dying is experienced and grief expressed need to be attended to by health care and social service providers. What is most important is that family and health care providers create choices and supports for the dying person, without making judgments about "the right way to die."

3. END-OF-LIFE-CARE

The concept of the dying process highlights the importance of the ways in which end-of-life care is provided, As noted earlier, although most older people prefer to die at home, the common practice has been to hospitalize them, with most deaths occurring in hospital intensive care units or nursing homes. Rather than death as a sudden from accident or infection, death is now most often the culmination of years with chronic illness, such as dementia, congestive heart failure, or cancer. The majority of older people die of chronic diseases and often suffer debilitating symptoms such as nausea, delirium or severe pain in the process. Since medicine focuses on treating the diseases, physicians and families may see death as a defeat, not an inevitable culmination. The traditional problem-oriented model of health care that emphasizes life-enhancing therapies falls short in guiding end-of-life care. Because of traditional medicine's emphasis on cure, many patients and families find that care provided at the end-of-life is inappropriate or unwanted. Even in illness with a predictable course, physicians considered an order to forgo resuscitation only in the patients' last few days (Christoper, 2003; Kaufmann, 2002; Schroepfer, 2006).

Medical experts agree that at least 90 percent of all serious pain can be effectively treated, yet at least 25 percent of dying patients receive inadequate pain medication (Dula & Williams, 2005). The pain of dying is intensified by the fact that terminal patients often experience helplessness, hopelessness, anticipatory grief and guilt. Both depression and delirium are under diagnosed in older patients, yet they are treatable causes of suffering at the end of life. The incidence of depression is perhaps not surprising. Certain findings about older patients with cancer, for example, have less symptom management than other age groups. One study finds that 25 percent of nursing home cancer patients who report daily pain receive no analgesia; in addition, patients who age 85 and over and those of color are more likely to receive no analgesia (Bern-Klug, Gessert, & Forbes, 2001). Although older patients have higher levels of untreated symptoms, there is limited information on pain and drug therapy among this group, especially elders of color. Additionally, older adults are often excluded from research trials and studies on pain management (Dula & Williams, 2005; Wilkinson & Lynn, 2001).

With palliative care, both patients and health care providers recognize that. Although the disease cannot be cured, quality of life can be enhanced. It doesn't treat the terminally ill patient as they are on the brink of death. It neither hastens nor postpones death. Instead, it simply recognizes that life can be meaningful and rewarding even with a diagnosis of a terminal illness (Richardson & Barusch, 2006). In many instances, psychological factors, such as loss of autonomy and control, lack of social support and limited enjoyment and meaning in life are more important than pain in older adults' wishes for a sleepy death. These findings underscore the importance of palliative care programs that have a holistic rather than a largely medical perspective (Jost, 2005; Schroepfer, 2006). Such care is characterized by respect for the patient's values and choices about privacy and end-of-life care, sensitive communication, encouragement to express feelings, a multidisciplinary team approach, music, art therapy, spiritual exploration and meaning at the end of life. The social support of friends and family can be a major source of strength and can enhance the quality of the dying process. Medical professionals now are more open in talking about death with their patients and families than in the past. Most believe that dying persons has the right to know their death. They now think of pain as the "fifth vital sign." Increasingly, the pursuit of a peaceful, pain-free death is viewed as the proper goal of medicine, even though less agreement exists on how this is to be achieved (e.g., how aggressively pain-killers should be used).This breaking of "professional silence" is in part a reaction to external pressures, including growing public support for physicians to provide aggressive pain control and palliative care along with patients who insist on having some control over their dying.

Some physicians still wrongly assume that they will be censured or prosecuted for giving controlled substances to the terminally ill, even when the controlled drug is the approved treatment. Despite the growth of Websites for "pain control" or "death and dying," many patients and their families are legally available. However, both professional and public awareness of these options is growing.

We turn next to discussing the primary delivery system for end-of-life care—hospice.

4. HOSPICE CARE

Another trend toward being more responsive to die patients and their families is the expansion of the hospice model of caring for the terminally ill. Hospice isn't always a "place" but a philosophy of and approach to care that is offered primarily in the home but also in hospital and nursing home settings. In fact, availability of hospice care along with caregiver support often determines whether an older person dies at home (Cantwell et al., 2000). Hospice is a central component of palliative care by providing integrated physical, medical, emotional, and spiritual care not only to the patient but also to his or her support system. As one type of end-of-life care, hospice is dedicated to helping individuals who are beyond medicine's curative power to remain in familiar surroundings where pain is reduced and personal dignity and control over the dying process maintained. Ensuring the patient's quality of life and assessing and coordinating the physical, psychosocial and spiritual needs of the patient and family are fundamental to the hospice approach. More nursing homes and hospitals responsive to a changing market are providing hospice care and pain management programs, although the percentage of nursing home residents or hospital patients who participate is only around 25 percent (Last Acts, 2002).

Hospice care benefits the patient both financially and in terms of extending life. Some studies have documented that hospice care is associated with lower medicare costs and financial savings to families, regardless of length of stay, compared to conventional care (Pyenson et al., 2004) .There is increasing evidence that hospice provides better quality of life for both end-of-life patients and their caregivers than hospitals (Last Acts, 2002). Most dramatically, a study of 8700 medicare patients with 16 different terminal conditions found that for all conditions, patients who age 65 and over in hospice lived longer than those in other settings (Brink, 2007). Despite these benefits, only about 30 percent of dying Americans of all ages participates in hospice, the majority of whom have cancer and are people who age 65 and older, even though it is estimated that twice as many probably should have received hospice (Abelson, 2007).

The reasons for this relatively low rate of participation are complex. One of the barriers to a "good death" is that doctors often refer patients to hospice too late. Despite technological advances, it is still difficult for doctors to predict length of terminally ill patients. In addition, some physicians remain uncomfortable with telling a person that he or she is dying. Instead, physicians tend to convey an optimistic bias when discussing prognoses with each other and sharing them with patients and families. They are likely to overestimate survival and future quality of life, partly because they may fear that a short prognosis will be self-fulfilling. As a result of late referrals, most patients come to hospice during a period of rapid physical decline and are often in crisis. At such times, the immediate management of symptoms and relieving the family overshadows the need to address the emotional and spiritual issues of remembering, forgiving and bringing closure to a person's life. When more time is available, the dying person can participate in the process of validating the past and planning for the future, and this gives the family the chance to enjoy or repair family relationships. As a result, some hospice professionals view this short-term use of medicare-covered services as a problem (Brickner et al., 2004). However, short periods of hospice utilization may actually represent an informed preference for delaying formal families and patients knowing about the truth. And even short hospice stays in the last month of life can be less expensive than end-of-life care in other settings, depending on the acuity of needs at the end (Miller et al., 2004). Nevertheless, the National Hospice Organization tries to educate physicians on how to predict appropriate entry points to hospice for various conditions so that patients are fully aware of their options for palliative care.

Another barrier is that the oldest-old are more likely to die from chronic ill, such as heart or lung diseases or dementia, rather than cancer. Despite the different definitions of death with dignity among culturally diverse groups, under utilization of hospice may also stem from inadequate knowledge of this service and the lack of culturally competent providers who are trained to discuss end-of-life care with persons of color.

CONCLUSION

Although most research on end-of-life care focuses on medicare utilization, medicaid also funds end-of-life care, including hospice care in the last 6 months of life. While Medicaid funding for hospice varies widely from state to state, medicaid accounts for about 5% of total hospice revenues. Most of Medicaid's funding for long-term care for the dually eligible, however, goes to nursing home care at the end of life. Although the proportion of hospice enrolls in nursing homes has increased from 9.9% in 1990 to 21.5 percent in 2002,a substantial percentage—ranging from estimates of 45% to 85% of nursing home residents—are in constant pain because of inadequate pharmacologic and nonpharmacologic pain treatment or none at all (Miller, Teno, & Mor, 2004; National Hospice and Palliative Care Organization, 2004; Teno et al., 2001; Won et al., 2004).The lack of pain management in nursing homes, even those that have hospice care, is generally attributed to shortage of nursing home physicians and nurses with adequate time and training to provide analgesics when hospice staff are unavailable (Kayser-Jones et al., 2006). Given the projected growth in long-term care it is essential that nursing home staff receives training and resources for palliative care.

Although death and dying have been taboo topics for many people in our society, they have become more legitimate issues for scientific and social discussion in these years. At the same time, there is a growing emphasis on the preparation of professionals to work effectively with the dying and their families, as well as a movement to permit death with dignity. A major framework advanced for understanding the dying process is the concept of stages of dying. However, the stage model is only an inventory of possible sequences, not fixed steps.

Based on above points, the foreign country talk about the old for end-of-life care is important for our country. It is good for us to build a better surrounding to our old people.

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